Original Paper

Patterns of HIV Cure and HIV Cure–Directed Research Discussions in an Online Community Over 14 Years: Global Social Listening Approach

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Abstract

Background: HIV cure research has advanced since the first reported cure case in 2008, but confirmed cure outcomes remain extremely rare. Community discussions on platforms such as Reddit's r/hivaids both reflect and shape perceptions of cure research, stigma, and willingness to participate in studies. Understanding this online dialogue is therefore critical for optimizing outreach, education, and information strategies.

Objective: The goal of our study was to determine whether social listening methods can characterize the scope, patterns, and content of online discourse about HIV cure and cure-directed research within a social media community.

Methods: We conducted a social listening analysis of more than 142,000 posts from 12,227 authors on r/hivaids (2011-2025). Using natural language processing, we characterized communication themes and engagement patterns and evaluated how discussion volume related to trends in the scientific publication landscape. User geography was inferred from self-disclosed information in posts and comments.

Results: Location analysis showed overrepresentation from North America, consistent with Reddit's largely US-based user population (approximately 49.6% of daily users), and limited participation from high-burden regions such as Africa and Asia. "Cure" was the most common term, whereas more specific research language (eg, "remission" or "functional cure") was rarely used. Cure-related discussion volume closely paralleled the appearance of new scientific reports rather than general news cycles. Thematic analysis identified "hope for a cure" as the dominant topic, with frequent positive and optimistic themes—particularly among non-US users. In contrast, US-based posts more often included limited content on research details and policy (eg, profitability and funding for HIV cure research, clinical trials, bone marrow transplantation, a vaccine, etc), while non-US posts also highlighted mental health challenges, optimism after diagnosis, and ongoing social issues such as stigma and discrimination. Only 16% (743/4644) of cure-related posts referenced cure-directed research directly. Engagement was highly concentrated among a small number of "nano-influencer" users.

Conclusions: Online HIV cure and HIV cure–directed research discussions on Reddit are largely optimistic, use relatively simple language, and show engagement peaks that align with new scientific data rather than general news cycles. These conversations also vary markedly by geography. Closing language gaps, strategically partnering with key community influencers, and extending outreach into high-burden regions should be priorities to maximize global impact.

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Keywords: HIV; cure research; social listening; natural language processing; internet; online community

Introduction

Since the first reported HIV cure case in 2008 (Timothy Ray Brown, the "Berlin patient") [1], HIV cure–directed research has steadily progressed, with approximately 10 adult and pediatric cure outcomes reported to date [2]. As scientific and pharmacologic approaches have evolved, the terminology used to describe HIV cure and cure-directed research has also changed, both in scientific literature and in lay media. Early terminology emphasized the distinction between "virologic" and "functional" cures, contrasting complete elimination of all the virus with durable control of viral replication in the absence of antiretroviral therapy (ART) [3]. More recent work has highlighted that some commonly used terms carry stigmatizing or negative connotations, including phrases such as "sterilizing cure" [4] and "eradication" [5]. Similarly, terms used to describe persistent ART-free control of HIV, such as "remission," "durable remission" (borrowed from oncology), or "functional cure," may be perceived as implying that the benefit is temporary or not a true alternative to lifelong ART [6]. Although expert groups have discouraged the use of stigmatizing language, it remains unclear to what extent media coverage and geographic context shape patterns of cure-related terminology.

With the support of dedicated research funding, numerous cure-directed strategies are being tested to reduce the size of the HIV latent reservoir and/or enhance immune-mediated control of viral replication in the absence of ART. Although a relatively small number of people living with HIV have been central to these efforts—through trial participation and multiple community engagement models [7], ongoing and future clinical and basic research face recruitment bottlenecks due to limited broader community participation. Prior successes using social media–based peer networks to support HIV prevention [8-12] suggest that similar approaches could strengthen education and outreach for HIV cure–directed studies. Understanding the timing and structure of HIV cure discussions on social media is therefore essential to designing accurate, equitable, and ethical information strategies.

Because of their ubiquity and relative user anonymity, social networks such as Reddit, Facebook, X (formerly known as Twitter), WeChat, and Instagram have become important sources of support for people living with HIV [13,14], particularly during the COVID-19 pandemic, by facilitating peer discussions and, in many cases, serving as primary sources of HIV-related information [15]. At the same time, these platforms are prone to misinformation, a problem that may be amplified by the use of AI-driven bots [16], with particularly harmful effects on geographically and economically diverse communities [17].

Reddit is a rapidly growing social media platform with an estimated 1.2 billion monthly active users (91.2 million daily users and more than 500 million accounts). The user base has nearly doubled between 2021 and 2024, making Reddit one of the most influential information sources worldwide [18,19]. The r/hivaids subreddit, created in 2011 as "a community dedicated to people living with HIV," now has more than 20,000 members and ranks in the top 5% of all subreddits by size [20]. It has shown steady growth, with pronounced increases between 2016 and 2022 [15], and is currently a common source of HIV-related information.

Despite this prominence and public accessibility, relatively few HIV-focused studies have analyzed Reddit content, and those that do have largely concentrated on preexposure prophylaxis [21-24], vaccine research awareness [25], or disease management during the COVID-19 pandemic [15].

