

The Perception of Shared Decision-Making in Hematology by Patients and Physicians Seems Satisfactory, but Important Steps are Still Ahead of Us

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

As the preference for decision involvement differs between patients with solid and hematological cancer,¹ the perception of SDM may also differ. We have some understanding of the perception of SDM in patients receiving medical therapy in solid oncology,⁵⁻¹⁰ but such data are scarce in hematologic oncology. Only one study with myeloma patients measured SDM, but did not report the actual scores.¹¹ These limited data are insufficient for hematologists wishing to integrate SDM in clinical decision-

making with patients, and more empirical information is needed to support them.

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

We report a cross-sectional survey that measured the perception of SDM in patients ≥ 65 years old with a hematologic malignancy and their physicians. The setting was an academic and a non-academic hospital in the southern region of the Netherlands. We hypothesized seeing more preference-sensitive decisions in this elderly population versus a younger population, as in our experience their treatment decisions have more trade-offs compared to younger patients, for example as they more often discuss palliative treatment. By using a list of applicable scenarios (Online Supplement 1, <http://links.lww.com/HS/A88>), preference-sensitive treatment decisions were identified by screening electronic patient health records over a period of 1.5 years. Decisions regarding newly diagnosed and relapsed or refractory patients were both included. Patients referred from another hospital (second opinion or tertiary center referrals) were excluded, unless the treatment decision was clearly only discussed in the hospital they were referred to. Patients could not enter this study more than once. Physicians could be included more than once if more than one of their patients were included.

Demographic and disease-specific data were collected from the patients and demographic and profession-related data were collected from the physicians (Online Supplement 2, <http://links.lww.com/HS/A88>). The patients and physicians received a battery of questionnaires, including the Dutch version of the Shared Decision Making Questionnaire 9-item patient (SDM-Q-9) and physician (SDM-Q-Doc) version (Online supplement 3, <http://links.lww.com/HS/A88> and 4, <http://links.lww.com/HS/A88> for the full description).¹² The patient questionnaire also included the Control Preferences Scale (CPS) single item measuring both the preferred and perceived involvement in the decision.¹³ After pre-consent by phone call, eligible patients and

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Table 1**Patient and Physician Characteristics.**

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

their physician were sent the questionnaire accompanied by a letter of introduction that also notified on which decision the questionnaire applied. Patients also received an informed consent form.

Data were analyzed using SPSS (SPSS statistics, version 23.0, IBM). Demographic data are reported with medians or frequencies. We calculated CPS scores on a scale of 1 (to make the decision alone) to 5 (doctor makes the decision). We calculated SDM-Q scores on a scale of 0 to 100 and report medians or frequencies. A higher score depicts a greater perceived extent of SDM. As there is no defined cut-off for SDM-Q and the

scores were not normally distributed, we also analyzed SDM-Q scores in 3 groups that we considered clinically relevant: first, the group of individuals with a maximum score of 100, as this group may contain patients who do not perceive any shortcomings regarding SDM. Second, the group of individuals with a score < 60, as this would require disagreement on at least one question. Third, the group of individuals with intermediate scores. The following subgroups were analyzed using the Mann-Whitney *U* test: patient age (≥ 75 years and < 75 years), gender and education (primary to secondary vocational and higher professional to university), treatment intention (curative or not), disease type (lymphoid, myeloid and plasma cell disease), physician and hospital type. Relative risks were calculated for a low (<60) or high (100) SDM-Q score for each subgroup. Each SDM-Q item was compared to the mean score of the questionnaire and tested for significance using the Wilcoxon ranks test. Sample size was calculated for a confidence level of 95% and a confidence interval of 5 points on the 0–100 SDM-Q-9 scale. The Medical Ethical Commission of Maastricht University Medical Centre confirmed that full ethical approval for the study was not indicated.

After electronic health record screening 195 patients were eligible for participation, of which 166 consented by phone to participate and were sent the questionnaire. Of those, 95 (57%) returned the questionnaire. Of the physician questionnaires matching to these 95 patients, 64 (67%) were returned. Seventeen physicians participated in the study with a median of 6 patients per physician (range 1–13). Patient and physician characteristics are shown in Table 1. The completion rate for each patient and physician questionnaire item was $\geq 90\%$. The median SDM-Q score was 84 for patients and 82 for physicians. A maximum score of 100 was given by 20 patients (23%) and 19 patients (22%) scored < 60 (Fig. 1). The physicians mostly (90%) scored in between these values, as none scored 100 and only 6 (10%) scored < 60. Patients scored the two questions regarding treatment preferences and weighing (item 6 and 7) significantly lower than the others. Physicians scored items 2 (knowing about patient's decision involvement preferences) and 6 (asking patient's preference) significantly lower than the others (also see Table 2). The CPS indicated that 12 patients (13%) preferred

