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Rare Cancers and Social Media: Analysis of Twitter Metrics in the First 2 Years of a Rare-Disease Community for Myeloproliferative Neoplasms on Social Media—#MPNSM

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Abstract
Purpose of review The use of social media has now become a standard means of communication for many individuals worldwide. The use of one specific form of social media, Twitter, has increased among healthcare providers, both as a means of information gathering and as a conduit for original content creation. Recently, major efforts by users have been put forward to help streamline the unprecedented amount of information that can be found on Twitter. These efforts have led to the creation of diseasespecific hashtag (#) medical communities and have greatly enhanced the ability to understand and better categorize the available data on Twitter. Specifically, for those involved in rare cancer fields, adhering to organically designed and consistently used hashtags has led to the rapid, reliable dissemination of information and the ability to efficiently discuss and debate topics of interest in the field. For the field of myeloproliferative neoplasms (MPNs), the creation of #MPNSM (myeloproliferative neoplasms on social media) in 2015 has facilitated interactions among healthcare stakeholders from all over the world in the MPN field.
Recent findings In order to better understand the trends and topics of interest to Twitter users of this novel medical community, we conducted the present analysis which focuses on Twitter analytics from the first two years of #MPNSM.
Summary In this analysis, we observed a sustained increase in the number of Twitter users, number of tweets, number of impressions, and number of retweets over time, demonstrating the feasibility of creating and maintaining a disease-specific hashtag for a rare cancer over time.

Keywords Social media · Twitter · Myeloproliferative neoplasm · MPN · Disease-specific hashtag · Myelofibrosis · Polycythemia vera · Essential thrombocytosis

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Introduction

The use of social media as a standard form of communication among the general public is rising over time [1] and its use, which historically was most prominent among younger age groups, is now noted among all age groups in the US [1, 2]. Similarly, regular engagement with social media, most commonly Twitter, has increased among healthcare providers [3, 4] who are using this platform for a variety of practical professional functions [5]. Among many hematologists/oncologists, Twitter use has become a staple for information gathering, a source to help keep up with journal reading, a reliable method for networking and career development, a forum to raise awareness of and discuss clinical trials, and a platform for discussion and debate of the key topics in the field [6–8].

Furthermore, the use of Twitter has been noted to be increased at the time of major medical conferences, allowing for more participants across the healthcare spectrum to actively participate in medical/scientific discussions than ever before [9–11].

Given the seemingly endless amount of data available on Twitter, investigators have long sought a variety of ways to help organize and better understand this information [12]. One of the most successful methods for the field of hematology/oncology has been through the creation and widespread usage of Disease-Specific Hashtags [13]. This project, which started with approximately 20 initial hashtags, has led to the uniform categorization of cancer topics—archived, easily retrievable information—and has spawned a constantly evolving set of newer hashtags over time (as detailed at sites: www.symplur.com/healthcare-hashtags/ontology and https://www.symplur.com/healthcare-hashtags/ontology/hematology/) [13]. In particular, it has been noted that for rare cancer fields, the existence of disease-specific hashtags has provided healthcare stakeholders a virtual space in which to quickly come together and raise awareness for disease areas that have been historically underrepresented online [14]. Indeed, there is urgent need for more forums for expert online information and virtual spaces for communication and discussion [12, 14]. One of the rare cancer fields that has benefited from this online organization is the myeloproliferative neoplasms. As described in Pemmaraju et al., #MPNSM (myeloproliferative neoplasms on social media) was officially registered at www.symplur.com @healthhashtags by founder Naveen Pemmaraju (@doctorpemm) with co-founders Ruben Mesa (@mpdrc), Michael Thompson (@mtmdphd), and Vikas Gupta (@Vikas_Gupta_1) on January 31, 2015 [15]. Now in its 3rd year of existence, the #MPNSM hashtag has provided healthcare stakeholders from across the myeloproliferative neoplasm (MPN) field a stable venue in which to learn about and contribute original content to the field [15]. After its 1st year in existence, an analysis demonstrated a high rate of uptake of the new hashtag among a variety of groups in the MPN field, including physicians and healthcare providers, patients, advocates, organizations, and companies, with a remarkably low rate of "spam" (nonsense/non-useful information) and a high usage rate around the time of major conferences [16]. In order to better understand the metrics of this novel Twitter rare-disease community, in this analysis, we sought to determine the dynamics of user characteristics and changes in trends of #MPNSM over time.

