



BACKGROUND

Myelodysplastic Syndromes (MDS) are a heterogeneous group of marrow failure diseases whose prognosis and treatments are guided by marrow morphology, degrees of cytopenias, and genetic changes. Due to the complexity of the disorder, combined with the advanced age and frailty of most patients, conveying crucial information for shared decision-making poses challenges. Despite efforts designed to enhance communication, there is limited understanding of these initiatives' effectiveness.

The aim of this study is to identify informational gaps of Cancer **Experience Registry (CER) participants with an MDS diagnosis.** METHODS

- The CER is an ongoing online research study conducted by the Cancer Support Community that seeks to uncover the emotional, physical, and financial impact of cancer.
- In association with the MDS Foundation, **140 participants with MDS** enrolled from August 2021-March 2023 and provided sociodemographic and clinical history information.
- A subset (*n*=120) also answered questions regarding whether they received additional assistance with MDS-related information and when this was provided.

PARTICIPANTS

| 1 = 140 | Mean/n |
|--------------------------------|----------------|
| Age (years) (range 34-93) | <i>M</i> =69.6 |
| Race & Ethnicity | |
| Non-Hispanic White | n=128 |
| Non-Hispanic other/Multiracial | <i>n</i> =8 |
| Hispanic | n=1 |
| Gender Identity | |
| Woman | n=72 |
| Man | n=66 |
| Education | |
| High school or less | <i>n</i> =26 |
| Some college, did not graduate | <i>n</i> =20 |
| Associate degree | n=7 |
| Bachelor degree | <i>n</i> =42 |
| Graduate degree or higher | n=44 |
| Household Income | |
| Less than \$40,000 | <i>n</i> =25 |
| \$40,000 - \$79,999 | <i>n</i> =38 |
| \$80,000 - \$119,999 | n=22 |
| \$120,000 and above | <i>n</i> =19 |
| Employment Status | |
| Employed | <i>n</i> =21 |
| Retired | n=98 |
| Unemployed | <i>n</i> =18 |
| Time Since Diagnosis | |
| 1 year or less | n=57 |
| 1-2 years | <i>n</i> =26 |
| 3-5 years | <i>n</i> =19 |
| 6 or more years | <i>n</i> =34 |
| Treatment Status | |
| Currently receiving treatment | n=72 |
| Previously received treatment | n=25 |
| Never received treatment | n=37 |

Note: Data for "I don't know" and "Prefer not to share" response options omitted from tal

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Communication that Enables Shared Decision-Making in Myelodysplastic Syndrome is Suboptimal: Early Results from the Cancer Experience Registry

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RESULTS

MDS participants reported significant gaps in the information that they received about important topics related to their MDS diagnosis and treatment.

Received information about...

- MDS WHO Subtype
- Genetic testing options to test for a mutation
 - MDS IPSS or IPSS-R Risk Score
 - Different treatment options
 - Transfusions
 - Transplants
 - Specific medications
 - MDS transforming into AML
 - Understanding what MDS is

Figure 1. From the patient's perspective, was MDS-related information communicated and when was the timing of its delivery (N=120)

MDS participants reported gaps in receiving diagnostic information which are critical determinants of prognosis and are used to inform treatment decisions.



Did not know their IPSS-R Risk Category



Did not know their

Figure 2. Gaps in knowledge about MDS diagnosis (*N*=140)

CONCLUSIONS AND IMPLICATIONS

- decision-making.

| | SD/% | | |
|------|--------------------------------|-----|--|
| | SD=1 ⁻ | 1.4 | |
| | 91% 6% 1% | | |
| | 51% 47% | | |
| | 19% 14% 5% 30% 31% | | |
| | 18% 27% 16% 14% | | |
| | 15% 70% 13% | | |
| | 41% 19% 14% 24% | | |
| | 50% 18% 26% | | |
| ble. | | | |
| quil | bb, | | |







- Did not know their Did not have or recall MDS WHO Subtype biomarker (molecular) testing genetic risk for cancer

Based on the early results of the CER derived from a cohort of highly educated and motivated MDS patients, it appears that effective communication about MDS, risk classification, and treatment options is suboptimal. • A significant proportion of respondents were unable to recall information about their diagnosis critical to informed shared

• Given the complexities of an MDS diagnosis, additional efforts to educate patients are necessary. Patient support organizations, such as the Cancer Support Community and the MDS Foundation, can serve as valuable educational resources.

• Among **24%** who did not know IPSS-R risk:

48% not told, 52% not sure/don't recall

Among **33%** who did not know their WHO morphologic subtype:

39% not told, 61% not sure/don't recall

Among 85% who did not know if they inherited mutations that increase their risk of cancer: **76% were never tested, 21% didn't know** if they were tested, **3%** were tested but **did not know their results**.





Please contact melissa@cancersupportcommunity.org with questions or for additional information