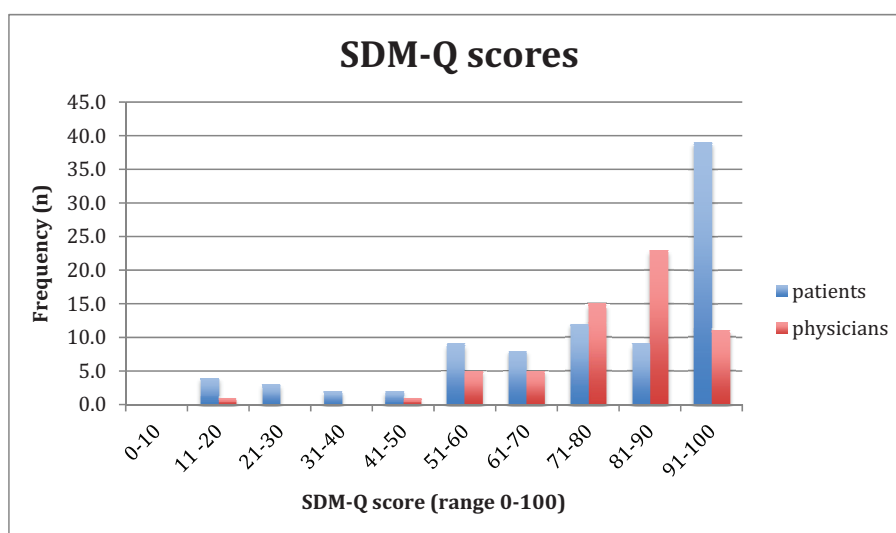


Figure 1. SDM-Q scores. Frequencies of SDM-Q scores are shown in tens for patients (blue) and physicians (red). Zero depicts low SDM and 100 depicts high SDM.

Table 2
SDM-Q Responses Per Item.

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

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

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

Patients <75 years more often filled out the maximum score than patients ≥75 years (relative risk 4.9, 95% CI 1.2–19.7). Patients who discussed curative treatment more often scored the maximum score than patients who discussed non-curative treatment, although the difference was not significant (relative risk 1.7, 95% CI 0.8–3.7). Hematologists in training more often scored <60 than fully trained hematologists (relative risk 6.1; 95% CI 1.3–30.2) and patients scored <60 more often when the physician was a hematologist in training, although not significant (relative risk 1.9, 95% CI 0.8–4.1). For all other subgroup analyses of the mean and grouped SDM scores, no significant differences were found.

According to our interpretation, it seems that patients and physicians perceived SDM to be satisfactory in general, but preference talk needs attention. To our knowledge we are the first to report thoroughly about patient and physician SDM perception in hematologic oncology. The high response rate of 57% in an elderly cancer patient population and the strong focus on a preference-sensitive decision make our results robust.

The best comparison for SDM perception in hematologic oncology is a handful of studies regarding patients with medical therapy for solid cancer.^{5–10} The mean score of 82 is relatively high, comparing to these studies where mean SDM-Q-9 scores vary from 63 to 87. Our finding of the relatively low scores of the items regarding treatment preferences and weighing was also shown in two of the three comparable studies in solid cancer^{5,8,10} and in a qualitative study in breast cancer.¹⁴ These items fit into the third step of SDM, 'preference talk', where the professional takes an explorative stance and tries to learn about the patient's preferences.³ It seems the hematologists perform well at informing patients, but are less able to extract information from the patient. As the latter is an essential part of the decision-making process, we recommend that interventions to optimize SDM in hematologic oncology focus on preference talk. For example, outside of the consultation patients may be supported by decision aids that include preference-elicitation exercises. During the consultation physicians may support patients by presenting options side-by-side in table format, aligned to the core outcomes and patients' frequently asked questions (FAQs).³

Some notable differences or trends in our results are worth mentioning: first, limitations to our sampling may be applied regarding age. As we purposefully selected an elderly population,

comparison with young patients was not possible. Patients aged ≥75 years experienced less SDM than patients aged 65 to 74 years old. Furthermore, patients that discussed non-curative treatment experienced less SDM than those who discussed curative treatment. Treatment intention may partially be related to patient age, and therefore SDM, as we had already hypothesized in our selection process. SDM poses several challenges in the elderly: there is often less evidence available, the medical situation is more complex and it may be difficult to share information with the elderly. Furthermore, decision-making with elderly may be more difficult due to cognitive, hearing, visual and stereotype problems.¹⁵ Future SDM initiatives should take age and treatment intention into consideration and SDM perception by younger patients may be evaluated. Second, we pooled various decisional moments for a variety of diseases in one analysis. Although every decision may differ with regard to SDM and may benefit separate analysis, we intended to reflect the everyday practice of a clinical hematologist. There were no significant differences between the three main disease categories, which supports the validity of the pooled analysis and data presentation. Third, patients and physicians perceived less SDM when the physician was a hematologist in training compared to a fully trained hematologist. This is a new finding. It may reflect limited attention paid to SDM in the educational program on the one hand, but on the other hand the physicians in training may just not be experienced enough to integrate SDM successfully in their daily clinical care. As they treat 'real' patients, this requires attention.

Finally, the patient and professional perspective are essential for the evaluation of SDM. Many subjective measures for SDM exist, although with variable quality. A topic of debate regards the use and interpretation of subjective and/or objective measures of SDM, which are not necessarily correlated.⁹ We applied SDM-Q-9 and SDM-Q-Doc, which are relatively robust subjective measures,¹⁶ as we believe SDM perception was the most important outcome. In future SDM initiatives, subjective and objective SDM measurement would ideally complement each other.

In conclusion, it seems that patients and physicians perceived SDM to be satisfactory in general, but preference talk needs more attention. This should be reflected in future initiatives to use and improve SDM in hematologic oncology and may provide educational opportunities.

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