

*Perceived need for information and treatment decision-making in patients
with hematological malignancies: not “one size fits all”*

Janneke Anna Jacoba Rood

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Author: Janneke Anna Jacoba Rood
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Janneke Anna Jacoba Rood
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promotoren:

prof.dr. I.M. Verdonck-de Leeuw

prof.dr. S. Zweegman

copromotoren:

dr. F. Stam

dr. F.J. van Zuuren

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prof.dr. A.M. Stiggelbout, Medische besliskunde, LUMC

prof.dr. J.C.J.M. de Haes, Emeritus Hoogleraar Medische Psychologie, UvA

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CHAPTER 1

INTRODUCTION

Receiving a diagnosis of cancer is distressing for patients and their informal caregivers. Patients with hematological malignancies (HM) are among the patient groups with the highest psychological distress.¹ Providing information tailored to the individual patient and caregiver on the disease, treatment and side-effects, the impact on quality of life, and supportive care options is important but also a challenge for physicians and nurses. As healthcare professionals (HCPs) should not only consider general disease and treatment characteristics, the possible side-effects and the impact on health related quality of life (HRQOL), but should adapt this information to the clinical situation of the individual patient. For instance, information on fertility which may become compromised by HM treatment, is relevant for younger patients but not for older patients, and information on survivorship care plans is relevant for patients with a good prognosis while information on palliative care may be more appropriate for patients with a poor prognosis. Besides, taking personal characteristics of patients into account is critical for providing good and tailored information.² Tailored information provision is a key component in the healthcare concept of shared decision-making (SDM), which aims to take into account the patients' preferences in treatment decision-making.³ In order to optimize information provision in HM-patients and their caregivers, it is of the utmost importance to know whether they currently are satisfied or dissatisfied with the information provided, what their specific needs are with regard to information provision, and to what extent they want to be involved in SDM. Also, it is important to know how HCPs view their role and expertise in providing tailored information to HM-patients. Lastly, the timing of information provision is also a challenge: should patients and caregivers already be informed on all possible side-effects and long-term impact on HRQOL before treatment, when they are encouraged to be involved in treatment decision-making, or is this too confronting?

This thesis aims to investigate the perceived need for information, the satisfaction with information provided and the SDM preference from the perspective of both HM-patients and their caregivers as well as from the perspective of HCPs. This introduction, first provides a description of the different types of HM and their treatments. Then, the concept of SDM is addressed and an overview is given of what is known about the perceived need for information and satisfaction with information provided among

HM-patients and their caregivers, and HCPs perception of these needs. Finally, the need for research and the objectives of this thesis are presented, as well as an outline of this thesis.

HEMATOLOGICAL MALIGNANCIES

Hematological malignancies are neoplasms of the blood, bone marrow, lymph and lymphatic system, with an incidence of almost 920.000 patients diagnosed worldwide each year⁴, and more than 7.500 in the Netherlands.⁵ For this thesis on information need, satisfaction and SDM, we categorized HM according to curative intent and the time allowed to provide information and to participate in decision-making. The most aggressive HM often requiring treatment in hours to days, are the acute leukemias. Acute leukemia, either myeloid or lymphatic, can be cured in a substantial number of patients. In addition, both aggressive non-Hodgkin lymphoma and the less aggressive Hodgkin lymphoma can be cured. However, in contrast to acute leukemia, in these diseases more time for considering treatment options is available. Almost all patients with chronic myeloid leukemia will reach old age with the novel tyrosine kinase inhibitors (TKIs) and especially the effect of long term treatment and subsequent side-effects during the entire life of patients require tailored patient information and SDM. Cure cannot be reached in the majority of patients with chronic lymphatic leukemia and indolent NHL. However, now numerous novel agents are available, greatly improving overall survival. But still life expectancy is less as compared to the healthy population when the disease is diagnosed at relatively young age. Moreover, the treatment options differ greatly, affecting the HRQOL of individual patients, and thus requiring tailored information. Multiple myeloma is also a non-curable disease; however, with the current available therapies life expectancy has a median of eight years in transplant-eligible (Tx) patients and five years in the non-Tx eligible patients. Continuous maintenance therapy improves progression free survival. In addition, preliminary data of a meta-analysis, also showed improvement in overall survival, although less pronounced.⁶ Therefore, information is needed to weigh the pros and cons of continuous treatment. Especially for patients diagnosed with an acute aggressive form of HM, it is particularly challenging to provide timely, efficient and accurate information, also to facilitate SDM, because treatment of these patients should be started soon after diagnosis. Whereas for the more chronic HM, information on the type and timing of different treatment strategies, allowing SDM, is more important. In order to better understand the impact of HM, specifically in relation to the need for information and SDM, a more detailed description of the clinical course of the HM and required treatments is given below.

AGGRESSIVE AND CURABLE HEMATOLOGICAL MALIGNANCIES

Acute Myeloid leukemia (AML) is characterized by an overproduction of immature myeloid progenitor cells (blasts). As a consequence normal blood cell production fails, with anemia, thrombocytopenia and neutropenia as a consequence. As this is a life threatening situation, in general therapy has to be started immediately. The therapy in AML consists of induction chemotherapy and consolidation therapy including conventional chemotherapy, followed by either autologous stem cell transplantation or allogeneic stem cell transplantation, depending on the leukemic genetic risk profile.^{7,8} The median age of AML patients is 69 years. In general, AML is cured in 35–40% of adult patients who are 60 years or younger, and in 5% to 20% of patients older than 60 years.⁹ Patients unable to receive intensive chemotherapy have a survival of approximately weeks to less than a year only. In the elderly patients, there is often discussion on whether to start therapy and the type of therapy at diagnosis. This highly depends on the genetic risk profile. High risk disease requires consolidation with allogeneic stem cell transplantation in order to reach survival. Given the possible negative impact on quality of life, especially elderly patients may prefer care instead of cure. But also in younger patients the positive effect of an allogeneic stem cell transplantation concerning survival at the long term, versus the negative impact on short term survival because of transplantation-related mortality and morbidity negatively affecting HRQOL is of importance to consider when discussing treatment options.

Acute lymphoid leukemia (ALL) occurs most frequently in childhood, but also in adults (20% of the adult leukemias), with an overall median age in adults of 39. Treatment and prognosis depend on genetic findings and age. These two factors dictate treatment, with consolidation with allogeneic stem cell transplantation in high risk versus two years of maintenance therapy in standard risk disease. In general, the same factors as mentioned above in AML are of importance with respect to information need and SDM. In general, cure-rates vary between 20 and 40% in adults.¹⁰

Aggressive non-Hodgkin lymphomas (NHL) include various types of lymphoma's, with diffuse large B cell lymphoma (DLBCL) being the most common subtype. Most patients are older than sixty. DLBCL is potentially curable, and treatment consists of chemotherapy in combination with rituximab, a monoclonal antibody, which improved the disease outcomes with an overall survival rate of approximately 60%.¹¹ In case of a relapse of the disease approximately half of the patients can be cured with autologous stem cell transplantation. In contrast to acute leukemia in general there is time to discuss

treatment during several days before start of treatment is required. The treatment is less intense and the duration limited. Therefore, in general there are less controversies to discuss.

Hodgkin lymphomas (HL) are worldwide diagnosed more than 65.000 per year⁴, and count for 15% of all lymphomas. HL mainly affect adults in their third and fourth decade of life.¹² With current available risk adapted treatment regimens, more than 80% of HL patients are cured.¹² Novel treatments, such as brentuximab, an anti-CD30 drug conjugate monoclonal antibody, are expected to even improve the outcome. The development of second primary malignancies is still a major concern as there was no decrease in the incidence of secondary malignancies in the years 1989–2000 compared with before 1989.¹³ To prevent the development of second primary malignancies, the use of radiotherapy has been limited both with respect to the number of patients, the field of radiotherapy and the dose. Another issue in young patients is the effect of chemotherapy on fertility. Limiting therapy to decrease toxicity with maintaining efficacy is of major interest with respect to need for information and SDM.

Chronic myeloid leukemia (CML) accounts for 15 to 20% of leukemias in adults, with a median age of 60 years. In general, CML patients can grow as old as the normal population, with the novel TKIs. Especially the effect of long term treatment and subsequent side-effects during the entire life of patients require patient information and SDM. Factors influencing choice of therapy include the phase of the CML, the response to treatment, the availability of a donor for SCT in case of refractory for TKIs, patients' age and comorbidity.¹⁴

NON-CURATIVE HEMATOLOGICAL MALIGNANCIES

Indolent lymphomas and Chronic Lymphatic Leukemia (CLL), the most common leukemia diagnosed in the Western world, are heterogeneous diseases, mostly diagnosed above sixty years of age, respectively with a median age of 71 years.¹⁵ Both are non-curable diseases, however with the increasing number of novel agents patients live long. Multiple subsequent treatments are required in order to control the disease. This makes information need continuously important as is SDM. Treatment depends on the subtype and stage of the disease, comorbidity and symptoms of the patient, and consists from watchful waiting, or monoclonal antibodies to chemotherapy and radiation therapy, mostly without but sometimes autologous or allogeneic stem cell transplantations are part of the treatment.^{16–19}

Multiple myeloma (MM) accounts for 13% of all HM. It primarily affects elderly patients with a median age at diagnosis of 70 year, and is an incurable disease. In patients <65–70 years of age standard treatment includes high dose therapy and autologous stem cell transplantation, based on age, performance status and comorbidity.²⁰ The overall survival and progression-free survival has improved since the introduction of new therapies.²¹ Median life expectancy is currently approximately eight years. For patients >70 years of age, often less intensive therapy is given, with a shorter median overall survival of approximately five years. The disease is characterized by recurrent relapses for which treatment is required. Because of the large number of treatment options, often with comparable efficacy but different side effect profiles and different requirements for hospital visits, SDM is increasingly occurring in clinical practice.

SHARED DECISION-MAKING AND RELATED FACTORS

SDM is “a model for decision-making to engage patients in the process of deciding about diagnosis, treatment and follow-up when more than one medically reasonable option is available”.³ SDM seeks the optimal balance by first, ensuring the presentation of information to the patient, and then incorporating both the patient’s and HCP’s values into the final decision.²² According to Stiggelbout, Pieterse & de Haes³, SDM consists of four steps: 1) The HCP informs the patient that a decision is to be made and that the patient’s opinion is important, 2) The HCP explains the options and the pros and cons of each relevant option, 3) The HCP and patient discuss the patients’ preferences; the HCP supports the patient in deliberation, and 4) The HCP and patient discuss patients’ decisional role preference, make or defer the decision, and discuss possible follow-up. It is clear that information provision is a key component of SDM. Research among patients in general²³, and among cancer patients²⁴, showed that most patients prefer a collaborative role, with an increased preference for SDM in the period since the year 2000, compared with the period before 2000.²³ However, there seem to be differences between HM and other cancer populations. A recent study showed that 63% of the HM-patients preferred the physician to make the treatment decision versus 30% of patients with solid cancers.²⁵ More information is warranted on the need for information with respect to SDM among HM-patients.

PERCEIVED NEED FOR INFORMATION AND SATISFACTION WITH THE INFORMATION PROVIDED AND RELATED FACTORS

Patients

Providing information is important, whether or not in the context of SDM. Even patients, who do not have a medical decision to make, need information tailored to their personal situation. Information needs are personal expressed needs for specific condition-related information.²⁶ Higher satisfaction with information provided is found to be related to better outcomes such as better illness perception^{27,28}, less decisional conflict²⁹, less psychological distress^{30–33}, and better HRQOL.^{27,31,32,34–36} Adequate information provision has also been found to be of importance for treatment adherence but scientific evidence is weak.³⁷ This weak evidence may be explained by the relatively high adherence rates in cancer patients and the multidimensional causes of non-adherence: socio-economic (e.g. low educational level), therapy-related (e.g. side-effects), patient-related (e.g. lack of self-efficacy), condition-related (e.g. depression), and health system (e.g. communication between physician and patient).³⁸

In earlier studies on the information needs of cancer patients in general, the most frequently reported need for information was treatment related information, followed by cancer specific information, especially at diagnosis and during treatment.^{39–41} Next to treatment, the main information needs are showed in a review, still regarding treatment, and also regarding recovery.³⁹ In general, if these information needs are known, they can be addressed through the provision of information by HCPs, who are the most frequent information source.³⁹

There are several factors that may moderate the perceived need for information and satisfaction with provided information among cancer patients. Information needs among cancer patients seem to be related to type of diagnosis^{42,43}, stage of the treatment of the disease^{39,44}, and treatment intensity.^{42,45} Need for and satisfaction with information also have been found to be associated with age^{43,46,47}, gender⁴⁸, education level⁴⁶, health literacy⁴⁹, personality⁵⁰, illness perceptions³⁶, and cognitive coping style.^{51,52} Health literacy is defined as the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information to maintain good health.⁵³ Type D personality has been described as the combination of negative affectivity and social inhibition. People who score high on negative affectivity have the tendency to experience negative emotions, while people who score high on social inhibition have the tendency not to express these emotions.⁵⁰ Cognitive coping style comprises two main

cognitive coping styles: monitoring (the tendency to seek threat-relevant information) and blunting (avoiding threatening information and actively seeking distraction under impending threat).^{51, 54}

Data on the perceived need for information and satisfaction with information provided obtained from general cancer populations may not be extended one-on-one to HM-patients, as there are distinct differences between solid cancers and hematological malignancies such as the often high urgency to start treatment with little time to inform patients.⁵⁵ Also, HM-patients often report poorer HRQOL, and a higher psychological distress compared to patients with solid cancer.^{1, 56, 57} Recently, a few studies were published on the perceived information provision and information satisfaction among HM-patients. Oerlemans⁵⁸ explored the perceived information provision and information satisfaction among lymphoma and multiple myeloma survivors and reported that two thirds of these survivors were satisfied with the amount of received information. Young age, being treated with chemotherapy, shorter time since diagnosis, using internet for information, and no comorbidities were related to higher satisfaction.⁵⁸ Almost 30% wanted more information, especially on cause and course of the disease, late effects of treatment, and psychosocial aftercare.⁵⁸ Husson et al³⁵ investigated satisfaction on information provision at baseline among lymphoma survivors and reported that satisfaction was related with HRQOL at baseline but not at follow-up. However, these studies involved only a subset of HM-patients, had a cross-sectional study design, and included patients who were at least six months up to ten years after diagnosis, and not at time of diagnosis.

Informal caregivers

Informal caregivers often play an important role in facilitating patients to make informed choices based on the information they received, by interpretation of medical diagnosis, offering explanations, and encouraging patients to comply with their treatment plan.⁵⁹ Similar to the large variety in information need of patients, informal caregivers will be heterogeneous in the information need. However, there is limited data only. A review showed that studies on the perceived need for information among caregivers of cancer patients in general are limited.⁶⁰ Only a small (n=13) retrospective study was published on the information priorities of caregivers of HM-survivors.⁶¹

Informal caregivers may not always want to know everything about the disease of the patient, as showed in a qualitative study among 22 caregivers diagnosed with all types of cancer.⁶² In contrast, patient more pronounced information seeking has been reported in a

review among caregivers of prostate cancer patients.⁶³ It is thus clear that more knowledge is needed on the need for information among informal caregivers of HM-patients.

Healthcare professionals

With regard to information provision, HCPs are generally advised to tailor type and amount of information to each patient's individual needs.^{31, 34, 51, 52, 64} However, several studies have shown that the information that cancer-patients receive from HCPs often does not correspond with their needs.^{65–76} A recent study on oncologists' judgment of patients' information desire found that oncologists correctly judged the information desire of 62% of patients with advanced cancer. Oncologists had the most difficulty identifying patients wanting and not wanting information about survival.⁷⁷ Patients often receive too much^{66, 69}, too limited^{65, 75, 78} or other^{68, 73, 74} information than they need. Studies that may explain these mismatches are limited and report contradictory results. Physicians are likely to give more information to patients who they perceive to be more intelligent or higher educated and emotionally stable, younger, and those who asking for information.^{79, 80} Furthermore, patients who were expressed more concerns and were more anxious received more information from their HCPs.⁸⁰ In contrast, another study reported that older patients and married patients received more information.⁸¹ Also, there is little knowledge on the possible influence of factors related to HCPs themselves or to the organization of care on providing tailored information. One earlier study was conducted and found no relation between the amount of information and HCPs personal characteristics. A relation with the work surroundings has been described; HCPs working in academic hospitals provided more information than HCPs working in non-academic hospitals.⁸² Lastly, it has been shown that a longer duration of the consultation was associated with the amount of information HCPs provide.⁸¹

NEED FOR RESEARCH

As described above, providing tailored information that satisfies HM-patients as well as their informal caregivers has become more and more important. Existing studies on the perceived need for information and satisfaction with information provided have several shortcomings.

Firstly, HM-patients were often not involved, and when involved, only subsets of HM-patients, mostly survivors, were included. In the vast majority of studies the informal caregivers were not interviewed.

Secondly, studies were often only performed once during the treatment, so therefore prospective studies are needed starting from the time of diagnosis and continued during the treatment, since need for information may change throughout the cancer trajectory.

Thirdly, more research is needed on which factors are associated with perceived need for information and satisfaction with information provided among HM-patients and their informal caregivers exactly. This knowledge is of clinical importance to be able to tailor information to the individual patient and caregiver as much as possible in the future. It is also important to know more about the tendency of HCPs to tailor information and whether this depends on certain characteristics of the HCPs themselves or the setting they are working in.

Finally, within the scope of SDM, more insight is needed whether HM-patients and caregivers prefer to be involved in SDM.

RATIONALE, SCOPE AND OUTLINE OF THIS THESIS

The main aim of this thesis is to obtain insight into the perceived need for information, satisfaction with information, and SDM preferences from the perspective of HM-patients, their informal caregivers and HCPs.

The first objective is to gain a better understanding on these needs among HM-patients. Three studies were carried out to reach this objective. First a literature review was conducted on the current knowledge on the perceived need for information among HM-patients (Chapter 2). Then, a questionnaire was composed to assess the perceived need for information and satisfaction with information provided: the Hematology Information Needs Questionnaire with 92 items (HINQ). The HINQ was used in a cross-sectional study to obtain deeper insight into the perceived need for information among HM-patients, their satisfaction with the information provided, and their preference for SDM. Also, possible sociodemographic and clinical moderating factors, HRQOL and cognitive coping style were explored (Chapter 3). The fourth study aimed to investigate HM-patients' cognitive coping style in relation to their need for information, information satisfaction, and SDM preference (Chapter 4).

The second objective is to prospectively investigate the perceived need for information, satisfaction with information provided and preference for SDM, from baseline to 18 months follow-up, among HM-patients as well as their informal caregivers, in relation to

sociodemographic and clinical characteristics, cognitive coping style and HRQOL. For that, a prospective study was designed using the HINQ with assessment times at diagnosis, and 3, 6, 12 and 18 months follow-up. This prospective study is ongoing, and in this thesis the results of HM-patients and their caregivers at time of diagnosis are presented (Chapter 5).

The third objective of this thesis is to investigate the way HCPs tailor information to individual HM-patients. For that, the perspectives of HCPs were explored on the need for information of fictive newly diagnosed HM-patients, and whether the estimated need was associated with HCPs' cognitive coping style, sociodemographic and work-related characteristics (Chapter 6).

Finally, since a validated HM-specific information needs questionnaire is not available with specific items associated with HM and their treatment, information needs are often assessed with study-specific questionnaires as was shown in a recent literature review (chapter 2), which hampers comparison of information needs of HM-patients across studies and in clinical practice. We used data from the previous studies (Chapter 3 and 4) to shorten the questionnaire (which we will call the HINQ) and investigate further the psychometric characteristics of the HINQ (Chapter 7).

This thesis is completed by Chapter 8 in which the main findings of this thesis are discussed, as well as the clinical implications and suggestions for future research.

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CHAPTER 2

PERCEIVED NEED FOR INFORMATION OF PATIENTS WITH HEMATOLOGICAL MALIGNANCIES; A LITERATURE REVIEW

J.A.J. Rood

C.M. Eeltink

F.J. van Zuuren

I.M. Verdonck-de Leeuw

P.C. Huijgens

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ABSTRACT

INTRODUCTION

Providing timely and accurate information to patients diagnosed with a hematological malignancy is a challenge in clinical practice; treatment often has to start promptly, with little time to inform patients. The aim of this literature review is to provide insight into the perceived need for information of patients with hematological malignancies.

METHODS

A comprehensive literature search was conducted from all available literature to May 2013 in the databases: CINAHL, PsycINFO and PubMed (Medline). Relevant studies were reviewed regarding the perceived need for information on various topics, sources of information and satisfaction with information provided.

RESULTS

The initial search revealed 215 articles, fourteen of which were relevant. Patients need basic information on the disease (diagnosis and diagnostics), treatment (various treatment options, side-effects and duration), prognosis (curability and prolonging life) and all other topics (recovery, self-care and psychosocial functioning). Need for detailed information varied between studies. Patients expressed a higher need for medical than psychosocial information. Patients preferred to receive information from their doctors the most, followed by nurses. Most studies described patients' satisfaction with the information provided.

CONCLUSION

Based on the limited number of data available, medical information is for patients of higher priority compared to psychosocial information. Patients need basic information on diagnosis, treatment, prognosis and all other topics. Need for detailed information varied between studies. Patients were satisfied with the provided information, preferably offered by doctors and nurses.

INTRODUCTION

In the past years there has been growing attention concerning the need for information and sources of information among cancer patients in general.^{1,2} Unfulfilled information needs may cause anxiety, depression, reduced ability to cope with the disease, difficulties in gaining control, non-compliance and sexual problems.²⁻⁵ On the other hand, benefits of enhanced provision of information include increased patient involvement in decision-making, realistic expectations, greater satisfaction with treatment choices and a better quality of life.^{2,4,6-8} Moreover, patients' recall of information is often hampered because they are overwhelmed by the diagnosis.⁹⁻¹³

Providing timely, efficient and accurate information is especially for patients diagnosed with a hematological malignancy, a challenge in clinical practice. These patients often have a substantial chance of cure, even though the diseases are almost always disseminated at diagnosis. However, intensive therapy has to be started early in order to be effective, especially in case of acute leukemia, aggressive lymphoma or multiple myeloma with organ failure, treatment has to start within a few days after diagnosis, to prevent more severe illness, permanent organ failure and complications. On the other hand, patients are subject to imminent and daily danger of serious and even fatal infections and bleeding due to the disease and the treatment, especially in case of high dose chemotherapy and autologous or allogeneic stem cell transplantation. Moreover, the impact of the disease and treatment on quality of life is substantial. Worldwide, on an annual base, more than 850.000 patients are diagnosed with a hematological malignancy.¹⁴ In spite of the large number of patients, detailed information on the information needs of patients with hematological malignancies is not readily available. It is essential to understand the need for information of this specific group of patients, because there are large differences between the behavior, treatment and outcome of hematological malignancies and solid tumors. Furthermore, because of the shift of tasks from doctors to clinical nurse specialists, clinical nurse specialists are the new professionals with whom cancer patients regularly come into close contact, and giving them a vital role in patient information provision.

The purpose of this literature review is to provide an overview of the studies investigating the information needs of patients with a hematological malignancy. Furthermore, we aim to examine the associated factors related to the need for information, the information sources used and the extent to which patients are satisfied with the information provided. The results will contribute to a better understanding of the perceived need

for information of patients with hematological malignancies and may help to improve existing sources of information, develop new ones and help doctors and (specialist) nurses with more patient targeted information provision.

METHODS

SEARCH STRATEGY

A literature search was conducted in the following databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO and PubMed (Medline). A collection specialist performed the search at June 2013. The following search terms were used as key word, free text word, and words in title and abstract: hematologic neoplasms, leukemia, lymphoma, multiple myeloma, combined with the search terms: information need, information needs, patient information, patient education, health education.

SELECTION CRITERIA

A study was eligible for inclusion if 1) reported on the perceived need for information by patients with hematological malignancies; and 2) were written in English or Dutch. No restrictions were made regarding the year of publication. Studies were excluded if they 1) described the development or implementation of a survey instrument, 2) reported on information needs of family members and carers of cancer patients, 3) reported on patients below eighteen years of age, 4) reported on coping or quality of life of patients with hematological malignancies, 5) evaluated the effectiveness of information courses for hematology patients, their family members or healthcare professionals, 6) describing various treatment related topics of patients with hematological malignancies and 7) reported on patients with solid tumors. The reference lists of all selected studies were screened for studies not identified in the database search. This yielded no additional articles.

STUDY SELECTION

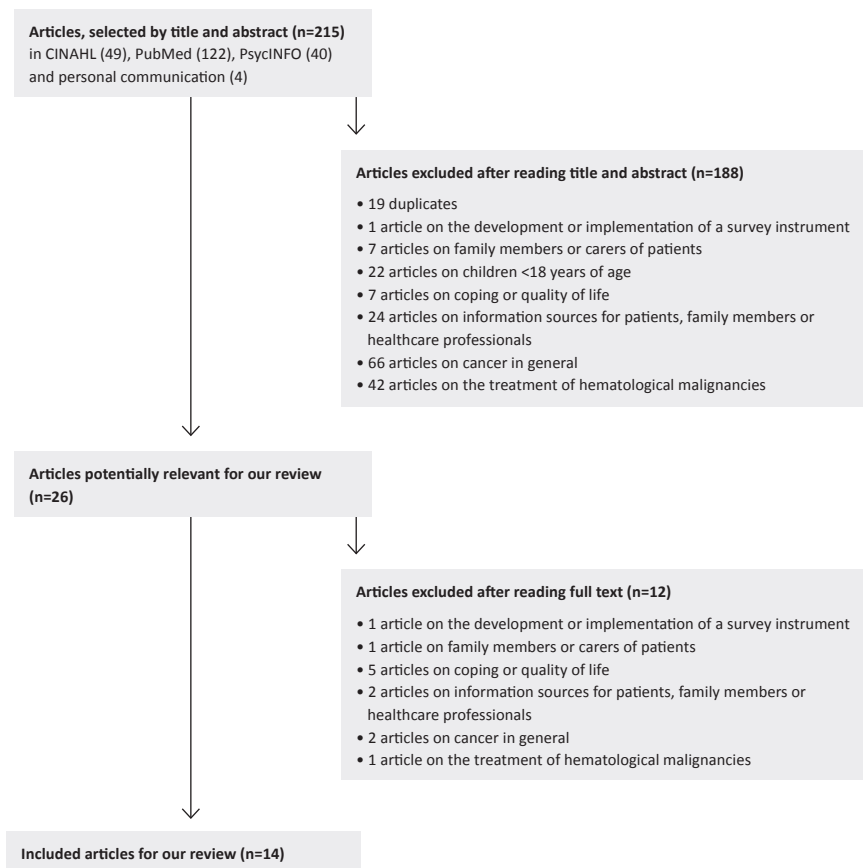
Studies were selected in two steps. First, independent from each other, an initial selection was made, using the inclusion and exclusion criteria, based on titles and abstracts. In case of ambiguity, the full text of articles was read. Second, studies that possibly met the inclusion criteria, studies without an abstract, and studies that could not clearly

be excluded based on title and abstract were retrieved in full text and scrutinized more extensively for eligibility by the two reviewers (JR and CE), independently of each other. Studies of uncertainly were discussed with a third researcher (PH) until consensus was reached.

SEARCH AND ARTICLE SELECTION

The initial search in CINAHL, PubMed (MedLine) and PsycINFO revealed 211 articles. Four articles were found by personal communication. Based on title and abstract, we excluded 189 articles that did not meet our inclusion criteria. Of the remaining 26 potentially relevant articles were read the full text, of which finally fourteen articles were relevant to our review^{15–28}. (See Figure 1).

Figure 1 Flowchart of article selection



QUALITY ASSESSMENT

The quality of the studies were reviewed by the first author (JR) and verified by a second reviewer (CE), using for quantitative or mixed method studies suitable topics of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist²⁹, the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement checklist³⁰, and the Meta-analysis of Observational Studies in Epidemiology (MOOSE) statement.³¹ In order to assess the quality of the qualitative studies we used the quality framework for social research.³² Each item that matched our criteria was assigned as one point. The maximum score on quantitative/mixed studies was 33 points; the maximum score on qualitative studies was seventeen points. Items with partially matched criteria were counted in the total score. Studies scoring two thirds or more of the maximum points were assessed as adequate quality. All fourteen studies met the assessment, and were of adequate quality. However, none of the studies reported details on how was dealt with missing data, and most studies did not describe details about possible bias of the studies. In all studies, the sample size was described, but none of the studies described the rationale of this chosen sample size. The quality of the four qualitative studies was also of adequate quality according to the framework of quality research³² (see the addendum).

CHARACTERISTICS AND QUALITY ASSESSMENT OF THE INCLUDED STUDIES

Twelve articles were published less than ten years ago, and seven articles recently (less than four years ago). All articles originated from Western countries. Three were retrospective studies, nine were cross-sectional studies, one study both cross-sectional and retrospective, and one was a longitudinal study. Most articles reported on a small sample size (less than seventy patients). Age of patients, type of hematological malignancy, and time since diagnosis and treatment modality varied substantially among the studies. To assess the need for information eight studies used questionnaires, four studies used interviews, and two studies used a combination of both. Table 1 gives an overview of all characteristics of the reviewed articles.

Table 1 Characteristics of the studies

Author	Year	Diagnosis	Time since diagnosis	Age	Patients	In or outpatients	Country	Method	Questionnaire	Study design	Participating hospitals
Orlemans	2012	NHL, HL, MM	Mean 3.7 years	Mean 61.6	1135	Out	The Netherlands	Survey	EORTC QLQ-INFO25	Cross-sectional	Ten hospitals
Tariman	2011	MM	At diagnosis	Mean 67.5	20	Out	United States	Semi structured interviews and survey	INQ	Cross-sectional	Two hospitals
Friedman	2010	NHL	Mean 4.7 year	Mean 64.2	67	Out	United States	Survey	Self made	Cross-sectional	Single centre
Gansler	2010	Leukemia, lymphoma, MM	All stages	Adults	29	-	United States	In-depth interview and ranking priorities	-	Cross-sectional	-
Grinyer	2010	HL	5-34 years	23-45	3	Out	United Kingdom	In-depth interview	-	Retrospective	-
Mohamedali	2010	AML	At diagnosis, 1 month after diagnosis and 5-6 months after diagnosis	18-59 and >60	35	Out	Canada	Survey	CPS, Decisional Regret Scale and SWD	Cross-sectional	Single center
Parry	2010	NHL, HL, MM, AML, ALL, CML, CLL	Mean 29 months since treatment	Mean 50.3	51	Out	United States	In-depth interview	-	Cross-sectional	-
Lobb	2009	NHL, HL, MM, leukemia	Mean 8 months since treatment	Mean 54	66	Out	Australia	Survey	CaSUN	Cross-sectional	Two hospitals
Yogaparan	2009	AML	At diagnosis	Mean 64	31	-	Canada	Survey	CPS	Cross-sectional	Single centre
Broeren	2008	MM	To more than 9 years	Median 60	15	Out	The Netherlands	In-depth interview	TINQ-BC, PMS and PINQ	Retrospective	-
Hammond	2008	NHL	2-5 years	Adults	250	Out	United States	Survey	-	Cross-sectional	-
Jonker-Pool	2004	NHL, HL	Median 7.6 years	Median 42	50	Out	The Netherlands	Survey	Adapted version of UCLA/RAND sexual module and the Groningen sexual questionnaire	Cross-sectional and Retrospective	Single centre
Fris	2003	AML	At diagnosis and 2-5 months later	Adults	21	First time in, second out	Denmark	In-depth interview	-	Longitudinal	Single centre
Turner	1996	HL	Median 8 years since treatment	Median 36	165	Out	United Kingdom	Survey	-	Retrospective	-

MM = multiple myeloma, NHL = non-Hodgkin lymphoma, HL = Hodgkin lymphoma, AML = acute myeloid leukemia, ALL = acute lymphatic leukemia, CLL = chronic lymphoid leukemia
 - = Unknown

DATA ABSTRACTION

Data of the studies were abstracted by JR, using a data abstraction form in Excel, and was verified by CE. The data that were abstracted included: design of the study, aim of the study, diagnosis, time since diagnosis, number of patients, median/ mean age of the patients, questionnaire used and participating hospitals. Based on a systematic review describing the need for information of cancer patients in general, the included studies were analyzed regarding the need for information on various important themes: 1) the diagnosis cancer, 2) treatment, 3) prognosis, 4) rehabilitation, 5) coping, 6) social functioning, 7) surveillance and health, 8) financial or legal issues, 9) the medical system and 10) body image / sexuality.¹

Furthermore, included studies were analyzed regarding 11) various sources of information, and 12) satisfaction with the information provided. Data of the included studies were analyzed by the two researchers JR and CE, independently of each other. By means of a consensus meeting we came to a common judgment.