The objective of this study was to characterize language and perceptions surrounding HIV cure and HIV cure–directed research and examine the recent evolution, structure, and content of HIV cure–related discussions on r/hivaids.

Methods

Overview and Study Design

We analyzed conversations from the r/hivaids subreddit as well as content from other health-related subreddits posted from January 2011 to April 2025. We used a proprietary natural language processing (NLP) engine (TREND Community) and open-source methodologies to analyze social media posts from public forums containing real patient conversations. Time stamps associated with posts allowed us to analyze data temporally, grouping them by quarter.

Data Sources

We analyzed publicly available data from the r/hivaids subreddit on Reddit. A total of 142,043 posts and comments from 12,227 authors published between January 2011 and April 2025 were included in the analysis. Supplementary data in 1009 additional health-related subreddits, including cure-related content posted by users reporting to be a person affected by HIV, were also included in the analysis, totaling 99,272 posts or comments by 2331 users.

Regarding scientific report output data, publications mentioning "HIV cure" were extracted using PubMed's search tools for the years 2011 to 2025. New media articles mentioning "HIV cure" (n=5951) were extracted using the search engine Articles+ (Penn Libraries, University of Pennsylvania) using the query terms "HIV cure" and "cure for HIV." Data on total National Institutes of Health funding related to HIV cure–directed research were obtained from the National Institutes of Health Office of AIDS Research [26].

Data Processing

We applied the following models for data processing. Clinical Span Recognition, Clinical Span Linking, and Assertion Status are components of the NLP engine described in the Overview and Study Design section; details for each are provided in Multimedia Appendix 1.

The Clinical Span Recognition model identifies and labels clinically relevant information within unstructured text. It can recognize various medical entities such as symptoms, diseases, drugs, etc. Clinical Span Linking is the process that follows Clinical Span Recognition. In Clinical Span Linking, extracted clinical terms are linked to standardized Unified Medical Language System concepts. This linkage allows us to connect words and phrases to various vocabularies used by research institutions, companies, and organizations. Assertion Status is a 2D model that classifies health conditions based on person assertion and status assertion. The Assertion Status model provides context and status of health conditions and distinguishes between general mentions of health conditions and real patient experiences. Topic modeling (BERTopic [27]) involves creating embeddings of texts, clustering those with similar semantic content, and assigning a meaningful label to each cluster. In this study, a topic model was run on the paragraphs containing a mention of a cure-related phrase, with topic granularity and other hyperparameters set as described in Multimedia Appendix 1. For Pattern Matching, regular expressions were used to identify mentions of cure terms. The patterns used are provided in Multimedia Appendix 2. Finally, in Geographic Analysis, mentions of locations were identified using spaCy's named entity recognition model [28]. Those mentions corresponding to the author's location were identified using pattern matching.

Statistical Analysis

We assessed correlations using the Kendall τ rank correlation coefficient. We performed user classification using k-means clustering analysis. All analyses were performed using JMP (version 18.2; Statistical Discovery LLC).

Ethical Considerations

We obtained exemption determination in accordance with Title 45 of the Code of Federal Regulations part 46.104(d)(4) from 2 independent institutional review boards: WCG and the Wistar Institute. Furthermore, we derived study data from Reddit, a publicly accessible source. As per Reddit policies, all posts and comments are anonymous, and authors' location can only be tracked if publicly disclosed in a post or comment body. IP addresses or any other personal identifiers were not tracked.

We chose to analyze the r/hivaids subreddit for a number of reasons. First, r/hivaids authors are anonymous, and no personal information (eg, HIV status, location, etc) is publicly available through the platform, with the exception of information that is publicly disclosed directly by the author with no expectation of privacy. Second, while r/hivaids is a moderated community, there are few limitations on the content that can be discussed or the format of the discussion [20], leading to spontaneous exchanges. In addition, moderator approval is not required to conduct research on this subreddit. Finally, we do not report direct quotes from the users, making it impossible to link our results to any specific author.

A complete ethics framework checklist for this work based on recent guidelines [29] and the literature [15,30,31] is provided in Multimedia Appendix 2.

Results

Author Characteristics

We analyzed a total of 142,043 documents (posts or comments) published in the r/hivaids subreddit between January 2011 and April 2025. This dataset included documents from 12,227 individual authors.

While specific demographics for the r/hivaids subreddit are not made available to the public, recent analyses have shown that Reddit users are relatively young (45% aged 18-29 years and 40% aged 30-49 years) and mostly male (59.8%). US-based users are ethnically diverse (21% White, 14% Black, 23% Hispanic, 36% Asian individuals). Finally, 46% of Reddit users have a college degree or higher.

To characterize authors based on their HIV status, we used the Clinical Span Recognition and Clinical Span Linking models to extract mentions of HIV and link them to a knowledge base (see also Multimedia Appendix 1), followed by the Assertion Status model to classify the person's relation to HIV status (eg, person affected by HIV [32] or person with no direct reference to being affected by HIV) for each mention. On the basis of this analysis, 19.1% (2331/12,227) of the authors were directly associated with HIV (ie, identified as people living with HIV [1804/2331, 77.4%], otherwise affected by HIV [324/2331, 13.9%], or both [200/2331, 8.6%]), contributing 59.2% (84,074/142,043) of the documents.

