ORIGINAL RESEARCH

Educational and Emotional Needs of Patients with Myelodysplastic Syndromes: An AI Analysis of Multi-Country Social Media

Pauline P. Frank · Mabel X. E. Lu · Emma C. Sasse

ABSTRACT

Introduction: Myelodysplastic syndromes (MDS) comprise a heterogeneous group of myeloid malignancies characterized by high symptom burden and limited treatment options. A central challenge to caring for patients with MDS is assessing their needs throughout the different phases of the disease. Patients and caregivers frequently consult online sources to address informational and emotional support needs.

Methods: We conducted a social listening analysis of publicly available online forums to identify unmet needs of patients with MDS and their caregivers in the USA, the UK, Spain, Canada, France, and China. We used artificial intelligence (AI) and natural language processing (NLP) to group categories of posts into seven overarching motivations for online engagement (Clinical, Emotional, Treatments, Transplant, Education and Logistics, Physical, and Diet and Lifestyle).

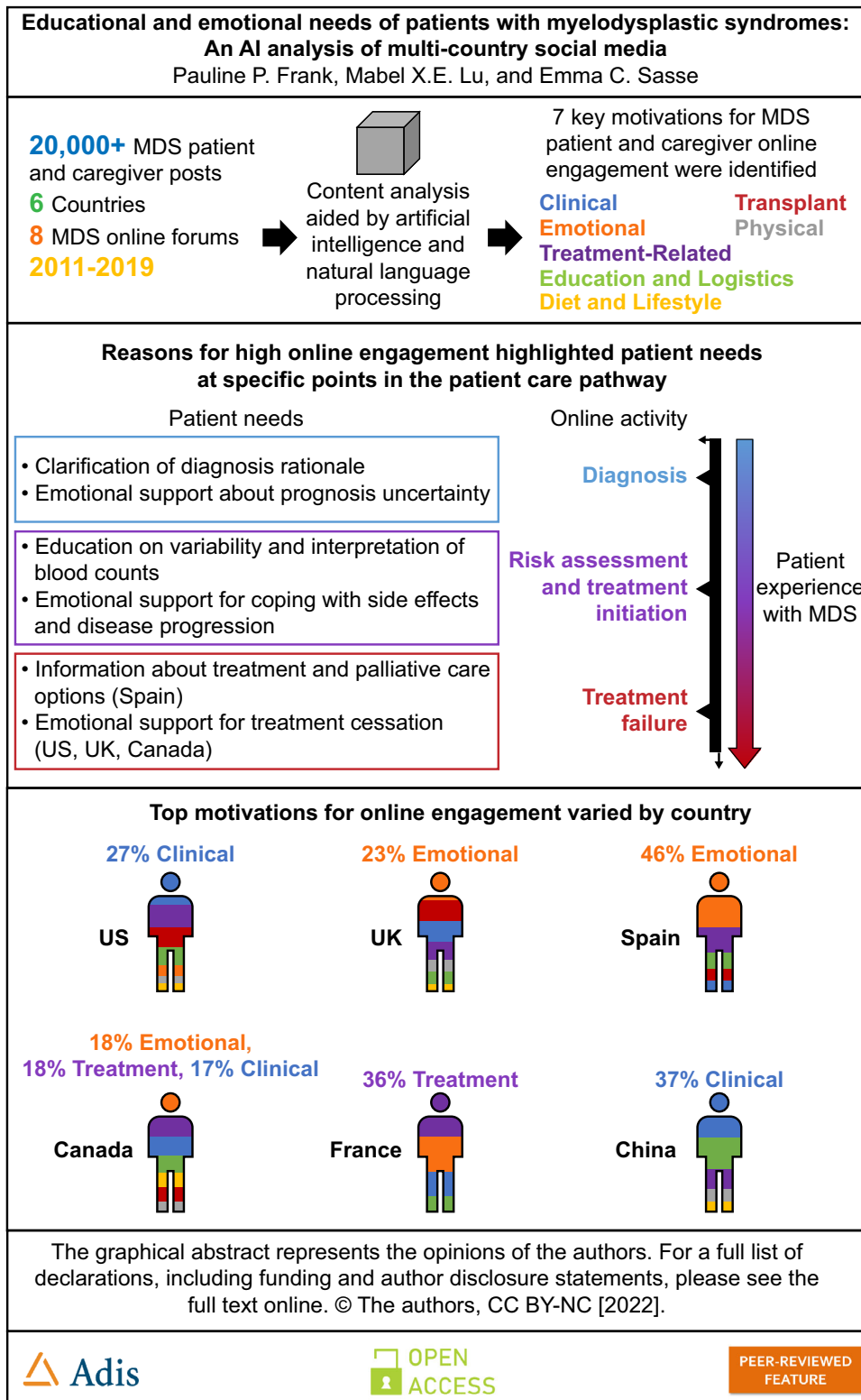***Results***: Posts from the USA and China commonly discussed clinical topics such as MDS diagnosis, disease monitoring, and progression. Posts from Canada and France were frequently about treatments and treatment options. Emotional concerns were key drivers of posts from Canada, Spain, and the UK. Additionally, we also identified topics associated with negative language at key phases during the treatment experience where patients and caregivers exhibited increased online engagement, revealing educational and emotional support gaps at the time of diagnosis, when patients are deciding between treatment options, and when treatment options fail.

Conclusion: In this research, based on social media listening analyzed using AI and NLP, potential information gaps and unmet needs among patients with MDS were identified. Addressing these gaps through targeted patient education and guidance to emotional support options during these phases could reduce the disease burden and emotional distress experienced by patients with MDS.