RESULTS

PERCEIVED NEED FOR INFORMATION

1. Cancer specific information

The theme cancer specific information was reported in eight out of fourteen (57.1%) included articles. Almost all patients wanted basic information about their diagnosis, such as the diagnosis and the curability.^{21, 25} However, the need for detailed information, such as different subtypes of their disease, varied between studies.^{21, 25} Patients with acute myeloid leukemia (AML) seemed to have a low need for detailed information at diagnosis.²¹ A low information need for details was present, especially in the elderly multiple myeloma (MM) and AML patients.^{21, 25} In contrast, one other study on patients with AML aged fifty and older, reported that these patients wanted to know details about their diagnosis.¹⁹ (For details on all information needs, see table 2a and 2b).

The priority of information needs varied, but overall, medical topics such as cancer specific information and treatment related information, seemed to have more priority than psychosocial information.^{17, 22, 23} Regarding the phase of the disease, the need for information was highest in the diagnostic and early treatment phase, at least in patients

with MM.²⁵ For disease specific information, the priorities at time of diagnosis were cancer type, diagnostics and risk factors for hematological malignancies.¹⁷ Survivors of lymphoma en MM wanted to have more information about the cause of the disease.²⁷

2. Treatment and decision-making

The most cited category was treatment and decision-making, described by eleven out of fourteen included studies (78.6%). Patients wanted basic information on treatment options, possible short- and long-term side-effects and the duration of treatment.^{17, 22, 25} Also, general information about stem cell transplantation was highly appreciated.²⁵ Information on clinical trials and recent advances in research was another important subject.¹⁷ In the first week after diagnosis, relevant information for patients with acute leukemia was related to practical and individual problems during treatment, such as the psychological and physical impact of the treatment and how to deal with various side-effects.²¹

After the completion of treatment, information on problems related to treatment or on the development of secondary malignancies was very important.^{16, 18, 23, 27} Other important topics were an overview of anti-cancer treatments, screening options for the recurrence of cancer and health problems due to cancer treatment.²³

Patients who did not reach cure expressed different needs for information. These patients were more interested in treatment plans, such as palliative treatment and supportive care. In one study, patients valued information about nutrition, vitamins, and complementary medicine as relevant²¹, but other studies reported information concerning complementary and alternative therapies as not very important.^{23, 25}

The need of detailed information concerning treatment varied between the studies, similar as diagnosis specific information. In the study by Yogaparan, patients with AML older than fifty considered details about treatment as important; almost all patients wanted to know the most important treatment options (94%), the possible side-effects (97%) and how treatment works (97%).¹⁹ Contradictory, admitted patients with AML and patient with MM did not attach importance to details about the therapy, such as the composition of chemotherapy medications, and how the treatment affects the immune system.^{21, 25}

Most patients were not actively involved in treatment decision-making. Less than half of the MM patients wanted to contribute to decision-making for their treatment plan.

These patients trusted their doctor in offering the best treatment options.²⁵ This is consistent with a study on 165 Hodgkin lymphoma (HL) patients, which reported that the doctor made all treatment decisions in 62% of the cases. In this study, 58% of the patients considered themselves as much involved as they wanted to be. These percentages were not influenced by the treatment outcome.²⁴ Patients considered early temporary side-effects as more important in treatment decision-making than late morbidity.²⁴ Most patients with acute leukemia also preferred and played a collaborative or passive role in treatment decision-making.^{19, 28} In contrast, Tariman and colleagues reported that most patients (95%) diagnosed with MM wanted shared and active roles in decision-making, possibly moderated by the higher education and income level of the patients in this study.²² Various factors influenced the patients' attitude in decision-making, such as gender, age and health status. Males played a more passive role than females.¹⁹ Elderly patients and physically ill patients with AML also were more likely to leave matters in the hands of the doctor²¹, but in another study with AML patients, no differences were found regarding age.²⁸ Furthermore, members of a patient association had a higher need for general information and detailed information and showed a higher involvement in decision-making.²⁵

3. Prognosis and follow up

Information concerning prognosis and follow up was mentioned in five out of fourteen studies included (35.7%). Overall, basic information concerning prognosis was important for patients. Of the patients with AML older than fifty, 94% wanted to know the chances of prolonging life with treatment.¹⁹ Moreover, patients with all kinds of hematological malignancies wanted to know the risks and treatment of recurrence of the disease.^{16, 17} But detailed survival information, such as remission rates, was not important for admitted AML patients, similar as diagnosis and treatment related information.²¹

4. Rehabilitation

One of the least mentioned themes is rehabilitation information with a score of three out of fourteen (21.4%). Patients mostly appreciated information about recovery in the home situation after completion of therapy, e.g. stem cell transplantation and information concerning care routines and home modifications.²⁵ Older patients with MM considered information on self-care as third priority, possibly due to the wish to stay independent.²² Other important issues were information about physical and psychosocial recovery and nutrition.¹⁶

5. Coping

Another not frequent mentioned theme is information concerning coping, mentioned in four out of fourteen studies (28.6%). Several studies reported reasons why patients avoided information, such as the fear of losing hope or lack of energy.^{21, 25} While other studies showed that patients wanted information about other patients and about the impact of the illness on their daily life.^{15–17, 21} However, other studies showed that a majority of the patients were not interested in contact with other patients.^{17, 25}

6. Social functioning

Information on social functioning was mentioned in six out of fourteen articles (42.9%). It was considered as important, but seems to have a low priority.^{17, 23, 25} Other important items were support for their partners, how the disease could affect their family situation and how to tell the children about the disease.²⁵ In most studies, only a minority of the patients were interested in information on psychosocial care for themselves or for their partners.^{15, 25, 27} Social support and how to talk with physicians were rated as the least important information needs^{17, 23}.

7. Surveillance and health

The least frequent mentioned theme was surveillance and health information, cited in two out of fourteen articles (14.3%). Information on health services was mentioned in two studies. Lobb reported that 68% of the patients with hematological malignancies needed information on available local health services.¹⁵ After treatment, patients younger than sixty, considered a plan for monitoring overall health service and mental health important. However, mental health service was valued as one of the least important information issues.²³

8. Financial and legal issues

Financial and legal information was mentioned in three out of fourteen articles (21.4%). Information about insurance and financial information related to the disease was important for survivors.^{16, 17, 23} This was especially important in the phase after initial treatment.¹⁷ Some patients expressed a need for information on financial compensation for home adjustments.²⁵

9. Body image / Sexuality

Body image and sexuality related information was discussed in five out of fourteen articles (35.7%). Although sexuality and fertility was one of the least important issues^{22, 23}, a need for information was expressed especially by young males with malignant

lymphoma.^{20, 23, 26} Males rated fertility and sexuality information as more important than women.^{23, 26} MM patients wanted information concerning the influence of medication on the fertility and the reaction of the body after SCT.²⁵

SOURCES OF INFORMATION

Sources of information were discussed in 53% percent of the reviewed articles^{15, 16, 19, 21, 22, 24, 25, 28} (See table 3). The most important information patients received came from their doctors^{16, 19, 25, 28}, followed by nurses.^{19, 21, 22, 28} Another important information source was printed material.^{16, 19, 21, 22, 24, 25, 28} Patients found that information leaflets provided control over the degree and the timing of absorbing information about their condition. They found it useful to know that the information was in their possession, so they would have access to it at a later stage, for example for questions that might arise at home.^{19, 24} One study found that printed information about leukemia in general was glanced at, but that the patients were rarely able to recall much of the content two months after diagnosis.²¹

Most patients found information via the Internet useful.^{16, 22, 25} Some reported that the information was not up to date, and some patients said the information was too overwhelming and confronted them too much with the possible course of the disease. For some patients this was a reason for not seeking information on the Internet. Others valued information on the Internet supplemental to the information provided by their doctor.²⁵ Meeting other patients with the same disease was also mentioned as a source of information.^{15, 22, 25}

SATISFACTION WITH INFORMATION

Satisfaction with the received information was discussed in eight of the fourteen reviewed articles^{18 -21, 24 -27} (see table 4). Satisfaction with the information received varies widely, ranging from 52 to 67%.^{20, 24, 27} Results of five studies revealed that patients were satisfied with the information received by their doctor.^{19, 21, 24, 25, 27} Patients found the doctors good judges of the amount of information the patients wanted.^{19, 25} Those who wanted little information about their condition appreciated the fact that the information was not forced on them.²⁵ Friis reported that some AML patients said they often received information they did not ask for.²¹

Table 2a Details of medical information needs per topic

Author	Cancer specific information	Treatment-related and decision-making information
Broeren	Almost all patients want information about their diagnosis. Most important information is how to tackle the disease. Only a few patients want information concerning procedures or tests.	Almost all patients want information about the best treatments and possible side-effects. They are not interested in detailed treatment information. Less than half of the patients are actively involved in decision-making. They are interested in different treatment options.
Friedman	Medical issues are rated as more important than psychosocial issues.	After completion of treatment patients rate a summary of the anti-cancer treatments as important. An alternative medicine technique is rated as least important information. After the completion of treatment patients rate a plan to screen for possible return of the cancer and health problems due the cancer treatment as important. Patients in partial remission want to have information about palliative treatment and supportive care, such as information about nutrition, vitamins and complementary medicine. In the first week after diagnosis relevant information seemed to be related to practical and individual problems during treatment, for instance how to deal with various side-effects
Friss	Apart from basic information such as the diagnosis, the curability and the duration of the treatment, patients are rarely interested in details of the diagnosis, prognosis and therapy.	At diagnosis, the most important information is treatment options and long-term side-effects of treatment. Patients also would like to have information on clinical trials and recent advances. After initial treatment, during relapse, remission or the maintenance of therapy most important information is prognostic information such as follow-up tests to detect recurrence. Medical information is more important compared to psychosocial and coping information. During treatment, information about treatment options, long-term side-effects and coping with side-effects is important for patients.
Gansler	At diagnosis, cancer type, diagnostics and risk factors for cancer, are the priorities for cancer specific information.	Patients lack information on the late effects of mantel field radiotherapy on the arise of secondary malignancies. This information was not easy to access.
Grinyer		
Hammond		
Jonker-Pool		
Lobb	66% of the patients want understandable information, 62% of the patients want up to date information about their disease	
Mohamedali		52% of the patients preferred to play a collaborative decision-making role. 37% preferred a passive role and 11% an active decision-making role.
Oerlemans	29% of the patients wanted more information. One topic, on which patients would like to have more information, was the course and cause of the disease (24-59% of the patients). Patients without comorbidity, using the internet for information or the hospital of treatment were associated with receiving more disease related information.	Patients want more information concerning late effects of treatment (30-50% of the patients). Receiving more information on treatment was associated with a younger age, less comorbidity, having a treatment of chemotherapy and the hospital of treatment. Receiving more information on medical tests was associated with less comorbidity, higher education level and the use of internet. Indolent-NHL patients and MM patients under active surveillance had a lower perceived level of received information concerning treatment.
Parry	Patients lack medical and psychosocial information after treatment. They don't know where to find this information	Patients want to know the risks of developing secondary malignancies and their treatment.
Tariman		Patients at diagnosis, rate the different types of treatment and the advantages and disadvantages of these treatments as most important information.
Turner		In deciding choice of therapy, 61% of the patients thought that short-term, temporary side-effects as nausea, vomiting and infections are most important, while 15% thought late problems as development of secondary malignancies and relapse of disease are more important. In 62% of the patients the doctor makes all treatment decisions. Of all patients, 58% were as much involved, as they wanted. These percentages were not influenced by the treatment outcome.
Yogaparan	97% of the patients (absolutely) want to know the specific medical name of the illness.	94%, 97% and 97% of the patients (absolutely) want to know respectively: the major treatment options, the possible side-effects and how treatment works. Most patients preferred and played a collaborative or passive role in treatment decision-making. Males played a more passive role than females.

Table 2a Details of medical information needs per topic (continuation)

Author	Prognostic information	Body image and sexuality information
Broeren	Only a few patients asked for their prognosis themselves, others read written information concerning prognosis. Patients want honest and straight ward information about their prognosis.	Patients want information concerning the influence of medication on their fertility. Information about the reaction of the body after SCT was also important.
Friedman		Sexuality and fertility is one of the least important issues.
Friis	Many patients don't want specific information about their prognosis.	
Gansler		
Grinyer		
Hammond		13% of the patients want more information about fertility. This is related to a younger age, non-white ethnicity, less co-morbidity, a better physical function and a less than excellent perceived quality of care. 28% of the patients want more information about sexual functioning. This is related to male gender and a treatment of SCT.
Jonker-Pool		27% of the patients need information concerning sexuality; this is related to a younger age.
Lobb		
Mohamedali		
Oerlemans		
Parry	Patients want to know the risks and treatment for recurrence of the disease.	
Tariman	The second priority of information is the likelihood of cure.	The lowest information priority for patients is feelings about the body and sexual attractiveness.
Turner		
Yogaparan	94% of the patients want to (absolutely) know the chances of prolonging life with treatment.	

Table 2b Details of psychosocial information needs per topic

Author	Rehabilitation information	Coping information	Social information	Surveillance and health information	Financial and legal information
Broeren	Information concerning the recovery in the home situation is highly appreciated, especially in patients receiving SCT.	Only a few patients need information concerning psychosocial support for themselves or partners. The majority of the patients are not interested in contact with fellow patients.	Few patients wanted information concerning how the disease could affect family situations. Psychosocial information is rated as less important than medical information. Social support is rated as one of the least important information needs.		Some patients need an advisor for financial help for supportive instruments.
Friedman				Mental health service is rated as one of the least important information priorities.	
Frijs		Several patients want information about other patients and the impact of the illness on their life. One of the reasons for not seeking information is the fear of losing hope. Patients are interested in ways to be involved with other cancer patients. One of the least important information priorities during all treatment phases is support groups.	How to talk with physicians is one of the least important information priorities.		Financial and insurance information is most important for patients in the phase after initial treatment
Gansler					
Grinyer					
Hammond					
Jonker-Pool					
Lobb		59% of the patients need to talk to others who have experienced cancer.	73% of the patients want support in concerns about return of the disease. 55% of the patients need information for their partner or family.	68% of the patients would like to have information about available local health service.	
Mohamedali					
Oerlemans					
Parry	Patients want to know information about the physical and psychosocial recovery.		Psychosocial aftercare was a topic survivors wanted more information about (10-30% of the patients).		
Tariman	For patients the third information priority is caring for their self at home.		Patients lack psychosocial information after treatment. They also want information about where to go for support groups and help with nutrition.		Patients want information about financial and insurance issues.
Turner					
Yogaparan					

Table 3 Sources of Information

Author	Sources of information
Broeren	Most important information came from doctors. Most information was sought from sources inside the healthcare. Other information came from the internet and a patient association.
Friedman	
Friis	Patients sought information by asking nurses and fellow patients. Printed information was glanced at, but patients could not recall this information.
Gansler	
Grinyer	
Hammond	
Jonker-Pool	
Lobb	Talk to others who experience cancer was one of the unmet needs of patients with hematological malignancies.
Mohamedali	Physicians, followed by nurses, were the most useful sources of information.
Oerlemans	
Parry	The most preferred information sources were health professionals, support groups, the internet, telephone or printed materials.
Tariman	Patients have different sources of information; the internet, doctors, family and friends, books, pamphlets, nurses, other patients and support groups.
Turner	90% of the patients would appreciate written information.
Yogaparan	Most common sources of treatment information were doctors, nurses and written material. The most uncommon sources were family and friends and other patients and the internet.

Table 4 Information satisfaction

Author	Satisfaction with the information received
	Overall patients were very satisfied with the information received by their specialist. The majority was satisfied with the information concerning prognosis, rehabilitation and treatment. Some patients lacked information about side effects of treatment.
Friedman	
Friis	Patients were satisfied with the information received.
Gansler	
Grinyer	Patients lacked information concerning the risks of secondary malignancies after radiotherapy for NHL.
Hammond	13 and 28% of the patients 2-5 years after diagnosis with non-Hodgkin lymphoma would have more information concerning respectively fertility and sexuality.
Jonker-Pool	50% of the patients thought the information about sexuality was (absolutely) insufficient.
Lobb	
Mohamedali	
Oerlemans	67% of the patients were satisfied with the information received. Satisfied patients received more information concerning disease, medical tests, treatment and other services. Satisfied patients found the information received more useful compared with dissatisfied patients. Patients with Hodgkin lymphoma were more satisfied than indolent non-Hodgkin lymphoma survivors. The satisfaction with information was positively associated with having treatment of chemotherapy and negatively with comorbidity.
Parry	
Tariman	
Turner	48% of the patients felt they had not received enough information, 51% had as much information as they needed. 52% of the patients were satisfied with the information; this was associated with a greater satisfaction with the involvement in decision-making. Treatment outcome did not influence this.
Yogaparan	The majority of patients felt that they received adequate information to make their treatment decision.

DISCUSSION

This literature review shows that there are few and contrasting data on the need for information in patients with a hematological malignancy.^{15–28} This is in contrast with the large number of data on the information needs of cancer patients in general, which was described in a review of 112 studies.¹ The results of the present review showed that patients with hematological malignancies need basic information on the disease (diagnosis and diagnostics), treatment (various treatment options, side-effects and duration), prognosis (curability and prolonging life) and all other topics (recovery, self-care and psychosocial functioning). Need for detailed information varied between the included studies. Patients expressed a higher need for medical than psychosocial information. Most studies reported a passive involvement in treatment decision-making. Patients preferred to receive information from their doctors the most, followed by nurses. Most studies described patients' satisfaction with the information provided.

These results of the present review show that the need for information seems similar in patients with a hematological malignancy and in cancer patients with solid tumors, but there are some important differences. Regarding the need for information on the disease and treatment, patients with cancer in general want as much information as possible, good as well as bad news^{33–35}, and they prefer to receive detailed, but tailored information.³⁵ Patients with hematological malignancies show a need for general information, but not for so much detailed information on their diagnosis, treatment and side-effects.^{19–21, 23, 25, 26} The lower need of detailed information in patients with hematological malignancies may be explained by the fact that a substantial number of these patients are initially in an acutely life-threatening situation and are often hospitalized at the moment of their diagnosis.²¹ Similar to patients with cancer in general, they showed a higher need for information on medical issues than on psychosocial issues.^{1, 17, 22, 23, 36, 37} This also may reflect the often acute life-threatening situation in patient with hematological malignancies, which may trigger the need to be informed on diagnosis and treatment, whereas a need for information on practical and long-term consequences of the disease is expressed at a later stage. A study on the quality of life of patients after allogeneic stem cell transplantation, revealed similar results. Across their transplant trajectory, treatment influenced the first period the physical related quality of life in particular, and thereafter treatment effects other quality of life dimensions including psychological and role functioning.³⁸

It seems that elderly patients have a lower need for information, are less interested in details and are more passive in decision-making than younger patients, both among patients with solid tumors and among patients with hematological malignancies.^{13, 21, 25, 34, 35, 39, 40} A possible explanation for the differences in degree of detailed information in the studies of Friis and Yogaparan may be the hospitalization in the first study, and possibly also the different methods of the studies.^{19, 21} Considering the higher cure rate in younger patients with hematological malignancies, information on sexuality and fertility is important.^{20, 23, 26}

Besides age, factors such as gender, socio-economic status, educational level, and coping style may also influence the need for information in cancer patients in general^{134, 35, 41–43}; little mention of these factors could be found in the studies reviewed. Despite the fact that demographic factors, were in none of the reviewed articles a primary or secondary objective, this review on hematologic cancer patients found no evidence that differences in gender^{21, 25}, education level^{21, 25, 25, 43}, partner status or income²², might be possible moderating factors. In one study, membership of a patient association influenced the need for information.²⁵ Regarding gender and need for information on fertility and sexuality, Friedman and Hammond reported that men with NHL had higher needs than women.^{23, 26} It may be possible that a different style of coping with the disease is a moderating factor.^{21, 25}

According to the literature, satisfaction with the information received is important, because information satisfaction, fulfilled information needs and fewer information barriers are related to a better quality of life.^{7, 8} Among patients treated for hematological malignancy, satisfaction with the information received varies widely, ranging from 52 to 67%.^{20, 24, 27}

Providing information could improve the treatment decision-making process.⁴⁴ A recent study reported that out of all the information sources, the treatment staff influences the treatment decision most.⁴⁵ Regarding shared decision-making, patients with cancer in general want to share responsibility for decision-making, while this seems less evident in patients with hematological malignancies.^{19, 21, 24, 25, 34} There are some factors that may explain this difference, such as coping style and physical condition. Coping style may be related to shared decision-making and the need for information: some patients may actively search information, while others tend to avoid getting information.^{21, 22, 25} A possible explanation for a lower need for detailed information in cancer patients, might be the coping style by avoidance.⁴⁶ Furthermore, patients with hematological

malignancies are often sick or hospitalized during their illness trajectory. As regards the factor age, which is known to have an influence on decision-making in general cancer patients; older patients are more likely to prefer the doctor to make treatment decisions^{6, 34, 40}, which may be related to the fact that older patients are more familiar with a paternalistic style of making treatment decisions.^{6, 40} However, this does not explain the more passive form of decision-making in hematology patients, because the age-distribution of hematology patients is in line with the age distribution in patients with cancer in general.⁴⁷

In the results of this review we focused on the information needs of patients. It is important to realize that patients can have a different perception of importance of information than doctors and nurses. Doctors attached importance to medical technical information such as the meaning of remission.²¹ Concordance on the importance of medical technical information seems to be high between doctors and patients, but this is not the case for psychosocial information.²³ Remarkably, patients' preferences for decision-making, information, and understanding of this information is rarely discussed between doctors and patients with hematological malignancies.⁴⁸ Doctors proved to be the most important source of information for general cancer patients as well as for patients with hematological malignancies.^{1, 19, 21, 25, 33, 49 – 52} However, nurses are also important in providing information.^{19, 21, 28, 51} An emerging information source is the Internet.^{25, 52 – 54} Older patients and less educated patients use the Internet less often^{19, 45, 50}, probably because this age group is less familiar with the Internet as an information source.

METHODOLOGICAL CONSIDERATIONS

The findings in this literature review may have been influenced by a number of factors: Firstly, the fourteen selected studies varied substantially regarding study design and outcome measures. Different methods involved different (study-specific) surveys (validated and not validated), interviews and questions, and thereby different answers. This makes it difficult to compare results of the different studies. The purpose of qualitative studies^{16 – 18, 21, 22, 25} is to investigate the need for information in depth by interviewing a small sample of patients until data satisfaction is reached. Results of qualitative studies are often used as input for the development of questionnaires to be used in quantitative studies. More than a quarter of the articles reviewed were retrospective studies^{18, 20, 24, 25}, with the consequence of recall bias. Moreover, in the selected articles information was often lacking on the characteristics of non-participants and how missing data were dealt with.

Most studies focused on patients who had received diagnosis or treatment several years before, which implies that they probably had different information needs than patients at diagnosis. Another limitation is response bias by more participation of patients in a better physical condition. Finally, most studies did not distinguish between patients with different hematological malignancies, who may have different needs for information due to the different nature of their diseases.

Despite these drawbacks, we presented as clear as possible an overview of the literature currently available on the perceived need for information among patients with hematological malignancies. It is clear that there is a lack of knowledge, especially on information needs of patients at time of diagnosis and of severely ill patients who are treated as in-patients. Besides, there is lack of insight into the long-term effects of treatment, in particular for newly developed treatments. Consequently, not all information needs can be fulfilled.

RELEVANCE TO CLINICAL PRACTICE

Hematologists and nurses both have their own central role in providing patients with basic information concerning diagnosis, treatment options, short and long-term side-effects, and prognosis of the disease. Although psychosocial aspects often have less priority according to this review, it is important to pay attention to the psychosocial aspects of diagnosis and treatment such as implications for work and social life, and rehabilitation. Nurses and other healthcare professionals can provide additional information on specific topics, if needed. Because of the shift of tasks from doctors to clinical nurse specialists, clinical nurse specialists are the new professionals' cancer patients regularly come into close and long-term contact, giving them a central role of responding to the perceived need for information. It is essential to verify whether patients completely understand and are satisfied with the information that is provided. It is also important to identify whether and when there is a need for additional information and a desire for shared decision-making. In addition to oral information, other sources of (multimedia) information may include brochures, websites or apps that should be offered to patients in a personalized manner.

FUTURE RESEARCH

To obtain a better understanding of the perceived need for information among patients across the disease span, future studies are needed, with a qualitative as well

as a quantitative approach, using a uniform assessment for all information categories, including sufficient in- and outpatients for each of the hematological malignancies in different phases of the disease, Furthermore, more insight is needed into the knowledge and attitude of hematologists, nurses and other healthcare professionals regarding the perceived need for information by patients, enabling to improve adequate and personalized information provision.

CONCLUSION

Based on the limited number of data available, patients with hematological malignancies need basic information on diagnosis, treatment, prognosis and other topics. Need for detailed information varied between studies. Medical information is for patients of higher priority compared to psychosocial information. The majority of the patients are satisfied with the information received, preferably offered by doctors and nurses. Providing information and shared decision-making may be improved towards a personalized approach. A large-scaled study is required to better assess the need for information during the entire trajectory, from diagnosis to survivorship or decease, taking into account important moderating factors such as age, type of cancer, treatment modality and coping style.

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ADDENDUM – QUALITY ASSESSMENT

Quantitative studies and mixed studies (qualitative and quantitative)											
STROBE checklist for observational studies											
First Author	Abstract	Background/ rationale	Objectives	Study design	Setting	Participants	Variables	Data sources	Bias	Study size	Statistical methods
Oerlemans	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes/No	Yes
Tariman	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes/No	Yes
Friedman	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes/No	Yes
Gansler	Yes	Yes	Yes	Yes	Yes	Yes/No	Yes	Yes	No	Yes/No	Yes
Mohamedali	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes/No	Yes
Lobb	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes/No	Yes
Yogaparan	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes/No	Yes/No
Hammond	Yes/No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes/No	Yes
Jonker-Pool	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes/No	Yes
Cavusoglu	Yes/No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes/No	Yes
Turner	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes/No	Yes
STROBE checklist for observational studies (continued)											
First Author	Non-participants	Descriptive data	Missing data	Outcome data	Main results	Key results	Limitations	Interpretation	Generalizability	Funding	Total of the maximum 22 points
Oerlemans	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	18
Tariman	No	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	18
Friedman	Yes	Yes	No	No	Yes	Yes	Yes	Yes	No	No	15
Gansler	No	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	No	15
Mohamedali	Yes/No	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	18
Lobb	No	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	17
Yogaparan	No	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	17
Hammond	Yes	No	No	Yes	Yes	Yes	No	Yes	No	No	13
Jonker-Pool	No	Yes	No	Yes	Yes	Yes	Yes/No	Yes	No	Yes	16
Cavusoglu	No	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	No	15
Turner	No	Yes	No	Yes	Yes	Yes	Yes/No	Yes	No	No	14

Quantitative studies and mixed studies (qualitative and quantitative)

First Author	PRISMA checklist										Total of the maximum 10 points
	Abstract	Rationale	Objectives	Eligibility criteria	Bias	Summary measures	Summary of evidence	Limitations	Conclusions	Funding	
Oerlemans	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	9
Tariman	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Friedman	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	No	8
Gansler	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	No	8
Mohamedali	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Lobb	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	9
Yogaparan	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Hammond	Yes/No	Yes	Yes	Yes	No	Yes	Yes	No	Yes	No	6
Jonker-Pool	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes/No	Yes	Yes	9
Cavusoglu	Yes/No	Yes	Yes	Yes	No	Yes	Yes	No	Yes	No	6
Turner	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes/No	Yes	No	7

Quantitative studies and mixed studies (qualitative and quantitative)												
First Author	MOOSE statement										Total of the maximum 11 points	
	Problem definition	Hypothesis statement	Description of outcomes	Study design	Study population	Description of statistical methods	Bias	Alternative explanations for results	Generalization of conclusions	Future research		Funding
Oerlemans	Yes	No	Yes	Yes	Yes	Yes	No	Yes	Yes	No	Yes	8
Tariman	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Friedman	Yes	No	Yes/No	Yes	Yes	Yes	No	Yes	Yes	Yes	No	7
Gansler	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	No	9
Mohamedali	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Lobb	Yes	No	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9
Yogaparan	Yes	No	Yes	Yes	Yes	Yes/No	Yes	Yes	Yes	Yes	Yes	9
Hammond	Yes	No	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	No	8
Junker-Pool	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	10
Cavusoglu	Yes	No	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	No	8
Turner	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	No	9

Qualitative studies									
Framework for qualitative research									
First Author	How credible are the findings?	How has knowledge/ understanding been extended by the research?	How well does the evaluation address its original aims and purpose?	Scope for drawing wider inference - how well is this explained?	How clear is the basis of evaluative appraisal?	How defensible is the research design?	How well defended is the sample design?	Sample composition	How well was the data collection carried out?
Parry	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Ginyer	Yes	Yes	Yes	Yes	Yes	Yes	Yes/No	Yes	Yes
Broeren	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Friis	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Framework for qualitative research (continued)									
First Author	How well has the approach to and formulation of the analysis been conveyed?	Context of data sources	How well has diversity of perspective and content been explored?	How well has detail, depth and complexity of the data been conveyed?	How clear are the links between data, interpretation and conclusions?	How clear and coherent is the reporting?	How clear are the assumptions/ theoretical perspectives/ values that have shaped the form and output of the evaluation?	How adequately has the research process been documented?	Total of the maximum 17 points
Parry	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	17
Ginyer	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	16
Broeren	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	17
Friis	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	17

CHAPTER 3

PERCEIVED NEED FOR INFORMATION AMONG PATIENTS WITH A HEMATOLOGICAL MALIGNANCY *ASSOCIATIONS WITH INFORMATION SATISFACTION AND TREATMENT DECISION-MAKING PREFERENCES*

J.A.J. Rood
F.J. van Zuuren
F. Stam
T. van der Ploeg
C.M. Eeltink
I.M. Verdonck-de Leeuw
P.C. Huijgens

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ABSTRACT

INTRODUCTION

For patients with hematological malignancies, information on disease, prognosis, treatment and impact on quality of life is of the utmost importance.

METHODS

To gain insight into the perceived need for information in relation to sociodemographic and clinical parameters, comorbidity, quality of life (QoL) and information satisfaction, we compiled a questionnaire based on existing validated questionnaires.

RESULTS

458 patients diagnosed with a hematological malignancy participated. The perceived need for information was moderate to high (40–70%). Multivariable regression analyses showed that a higher need for information was related to younger age, worse QoL, being member of a patient association and moderate comorbidity. The need for disease and treatment-related information was higher than the need for psychosocial information. A higher need for disease and treatment related information was associated with being diagnosed with multiple myeloma. A higher need for psychosocial information was related to a lower educational level. The information provision could be improved according to 41% of the patients. Higher satisfaction with provided information was associated with better QoL. Most patients (82%) reported that they wanted to be fully informed about their illness and actively involved in treatment decision-making.

CONCLUSION

The results contribute to improving patient tailored information provision and shared decision-making in clinical practice.

INTRODUCTION

Optimal patient information is increasingly recognized as one of the pillars of modern medicine.¹ A review highlighted the growing interest in need for information among cancer patients.² Unfulfilled information need is a risk factor, because it may cause problems such as reduced ability to cope with the disease, difficulties in gaining control, non-compliance, anxiety, depression and sexual dysfunction.³⁻⁶ On the other hand, benefits of adequate provision of information include increased patient involvement in decision-making, more realistic expectations, greater satisfaction with treatment choices, and a better quality of life (QoL).^{4, 6-9}

While worldwide more than 850.000 patients are annually diagnosed with a hematological malignancy¹⁰, detailed information on the perceived need for information in these particular patients is scarce.¹¹ Possible explanations for this scarcity may be the heterogeneity of this patient group, their relative small number in comparison with solid cancer patients, their often acute and severe presentation, and complex and serious treatment options including high dose chemotherapy and autologous or allogeneic stem cell transplantation (SCT). In addition, in the past years, new and better treatments have become available resulting in a shift from need for information regarding palliative treatment to information targeting cancer survivorship.¹²⁻¹⁵

The aim of this study was to gain insight into the perceived need for information and the satisfaction with information among patients with a hematological malignancy, including information about the disease itself, diagnostic tests, treatment modalities, possible side-effects and complications, physical and psychosocial functioning and supportive care. In addition, we investigated whether sociodemographic and clinical parameters, comorbidity and QoL are associated with the perceived need for information.

