





Patients/Caregivers

Establishing Goals of Therapy While

Managing Myelodysplastic Syndromes

Patient

15,309

engagements

f

14,687

social media

engagements





A Patient Centered and Risk-Adapted Approach to Management of Myelodysplastic Syndrome

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INTRODUCTION

The latest research advances in myelodysplastic syndrome (MDS) pave the way for new treatment options and improved outcomes for patients with this rare and challenging-to-treat disease. Several investigational agents are in late-phase trials and recent approvals require physicians to stay up to date with emerging data on clinical efficacy and safety to make appropriate and individualized treatment choices. Patients and caregivers also require education to help understand disease subtypes, prognosis and expectations of treatment, management of side effects, and the benefits of enrollment in clinical trials.

METHODOLOGY

Educational Initiative and Evaluation



Partners

Advocacy group: Aplastic Anemia & MDS International Foundation (AAMDS) Education: PlatformQ Health. Postgraduate Institute for Medicine



nterventions

Tethered education comprised of one 60-min CME activity for HCPs and one 60-min patient/caregiver activity

Patient Vignette Speaker

Ruth Cuadra

best for her.

MDS Patient and Advocate

Ruth discussed the symptoms she experienced

limitation of treatment choices, her goals for

doctors to decide what treatment would work

treatment, and how she worked with her

and how they were managed. She also

explained how she was diagnosed, the



and self-efficacy behaviors

Assessments

Questions asked before and immediately after the activity. Two-month follow-up survey was sent to learners to evaluate changes in practice and behavior. Chi-Square

HCPs: practice patterns, knowledge,

competence, engagement, and perceptions

Patients/Caregivers: knowledge, communication

tests used for statistical analysis.

Faculty



Hetty Carraway, MD, MBA Director, Leukemia Program Vice Chair, Strategy and Enterprise Development Associate Professor, Cleveland Clinic Taussig Cancer Center Cleveland Clinic



Mikkael A. Sekeres, MD, MS

Professor of Medicine University of Miami Sylvester Cancer Center



were shared

I can identify more patients [who are] eligible for luspatercept.

> Patient was able to switch forms of their medication which provided improved quality of life.

RESULTS

HCPs

Applying Risk-Adapted Approaches to

Management of MDS

MD/NP/PA/RN

average MDS

patient visits

impacted weekly

patient

0

Clinician

total clinicians

themselves as



reported the activity

positively impacted

experiences/outcomes

reported the activity

positively impacted

clinical practice



Clinician

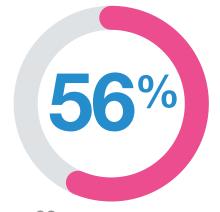
certificates

awarded

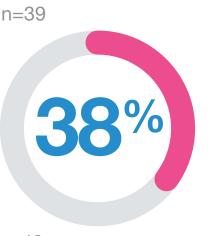
Positive Impact on **Positive Impact on Patient Health-Related Behavior and Outcomes and Clinical Practice** Communication

on-platform

engagements



reported the activity positively impacted communication with their HCP



reported they felt more in control of their health-care decisions

write-in examples were shared

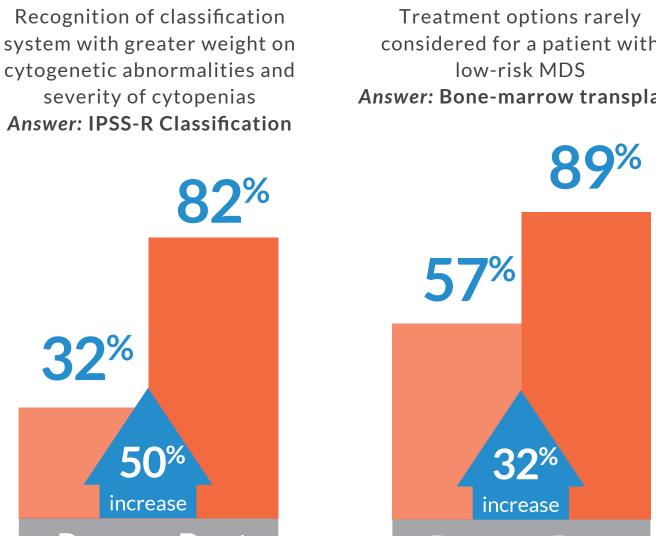
I feel more aware of making health-related changes that will hopefully influence my journey with MDS in a positive way.