Geographical Representation

Over a quarter (599/2331, 25.7%) of HIV-associated authors disclosed their geographic location in their posts. Of these, most (389/559, 65%) were from North America, followed by Europe, Asia, South America, Africa, Oceania, and the Middle East, with 54 countries represented in the sample (Table 1). We observed a similar geographic distribution for authors not directly associated with HIV.

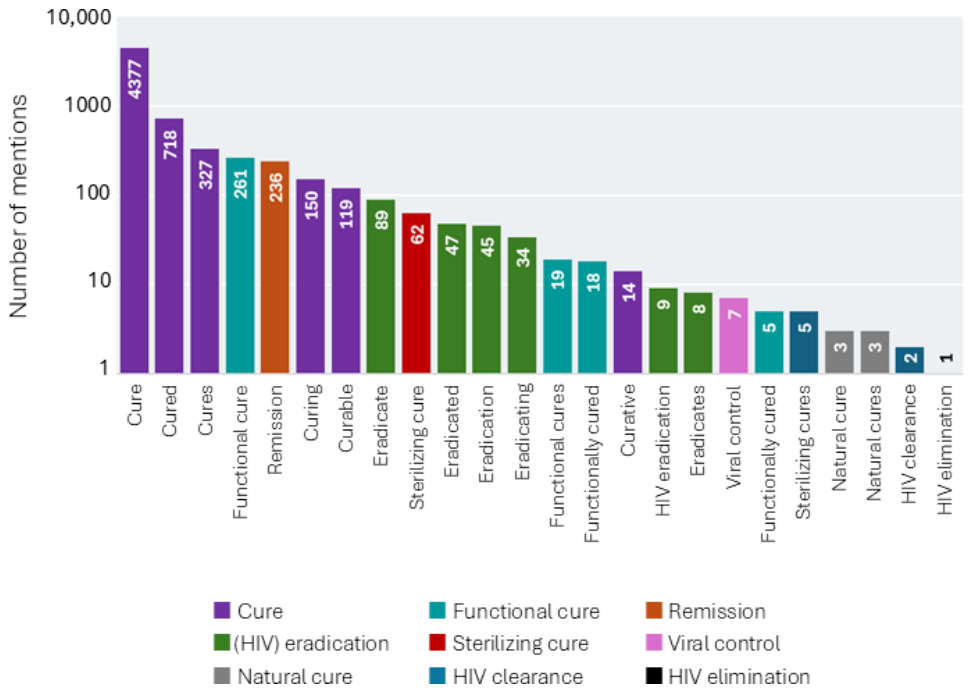
Table 1. Geographic location of r/hivaids subreddit users.

Location	HIV-associated authors, n (%)	Non–HIV-associated authors, n (%)
North America	389 (64.9)	216 (52.2)
Europe	97 (16.2)	84 (20.3)
Asia	59 (9.9)	54 (13)
South America	18 (3.0)	19 (4.5)
Africa	14 (2.3)	16 (3.9)
Oceania	12 (2)	13 (3.1)
Middle East	10 (1.7)	12 (2.9)