P. P. Frank · E. C. Sasse (✉)
Novartis Oncology, Global Medical Affairs, Novartis Pharma AG, Novartis Campus, Fabrikstrasse 18, 4002 Basel, Switzerland
e-mail: emma.sasse@novartis.com

M. X. E. Lu
NetBase Quid, Santa Clara, CA, USA

Graphic abstract:

**Educational and emotional needs of patients with myelodysplastic syndromes:
An AI analysis of multi-country social media**
Pauline P. Frank, Mabel X.E. Lu, and Emma C. Sasse

20,000+ MDS patient
and caregiver posts
6 Countries
8 MDS online forums
2011-2019

Content analysis
aided by artificial
intelligence and
natural language
processing

7 key motivations for MDS
patient and caregiver online
engagement were identified

Clinical   **Transplant**
Emotional   **Physical**
Treatment-Related
Education and Logistics
Diet and Lifestyle

**Reasons for high online engagement highlighted patient needs
at specific points in the patient care pathway**

Patient needs

- Clarification of diagnosis rationale
- Emotional support about prognosis uncertainty

- Education on variability and interpretation of blood counts
- Emotional support for coping with side effects and disease progression

- Information about treatment and palliative care options (Spain)
- Emotional support for treatment cessation (US, UK, Canada)

Online activity

Diagnosis

**Risk assessment
and treatment
initiation**

**Treatment
failure**

Patient
experience
with MDS

Top motivations for online engagement varied by country

27% Clinical
US

23% Emotional
UK

46% Emotional
Spain

**18% Emotional,
18% Treatment, 17% Clinical**
Canada

36% Treatment
France

37% Clinical
China

The graphical abstract represents the opinions of the authors. For a full list of
declarations, including funding and author disclosure statements, please see the
full text online. © The authors, CC BY-NC [2022].

△ Adis

OPEN
ACCESS

PEER-REVIEWED
FEATURE

PLAIN LANGUAGE SUMMARY

To better understand patients' needs, we conducted a social listening analysis of frequently discussed topics on public online MDS forums in the USA, UK, Spain, Canada, France, and China. We used artificial intelligence and natural language processing to group motivations for online engagement into seven themes: Clinical, Emotional, Treatments, Transplant, Education/Logistics, Physical, Diet/Lifestyle. Forum posts from the USA and China usually discussed clinical topics like diagnosis, disease monitoring, and disease progression. Posts about treatments and exploring treatment options were a priority in Canada and France. Emotional concerns were a key focus among posts from Canada, France, Spain, and the UK.

We also identified topics that contained strong negative sentiment at key milestones where patients/caregivers had increased online engagement. This revealed that educational/emotional support was most insufficient at the time of diagnosis, when patients are deciding between treatments, and when treatments fail. Addressing these concerns through improving patient education and offering guidance to emotional support options during specific phases of the disease journey could help manage the impact of patients' symptoms, improve their disease and treatment experience, and thus potentially enhance the quality-of-life of patients with MDS.

Keywords: Artificial intelligence; Myelodysplastic syndrome; Natural language processing; Patient journey; Patient needs; QoL; Quality of life; Social media; Social media listening; Unmet needs

Key Summary Points
Myelodysplastic syndromes (MDS) is characterized by high symptom burden and limited treatment options.
Patient needs differ throughout the disease phases, leading patients and their caregivers to seek information online.
This social listening analysis was done to identify the unmet needs of patients with MDS/caregivers in the USA, the UK, Spain, Canada, France, and China.
Potential gaps and unmet needs of patients with MDS were identified in this research, including disease/treatment information, emotional support, and guidance through the patient care pathway, which may vary by country.
Social media listening can identify informational and support needs of patients with MDS/caregivers that may not be shared with healthcare providers, which could help increase awareness of these gaps and unmet needs and improve patient care.

DIGITAL FEATURES

This article is published with digital features, including a graphical abstract, to facilitate understanding of the article. To view digital features for this article, go to https://doi.org/10.6084/m9.figshare.20338857.

INTRODUCTION

Myelodysplastic syndromes (MDS) comprise a diverse group of myeloid malignancies with ineffective hematopoiesis and progressive bone marrow failure [1, 2]. Prognosis varies by risk level at diagnosis [1, 2]. Disease management can include a watch-and-wait period, blood transfusions, therapeutic interventions, and allogeneic stem cell transplant, depending on disease profile [1].

Patients with low-risk MDS can be monitored without treatment or receive interventions for cytopenias [1]. Transfusion-dependent patients with low-risk MDS may receive lenalidomide, low-dose hypomethylating agents (HMAs), erythroid-stimulating agents, and/or iron-chelating therapy based on disease subtype and treatment history [1]. For patients with higher-

risk MDS, hematopoietic stem cell transplant is currently the only potential curative option, whereas HMAs are standard of care for transplant-ineligible disease [3, 4]. Quality-of-life is compromised as assessed by functional and disease-specific components, including significant fatigue levels [5–7].

A central challenge to care of patients with MDS is identifying their needs (informational, functional, and emotional) and how these change throughout disease phases [8]. Patients/caregivers may encounter challenges to obtaining adequate information or emotional support from physicians and turn to other sources, including online forums [8–11].

Online patient communities may reveal concerns and educational gaps that are not shared with physicians [9–11]. The US Food and Drug Administration encourages social media as a tool to gain insight into patients' perspectives on disease impact [12]. How patients engage online could reveal similarities/differences between patients with MDS from different cultures and healthcare settings [10, 13].

Online forum data are unstructured and cannot be objectively analyzed using traditional approaches relying on structured data [14]. Unstructured data are analyzed by machine-learning techniques such as artificial intelligence (AI) and natural language processing (NLP) [13, 15–17]. Applying these to forum posts can identify unbiased common themes.