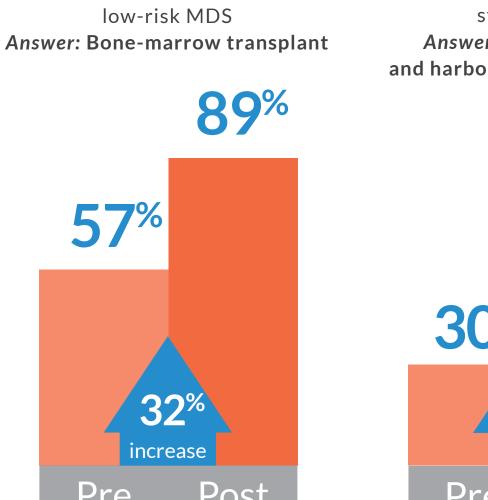
> I feel like I can advocate more for myself as I feel more confident in the knowledge I gained through this program. I learned a lot and appreciated this kind of service being available to patients like me.

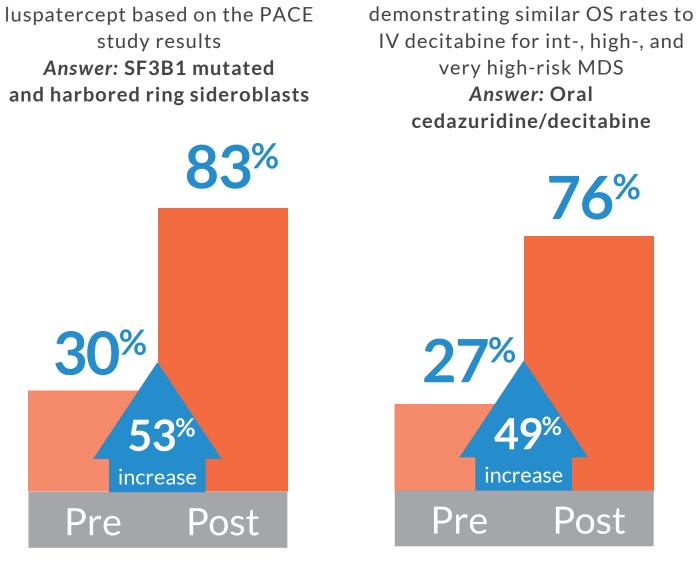
Changes in Knowledge/Competence

n = 1,644 pre, n = 1,287 post, P < 0.05

education material 2% adherence/outcomes





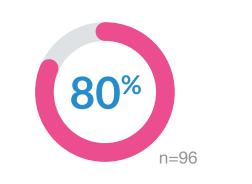


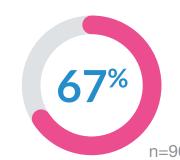
37%

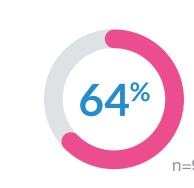
treatment-related

Γailoring treatment

Patient/Caregiver Empowerment and Decision-Making







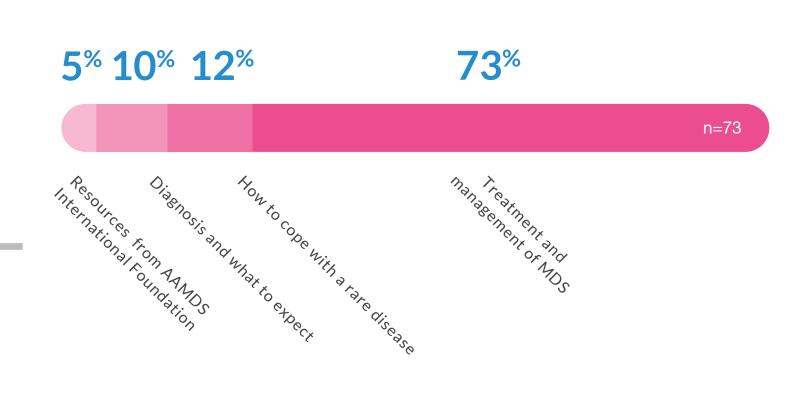
bring up concerns with HCPs

Confident in ability to Preference for shared manage condition

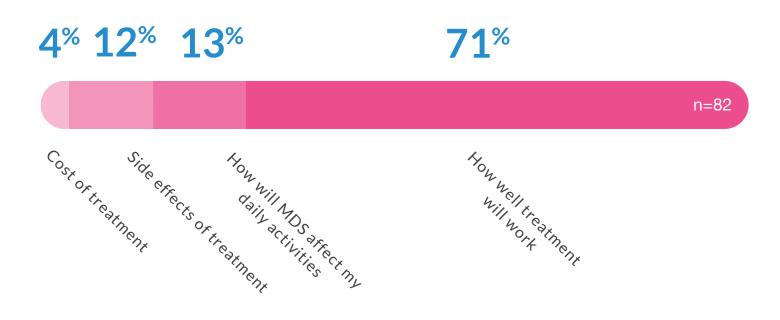
decision-making

Patient Insights Regarding Treatment and Future Education

What are you most interested in learning more about?