Prevalence and Structure of HIV Cure Conversations

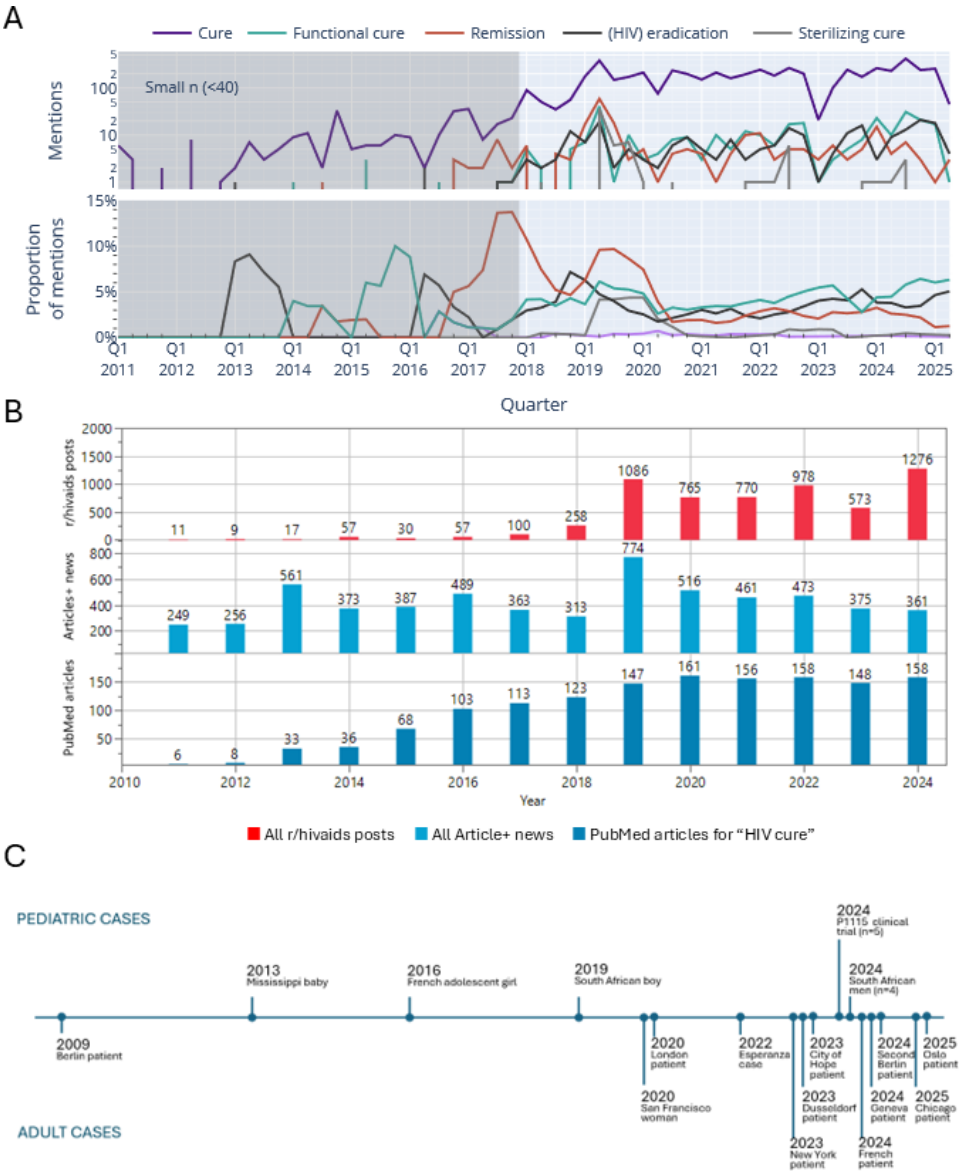
In total, 2.6% (3684/142,043) of the total documents, which were contributed by 9.5% (1158/12,227) of the authors, mentioned "HIV cure" as a single term or a related phrase (see the cure term list in Multimedia Appendix 1). As illustrated in Figure 1, the prevalent terms were "cure" (4377 mentions) and related variants ("cured" or "cures" with 5705 mentions collectively; see also Multimedia Appendix 3). Terms commonly used by HIV researchers, such as "functional cure," "remission," "eradication," and their variants, were much less commonly used, totaling slightly more than 750 mentions, indicating a possible disconnect between the language used in scientific research and the language used by the HIV community. The expression "sterilizing cure(s)," which has been used by investigators to indicate a complete elimination of HIV reservoirs, was mentioned 67 times. Finally, "natural cure" and derivatives were only mentioned 6 times collectively.

Figure 1. Use of cure-related vocabulary in r/hivaids discussions. Posts and comments published in the r/hivaids subreddit [20] between January 2011 and April 2025 were analyzed for mentions of HIV cure–related terms. The bars and numbers represent the number of HIV cure–related words or phrases detected. Root terms are color-coded, with variations of the word "cure" represented by purple bars; terms that are considered stigmatizing are represented by red bars. A complete list of words and phrases searched for is included in Multimedia Appendix 1.



To understand the evolution of cure-related conversation, we analyzed the mentions of specific cure-related terms over time between January 2011 and April 2025. As illustrated in Figure 2A, we observed an exponential increase in posts containing terms related to HIV cure ("cure," "functional cure," "remission," and "HIV eradication") over the observation window up to 2019, followed by a relatively stable number of mentions thereafter. Spikes in cure-related mentions were observed in quarter 2 of 2019 and quarter 3 of 2024. Of note, data from January through April 2023 were limited or not available due to changes in Reddit's data access policies. Proportionally, mentions of "eradication" peaked in quarter 2 of 2013, quarter 2 of 2016, and quarter 4 of 2018, always remaining under 10%. We observed a peak in the relative use of the term "functional cure" (3/30, 10%) in quarter 4 of 2015, and the use of "remission" peaked in quarters 3 and 4 of 2017 (14/102, 14%). Use of all these terms stabilized around 3% to 5% after quarter 2 of 2020. The use of "sterilizing cure" peaked in 2019 (50/1142, 4%) but decreased in the following years.

Figure 2. Use of cure-related terms over time. Occurrence of HIV cure–related terms in the r/hivaids subreddit compared to HIV cure–related scientific articles (PubMed), news reports (Articles+), and reports of individuals cured from HIV between 2011 and 2025. (A) Mentions of HIV cure–related words and phrases grouped by their root form in each quarter that occurred in r/hivaids or in documents by authors identifying as people affected by HIV in other health-related subreddits. Top panel: number of mentions. Bottom panel: relative proportion (percentage) of individual terms (excluding "Cure" for clarity). The dip in mentions observed between January and April 2023 corresponds to a lack of data due to changes in Reddit's data access policies. (B) Aggregated yearly occurrences of HIV cure–related terms in r/hivaids (top panel), news articles containing the terms "HIV cure" and "cure for HIV" (Article+; middle panel), and scientific articles containing the same terms (PubMed: bottom panel) between 2011 and 2024. (C) Timeline of scientific reporting of cases of people living with HIV who were cured of the disease (cure or durable remission).