We used AI and NLP to analyze public, anonymous online patient and disease forum posts to understand the motivations of patients/caregivers to engage online from six countries: USA, UK, Spain, Canada, France, and China. The goal was to understand patient/caregiver needs as they navigate through diagnosis, management, and treatment. Discussions regarding patient/caregiver experience in these forums are an important coping mechanism and cover needs that are not usually shared during short medical visits. Insights provided could help guide development of educational/support programs by country to more effectively address patient needs and guide them through their disease/treatment pathway. Additionally, these insights could help healthcare providers (HCPs) better understand patient healthcare information needs and emphasize the phases throughout the patient journey wherein patients seek online help. This could heighten HCPs' awareness of potential information gaps and allow HCPs to tailor information and the time spent on patient discussions.

METHODS

Next-generation proprietary technologies (NetBase Quid, California, USA) comprising AI and NLP were used to algorithmically analyze more than 20,000 public, anonymous online forum posts across six countries (USA, UK, Spain, Canada, France, and China) from 2011 to 2019. This date range was chosen to align with worldwide availability of HMAs that emerged between their first approval in 2008 and 2011 and to ensure adequate sample size of posts from a limited population of patients with MDS/caregivers.

After examining all publicly available online forums for patients with MDS, eight were identified for analysis on the basis of their high levels of activity (Table 1). Posts were isolated from six countries with sufficient activity to enable qualitative analysis (Table 1). Posts from patients/caregivers were analyzed together and are here collectively referred to as participants.

The NLP algorithm grouped posts by similarity of keywords and associated semantic context, enabling identification of common topics discussed online. Topics represented the most common keywords that unified a group of posts, although each post could fall under multiple, overarching themes, here described as motivations for engaging online. For quantification purposes, each post was assigned to the motivation that was its main focus. For example, although the statement "Has anyone else experienced really unusual pain? Because I'm frightened of it happening again" would fall under both physical and emotional motivations, it was classified under physical because the question focused on pain. Aside from simply identifying the number of occurrences in which a topic is mentioned, the AI incorporates the quantitative element by identifying

Table 1 Table of main (most active) forums and number of patient posts from different countries

Country	Main (most active) forums	Number of posts
USA	MarrowForums	15,000
	Myelodysplastic Syndromes Foundation	
	Leukemia & Lymphoma Society	
UK	MarrowForums	2700
	Myelodysplastic Syndromes Foundation	
	Leukemia & Lymphoma Society	
	Macmillan Cancer Support	
	MDS UK Patient Support Group	
Spain	The Josep Carreras Foundation	2200
Canada	MarrowForums	1800
	Myelodysplastic Syndromes Foundation	
	Leukemia & Lymphoma Society	
France	Vulgaris Medical	1500
China	Baidu Tieba	750

For global forums (e.g., MDS Foundation, MarrowForums, Leukemia & Lymphoma Society), posts were separated by country using the geographical location associated with the participant

patterns and commonalities across posts to establish how connected each post and the overall discussion is, thus creating a "network" of discussion topics (Fig. 1). Through this, we are able to understand how related certain topics are and how they are discussed by participants online (e.g., do users talk about information and diagnosis together?).

To analyze reasons for online activity at key phases in the patient care pathway, ontologies (lists of keywords used by participants) were built to segregate posts into groups according to disease phase (diagnosis, treatment initiation, or treatment-experienced). Each subset was analyzed to identify common conversation topics. As firewall restrictions limited accessibility to Chinese posts, this analysis was only conducted on posts from the USA, UK, Spain, Canada, and France.

An automated sentiment classifier identified and quantified positive/negative language within posts. It first assessed whether words in the post were mostly positive (e.g., better, improving), negative (e.g., painful, disappointed), or neutral in connotation. Each post was assigned a score that was then normalized to the overall set of scores to determine the final sentiment score for that post. This automated classifier's performance was verified against an independent human classification of a subset of posts.

The sentiment classifier was applied to all posts analyzed for reasons for online activity at key phases of the patient care pathway. Posts that mentioned transplants or treatments were also separately analyzed for sentiment to understand treatment perceptions. However, as a result of the limited numbers of posts mentioning treatments or transplants from some countries, we were only able to conduct this focused sentiment analysis on posts from the USA, UK, and Canada. This research was based on secondary data from publicly available, anonymous forum posts. Data collected only included post text, date, and threads; hence, ethics committee approval was not required.

RESULTS

More than 20,000 posts were analyzed from six countries: USA, UK, Spain, Canada, France, and China (Table 1). Most posts (15,000) were from the USA. Among all countries, participants tended to refer to the diagnosis as "MDS," "AML," or "cancer," but also used terms such as "chronic myelomonocytic leukemia," "refractory anemia with excess blasts," or "anemia." "MDS" was the most frequent term used in all countries (ca. 85% of approximately 8000 posts