Table 1 Key Twitter metrics over the two study periods for #MPNSM

	Key Twitter metrics	Jan 2015–Jan 2016 No.	Jan 2016–Jan 2017 No.
1	Tweets	3462	5627
2	Users	442	604
3	Impressions	7,159,253	12,436,302
4	Hyperlinks included	1977	3537
5	Mentions	2693	4812
6	Photographs included	764	1014
7	Retweets	1989	3456

Table 2 Top ten most commonly tweeted terms using #MPNSM over two time periods

	Jan 2015–Jan 2016		Jan 2016–Jan 2017	
	Terms	No. of Tweets mentioned	Terms	No. of Tweets mentioned
1	mpn	613	mpn	1638
2	patients	384	patients	1046
3	myelofibrosis	327	mpns	821
4	pts	248	myeloproliferative	582
5	myeloproliferative	245	media	536
6	jak	231	social	536
7	mpns	213	community	470
8	neoplasms	187	myelofibrosis	440
9	session	183	neoplasms	434
10	social	178	mesa	424

Methods

All tweets, which are publically available, were examined with the analytics support of Symplur LLC (www.symplur.com) via its Symplur Signals program, a platform that allows for advanced metrics on Twitter-related data using previously described methodologies [16]. The project was made possible through Symplur's Healthcare Hashtag Project and the Cancer Tag Ontology Project, a collaborative, free, and open set of platforms which assists in organization of healthcare-related information on Twitter [13]. We analyzed all tweets using the hashtag #MPNSM during the study-defined 2-year period (January 1, 2015—January 1, 2017; total n = 9089 tweets). The study analysis period was over 2 years and was divided into two distinct 1-year periods in order to allow for comparison over time: January 1, 2015–January 1, 2016 (n = 3462 tweets) and January 2, 2016–January 1, 2017 (n = 5627 tweets). The primary objective of this study was to determine the number of Twitter users, characteristics of content generated, and number of impressions over time since the creation of the #MPNSM medical

Fig. 1 **a** Pictograph of all terms used in #MPNSM during the first study period: January 2015–January 2016. **b** Pictograph of all terms used in #MPNSM during the second study period: January 2016–January 2017