To determine whether the volume of r/hivaids cure-related posts was temporally associated with or driven by research-related news reports, we estimated the number of English-language news articles mentioning HIV cure by submitting the query terms "HIV cure" and "cure for HIV" in the library platform Articles+. The total yearly number of news articles satisfying the query terms is shown in Figure 2B. Similarly, we extracted the number of scientific publications addressing HIV cure–related findings using PubMed's search tools [33] for the years 2011 to 2025 (Figure 2B). For temporal reference of clinical cure-related reports, a timeline of the reports of individuals who were cured of HIV or considered to have "durable remission" in the period studied is reported in Figure 2C. To assess the degree to which yearly r/hivaids cure-related posting was associated with the other metrics, we performed Kendall correlation tests (Table 2). The yearly number of news articles was not significantly associated with the yearly number of HIV cure mentions in r/hivaids (Kendall τ=0.2431; P=.23), whereas we detected a significant positive association between these mentions and the number of scientific reports indexed in PubMed (Kendall τ=0.7889; P<.001) in the same year, suggesting that subreddit discussions may track with, and potentially be influenced by, the volume of scientific publications rather than news coverage.

Table 2. Association among r/hivaids cure-related activity and news media and scientific articles and National Institutes of Health (NIH) HIV cure–targeted funding.

Variable 1	Variable 2	Kendall τ	*P* value
r/hivaids posts	PubMed articles	0.7889	<.001
NIH funding	PubMed articles	0.5746	.004
r/hivaids posts	NIH funding	0.5083	.01
PubMed articles	Articles+ news	0.2873	.15
r/hivaids posts	Articles+ news	0.2431	.23
NIH funding	Articles+ news	0.0769	.70

To understand the structure of HIV cure conversations, for each author who had initiated at least one conversation about HIV cure (n=845), we assessed the number of HIV cure–related threads started vs the number of comments posted in these threads by other users. A visual examination indicated the existence of distinct patterns of engagement, with evidence of a group of high-engagement individuals who initiated a large number of threads generating numerous comments. The existence of distinct posting patterns was further assessed using k-means clustering; r/hivaids users could be grouped in 4 or 5 clusters (optimal Cubic Clustering Criterion; JMP) with distinct posting patterns. The 5-cluster option provided the best isolation of high-engagement individuals (Figure 3), identifying 5 distinct posting patterns:

- Inactive: low posting and low engagement
- Engaged: moderate posting and engagement
- Popular: highest posting and engagement
- Influential: low to medium posting with high engagement
- Contributor: low to medium posting with low engagement

For each author who started at least one conversation thread about HIV cure (n=845), the number of threads initiated is shown (y-axis) against the total number of comments by other users in each thread (x-axis). Details about each cluster posting behavior are provided in Table 3. Given the exploratory nature of this study, we did not further validate the stability and separation of the clusters. Barring a few individuals whose threads received a large number of comments and could therefore be considered "nano-influencers" [34-37], most HIV cure–related conversations were fragmented, occurring between authors who initiated a very small number of threads and users who posted very few comments.

Figure 3. Structure of cure-related conversations. Assessment of the number of HIV cure–related threads started vs the number of comments posted in those threads by other users in the r/hivaids subreddit between 2011 and 2025. Colors represent k-means clusters indicating the following conversation engagement patterns: blue: cluster 1, "inactive"; red: cluster 2, "engaged"; green: cluster 3, "popular" (also known as "nano-influencer," having 1000-10,000 followers); purple: cluster 4, "influential,"; orange: cluster 5, "contributor." Dot size is proportional to the number of initiated conversation threads.

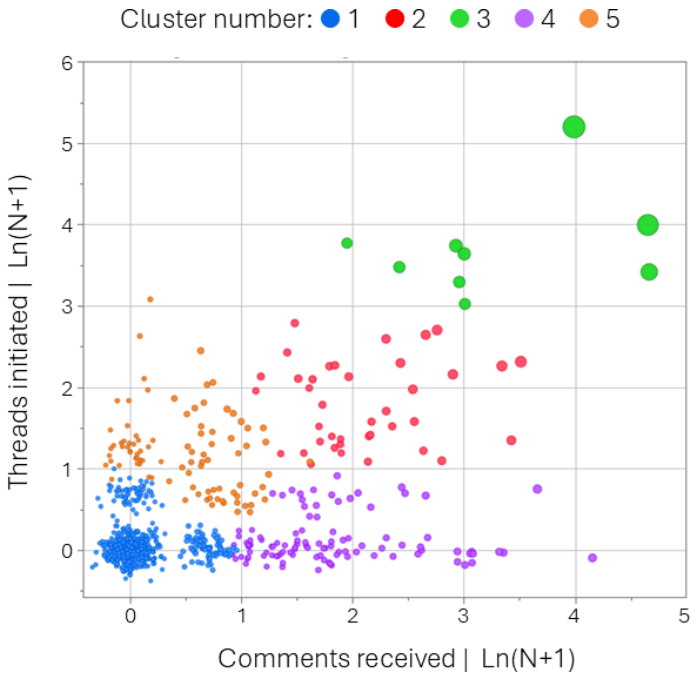


Table 3. Patterns of posting behavior.