METHODS

PATIENTS

Adult patients were asked to participate in the study when they visit the outpatient clinic Hematology at the VU University Medical Center (VUmc), Amsterdam or the Medical Center Alkmaar (MCA), Alkmaar, the Netherlands, between April and December 2010. Participation was restricted to those diagnosed with a hematological malignancy: acute myeloid leukemia (AML), acute lymphoid leukemia (ALL), chronic myeloid leukemia (CML), chronic lymphoid leukemia (CLL), Hodgkin lymphoma (HL), non-Hodgkin lymphoma (NHL), and multiple myeloma (MM). Exclusion criteria were concurrent treatment of another malignancy, terminal phase of the disease, mental or physical inability to participate in the study and lack of basic fluency in the Dutch language. No restrictions were made regarding treatment modality or time since diagnosis.

INSTRUMENTS

To measure the perceived need for information regarding the disease itself, diagnostic tests, treatment modalities, possible complications and side-effects, physical and psychosocial functioning and supportive care, we compiled a questionnaire using existing validated and reliable instruments with complementary subscales: the Toronto Information Needs Questionnaire-Breast Cancer (TINQ-BC)¹⁶, the Patient Information Need Questionnaire (PINQ)¹⁷ and the Patient Learning Needs Scale (PLNS).¹⁸ The English items were translated into Dutch by means of backward and forward translation by a native English speaker and the first and fifth author (native Dutch speakers) of this manuscript, and compared with the original English version. Satisfaction with the current information provision and treatment decision-making was measured by means of the Information Satisfaction Questionnaire (ISQ).¹⁹ QoL was assessed using the European Organization for Research and Treatment of Cancer (EORTC) QLQ-C30 (version 3.0 (Dutch version)).²⁰

Sociodemographic parameters were collected via a short study-specific questionnaire and patient files were consulted to obtain data on type of hematological malignancy. Comorbidity was measured by means of the Adult Comorbidity Evaluation-27 (ACE-27) Test.²¹

INFORMED CONSENT AND PROCEDURE

The study was approved by the Medical Ethical Committee (METC) of VUmc and the METC North-Holland. Written informed consent was obtained from all patients. Patients were offered the choice to complete the questionnaires online, or on paper. If patients did not respond within three weeks, they were contacted once again.

STATISTICAL ANALYSIS

The required sample size consisted of at least 384 patients, based on a 95%-confidence level and an accuracy of 0.05. Moreover, at least thirty patients per diagnosis were desirable for subgroup analysis. Descriptive statistics were generated for outcome measures. All continuous variables were tested for normality with the Kolmogorov Smirnov test. Reliability analysis (Cronbach's alpha) was used to assess the internal consistency of the questionnaire subscales. The Friedman test was used to test differences between subscales. Total and subscale scores were normalized to a 100 scale.

The Mann-Whitney and Kruskal-Wallis tests were used to test differences in information need (total scores and subscales of the TINQ, PLNS and PINQ) between respectively two subgroups and more than two subgroups. The Chi-square test was used to test the association between decision-making preference (ISQ 1) sociodemographic and clinical variables. Spearman correlation coefficients were used to test the association between the perceived need of information and age (years), quality of life (EORTC-QLQ-C30 subscale global functioning), and satisfaction with information (total ISQ score).

Linear regression was used as a multivariable technique to test the relation between the need of information as dependent variable and the independent sociodemographic and clinical variables. Variables with a significance level of $p < 0.10$ in univariate analysis on the (sub) scales of the TINQ, PINQ and PLNS were entered in multivariable regression models.

Pearson's chi square and Mann-Whitney tests were used to test differences concerning sociodemographic and clinical variables between participants and non-participants. For all statistical analyses a p -value < 0.05 was considered to indicate a statistically significant difference. For all analyses we used the statistical software package SPSS, version 19.0

RESULTS

STUDY POPULATION

In total, 458 patients out of 691 patients returned the questionnaire (66% response rate). A minority (7%) completed the questionnaire online. Most patients (64%) were recruited at VUmc. The mean age was 60.2 years and 55% were male. An overview of all sociodemographic and clinical data is presented in table 1 and 2. The majority (62%) also used the Internet as a source of information. The majority of the patients were diagnosed with a lymphoma (45%) and were diagnosed more than two years ago (61%). A substantial number of patients (30%) underwent SCT. Many patients had comorbidity (43%). Between patients who participated in the study and non-participants we found no significant differences in sociodemographic and clinical characteristics, except for treatment intent; among participants this was more frequently active surveillance and treatment with curative intent than among non-participants (table 3).

Table 1 Overview of sociodemographic characteristics of the patients (n=458)

		n	%
Gender	Female	207	45.2%
	Male	251	54.8%
Age	Mean	60.2 (SD 13.7)	
Nationality	Dutch	444	97.6%
	Other	11	2.4%
Hospital	VU University Medical Center	294	64.2%
	Medical Center Alkmaar	164	35.8%
Educational level	Primary education	91	20.6%
	Secondary education	193	43.8%
	Higher education	157	35.6%
Marital status	Single, divorced or widowed	103	22.8%
	Living together or married	349	77.2%
Member patient association	Yes	73	16.3%
	No	376	83.7%
Patient association	Foundation Contact Leukemia	12	18.5%
	Contactgroup Kahler and Waldenstrom patients	30	46.2%
	Lymphoma Association Netherlands	21	32.3%
	Contact group SCT	2	3.1%
Internet use for information	Yes	256	56.8%
	No	195	43.2%

Table 2 Overview of clinical characteristics of the patients (n=458)

		n	%
Diagnosis	Acute lymphatic leukemia	10	2.2%
	Acute myeloid leukemia	28	6.1%
	Chronic lymphatic leukemia	72	15.7%
	Chronic myeloid leukemia	38	8.3%
	Multiple myeloma	104	22.7%
	Hodgkin's lymphoma	33	7.2%
	Non-Hodgkin lymphoma	173	37.8%
Time since diagnosis	< 3 months	35	7.7%
	3 months - < 1 year	69	15.3%
	1 year - < 2 years	72	15.9%
	2 years - < 5 years	134	29.6%
	≥ 5 years	142	31.4%
Treatment intent	Active surveillance	136	37.0%
	Curative	176	47.8%
	Maintenance	29	7.9%
	Palliative	27	7.3%
Treatment response	Complete remission	174	49.3%
	Partial remission	27	7.7%
	Stable disease	118	33.4%
	Progressive disease	34	9.6%
Stem cell transplantation	Not transplanted	282	69.5%
	Transplanted	124	30.5%
Stem cell treatment	Autologous transplantation	58	46.8%
	Allogeneic transplantation	36	29.0%
	Allogeneic and Autologous	30	24.2%
Comorbidity	No comorbidity	229	57.2%
	Mild comorbidity	75	18.8%
	Moderate comorbidity	74	18.5%
	Severe comorbidity	22	5.5%

Table 3 Overview of the sociodemographic and clinical characteristics of participants and non-participants

Variable		Participants	Non-participants	p-value
		Mean	Mean	
Age		60.2	58.6	0.59
Gender	Female	45.2%	36.8%	0.32
	Male	54.8%	63.2%	
Diagnosis	Acute leukemia	8.3%	10.5%	0.97
	Chronic leukemia	24.0%	23.7%	
	Multiple myeloma	22.7%	21.1%	
	Lymphoma	45.0%	44.7%	
Stem cell transplantation	Transplanted	27.1%	23.7%	0.65
	Not transplanted	72.9%	76.3%	
Treatment response	Complete remission	49.3%	64.7%	0.31
	Partial remission	7.6%	8.8%	
	Stable disease	33.4%	20.6%	
	Progressive disease	9.6%	5.9%	
Comorbidity	No comorbidity	57.3%	67.6%	0.066
	Mild comorbidity	18.8%	27.0%	
	Moderate comorbidity	18.5%	5.4%	
	Severe comorbidity	5.5%	0.0%	
Treatment intent	Active surveillance	37.0%	18.9%	<0.001
	Curative	47.8%	37.8%	
	Maintenance	7.9%	32.4%	
	Palliative	7.3%	10.8%	
Time since diagnosis	< 3 months	7.7%	5.3%	0.64
	3 months - < 1 year	15.3%	23.7%	
	1 year - < 2 years	15.9%	13.2%	
	2 years - < 5 years	29.6%	23.7%	
	≥ 5 years	31.4%	34.2%	

Table 4 Internal consistency (Cronbach's α) of the various (sub)scales of the questionnaires on need for information (PINQ, TINQ, PLNS) and information satisfaction (ISQ)

Instrument	(Sub)scale	Cronbach's α
PINQ	Active	0.88
	Disease	0.91
TINQ	Disease	0.89
	Investigative tests	0.92
	Treatment	0.96
	Physical	0.91
	Social	0.91
	Total	0.98
PLNS	Support and care in community	0.92
	Medication	0.95
	Treatment and activities of living	0.91
	Complications and symptoms	0.93
	Illness related factors	0.85
	Total	0.98
ISQ	Total	0.79

Table 5 Overview of mean, SD and ranking of the TINQ (top), PLNS (middle) and PINQ (bottom) questionnaires.

TINQ							
	Disease	Investigative tests	Treatments	Physical	Psychosocial	Friedman χ^2	p-value
Mean (SD)	65.4 (25.2)	64.6 (25.6)	66.1 (25.2)	51.7 (26.2)	40.2 (24.8)	374.2	<0.001
Rank	3.7	3.7	3.9	2.3	1.5		
PLNS							
	Complications and symptoms	Medication	Treatment and activities of living	Illness related concerns	Support and Care in the community	Friedman χ^2	p-value
Mean (SD)	67.6 (25.0)	63.4 (27.9)	60.4 (25.4)	51.5 (24.6)	41.8 (22.9)	679.9	<0.001
Rank	4.2	3.6	3.3	2.4	1.4		
PINQ							
	Disease	Action			Friedman χ^2	p-value	
Mean (SD)	69.5 (28.8)	50.1 (28.0)			176.3	<0.001	
Rank	1.8	1.2					

PSYCHOMETRIC CHARACTERISTICS OF THE QUESTIONNAIRE

The internal consistency of the (sub)scales of all information needs questionnaires was high (Cronbach's $\alpha \geq 0.85$), see table 4. Regarding feasibility, missing item responses ranged from 0% to 39.7% (mean 5.3%) for all questions. The various subscales could be calculated for 53.9% to 88.9% (mean 82.8%) of the patients.

PERCEIVED NEED FOR INFORMATION

Table 5 presents an overview of the mean scores and ranking of the various subscales of the TINQ, PINQ and PLNS. The perceived need for information was moderate to high, ranging from 40.2 to 69.5. Friedman tests revealed that the information need was highest for medical issues and lowest for psychosocial concerns. More specifically, the need for information as assessed with the TINQ showed the following order of importance: treatment, disease, investigative tests, physical and psychosocial information. The same pattern was seen in the PLNS and PINQ; the need for medical information ranked higher than the need for information about care and psychosocial concerns.

PREDICTORS OF OVERALL INFORMATION NEED

Several sociodemographic and clinical variables were significantly related to the overall need for information (total score on TINQ, PINQ and PLNS). Results revealed that younger age, worse QoL, being a member of a patient association, and moderate comorbidity were significantly associated with a higher need for information (See table 6).

Table 6 Overview of univariate and multivariable relations between need for information (total scores) on TINQ, PLNS and PINQ and sociodemographic and clinical variables and quality of life (global quality of life scale of the EORTC QLQ-C30)

	TINQ			PLNS			PINQ		
	Univariate		Z	Univariate		Z	Univariate		Z
	p-value	B		p-value	B		p-value	B	
Gender	-2.2	0.029	-	NS	-2.2	0.045	-	NS	-1.6
Marital Status	-1.9	0.059	-	NS	-0.75	0.45	-	NS	-0.58
Member patient association	-1.4	0.17	-	NS	-2.3	0.022	-	NS	-3.1
Stem cell transplantation	-1.3	0.19	-	NS	-2.4	0.019	-	NS	-1.8
Hospital	-0.71	0.48	-	NS	-2.0	0.049	-	NS	-1.8
Diagnosis	χ^2	B	p-value	χ^2	B	p-value	χ^2	B	p-value
Time since diagnosis	6.7	0.082	-	NS	6.3	0.099	-	NS	8.8
Education level	3.0	0.56	-	NS	0.38	0.98	-	NS	2.8
Treatment intent	2.8	0.25	-	NS	2.2	0.33	-	NS	1.1
Treatment response	8.5	0.037	-	NS	3.6	0.31	-	NS	3.9
Comorbidity*	8.1	0.044	-	NS	6.1	0.11	-	NS	6.8
	7.2	0.067	-	NS	12.4	0.006	19.5	0.005	5.6
Age	r	p-value	B	r	p-value	B	r	p-value	B
Global quality of life	-2.0	0.007	-0.36	-1.4	0.001	-0.34	-1.4	0.006	-0.30
	-0.046	0.54	NS	-0.16	0.004	-0.97	-0.15	0.004	-0.18

Gender (male/female), marital status (alone vs. together), member patient association (yes/no), stem cell transplantation (yes/no), hospital (VUmc/MCA), diagnosis (acute leukemia, chronic leukemia, multiple myeloma, lymphoma), time since diagnosis (0-3 months, 3 months-1 year, 1 year-2 years, 2 years-5 years, ≥5 years), educational level (primary, secondary, higher education), treatment intent (active surveillance, curative, maintenance, palliative), treatment response (complete remission, partial remission, stable disease, progressive disease), comorbidity (no, mild, moderate, severe), age (in years), global quality of life (EORTC QLQ-C30).

Variables with a p-value <0.10 were entered in the multivariate regression analysis

* Comorbidity: 0 NS (None B=7.07, Mild B=11.008, Moderate B=19.465 (p=0.007), Severe B=0)

PREDICTORS OF SPECIFIC INFORMATION NEEDS

Several sociodemographic and clinical variables were related to a higher need for information on specific topics, as measured with the subscales of the TINQ, PINQ and PLNS (See table 7). A higher need for psychosocial information and information on practical care and concerns was predicted by lower age, being a member of a patient association, moderate comorbidity, and worse quality of life.

Additionally, a higher educational level predicted a lower need for non-medical information. A higher need for disease- and treatment-related information was predicted by younger age, moderate comorbidity and worse quality of life. Patients diagnosed with multiple myeloma had a higher need for information on investigative tests.

Table 7 Overview of univariate and multivariable associations between specific information needs (subscales of the TINQ, PLINQ and PINQ) and sociodemographic and clinical variables

	Disease	TINQ																			
		Investigative tests						Treatment						Physical				Psychosocial			
		Univariate		Multivariable				Univariate		Multivariable				Univariate		Multivariable					
	Z	p-value	B	p-value	Z	p-value	B	p-value	Z	p-value	B	p-value	Z	p-value	B	p-value	Z	p-value	B	p-value	
Marital Status	Gender	-2.3	0.022	-	NS	-3.6	<0.001	-	NS	-2.0	0.045	-	NS	-1.2	0.23	NI	-2.3	0.022	-	NS	
	Marital Status	-1.1	0.26	NI	-0.54	0.56	NI	-1.5	0.15	NI	-1.8	0.076	-	NS	-1.6	0.11	NI	-1.6	0.11	NI	
	Member patient association	-1.3	0.21	NI	-2.3	0.025	-	NS	-1.5	0.14	NI	-1.9	0.062	-	NS	-2.7	0.007	8.3	0.028		
	Stem cell transplantation	-2.1	0.038	-	NS	-1.2	0.23	NI	-2.3	0.023	-	NS	-1.6	0.10	NI	-2.4	0.018	-	NS		
	Hospital	-1.7	0.091	-	NS	-1.6	0.11	NI	-1.3	0.075	-	NS	-0.69	0.49	NI	-0.78	0.44	NI			
Diagnosis*	χ ²	12.0	0.007	-	NS	8.0	0.045	12.0	0.024	12.5	0.006	-	NS	3.5	0.32	NI	6.2	0.10	NI		
	Time since diagnosis	4.4	0.35	NI	3.8	0.50	NI	1.1	0.90	NI	2.2	0.70	NI	2.2	0.57	NI	2.2	0.57	NI		
	Educational level	4.1	0.13	NI	4.4	0.11	NI	2.1	0.36	NI	1.7	0.43	NI	7.2	0.003	-	NS				
	Treatment intent	8.0	0.047	-	NS	1.2	0.76	NI	7.5	0.057	-	NS	9.1	0.028	-	NS	3.3	0.36	NI		
	Treatment response	13.5	0.004	-	NS	7.2	0.066	-	NS	12.3	0.007	-	NS	9.2	0.027	-	NS	9.9	0.27	NI	
Comorbidity**	χ ²	12.6	0.005	22.9	0.006	2.1	0.16	NI	4.7	0.20	NI	4.5	0.21	NI	7.3	0.063	15.5	0.018			
	p-value	0.007	-	NS	8.0	0.045	12.0	0.024	12.5	0.006	-	NS	3.5	0.32	NI	6.2	0.10	NI			
Age	B	0.007	-	NS	8.0	0.045	12.0	0.024	12.5	0.006	-	NS	3.5	0.32	NI	6.2	0.10	NI			
	p-value	0.007	-	NS	8.0	0.045	12.0	0.024	12.5	0.006	-	NS	3.5	0.32	NI	6.2	0.10	NI			
Global quality of life	B	-0.17	0.001	-0.39	0.004	-0.11	0.023	-	NS	-0.18	0.004	-0.34	0.034	0.24	<0.001	-0.41	0.002	0.13	0.009	-0.27	0.019
	p-value	0.060	-	NS	-0.084	0.10	0.10	0.10	NI	-0.092	0.45	0.15	NI	-0.05	0.35	NI	0.16	0.001	-2.7	0.014	

Table 7 Overview of univariate and multivariate associations between specific information needs (subscales of the TINO, PLNS and PINQ) and sociodemographic and clinical variables (continued)

	Support and care in the community				Medication				PUNs				Complications and symptoms				Illness related concerns								
	Univariate		Multivariable		Univariate		Multivariable		Univariate		Multivariable		Univariate		Multivariable		Univariate		Multivariable						
	Z	p-value	B	p-value	Z	p-value	B	p-value	Z	p-value	B	p-value	Z	p-value	B	p-value	Z	p-value	B	p-value					
Gender Marital Status Member patient association Stem cell transplantation Hospital	-3.4	0.001	-	NS	-2.7	0.007	-	NS	-1.2	0.24	NI	-2.8	0.006	-	NS	-1.5	0.13	NI	-1.7	0.095	-	NS			
	-0.005	1.0	NI	-0.027	0.98	NI	-1.2	0.23	NI	-0.57	0.57	NI	-0.57	0.57	NI	-1.7	0.095	-	NI	-1.7	0.095	-	NS		
	-2.6	0.008	7.8	0.018	-1.4	0.15	NI	-2.0	0.046	-	NS	-1.4	0.15	NI	-1.4	0.17	NI	-1.4	0.17	NI	-1.4	0.17	NI		
	-1.5	0.14	NI	-1.1	0.27	NI	-1.1	0.32	NI	-3.2	0.001	-	NS	-1.8	0.077	-	NS	-2.9	0.004	-	NS				
	-0.54	0.59	NI	-0.81	0.42	NI	-2.4	0.016	-	NS	-2.1	0.039	-	NS	-1.1	0.26	NI	-1.1	0.26	NI	-1.1	0.26	NI		
	χ^2	p-value	B	p-value	χ^2	p-value	B	p-value	χ^2	p-value	B	p-value	χ^2	p-value	B	p-value	χ^2	p-value	B	p-value	χ^2	p-value	B	p-value	
	5.4	0.15	NI	3.8	0.29	NI	7.4	0.061	-	NS	7.6	0.056	-	NS	6.7	0.082	-	NS	6.7	0.082	-	NS			
	0.41	0.98	NI	0.97	0.92	NI	1.0	0.90	NI	1.6	0.82	NI	1.6	0.82	NI	1.5	0.84	NI	1.5	0.84	NI	1.5	0.84	NI	
	11.5	0.003	8.2	0.049	2.9	0.24	NI	0.28	0.87	NI	2.7	0.26	NI	2.7	0.26	NI	10.2	0.006	8.5	0.024	10.2	0.006	8.5	0.024	
	1.1	0.78	NI	0.76	0.86	NI	5.6	0.13	NI	1.7	0.66	NI	1.7	0.66	NI	5.2	0.16	NI	5.2	0.16	NI	5.2	0.16	NI	
Treatment intent Treatment response Comorbidity**	5.5	0.14	NI	6.2	0.10	NI	8.5	0.037	-	NS	6.2	0.11	NI	6.0	0.11	NI	6.0	0.11	NI	6.0	0.11	NI	6.0	0.11	NI
	11.1	0.011	18.7	0.003	7.9	0.048	24.8	0.005	7.7	0.052	-	NS	9.6	0.022	17.5	0.012	8.2	0.042	19.4	0.004	8.2	0.042	19.4	0.004	
	r	p-value	B	p-value	r	p-value	B	p-value	r	p-value	B	p-value	r	p-value	B	p-value	r	p-value	B	p-value	r	p-value	B	p-value	
	-0.055	0.28	NI	-0.12	0.018	-0.29	0.011	-0.18	0.011	-0.18	0.011	-0.17	0.001	-0.39	0.001	-0.16	0.002	-0.39	0.002	-0.16	0.002	-0.39	0.002		
Age Global quality of life	-0.19	<0.001	-3.3	0.001	0.12	0.017	-3.1	0.010	-0.17	0.001	-3.6	0.003	-0.15	0.004	-2.6	0.013	0.18	<0.001	-2.3	0.030	0.18	<0.001	-2.3	0.030	

Table 7 Overview of univariate and multivariable associations between specific information needs (subscales of the TINO, PINs and PINQ) and sociodemographic and clinical variables (continued)

	Disease				PINQ			
	Univariate		Multivariable		Univariate		Active	
	Z	p-value	B	p-value	Z	p-value	B	p-value
Gender	-0.91	0.37		NI	-2.8	0.005	5.8	0.032
Marital Status	-0.37	0.71		NI	-1.6	0.10		NI
Member patient association	-2.5	0.012	9.4	0.035	-3.0	0.002	10.2	0.005
Stem cell transplantation	-1.6	0.10		NI	-1.1	0.25		NI
Hospital	-2.6	0.009	-	NS	-0.48	0.63		NI
	χ^2	p-value	B	p-value	χ^2	p-value	B	p-value
Diagnosis	13.4	0.004	-	NS	2.6	0.45		NI
Time since diagnosis	3.5	0.48		NI	2.4	0.66		NI
Educational level	3.5	0.17		NI	4.7	0.096	-	NS
Treatment intent	6.1	0.11		NI	1.6	0.66		NI
Treatment response	11.0	0.012	-	NS	3.3	0.35		NI
Comorbidity	7.0	0.071	-	NS	3.8	0.29		NI
	r	p-value	B	p-value	r	p-value	B	p-value
Age	-0.15	0.004	-0.17	0.012	-0.11	0.026	-	NS
Global quality of life	-0.11	0.027	-	NS	-0.15	0.003	-2.5	0.020

Gender (male/female), age (in years), marital status (alone vs. together), educational level (primary, secondary, higher education), time since diagnosis (0-3 months, 3 months-1 year, 1 year-2 years, ≥2 years, ≥5 years), member patient association (yes/no), diagnosis, stem cell transplantation (yes/no), Hospital (VUMC/MICA), treatment response (complete remission, partial remission, stable disease, progressive disease), treatment intent (active surveillance, curative, maintenance, palliative), comorbidity (no, mild, moderate, severe), global quality of life (EQ-5D, EQ-5D-5L, EQ-5D-6L, EQ-5D-8L).

Variables with a p-value <0.10 were entered into the multivariable regression analysis.

* p < 0.05, ** p < 0.01, *** p < 0.001. NI = Not Included, NS = Not Significant, B = Beta, SE = Standard Error, CI = Confidence Interval, OR = Odds Ratio, P = Probability, R = Regression, R² = Coefficient of Determination, F = F-statistic, t = t-statistic, Z = Z-statistic, p = p-value, p-value = probability of the null hypothesis being true.

†† Comorbidity: TINO psychosocial p=0.018, (None B=4.617 (p=0.471), Mild B=4.536 (p=0.340), Moderate B=15.455 (p=0.023), Severe B=0), PINs illness related concerns: p=0.004, (None B=8.263 (p=0.186), Mild B=11.277 (p=0.085), Moderate B=19.386 (p=0.003), Severe B=0), PINs support and care in the community: p=0.003, (None B=8.178 (p=0.149), Mild B=10.820 (p=0.076), Moderate B=18.702 (p=0.002), Severe B=0)

TINO disease p=0.006, (None B=11.436 (p=0.122), Mild B=15.240 (p=0.048), Moderate B=22.899 (p=0.003), Severe B=0), PINs complications and symptoms p=0.012, (None B= 8.291 (p=0.171), Mild B= 13.205 (p=0.041), Moderate B=17.489 (p=0.007), Severe B=0), PINs

*** Educational level: PINs support and care p=0.048, Primary B=8.240 (p=0.017), Secondary B=4.402 (p=0.113), Higher B=0), PINs illness related concerns p = 0.024 (Primary B=8.453 (p=0.026) Secondary B= 7.067 (p=0.016), Higher B=0)

INFORMATION SATISFACTION

We measured the satisfaction with the information provided via the ISQ questionnaire. The mean total score on the ISQ was 17.34 (SD=3.20, range 0–24), with a mean satisfaction from high to low, with information on the following items: the illness (3.3), treatments available (3.1), overall information provided (3.0), side-effects (2.9), lifestyle (2.6) and practical daily issues (2.5). Of the 458 patients, 40.6% felt that the information provision could have been improved. A higher satisfaction with the information provided was predicted by better quality of life as measured with the global quality of life scale of the EORTC-QLQ-C30 ($r=0.32$; $p<0.001$). More patients with a higher need for information (total scores on the PINQ, TINQ and PLNS) reported that information provision could be improved, as assessed by the item “Do you feel information provision could have been improved, Yes or no?” (table 8).

DECISION-MAKING

Of all patients, 81.6% would like to have all the available information and would be involved in decision-making, whereas 14.7% would like limited information and would prefer the doctor to make decisions. The remaining (3.7%) would only like positive information about their illness. Patients who wanted to be involved in decision-making generally were younger, had a higher educational level, used the Internet to search for information, were member of a patient association and were treated in VUmc (See table 9).

DISCUSSION

The aim of this study was to gain more insight into the perceived need for information among patients diagnosed with a hematological malignancy. The need for information among 458 participating patients was moderate to high, and higher for disease- and treatment-related information than for psychosocial information. A higher need for information was related to younger age, moderate comorbidity, worse QoL, and being a member of a patient association.

The finding that information need is higher for medical issues such as diagnosis, treatment and diagnostic tests than for psychosocial aspects and supportive care, is consistent with the literature on patients with hematological malignancies^{22–24} as well as patients with solid tumors.^{2, 25, 26} This finding may be explained by the fact that in general,

Table 8 Associations between information need (total scores of the TINQ, PLNS and PINQ) and information satisfaction (ISQ total) with Spearman (correlation coefficient (*r*)) and improvement information provision (ISQ 2 Yes/No) with Mann-Whitney test (*Z*) Significant associations are shown in Italics

		r	p-value
ISQ total (question 3 to 8)	TINQ total	-0.047	0.520
	PLNS total	-0.093	0.100
	PINQ total	-0.052	0.335
		Z	p-value
The information provision could have been improved, yes/no	TINQ total	-1.906	0.057
	PLNS total	-3.201	<i>0.001</i>
	PINQ total	-3.088	<i>0.002</i>

Table 9 Associations between decision making preference (ISQ) and sociodemographic and clinical variables.

		Which one of the following categories most applies to you?							
		I would like all available information & be involved in decision about my illness		I would only like positive information about my illness		I would only like limited information & would prefer the doctor to make the decisions		Pearson χ^2	p-value
		n	%	n	%	n	%		
Gender	Female	165	85.1%	9	4.6%	20	10.3%	5.9	0.052
	Male	185	78.7%	7	3.0%	43	18.3%		
Age	≤ 52	103	89.6%	0	0.0%	12	10.4%	13.9	0.031
	53 - < 62	99	83.9%	4	3.4%	15	12.7%		
	63 - < 70	76	76.8%	7	7.1%	16	16.2%		
	≥ 71	72	74.2%	5	5.2%	20	20.6%		
Marital status	Alone	74	78.7%	6	6.4%	14	14.9%	2.3	0.32
	Together	271	82.4%	10	3.0%	48	14.6%		
Educational Level	Primary Education	63	76.9%	2	2.6%	16	20.5%	10.1	0.040
	Secondary Education	143	77.7%	11	6.0%	30	16.3%		
	Higher Education	136	88.3%	3	1.9%	15	9.7%		
Time since diagnosis	< 3 months	29	85.3%	1	2.9%	4	11.8%	8.7	0.37
	3 months - < 1 year	56	84.8%	3	4.5%	7	10.6%		
	1 year - < 2 year	53	81.5%	1	1.5%	11	16.9%		
	2 year - < 5 year	100	78.1%	3	2.3%	25	19.5%		
	≥ 5 year	109	83.2%	8	6.1%	14	10.7%		
Member patient association	Yes	65	94.2%	0	0.0%	4	5.8%	9.2	0.010
	No	279	79.0%	15	4.2%	59	16.7%		
Diagnosis	Acute leukemia	30	83.3%	2	5.6%	4	11.1%	2.0	0.92
	Chronic leukemia	83	79.8%	5	4.8%	16	15.4%		
	Multiple myeloma	81	84.4%	3	3.1%	12	12.5%		
	Lymphoma	156	80.8%	6	3.1%	31	16.1%		
Treatment of SCT	Yes	99	83.2%	3	2.5%	17	14.3%	1.3	0.53
	No	205	79.2%	12	4.6%	42	16.2%		
Treatment intent	Active Surveillance	95	74.8%	11	8.7%	21	16.5%	10.1	0.12
	Curative	135	82.8%	3	1.8%	25	15.3%		
	Maintenance	23	82.1%	0	0.0%	5	17.9%		
Treatment response	Palliative	22	84.6%	1	3.8	3	11.5%	6.2	0.34
	Complete remission	134	83.2%	4	2.5%	23	14.3%		
	Partial remission	19	73.1%	1	3.8%	6	23.1%		
	Stable disease	85	75.9%	8	7.1%	19	17.0%		
Comorbidity	Progressive disease	27	87.1%	1	3.2%	3	9.7%	10.9	0.093
	No comorbidity	181	83.4%	6	2.8%	30	13.8%		
	Mild comorbidity	55	80.9%	4	5.9%	9	13.2%		
	Moderate comorbidity	53	77.9%	3	4.4%	12	17.6%		
	Severe comorbidity	11	55.0%	2	10.0%	7	35.0%		
Hospital	VU University Medical Center	244	87.1%	6	2.1%	30	10.7%	17.2	<0.001
	Medical Center Alkmaar	106	71.1%	10	6.7%	33	22.1%		
Internet use for information	Yes	216	88.5%	6	2.5%	22	9.0%	19.7	<0.001
	No	128	71.5%	10	5.6%	41	22.9%		

for many patients the first priority is to survive, and only thereafter other concerns seem to become important.

Regarding sociodemographic parameters, older patients wanted less information about their disease than younger patients, which is in line with earlier studies on patients with AML and MM^{27, 28}, and on patients with cancer in general.^{29–33} Gender was not related to an overall difference in need for information, confirming earlier studies on hematological malignancy patients^{27, 28}, but contradicting one study that reported that hospitalized women with cancer in general had a higher need for information than men.³⁴ In the present study, sixteen percent of the patients were member of a patient association, and these patients expressed a higher need for information, which is in line with an earlier study.²⁷

Educational level was not related to the overall information needs of patients with a hematological malignancy, confirming results of a study on patients with AML during the first months after diagnosis.²⁸ Looking in more detail, in the present study a higher level of education was associated with a lower need for non-medical information, such as information about supportive care and how to communicate about the illness. An explanation for this might be that patients with a higher education are more familiar with this kind of care than patients with a lower education. Another possibility is the more independently search for information by higher educated patients. Another interesting result of the present study was that patients with moderate comorbidity had a higher need for information than patients without or with severe comorbidity. An explanation for this result might be that patients with severe comorbidity are saturated with information; another explanation might be that patients with severe comorbidity are too sick to be interested in additional information. An explanation for the lower need for information of patients without comorbidity might be that these patients are less acquainted with medical information than patients with comorbidity. Also, patients with a worse QoL expressed a higher need for information. This was contrary to our expectation, that QoL was positively associated with the need for information. A possible explanation might be that a poorer QoL creates a desire for a better QoL which increases the need for information. Another explanation might be that when patients feel well, they want to enjoy it, and there is no need for further information.