Similar nodes cluster together, and clusters are grouped by color.
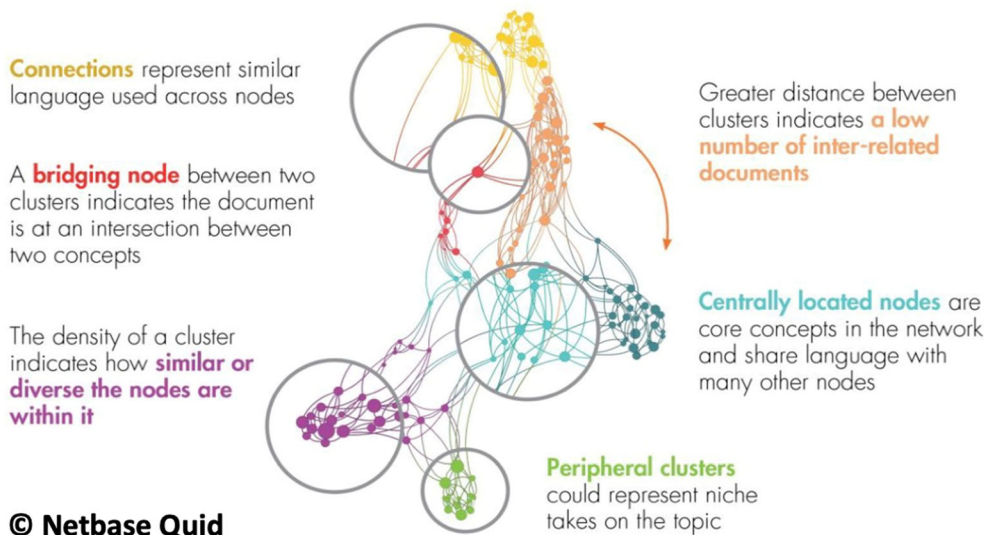Each node represents a document.

Connections represent similar language used across nodes

A **bridging node** between two clusters indicates the document is at an intersection between two concepts

The density of a cluster indicates how **similar or diverse the nodes are within it**

© **Netbase Quid**

Greater distance between clusters indicates **a low number of inter-related documents**

Centrally located nodes are core concepts in the network and share language with many other nodes

Peripheral clusters could represent niche takes on the topic

Fig. 1 Explanation of how to interpret the network visualizations. Reprinted from NetBase Quid with permission

mentioning the disease). In Spain, among 141 posts mentioning the disease, "cancer" (52%), "AML" (42%), or "MDS" (40%) were all frequently used. "Cancer" (7%) and "AML" (8%) were rarely used among 470 disease mentions from China, while "anemia" was more common (34%). MDS risk level was only mentioned among approximately 3000 posts, 2500 of which were US posts, limiting our ability to analyze content by MDS risk level within most countries.

Motivations for Online Engagement

Posts were clustered into seven groups, highlighting similarities/nuances in participant motivations for online engagement between the six countries (Fig. 2). We labeled these groups by the common motivation that unified the posts (Emotional, Treatments, Transplants, Clinical, Education and Logistics, Physical, and Diet and Lifestyle; Table 2), and ranked each group's contribution to total posts by country (Table 3).

USA

Of the 15,000 US posts, more than one-quarter (27%) were clinically motivated, involving participants sharing questions/experiences with disease diagnosis, progression, and monitoring ("What do the changes in counts mean: is treatment working or am I progressing?"). Among these posts, participants most frequently engaged with others to gain a better understanding of the implications of their blood counts, cytogenetic profile, or diagnosis (ca. 12%).

Discussion about treatments (19%), transplants (17%), and education and logistics (16%) were also common motivations for participants' engagement online. Treatment inquiries focused on getting more information about specific treatments and managing side effects ("How did you respond to various treatments for MDS?"). Discussion of treatments tended to be more negative than positive. Reasons for positivity included improved blood counts, full remission, and transfusion independence. Reasons for negativity related to perceived limited duration of efficacy and burdensome side effects.
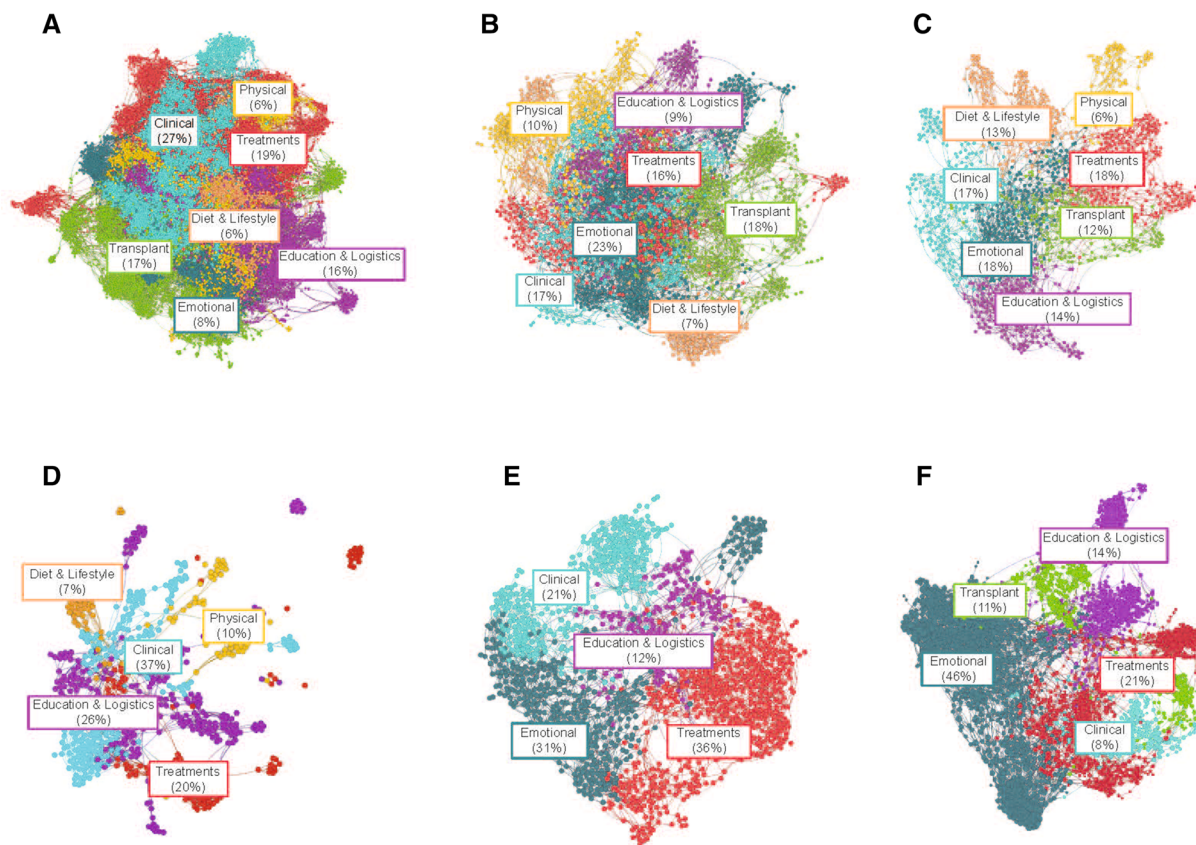
Fig. 2 Network visualizations of posts from patients with MDS on forums with the seven themes mapped. **A** USA. **B** UK. **C** Canada. **D** China. **E** France. **F** Spain