Cluster	Authors, n	Definition	Posts (Ln N)			Comments in threads (Ln N+1)		
			Median (IQR)	Range	Mean (SD)	Median (IQR)	Range	Mean (SD)
1	600	Inactive	1 (1-1)	1-2	1.1 (0.3)	0 (0-0)	0-1	0.12 (0.3)
2	39	Engaged	5 (4-9)	3-14	6.5 (3.3)	7 (4-11)	2-33	9 (7.4)
3	9	Popular	37 (29-54)	19-187	53.5 (51.6)	20 (14-75.5)	6-132	42 (43.9)
4	104	Influential	1 (1-1)	1-2	1.2 (0.4)	4 (2.25-7)	2-51	6.8 (7.8)
5	93	Contributor	3 (2-4)	2-19	3.74 (2.4)	1 (0-1)	0-3	0.86 (0.9)

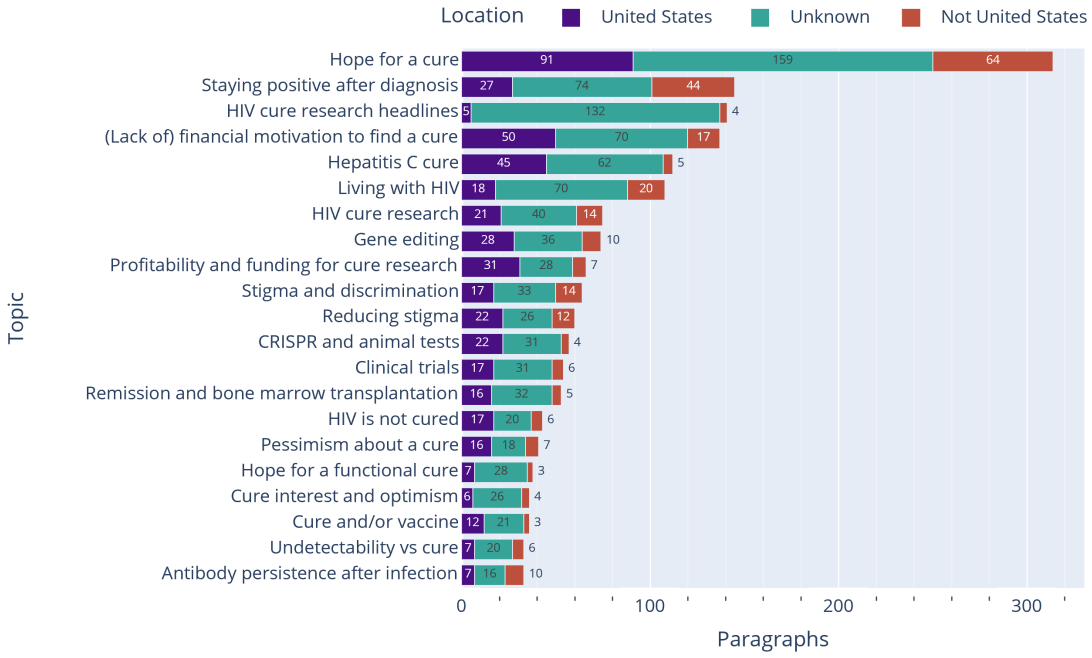
Topics of HIV Cure–Related Conversations

To understand the context of HIV cure–related conversations, we used BERTopic to identify the most common topics in the 4644 paragraphs from r/hivaids that mentioned HIV cure. Results of this assessment are summarized in Figure 4. The theme of hope or hoping for a cure was expressed more than twice as frequently as any other cure topic, with 314 paragraphs. Ranking second to fourth, with similar frequencies, were the topics of "staying positive after an HIV diagnosis," the discussion of HIV cure research headlines, and the discussion of the lack of financial motivation from industry partners (eg, pharmaceutical companies) to find a cure, respectively.

Overall, topics associated with HIV cure–related research, including themes such as HIV cure research headlines, HIV cure research, gene editing, clustered regularly interspaced short palindromic repeats (CRISPR) and animal tests, etc, were cumulatively represented in 1198 paragraphs.

The analysis showed that conversations in the r/hivaids subreddit more often expressed positive perspectives, including hope for a cure, maintaining a positive outlook after diagnosis, optimism about a functional cure, and interest in cure research (533 paragraphs). In contrast, fewer paragraphs reflected negative perspectives, such as concerns about the lack of financial incentives to develop a cure, experiences or concerns related to stigma and discrimination, and pessimism about the prospects of a cure (242 paragraphs). Importantly, only 16% (743/4644) of cure-related posts specifically referred to HIV cure–related research, as determined by the inclusion of a word such as "research," "study," or "trial," suggesting that, although cure-related conversations appeared to track closely with the volume of scientific publications, they did not seem to include substantial discussion of the underlying research or where most HIV cure work is actually taking place. Posts from individuals reporting a US or North American location were more likely to discuss themes specifically linked to HIV cure–related research (eg, profitability and funding for HIV cure research, CRISPR and animal tests, clinical trials, remission and bone marrow transplantation, cure and a vaccine, etc) compared to posts from individuals associated with non-US locations, which focused mostly on mental health (eg, staying positive after diagnosis) or social issues (eg, stigma and discrimination).