Regarding differences in the information needs between subgroups of patients with hematological malignancies, the higher need for information on diagnostic tests in patients with MM, compared with leukemia and lymphoma patients, may be due to the fact that MM is a less well known disease in the community, compared to leukemia and

lymphoma. Furthermore, patients with MM, more elaborate testing before and during treatment, especially skeleton X-rays in patients with bone pain, which may lead to more need for information on diagnostic tests.

In the present study we did not find a relation between information need and time since diagnosis, which is in line with findings in patients with cancer in general.³² However, some earlier studies on cancer in general and MM patients reported that patients at time of diagnosis had more need for information about disease and treatment than patients who were in the post-treatment phase of the disease.^{2,27} The cross-sectional design of the present study could have influenced our results on this aspect, because patients may have confounded their needs at time of the survey with their information needs at time of diagnosis. Furthermore, in our study, treatment response and intent of treatment (palliative or curative) were not related to the need for information, this is contrary to the findings of previous qualitative studies, which showed that patients with a poor outcome, and patients with AML in partial remission, were more interested in palliative treatment, supportive care and information about nutrition, vitamins and complementary medicine than patients in complete remission.^{28,35} It is obvious that prospective studies are needed to obtain more insight into the course of the perceived need for information from time of diagnosis to survivorship care or palliative treatment.

In this study, patient satisfaction with the provided information was good, which is similar to earlier studies on patients with hematological malignancies.^{27,28,36-39} However, over 40% of the patients felt that information provision could have been improved. Importantly, higher satisfaction with the information provided was associated with better quality of life, confirming the outcomes of earlier studies.^{8,9,40} Furthermore, receiving more disease-specific information was associated with a better understanding of and control over the disease, and more satisfaction with the information received was associated with better illness perception.^{41,42}

The majority of the patients (82%) reported that they wanted to be fully informed about their illness and actively involved in treatment decision-making. This involvement in decision-making may be a feature of modern times, since our findings are in line with a recent study on relatively highly educated patients who had relatively highly incomes and were mostly treated in a university hospital²⁴, whereas earlier studies showed a more passive attitude in decision-making in patients with hematological malignancies.^{27,37,39,43} The association between the desire for active decision-making and younger age has been reported earlier^{7,31}, probably because older patients are more familiar with a

paternalistic style of treatment decision-making.³⁰ Rather new, however, are the other associations with active decision-making we found, such as treatment hospital (academic or non-academic), being a member of a patient association, and higher educational level. These factors might contribute, in the future, to an increase in the number of patients who prefer shared decision-making.

In the present study, more than 60% of the patients used the Internet to search for information. Previous studies have shown that cancer patients with higher unmet information needs and patients who are dissatisfied with the information received are more likely to search for information on the Internet.^{44,45} Higher level of Internet use by cancer patients is associated with more active involvement in the treatment decision-making process.^{46,47} It is therefore of the utmost importance that patients have access to valid and reliable online information.

A limitation of this study is the fact that we only included outpatients, who probably were in a better physical condition. This may have influenced the need for information. Furthermore, the cross-sectional design of the study might explain why we did not find a difference between information need at time of diagnosis and in later stages of the disease and treatment. Another limitation is the fact that patients who responded to our invitation had a better treatment intent than to non-participants, which could have influenced the results positively when generalized to the community. However, treatment intent was not related to need for information, nor to preference in decision-making.

Further studies should focus on inpatients as well as outpatients with hematological malignancies, and should have a longitudinal design, from time at diagnosis to later on in disease and treatment, in order to more precisely define the evolution of information needs of this patient group during the course of illness and treatment.

In conclusion, hemato-oncological patients' needs for information were higher for disease- and treatment-related information than for psychosocial information. The need for information was related to age, comorbidity, educational level, QoL, and membership of a patient association. Most patients were satisfied with the information provided, but felt that it could be improved. Most patients wanted to be fully informed about their illness and actively involved in treatment decision-making. Our results contribute to the improvement of patient tailored information provision and shared decision-making in clinical practice. Only prospective cohort studies will obtain more precise insight into the course of the perceived need for information from diagnosis and treatment to survivorship care or palliative care.

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ADDENDUM—METHODS

The TINC-BC is a five-point, 51-item questionnaire with five subscales including 1) Disease (information about the disease, its course and prognosis), 2) Investigative tests (procedures used to assess extent of disease), 3) Treatment (various cancer treatments and possible side-effects), 4) Physical (preventive, restorative and maintenance care that the body requires as a result of the disease), and 5) Psychosocial (how to handle the patient's or the family's feelings and concerns). The PINQ is a four-point 17-item questionnaire which measures the information need on two subscales: 1) Disease-oriented scale: information about the disease and treatment, and 2) Action-oriented scale: information about access to help and solutions for practical problems. The PLNS is a five-point 40-item questionnaire measuring the information needs at time of discharge from the hospital. This questionnaire has five subscales: 1) Support and care in the community (information about the healthcare system, intrapersonal support and preventive skin care), 2) Medication (information medication effects and administration of medication), 3) Treatment and activities of daily living (information about the treatment, physical activity, nutrition and sleep), 4) Complications and symptoms (information about the illness, management of symptoms and complications), and 5) Illness-related concerns (information about how to communicate about the illness, rest and elimination problems). From all of these three questionnaires we used from total scores and subscale scores a normalization to a 100 scale for further analysis. From these instruments duplicated items and irrelevant items (for instance on mammography) were removed, resulting in a 92-item questionnaire.

The ISQ measures the information satisfaction regarding 1) Explanation of the illness (diagnosis, outcome, aggressiveness, genetic risk), 2) Side-effects (how treatment affects the patient, early and late side-effects), 3) Types of treatments available (options available, relative benefits and clinical trials), 4) Advise on lifestyle (diet, exercise, complementary medicine and support groups), 5) Practical daily issues (parking, transport, follow-up plans) and 6) Overall information provided. Each table scores from 0 (very unsatisfied) to 4 (very satisfied). Mean total scores of 0–4, 5–9, 10–14, 15–19 and 20–24 represent respectively very poor, poor, fair, good and excellent satisfaction with the information provided.

Additionally, the ISQ measures the degree and nature of information (all, only positive, or limited information), and the patient's involvement in decision-making (I would like all available information & be involved in decision about my illness / I would only like positive information about my illness / I would only like limited information & would

prefer the doctor to make the decisions). Finally, the room for improvement of information provision was studied with the question: Do you feel information provision could have been improved, Yes or no?.

The EORTC QLQ-C30 is a cancer-specific questionnaire and comprises a global health related quality of life (HRQOL) scale (2 items) and five functional scales: physical functioning (5 items), role functioning (2 items), emotional functioning (4 items), cognitive functioning (2 items) and social functioning (2 items). It further consists of three symptom scales and six single items. Following EORTC guidelines, the scores of the QLQ-C30 were linearly transformed to a 0–100 scale. For functioning scales and the global HRQOL scales (outcome variables used in the present study), higher scores correspond to better levels of functioning.

Sociodemographic parameters were collected via a short study-specific questionnaire, including: nationality, marital status (single / married or living with a partner), educational level (primary / secondary / higher) and membership of a patient association (yes / no) and which patient association.

The patient files were consulted to obtain data on clinical parameters. type of hematological malignancy (ALL / AML / CLL / CML / MM / HL / NHL), treatment modality (active surveillance / curative / maintenance / palliative), treatment result (complete remission / partial remission / stable disease / progressive disease), and comorbidity (none / mild / moderate / severe).

Comorbidity was measured by means of the Adult Comorbidity Evaluation-27 (ACE-27) Test and included cardiovascular, respiratory, gastro-intestinal, renal, endocrine, neurological, and immunological disorders, previous malignancy, severe weight loss or excessive alcohol intake. The ACE-27 was designed specifically for cancer patients and classifies patients into 4 grades of comorbidity.

The Mann-Whitney test was used to test differences in information need (total scores and subscales of the TINQ, PLNS and PINQ) between subgroups: hospital (VUmc / MCA), gender (male / female), marital status (single / married or living with a partner), member of a patient association (yes / no), treatment by means of SCT (yes / no), Internet as information source (yes / no), and improvement of information provision (yes / no). The Kruskal-Wallis test was used to test differences in information need (total scores and subscales of the TINQ, PLNS and PINQ) between more than two subgroups: educational level (primary/secondary/higher), treatment modality

(active surveillance / curative / maintenance / palliative), comorbidity (no / mild / moderate / severe), diagnosis (ALL / AML / CLL / CML / MM / HL / NHL), and time since diagnosis (< 3 months / 3 – <12 months / 1 – <2 year / 2 – < 5 year / ≥ 5 year).

The Chi-square test was used to test the association between decision-making preference (ISQ 1) sociodemographic variables (gender (male / female), educational level (primary / secondary / higher), hospital (VUmc / MCA), marital status (single / married or living with a partner), member of a patient association (yes / no), use of the Internet as information source (yes/no)) and clinical variables (diagnosis (ALL / AML / CLL / CML / MM / HL / NHL), time since diagnosis (< 3 months / 3 – <12 months / 1 – <2 year / 2 – < 5 year / ≥ 5 year), treatment modality (active surveillance / curative / maintenance / palliative), treatment response (complete remission / partial remission / stable disease / progressive disease), treatment by means of SCT (yes / no), and comorbidity (no / mild / moderate / severe)).

Spearman correlation coefficients were used to test the association between the perceived need of information (total scores and subscales of the TINQ, PLNS and PINQ) and, age (years), quality of life (EORTC-QLQ-C30 subscale global functioning), and satisfaction with information (total ISQ score).

Linear regression was used as a multivariable technique to test the relation between the need of information as dependent variable (total scores and subscale scores of the TINQ, PINQ and PLNS) and the independent sociodemographic variables (gender (male / female), educational level (primary / secondary / higher), hospital (VUmc / MCA), marital status (single / married or living with a partner), member of a patient association (yes / no)) and clinical variables (diagnosis (ALL / AML / CLL / CML / MM / HL / NHL), time since diagnosis (< 3 months / 3 – <12 months / 1 – <2 year / 2 – < 5 year / ≥ 5 year), treatment modality (active surveillance / curative / maintenance / palliative), treatment response (complete remission / partial remission / stable disease / progressive disease), treatment by means of SCT (yes / no), and comorbidity (no / mild / moderate / severe)). Variables with a significance level of $p < 0.10$ in univariate analysis on the (sub) scales of the TINQ, PINQ and PLNS were entered in multivariable regression models.

Pearson's chi square and Mann-Whitney tests were used to test differences concerning sociodemographic and clinical variables between participants and non-participants. For all statistical analyses (except the input of multivariable regression analyses), a p -value < 0.05 was considered to indicate a statistically significant difference. For all analyses we used the statistical software package SPSS, version 19.0.

CHAPTER 4

COGNITIVE COPING STYLE (MONITORING AND BLUNTING) AND THE NEED FOR INFORMATION, INFORMATION SATISFACTION AND SHARED DECISION-MAKING AMONG PATIENTS WITH HEMATOLOGICAL MALIGNANCIES

J.A.J. Rood

F.J. van Zuuren

F. Stam

T. van der Ploeg

P.C. Huijgens

I.M. Verdonck-de Leeuw

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ABSTRACT

INTRODUCTION

A hematological malignancy is a serious, life-altering disease, and may be characterized as an uncontrollable and unpredictable stress situation. In dealing with potentially threatening information, individuals generally utilize two main cognitive coping styles: monitoring (the tendency to seek threat-relevant information) and blunting (avoiding threatening information and seeking distraction). The aim of this study was to obtain insight into the association between cognitive coping style and 1) need for information, 2) satisfaction with information, 3) involvement in decision-making, and 4) quality of life (QoL).

METHODS

In this cross-sectional study, coping style was assessed among adult patients diagnosed with a hematological malignancy, using an adapted version of the Threatening Medical Situations Inventory. Information need, information satisfaction, decision-making preference and QoL were measured with validated questionnaires.

RESULTS

In total, 458 patients returned the questionnaire (66%). A monitoring coping style was positively related to need for both general and specific information. Blunting was positively and QoL was negatively related to need for information. Monitoring was positively related to involvement in decision-making and negatively to information satisfaction. Using multivariable analysis, this relation between monitoring and information satisfaction disappeared and for blunting we found a negatively significant relation. QoL was not related to coping style.

CONCLUSION

Among patients with hematological malignancies, coping style is related to a need for information, information satisfaction, and involvement in treatment decision-making. Therefore, it is important for healthcare professionals to be aware of individual differences in cognitive coping style.

INTRODUCTION

Providing timely and accurate information to patients diagnosed with a hematological malignancy is a challenge in clinical practice. In case of acute leukemia, aggressive non-Hodgkin lymphoma or multiple myeloma treatment frequently has to start promptly, with little time to inform patients. Furthermore, it is particularly difficult to inform the patient on the diagnosis, prognosis and various intensive therapy options, which are all associated with serious and even fatal complications.

With regard to information provision, healthcare professionals generally advised to tailor type and amount of information to patients' individual needs¹, but knowledge on the perceived need for information in patients with hematological malignancies is scarce.² At the same time, unfulfilled information need is a risk factor for the patient because it may cause several problems such as a reduced ability to cope with the disease³, whereas satisfaction with information received is associated with better health outcomes.⁴⁻⁶

Worldwide more than 850,000 patients are diagnosed with a hematological malignancy each year.⁷ A diagnosis of a hematological malignancy constitutes a serious uncontrollable and unpredictable medical stress situation. According to the literature, individuals dealing with potentially threatening information may use two main cognitive coping styles: monitoring (the tendency to seek threat-relevant information) and blunting (avoiding threatening information and actively seeking distraction under impending threat).¹ Under impending medical threat, high monitors are highly concerned about their risks, scan for potentially threatening health information, increase the threatening cues and worry about these signals. Low monitors however, refrain from engaging in this behaviour.⁸ It has been shown that high monitors are less satisfied with the information provided than low monitors.^{8,9} The blunting coping style has empirically been shown to be independent of monitoring.¹⁰ High blunters avoid confrontation with potentially threatening information, minimize informational uptake and instead engage in distracting cognitions and behaviors.

According to several studies, information is more effective and patients adapt better to the situation if the provided information is tailored to their monitoring or blunting coping style.^{8,11} Furthermore, cognitive coping style influences the involvement in the decision-making process.^{8,9,12-14} Monitoring and blunting may therefore be useful concepts in clinical cancer care in order to tailor the information to the individual patient.

The aim of this study was to test the following hypotheses in patients with hematological malignancies: 1) monitoring is positively and blunting is negatively associated with the need for information regarding the disease, its treatment and related psychosocial issues, 2) monitoring is negatively related with information satisfaction, 3) monitoring is positively and blunting is negatively related with involvement in decision-making, and 4) monitoring is negatively related with QoL.

METHODS

PATIENTS

Patients, eighteen years and older, were asked to participate in the study when they were visiting the outpatient Hematology clinic at the VU University Medical Center (VUmc), Amsterdam or the Medical Centre Alkmaar, Alkmaar, the Netherlands, between April and December 2010. Participation was restricted to those diagnosed with a hematological malignancy: acute and chronic myeloid or lymphatic leukemia, Hodgkin and non-Hodgkin lymphoma or multiple myeloma. Exclusion criteria were concurrent treatment of another malignancy, terminal phase of the disease, mental or physical inability to participate in the study, and lack of basic fluency in Dutch. No restrictions were made regarding treatment modality or time since diagnosis.

MEASUREMENTS

Coping style was measured with an adapted version of the Threatening Medical Situations Inventory (TMSI), devised to measure two cognitive coping styles in the domain of threatening medical situations.^{1, 10} We used the psychometrically tested abbreviated version, which comprises two of the original four threatening situational descriptions^{10, 12}, and added a third situation, i.e. receiving the diagnosis of a hematological malignancy, in order to improve the relevance of the questionnaire for our patients. The TMSI is devised to measure two cognitive coping styles in the domain of threatening medical situations: monitoring and blunting¹. Each threatening description is followed by six items, three monitoring and three blunting, in a random order, to be answered on 5-point Likert scale. Total monitoring and blunting scale scores were analyzed as continuous variables (for detailed description see addendum).

To measure the perceived need for information, we compiled a questionnaire using existing validated and reliable instruments with complementary subscales: the Toronto Information Needs Questionnaire-Breast Cancer (TINQ)¹⁵, the Patient Information Need Questionnaire (PINQ)¹⁶ and the Patient Learning Needs Scale (PLNS).¹⁷ From these instruments, duplicated items and irrelevant items (for instance on mammography) were removed, resulting in a 92-item questionnaire. The English items were translated into Dutch by means of backward and forward translation by a native English speaker and the first author (native Dutch speaker) of this manuscript, and compared with the original English version. Satisfaction with the current information provision was measured using the Information Satisfaction Questionnaire.¹⁸ QoL was assessed using the European Organization for Research and Treatment of Cancer QLQ-C30 (version 3.0, Dutch version).¹⁹

Sociodemographic information was collected via a short study-specific questionnaire. Comorbidity was measured using the Adult Comorbidity Evaluation-27.²⁰ (For details of the various instruments, see the Addendum). To evaluate possible participant bias, we also collected sociodemographic data and clinical parameters from the medical records of non-participants. For more information of the used questionnaires, see the addendum.

INFORMED CONSENT AND PROCEDURE

This study was approved by the Medical Ethical Committee of the VUmc. Written informed consent was obtained from all patients. After hospital visit, patients could complete the questionnaires online or on paper. After three weeks, patients who had not responded were contacted once again.

STATISTICAL ANALYSIS

Based on a 95%-confidence level and an accuracy of 0.05, the required sample size was at least 384 patients. Moreover, at least thirty patients per diagnosis were desirable for subgroup analysis. All continuous variables were tested for normality with Kolmogorov Smirnov tests and Cronbach's alpha was used to assess the internal consistencies of all subscales. Associations between need for information and information satisfaction with coping style were tested with Spearman correlation coefficients. Mann-Whitney tests were used to test differences in information satisfaction versus coping style. The Kruskal-Wallis test was used to test differences in decision-making preference between coping styles. Chi-square tests and Mann-Whitney tests were used to test differences in respectively ordinal and

continues demographic and clinical variables between participants and non-participants and between missing values and non-missing values.²¹

Linear regression was used as a multivariable technique to test the relation between the need for information as a dependent variable (total scores of the TINQ, PINQ and PLNS) and the independent clinical and demographic variables. Logistic regression analysis was used as a multivariable technique to test the relation between first information satisfaction, and second treatment decision-making and the clinical and demographic variables, coping style and QoL. For the second analysis, we combined the two last answer options into one variable "limited information".

Univariate variables with a significance of $p < 0.10$ were entered into the multivariable regression analysis. For all the other statistical analyses a $p < 0.05$ was considered to indicate a statistically significant difference. For each analysis we used the statistical software package SPSS, version 19.0.

RESULTS

STUDY POPULATION

In total, 458 patients returned the questionnaire (66% response rate). A minority (7%) completed the questionnaire online. The mean age was 60.2 years and 55% were male. The majority of the patients was diagnosed with a lymphoma (45%) and most were diagnosed more than two years ago (61%). For an overview of all sociodemographic and clinical data, see an earlier published article (Chapter 3).²¹

Patients who participated in the study did not differ from non-participants in terms of sociodemographic or clinical characteristics, except for treatment intent (Pearson $\chi^2=24.4$, $p<0.001$). For detailed description and psychometric findings of the used questionnaires, see addendum.

COPING STYLE AND THE NEED FOR INFORMATION

Monitoring was significantly and positively related to the need for information for all total scores on the three questionnaires (TINQ, PLNS and PINQ) and for all subscales, with moderate correlations around 0.25–0.30 (see table 1). Also, blunting was significantly and positively related with need for information regarding the total scores of two of the three questionnaires (PLNS and PINQ) and for all subscales, except for TINQ treatment and PINQ active. However, the correlations were low (mostly between 0.10–0.20).

Multivariable regression analysis revealed that monitoring had a significant positive relation with need for information on all three questionnaires (TINQ, PLNS and PINQ). On two of the three total scales (PLNS and PINQ), blunting was positively related and QoL negatively related with the need for information. Demographic and clinical variables were not related with the need for information (see table 2).

Table 1 Overview of Spearman correlations between coping style and information need subscales

	(Sub)scale	Monitoring		Blunting	
		r	p-value	r	p-value
TINQ	Total	0.32	<0.001	0.11	0.15
	Disease	0.30	<0.001	0.18	0.001
	Investigative tests	0.27	<0.001	0.16	0.003
	Treatment	0.30	<0.001	0.09	0.20
	Physical	0.24	<0.001	0.24	<0.001
	Psychosocial	0.23	<0.001	0.14	0.009
PLNS	Total	0.29	<0.001	0.17	0.003
	Support and care in the community	0.26	<0.001	0.14	0.008
	Medication	0.22	<0.001	0.14	0.009
	Treatment and activities of living	0.27	<0.001	0.16	0.002
	Illness related factors	0.27	<0.001	0.17	0.001
	Complications and symptoms	0.17	0.002	0.13	0.016
PINQ	Total	0.31	<0.001	0.14	0.013
	Disease	0.34	<0.001	0.13	0.018
	Active	0.25	<0.001	0.10	0.051

TINQ: Toronto Information Needs Questionnaire, PLNS: Patient Learning Needs Scale, PINQ: Patient Information Needs Questionnaire.

Table 2 Overview of the relations between need for information (total scores) on TINQ, PLNS and PINQ and sociodemographic and clinical variables, quality of life (global quality of life on EORTC-QLQ-C30) and coping style (TMSI)

Variable	TINQ			PLNS			PINQ				
	Univariate	Multivariable		Univariate	Multivariable		Univariate	Multivariable			
	Z / χ^2 / r	p-value	B	p-value	Z / χ^2 / r	p-value	B	p-value	B		
Gender	-2.2	0.029		NS	-2.2	0.045		NS	-1.6	0.11	NI
Age	-2.0	0.007		NS	-1.4	0.001		NS	-1.4	0.006	NS
Marital Status	-1.9	0.059		NS	-0.75	0.45		NI	-0.58	0.57	NI
Education level	2.8	0.25		NI	2.2	0.33		NI	1.1	0.57	NI
Diagnosis	6.7	0.082		NS	6.3	0.10		NS	8.8	0.032	NS
Time since diagnosis	3.0	0.56		NI	0.38	0.98		NI	2.8	0.60	NI
Comorbidity	7.2	0.067		NS	12.4	0.006		NS	5.6	0.13	NI
Stem cell transplantation	-1.3	0.19		NI	-2.4	0.019		NS	-1.8	0.081	NS
Treatment intent	8.5	0.037		NS	3.6	0.31		NI	3.9	0.037	NS
Treatment response	8.1	0.044		NS	6.1	0.11		NI	6.8	0.077	NS
Hospital	-0.71	0.48		NI	-2.0	0.049		NS	-1.8	0.077	NS
Member patient association	-1.4	0.17		NI	-2.3	0.022		NS	-3.1	0.002	NS
Total monitoring	0.32	<0.001	0.98	<0.001	0.29	<0.001	0.69	<0.001	0.31	<0.001	0.87
Total blunting	0.11	0.15		NI	0.17	0.003	0.49	0.015	0.14	0.013	0.49
Global quality of life	-0.05	0.54		NI	-0.16	0.004	-0.22	0.001	-0.15	0.004	-0.20

TINQ: Toronto Information Needs Questionnaire; PLNS: Patient Learning Needs Scale; PINQ: Patient Information Needs Questionnaire.
Univariate variables with a p-value <0.10 were entered in the multivariate regression analysis.

COPING STYLE AND SATISFACTION WITH INFORMATION

Monitoring was related with the perception that the information provision could have been improved (Mann-Whitney $U=10728.0$, $Z=-2.4$; $p=0.018$). With respect to blunting, no significant difference was found (Mann-Whitney $U=11260.0$, $Z=-1.8$; $p=0.067$). There were no significant associations between coping style and information satisfaction questions (ISQ 3 to 8 together (ISQ total)) for either monitoring ($r=-0.074$, $p=0.16$) or blunting ($r=-0.036$, $p=0.49$).

Using multivariable logistic regression analysis the relation between the monitoring coping style and information satisfaction disappeared ($B=-0.015$, $p=0.40$). For blunting, we found a slightly negative relation between a high blunting coping style and information satisfaction ($B=-0.038$, $p=0.048$). Other demographic and clinical variables were not related with information satisfaction (see table 3).

COPING STYLE AND DECISION-MAKING PREFERENCE

In response to the ISQ question on how much information patients desire and the preferred involvement in decision-making, high monitors showed a stronger desire for more information and more involvement in decision-making than low monitors ($p<0.001$). For blunting, no differences were found ($p=0.350$)(see table 4).

Multivariable regression analysis revealed that this relation between a high monitoring coping style and treatment decision-making persisted ($B=-0.17$, $p<0.001$). Other demographic and clinical variables were not related with treatment decision-making (see table 3).

COPING STYLE AND QUALITY OF LIFE

No significant relation was found between coping style and QoL (monitoring $r=0.065$ $p=0.20$, blunting $r=0.042$ $p=0.41$).

Table 3 Overview of the relations between information satisfaction (ISQ2), treatment decision-making (ISQ1) and sociodemographic and clinical variables, quality of life (EORTCglob) and cognitive coping style (TMSI)

Variable	Information satisfaction		Treatment decision-making	
	Univariate	Multivariable	Univariate	Multivariable
	p-value	B p-value	p-value	B p-value
Gender	0.78	NI	0.052	NS
Age	0.016	NS	0.003	NS
Marital Status	0.91	NI	0.32	NI
Education level	0.003	NS	0.040	NS
Diagnosis	0.023	NS	0.92	NI
Time since diagnosis	0.25	NI	0.37	NI
Comorbidity	0.13	NI	0.093	NS
Stem cell transplantation	0.88	NI	0.53	NI
Treatment intent	0.54	NI	0.12	NI
Treatment response	0.17	NI	0.40	NI
Hospital	0.27	NI	<0.001	NS
Member patient association	0.032	NS	0.010	NS
Total monitoring	0.018	NS	<0.001	-0.17 <0.001
Total blunting	0.067	-0.038 0.048	0.35	NI
Quality of life	0.041	NS	0.074	NS

Univariate variables with a p-value <0.10 were entered in the multivariable regression analysis.

Table 4 Associations between decision-making (ISQ 1) and cognitive coping style (total monitoring and blunting) with Kruskal Wallis test

Which one of the following categories most applies to you?							
	I would like all available information & be involved in decisions about my illness		I would only like positive information about my illness		I would only like limited information & would prefer the doctor to make the decisions		
	Median (IQR)	N	Median (IQR)	N	Median (IQR)	N	p-value
Monitoring	29.0 (10.0)	314	21.5 (10.0)	12	19.0 (9.3)	54	<0.001
Blunting	29.0 (9.0)	314	24.0 (17.0)	13	29.0 (9.0)	53	0.35

DISCUSSION

The finding that a monitoring coping style was positively related with the need for information (hypothesis 1) is consistent with our hypothesis and confirms the results of previous studies in patients with cancer and during gastrointestinal endoscopy.^{8, 12, 13, 22} More precisely, they are in line with previous research, which found a higher need for medical as well as psychosocial information in patients with a monitoring coping style.¹³ However, it should be mentioned that in all these studies, the correlations found were moderate, indicating that other factors may also influence the need for information. However, using linear regression analysis, only coping style and global quality of life were related with the need for information.

In the present study, contrary to our expectations, patients with a blunting cognitive coping style also had a high need for information, which is in contrast to previous studies investigating coping style during gastroscopy, before an electric shock, and during palliative and curative radiotherapy consultations, and it is also in contrast with the original theory, in which high blunting was associated with a lower need for information.^{1, 13, 22} An explanation for the absence of a negative relation in the present study might be that most patients were included more than two years after diagnosis, when their lives were no longer dominated by dealing with potentially threatening circumstances as at the time of the overwhelming diagnosis. In this new situation, information might be welcome anyway as a form of distraction, for high as well as for low blunters. This is also in accordance with the study of Baker, in which high monitoring patients prefer information later on in their disease.²³ Furthermore, we studied coping style among patients with a treatment intent of palliation, curation, maintenance and active surveillance, which might also mean that this patient group was in a less threatening situation than the participants of the study of Timmermans et al., where a relation was found only in case of palliative radiotherapy.¹³ In any case, when possible during the whole disease process, it is important to match the amount of information to each patient's cognitive coping style, as this can reduce the patient's level of stress.⁸

Consistent with the literature and with our second hypothesis, we found with univariate analysis that monitoring was related to lower satisfaction with the information received^{8, 13, 24}. Timmermans et al. found that in palliative radiotherapy consultations, high monitoring patients were less satisfied with the information received concerning treatment procedures, side-effects and physical impact of the treatment. Also, in

curative radiotherapy consultations, high monitoring patients were less satisfied with the information received on treatment procedures and on the emotional impact of the treatment.¹³ Furthermore, high monitoring survivors and patients with breast cancer and healthy women were less satisfied with the prognostic information.²⁴ In the present study, using multivariable analysis this relation disappeared, which is consistent with the absent relation between information satisfaction and monitoring coping style described in recent literature on information satisfaction in patients with a history of cancer and undergoing chemotherapy due to cancer.^{14, 25} It should be noted that none of the previous authors, except van Vliet et al., performed a multivariable analysis of the information satisfaction and therapy decision-making; only univariate analysis were performed. Regarding the coping style blunting, we found just a negative relation with satisfaction with the information received. Previous studies disagree with each other on the relation between a blunting coping style and satisfaction with the information received.^{8, 13, 14, 24} Timmermans et al. found a higher satisfaction among only palliative high blunting patients.¹³ In addition, Elf and colleagues found, as did our present study, that high blunters were more dissatisfied with the information received.¹⁴ Van Vliet et al. did not find a relation between information satisfaction and high blunting.²⁴ A possible interpretation would be that in accordance with the theory of blunting coping style, high blunters are not interested in information and do not seek information, and might therefore not receive enough information.¹¹

As expected, and in line with the results of Timmermans et al.¹³ and Ong et al.¹², monitoring was associated with the preference to be more involved in decision-making (hypothesis 3). In contrast, Miller found a more passive role in decision-making in high monitors, possibly because these monitoring patients tended to give the decisional control to a more competent individual, such as a physician.⁸ Other research has shown that blunting was related to a more passive way of decision-making, except in palliative radiotherapy consultations.¹³ The absence of a relation between blunting and decision-making found in the present study, may support the idea that a patient with a hematological malignancy is already in a further phase of the threatening situation, and therefore the need for information and involvement in decision-making is present in the same degree in both lower and higher blunting.

In the present study, coping style was not related to quality of life (hypothesis 4). There are no previous studies on the relationship between coping style and QoL, except a recent study of Michel et al. on survivors of cancer, where QoL was studied as generic QoL (physical and mental), and survivor specific QoL (psychological problems and social

problems)²⁵. According to this study, only a relation between high monitors and more psychological problems was found, the other three QoL sections were not related, as was the case in the current study.²⁵ It should be noted that they used the TMSI in a different way, by means of the calculation of a combined monitoring scale by subtracting the blunting score from the monitoring score.²⁵

To our knowledge, this is the first study investigating the cognitive coping styles of patients with a hematological malignancy in relation to need for information, satisfaction with the information received, and preferences regarding shared decision-making. Some limitations should be mentioned. The inclusion of outpatients impeded the generalizability of the results to all patients diagnosed with a hematological malignancy. Most importantly, the cross-sectional design of the study, in which patients participated at various stages in their disease and treatment, does not reflect the development of information satisfaction and need for information throughout the disease process. Future prospective studies should focus on inpatients and outpatients with a hematological malignancy during their entire disease trajectory.

Our results have important implications for clinical practice. It is important for healthcare professionals to be aware of individual differences in cognitive coping style and the associated need for information, satisfaction with information and the wish to be involved in decision-making among patients with hematological malignancies.

CONCLUSION

Among patients with hematological malignancies, cognitive coping style is related to a need for information, information satisfaction and the wish to be involved in shared decision-making. Moreover, high blunting does not imply a reduced need for information in this patient group. Therefore, it is important for healthcare professionals to be aware of individual differences in cognitive coping style. Further research is needed to develop and evaluate assessment tools for quick recognition of coping styles that can be used in clinical practice.

