

The role of patient-driven education in decision-making for relapsed/refractory multiple myeloma

BACKGROUND

This study examines decision-making resources and outcomes among patients with relapsed/refractory multiple myeloma (RRMM). The study aimed to identify shifts in resource utilization over time and evaluate the relationships of these with patient education outcomes.

METHODS

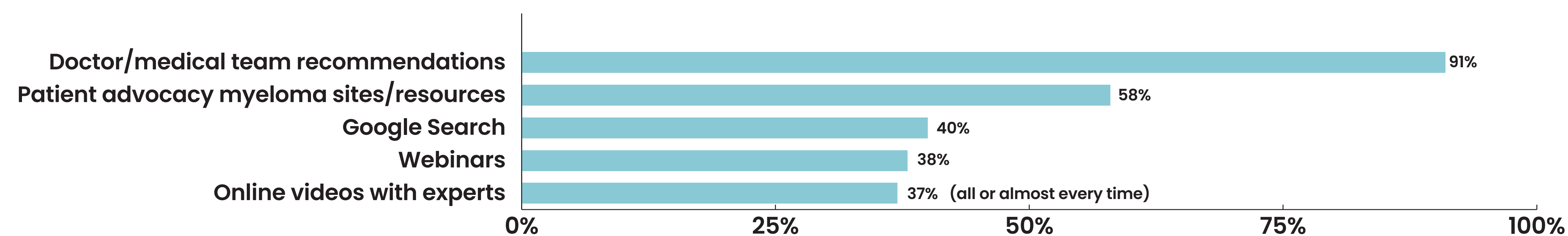
HealthTree Cure Hub, a retrospective cross-sectional survey was conducted exploring the experiences of RRMM patients undergoing therapy changes. Likert scales assessed educational resource utilization frequency (1-never to 5-all the time), healthcare team explanations rating (1-very poor to 5-very good), comfort level with final treatment decision (1-very uncomfortable to 5 - very comfortable), education satisfaction (1-very dissatisfied to 5-very satisfied) and time given and used to make a treatment decision.

RESULTS

Total Participants: **294 RRMM**
 Age: **66 years (SD ± 9)**
 Gender Distribution: **53% were Female**
 Ethnicity Distribution: Of 219 demographics respondents, **91% were white**
 Education level: **49% had graduate level education**

Top Educational Resources (1st change in treatment)

*Answers ranging from Almost to Everytime



Use of an additional three educational resources increased:

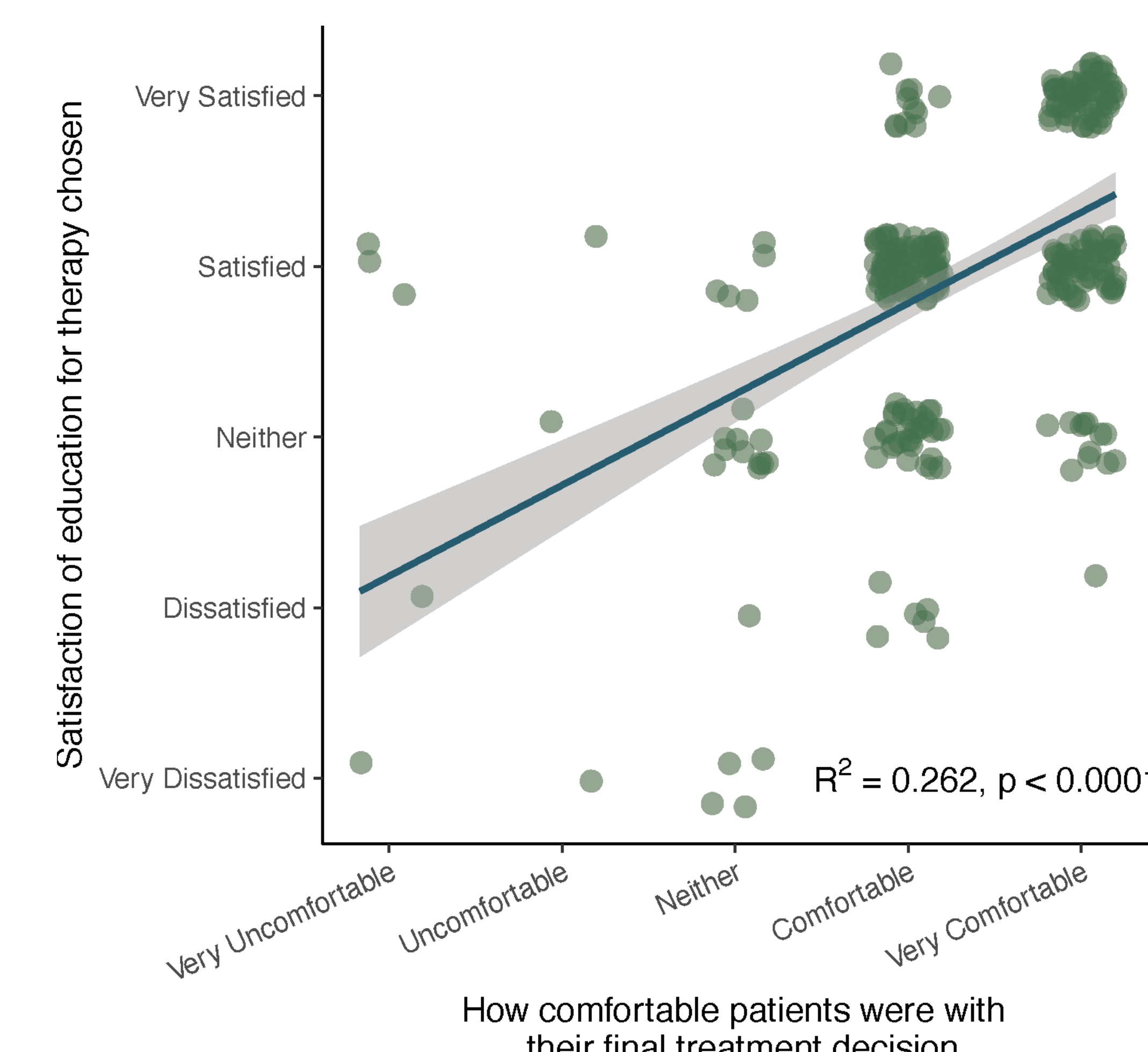
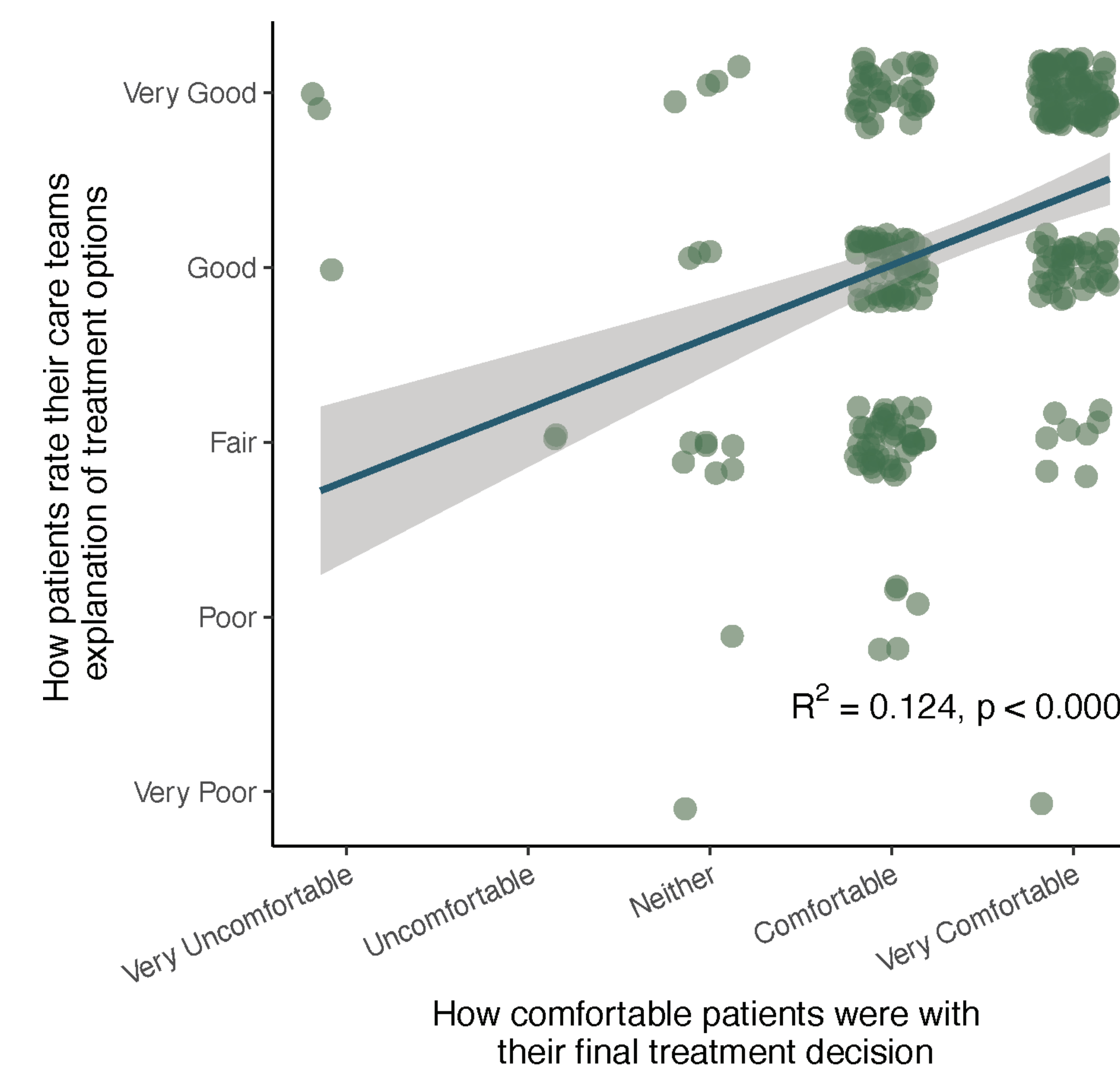
- articles in medical journals** - 2nd change: 2.3±1.1; > 3 changes: 3.1±1.3, p < 0.05
- NCCN, ASCO, mSMART or other blood cancer society guidelines** - 1st change: 2.0±1.1; > 1 changes: 2.3±1.3, p < 0.05
- social media posts from myeloma experts** - 1st change: 2.5±1.2; > 1 change: 2.7±1.3, p < 0.05