Figure 4. Discursive themes of cure-related conversations. The topics of cure-related posts on the r/hivaids subreddit between 2011 and 2025 were extracted using the BERTopic modeling technique. Bars represent the total number of paragraphs related to each listed theme by users disclosing a US location (purple), non-US location (ochre), or undisclosed location (green). CRISPR: clustered regularly interspaced short palindromic repeats.



Discussion

Principal Findings

Several recent studies have applied computational and NLP methods to characterize HIV-related discourse on social media platforms. Zhan et al [38] analyzed nearly 192,000 HIV-related X posts using machine learning and topic modeling to characterize the evolution of public discourse over time. Using the Reddit platform, Abouelmagd et al [39] explored HIV discussion in Middle Eastern and North African communities examining topic prevalence and emotional tone, while Godinez et al [22] analyzed conversations centered on the topic of preexposure prophylaxis regimens.

A separate body of qualitative work has examined how people living with HIV and affected communities in South Africa and China perceive and conceptualize a cure [40-43].

While a body of literature assessing stakeholder perspectives and willingness to engage in HIV cure research exists (reviewed in the study by Noorman et al [44]), to our knowledge, ours is the first systematic specific analysis of HIV cure–related language, topics, and engagement patterns in a social media community using NLP-based social listening methods.

Our results indicate that an increasing number of members of the r/HIV subreddit community engage in HIV cure and cure-related research discussions. Engagement increased over time from 2011 to 2025. The number of posts was positively associated with the number of scientific HIV cure–related publications (PubMed index) but not with the number of similarly focused news articles, suggesting that the discussion may not be driven by news reports but rather by other sources of information (eg, scientific reports in specialized media, etc). This reflects prior work by Rabin et al [45], who used a mixed methods approach to analyze social media perception of a prospective HIV vaccine, finding that public sentiment tracked scientific and clinical trial milestones. While reports of individual cases of HIV cure outcomes or ART-free durable control have grown over time since the first report in 2009 (Timothy Ray Brown, or the "Berlin patient") [1], we did not observe a direct association between the number of posts per quarter and the publication of individual cases of cured individuals in the corresponding periods. Our study cannot directly address the reasons for this association; however, we speculate that the r/hivaids discussion may be driven by individuals (eg, people living with HIV, HIV health activists, HIV care providers, etc) who follow scientific literature either directly (eg, via PubMed alerts) or through specialized sites such as Aidsmap [46], POZ [47], or Treatment Action Group [48]. Further research is needed to confirm this hypothesis.

Altogether, our study indicates the presence of Reddit HIV discussion of a cure for HIV and provides evidence that this discussion is associated with scientific progress (ie, number of scientific publications) in the field.

The social media engagement observed was mostly reflected in messages of hope and positivity, yet distrust in the motivations of the HIV research establishment and industry was also present, confirming prior sociobehavioral findings [49], and should be addressed. The economic aspects of HIV cure–directed research were also discussed, both positively (profitability and funding) and negatively (lack of financial motivation to find a cure), without a predominant view emerging. Importantly, r/hivaids users consistently expressed hope for an "HIV cure" but with substantially less attention devoted to discussing the underlying scientific research that could make a cure possible or the funding mechanisms and political commitment required to sustain such work. Although interest in specific cure-directed research areas such as gene editing was noted, the lack of sustained discussion on any one research-directed activity suggests a gap in grasping the impact or limitations of the underlying research. Consequently, given both this imbalance in discourse and the incremental, long-term nature of cure research, public expectations regarding the achievability of an HIV cure may be unrealistically high and warrant careful management, supporting a need to better communicate and manage expectations in the community. These nuanced aspects of the HIV cure and HIV cure–directed research conversations may be relevant to designing social media–based messages.

The terms used in the discussion are mostly associated with the root term "cure," with other related terms such as "remission," "eradication," "elimination," and "viral control" coming far behind. Specifically, terms such as "cure research" and modifiers such as "functional cure," which are commonly used by HIV researchers, were used in a small proportion of posts, supporting prior observations that these terms might not be well understood or accepted in the community [6] and suggesting that messages aimed at online communities may benefit from simpler language (ie, "sustained control" and "complete cure"). The modifier "sterilizing cure," which has been considered stigmatizing [4], was used in up to 10% of the posts in the period between 2019 and 2020, but its use declined in more recent times, possibly due to efforts to use more patient-centered and nonstigmatizing language in HIV cure–related research [4]. However, other terms less favored by the community, such as eradication, continue to be used. Overall, our results suggest that the social media conversation around HIV cure–related topics focused more on holistic or unifying terms, referring to the recovery or relief from a disease, rather than on specific treatments or research.