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CHAPTER 5

SHARED DECISION-MAKING AND PROVIDING INFORMATION AMONG NEWLY DIAGNOSED PATIENTS WITH HEMATOLOGICAL MALIGNANCIES AND THEIR INFORMAL CAREGIVERS, NOT ONE SIZE FITS ALL

J.A.J. Rood

I.H. Nauta

B.I. Witte

F. Stam

F.J. van Zuuren

A. Manenschijn

P.C. Huijgens

I.M. Verdonck- de Leeuw

S. Zweegman

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ABSTRACT

INTRODUCTION

In order to optimize personalized medicine for patients with hematological malignancies (HM), knowledge on patient preferences with regard to information provision and shared decision-making (SDM) is of the utmost importance. The aim of this study was to investigate the SDM preference and the satisfaction with and need for information among newly diagnosed HM-patients and their informal caregivers, in relation to sociodemographic and clinical factors, cognitive coping style, and health related quality of life.

METHODS

Newly diagnosed patients and their caregivers were asked to complete the Hematology Information Needs Questionnaire, the Information Satisfaction Questionnaire and the Threatening Medical Situations Inventory. Health related quality of life of participants, was assessed using the EORTC QLQ-C30 (patients) or EQ-5D-5L (caregivers). Medical records were consulted to retrieve sociodemographic and clinical factors and comorbidity by means of the ACE-27.

RESULTS

Questionnaires were completed by 138 patients and 95 caregivers. SDM was preferred by the majority of patients (75%) and caregivers (88%), especially patients treated with curative intent (OR=2.7, $p=0.041$), and patients (OR=1.2, $p<0.001$) and caregivers (OR=1.2, $p=0.001$) with a higher monitoring cognitive coping style (MCCS). Among patients, total need for information was related to MCCS ($p=0.012$), and need for specific information was related to MCCS and several clinical factors. Importantly, dissatisfaction with the information they received was reported by a third of the patients and caregivers, especially patients who wanted SDM ($\chi^2=7.3$, $p=0.007$), and patients with a higher MCCS (OR 0.94, $p=0.038$).

CONCLUSION

The majority of HM-patients want to be involved in SDM but the received information is not sufficient. Patient-tailored information is urgently needed, in order to improve SDM.

INTRODUCTION

Benefits of shared decision-making (SDM) are better treatment decision-making¹, greater satisfaction with treatment² and a better health-related quality of life (HRQOL).³ In order to enable SDM, a key element is providing good information to both patients⁴ and their informal caregivers, whose supporting role is important in facilitating patients to make informed choices based on the information received.⁵ Caregivers may want to know less⁶, or more than the patient.⁷ The amount of information and degree of details that patients judge to be essential in SDM vary considerably among cancer patients.⁸ There have been reports describing that patients with hematological malignancies (HM) have less desire for information and are less actively involved in SDM than patients with solid cancer.^{1,9} This may be due to HM-treatment-related complications and a high level of psychological distress and worsened HRQOL.^{10,11} It is known that HRQOL is related to information satisfaction or dissatisfaction¹², intensity of treatment is related to patients' need for and source of information¹³, and cancer type is related to SDM preference.^{1,9,14} Furthermore, cognitive coping style (CCS) is also a factor associated with information satisfaction¹⁵⁻¹⁷, need for information¹⁶⁻¹⁹ and SDM preference.^{16,17,19} HM-patients and their caregivers often face decisions regarding participation in clinical trials, wait-and-see management, medication doses-reduction, stem cell transplantation and palliative care. Despite the uniqueness of HM, studies on preferences of newly diagnosed HM-patients a few weeks after diagnosis and their caregivers are lacking. Furthermore, the influence of CCS on these preferences has never been studied among HM-patients. In addition to our literature review²⁰ and our previous work regarding need for information, information satisfaction and SDM preference of HM-patients at all times since diagnosis^{18,21}, the aim of this study was to gain insight into these preferences of newly diagnosed HM-patients and their caregivers, and possible multivariable relations of these preferences with sociodemographic and clinical factors, CCS, and HRQOL.

PATIENTS AND METHODS

PATIENTS

This cross-sectional study included newly diagnosed (≤ 6 weeks after diagnosis) HM-patients (acute or chronic leukemia, Hodgkin or non-Hodgkin lymphoma, or multiple myeloma). During a 1 year (2013–2014) period, HM-patients visiting the in- and outpatient clinics of the VU University Medical Centre (VUmc), Northwest Clinics, and Isala, the Netherlands were asked to participate. Inclusion-criteria were: age ≥ 18 years and Dutch language proficiency. Exclusion-criteria were: concurrent treatment of another malignancy, terminal phase, and mental/physical inability to participate. Medical records were consulted to retrieve sociodemographic (age, gender) and clinical factors (diagnosis, treatment intent (curative/non-curative), and comorbidity by means of the ACE-27²²). A study-specific questionnaire was used to retrieve additional sociodemographic factors (marital status, educational level, nationality and patient-association membership).

INFORMAL CAREGIVERS

Participating patients were requested to provide contact details for invitation of an informal caregiver (partner, relative or another closely related person). Inclusion-criteria were age ≥ 18 years, Dutch language proficiency, and mental/physical ability to participate. A study-specific questionnaire was used to retrieve sociodemographic factors (gender, age, relation to the patient, educational level, and nationality).

PATIENT REPORTED OUTCOME MEASURES

Participants' wish for SDM and satisfaction with the information provision were assessed with the Information Satisfaction Questionnaire (ISQ).²³ SDM preference was categorized as 1) "I would like all available information & be involved in decisions about my illness", 2) "I would only like positive information", and 3) "I would only like limited information & would prefer the doctor to make the decisions". Satisfaction with information was measured with the question: Do you feel information provision could have been improved? Yes/No. The level of satisfaction with information was measured on various domains (0 (very dissatisfied)–4 (very satisfied)). The need for information on various domains was assessed with a modified version of the Hematology Information

Needs Questionnaire (HINQ).²¹ Monitoring Cognitive Coping Style (MCCS) and Blunting Cognitive Coping Style (BCCS)) were measured with the Threatening Medical Situations Inventory.²⁴ HRQOL of participants, was assessed using the EORTC QLQ-C30 (version 3.0 (Dutch)) (patients)²⁵ and the EQ-5D-5L (version 2 (Dutch))(caregivers).²⁶ For details of all questionnaires, see Addendum–Methods.

INFORMED CONSENT AND PROCEDURE

This study was approved by the Medical Ethical Committee of the VUmc, reference number 2009/300. Participants were asked to sign informed consent, and to complete the questionnaires online or on paper. After two weeks, non-responders received a reminder; after two more weeks non-responders were contacted by telephone.

STATISTICAL ANALYSIS

We described nominal and ordinal variables in terms of numbers and percentages, continuous variables in terms of means/medians and standard deviations/ranges. Participants' preferences regarding SDM, satisfaction with information, and need for information (dependent variables) were tested for differences with respect to socio-demographic and clinical characteristics, CCS and HRQOL (independent variables) using the independent samples t-test, ANOVA, Chi-square, Pearson correlation coefficients, Mann-Whitney U-test or Kruskal-Wallis test, as appropriate. Multiple linear and logistic regression models were obtained via backward (HINQ) and forward selection (ISQ) (p-removal/entry $p < 0.05$); only variables with a univariate $p < 0.10$ were included in the selection procedure. SPSS (version 19) was used, and $p < 0.05$ was considered significant.

RESULTS

STUDY POPULATION

In total, 138 patients and 95 caregivers participated (response rate 69% and 66%). For declining participation reasons, see the Addendum Figure 1. Demographic characteristics are provided in Table 1a (patients) and Table 1b (informal caregivers). The most prevalent diagnosed HM was non-Hodgkin lymphoma (37%), and most patients were treated with curative intent (66%).

Table 1a Overview of sociodemographic and clinical characteristics of patients (n=138)

		n	%
Gender	Female	54	39.1%
	Male	84	60.9%
Age	Mean	58.7 (SD 15.6)	
Marital status	Unmarried	18	20.0%
	Married	52	57.8%
	Cohabiting	4	4.4%
	Widowed	9	10.0%
	Divorced	7	7.8%
Educational level	Primary education	51	37.2%
	Secondary education	47	34.3%
	Higher education	39	28.5%
Nationality	Dutch	134	97.1%
	Otherwise	4	2.9%
Diagnosis	Acute leukemia	27	20.3%
	Chronic lymphatic leukemia	8	6.0%
	Chronic myeloid leukemia	13	9.8%
	Multiple Myeloma	22	16.5%
	Hodgkin lymphoma	14	10.5%
	Non-Hodgkin lymphoma	49	36.8%
Treatment intent	Curative	86	65.6%
	Non-curative	45	34.4%
Comorbidity	No comorbidity	70	54.7%
	Mild comorbidity	34	26.6%
	Moderate comorbidity	19	14.8%
	Severe comorbidity	5	3.9%
Treated hospital	Academic	64	46.4%
	Non-academic	74	53.6%
Hospitalized at time of the study	No	126	92.6%
	Yes	10	7.4%
Member patient association	No	129	94.9%
	Yes	7	5.1%

Table 1b Overview of sociodemographic characteristics of informal caregivers (n=95)

		n	%
Gender	Female	66	70.2%
	Male	28	29.8%
Age	Mean	55.0 (SD 12.9)	
Relation to patient	Spouse	66	69.5%
	Parent	14	14.7%
	Child	7	7.4%
	Otherwise	8	8.4%
Educational level	Primary education	29	30.5%
	Secondary education	31	32.6%
	Higher education	35	36.8%
Nationality	Dutch	92	97.9%
	Otherwise	2	2.1%

SHARED DECISION-MAKING

In the present study, answer option “I would only like positive information” was chosen by a small number of patients (4%, n=5) and none of the caregivers (n=0). Therefore, the outcome on SDM was combined and recoded into a dichotomous outcome, resulting in an explicit response option for SDM²⁷: “I would like all available information & be involved in decisions about my illness” as well as for decision delegation: “I would only like limited information & would prefer the doctor to make the decisions”. SDM was preferred by the majority of the patients (n=104/138, 75%) and caregivers (n=84/95, 88%). Multiple logistic regression analysis (MRA) showed that among patients, a higher wish for SDM was associated with 2 out of 5 selected variables: treatment with curative intent (OR 2.7, p=0.041), and a higher MCCA (OR 1.2, p<0.001) (Table 2). Among caregivers, MRA showed that the wish for SDM was associated with 1 out of 2 selected variables: MCCA (OR 1.2, p<0.001).

SATISFACTION WITH THE INFORMATION PROVIDED

Overall, total information satisfaction was good among patients (mean=16.9, SD 3.1) and caregivers (mean=16.7, SD 3.4) (mean item scores 2.5–3.2 (range 0 (very dissatisfied) to 4 (very satisfied) (Addendum Table 3)). Information provision could be improved according to almost a third of the patients (n=39/131) and caregivers (n=30/91). Dissatisfied participants were dissatisfied on all domains, except for “types of treatment available”.

MRA showed that a higher MCCA was associated with dissatisfaction with the information provided among patients (OR 0.95, p=0.038) and caregivers (OR 0.85, p<0.001). For caregivers, information dissatisfaction was also associated with younger age (OR 0.96, p=0.05)(Table 2).

The level of satisfaction was negatively associated with the wish for SDM; 36% of patients who preferred SDM were dissatisfied with the information provided, versus 10% of patients who did not prefer SDM ($\chi^2=7.3$, p=0.007). For caregivers, these numbers were 35% and 11% (p=0.14).

Table 2 Multiple logistic regression analysis of patients' and caregivers' involvement in treatment decision-making (ISQ) and information satisfaction (ISQ yes/no) in relation to univariate sociodemographic and clinical variables, cognitive coping style and health related quality of life with a p<0.10.

	Patients									
	Shared decision-making					Information satisfaction				
	Univariate		Multivariable			Univariate		Multivariable		
	OR	95% CI	p-value	OR	95% CI	p-value	OR	95% CI	p-value	p-value
Gender										
Nationality ^a			0.60			NI			0.73	NI
Member patient association			0.57			NI			0.079	NI
Treating hospital			1.0			NI			0.67	NI
Hospitalized			0.45			NI			0.23	NI
Marital status			0.89			NI			0.45	NI
Educational level			0.15			NI			0.82	NI
Diagnosis			0.041 *			NI			0.14	NI
Treatment intent [#]	2.4	[1.1 - 5.5]	0.032 *	2.7	[1.0 - 7.0]	0.041 *			0.49	NI
Comorbidity			0.050			NS			0.36	NI
Age			0.14			NI			0.76	NI
Monitoring coping style			<0.001 *	1.2	[1.1 - 1.3]	<0.001 *	0.95	[0.90 - 1.0]	0.089	NS
Blunting coping style	1.2	[1.1 - 1.3]	0.013 *			NS			0.037 *	0.038 *
Health Related Quality of Life			0.60			NI			0.22	NI
									0.077	NS
Caregivers										
Gender										
Nationality ^a			0.72			NI			0.54	NI
Relation to patient			1.0			NI			1.0	NI
Educational level			0.51			NI			0.72	NI
Age			0.52			NI			0.021 *	NS
Monitoring coping style	0.95	[0.90 - 1.0]	0.092			NS			0.005 *	0.05 *
Blunting coping style	1.2	[1.1 - 1.3]	<0.001 *	1.2	[1.1 - 1.3]	0.001 *	0.85	[0.78 - 0.93]	<0.001 *	<0.001 *
Health Related Quality of Life			0.32			NI			0.61	NI
			0.57			NI			0.30	NI

ISQ = Information Satisfaction Questionnaire. Do you think the information provision could have been improved yes/no

* Significant at p<0.05 NS = Not significant NI = Not included in final model because univariate p<0.10

Tested with Mann-Whitney U test, not included in the multiple regression analysis

Treatment intent: curative compared with non-curative

NEED FOR INFORMATION

The need for information was high among patients (median 4.7, range 1.1–5.0) and caregivers (median 4.8, range 2.6–5.0) (Addendum Figure 2). Both the patients and the caregivers rated the medical topics as more important than psychosocial topics. Caregivers expressed a significantly higher need for information than patients ($p=0.003$), especially on psychosocial information ($p=0.001$).

MRA (Table 3) showed that, among patients, a higher MCCS was associated with higher need for information on the subscales “disease, symptoms, treatment and side-effects” ($B=0.022$, $p=0.011$), “medical tests and prognosis” ($B=0.029$, $p=0.001$), and a higher total need for information ($B=0.021$, $p=0.012$). Furthermore, treatment in an academic hospital was associated with a lower need for information on “medical tests and prognosis” ($B=-0.42$, $p=0.002$), and “etiology, sleep and physical changes” ($B=-0.32$, $p=0.026$). Among caregivers, only a lower educational level ($B=0.34$, $p=0.042$) was associated with a higher need for information on “etiology, sleep and physical changes”. Furthermore, information need was not associated with information satisfaction in general ($p=0.70$ (patients) and $p=0.87$ (caregivers)) or SDM preference ($p=0.89$ (patients) and $p=0.58$ (caregivers)). For details of all univariate and multivariable analyses see Addendum–Results tables 4 and 5.

Table 3 Patients' sociodemographic and clinical characteristics, cognitive coping style and HRQOL in relation to need for information (HINQ)

	Patients											
	Disease, symptoms, treatment and side-effects				Medical tests and prognosis				Self-care			
	Univariate	Multivariable		P-value	Univariate	Multivariable		P-value	Univariate	Multivariable		P-value
	p-value	B	95% CI	P-value	p-value	B	95% CI	P-value	p-value	B	95% CI	P-value
Gender	0.002			NS	0.24			NI	0.002			NS
Nationality ^a	0.64			NI	0.032			NI	0.034			NI
Membership	0.77			NI	0.84			NI	0.87			NI
patient association												
Treating hospital*	0.31			NI	0.096	-0.42	[-0.67 - 0.16]	0.002	0.40			NI
Hospitalized	0.68			NI	0.067			NS	0.56			NI
Marital status	0.45			NI	0.64			NI	0.57			NI
Educational level	0.037			NS	0.28			NI	0.51			NI
Diagnosis ^b	0.22			NI	0.18			NI	0.43			NI
Treatment intent	0.62			NI	0.35			NI	0.83			NI
Comorbidity	0.86			NI	0.30			NI	0.39			NI
Age	0.81			NI	0.30			NI	0.86			NI
MCCS	<0.001	0.022	[0.005 - 0.039]	0.011	0.010	0.029	[0.012 - 0.047]	0.001	0.20			NI
BCCS	0.51			NI	0.90			NI	0.24			NI
HRQOL	0.52			NI	0.59			NI	0.82			NI

HINQ = Hematology Information Needs Questionnaire, tested with Mann-Whitney U test, Kruskal Wallis test and Spearman correlation coefficient test. Univariate variables with a p-value <0.10 were included in the multiple linear regression model.

MCCS = Monitoring Cognitive Coping Style; BCCS = Blunting Cognitive Coping Style; HRQOL = Health Related Quality Of Life

^aNationality: Not included in the linear regression model, due to this small number of non-Dutch participants

NS = Not significant NI = Not included, because univariate p>0.10

*Treating hospital: Reference = non-Academic

DISCUSSION

SDM was preferred by the majority of the participants, especially by participants with a higher M CCS, and by patients treated with curative intent. However, a third of the patients and caregivers who preferred SDM were not satisfied with the information received, whereas among the participants who did not prefer SDM, only 10% of the patients, and 11% of the caregivers were dissatisfied with the information received. Moreover, dissatisfaction with the information received was associated with a higher M CCS in patients and caregivers, and with younger age in caregivers.

Our results confirm the findings of recent studies indicating that the great majority of HM-patients prefer SDM.^{28–30} In contrast, studies of Ernst⁹ and Yogaparan³¹ reported that fewer patients prefer SDM, which can probably be explained by the overall increase of SDM preference the past few years.²⁷ Another explanation may be that Ernst's study⁹ included a higher number of in-patients (almost two third) than our study. However, in that study SDM preference was not influenced by treatment setting⁹, and in our study we could not calculate this due to the low number of in-patients. Preference for SDM was associated with several factors. First, with a higher M CCS, which is consistent with earlier studies on general cancer patients.^{16, 17, 19} A second, novel finding is the observation that patients with a curative treatment intent were more likely to prefer SDM than incurable patients (81 versus 64%). This association has not been found earlier in HM-patients.⁹ Possibly, the condition of patients with an incurable disease might negatively impact the wish for SDM. More probably however, the possibility of cure offers a future and thereby encourages autonomy. However, further qualitative research is required. It must be noted that SDM preference depends on the used questionnaire, which was dichotomous in our study, whereas Ernst⁹ used a five-response-categories-question on how much decision-control they would like to have, with 5 control options: active, active shared, collaborative, passive shared and passive.

Good quality information is of course essential in SDM⁴, but our results showed that a third of the patients and caregivers were not satisfied with the information they received, which is comparable with previously described satisfaction-percentages among HM-patients which ranged from 52–67%.^{20, 21, 32} This highlights the need for more tailored information. Our analysis confirms the previously found relation between M CCS and information satisfaction in oncology patients^{15–17}, and it appeared that for patients information dissatisfaction was only associated with a high M CCS. This probably precludes

the possibility to predict information dissatisfaction in daily practice. Therefore, it will be necessary to establish the specific information preferences on an individual basis. Besides the relation between information satisfaction and MCCS in caregivers, the higher information satisfaction found in older caregivers is in line with the theory that older people have a greater reliance on information provided by physicians.³³ Furthermore, patients satisfied with the information had a lower wish for involvement in SDM. Possibly this is a less critical group of patients, who are easily satisfied and who leave decisions to the physician.

In order to enable clinicians to individualize the supply of information, we investigated which factors might be associated with need for information. We found that patients and caregivers do indeed have a high need for information, especially for medical information. This finding is in line with findings on general cancer patients and their family^{5,34}, and on HM-patients during their disease.^{20, 21, 29, 35, 36} Need for information was associated with a higher MCCS, which confirms the results of previous studies in patients with cancer¹⁶⁻¹⁹, especially related with a higher need for medical information, which can possibly be explained by that high MCCS-patients cope better with predictable information to control about what to expect for the future.^{17, 18} Patients treated in an academic hospital had a lower need for information on medical tests and prognosis, and etiology, sleep and physical changes, this might be explained by the fact that some of these patients had been referred to an academic hospital at the time of diagnosis, and may already have received information on these subjects, while they were subjected to investigations in the referring hospital.

CLINICAL IMPLICATIONS

We did not find higher needs for information in patients and caregivers who were dissatisfied with the information they received and who preferred involvement in SDM. This shows that providing more information does not guarantee satisfaction and preference for involvement, but that it might be necessary to tailor the content of the information or the way the information is presented. A more emotionally supporting way of information provision has been suggested.³⁷ This was reasoned by lymphoma and MM survivors' information satisfaction, which was related to the for example, the usefulness of information.³² Furthermore, in the present study, we found no association between HRQOL and information satisfaction, which may be due to the fact that we used a generic cancer questionnaire (EORTC QLQ-C30) rather than a HM-specific HRQOL-questionnaire which did not exist at the time of this study.

STUDY LIMITATIONS

There were some limitations to our study. Although the response rate among patients and caregivers was reasonable, a bias cannot be ruled out, since we did not have the permission to examine the sociodemographic and clinical characteristics of non-participants. However, the age and gender distribution of the participating patients was comparable with HM-patients in general in the Netherlands.³⁸ Another possible limitation is that we included relatively many patients with acute leukemia and CML and relatively few patients with NHL and CLL. However, the type of diagnosis was not associated with the outcomes. Therefore, the results of this study seem to be generalizable to these underrepresented diagnoses as well. Another limitation is that we included 138 patients and 95 caregivers. Some of the significant findings might have been statistically significant only by chance. For every 20 true null hypotheses we expect one to be (falsely) rejected, although there is no clear consensus on how to correct for multiple comparisons.³⁹ However, most significant findings were <0.01 . Also, the outcome measure on SDM preference included both desire for information and SDM preference, which partly overlaps with the item on need for information. Finally, we restricted ourselves to testing CCS and HRQOL as possible independent variables. In the future, it might be interesting to include associations with other issues as well, e.g. anxiety or depression.

In conclusion, the majority of patients and caregivers wanted SDM, but approximately a third were dissatisfied with the information they received. Important factors to take into account for providing tailored information to HM-patients in the context of SDM are CCS, treatment intent, and type of hospital. Caregivers had higher needs for information than patients, and caregivers' CCS, educational level and age are important factors to take into account for providing tailored information and SDM.

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ADDENDUM—METHODS

PATIENT REPORTED OUTCOME MEASUREMENTS

For patients and informal caregivers, satisfaction with the current information provision and preferences for involvement in shared decision-making (SDM) was assessed by means of the Information Satisfaction Questionnaire (ISQ)¹, which has been used in patients with cancer in general¹, and in breast and prostate cancer patients², and which we validated in our cross-sectional study of patients with a hematological malignancy.³ The ISQ comprises six questions about the satisfaction with the information received: explanation of the illness, on side-effects, types of treatments available, advice on lifestyle, practical day issues and one on the overall information provided. Total information satisfaction was calculated by summing up the individual items ranging from 0 (very dissatisfied) to 4 (very satisfied). Total scores 0–4 represent very poor satisfaction, 5–9 poor, 10–14 fair, 15–19 good, and 20–24 excellent satisfaction. An additional question was: Do you feel information provision could have been improved? Yes or No.

Preferences regarding SDM were analyzed by means of an adapted format. Since only five patients chose the original answer option 2 (only positive information), we combine these answer options 2 with 3 (limited information & would prefer the doctor to make the decisions) for analysis, resulting in two categories of SDM preference; 1) I would like all available information & be involved in decision about my illness; versus 2) I would only like limited information & would prefer the doctor to make the decisions.

Cognitive coping style was measured with an adapted version of the Threatening Medical Situations Inventory (TMSI)⁴, comprising two of the original four descriptions of threatening situations^{5, 6}, that were validated in gynecology patients and oncology patients.⁵ Furthermore, we added a third threatening situation, i.e. receiving the diagnosis of a hematological malignancy⁷, in order to increase the relevance of the questionnaire for our participants. The TMSI is intended to measure two cognitive coping styles in the domain of threatening medical situations: monitoring (the tendency to acquire information under impending threat) and blunting (the tendency to avoid confrontation and to seek distraction in threatening medical situations).⁸ Each description of a threatening situation is followed by six possible reactions, three monitoring and three blunting, in a random order, to be scored on a 5-point Likert scale (ranging from 1= “not at all applicable to me” to 5= “strongly applicable to me”). Summing up the scores of the individual monitoring

and blunting items, resulted in the total monitoring cognitive coping style (MCCS) and blunting cognitive coping style (BCCS) scores, ranged from 9 (lowest) to 45 (highest).

HRQOL of the patients was assessed using the European Organization for Research and Treatment of Cancer (EORTC) QLQ-C30 (version 3.0 (Dutch))⁹, which is an integrated system for assessing the health related quality of life (HRQOL) of cancer patients participating in international clinical trials. HRQOL of informal caregivers was assessed with the EQ-5D-5L of the EuroQol Group (version 2 (Dutch))¹⁰, which is used internationally to measure generic health status.¹⁰ Comorbidity of the patients was measured with the ACE-27¹¹, a 27-item validated comorbidity index used in patients with cancer. The ACE-27 grades specific diseases and conditions into 1 of 3 levels of comorbidity, grade 1 (mild), grade 2 (moderate), or grade 3 (severe), according to the severity of individual organ decompensation and prognostic impact. Once the patient's individual diseases or comorbidity conditions have been classified, an overall comorbidity score (none, mild, moderate, or severe) is assigned based on the highest ranking single ailment. For patients in which 2 or more moderate ailments occur in different organ systems or disease groupings, the overall comorbidity score is designated as severe.

So far, there is no validated questionnaire for assessing the need for information of patients with hematological malignancies. In an earlier cross-sectional study³, we developed a first version of the Hematology Information Needs Questionnaire (HINQ), comprising 92 questions. For the present study, this questionnaire was adjusted (see modification of the HINQ below). The adjusted HINQ comprises 62 items, grouped in five subscales: “disease, symptoms, treatment and side-effects” (regarding the disease, with its symptoms, the treatment and possible side-effects of treatment), “medical tests and prognosis” (regarding the various tests, reasons and procedures of the tests, and prognosis of the disease and the influence of disease for the future), “selfcare” (regarding information on nutrition, social life and sport), “etiology, sleep and physical changes” (regarding the and illness the etiology of the illness and changes on physical appearance and sleep problems), and “psychosocial” (regarding patients’ feelings, help and communication with HCPs, family and others). The items of the HINQ are scored on a Likert scale ranging from 1 (totally disagree) to 5 (totally agree).

MODIFICATION OF THE HINQ

In order to adapt the first version of the HINQ for the present study, we aimed to compress the number of questions. We first performed an exploratory factor analysis with the 92 items derived from data of our earlier cross-sectional study³ which included 458 patients. All items had to be answered on a 5-point Likert scale with the question “It’s important for me to have information about”, ranging from 1 (totally disagree) to 5 (totally agree) with a sixth option (not applicable to me). Principal component analysis with varimax rotation provided eleven factors with eigenvalues greater than 1, indicating an eleven-factor solution. Of these eleven factors, seven showed few loadings, therefore we performed a forced factor analysis with four factors. Secondly, we computed inter-item correlations. Twenty-six items were deleted because they had a correlation of 0.75 or higher with two other items, and another seven items were deleted due to overlap of content with other items, these deleted items were confirmed by factor analysis (i.e. they loaded on the same factor). Next, we critically reviewed the remaining 59 items with a group of hematologists, oncologists and hematology nurse specialists, and we reached consensus about the items belonging to the adjusted Hematology Information Needs Questionnaire (HINQ). Three important items were added, namely items concerning fertility information need, sexuality information need and information need concerning concentration and memory problems. This adjusted HINQ, which now contained 62 items, was further investigated using the data obtained from the first 138 patients of the present study. In an exploratory factor analysis, we aimed to explain at least 70% of the variance with a restricted number of factors. Free analysis provided nine factors with eigenvalues greater than 1.0, indicating a nine-factor solution. Additionally, since only a few items belonged to the factors six to nine, factor analysis was performed forcing a five-factor solution. Item clustering on each factor was studied in relation to the factor structure that was proposed to emerge from the data to determine a conceptual interpretation of the factors. It appeared that the first factor indicates information about the disease, symptoms, treatment and side-effects of the treatment. The items that loaded on the second, third, fourth and fifth factor indicated information about medical tests and prognosis, self-care, etiology and sleep and physical changes, and psychosocial information, respectively. Total scale scores were computed by summing the item scores per scale.

ADDENDUM – RESULTS

Table 1 Internal consistency (Cronbachs alpha) of the various subscales of the used questionnaires

Instrument	Subscale	Patients	Caregivers
		Cronbach's α	Cronbach's α
HINQ	Disease, symptoms, treatment and side-effects	0.99	0.90
	Medical tests and prognosis	0.97	0.87
	Self-care	0.95	0.83
	Etiology, sleep and physical changes	0.87	0.78
	Psychosocial	0.90	0.91
TMSI	Monitoring	0.78	0.79
	Blunting	0.78	0.79

Table 2 Psychometric findings of the used questionnaires

	Patients	Caregivers
	Range (mean) %	Range (mean) %
Missing item responses		
ISQ	0 - 5.4 (1.3)	1.2 - 4.8 (1.6)
HINQ	0.0 - 1.6 (0.1)	5.0 - 6.3 (5.4)
TMSI	0.8 - 5.4 (3.7)	2.4 - 4.8 (4.2)
Total score calculations		
ISQ	mean %	mean %
ISQ	100	96.2
HINQ (mean subscales)	95.4-96.2 (96)	95.2 - 96.4 (96.2)
TMSI	99.2	95.8

Supplementary figure 1 Reasons for declined participation

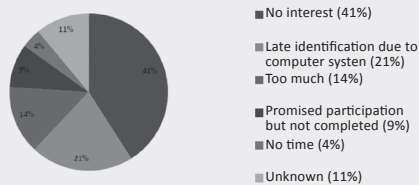


Table 3 Overview of patients' and informal caregivers' information satisfaction and differences between satisfied and dissatisfied patients and caregivers (ISQ)

Subscale	Patients (n=138)				Informal caregivers (n=95)			
	All patients mean (sd)	Satisfied patients mean (sd)	Dissatisfied patients mean (sd)	p-value	All caregivers mean (sd)	Satisfied caregivers mean (sd)	Dissatisfied caregivers mean (sd)	p-value
Explanation of the illness	3.2 (0.7)	3.3 (0.5)	2.8 (0.8)	<0.001 *	3.0 (0.8)	3.3 (0.5)	2.4 (0.9)	<0.001 *
Information on side-effects	3.0 (0.7)	3.1 (0.6)	2.6 (0.8)	<0.001 *	2.9 (0.8)	3.2 (0.5)	2.3 (1.0)	<0.001 *
Types of treatments available	2.5 (0.9)	2.6 (0.8)	2.3 (1.0)	0.16	2.5 (1.0)	2.6 (0.9)	2.4 (1.0)	0.56
Advice on lifestyle	2.8 (0.8)	2.9 (0.7)	2.4 (0.9)	0.003 *	2.8 (0.7)	2.9 (0.6)	2.5 (0.8)	0.010 *
Other practical day issues	2.5 (0.8)	2.7 (0.7)	2.2 (0.9)	0.018 *	2.6 (0.9)	2.9 (0.6)	2.1 (1.1)	0.001 *
Overall information provided	2.9 (0.7)	3.0 (0.6)	2.5 (0.8)	<0.001 *	2.9 (0.6)	3.1 (0.5)	2.5 (0.7)	<0.001 *
Total information satisfaction	16.9 (3.1)	17.7 (2.6)	14.9 (3.2)	<0.001 *	16.7 (3.4)	17.9 (2.5)	14.2 (3.4)	<0.001 *

Do you think the information provision could have been improved yes (dissatisfied)/ no (satisfied)
 Information satisfaction subscales vary from 0 (very dissatisfied) to 4 (very satisfied).
 Tested with the independent sample t-test

Table 4 Caregivers' sociodemographic and clinical characteristics, coping style and HRQoL in relation to need for information (HINQ)

	Caregivers											
	Disease, symptoms, treatment and side-effects				Medical tests and prognosis				Self-care			
	Univariate				Univariate				Univariate			
	p-value	B	95% CI	p-value	p-value	B	95% CI	p-value	p-value	B	95% CI	p-value
Gender	0.17	NI	NI	0.35	NI	0.98	NI	0.61	NI	0.55	NI	0.67
Nationality	0.54	NI	NI	0.30	NI	0.78	NI	0.77	NI	0.52	NI	0.86
Relation to patient	0.81	NI	NI	0.69	NI	0.94	NI	0.72	NI	0.80	NI	0.94
Educational level	0.16	NI	NI	0.42	NI	0.069	NS	0.014	0.34	0.042	0.19	NI
Age	0.39	NI	NI	0.21	NI	0.085	NS	0.12	NI	0.092	NS	NS
MCCS	0.45	NI	NI	0.34	NI	0.60	NI	0.98	NI	0.80	NI	0.88
BCCS	0.81	NI	NI	0.88	NI	0.61	NI	0.39	NI	0.76	NI	0.75
HRQoL	0.97	NI	NI	0.34	NI	0.67	NI	0.83	NI	0.17	NI	0.46

HINQ = Hematology Information Needs Questionnaire, tested with Mann-Whitney U test, Kuskal Wallis test and Spearman correlation coefficient test.