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Organizations: HealthTree Foundation, Lehi, UT; The University of Texas MD Anderson Cancer Center, Houston, TX; GlaxoSmithKline plc, Durham, NC; Sanofi, Washington, DC; Regeneron Pharmaceuticals, Tarrytown, NY.

The patients' rating of their care teams' explanations of the treatment options was on average good (4.0±1.1) at 1st change in therapy with (95% of patients rating as acceptable or better) and this improved at > 3 changes in therapy (4.4±0.7, p < 0.05), with 100% rating these as acceptable or better.

Patients' comfort level with their final treatment decision (4.3±0.8) was related to the care team's explanation rating (r = 0.406, p < 0.001) and overall level of treatment education satisfaction (4.0±0.8, r = 0.503, p < 0.001), but it was not related to time given (4.7±9.3 wk) or used (2.2±5.4 wk) to make the treatment decision.



CONCLUSION

While doctor/medical team recommendations remain central, RRMM patients increasingly turn to a diverse set of educational resources as they gain more experience. This is likely driven by an effort to reach a comfortable treatment decision and to obtain a satisfactory disease and treatment education level. Patients' utilization of patient advocacy websites, medical journals, society guidelines, and social media expert posts indicates a broadening of resources used to build an information base. Acknowledging this evolving paradigm is vital for understanding viable avenues for patient engagement to enhance treatment choice and decision making.