Studying the r/hivaids community, we uncovered different posting patterns: while many authors had relatively low engagement (initiated a low number of threads that received a low number of comments), some users appeared to have greater engagement, initiating more threads and receiving quite a large number of comments. This suggests that a small number of community members (ie, HIV cure "nano-influencers") may be able to distribute messages and engage their audience to participate in larger debates. This observation suggests that reaching authors of this type with specific information may promote rapid and effective diffusion in the network. Our findings provide the basis to design future interventions (eg, engagement in cure-related clinical

trials, novel discoveries, or counteracting misinformation with accurate scientific facts).

Altogether, our findings provide a new insight on the mechanisms through which HIV cure–related information is spread in a social media network. If confirmed in future studies on a more representative set of social networks, this could provide the basis for the design of interventions (eg, leveraging nano-influencers, simplifying cure-related language, etc) aimed at optimizing the distribution of information in specialized networks.

Limitations

Our study has some limitations linked to specific characteristics of the chosen data source. First, the analysis between January 2011 and April 2025 lacked data from the first quarter of 2023 due to changes in Reddit's data access policies. Second, our analysis did not include direct demographic or geographic information. While general demographic data for Reddit users are available (see the Author Characteristics subsection in the Results section) indicating a prevalence of young male individuals, r/hivaids does not collect or release demographic information; therefore, potential age- and gender-related differences in communication patterns should be investigated in future direct engagement studies where additional information could be collected from consenting users.

Regarding geographical information, Reddit does not collect location data associated with individual posts or authors. While it has been reported that 49.6% of daily Reddit users are US based, with large representation from India, the United Kingdom, Canada, Brazil, and Germany [18,19], we analyzed location information only from those users who disclosed their location in their posts. On the basis of this information, we observed an overrepresentation of North America, with low representation of regions highly affected by HIV, such as Africa, South America, and Asia, even though Brazil and India are known to have a relatively large number of Reddit users [50]. This lack of representation may stem from differences in social media use patterns, community acceptance of public health discussions, and access. In addition, users in underrepresented areas may be less likely to engage in HIV-related discussions or less likely to disclose their location due to stigma or fear of disclosure. It is difficult to generalize our observations worldwide, but we believe that they are representative of this segment.

Finally, topic labeling relied on the final qualitative judgment of a single researcher, introducing potential subjective bias into thematic interpretation. To minimize arbitrary naming, we implemented a semiautomated workflow (see Multimedia Appendix 1 for details). Future research should engage independent secondary researchers to participate in a consensus-coding process during the qualitative labeling stage.

Conclusions

To our knowledge, this is the first quantitative assessment of the themes and structure of HIV cure–related conversation on a social media platform. Our findings, particularly those identifying "conversation leaders," may help design future studies aimed at disseminating knowledge related to cure-oriented studies in affected communities, which may increase equitable participation. Due to the limitations associated with the use of a single, North American–centered platform, further studies on additional social networks, particularly outside the United States, are warranted.

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Generative AI Use

The authors declare the use of generative AI (GenAI) in the research and writing process. According to the Generative AI Delegation Taxonomy (2026), the following tasks were delegated to GenAI tools under full human supervision: literature search and systematization, proofreading and editing, and reformatting. The GenAI tool used was Claude Sonnet 5 (Anthropic). Responsibility for the final manuscript lies entirely with the authors. GenAI tools are not listed as authors and do not bear responsibility for the final outcomes.

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Data Availability

This study analyzed publicly available content from Reddit. The proprietary natural language processing models used in this analysis were developed by and are property of TREND Community, LLC. Aggregate analytical outputs may be made available on reasonable request to the corresponding author.

Authors' Contributions

Conceptualization: LA, ZC, CDF, MP, KD, LJM
Data curation: LA, ZC
Formal analysis: LA, ZC
Funding acquisition: LJM

Investigation: LA, ZC, AC, LD, CDF, MP
Methodology: LA, ZC, CDF, MP
Project administration: AC, LD, CDF, PM, LJM
Resources: LA, ZC, CGF, MP, LJM
Software: ZC, CDF, MP
Supervision: LA, CDF, PM, LJM
Validation: LA, RJ, KD, LJM
Visualization: LA, ZC, LJM
Writing—original draft: LA, ZC, CDF, MP, KD, LJM
Writing—review and editing: LA, ZC, CDF, MP, KD, LJM

Conflicts of Interest

ZC, CDF, MP, AC, and LD are employees of TREND Community, LLC. KD provides consultancy services to Gilead Sciences and receives grant funding from Merck & Co not related to this project. All other authors declare no other conflicts of interest.

Multimedia Appendix 1

Supplementary methods.
[DOCX File (Microsoft Word File), 74 KB-Multimedia Appendix 1]

Multimedia Appendix 2

Ethics framework.
[DOCX File (Microsoft Word File), 129 KB-Multimedia Appendix 2]

Multimedia Appendix 3

Counts of mentions of each root cure-related word or phrase that occurred in r/hivaids or in documents by authors associated with HIV in other health-related subreddits. These root phrases are color-coded by whether they are considered stigmatizing.
[DOCX File (Microsoft Word File), 129 KB-Multimedia Appendix 3]

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Abbreviations

ART: antiretroviral therapy
CRISPR: clustered regularly interspaced short palindromic repeats
NLP: natural language processing

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