MCCS = Monitoring Cognitive Style BCCS = Blurring Cognitive Style

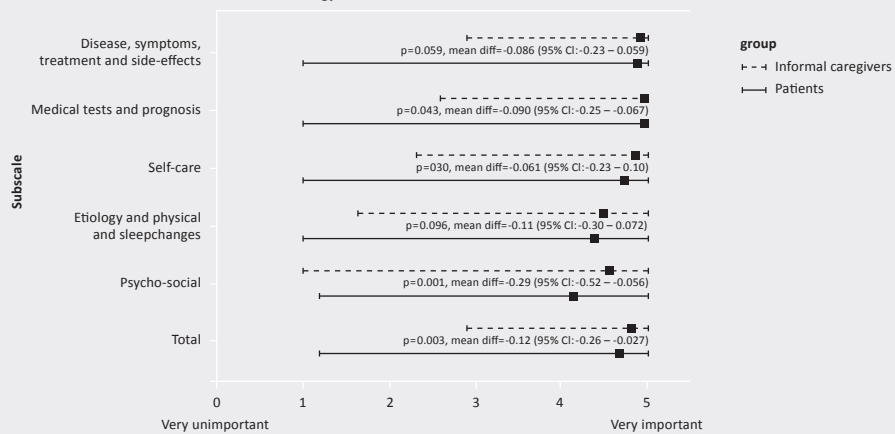
NS = Not significant NI = Not included

Univariate variables with a p-value < 0.10 were included in the multiple linear regression model.

Educational level: Primary education: B=0.34, p=0.022, Secondary education: B=0.016, p=0.91, Higher education: B=0.

Table 5 Differences in need for information subscales between may/ may not involvement in decision-making and satisfied/dissatisfied patients and their caregivers

Subscale	Treatment decision-making		Information satisfaction	
	Patients	Caregivers	Patients	Caregivers
	p-value	p-value	p-value	p-value
Disease, symptoms, treatment and side-effects	0.49	0.80	0.49	0.43
Medical tests and prognosis	0.17	0.18	0.88	0.89
Self-care	0.90	0.69	0.35	0.58
Etiology, sleep and physical changes	0.39	0.68	0.61	0.54
Psychosocial	0.24	0.44	0.16	0.91
Total information	0.89	0.58	0.68	0.87

Supplementary figure 2 Patients' and caregivers' need for information on the Hematology Information Needs Questionnaire

ADDENDUM—QUESTIONNAIRE

Questions regarding the diagnosis

It's important for me to have information about:

	Totally disagree	Slightly disagree	Neutral	Slightly agree	Totally agree	Inapplicable
What symptoms you may have related to your illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How the cancer acts in the body	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If there is cancer anywhere else in your body	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your present condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The medical name for your type of cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The cause of your illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If your illness is hereditary	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The possible course of your illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Questions regarding the various medical tests

It's important for me to have information about:

	Totally disagree	Slightly disagree	Neutral	Slightly agree	Totally agree	Inapplicable
The reasons the doctor suggests certain tests	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How the test are done	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Why they need to test your blood	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When to have a bone marrow biopsy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What the results of your blood tests mean	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Questions regarding the treatment**It's important for me to have information about:**

	Totally disagree	Slightly disagree	Neutral	Slightly agree	Totally agree	Inapplicable
What types of treatment are available	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The treatment procedures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How the treatment works against the cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What the purposes of your treatment are	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How long you will be receiving treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Why you need to take each medication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When to take each medication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The possible side effects of your treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The possible reactions to each medication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If there are ways to prevent treatment side effects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What side effects you should report to the doctor/nurse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If you are prone to infection because of your treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What complications might occur from your illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Who to talk with if you hear about treatments other than surgery, radiation or chemotherapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Questions regarding possible symptoms**It's important for me to have information about:**

	Totally disagree	Slightly disagree	Neutral	Slightly agree	Totally agree	Inapplicable
How to manage the symptoms you may experience	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to manage your pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If the treatment will alter the way that you look	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How much rest you should be getting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How you can avoid stress	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What to do if you cannot sleep properly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What to do if you have trouble urinating	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What to do if you have trouble with your bowels	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to care for your wound or incision	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What you should do if you have problems with your memory or concentration	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Changes in the field of fertility	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Changes in the field of sexuality	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Questions regarding the prognosis and future**It's important for me to have information about:**

	Totally disagree	Slightly disagree	Neutral	Slightly agree	Totally agree	Inapplicable
Possible results of your treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How the illness may affect your life over the next few months	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How the illness may affect your life in the future	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If the cancer will come back	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Survival rates for your illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Questions regarding contact and communication**It's important for me to have information about:**

	Totally disagree	Slightly disagree	Neutral	Slightly agree	Totally agree	Inapplicable
If there are groups where you can talk with other people with cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Who you should call if you have questions while you are still getting treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What is the best way to talk or interact with a physician	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to recognize your feelings toward your illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Where you can get help to deal with your feelings about your illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to talk to family/ friends about your illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to tell if the cancer has come back	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Opportunities for getting immediate help if you experience problems and have questions about your illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What to do and who to talk to if you become concerned about dying	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Where to get good educational material or literature about your illness or treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Who you should call if you have questions after all the treatments are over	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Questions regarding contact and communication**It's important for me to have information about:**

	Totally disagree	Slightly disagree	Neutral	Slightly agree	Totally agree	Inapplicable
If there are groups where you can talk with other people with cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Who you should call if you have questions while you are still getting treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What is the best way to talk or interact with a physician	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to recognize your feelings toward your illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Where you can get help to deal with your feelings about your illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to talk to family/ friends about your illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to tell if the cancer has come back	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Opportunities for getting immediate help if you experience problems and have questions about your illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What to do and who to talk to if you become concerned about dying	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Where to get good educational material or literature about your illness or treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Who you should call if you have questions after all the treatments are over	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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CHAPTER 6

HEMATOLOGISTS' AND SPECIALIST NURSES' PERSPECTIVES ON THE NEED FOR INFORMATION AMONG PATIENTS WITH HEMATOLOGICAL MALIGNANCIES

J.A.J. Rood

I.H. Nauta

B.I. Witte

F.J. van Zuuren

F. Stam

P.C. Huijgens

S. Zweegman

I.M. Verdonck-de Leeuw

Submitted 2017

ABSTRACT

INTRODUCTION

In cancer care, it is known that patients' information needs do not always correspond with the information received from healthcare professionals (HCPs). This may influence patients' involvement in shared decision-making, satisfaction with care, and health-related quality of life. The aim of this study was to explore the perspectives of HCPs on the need for information of newly diagnosed patients with hematological malignancies, and whether the estimated need was associated with HCPs' cognitive coping style, sociodemographic and work characteristics.

METHODS

Ninety-six hematologists and 27 specialist nurses completed the adapted version of the Hematology Information Needs Questionnaire regarding fictive newly diagnosed patients. HCPs' age, gender, years of work experience, hospital affiliation, and cognitive coping style were assessed.

RESULTS

HCPs ranked information concerning disease, treatment, side-effects, medical tests and prognosis higher than psychosocial and selfcare information. Need for information on selfcare was estimated higher in female HCPs ($B=0.23$, $p=0.036$) and in HCPs with a higher monitoring cognitive coping style ($B=0.040$, $p=0.012$). Need for information on medical tests and prognosis was estimated higher in HCPs with a higher monitoring cognitive coping style ($B=0.024$, $p=0.021$).

CONCLUSION

The results of this study suggest that HCPs do only slightly tailor information to individual patients. HCPs should be aware that their own gender and CCS may affect their estimation of patients' information needs.

INTRODUCTION

It is important to provide adequate information to patients, as this has been found to be associated with better compliance¹, and better health related quality of life (HRQOL).^{2–4} Besides, adequate information provision is a key element for patient involvement in treatment decision-making.⁵ Nevertheless, it is known that patients' information needs often do not correspond with the information they received from healthcare professionals (HCPs).^{6–17} These results are heterogeneous, showing discrepancies between the perceived need for information assessed by HCPs and the actual need for information of patients diagnosed with solid tumors, in which HCPs give too much^{18, 19}, too limited^{6, 20, 21} and other^{9, 14, 15} information, compared with patients' needs. It is largely unknown which factors influence HCPs' estimated need for information of their patients. One qualitative study stated that HCPs are influenced by their own professional knowledge and experiences.²² Based on what we found in a previous study on patients newly diagnosed with a hematological malignancy²³, HCPs estimated need for information of their patients might be influenced by their own cognitive coping style. To the best of our knowledge, the perspectives of hemato-oncology HCPs on their patients' need for information are currently unknown. Therefore we aimed to explore HCPs' estimated need for information of patients, and to assess whether these estimations were influenced by the HCPs' own cognitive coping style, sociodemographic factors, work experience and hospital affiliation

METHODS

PARTICIPANTS

Invitations to participate in the study were sent by email to all hematologists in the Netherlands who take part in the Dutch-Belgian Cooperative Study group for hematooncology (HOVON) and to all hematology specialist nurses of the Special Interest Group (SIG) hematology. HCPs who did not respond within three weeks, were contacted two more times by email.

HCPs were asked to complete an online questionnaire (an adapted version of the Hematology Information Needs Questionnaire) to estimate the expected need for information of four fictitious patients with a recently diagnosed hematologic malignancy.

Participants were allocated at random to one of these four cases, and the following information was presented in text to the HCPs as follows: 1) a 25-year-old unmarried woman, cohabiting, who was suddenly diagnosed with acute myeloid leukemia (immediate treatment life threatening), 2) a 73-year-old married man, two children living away from home, with long-standing back problems and recurrent infections, who was diagnosed with multiple myeloma (chronic disabling disease), 3) a 70-year-old married woman, with little comorbidity and longstanding fatigue, who was recently diagnosed with chronic lymphoid leukemia (chronic disease not affecting HRQOL), 4) a 45-year-old married man, two children living at home, presenting with enlarged lymph nodes in the neck for several weeks, who was diagnosed with aggressive B-cell non-Hodgkin lymphoma (life threatening disease with less intensive therapy). These four cases were composed based on previous research showing that age, gender, marital status, comorbidity, type of HM, and health status are likely to influence the need for information.

Additionally, HCPs were asked to complete a study-specific questionnaire regarding demographic information, which included the HCPs profession (hematologist / hematology specialist nurse), number of years practicing in the current function, gender (male / female), age, and hospital affiliation (academic hospital / non-academic hospital). Furthermore, they were asked to complete a questionnaire on cognitive coping style (Threatening Medical Situations Inventory).

INSTRUMENTS

Participants assessed patients expected information needs using a modified version of the Hematology Information Needs Questionnaire (HINQ), which was used before in patients with hematological malignancies.^{24, 25} This modified HINQ consists of 62 information items with the subscales: “disease, symptoms, treatment and side-effects” (regarding the disease, with its symptoms, the treatment and possible side-effects of treatment), “medical tests and prognosis” (regarding the various tests, reasons and procedures of the tests, and prognosis of the disease and the influence of disease for the future), “selfcare” (regarding information on nutrition, social life and sport), “etiology, sleep and physical changes” (regarding the and illness the etiology of the illness and changes on physical appearance and sleep problems), and “psychosocial” (regarding patients’ feelings, help and communication with HCPs, family and others). All items are embedded in the question “It’s important for me to have information about” with answers on a 5-point Likert scale, ranging from 1 = “totally disagree” to 5 = “totally agree”, and a

sixth option “not applicable to me”. See the addendum for the HINQ and the psychometric findings in the present study.

The coping style of the HCPs was measured with the Threatening Medical Situations Inventory (TMSI)²⁶, which has been validated for use in cancer patients, as well as in non-patients.^{26, 27} The exact wording of the situational descriptions was adapted to the medical knowledge of the present participants. The TMSI is used to measure two cognitive coping styles: monitoring (MCCS), i.e. the need for information under impending threat, and blunting (BCCS), i.e. the tendency to avoid confrontation and to seek distraction in the domain of threatening medical situations.²⁸ Each threatening description is followed by six items, three monitoring and three blunting, in random order, to be answered on a 5-point Likert scale (ranging from 1 = “not at all applicable to me” to 5 = “strongly applicable to me”). Total monitoring (TM) and blunting (TB) scale scores are obtained by summing the individual items and range from 6 (lowest) to 30 (highest).

STATISTICAL ANALYSIS

We described nominal and ordinal variables in terms of numbers and percentages, continuous variables in terms of means/medians and standard deviations/ranges. The Kruskal-Wallis test was used to test differences between the four fictive patients among hematologists and hematology nurse specialists, separately as well as for all HCPs together. Subsequently the Mann-Whitney test was used for post-hoc analyses with Bonferroni correction and differences between cases with respect to the socio-demographic variables and cognitive coping style. Associations between HCPs' estimated patients' need for information and the HCPs' age, number of working years and cognitive coping style were tested with Spearman correlation coefficients. The Mann-Whitney test was used to assess differences in the estimated information needs with respect to HCPs gender, hospital affiliation and profession. Friedmans' test was used to test differences within HCPs between the information need subscales. Multiple linear regression models were obtained via backward selection (p-removal <0.05) to assess which factors influenced the HCPs estimated patients' need for information; only variables with an univariate $p < 0.10$ were included in the selection procedure. For all statistical analyses we used the statistical software package SPSS, version 23.0, and a $p < 0.05$ was considered to indicate a statistically significant difference.

RESULTS

STUDY POPULATION

In total, 96 hematologists and 27 specialist nurses participated in this study, representing a response rate of 45% and 52% respectively. Reasons for non-response are unknown. The median age of the hematologists was 47.0 (range 34–66) years and of the specialist nurses 42.0 (range 29–56) years. Of the hematologists, 58% were male versus 19% of the specialist nurses. Sixty percent of the hematologists and 52% of the specialist nurses were working in a non-academic hospital (for all sociodemographic characteristics, see table 1).

FICTIVE CASES

Among hematologists, we found no significant differences on the subscales and total scales of the HINQ between the four fictive cases. Among hematology nurse specialists ($\chi^2=8.5$, $df=3$, $p=0.037$), the estimated need for information on etiology and physical and sleep problems differed significantly between the cases. This was also the case for the HCPs together ($\chi^2=10.4$, $df=3$, $p=0.016$). Post-hoc analyses with Bonferroni's correction revealed no significant differences between the cases among hematology nurse specialist ($p>0.05$ for all pair wise comparisons). All HCPs together estimated patients' need for information in case 1 minimally higher than in case 2 ($p=0.042$). Since there were no differences with respect to sociodemographic variables and cognitive coping style of the HCPs between the four cases, the case is not considered a confounder and all cases were analyzed together in the next sections.

INFORMATION NEED SUBSCALES

We found no differences in information need (sub)-scales between hematologists and specialist nurses (see table 2). Medical information was ranked higher than psychosocial information by hematologists ($\chi^2=166.3$, $df=4$, $p<0.001$) and hematology specialist nurses ($\chi^2=51.4$, $df=4$, $p<0.001$) and all HCPs together ($\chi^2=216.9$, $df=4$, $p<0.001$) (see table 2). The two subscales "disease, symptoms, treatment and side-effects" and "medical tests and prognosis" were estimated as most important, followed by the subscales "self-care", "etiology, sleep and physical changes" and "psychosocial".

Table 1 Overview of sociodemographic characteristics of hematologist and specialist nurses

		Hematologists (n=96)		Specialist nurses (n=27)	
		n	%	n	%
Gender	Female	40	41.7%	22	81.5%
	Male	56	58.3%	5	18.5%
Age (years)	median (range)	47.0 (34-66)		42.0 (29-56)	
Working experience (years)	median (range)	10.0 (1-36)		4.5 (1-25)	
Type of hospital	Non-academic	58	60.4%	14	51.9%
	Academic	38	39.6%	13	48.1%

Table 2 Mean (range) missing item responses of the HINQ-62 in phase 1 and 2

	Phase 1		Phase 2	
	n	%	n	%
Missing item responses	2-4 (2.7)	1.5 - 3.1% (2.4%)	2-5 (3.2)	1.0-2.6% (1.7%)
Response option: inapplicable	10-57 (15.9)	6.9-39.3% (11.0%)	2-71 (12.1)	1.0-36.4% (6.2%)

Table 3 Healthcare professionals sociodemographic characteristics and cognitive coping style in relation to patients' estimated need for information

	Disease, symptoms, treatment and side-effects			Medical tests and prognosis			Self-care			Etiology, sleep and physical changes			Psychosocial			Total		
	Univariate	Multivariable	Univariate	Multivariable	Univariate	Multivariable	Univariate	Multivariable	Univariate	Multivariable	Univariate	Multivariable	Univariate	Multivariable	Univariate	Multivariable	Univariate	Multivariable
	p-value	p-value	p-value	p-value	p-value	p-value	p-value	p-value	p-value	p-value	p-value	p-value	p-value	p-value	p-value	p-value	p-value	p-value
Gender [§]	0.37	NI	0.69	NI	0.033	-0.23	[0.445 - -0.015]	0.036	0.53	NI	0.85	NI	0.85	NI	0.33	NI	NI	NI
Hospital	0.34	NI	0.30	NI	0.42	NI	0.75	NI	0.75	NI	0.90	NI	0.90	NI	0.37	NI	NI	NI
Age	0.020	NS	0.047	NS	0.47	NI	0.16	NI	0.16	NI	0.40	NI	0.40	NI	0.085	NS	NS	NS
Working years	0.16	NI	0.12	NI	0.31	NI	0.56	NI	0.56	NI	0.83	NI	0.83	NI	0.47	NI	NI	NI
Profession	0.52	NI	0.47	NI	0.15	NI	0.77	NI	0.77	NI	0.59	NI	0.59	NI	0.27	NI	NI	NI
Total monitoring	0.27	NI	0.05	0.024	[0.004 - 0.043]	0.021	0.014	0.040	[0.009 - 0.071]	0.012	0.56	NI	0.36	NI	0.10	NI	NI	NI
Total blunting	0.89	NI	0.77	NI	0.46	NI	0.82	NI	0.82	NI	0.30	NI	0.30	NI	0.93	NI	NI	NI

Gender (male/female) and hospital (university/affiliated) were tested with the Mann-Whitney U-test, age, working years and cognitive coping styles were tested with the Spearman's ranking coefficient. Variables with a p-value <0.10 were included in the multiple regression analysis with backward selection.

[§] Gender: p=0.036 Male: B=-0.23, Female B=0

NS= Not significant NI= Not included

HCPs' SOCIODEMOGRAPHIC VARIABLES AND COGNITIVE COPING STYLE IN RELATION TO ESTIMATED NEED FOR INFORMATION

Multiple regression analyses (table 3) showed that patients' need for information on "medical tests and prognosis" was estimated higher by HCPs with a higher MCCS than HCPs with a lower MCCS ($B=0.24$, $p=0.021$). Patients' need for information on the subscale "selfcare" was estimated higher by HCPs who were female ($B=0.23$, $p=0.036$), and by HCPs with a higher MCCS ($B=0.040$, $p=0.012$) compared to patients with a lower MCCS. HCPs' estimated patients' need for information was not related to hospital affiliation or working experience in years.

DISCUSSION

This is the first study investigating hematologists' and hematology specialist nurses' estimated need for information of patients with hematological malignancies and possible associated factors. Both the hematologists and the hematology specialist nurses ranked the need for medical information higher than the need for psychosocial information. Information on disease and treatment, on medical tests and prognosis was rated as more important than information on self-care and psychosocial information. HCPs' monitoring cognitive coping style was positively associated with a higher estimated patients' need for information on medical tests and prognosis, and on selfcare. Female HCPs estimated patients' need for information on selfcare higher than male hematologists.

The higher priority that HCPs accorded to medical information corresponds with the higher need for medical information that we recently found in a separate population of newly diagnosed hematology patients.²⁴ In that study, patients' need for information was high, prioritizing from high to moderate information on medical tests and prognosis, disease, symptoms, treatment and side-effects, self care, etiology and physical changes and sleep problems and psychosocial information.²⁴ This ranking is in accordance with earlier studies investigating information needs among patients with hematological malignancies.^{25, 29–32} At the same time however, there are numerous studies showing that there is a discrepancy between the information patients wish, and the information provided by HCPs.^{6, 18–22, 33–37} This discrepancy was studied in patients diagnosed with solid tumors, where patients' information need was higher^{6, 20, 21}, lower^{18, 19}, and different^{9, 14, 15} compared with HCPs. This suggests that the ranking of information need topics is well estimated by HCPs, but that the information provided does not necessarily satisfy

the patients' needs. It is not clear whether this relates to the content of the information provided, the level of details, or the way the information is given. Importantly, in our earlier study patients' need for information was also related to the patients' treating hospital and their own cognitive coping style.²⁴ In the present study, although the fictive patients differed regarding age, gender, and disease, HCPs only slightly differentiated between these fictive patients. This is remarkable because earlier research showed that a one-size-fits-all approach is not the best way to provide information.²⁴ Information provision should be tailored to the individual patient, taking into account type of hospital and the cognitive coping style of the patient.²⁴

Female HCPs estimated the need for information on selfcare higher than male HCPs. This is not in line with an earlier study among prostate cancer patients, where HCPs' gender was not associated with the estimated patient information need.¹⁹

Regarding HCPs' cognitive coping style, a higher MCCS was associated with a higher estimated need for information regarding medical tests and prognosis, and self-care. To our knowledge, the relation between HCPs' cognitive coping styles and their estimations of patients' need for information has not been studied before. Our previous study among patients with a hematological malignancy²³ and other studies revealed that a high MCCS style is associated with a higher need for information.^{27, 38–40} Furthermore, patients with a high MCCS cope better with predictable information to control about what to expect for the future.³⁹ Possibly HCPs are guided by their own values and MCCS when they estimate their patients' need for information while giving information.

In the present study we evaluated how HCPs estimated the need for information among patients by using standardized fictive patients. This simulation allowed us to present to all participating HCPs 1 out of 4 fictive patients with clearly different (hypothesized) information needs. We hypothesized that HCPs would differentiate between these four fictive cases, but we did not define the "estimated need" upfront. This limitation implies that the results of this study may not be applicable to real life situations, and further research is needed. Future research should include pairs of HCPs and real patients to investigate whether factors such as cognitive coping style of both the HCP and patient influence the HCP's provision of information and the patients' satisfaction with the provided information, as well as possible interactions.

A second limitation is that, although validated in the general populations and clinical samples^{26, 41}, the TSMI is not yet validated for use among HCPs. Also, CCS may vary

between changing situations (time or event related) and therefore raises the question of whether a person applies and reapplies a given coping strategy each time they are faced of adversity. However, the present study had a cross-sectional design and no prospective data are available yet. These limitations impede the understanding of our findings on the relationship between CCS and need for information.

CONCLUSION

In conclusion, HCPs seem to rank information needs comparable to patients in literature: both express a higher need for information on medical tests and prognosis, disease, symptoms, treatment and side-effects than for information on selfcare and psychosocial issues. HCPs do not seem to tailor information to individual patients. Furthermore, HCPs should be aware that their own gender and cognitive coping style may influence how they estimate their patients' need for information.

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ADDENDUM — METHODS

In this study, we used a questionnaire developed from the first version of the Hematology Information Needs Questionnaire (HINQ), which was used in an earlier cross-sectional study, because a validated questionnaire for need for information of patients with hematological malignancies is lacking. This questionnaire comprises 92 questions, which we adjusted further (see modification of the HINQ below). The adjusted HINQ comprises 62 items, grouped in five subscales: “disease, symptoms, treatment and side-effects” (regarding the disease, with its symptoms, the treatment and possible side-effects of treatment), “medical tests and prognosis” (regarding the various tests, reasons and procedures of the tests, and prognosis of the disease and the influence of disease for the future), “selfcare” (regarding information on nutrition, social life and sport), “etiology, sleep and physical changes” (regarding the and illness the etiology of the illness and changes on physical appearance and sleep problems), and “psychosocial” (regarding patients’ feelings, help and communication with HCPs, family and others). All items are embedded in the question “It’s important for me to have information about” with answers on a 5-point Likert scale ranging from 1 = “totally disagree” to 5 = “totally agree” with a sixth option “not applicable to me”.

MODIFICATION OF THE HINQ

In order to compress the first version of the HINQ for the present study, we first performed an exploratory factor analysis with the ninety-two items based on data of our earlier cross-sectional study[1] which comprised 458 patients. All items had to be answered on a 5-point Likert scale, with a sixth option “not applicable to me”. Principal component analysis with varimax rotation provided eleven factors with eigenvalues greater than 1, indicating an eleven-factor solution. Of these eleven factors, seven showed few loadings, therefore we performed a forced factor analysis with four factors. Secondly, we computed inter-item correlations. Twenty-six items were deleted because they had a correlation of 0.75 or higher with two other items, and another seven items were deleted due to the overlap of content with other items, both confirmed by the factor analysis (i.e. they loaded on the same factor). Then, we critically reviewed the remaining 59 items with a group of hematologists, oncologists, nurse specialists hematology and reached consensus about the items eligible for the adjusted Hematology Information Needs Questionnaire (HINQ). Three important items were added, namely items concerning the need for information on fertility, on sexuality, and on concentration and memory problems.

This adjusted HINQ, with 62 items, was further investigated using the 138 patients of a prospective study (Chapter 5 and 7). In an exploratory factor analysis, we aimed to explain 70% of the variance with a restricted number of factors. Free analysis provided nine factors with eigenvalues greater than 1.0, indicating a nine-factor solution. Additionally, since only a few items belonged to the factors six to nine, factor analysis was performed forcing a five-factor solution. Item clustering on each factor was studied in relation to the factor structure that was proposed to emerge from the data to determine a conceptual interpretation of the factors. It appeared that the first factor indicates information about the disease, symptoms, treatment and side-effects of the treatment. The items that loaded on the second, third, fourth and fifth factor indicated information about medical tests and prognosis, self-care, etiology and sleep and physical changes, and psychosocial information, respectively. Total scale scores were computed by the mean of the valid (non-missing) items.

ADDENDUM – RESULTS

DISTRIBUTION OF THE FICTITIOUS CASES

HCPs were allocated at random with the computer program Netquestionnaire to one of the four cases after the start of the online questionnaire. Of the hematologists, 22.9% was assigned to casus 1, 21.9% to casus 2, 34.4% casus 3 and 20.8% casus 4. Of the nurse specialists, 18.5% were allocated to casus 1, 44.4% tot casus 2, 18.5% tot casus 3, and 18.5% to casus 4.

PSYCHOMETRIC FINDINGS OF THE USED QUESTIONNAIRES

Internal consistencies of the subscales of the HINQ were high (Cronbach's α for respectively hematologist and specialist nurses > 0.84 , > 0.77) (table 1). Reliability analysis of the other questionnaires was also moderate to high (table 1). Regarding feasibility, missing item responses was 0% for all items, due to the online format of the questionnaire and therefore subscales could be calculated for all HCPs (data not shown).

Table 1 Internal consistency (Cronbach's alpha) of the various (sub)scales of the used questionnaires by profession

Instrument	(Sub)scale	Hematologist	Specialist nurse	HCP
		Cronbach's α	Cronbach's α	Cronbach's α
HINQ	Disease, symptoms, treatment and side-effects	0.94	0.89	0.93
	Medical tests and prognosis	0.84	0.77	0.83
	Self-care	0.88	0.82	0.87
	Etiology, sleep and physical changes	0.86	0.80	0.85
	Psychosocial	0.91	0.88	0.90
TMSI	Monitoring	0.55	0.57	0.56
	Blunting	0.63	0.52	0.61

RESPONSE RATE

Of the 214 invited hematologists 50 participated after the first invitation (23%), after the first and second reminder the response was respectively 23/164 (14%) and 23/141 (16%) with a total response rate of 45%.

Regarding the hematology specialist nurses, 16 of the 52 (30%) participated after the first invitation, 8 of the 36 (22%) and 3 of the 28 (11%) participated after the first and second reminder, with a total response rate of 50%.

CHAPTER 7

THE NEED FOR INFORMATION AMONG PATIENTS WITH HEMATOLOGICAL MALIGNANCIES: PSYCHOMETRIC ANALYSES OF THE 62-ITEM HEMATOLOGY INFORMATION NEEDS QUESTIONNAIRE (HINQ-62)

J.A.J. Rood
B.I. Witte
C. Eeltink
F. Stam
F.J. van Zuuren
S. Zweegman
I.M. Verdonck- de Leeuw

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ABSTRACT

INTRODUCTION

The purpose of this study was to investigate the psychometric characteristics (content validity, internal consistency, and subscale structure) of the Hematology Information Needs Questionnaire-62 (HINQ-62), a questionnaire for assessing the need for information among patients with hematological malignancies (HM-patients).

METHODS

Baseline data were used from a prospective study on the need for information which 336 newly diagnosed HM-patients had completed. In cohort 1 (design phase), data from the first 135 patients were used and in cohort 2 (validation phase), data from the remaining 201 HM-patients were used. Content validity was analyzed by examining irrelevance of items. Items were considered irrelevant if more than 10% of the patients scored totally disagree on that item. The subscale structure of the HINQ-62 was investigated with Factor analysis (FA) (exploratory FA in phase 1 and confirmatory FA in phase 2). Cronbach's α was computed for the different subscales and $>.70$ was considered as good internal consistency.

RESULTS

None of the 62 HINQ-items were irrelevant. Exploratory FA identified five subscales: "disease, symptoms, treatment and side-effects", "etiology, sleep and physical changes", "selfcare", "medical tests and prognosis", and "psychosocial". Root Mean Square Error of Approximation (RMSEA) among patients was 0.037 in cohort 1 and 0.045 in cohort 2. The comparative fit index (CFI)/Tucker-Lewis index -non-normed fit index among patients was 0.984/0.983 and 0.948/0.946, in cohort 1 and 2 respectively. The internal consistency of the subscales was good, with Cronbach's α 0.82–0.99.

CONCLUSION

The HINQ is a valid questionnaire for assessing the need for information among Dutch HM-patients at diagnosis.

INTRODUCTION

To optimize personalized medicine and care in patients with hematological malignancies (HM), it is essential to know these patients' preferences regarding information provision. It is important to provide adequate information to cancer patients in general, as this has been found to be associated with better compliance with treatment¹ and better health related quality of life (HRQOL).²⁻⁴ Moreover, adequate information to patients is a key element for shared treatment decision-making.⁵

Detailed information on the perceived need for information among HM-patients is scarce⁶, even though worldwide incidence of HM is growing. Annually, almost 920.000 patients are diagnosed with a HM⁷ and the survival rate of most of these diseases has increased.^{7,8} A recent literature review showed that information needs of HM-patients have only been assessed with study-specific questionnaires and that no validated HM-specific information needs questionnaire is available. This hampers the comparison of information needs of HM-patients across studies and the assessment of a particular patients' information need in clinical practice.⁶ On the basis of a cross-sectional study⁹, we previously developed a first version a questionnaire, which comprised 92 questions regarding the need for information among HM-patients.^{9,10} Subsequently, using exploratory Factor Analysis (FA) and inter-item correlation, we shortened the questionnaire with 30 items, resulting in the HINQ-62. The aim of the current study was to assess the psychometric properties (i.e. internal consistency and validity) of the HINQ-62 among newly diagnosed patients with hematological malignancies.

PATIENTS AND METHODS

STUDY DESIGN

In this study we used the baseline data of a prospective study among newly diagnosed HM-patients who had been recruited during two stages. During the first stage, from September 2013 to September 2014, patients were recruited at the in- and outpatient clinics of the VU University Medical Centre (VUmc), Amsterdam, Northwest Clinics, Alkmaar and Isala, Zwolle, the Netherlands. The second phase was conducted from September 2014 to July 2015 at the in- and outpatient clinics of the VUmc in Amsterdam,

Northwest Clinics in Alkmaar, Isala in Zwolle, Westfriesgasthuis in Hoorn, and Spaarne Hospital in Hoofddorp, all in the Netherlands.