Transplant-related topics primarily included patient experiences with transplants and logistics around the procedure ("Was the transplant successful for you? Any post-transplant problems?"). Patients expressed positive and negative sentiment evenly when discussing transplants. Curative effect and positive responses associated with transplants were reasons for positive discussion, while graft-versus-host disease risk, relapse/limited improvement, and access issues to transplants were drivers for negative posts.

Posts motivated by educational needs primarily requested information about MDS or treatment centers ("Are you anywhere near an MDS CoE [Center of Excellence]?").

UK
Emotional support was identified as the main focus in 23% of the 2700 total UK MDS posts

analyzed. These largely involved participants sharing personal updates and seeking others with shared experiences. Participants leveraged forums to organize local/regional meetings to engage in person with other participants (7%). Another common reason for sharing emotional concerns online was the ambiguity and lack of active treatment during the watch-and-wait approach (4%). Participants tended to seek clarity about risks and benefits of this approach, as well as provide emotional support for each other during this time.

Other common motivators for online engagement included transplants (18%), clinical (17%), and treatment-related discussion (16%). Transplant-related topics, mostly positive in sentiment, centered on finding a donor match and donor lymphocyte infusions. Reasons for positivity included improvements in blood counts and chance of remission. Negative

Table 2 Definitions of seven main themes for patient or caregiver engagement

Theme	Definition of post content
Clinical	Posts relating to patient condition, and diagnosis, progression, and monitoring of the disease
Diet and Lifestyle	Posts focusing on diet changes and day-to-day issues of living with MDS
Education and Logistics	Posts centered on learning about the disease and understanding available care options
Emotional	Posts that provide or seek emotional support between patients or patients and caregivers
Physical	Posts about managing disease symptoms and treatment side effects
Transplants	Posts about the benefits, risks, and experiences with transplants
Treatments	Posts related to questions or concerns about treatments, including cycles, regimens, and treatment decisions

posts mentioned severe illness after transplant and donor lymphocyte infusions. Clinically motivated posts commonly discussed management of blood counts, whereas treatment-motivated posts mentioned "chemotherapy" treatments, which occasionally referred to specific medications, including HMAs. Mentions of treatment were more often positive than negative. Reasons for positivity included stabilized blood counts and long-term efficacy, while negativity focused on side effects (fatigue, loss of taste).

Canada
Among 1800 Canadian participants' posts, most frequent reasons for online engagement were asking others for specific treatment experiences to help evaluate treatment options (18%), sharing and addressing emotional needs (18%), or raising clinical questions and concerns (17%). Treatment-related posts discussed symptoms and side effects ("Any idea why I'm

getting this problem?"), and efficacy-related questions such as time to response. Positive and negative treatment discussions were similarly prevalent. Reasons for positivity included blood count improvements; reasons for negativity included limited long-term efficacy and side effects (fatigue, fever). Posts motivated by emotional needs largely sought emotional support ("What does it mean when a treatment stops working? Is the end near?"). Clinically motivated posts focused on diagnosis and risk profiling ("Do you have experience with this mutation? Will it lead me to leukemia?").

Spain
Emotional support motivated almost half (46%) of the 2200 posts from Spain participants. Participants tended to engage with forums to request updates on how other patients were faring and offer emotional support ("How is he doing? Tell him to take care of himself, okay?"). Treatments were the second motivating factor (21%). Participants posted queries to learn from other patients' treatment experiences and better understand expected outcomes and side effects.

France
Most of the 1500 posts from France were motivated either by treatment discussions (36%) or emotional support (31%). Among treatment-related posts, French participants were most interested in learning about other patients' treatment experiences (22%; "How long did you have to wait to feel the effects of the treatment?") and the impact of treatments on blood levels (14%). Posts about treatments were mostly positive, involving discussion of stabilized/improved blood counts. Reasons for negativity included side effects (fatigue, depression, pain). Among posts focusing on emotional support, the most prominent categories were about encouragement (24%; "I wholeheartedly hope her next treatment round brings the desired result") and advice on how to boost patient morale (7%).

