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# Patients' Perspectives on Oral Decitabine and Cedazuridine for the Treatment of Myelodysplastic Syndromes

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## Background

- Until recently, approved hypomethylating agents (HMAs) for higher-risk myelodysplastic syndromes (HR-MDS) included intravenous (IV) decitabine and IV and subcutaneous (SC) azacitidine[1,2]; however, IV/SC HMAs are underutilized in clinical practice.[3,4]
- In real-world studies (2010–2020), 44–65% of patients with HR-MDS did not receive HMA therapy,[3–6] and 44% of patients receiving HMAs were nonpersistent with treatment (received <4 cycles or had a gap of ≥90 days between cycles).[3,6]
- Underuse of HMA therapy has been associated with higher healthcare resource utilization and worse survival outcomes.[3,5–7]
- The burden of IV and SC administration of HMA therapy could potentially contribute to underuse; a patient survey reported pain/anxiety, interference with daily activities, and logistical challenges related to IV/SC administration of HMAs (**Table 1**).[8]
- Approximately 70% of patients receiving IV/SC HMAs indicated they would prefer to switch to an oral treatment.[8,9]
- Oral decitabine and cedazuridine (DEC-C) could reduce patient burden through self-administration at home compared with IV/SC administration in the clinical setting.[10]

**Table 1: Patients' treatment experience with IV/SC HMAs (N=141)[8,a]**

| Survey question (response) | n (%) |
|---|---|
| **Pain, swelling, redness, or discomfort during treatment (yes)** | 107 (75.9) |
| **Anxiety before treatment (yes)** | 112 (79.4) |
| **Treatment interferes with regular daily activities (a great deal, quite a bit)** | 45 (31.9) |
| **Treatment interferes with social activities (a great deal, quite a bit)** | 43 (30.5) |
| **Travel time to treatment center (≥1 hour)** | 59 (41.8) |

[a]Online cross-sectional survey among adult MDS patients (or caregivers as proxies) invited by two MDS patient advocacy groups in the United States. Patients were required to have received an IV/SC HMA within 6 months of the survey.[8]
HMAs, hypomethylating agents; IV/SC, intravenous and subcutaneous; MDS, myelodysplastic syndromes.

## Objective

- To evaluate the perspectives of patients with MDS receiving oral DEC-C as an alternative to IV/SC HMAs, including patients' views on:
  - Convenience/satisfaction with treatment.
  - Impact on quality of life.
  - Impact on daily activities.
  - Oral DEC-C treatment compared with other HMA therapies.

## Methods

### Patient survey design and respondent selection

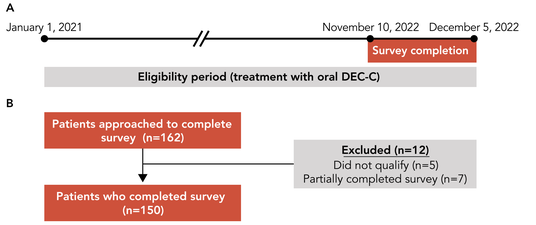
- An online survey was conducted among adult patients with MDS in the United States who had filled a prescription for oral DEC-C between 2021 and 2022 (**Figure 1A**).
- Hematologists/oncologists were asked to identify eligible patients within their practice.
- The survey was completed between November 10, 2022 and December 5, 2022.
- The online survey was a 25-item questionnaire comprising 23 fixed-response questions and 2 free-text questions; estimated time for completion was 15 minutes.
- Of 162 patients who were approached to participate in the survey, 12 were excluded (5 patients did not meet the inclusion criteria and 7 patients completed only part of the survey; **Figure 1B**).

## Results

### Study population and patient demographics

- Among 150 patients who completed the survey, 61% were aged ≥60 years (n=92), and 63% were male (n=94; **Table 2**).
- At the time of the survey, 82% of patients (n=123) were still receiving oral DEC-C, and 18% (n=27) had stopped.
- 50% of patients (n=75) had taken oral DEC-C for ≥6 months.
- 61% of patients (n=91) had received IV/SC HMAs prior to oral DEC-C treatment.

**Figure 1: Patient survey design (A) and respondent selection (B)**




DEC-C, decitabine and cedazuridine.

**Table 2: Demographics and treatment experience among respondents (N=150)**

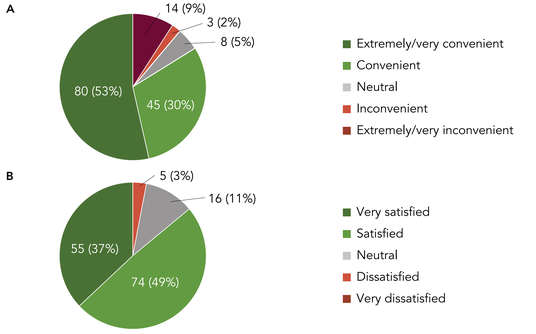
| Characteristic | n (%) |
|---|---|
| **Aged ≥60 years** | 92 (61.3) |
| **Male** | 94 (62.7) |
| **Race[a]** | |
| African American or Black | 27 (18.0) |
| Asian | 11 (7.3) |
| White or Caucasian | 106 (70.7) |
| Other/prefer not to answer | 9 (6.0) |
| **Currently receiving oral DEC-C** | |
| Yes | 123 (82.0) |
| No | 27 (18.0) |
| **Duration of treatment** | |
| <6 months | 75 (50.0) |
| ≥6 months | 75 (50.0) |

[a]Participants could be included in ≥1 category; therefore, percentages do not total 100%.
DEC-C, decitabine and cedazuridine.