PARTICIPANTS

Patients visiting the in- and outpatient clinics of the participating hospitals were asked to participate by an employee of the treating physician team if they were newly diagnosed (i.e. up to six weeks after diagnosis) with HM (acute or chronic leukemia, Hodgkin or non-Hodgkin lymphoma, or multiple myeloma). Inclusion-criteria were: age ≥ 18 years and Dutch language proficiency. Exclusion-criteria were: concurrent treatment of another malignancy, terminal phase, and mental or physical inability to participate.

INFORMED CONSENT AND PROCEDURE

This study was approved by the Medical Ethical Committee of the VUmc. Informed consent was obtained from all participants both orally and in written by a patient information file and informed consent form. Participants were asked to complete the questionnaires online or on paper. After two weeks, non-responders received a reminder, and after two more weeks non-responders were contacted by telephone by the first author or a study employee. This study was approved by the Medical Ethical Committee of the VUmc

THE HEMATOLOGICAL INFORMATION NEED QUESTIONNAIRE (HINQ)

In an earlier cross-sectional study⁹ (Chapter 3), we developed the basic of this first version of the HINQ, which comprised 92 questions derived from three original validated questionnaires.^{11–13} The Patient Learning Need Scale (PLNS), which measures the need for information of general medical or surgical patients about the topics that are especially important during discharge from hospital. The Toronto Information Needs Questionnaire-Breast Cancer, which measures the need for general information using various subscales and the Patient Information Needs Questionnaire, which assessed the information needs of cancer patients. These original and validated questionnaires were chosen because they 1) measure the need for information in various settings, and not only, for example, during palliative treatment, 2) have good validity and reliability, 3) require limited time for completion, and 4) are supplementary to each other. The third questionnaire (PINQ) was added, because it contains important items with an additional value, such as where to find good information on education material and literature,

whether patients wanted to know their specific survival rates and their present condition, and whether patients want to know how to communicate with a physician. Items from these existing oncology questionnaires were supported with the ten categories of general cancer patients' information needs in the literature¹⁴: cancer-specific, treatment related, prognosis, rehabilitation, surveillance and health, coping, interpersonal/social, financial/legal, medical system and body image/sexuality), and supported with a literature review on patients with hematological malignancies.⁶ The English items were translated into Dutch by means of backward and forward translation by a native English speaker and the first and third author (native Dutch speakers) of this manuscript, and compared with the original English version. All items were discussed within an expert group of 8 people, consisting of internists, hematologists, clinical psychologists, and hematology nurse specialists, and the first author. The items were textually tailored to our HM-patients. For example: TINQ-BC item 51 "When to have a mammogram" was changed into "When to have a bone marrow biopsy".

In order to shorten the first version of the HINQ, we first performed an exploratory FA with the 92 items derived from data of our earlier cross-sectional study⁹ (Chapter 3), which included 458 patients. FA with varimax rotation provided eleven factors with eigenvalues greater than 1, indicating an eleven-factor solution. Of these eleven factors, seven showed few loadings; therefore we performed a forced factor analysis with four factors. Secondly, we computed inter-item correlations. With the expert group, we reached consensus to delete twenty-six items because they had a correlation of 0.75 or higher with two other items, and to delete another seven items due to overlap of content with other items. This overlap was confirmed by FA, in which these seven items loaded on the same factor. Slight disagreements were solved through discussion to generate one version. Furthermore, based on remarks of several patients, three items were added, one question each on need for information on fertility, on sexuality, and on concentration and memory problems.

The items of the resulting 62-item HINQ are scored on a Likert scale ranging from 1 (totally disagree) to 5 (totally agree) and a sixth option "not applicable". Total scale scores were computed by summing up the item scores per scale and dividing the sums by the number of non-missing items, a higher score indicating a higher need for information.

PSYCHOMETRIC ANALYSES OF THE HINQ-62

The psychometric characteristics of the HINQ-62 were further investigated in two

phases. Baseline data were used of a total of 336 newly diagnosed HM-patients who participated in a prospective study on need for information. Data of the first 135 patients were used in cohort 1 (design phase). In the validation phase, we used the data of the 201 HM-patients recruited during the second stage (cohort 2). Content validity was analyzed by examining irrelevancy of items. Items were considered irrelevant if >90% of the patients scored < 2 (i.e. totally disagree) on that item.

The factor structure of the HINQ-62 was analyzed with FA with varimax rotation of factors with eigenvalues >1.0. In phase 1, the structure of the HINQ-62 was investigated with exploratory FA. In phase 2, a confirmatory FA was used to analyze whether five-factor structure derived in phase 1 could be replicated. Criteria for an acceptable fit were root mean square error of approximation (RMSEA) <0.06, comparative fit index (CFI) and Tucker-Lewis index -non-normed fit index (TLI) ≥ 0.9 .

The internal consistency of the subscales of the HINQ-62 was assessed with Cronbach's alpha on the items belonging to that subscale, and values >.70 were considered good internal consistency.

RESULTS

STUDY SAMPLE

In total, data was used from 336 newly diagnosed HM-patients (135 in phase 1 and 201 in phase 2). The response rate of phase 1 was 69% and for phase 2 71%. The socio-demographic and clinical characteristics of the participants are presented in table 1. The groups in phase 1 and phase 2 did not differ with respect to gender, age, educational level, nationality, membership of a patient association or hospitalization. Patients in cohort 2 differed from those in cohort 1 with respect to their diagnosis ($p=0.011$), treatment intent ($p<0.001$), marital stage ($p=0.019$) and type of hospital where the treatment was received ($p<0.001$) (See table 1).

On all HINQ-62 items, a need for information (score ≥ 2) was reported by more than 10% of the patients, indicating that none of the items were irrelevant or inapplicable. In 2.4% and 1.7% respectively item responses were missing (see table 2).

Table 1 Overview of sociodemographic and clinical characteristics of patients of Phase 1 (n=135) and Phase 2 (n=201)

		Phase 1		Phase 2		p-value
		n	%	n	%	
Gender	Female	53	39.3%	80	39.8%	0.92
	Male	82	60.7%	121	60.2%	
Age	Mean	58.8 (SD 15.6)		60.1 (SD 13.8)		0.64
Marital status	Unmarried	27	20.3%	22	10.9%	0.019
	Married	79	59.4%	148	73.6%	
	Cohabiting	9	6.8%	16	8.0%	
	Widowed	10	7.5%	9	4.5%	
	Divorced	8	6.0%	4	2.0%	
	Living with parents	0	0.0%	2	1.0%	
Educational level	Primary education	49	36.6%	75	37.7%	0.93
	Secondary education	46	34.3%	70	35.2%	
	Higher education	39	29.1%	54	27.1%	
Nationality	Dutch	132	97.8%	201	100.0%	0.064
	Otherwise	3	2.2%	0	0.0%	
Diagnosis	Acute Leukemia	28	20.7%	15	7.5%	0.011
	Chronic Lymphatic Leukemia	8	5.9%	20	10.0%	
	Chronic Myeloid Leukemia	13	9.6%	15	7.5%	
	Multiple Myeloma	24	17.8%	44	22.0%	
	Hodgkin Lymphoma	14	10.4%	20	10.0%	
	Non-Hodgkin Lymphoma	48	35.6%	86	43.0%	
Treatment intent	Curative	86	63.7%	77	38.5%	<0.001
	Non-curative	49	36.3%	123	61.5%	
Comorbidity	No comorbidity	73	54.1%	99	54.1%	1.0
	Mild comorbidity	37	27.4%	49	26.8%	
	Moderate comorbidity	20	14.8%	28	15.3%	
	Severe comorbidity	5	3.7%	7	3.8%	
Treated hospital	Academic	64	47.4%	51	25.4%	<0.001
	Non-academic	71	52.6%	150	74.6%	
Hospitalized at time of the study	No	124	93.2%	195	97.5%	0.057
	Yes	9	6.8%	5	2.5%	
Member patient association	No	126	94.7%	183	92.0%	0.33
	Yes	7	5.3%	16	8.0%	

Table 2 Mean (range) missing item responses of the HINQ-62 in phase 1 and 2

		Phase 1		Phase 2	
		n	%	n	%
Missing item responses		2-4 (2.7)	1.5 - 3.1% (2.4%)	2-5 (3.2)	1.0-2.6% (1.7%)
Response option: inapplicable		10-57 (15.9)	6.9-39.3% (11.0%)	2-71 (12.1)	1.0-36.4% (6.2%)

SUBSCALE STRUCTURE OF THE HINQ-62

Exploratory FA was used to investigate the subscale structure of the HINQ-62 in phase 1. We aimed to explain 70% of the variance with a restricted number of factors. Free FA provided nine factors with eigenvalues greater than 1.0. Since only a few items belonged to the factors six to nine, FA was forced into a five-factor solution. Item clustering on each factor was studied in relation to the factor structure that was proposed to emerge from the data to determine a conceptual interpretation of the factors. It appeared that the five factors could be labeled as 1) “disease, symptoms, treatment and side-effects” (information regarding the disease, with its symptoms, the treatment and possible side-effects of treatment), 2) “medical tests and prognosis” (information regarding the various tests, reasons and procedures of the tests, and prognosis of the disease and the influence of disease for the future), 3) “selfcare” (information regarding nutrition, social life and sport), 4) “etiology, sleep and physical changes” (information regarding the illness and the etiology of the illness, regarding changes in physical appearance and sleep problems), and 5) “psychosocial” (information regarding feelings, available help and communication with HCPs, family and others).

In phase 2, confirmatory FA showed an RMSEA of 0.037 (phase 1) and 0.045 (phase 2), which means a good fit. Furthermore, the CFI and TLI -non-normed fit index also showed a good fit (≥ 0.9) (see table 3).

INTERNAL CONSISTENCY AND FACTOR LOADINGS

The internal consistency of all HINQ-62 subscales in patients was high (≥ 0.82) and is presented in table 4. The factor loadings of all HINQ-62 items are presented in table 5.

Table 3 Fit indices of the HINQ

Phase	RMSEA ¹	CFI / TLI ²
Phase 1	0.037	0.984 / 0.983
Phase 2	0.045	0.948 / 0.946

¹ RMSEA<0.06 acceptable fit; <0.05 good fit² CFI/TLI≥0.9 acceptable fit; ≥0.95 good fit**Table 4 Internal consistency (Cronbach's α) of subscales of the HINQ**

Subscale	Phase 1	Phase 2
Disease, symptoms, treatment and side-effects	0.99	0.97
Medical tests and prognosis	0.97	0.91
Self-care	0.95	0.90
Etiology, sleep and physical changes	0.87	0.82
Psychosocial	0.90	0.90

Table 5 Factor loadings of the items on the Hematology Information Needs Questionnaire for study 1

	Factor				
	1	2	3	4	5
1 What symptoms you may have related to your illness	0.70				
2 How the cancer acts in the body	0.81				
3 If there is cancer anywhere else in your body	0.79				
4 Your present condition	0.84				
5 The medical name for your type of cancer				0.55	
6 The cause of your illness				0.64	
7 If your illness is hereditary				0.57	
8 The possible course of your illness		0.74			
9 The reasons the doctor suggests certain tests		0.88			
10 How the test are done		0.85			
11 Why they need to test your blood		0.79			
12 When to have a bone marrow biopsy		0.85			
13 What the results of your blood tests mean		0.86			
14 What types of treatment are available	0.63				
15 The treatment procedures	0.71				
16 How the treatment works against the cancer	0.70				
17 What the purposes of your treatment are	0.73				
18 How long you will be receiving treatment	0.67				
19 Why you need to take each medication	0.59				
20 When to take each medication	0.79				
21 The possible side effects of your treatment	0.60				
22 The possible reactions to each medication	0.54				
23 If there are ways to prevent treatment side effects	0.72				
24 What side effects you should report to the doctor/nurse	0.86				
25 If you are prone to infection because of your treatment	0.81				
26 What complications might occur from your illness	0.66				
27 Who to talk with if you hear about treatments other than surgery, radiation or chemotherapy				0.41	
28 How to manage the symptoms you may experience	0.86				
29 How to manage your pain	0.75				
30 If the treatment will alter the way that you look				0.63	
31 How much rest you should be getting				0.46	
32 How you can avoid stress				0.66	
33 What to do if you cannot sleep properly				0.51	
34 What to do if you have trouble urinating	0.70				
35 What to do if you have trouble with your bowels	0.74				
36 How to care for your wound or incision	0.69				
37 What you should do if you have problems with your memory or concentration	0.47				
38 Changes in the field of fertility				0.70	
39 Changes in the field of sexuality				0.69	
40 Possible results of your treatment	0.64				
41 How the illness may affect your life over the next few months		0.63			
42 How the illness may affect your life in the future		0.53			
43 If the cancer will come back		0.79			

Table 5 Factor loadings of the items on the Hematology Information Needs Questionnaire for study 1

	Factor				
	1	2	3	4	5
44 Survival rates for your illness		0.76			
45 What you can do (or are allowed to do) in your situation (work, hobbies and social life)			0.76		
46 How to keep or become physically fit (exercises and diet)			0.61		
47 Which vitamins and supplements you should take			0.84		
48 Which foods you can or cannot eat.			0.79		
49 How to prepare the foods you are going to eat			0.67		
50 How to get through the "red tape" to get services at home			0.79		
51 Possibilities for your physical appearance during your treatment, e.g. wigs			0.45		
52 If there are groups where you can talk with other people with cancer					0.69
53 Who you should call if you have questions while you are still getting treatment	0.76				
54 What is the best way to talk or interact with a physician			0.57		
55 How to recognize your feelings toward your illness					0.72
56 Where you can get help to deal with your feelings about your illness					0.74
57 How to talk to family/ friends about your illness					0.69
58 How to tell if the cancer has come back					0.63
59 Opportunities for getting immediate help if you experience problems and have questions about your illness					0.57
60 What to do and who to talk to if you become concerned about dying					0.80
61 Where to get good educational material or literature about your illness or treatment	0.43				
62 Who you should call if you have questions after all the treatments are over	0.79				
Eigenvalue	32.6	4.4	3.8	2.8	2.0
Percentage variance explained	52.5	7.0	6.1	4.5	3.3

DISCUSSION

The aim of the current study was to assess the psychometric properties (i.e. internal consistency and validity) of the HINQ-62 among newly diagnosed patients with hematological malignancies. We developed the HINQ-62 to assess the need for information of HM-patients in order to optimize individual patient information in clinical practice and to allow future comparison of data on information needs obtained from clinical trials. To our knowledge, we are the first to publish the development of a questionnaire (HINQ-62) assessing the need for information among patients with a hematological malignancy, and to investigate the psychometric properties of such a questionnaire. We validated the HINQ in a large population of patients who had different hematological malignancies, and were treated in academic as well as in non-academic centers, thus allowing a broad implementation in hemato-oncology care. The psychometric properties assessed were content validity, structure validity and internal consistency.

Analyses of the content validity of the HINQ-62 showed that none of the items of the HINQ-62 are irrelevant for assessing the need for information. The five factor structure of the HINQ-62 can be interpreted in a clinical meaningful way with the subscales: “disease, symptoms, treatment and side-effects”, “etiology, sleep and physical changes”, “selfcare”, “medical tests and prognosis”, and “psychosocial”. The internal consistency of the five subscales was high (Cronbach’s $\alpha > 0.82$). Confirmatory FA derived from phase 1, also showed good fits in phase 2, thus validating the HINQ-62.

The HINQ-62, which has now qualified psychometrics and has been independently validated, can easily be implemented in daily clinical practice. We are of the opinion that this is important for several reasons. Firstly, data from the first subscale: “disease, symptoms, treatment and side-effects” is important, because adequate information on the disease and its treatment has been found to lead to a better compliance with treatment.¹⁵ In chronic myeloid leukemia patients, non-adherence has been found to be predicted by a lower satisfaction with the information received.¹⁵ Importantly, non-adherence was associated with a lower incidence of molecular remission of the disease and inferior clinical outcome.¹⁶ In addition, information about the different treatment options is also important, because adequate information is the key for shared decision-making¹⁷, as it is known to be associated with a better appraisal of the treatment decision-making by patients^{5, 18}, greater satisfaction with treatment¹⁹, better treatment adherence²⁰ and better HRQOL on

various QoL outcomes.²¹ Moreover, information on the cause of HM was found to be of added value for patients. It has been described that up to 59% of lymphoma and multiple myeloma survivors desired more information on the cause and course of the disease than they received.²²

Secondly, it is important to address factors in the subscale, “etiology, sleep and physical changes”, such as how to deal with fatigue. For instance, fatigue is a problem in many patients with HM²³; it is associated with a decrease in HRQOL²⁴ and has negative effects on a patients daily life.²⁵

Thirdly, information on “Self-care” including information on supportive care, is increasingly important in view of growing willingness and ability of cancer patients to manage on their own and to cope with the consequences of being treated for cancer by themselves.^{26, 27}

Fourthly, it is known that information about medical tests is one of the most often perceived needs among cancer patients²⁸, and prognostic information is rated as essential by HM-patients²⁹⁻³¹. However, this information should be tailored to the individual patient as a qualitative study by Friis showed that AML patients were given too much prognostic information that they did not ask for.³²

The importance of the last subscale, “psychosocial” confirmed by earlier studies that revealed that survivors of leukemia and lymphoma lacked information on support groups³⁰ and that survivors of lymphoma and multiple myeloma often experience a lack of psychosocial aftercare.²² Psychosocial aftercare is particularly important among HM-patients, because they are among the patient groups with the highest psychological distress³³⁻³⁵, for whom psychological information and support may be necessary during diagnosis, treatment and follow-up.

In clinical practice, the standardized and validated HINQ-62 may be used to ensure individualized information provision for HM-patients. In addition, use of the HINQ-62 will ensure the comparability of the results of various studies on information needs for HM-patients. By reviewing the literature⁶ we have shown that this comparison is currently impossible, due to the use of different mostly self-made questionnaires and domains.^{29, 31, 36-41} Furthermore, an important advantage of the HINQ-62 is that this shortened questionnaire will be faster to complete than the earlier version of the HINQ with 92 questions.^{9, 10}

There are some limitations of this study. We included HM-patients at time of diagnosis only, which limits the generalizability to HM-patients during treatment, after treatment and during follow-up. Previous studies showed that HM-patients may have different information needs during different phases of the disease.^{14, 42, 43} Therefore, this questionnaire needs to be validated among HM-patients in various phases of the disease, which we will do when the follow-up of the prospective study to the need for information from diagnosis to 18 months after diagnosis, is completed. A second limitation is that patients were not structurally involved in the initial development of the HINQ. However, during the second developmental phase of the HINQ-62, we asked patients to report any additional information needs, which were then implemented in the current version. A third limitation is that we did not perform a test re-test analysis. Future research might focus on shortening the HINQ further for use in clinical practice and among HM-patients during treatment and follow-up.

CONCLUSION

The HINQ-62 is a valid and reliable instrument for assessing the need for information among HM-patients at time of diagnosis. This questionnaire will facilitate individualized information provision in clinical practice and will enable future comparisons between studies on the information needs of HM-patients.

**HEMATOLOGY INFORMATION NEEDS QUESTIONNAIRE
(ENGLISH TRANSLATION OF DUTCH VERSION 1.0)**

01. What symptoms you may have related to your illness
02. How the cancer acts in the body
03. If there is cancer anywhere else in your body
04. Your present condition
05. The medical name for your type of cancer
06. The cause of your illness
07. If your illness is hereditary
08. The possible course of your illness
09. The reasons the doctor suggests certain tests
10. How the test are done
11. Why they need to test your blood
12. When to have a bone marrow biopsy
13. What the results of your blood tests mean
14. What types of treatment are available
15. The treatment procedures
16. How the treatment works against the cancer
17. What the purposes of your treatment are
18. How long you will be receiving treatment
19. Why you need to take each medication
20. When to take each medication
21. The possible side-effects of your treatment
22. The possible reactions to each medication
23. If there are ways to prevent treatment side-effects
24. What side-effects you should report to the doctor/nurse
25. If you are prone to infection because of your treatment
26. What complications might occur from your illness
27. Who to talk with if you hear about treatments other than surgery, radiation or chemotherapy
28. How to manage the symptoms you may experience
29. How to manage your pain
30. If the treatment will alter the way that you look
31. How much rest you should be getting
32. How you can avoid stress
33. What to do if you cannot sleep properly
34. What to do if you have trouble urinating
35. What to do if you have trouble with your bowels
36. How to care for your wound or incision
37. What you should do if you have problems with your memory or concentration

38. Changes in the field of fertility
39. Changes in the field of sexuality
40. Possible results of your treatment
41. How the illness may affect your life over the next few months
42. How the illness may affect your life in the future
43. If the cancer will come back
44. Survival rates for your illness
45. What you can do (or are allowed to do) in your situation (work, hobbies and social life)
46. How to keep or become physically fit (exercises and diet)
47. Which vitamins and supplements you should take
48. Which foods you can or cannot eat.
49. How to prepare the foods you are going to eat
50. How to get through the "red tape" to get services at home
51. Possibilities for your physical appearance during your treatment, e.g. wigs
52. If there are groups where you can talk with other people with cancer
53. Who you should call if you have questions while you are still getting treatment
54. What is the best way to talk or interact with a physician
55. How to recognize your feelings toward your illness
56. Where you can get help to deal with your feelings about your illness
57. How to talk to family/ friends about your illness
58. How to tell if the cancer has come back
59. Opportunities for getting immediate help if you experience problems and have questions about your illness
60. What to do and who to talk to if you become concerned about dying
61. Where to get good educational material or literature about your illness or treatment
62. Who you should call if you have questions after all the treatments are over

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CHAPTER 8

GENERAL DISCUSSION

INTRODUCTION

The main aim of this thesis was to obtain insight into the perceived need for and satisfaction with information and need for shared decision-making (SDM), from the perspective of patients with hematological malignancies (HM), their informal caregivers, and healthcare professionals (HCPs). We found that the majority of the patients and caregivers had a high need for information and wanted SDM, but 30 to 40% of them were not satisfied with the information provided. Although dissatisfaction was associated with the need for information in our crosssectional study, it was not associated with the need for information among newly diagnosed patients. This suggests that it is not merely due to a lack of information, but more the type of and the way of giving information. The fact that a considerable number of patients are not satisfied indicates that improvement should be aimed for. We here discuss the results in more detail and describe implications for clinical practice as well as recommendations for future research. Moreover, the strengths and limitations of the research described in this thesis are discussed.

RATIONALE FOR THE STUDIES DESCRIBED IN THIS THESIS

We first performed a literature review on the current knowledge on the perceived need for information among HM-patients (Chapter 2). We showed that there are few and contrasting data on the need for information in patients with a hematological malignancy, being in contrast with the large number of data on the information needs of cancer patients in general. HM-patients were found to have a high need for information, prioritized medical information over psychosocial information and 40 to 67% of HM-patients were satisfied with the provided information.¹⁻⁵ Hence, the perceived need for information and the satisfaction with the information provided differed strongly between patients. In addition, the needs of the informal caregivers and the perspectives of the HCP were largely unknown. This was the reason for our studies described in this thesis (Chapter 3–6).

Moreover, our literature review revealed the lack of a validated questionnaire for evaluating information needs among HM-patients in particular. Therefore, a questionnaire was composed (in this Chapter is called the HINQ) from three original validated questionnaires (PINQ, PLNS and TINQ-BC) to assess the perceived need for information. The HINQ was shortened to 62 items in order to increase its use in clinical practice (HINQ-62). The psychometric characteristics of the HINQ-62 were investigated in more detail (Chapter 7).

CLINICAL CROSS-SECTIONAL AND LONGITUDINAL STUDIES

The HINQ was first applied in a cross-sectional study among 458 HM-patients (ranging from pre-treatment to up to more than five years after treatment), to obtain more insight into their perceived need for information, their satisfaction with the information provided, and their preference for SDM. In addition, the relation with sociodemographic and clinical moderating factors was investigated (Chapters 3 and 4). The perceived need for information in this cross sectional study was moderate to high (40–70%). The need for disease-related and treatment-related information was higher than the need for psychosocial information. According to 41% of the HM-patients, the information provision by their healthcare professionals could be improved. Many patients (82%) reported that they wanted to be fully informed about their illness and actively involved in treatment decision-making. A higher need for disease- and treatment-related information was predicted by younger age, moderate comorbidity and worse quality of life. Patients diagnosed with multiple myeloma had a higher need for information on investigative tests. A higher need for psychosocial information and information on practical care and concerns was predicted by lower age, being a member of a patient association, moderate comorbidity, and worse quality of life. A lower need for non-medical information was associated with a higher educational level predicted (Chapter 3). However, when we introduced cognitive coping style into the multivariable models (Chapter 4), it appeared that only cognitive coping style and quality of life (but not sociodemographic or clinical factors) were significantly related to the perceived need for information. In addition, satisfaction with information provided, and to the preference to be involved in SDM was solely related to the cognitive coping style.

In addition to this cross-sectional analysis, the second objective was to prospectively investigate the perceived need for information, the satisfaction with the information provided and the preference for SDM among newly diagnosed HM-patients as well as among their informal caregivers. Moreover, it was determined which factors were associated with these needs and preferences. Therefore, the pre-treatment data of an ongoing prospective study of 138 newly diagnosed HM-patients and 95 informal caregivers were analyzed regarding these three items, in relation to sociodemographic, clinical factors, cognitive coping style, and quality of life (Chapter 5). The majority of patients (75%) and caregivers (88%) wanted SDM, especially patients, who were treated with curative intent, and those patients and caregivers with a higher monitoring cognitive coping style. Among patients, the need for information in general was related solely to cognitive coping style, but the need for specific information was related to

cognitive coping style and several clinical factors. A higher monitoring cognitive coping style was associated with a higher need for information, especially on medical topics. Patients treated in an academic hospital were found to have lower needs for information on medical tests and prognosis, and on the etiology, sleep and physical changes. And caregivers with a lower educational level reported higher needs for information to the etiology, sleep and physical changes. Approximately 30% of the patients and caregivers were not satisfied with the information they received, especially those patients who wanted SDM and patients with a monitoring coping style.

The third objective of this thesis was to investigate the way HCPs tailor information to individual HM-patients. For that, the perspectives of 96 hematologists and 27 nurse specialists were explored on the need for information of fictive newly diagnosed HM-patients, and on whether the estimated need was associated with the HCPs' cognitive coping style or their sociodemographic or work-related characteristics (Chapter 6). HCPs ranked information concerning disease, treatment, side-effects, medical tests and prognosis higher than information on psychosocial and self-care topics, which is comparable with the ranking of information needs reported by HM-patients and caregivers (Chapters 2–5). The need for information on self-care was estimated higher by female HCPs and by HCPs with a higher monitoring coping style. Need for information on medical tests and prognosis was estimated higher by HCPs with a higher monitoring cognitive coping style. Importantly, we found that HCPs did only slightly tailor information to individual patients.

Finally, as a validated HM-specific information needs questionnaire with specific items associated with hematological malignancies and their treatment is not available, we developed the Hematology Information Needs Questionnaire (HINQ-62)(Chapter 7), using the data of patients described in Chapter 3 and 4. The validation of this HINQ-62 is occurred in 135 newly diagnosed HM-patients in cohort 1 (design phase) and 201 newly diagnosed HM-patients in cohort 2 (validation phase), the cohorts also being described in Chapter 5. The HINQ-62 was found to have a strong content validity and construct validity using exploratory and confirmatory principal component analysis. No irrelevant items could be determined. In addition, the reliability using Cronbach's alpha was found to have a good internal consistency.

CLINICAL IMPLICATIONS OF OUR RESULTS FOR DAILY CLINICAL PRACTICE

The clinical importance of providing tailored information to individual HM-patients and caregivers is stressed by the fact that the majority of (but not all) the HM-patients and their informal caregivers wanted to be involved in treatment decision-making, that they reported a high need for information, but that 41% (Chapter 3 and 4) and 30% of the patients and caregivers (Chapter 5) were not satisfied with the information received. Not only because of satisfying the patients as such, but especially because satisfaction with information has been found to be related to better outcomes such as better illness perception^{6,7}, less decisional conflict⁸, less psychological distress⁹⁻¹², and better HRQOL.^{6,10,11,13-15} Adequate information provision has also been found to be of importance for treatment adherence, although, the scientific evidence is weak.¹⁶ Furthermore, it is clear that providing tailored information is important in the context of SDM.¹⁷ Below we will discuss several possibilities to improve information provision to patients and their informal caregivers.

Importantly, we found that satisfaction with the information did not correlate with information need in patients with newly diagnosed HM. Therefore, simply adapt the extent of information is not expected to improve the satisfaction with information. Probably the way information is given should be personalized in order to increase satisfaction.

Firstly, a more emotionally supporting way of information provision has been suggested.¹¹ This was reasoned by a study among lymphoma and multiple myeloma patients, whose information satisfaction was for example related to the usefulness of information.⁵

Secondly, when looking into detail to the type of information, we clearly show that HM-patients and their informal caregivers prioritize information on medical issues over information on psychosocial care and self-care. In general, HCPs have similar priorities and do provide this type of information and most hospitals also have this information available via brochures or websites. This suggests that the methods of providing medical information are not sufficient, and should be the topic of further research (see “recommendations for future research”). As different needs are expected between patients and within patients over time, a more interactive digital method of patient information could be a possibility to increase the level of satisfaction. Such a system should allow the patients to either choose for limited information, or choose to get more in depth information by interactive linking to modules or pages with more specific information. This would also allow to provide personalized information of patients and

their formal caregivers, as we showed that perspectives might be different between them. The definition of limited information minimally required for safe treatment should be investigated, involving both HCP and patients.

Thirdly, the preference for medical information over information on psychosocial care and self-care is expected to change over time. It may well be that patients and caregivers are occupied with the direct medical issues in this phase of the cancer trajectory and therefore have less need for psychosocial and self-care issues, will experience different needs later on during the treatment. It may also be that information on the impact of cancer and treatment on quality of life is too confronting for some of the HM-patients and caregivers. In general practice, information tends to be given at diagnosis and at the time there is a relapse requiring initiation or change of treatment. However, not only treatment but also the disease itself may influence life. Regular checking the need for information, especially in the outpatient clinic setting when encounters are limited both in frequency and time, should be implemented in clinical practice. We hope to provide more guidelines for clinical practice when having analyzed our longitudinal study on the need for information.

Fourthly, an important issue is, whether we can foresee the requirements of individual patients, which is also challenging. We identified several factors that may influence the need for various types of information and that can be used to tailor the information to the individual HM patient or caregiver. Firstly, a higher monitoring cognitive coping style was associated with a higher need for information, on medical topics in particular. This is consistent with the literature on general cancer in which patients with a higher monitoring cognitive coping style (MCCS) had a higher need for information than patients with a lower MCCS^{18,19}, possibly be explained by the fact that high MCCS-patients cope better with predictable information to allow them to control what to expect for the future.²⁰ Therefore, to explore ways to determine the coping style of patients on beforehand and adapt the information given would be an interesting topic of further research. Other factors associated with the need for information were being treated in an academic hospital; a lower need for information on medical tests and prognosis and on the etiology, sleep and physical changes was found. To our knowledge, this association has not been found earlier. This might be explained by the fact that some of these patients had been referred to an academic hospital at the time of diagnosis, and may already have received information on these subjects, while they were subjected to investigations in the referring hospital. Therefore, we do not think that this is an issue that should be implemented in clinical practice and if true can be circumvented by individualized digital

information as described above. Furthermore, caregivers with a lower educational level reported higher needs for information to the etiology, sleep and physical changes.

Finally, an increased awareness of HCPs for individual differences is important. We found that many HCP only slightly tailor information to individual patients. Accordingly, a recent study among hematologists and newly diagnosed HM-patients showed that hematologists underutilized many communication behaviors, such as establishing the patient's preference for information and for decision-making roles, and checking the patient's understanding of presented information.²¹ Easy interventions, such as asking patients whether they completely understood the information and whether they are satisfied with the information provided, and of identifying whether and when they need additional or less information should be implemented in clinical practice.

Communication training targeting hematologists may enhance the usefulness of the consultation, because they can learn to check the patient's understanding of information and to evaluate whether the information is being absorbed, so that the communication is better tailored to the patient's needs.²¹ Furthermore, we found that the coping style of the HCP influenced the estimated perceived need for information of the patient. So therefore, HCPs should be aware of their own prejudices when providing information.

SHARED DECISION-MAKING

The above described possibilities to improve satisfaction about the information that has been provided may support SDM. There is a growing interest in healthcare policy to actively involve patients in SDM.²² The importance of SDM is also recognized in the Netherlands, and many efforts are undertaken to implement SDM in clinical practice.^{23, 24} This thesis showed that the majority of HM-patients (75%) and caregivers (88%) indeed want SDM. The high interest in SDM is important because the benefits of SDM are a better appraisal of the treatment decision-making^{25, 26} greater satisfaction with the treatment²⁷, better treatment adherence²⁸ and better quality of life.²⁹ However, SDM is only valuable if more than one medically reasonable option is available.¹⁷ In HM, this is for example the case in patients with an indolent lymphoma or chronic lymphoid leukemia who can choose between watchful waiting versus immune- or chemotherapy with or without radiation therapy. Another example are elderly patients with acute leukemia or aggressive lymphoma who can choose between treatment with curative intent but with the chance of severe side-effects and worse quality of life versus less

intensive treatment without the possibility of cure but with fewer side-effects and better quality of life. Furthermore, many patients are requested to participate in a clinical trial, which certainly require SDM.