China
Almost 80% of the 750 posts in China were information motivated. Participants tended not

Table 3 Ranking of the seven themes by country

Rank	USA	UK	Canada	China[a]	France[b]	Spain[c]
1	Clinical	Emotional	Treatments	Clinical	Treatments	Emotional
2	Treatments	Transplants	Emotional	Education and Logistics	Emotional	Treatments
3	Transplants	Clinical	Clinical	Treatments	Clinical	Education and Logistics
4	Education and Logistics	Treatments	Education and Logistics	Physical	Education and Logistics	Transplants
5	Emotional	Physical	Diet and Lifestyle	Diet and Lifestyle		Clinical
6	Physical	Education and Logistics	Transplants			
7	Diet and Lifestyle	Diet and Lifestyle	Physical			

[a]Although 29% of posts from China mentioned transplants, in no cases were transplants the main focus of the posts
[b]Posts from France that mentioned transplants or side effects were focused on treatments and grouped under that theme
[c]Posts from Spain mentioning physical side effects were included under treatment and transplant discussions depending on the dominant theme

to share emotional or personal experiences. Primary motivators for online engagement included clinical themes (37%), education and logistics (26%), and treatment-related discussion (20%). Clinically motivated posts were dominated by posts about understanding how MDS relates to other diseases (14%; "How closely related is MDS and aplastic anemia?"), and HCP interactions (13%; "Can you get MDS within half a year? Did the doctor/hospital misdiagnose?").

When motivated by educational needs, participants from China primarily asked about risk groups or MDS information ("How long can my mother survive after chemotherapy if she has moderate-risk MDS?"). Half of treatment-motivated posts (10% of all posts) involved questions about traditional Chinese medicine. From analysis of posts mentioning MDS risk level in China, patients were often recommended traditional Chinese medicine with low-risk disease (54 posts), and Western medicine with high-risk disease (91 posts). A combination of traditional Chinese and Western medicine was also recommended in both sets of posts.

Motivation Patterns by Country Within Forums

Participants from different countries focused on distinct themes within individual forums. We analyzed top motivations of posts across MarrowForums, the MDS Foundation, Macmillan Cancer Support, the MDS UK Patient Support Group, and the Leukemia & Lymphoma Society (LLS) forums. Motivations were analyzed by forum and country in the USA, UK, and Canada.

Within the MDS Foundation forum, US and Canadian participants tended to discuss clinical aspects of the disease, whereas UK participants focused on emotional support. Within MarrowForums, participants from the USA and UK discussed transplant experiences, whereas Canadian participants searched for emotional support. Within the LLS forum, both UK and Canadian participants focused on treatment questions. In the UK, posts within the MDS UK Patient Support Group involved emotional support, whereas posts within the Macmillan Cancer Support forum discussed transplants.

Disease Phases of Higher Online Engagement

Patients with MDS may experience increased educational and emotional needs at certain phases of their journey that prompt online engagement. Reasons for high engagement online were identified during three key phases of the patient care pathway for those in the USA, UK, Spain, Canada, and France: at diagnosis, treatment initiation, and after experiencing treatment. Sentiment analysis was conducted to determine positivity and negativity associated with these reasons for engagement. Topics associated with negative sentiment were analyzed to inform where further education and support efforts are needed. Patients shared similar reasons for online engagement across the five analyzed countries.

Diagnosis

Online activity and negativity were highest when patients received their initial MDS diagnosis. Patients searched for clarity about their diagnosis, risk profile, and cytogenetics. Negativity within these posts included confusion and anxiety about MDS and their prognosis, and how the doctor arrived at the diagnosis.

Patients in the USA, UK, and Canada also discussed seeking a second opinion from specialists. Negativity among these posts referred to experiences that highlighted educational and awareness gaps of their doctors and uncertainty of treatment outcomes due to individual disease variability. Negative patient experiences included general inexperience with MDS of non-specialist physicians (inconsistency in diagnosis and treatment options presented compared with specialist physicians at MDS CoE), conflicting treatment recommendations, and unclear information about diagnosis and testing.

These findings highlight a need for education of non-specialist physicians to clarify current diagnostic criteria and improve communication, referral, and collaboration with specialists at MDS CoE. Patient education efforts (patient brochures and instructional videos) could describe MDS and its progression, and explain the rationale for diagnosis. Emotional support at diagnosis should guide patients through the uncertainty of their prognosis, and could involve providing questions patients could ask their doctor to help them understand MDS.

Treatment Initiation

Online activity levels were lower during treatment initiation than at diagnosis, with moderate negativity among posts (36–50% were negative). Posts centered on choosing between various treatment options and coming to terms with the watch-and-wait approach.

Choosing between treatment options included continuing symptomatic treatment versus starting active treatment or enrolling in clinical trials versus choosing approved treatments. Negativity about treatment options focused on the evaluation of quality-of-life and side effects versus length of life, lack of consistency in blood counts, and disease progression on a given treatment.

Low-risk patients in the USA, UK, and Canada discussed both the watch-and-wait approach and the value of supplements. Posts about watch-and-wait frequently mentioned anxiety regarding disease progression and difficulty with waiting for treatment/transplant. Participants shared their personal experiences and discussed how to cope with symptoms and fear of infection, including changes in diet or lifestyle.

These findings highlight specific patient educational gaps at treatment initiation in interpreting blood counts and expected variability of blood counts, along with emotional needs about side effects, disease progression, and waiting to see improvements/results.

Treatment-Experienced

After patients experienced treatment, key reasons for online engagement included when their physician presented the option of getting a transplant (all five countries), when the patient was making the decision to continue or pause treatment after initial treatment cycles (USA, UK), when active treatment stopped working (USA, UK, Canada), and when the

patient decided to stop treatment or enter hospice (USA, UK, Spain, Canada). These patients displayed a moderate level of online activity and high negativity among posts (at least 51% were negative), especially when treatment halted because of lack of efficacy or patient decision.

Among transplant-related posts, negativity surrounded outcome uncertainty and chances of relapse, side effects, and factors that prevent eligibility. When deciding to continue or pause active treatment, participants expressed negativity about side effects, uncertainty of efficacy, and dealing with length of treatment necessary to see improvements.