### Convenience and satisfaction with oral DEC-C

- Most patients reported that oral DEC-C treatment was convenient or extremely/very convenient (83%; **Figure 2A**).
- Most patients also reported that they were satisfied or very satisfied with oral DEC-C treatment (86%; **Figure 2B**).

**Figure 2: Convenience (A) and satisfaction (B) with oral DEC-C treatment (N=150)**

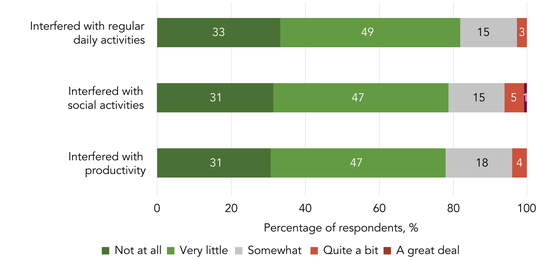



Note: Some percentages do not total 100% due to rounding.
DEC-C, decitabine and cedazuridine.

### Impact of oral DEC-C treatment on daily activities

- Most patients reported no or very little interference from oral DEC-C treatment on regular daily activities (82%), social activities (78%), and productivity (78%; **Figure 3**).
- Side effects were the most commonly reported negative impact on quality of life (30% of respondents).

**Figure 3: Impact of oral DEC-C treatment on respondents' daily activities (N=150)**

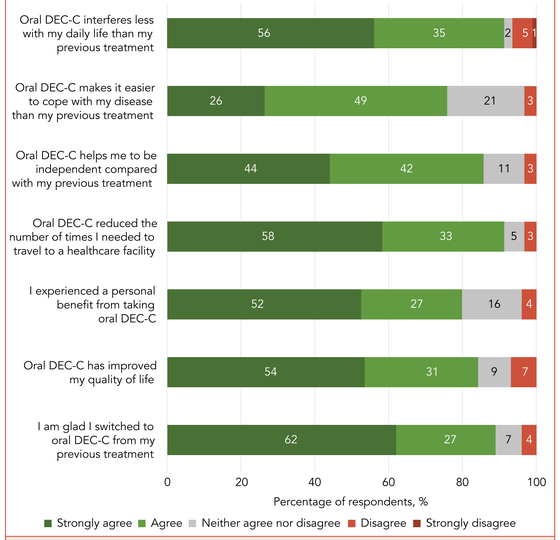



Note: Some percentages do not total 100% due to rounding.
DEC-C, decitabine and cedazuridine.

### Comparison of oral DEC-C treatment versus prior IV/SC HMA treatment

- Most patients who had received prior IV/SC HMAs (n=91) reported that oral DEC-C interfered less with daily life (91%), made it easier to cope with the disease (75%), and reduced the number of times needed to travel to a healthcare facility (91%; **Figure 4**).
- Most respondents felt a personal benefit (79%) and experienced an improvement in quality of life (85%) from oral DEC-C compared with previous IV/SC treatment.
- Most respondents were glad they switched to oral DEC-C from previous treatment (89%).

**Figure 4: Patient experience with oral DEC-C compared with IV/SC HMAs (N=91)**




Note: Some percentages do not total 100% due to rounding.
DEC-C, decitabine and cedazuridine; HMAs, hypomethylating agents; IV/SC, intravenous and subcutaneous.

## Limitations

- Potential for selection bias.
  - Use of online surveys may bias the pool of participants to a younger, more technologically proficient population.
  - Hematologists/oncologists were responsible for offering the survey to patients.
  - People with a positive experience may be more likely to respond to the survey.
- Treatment history was self-reported by respondents and not confirmed with physicians or medical records.
- Inclusion criteria did not differentiate between higher- or lower-risk MDS patient groups; however, it is expected that the majority of the population would have higher-risk disease based on the treatment.
- Reasons for stopping treatment were not captured in this survey.

## Conclusions

- This was the first survey of patient experience with an oral HMA for MDS.
- Survey results suggested very little or no impact on regular daily activities from oral DEC-C treatment.
- Patients reported a personal benefit from receiving oral DEC-C compared with IV/SC treatment and an improvement in quality of life.
- Oral DEC-C reduced the number of times needed for patients to travel to healthcare facilities.
- Our findings suggest the potential for oral DEC-C to reduce treatment burden of HMA therapy.
- Studies on real-world treatment patterns of patients with MDS receiving oral DEC-C are ongoing.[11]

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