As was described in the General Introduction of this thesis (Chapter 1), Stiggelbout, Pieterse & de Haes¹⁷ suggested that SDM should consist of four steps. Based on the findings in this thesis, these four steps can be enhanced to effectively target HM-patients and caregivers: 1) The HCP informs the patient that a decision is to be made and that the patient's opinion is important. Based on this thesis, the informal caregiver should also be informed and involved in the decision-making. 2) The HCP explains the options and the pros and cons of each relevant option. This thesis showed that HCP should provide information on the medical issues (cause of HM, HM as such, diagnostic procedures, treatment options) as well as on possible side-effects, psychosocial concerns and quality of life issues. 3) The HCP and the patient discuss the patient's preferences; the HCP supports the patient in deliberation, and 4) The HCP and the patient discuss the patient's decisional role preference, make or defer the decision, and discuss possible follow-up.

This thesis showed that also in the context of SDM, information provision should be tailored to the individual patient and caregiver, taking into account all the above described factors that were associated with the need for information. With respect to SDM in specific, we found patients' and caregivers' cognitive coping style was associated with preference for SDM: consistent with the literature on general cancer patients^{19, 20, 30} Moreover, the association of patients treated with curative intent with more actively SDM preference, is important in providing tailored information and the SDM process.

There are several tools available that aim to facilitate communication between patients and HCPs.²³ With respect to SDM, development of a clinical decision support tool, such as a clearly display of various treatment options with the pro's en cons, may be of help HCPs to tailor information provision for HM-patients. The development, implementation and effect of such a tool requires further research.

STRENGTHS AND LIMITATIONS

An important strength of this thesis is that the need for information and SDM, and satisfaction with information provided was not only investigated from the perspective of HM-patients, but also from their informal caregivers, as well as HCPs. This is of added value to existing literature, as to the best of our knowledge such information is scarce. In view of the changing needs for information over time, it is important that we did not only investigate the need for and satisfaction with information in a cross-sectional study, but also in a longitudinal way. Unfortunately, the follow-up is still short and in this thesis only the data of newly diagnosed HM-patients and their informal caregivers are described. However, these data as such are interesting in the view of SDM as these patients were just recently diagnosed with cancer and were facing difficult treatment decisions. Furthermore, various sociodemographic and clinical factors as well as cognitive coping style and quality of life were investigated in multivariable models to obtain insight into which factors influence the need for information and SDM, and the satisfaction with information provided. This will allow rational interventions to improve information provision.

However, there are some limitations that need to be addressed. Firstly, the concept of SDM is difficult to measure.^{31,32} In addition, the decision role preference is sensitive to the format and wording of the questions and the response options.³³ We assessed the need for SDM with items derived from the Information Satisfaction Questionnaire through the 3 following items: 1) I would like all available information & to be involved in decisions about my illness, 2) I would only like positive information about my illness, 3) I would only like limited information & would prefer the doctor to make the decisions. The wording of these items might have created a bias, as it combines information on the need for information and the wish for SDM, which might be discrepant. In addition, we were forced to combine option 2 and 3 and defined these as no wish for SDM. Option 2 suggests that patients do not want to be involved in SDM, as information is needed to optimally decide. However, it is not an answer that precludes the wish for SDM, so therefore data maybe less reliable. The fact that only few patients (n=5) and no caregivers (n=0) choose option 2 suggests however that the bias is limited. Recently (i.e. after we started the research as presented in this thesis), a SDM questionnaire became available in the Netherlands: the Shared Decision-making Questionnaire (SDM-Q-9).³¹ However, the main focus of the SDM-Q-9 is on the process of SDM instead of the preference for SDM. So therefore, we probably would have obtained similar

results, but we propose to use a standardized questionnaire in the future in order to get more precise data that can be compared.

A second limitation of this thesis is that, although the HINQ-62 appeared to have good psychometric characteristics as described in Chapter 7, not all psychometric criteria were investigated. For instance, no information is available yet on criterion validity, responsiveness, or cross-cultural validity. Also, the psychometric characteristics of the HINQ-62 have not been tested among informal caregivers. Therefore, in the future the HINQ-62 has to be tested for all psychometric characteristics.

A third limitation is that, despite the fact that monitoring and blunting are valid constructs of cognitive coping style^{34,35}, the instrument (TMSI) we used to determine cognitive coping style had not been validated yet for HM-patients and their caregivers, nor for HCPs. However, the TMSI is validated on several oncology, gynecology, HIV and dental patients, and also in non-patients (students).³⁰

A fourth limitation concerns a possible bias of patients and caregivers included in the studies described in Chapters 3 to 5. Despite strenuous efforts to recruit participants, not all were reached or wanted to participate, and it is unknown whether the findings presented in this thesis are generalizable to the entire population of HM-patients and caregivers. However, age and gender distribution of the participating patients were comparable with those of HM-patients in general in the Netherlands, precluding a bias concerning these factors.³⁶ Furthermore, acute leukemia and chronic myeloid leukemia were relatively overrepresented, and non-Hodgkin lymphoma and chronic lymphoid leukemia underrepresented, as compared to the general population, however as the type of diagnosis did not influence the need for information, (except the association of MM and higher need for information on investigative tests in the cross-sectional study), and the wish for SDM, we feel this bias is limited at the most.

A fifth limitation of this thesis is that the study on the perspective of HCPs with respect to HM-patients' need for information was based on fictional patients and future studies are needed that include pairs of HCPs and their patients, which will be needed to further improve on knowledge indeed. Nevertheless, this is the first study investigating HCPs characteristics in relation their estimation of HM-patients' need for information.

Furthermore, some of the significant findings might have been statistically significant only by chance. Indeed, for every 20 true null hypotheses we expect one to be (falsely) rejected.

One could correct for multiple comparisons, however there is no clear consensus on how to address this issue.³⁷

Finally, in this thesis we did not investigate how patients' and caregivers' need for information and SDM and satisfaction with information provided may change during their illness-trajectory from pre-treatment to follow-up. However, as mentioned in Chapter 1, an observational prospective cohort study is ongoing and data are expected by the end of 2017.

RECOMMENDATIONS FOR FUTURE RESEARCH

In this thesis, much effort was undertaken to validate the HINQ-62 for newly diagnosed HM-patients. However, some validation criteria have not yet been met and further validation research is needed. Future studies are also needed to validate the HINQ-62 for HM-patients who are in the treatment and post-treatment phase, and also for the informal caregivers .

Furthermore, research is needed to investigate how HCPs tailor information to individual HM-patients and their caregivers in real life instead of fictive patients, and whether this can be improved, for instance by a specific training. In such a training, HCPs can learn how to assess a patient's need for information, how to provide information and SDM, how to explain the possible treatment options to patients, including the side-effects and implications for quality of life, and how to ask patients whether they want to be involved in SDM and in which way and to professionalize their communication behaviors to check each patient's needs and preferences for involvement in SDM. Via this training HCPs will become more aware of patients' and caregivers' individual needs, and patients may feel better understood. In addition, as described above, a digital support system providing information on a personalized basis allowing for obtaining more precise information on demand by the use of linking modules or web pages might be an interesting tool to personalize information.

The findings of this thesis are expected to be very helpful for developing a clinical decision support tool that helps HCPs to tailor information to the individual patient and caregiver. Such a tool should incorporate cognitive coping style, as well as the several sociodemographic and clinical parameters as described above. A new project that aims to develop such a tool would have to use a participatory design approach, involving

all stakeholders (patients, caregivers, HCPs, and others) from the beginning to ensure that the eventual clinical decision support tool will have a high up-take. If such a tool is proven feasible, a randomized controlled trial is needed to assess whether this tool is effective as well as cost-effective by comparing information provision and satisfaction among pairs of patients and HCPs who make use of the tool versus care as usual.

Besides training HCPs, interventions for patients themselves might also be considered, because weak evidence has shown that interventions targeting patients and HCPs together may be more promising than interventions targeting only patients or HCPs.³⁸ It is not known which type of interventions are to be recommended for patients' SDM and HRQOL (education meetings, education materials, computer based, decision aids, patient coaching, patient activation or pharmacist consultation)³⁸, but one randomized clinical trial on postmenopausal women with osteoporosis found that a decision aid was preferred over a booklet, resulting in better outcomes in terms of knowledge, SDM and treatment adherence.³⁹ Decision aids, which are often used in oncology clinical practice, may be of value in Hematology care, in the selected cases where the decisions to be made, e.g. in patients with an indolent lymphoma or chronic lymphoid leukemia, in elderly patients with acute leukemia or aggressive lymphoma, or in patients who have the opportunity to participate in a clinical trial.

Finally, HM-patients' and caregivers' need for information and their preference for involvement in decision-making is not a fixed situation, but may be subject to changes over time, illness development or response to treatment. Therefore it is necessary to measure these needs and the involvement preferences across the disease span, from diagnosis to follow-up or decease. Importantly, a study of HM-patients and their caregivers from diagnosis to 18 months after diagnosis is ongoing, and results will be available by the end of 2017.

CONCLUSION

This thesis provided a better understanding of HM-patients and caregivers need for information and SDM, and their satisfaction with information provided, both from the perspective of HM-patients and caregivers and from the perspective of HCPs. The need for information and SDM were high. Importantly, we found that more than thirty percent of the patients was dissatisfied with the information they received. The most important factor predicting dissatisfaction was a cognitive coping style. Furthermore, it appeared

that the satisfaction with information was not merely related to the need for information. This indicates that the volume information should not just be increased, but much more personalized. In the paragraphs before we gave some guidelines for future information provided, such as a more interactive digital method of patient information. Importantly, we show that currently HCPs hardly adapt the information on an individual basis, indicating that HPCs should be much more aware of the diversity of patients.

We feel that already now information provision and SDM can be individualized, however, more research, especially towards information need changes over time, a tool predicting patients' cognitive coping style and associated need for information, a digital support system providing information, and a clinical decision support tool should be performed in the near future to optimize patient information.

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SUMMARY

This thesis aimed to investigate the perceived need for information, the satisfaction with information provided, and the shared decision-making (SDM) preference from the perspective of both patients with a hematological malignancy (HM) and their informal caregivers as well as from the perspective of their healthcare professionals (HCPs). First a literature review was conducted on the current knowledge on the perceived need for information among HM-patients. Then, a questionnaire was composed to assess the perceived need for information and satisfaction with information provided and was used in a cross-sectional study to obtain detailed insight into the perceived need for information among HM-patients, their satisfaction with the information provided, and their preference for SDM. Also, possible sociodemographic and clinical moderating factors, health related quality of life (HRQOL), and cognitive coping style were explored. Subsequently, we investigated the way HCPs may tailor information to individual HM-patients. Furthermore, the information needs- and satisfaction, and SDM preference among newly diagnosed patients and their informal caregivers were studied, in relation with possible sociodemographic and clinical moderating factors, HRQOL and cognitive coping style. Finally, we shortened the HM-specific information needs questionnaire and investigated further the psychometric characteristics of the questionnaire.

Chapter 2 described a literature review on the, at that time, current knowledge on the perceived need for information of HM-patients, in which fourteen studies were included. Results showed that patients need basic information on the disease (diagnosis and diagnostics), treatment (various treatment options, side-effects and duration), prognosis (curability and prolonging life) and all other topics (recovery, self-care and psychosocial functioning). Need for detailed information varied between studies. Patients expressed a higher need for medical than psychosocial information. Patients preferred to receive information from their doctors the most, followed by nurses. Most studies described patients' satisfaction with the information provided, ranging from 52 to 67% satisfied patients. However, most of the included studies used study-specific questionnaires, with a limited number of patients, mostly HM survivors, and multivariable analyses were rarely performed, which underlines the need for more studies investigating the need for information among HM-patients as well as their informal caregivers.

Chapter 3 focused on the perceived need for information and SDM preference of 458 HM-patients ranging from diagnosis to up to more than five years after diagnosis.

We compiled a questionnaire with existing validated questionnaires. The perceived need for information was moderate to high (40–70%). Multivariable regression analyses showed that a higher need for information was related to younger age, worse HRQOL, being member of a patient association, and moderate comorbidity. The need for disease- and treatment-related information was higher than the need for psychosocial information. A higher need for psychosocial information was related to a lower educational level. The information provision could be improved according to 41% of the patients. Higher satisfaction with provided information was associated with better HRQOL. Most patients (82%) reported that they wanted to be fully informed about their illness and actively involved in treatment decision-making.

A HM is a serious, life-altering disease, and may be characterized as an uncontrollable and unpredictable stress situation. In dealing with potentially threatening information, individuals generally utilize two main cognitive coping styles: monitoring (the tendency to seek threat-relevant information) and blunting (avoiding threatening information and seeking distraction). The aim of **Chapter 4** was to obtain insight into the association between cognitive coping style and 1) need for information, 2) satisfaction with information, 3) involvement in decision-making, and 4) HRQOL. In a cross-sectional study, coping style was assessed among adult patients diagnosed with a hematological malignancy, using an adapted version of the Threatening Medical Situations Inventory. Information need, information satisfaction, decision-making preference and HRQOL were measured with validated questionnaires. In total, 458 patients returned the questionnaire (66%). A monitoring cognitive coping style (MCCS) was positively related to need for both general and specific information. Blunting was positively and HRQOL was negatively related to need for information. Monitoring was positively related to involvement in decision-making and negatively to information satisfaction. Using multivariable analysis, this relation between monitoring and information satisfaction disappeared and for blunting we found a negatively significant relation. HRQOL was not related to coping style. It was concluded that coping style is related to a need for information, information satisfaction, and involvement in treatment decision-making. Therefore, it is important for HCPs to be aware of individual differences in cognitive coping style.

The aim of the study described in **Chapter 5** was to investigate the SDM preference and the satisfaction with and need for information among newly diagnosed HM-patients and their informal caregivers, in relation to sociodemographic and clinical factors, cognitive coping style, and HRQOL. Newly diagnosed patients and their caregivers were asked to complete the Hematology Information Needs Questionnaire, the Information Satisfaction

Questionnaire and the Threatening Medical Situations Inventory. Medical records were consulted to retrieve sociodemographic and clinical factors and comorbidity by means of the ACE-27. Questionnaires were completed by 138 patients and 95 caregivers. SDM was preferred by the majority of patients (75%) and caregivers (88%), especially patients treated with curative intent), and patients and caregivers with a higher M CCS. Among patients, total need for information was related to M CCS, and need for specific information was related to M CCS and several clinical factors. Importantly, dissatisfaction with the information they received was reported by a third of the patients and caregivers, especially patients who wanted SDM, and patients with a higher M CCS. It was concluded that the majority of HM-patients want to be involved in SDM but the received information is not sufficient. Patient-tailored information is urgently needed, in order to improve SDM.

In cancer care, it is known that patients' information needs do not always correspond with the information received from HCPs. This may influence patients' involvement in treatment decision-making, satisfaction with care, and health-related quality of life. The aim of this study described in **Chapter 6** was to explore the perspectives of HCPs on the need for information of newly diagnosed patients with hematological malignancies, and whether the estimated need was associated with HCPs' own cognitive coping style, sociodemographic and work characteristics. Ninety-six hematologists and 27 specialist nurses completed the adapted version of the Hematology Information Needs Questionnaire regarding fictive newly diagnosed patients. HCPs' age, gender, years of work experience, hospital affiliation, and cognitive coping style were assessed. HCPs ranked information concerning disease, treatment, side-effects, medical tests and prognosis higher than psychosocial and selfcare information. Need for information on selfcare was estimated higher in female HCPs and in HCPs with a higher monitoring coping style. Need for information on medical tests and prognosis was estimated higher in HCPs with a higher monitoring cognitive coping style. It was concluded that HCPs do only slightly tailor information to individual patients. HCPs should be aware that their own cognitive coping style affect their estimation of their patients' need for information.

As a validated HM-specific information needs questionnaire with specific items associated with HM and their treatment were not available, we developed and validated the Hematology Information Need Questionnaire (HINQ-62), described in **Chapter 7**. The psychometric characteristics (content validity, internal consistency, and subscale structure) HINQ-62 were investigated. Baseline data were used from a prospective study on the need for information among 336 newly diagnosed HM-patients. In cohort

1 (design phase), data from the first 135 patients were used and in cohort 2 (validation phase), data from the remaining 201 HM-patients were used. None of the 62 HINQ-items were irrelevant. Exploratory FA identified five subscales: “disease, symptoms, treatment and side-effects”, “etiology, sleep and physical changes”, “selfcare”, “medical tests and prognosis”, and “psychosocial”. Root Mean Square Error of Approximation (RMSEA) among patients was 0.037 in cohort 1 and 0.045 in cohort 2. The comparative fit index (CFI)/Tucker-Lewis index -non-normed fit index among patients was 0.984/0.983 and 0.948/0.946, in cohort 1 and 2 respectively. The internal consistency of the subscales was good, with Cronbach’s α 0.82–0.99. It was concluded that the HINQ is a valid questionnaire for assessing the need for information among Dutch HM-patients at diagnosis.

In **Chapter 8** is the research in this thesis summarized, that provides a better understanding of HM-patients and caregivers need for information and SDM, and their satisfaction with the information provided, both from the perspective of HM-patients and informal caregivers and from the perspective of HCPs. The need for information and SDM was high. Importantly, we found that more than thirty percent of the patients were dissatisfied with the information they received. The most important factor associated with this dissatisfaction was a monitoring cognitive coping style. Furthermore, it appeared that the satisfaction with information was not merely related to the need for information. This finding indicates that the amount of information should not just be increased, but much more personalized. However, HCPs do not seem to tailor the information to the individual (fictive) patient, indicating that HCPs should be much more aware of the diverse needs of their patients. More research is needed on how to tailor information to HM-patients and their caregivers that may change over time. Possible ways to improve personalized information that might be explored are a tool that can be used in clinical practice to predict patients’ cognitive coping style and associated need for information, and an online clinical decision support application to provide tailored information.

NEDERLANDSE SAMENVATTING

Het doel van dit proefschrift is om inzicht te krijgen in de informatiebehoefte en de tevredenheid met de ontvangen informatie en de wens tot gedeelde besluitvorming van zowel patiënten met een hematologische maligniteit (HM) (kwaadaardige bloedziekten) als hun naasten, en daarnaast hoe zorgverleners omgaan met de informatiebehoefte van HM-patiënten. Eerst werd een literatuur review uitgevoerd om de huidige kennis van de informatiebehoefte van HM-patiënten in kaart te brengen. Daarna werd een vragenlijst ontwikkeld om de informatiebehoefte en tevredenheid met de ontvangen informatie, en de wens tot gedeelde besluitvoering in een cross-sectionele studie onder HM-patiënten te onderzoeken. Daarbij werden verschillende sociodemografische en klinische factoren, alsook kwaliteit van leven en cognitieve coping-stijl onderzocht die daarop mogelijk van invloed zijn. Tevens werd onderzocht in hoeverre zorgverleners de informatie toespitsen op individuele HM-patiënten. Verder is de informatiebehoefte en -tevredenheid en wens tot gedeelde besluitvorming onderzocht in nieuw gediagnosticeerde HM-patiënten en hun naasten, in relatie tot sociodemografische en klinische factoren, kwaliteit van leven en cognitieve coping-stijl. Tenslotte werd de HM-specifieke informatiebehoefte vragenlijst (Hematology Information Needs Questionnaire) ingekort en gevalideerd in een cohort van nieuw gediagnosticeerde HM-patiënten.

Hoofdstuk 2 beschrijft een literatuuroverzicht over de destijds bestaande kennis van de behoefte aan informatie van HM-patiënten, waarin veertien studies werden opgenomen. Resultaten toonden aan dat patiënten basisinformatie nodig hebben over de ziekte (diagnose en diagnostiek), behandeling (behandelingsopties, bijwerkingen en duur), prognose (kans op genezing of verlenging van het leven) en onderwerpen op het gebied van kwaliteit van leven en nazorg (herstel, zelfzorg en psychosociale werking). De behoefte aan informatie varieerde sterk tussen studies, maar over het algemeen bleek dat patiënten meer behoefte hadden aan medische dan aan psychosociale informatie. Patiënten hadden de voorkeur om informatie van hun artsen te ontvangen, gevolgd door informatie van verpleegkundigen. De meeste studies beschreven ook de tevredenheid van de patiënten met de verstrekte informatie, waarbij 52 tot 67% van de patiënten tevreden was. Het merendeel van de studies gebruikte echter studie-specifieke vragenlijsten, met een beperkt aantal patiënten, meestal langere tijd na diagnose, en multivariabele analyses werden zelden uitgevoerd. Het goed inschatten van informatiebehoefte in de dagelijkse praktijk bleek veelal niet mogelijk, hetgeen de reden voor de uitvoering van de studies zoals beschreven in dit proefschrift.

Hoofdstuk 3 richt zich op de behoefte aan informatie en wens tot gedeelde besluitvorming van 458 HM-patiënten, variërend van het tijdstip vlak na diagnose tot maximaal vijf jaar na diagnose. Een vragenlijst werd samengesteld uit bestaande gevalideerde vragenlijsten. De informatiebehoefte was middelmatig tot hoog (40–70%). Multivariabele regressieanalyses toonden aan dat een hogere behoefte aan informatie geassocieerd was met een jongere leeftijd, matige comorbiditeit (aanwezig zijn van andere aandoeningen), slechtere kwaliteit van leven, en lid zijn van een patiëntenvereniging. De behoefte aan ziekte- en behandeling gerelateerde informatie was hoger dan de behoefte aan psychosociale informatie. Een hogere behoefte aan psychosociale informatie was gerelateerd aan een lager opleidingsniveau. In totaal vond 41% van de patiënten dat de informatievoorziening verbeterd had kunnen worden. Hogere tevredenheid met de verstrekte informatie was geassocieerd met betere kwaliteit van leven. De meeste patiënten (82%) meldden dat zij volledig geïnformeerd en actief betrokken wilden worden bij de besluitvorming over de ziekte.

Een HM is een ernstige, soms levensbedreigende ziekte, en kan worden gekenmerkt als een oncontroleerbare en onvoorspelbare stress situatie. Bij het omgaan met potentieel bedreigende informatie kunnen mensen over het algemeen twee typen cognitieve coping-stijl gebruiken: monitoring (de neiging om relevante informatie te zoeken) en blunting (het vermijden van dreigende informatie en het zoeken naar afleiding). Het doel van de studie zoals beschreven in **Hoofdstuk 4** was om inzicht te krijgen in de associatie tussen cognitieve coping-stijl en 1) informatiebehoefte, 2) tevredenheid met informatie, 3) betrokkenheid bij besluitvorming en 4) kwaliteit van leven. In een cross-sectionele studie werd de coping-stijl gemeten bij 458 volwassen HM-patiënten, met behulp van een aangepaste versie van de Threatening Medical Situations Inventory. Informatiebehoefte, informatietevredenheid, wens tot gedeelde besluitvorming en kwaliteit van leven werden gemeten met gevalideerde vragenlijsten. Geconcludeerd werd dat een monitoring cognitieve coping-stijl (MCCS) is gerelateerd aan een hogere behoefte aan informatie, lagere informatie tevredenheid en grotere wens om betrokken te zijn bij gedeelde besluitvorming. Daarom is het belangrijk voor zorgverleners om zich bewust te zijn van individuele verschillen in cognitieve coping-stijl bij het verstrekken van informatie en het betrekken van patiënten bij gedeelde besluitvorming.

Hoofdstuk 5 beschrijft een studie die tot doel had om de wens tot informatie en tevredenheid met de verstrekte informatie en de behoefte aan gedeelde besluitvorming bij nieuw gediagnosticeerde HM-patiënten (138) en hun naasten (95) te onderzoeken, in relatie tot sociodemografische en klinische factoren, cognitieve coping-stijl en kwaliteit

van leven. HM-patiënten hadden een hoge behoefte aan informatie, met name medische informatie. Dit was gerelateerd aan een hoge monitoring cognitieve coping-stijl (MCCS). De meerderheid van de patiënten (75%) en naasten (88%) had de wens tot gedeelde besluitvorming, vooral patiënten die behandeld werden met curatieve intentie en patiënten en naasten met een hoge MCCS. Een opvallende bevinding was dat een derde van de patiënten en naasten ontevreden was over de informatie die zij hadden ontvangen, met name patiënten die de wens hadden tot gedeelde besluitvorming en patiënten met een hogere MCCS.

Uit onderzoek en de klinische praktijk blijkt dat de informatiebehoefte van patiënten niet altijd overeenstemt met de informatie die door hun zorgverleners wordt gegeven. Dit kan de betrokkenheid van patiënten bij gedeelde besluitvorming, hun tevredenheid met zorg en hun kwaliteit van het leven negatief beïnvloeden. Aanvullend op het onderzoek bij patiënten en naasten (Hoofdstuk 3, 4 en 5) wordt in **Hoofdstuk 6** in kaart gebracht in hoeverre zorgverleners de informatie aan HM-patiënten op maat aan zouden bieden. Bij 96 hematologen en 27 verpleegkundig specialisten hematologie werd onderzocht hoe zij de informatiebehoefte van (fictieve) HM-patiënten inschatten, en of deze geschatte informatiebehoefte gerelateerd is aan de cognitieve coping-stijl, sociodemografische en werkkenmerken van zorgverleners zelf. De zorgverleners bleken nauwelijks verschil te maken tussen 4 fictieve patiënt casus die verschilden wat betreft leeftijd, geslacht, type HM en behandeling. Wel schatten de zorgverleners, net als patiënten en naasten (Hoofdstuk 3, 4 en 5) de behoefte aan informatie over ziekte, behandeling, bijwerkingen, medische tests en prognose hoger in dan informatie over psychosociale en zelfzorg informatie. De inschatting van de behoefte aan informatie van patiënten bleek samen te hangen met de cognitieve coping-stijl: zorgverleners met een hoge MCCS schatten de behoefte aan informatie bij patiënten hoger in dan hun collega's met een lage MCCS. Voor de klinische praktijk is het belangrijk dat zorgverleners beter onderscheid maken tussen patiënten en dat de zorgverleners zich ervan bewust zijn dat hun eigen cognitieve coping-stijl van invloed kan zijn op hun inschatting van de behoefte aan informatie van HM-patiënten.

Hoofdstuk 7 beschrijft het psychometrisch onderzoek naar de verdere validatie van de in Hoofdstuk 3 samengestelde vragenlijst over HM specifieke informatiebehoefte met onderwerpen over de diagnose HM, de behandeling, en de gevolgen voor de kwaliteit van leven en over nazorg: de Hematology Information Need Questionnaire (HINQ-62) (Hematologie Informatiebehoefte vragenlijst). Baseline data werden gebruikt uit een prospectief onderzoek naar de behoefte aan informatie bij 336 nieuw

gediagnosticeerde HM-patiënten. In cohort 1 (ontwerpfase) werden gegevens van de eerste 135 patiënten gebruikt en in cohort 2 (validatie fase) werden gegevens van de overige 201 HM-patiënten gebruikt. Geen van de 62 HINQ-items was irrelevant. Exploratieve Factor analyse identificeerde vijf subschalen: “ziekte, symptomen, behandeling en bijwerkingen”, “Etiologie, slaap en fysieke veranderingen”, “zelfzorg”, “medische tests en prognose” en “psychosociaal”. Root Mean Square Error of Approximation (RMSEA) bij patiënten was 0,037 in cohort 1 en 0,045 in cohort 2. De comparative fit index (CFI)/Tucker-Lewis index -non-normed fit index onder patiënten was goed 0,984 / 0,983 en 0,948 / 0,946, in cohort 1 en 2 respectievelijk. De interne consistentie van de subschalen was goed, met Cronbach’s α variërend van 0,82–0,99. De HINQ-62 een valide vragenlijst voor de beoordeling van de behoefte aan informatie bij Nederlandse HM-patiënten bij diagnose.

In **Hoofdstuk 8** wordt samengevat dat het onderzoek zoals beschreven in dit proefschrift heeft geleid tot een beter inzicht in de informatiebehoefte, -tevredenheid en wens tot gedeelde besluitvorming zowel vanuit het perspectief van HM-patiënten en naasten, als vanuit het perspectief van gezondheidszorg professionals. De behoefte aan informatie en wens tot gedeelde besluitvorming was hoog bij zowel patiënten als naasten. Echter, meer dan dertig procent van hen was ontevreden over de informatie die ze hadden ontvangen van hun zorgverleners. Monitoring cognitieve coping-stijl is van grote invloed op de behoefte aan informatie, tevredenheid met de verkregen informatie en de wens tot gedeelde besluitvorming bij HM-patiënten en hun naasten, en ook van invloed op hoe zorgverleners de behoefte aan informatie bij patiënten schatten.

In dit hoofdstuk worden enkele mogelijkheden gegeven die kunnen bijdragen aan het optimaliseren van gepersonaliseerde informatievoorziening aan HM patiënten en hun naasten in de klinische praktijk, zoals het doorontwikkelen van de vragenlijst naar cognitieve coping-stijl, en het gebruik van de HINQ-62 in de praktijk, evenals een online applicatie om informatievoorziening op maat aan te kunnen bieden. Echter, verder onderzoek naar deze mogelijkheden is nodig, evenals onderzoek naar de informatie-behoefte en de tevredenheid met de informatie, in de loop van de tijd vanaf diagnose en behandeling tot aan de genezing van kanker of het levenseinde.

LIST OF PUBLICATIONS

1. **Rood JA**J, Eeltink CM, van Zuuren FJ, Verdonck-de Leeuw IM, Huijgens PC. Perceived need for information of patients with hematological malignancies: a literature review. *J Clin Nurs* 2015;24(3–4):353–369.
2. **Rood JA**J, van Zuuren FJ, Stam F, van der Ploeg T, Eeltink C, Verdonck-de Leeuw IM, Huijgens PC. Perceived need for information among patients with a hematological malignancy: associations with information satisfaction and treatment decision-making preferences. *Hematol Oncol* 2015;33(2):85–98.
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4. **Rood JA**J, Nauta IH, Witte BI, Stam F, van Zuuren FJ, Manenschijn A, Huijgens PC, Verdonck-de Leeuw IM, Zweegman S. Shared decision-making and providing information among newly diagnosed patients with hematological malignancies and their informal caregivers: not "one-size-fits-all". *Accepted Psychooncology* 2017;6.
5. **Rood JA**J, Nauta IH, Witte BI, van Zuuren FJ, Stam F, Huijgens PC, Zweegman S, Verdonck-de Leeuw IM. Hematologists' and specialist nurses' perspectives on the need for information among patients with hematological malignancies. *Submitted*
6. **Rood JA**J, Witte BI, Eeltink C, Stam F, van Zuuren FJ, Zweegman S, Verdonck-de Leeuw IM. The need for information among patients with hematological malignancies: Psychometric analyses of the 62-item Hematology Information Needs Questionnaire (HINQ-62). *Submitted*

CURRICULUM VITAE

Janneke Rood werd geboren op 13 oktober 1983 in Hoorn. Ze groeide in Andijk op met haar ouders en jongere broer en zus Diederik en Femke. Ze haalde in 2002 haar atheneumdiploma aan de Regionale Scholen Gemeenschap in Enkhuizen. Na het behalen van de propedeuse biomedische wetenschappen startte zij in 2003 met de studie geneeskunde aan de Vrije Universiteit waar ze in 2009 haar artsexamen haalde. In september 2009 startte ze als arts-assistent interne geneeskunde in het destijds Medisch Centrum Alkmaar. Hier mocht ze ook in september 2010 starten in opleiding tot internist (opleider dr. F. Stam). Gedurende 4 jaar werd de opleiding gecombineerd met 1 dag per week onderzoek onder leiding van prof.dr. P.C. Huijgens en prof.dr. I.M. Verdonck- de Leeuw, dr. F. Stam en dr. F.J. van Zuuren, later aangevuld met prof.dr. S. Zweegman, wat heeft geleid tot het promotieonderzoek in dit proefschrift beschreven. Zij is sinds mei 2015 gestart met de subspecialisatie nefrologie in het VU medisch centrum, en hoopt in januari 2018 haar opleiding tot internist-nefroloog af te ronden. Ze woont sinds 2014 in Grootebroek met Coen Degeling en ze hebben 2 dochters, Tess en Eef.

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