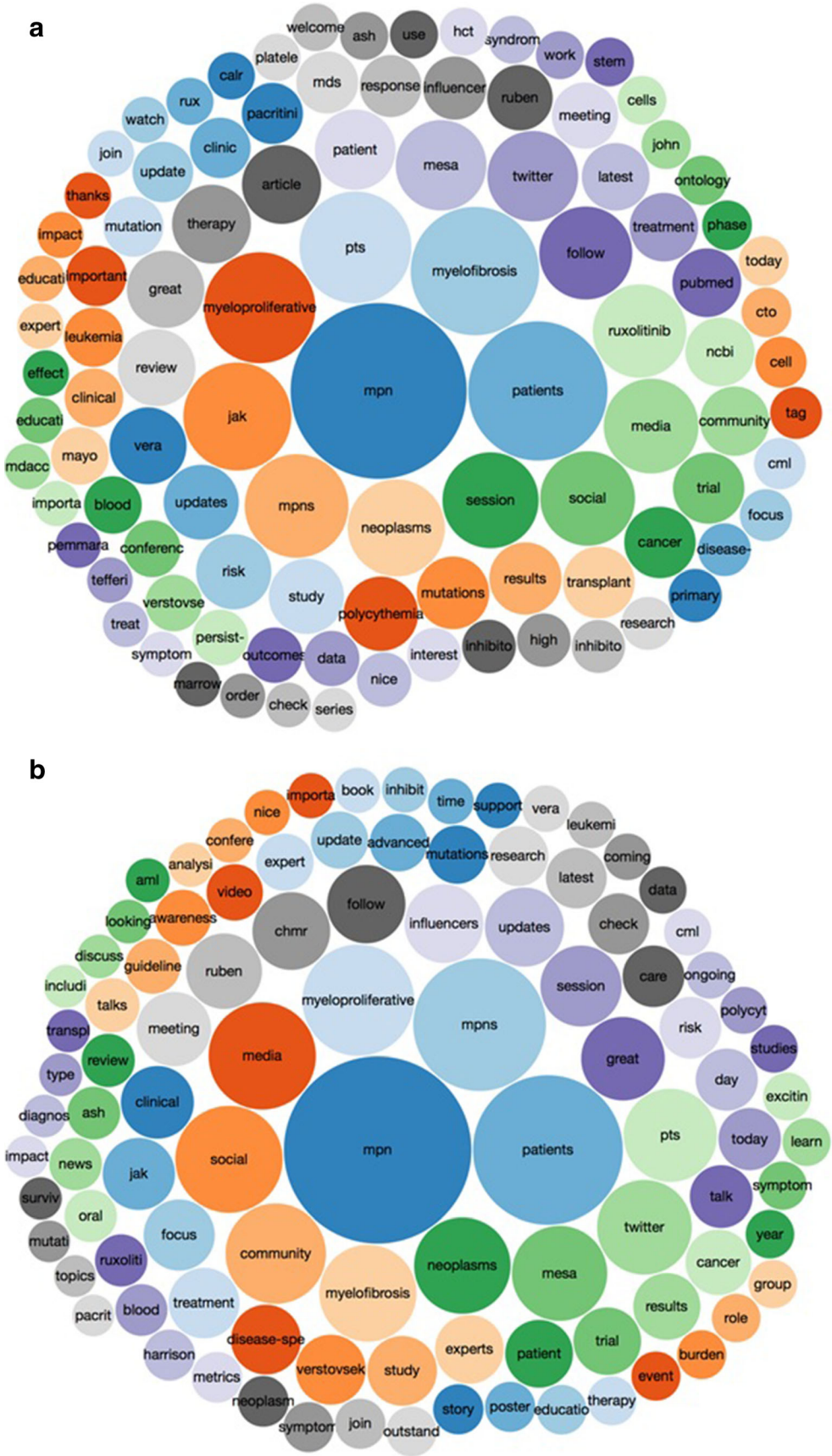
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Table 3 Peak use dates for number of tweets for #MPNSM: 2015–2016 and 2016–2017

	Jan 2015–Jan 2016		Jan 2016–Jan 2017	
	Dates	No. of Tweets using #MPNSM	Terms	No. of Tweets using #MPNSM
1	December 5	166	December 5	254
2	December 7	153	December 4	180
3	December 6	146	December 6	121
4	February 9	112	December 3	103
5	May 30	102	December 2	89

community. All definitions for Twitter terms and parameters that we used for this analysis adhere to those described in our two previous reports by Pemmaraju et al. [15, 16].

Results

From the 1st-year analysis period (January 1, 2015–January 1 2016), the number of tweets using the #MPNSM hashtag was 3462. During this time, 442 unique users were observed, generating over 7,159,253 impressions. In terms of the information-sharing capability of the contents of the tweets generated, there were 1977 Internet hyperlinks included in tweets. In total, there were 764 photographs included in tweets during this time period. Users often cited other Twitter users, for 2693 mentions, and the number of retweets (RT) was 1989.

In comparison, during the second time period (January 2, 2016–January 1, 2017), we observed an increase in the number of tweets (from 3462 to 5627), representing an approximately 1.5 times increase from the year before. In terms of unique users, an increase was also noted from 442 users in the previous time period to 604. Most notably, the number of Twitter impressions increased to 12,436,302 in the second time period. The number of links and mentions both increased over the two time periods, from 1977 to 3537 for links and from 2693 to 4812 for mentions. The number of photographs similarly increased. Finally, the number of retweets (RTs) had also increased over time from 1989 to 3456 (see Table 1 for details).

In order to ascertain an understanding of which topics/terms are discussed on #MPNSM, we performed an unfiltered analysis of the #MPNSM hashtag dataset to determine the most commonly used terms. The top ten most commonly tweeted terms using #MPNSM during the two study periods are shown in Table 2. In our analysis, we observed that the top two most commonly tweeted terms in both study periods was "MPN" and "patients," with an approximately 2.5-fold increase in both terms mentioned in the 2nd year. Other terms included in the top five for both years were all expected terms, with variations on the top two terms including "pts" (medical and Twitter shorthand for "patients"). See Fig. 1a, b for a visual depiction in pictograph form of all terms used for the two study periods.