In the USA, UK, and Canada, negativity reflected the feeling of running out of treatment options alongside disease progression and worsening side effects. In Spain, patients currently on active treatments requested information about expected length of treatment efficacy and post-chemotherapy/post-HMA options to improve quality-of-life, including palliative care.

These findings highlight variability in patient needs depending on country of residence and current treatment options. In Spain, educational efforts could provide a broader view of treatment and palliative care options through end of life to patients for whom active treatments are still effective. Patients in the USA, UK, and Canada would benefit from more emotional support through later phases of treatment and treatment cessation. Targeted education about expected outcomes (efficacy, quality-of-life, etc.) and transplant side effects could also provide clarity for eligible patients.

DISCUSSION

Patients may engage online to address a variety of emotional/informational needs, most commonly to exchange experiences with other patients, satisfy their curiosity, evaluate information provided by their physician, or gather information beyond what their physician provided [18]. Online communities such as disease-focused forums provide a space for patients to share questions and concerns throughout the patient care pathway that they may not feel comfortable discussing with their physician [18].

In a survey assessing information-seeking behavior in 4270 French patients with cancer (7% with hematological cancers), 40% of patients indicated that the media, including online sources, was a primary source of information. Additionally, 13% reported that the medical team in charge of their treatment was not one of their main sources of information, potentially because of communication difficulties [9]. Among these 532 patients, 63% considered the media to be one of their main sources of information [9]. Examining online conversations may provide insights into the needs of various patients who seek information online, including those who cannot or do not access an HCP, and those who have consulted an HCP but did not fully understand the information provided, did not receive the information they required, or were not able to ask all of their questions during consultations.

Previous research utilized social media posts to understand the perspectives and needs of patients with AML and MDS ineligible for intensive chemotherapy. A smaller number of posts were manually reviewed to identify the overall themes [13]. In comparison, the current research analyzed a much larger and broader online population of patients with MDS, irrespective of eligibility for intensive chemotherapy, and identified their drivers for online engagement. Additionally, by using AI and NLP to organize and analyze the large volume of data, it enabled both a larger data set to be analyzed as well as limited the possibility of bias. The findings from this new analysis showed additional challenges that patients/caregivers face, thereby adding to and elaborating on prior findings of patient needs from analysis of online forums.

Our analysis identified potential information gaps and unmet needs among patients with MDS. In particular, emotional concerns and understanding the disease and treatment options were the most prevalent motivations across forums from all six countries that we examined.

We also found differences in motivations for engaging online and types of information gaps by country that may reflect cultural differences and access to different levels of care. European participants were more likely to turn to online sources to meet their emotional needs, whereas those in the USA, Canada, and China tended to search online about their disease. Greater awareness by HCPs of differences in these informational and supportive gaps by country could improve patient care.

Through our analysis of reasons for online engagement, we identified educational needs at specific phases of the patient care pathway. Key gaps included need for clarity about diagnosis and diagnostic criteria, interpretation of blood counts during treatment, and options after active treatment stops working in treatment-experienced patients.

Emotional needs were observed throughout the patient care pathway, even more among treatment-experienced patients. Support is continuously needed for dealing with side effects. Targeted support could be provided when patients are most likely to seek out emotional support in online communities: immediately after diagnosis, throughout the watch-and-wait phase in low-risk patients, and upon disease progression. Guidance focusing on specific phases could more effectively navigate patients/caregivers through the care pathway, and alleviate the concerns that patients raised in online communities.

The COVID-19 pandemic may have changed how patients use online platforms for support. Patients may be more comfortable with technology, and the ability to extend support online may be stronger than before. An increase in online engagement by patients/caregivers for support is anticipated.

Limitations

While we report primarily a qualitative analysis of participant posts, conclusions drawn from these data are still with limitations. Primarily, as posts are all self-generated, the sample only includes participants who seek out information or a feeling of community online. Patients who turn to in-person patient support groups such as those listed on the MDS Foundation's website, friends, family, and colleagues are not captured here [9].

Online forum data were not comprehensive of all online communities. Data extraction was limited to publicly available forums, excluding forums such as private Facebook groups and limiting data obtainable from Chinese forums as a result of firewall restrictions. Lack of consistency in online engagement patterns from patients with MDS/caregivers, alongside limited available forums, restricted data sample sizes in some countries. This limitation was evident in comparatively low sample sizes for Spain, Canada, France, and China. Posts from Germany were initially considered for the analysis; however, posts on publicly available German forums were low during the time period assessed, potentially because of data privacy regulations or cultural resistance to sharing personal information online [19]. This resulted in an insufficient number of posts to warrant analysis. In Canada, the Aplastic Anemia and Myelodysplasia Association of Canada does not support an online forum and instead has links to other forums, the most visited of which are USA-based. The LLS is the only forum from the list that has a Canadian base but information from MarrowForums and MDS Foundation was still analyzed as Canadian data where appropriate. Aside from this, patients from Canada are often frustrated by lag in access to healthcare and clinical trials, with some provinces lagging more than others, leading them to participate in USA-based forums. Overall, although the online nature of these forums allows wide accessibility of information, centers that treat these patients would be unknown. Patients being treated in MDS CoE or other large urban centers would likely have access to hospital-based support programs and may be less likely to seek support online. Furthermore, patients from rural areas would have difficulty in accessing the urban centers, leading to limited awareness of support programs available to those living in urban areas.

Limited data in public forums constrained our analyses of reasons for online engagement during key treatment phases, as these were

conducted on a subset of posts within each country. We focused on qualitative analysis to determine common topics found among all countries rather than unique topics in individual country data sets, which may have been biased by a small set of posts. This limited our ability to identify reasons for online engagement that may differ between countries or be specific to an individual country, which could be expected on the basis of what we observed in our larger-scale motivation analysis.