What concerns you most about treatment?



Thematic Analysis of Patient Behavior Changes

Thematic Analysis of Clinical Practice Impact

Patient

education

specialist

consultation

cytogenetics &

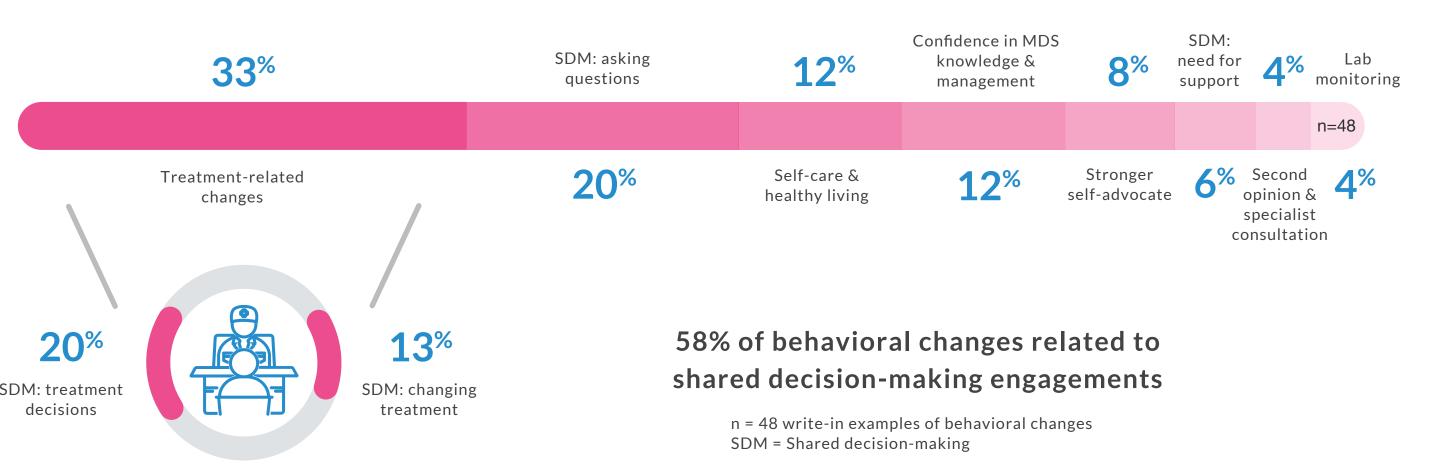
risk-stratification

37% of clinical changes directly

related to treatment practices

n = 45 write-in examples

of practice change



Improved confidence

in MDS management

20%

Changed treatment 5%

Luspatercept

clinical trials

eligibility & benefit

Enrolled patients in

CONCLUSION

This patient-provider (tethered) initiative was successful in improving knowledge and competence of providers from observed baseline levels and increasing confidence of patients to engage in shared decision-making. Insights into patient experiences, concerns, and preferences for education are important to share with providers to better refine patient care practices in the future.