One measure used for trending Twitter activity is to analyze peak dates of use for a particular hashtag. We reviewed all dates during the study period and found that there were a total of nine dates across the two study periods with 100 or greater tweets using #MPNSM. Among the top five most commonly tweeted dates using #MPNSM in each study period, we observed that eight out of ten of these dates were in December—exactly coinciding with the American Society of Hematology (ASH) annual meeting for each year (Table 3), including the highest peak use date across both study periods—December 5, 2016—which registered 254 tweets, also during the time of an ASH meeting (ASH 2016).

Another measure of user activity under a specific hashtag is examining the number of RTs generated. Over the two study periods, the top three most RT'd tweets are listed in Tables 4 and 5. In the first study period, only one tweet had ten or more RT, whereas in the second study period, there were three tweets found in this category.

Discussion

Twitter use is increasing among hematologists/oncologists in all practice settings [4, 6, 17]. This has particularly been

Table 4 Top three most common retweets of #MPNSM (January 2015–January 2016)

User	Tweet	Date/time	User type	No. of RTs
@pvreporter	Social media at #ash15 is expanding exponentially! This is a good thing for #patients and #doctors #mpnsm https://t.co/NwnKCqTovB	Tue, Dec 8, 2015, 9:29 AM	Patient/advocate	11
@ash_hematology	The Tumor Microenvironment as a Key to MPN Pathogenesis: http://ow.ly/MxBbc via The Hematologist #mpnsm	Tue, May 5, 2015, 8:50 AM	Organization/society	9
@luriecancer	Promising treatment strategy for rare #leukemia discovered by @LurieCancer scientists http://news.feinberg.northwestern.edu/2015/11/promising-strategy-for-treating-rare-forms-of-leukemia-discovered/ @NatureMedicine #mpnsmTue, Nov 17, 2015, 7:42 AM			

Table 5 Top three most common retweets of #MPNSM (January 2016–January 2017)

User	Tweet	Date/time	User type	No. of RTs
@cure_magazine	We talked to @doctorpemm about the importance of open patient-physician conversations #mpnsm http://www.curetoday.com/articles/on-twitter-mpn-patients-and-physicians-connect-in-real-time https://t.co/ERKc796hBS	Tue, Jun 28, 2016, 11:28 AM	Organization, media	16
@jnccn	#NCCN Publishes New Clinical Practice Guidelines for Myeloproliferative Neoplasms: http://bit.ly/2cSlw59 #mpnsm	Tue, Sep 27, 2016, 5:35 AM	Medical journal	11
@malinhultcrantz	@doctorpemm doing a great job moderating the MPN session! #ASH16 #mpnsm https://t.co/iOYbvS8l1L	Mon, Dec 5, 2016, 3:16 PM	Academic physician	10

observed not only among physicians but also by many other healthcare stakeholders, especially in the rare cancer fields [2, 14, 18]. Many groups have found that Twitter, with its wealth of archived and rapidly retrievable information, allows for the ability for novel research questions to be asked via its publically available databases [7, 19, 20]. In our study, we aimed to better understand the metrics of Twitter use over time in #MPNSM, a Twitter medical community created in 2015 to bring together all of those parties interested in the MPNs.

In this collaborative analysis performed with Symplur.com and the @healthhashtags Project, we were able to observe a clear increase in use of the #MPNSM hashtag over time. We focused our analysis over two distinct 1-year time periods encompassing the first 2 years since the creation of the #MPNSM hashtag (2015–2016 and 2016–2017). One notable finding is the diversity of backgrounds of the users highlighted among the most common RT's. Each of the six most common RTs was generated by six distinct users, encompassing healthcare stakeholders from all over the MPN field, including a patient/patient advocate, a medical journal, a medical society, a university, an individual academic physician, and a media/organization (Tables 4 and 5). This encouraging trend suggests that over time, the #MPNSM community continues to feature a variety of voices from all parts of the field, not just those from key opinion leaders/academic physicians. Furthermore, it demonstrates the ongoing viability of a novel hashtag, in that users other than the four co-founders are featured in this portion of the analysis, suggesting a wide uptake of the hashtag to other members of the greater MPN community.