Inherent in AI and NLP are differences in data classification and sentiment analysis dependent on the data that the AI was trained on and how sentiment is assessed, alongside biases from human supervision during AI training, and interpretation of the final results [20, 21]. Our approach included human classification verification and sentiment score normalization to minimize these biases, but even so, such biases could have incorrectly categorized some posts. To mitigate these anticipated effects, we focused on common reasons for online engagement among all examined countries.

CONCLUSION

With recent increases in virtual communication, further amplified by the COVID-19 pandemic, analyzing online discussions of patients with MDS/caregivers should be considered for future drug development and medical education programs to better understand patient needs, inform patient and HCP education efforts and patient support programs, and gauge patient awareness of treatment options. Understanding what motivates patients to go online can enable strategies to provide patients with the content they are seeking via online channels they prefer, including avenues for obtaining support. Such efforts could encourage patients to play a more active role in managing their disease, gain a better understanding of what to expect from their disease experience, and develop a support network to address their emotional needs as they arise.

Data Availability. For data sharing, please contact Emma C. Sasse via email at emma.sasse@novartis.com.

REFERENCES

1. Montalban-Bravo G, Garcia-Manero G. Myelodysplastic syndromes: 2018 update on diagnosis, risk-stratification and management. Am J Hematol. 2018;93(1):129–47.

2. Cogle CR. Incidence and burden of the myelodysplastic syndromes. Curr Hematol Malig Rep. 2015;10(3):272–81.

3. Carraway HE. Treatment options for patients with myelodysplastic syndromes after hypomethylating agent failure. Hematol Am Soc Hematol Educ Program. 2016;2016(1):470–7.

4. Uy N, Singh A, Gore SD, Prebet T. Hypomethylating agents (HMA) treatment for myelodysplastic syndromes: alternatives in the frontline and relapse settings. Expert Opin Pharmacother. 2017;18(12):1213–24.

5. Efficace F, Gaidano G, Breccia M, et al. Prevalence, severity and correlates of fatigue in newly diagnosed patients with myelodysplastic syndromes. Br J Haematol. 2015;168(3):361–70.

6. Escalante CP, Chisolm S, Song J, et al. Fatigue, symptom burden, and health-related quality of life in patients with myelodysplastic syndrome, aplastic anemia, and paroxysmal nocturnal hemoglobinuria. Cancer Med. 2019;8(2):543–53.

7. Oliva EN, Finelli C, Santini V, et al. Quality of life and physicians' perception in myelodysplastic syndromes. Am J Blood Res. 2012;2(2):136–47.

8. Thomas ML, Crisp N, Campbell K. The importance of quality of life for patients living with myelodysplastic syndromes. Clin J Oncol Nurs. 2012;16(suppl):47–57.

9. Protiere C, Moumjid N, Bouhnik AD, Le Corroller Soriano AG, Moatti JP. Heterogeneity of cancer patient information-seeking behaviors. Med Decis Making. 2012;32(2):362–75.

10. McRoy S, Rastegar-Mojarad M, Wang Y, Ruddy KJ, Haddad TC, Liu H. Assessing unmet information needs of breast cancer survivors: exploratory study of online health forums using text classification and retrieval. JMIR Cancer. 2018;4(1):e10.

11. van Uden-Kraan CF, Drossaert CH, Taal E, Seydel ER, van de Laar MA. Self-reported differences in empowerment between lurkers and posters in online patient support groups. J Med Internet Res. 2008;10(2):e18.

12. US Food and Drug Administration. Patient-focused drug development: collecting comprehensive and representative input. https://www.fda.gov/downloads/Drugs/GuidanceComplianceRegulatoryInformation/Guidances/UCM610442.pdf. Accessed 4 Dec 2020.

13. Booth A, Bell T, Halhol S, et al. Using social media to uncover treatment experiences and decisions in patients with acute myeloid leukemia or myelodysplastic syndrome who are ineligible for intensive chemotherapy: patient-centric qualitative data analysis. J Med Internet Res. 2019;21(11):e14285.

14. Abhyankar S, Demner-Fushman D, Callaghan FM, McDonald CJ. Combining structured and unstructured data to identify a cohort of ICU patients who received dialysis. J Am Med Inf Assoc. 2014;21(5):801–7.

15. Adikari A, de Silva D, Ranasinghe WKB, et al. Can online support groups address psychological morbidity of cancer patients? An artificial intelligence based investigation of prostate cancer trajectories. PLoS ONE. 2020;15(3):e0229361.

16. De Silva D, Ranasinghe W, Bandaragoda T, et al. Machine learning to support social media

empowered patients in cancer care and cancer treatment decisions. PLoS ONE. 2018;13(10): e0205855.

17. Lee J, Park HA, Park SK, Song TM. Using social media data to understand consumers' information needs and emotions regarding cancer: ontology-based data analysis study. J Med Internet Res. 2020;22(12):e18767.

18. Li N, Orrange S, Kravitz RL, Bell RA. Reasons for and predictors of patients' online health information seeking following a medical appointment. Fam Pract. 2014;31(5):550–6.

19. Morey T, Forbath T, Schoop A. Customer data: designing for transparency and trust. Harv Bus Rev. 2015; p 96–105. https://hbr.org/2015/05/customer-data-designing-for-transparency-and-trust. Accessed 9 July 2021.

20. Juhn Y, Liu H. Artificial intelligence approaches using natural language processing to advance EHR-based clinical research. J Allergy Clin Immunol. 2020;145(2):463–9.

21. Sharma C, Whittle S, Haghighi PD, Burstein F, Keen H. Sentiment analysis of social media posts on pharmacotherapy: a scoping review. Pharmacol Res Perspect. 2020;8(5):e00640.