Another notable finding is in the peak usage for #MPNSM by date. Remarkably, eight out of the ten most commonly tweeted dates were during December over the two study periods. Upon review, these dates are not accidental—rather they exactly coincide with the ASH meetings held in each of those years. This highlights the observation in hematology/oncology that social media use, in particular Twitter, increases dramatically at the time of a major national/international medical conference [21] and that this trend has only increased in importance as a major source of meeting-derived information, debate, and discussion among Twitter users over time [20]. Therefore, our dataset suggests that tweets under the #MPNSM are in line with these observations, and that even in a rare cancer field, around the time of major developments, dates of major information release, and major medical gatherings, hundreds of tweets can be generated on a single day, resulting in rapid flow of information to many healthcare stakeholders at one time.

In terms of understanding the topics tweeted under #MPNSM, we analyzed all terms used and compared them over the two study periods (Table 2). Of note, both "patients" and "pts" appeared frequently in the top five terms in both study periods, highlighting the continued overall clinically relevant focus of the #MPNSM hashtag community over time. The only major difference in the top five terms used was in the latter study period, in which the term "media" (referring to "social media") was the fifth most used term and was not present in the top five from the previous study period. All 20 of the terms (top ten in each of the study periods) were highly pertinent words related to the MPN and #MPNSM field (in other words, no spam words/unnecessary terms noted). Only one of the 20 terms in the two study periods was the name of an individual Twitter user (Ruben Mesa, @mpdrc, who is a leading MPN investigator in the field, and one of the co-authors on this paper).

The continued low rate of spam tweets/spam users, as noted in our first analysis of #MPNSM, has been one of the key factors in the disease-specific hashtag project in general and for the successful use and continued uptake for users of the #MPNSM hashtag over time as it helps to separate the "signal from the noise" for the majority of Twitter users [13, 16, 20]. This may be a strong reason to use a specific hashtag such as #MPNSM instead of just MPN or other terms. Given the success of #MPNSM and other similar rare hematologic cancer hashtags, and in order to build more hashtags of use to the field in hematology, the Hematology Tag Ontology (HTO) was proposed. The HTO conceived by @mtmdphd, @subatomicdoc, and @audvin can be found at @symplurIntro (https://www.symplur.com/blog/introducing-

hematology-tag-ontology/ List: https://www.symplur.com/healthcare-hashtags/ontology/hematology/) [18].

With regards to academic research, Twitter has been thought of as a novel method to improve one's career development, raise awareness of one's research, and find other colleagues with similar interests in a given area [6, 22, 23]. Indeed, in line with these observations, the authors of this manuscript have observed that a major benefit of the creation of #MPNSM has been the rapid coordination of research collaborations and projects, enhanced professional networking among key opinion leaders with each other (including the authors of this paper) and with other stakeholders in the field, and the rapid dissemination of MPN-related information directly to patients and advocates from medical conferences in real-time.

In summary, over a 2-year study period, we found that there was a distinct increase in all of the major parameters of Twitter activity for #MPNSM, including the number of Twitter users, number of tweets, Twitter impressions, number of hyperlinks to additional information used, number of mentions, and number of retweets, suggesting the overall feasibility of creating and maintaining a Twitter medical community even for rare cancer fields.

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Authorship Contributions NP, AU, VG, JJK, RM, and MT collected and analyzed the data and wrote and approved the final manuscript prior to publication.

Compliance with Ethical Standards

Conflict of Interest Naveen Pemmaraju reports honorarium/consulting and/or research/Grant and clinical trial support: Novartis, LFB, Incyte, Stemline, Cellectis, Abbive, Affymetrix, Roche Diagnostics. Dr. Pemmaraju is a section editor for *Current Hematologic Malignancy Reports*.

Vikas Gupta received research grants from Novartis, Incyte, Gilead, and Promedior through his institution, served on scientific advisory board of Novartis, Incyte, and received honorarium from Novartis/Incyte.

Audun Utengen is a co-founder of Symplur.

Michael A. Thompson has been on Advisory Boards for AIM Specialty Health, BMS, Celgene, Doximity, Takeda, and Via Oncology. MT owns stock in Doximity. He is a peer reviewer for plasma cell dyscrasias for UpToDate and has royalty in UpToDate.

J. J. Kiladjian declares no potential conflicts of interest.

Ruben Mesa is Editor-in-Chief of *Current Hematologic Malignancy Reports*.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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