Stigma, the Media, and Pre-exposure Prophylaxis for HIV Prevention: Observations for Enhancing Knowledge Translation and Resisting Stigma in the Canadian Context

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Abstract

Pre-Exposure Prophylaxis (PrEP) is an effective, though sometimes stigmatized, strategy for HIV prevention. With the goal of examining how PrEP stigma can be addressed, this study examined the media's handling of stigma related to PrEP by searching the Canadian Newsstream and Daily Xtra news databases for key terms related to PrEP. Overall, 101 media articles were thematically coded in triplicate; 36.3% of which included mentions of PrEP stigma. LGBT media sources were more likely than mainstream sources to have included content coded as relating to PrEP stigma ($p = 0.02$). In these articles, uncertainty regarding PrEP, and neo-liberal attitudes towards sexual responsibility were major factors associated with media discussion of PrEP stigma. We discuss the role that heuristics play in shaping lay readers perceptions and interpretation of PrEP media coverage and discuss methods for overcoming stigma using evidence-based communication strategies.

Introduction

Pre-exposure prophylaxis (PrEP) with Tenofovir and Emtricitabine is an effective HIV prevention strategy [1,2,3,4,5] supported by a number of clinical trials which together demonstrate a strong dose–response relationship between PrEP adherence and reduction in HIV transmission [6,7,8]. At a population-level, network models suggest that PrEP can reduce HIV incidence even in the face of rising risk compensation and declining condom use [9, 10]. However, access to PrEP is largely dependent on prescription drug coverage; while some Canadian provinces have added PrEP to provincial drug coverage plans, in most settings PrEP remains uncovered by either provincial or private drug insurers [11, 12].

Among several potential barriers to expanding PrEP access, stigma toward PrEP use has been regularly reported [13,14,15]. Conceptually, stigma can be described as a form of social control in which particular attitudes, behaviors, or characteristics are devalued, treated with contempt by others, or used as a form of social distinction. Theoretical discussions of stigma distinguish between felt stigma (i.e., perceived or anticipated stigma), enacted stigma (i.e., expressed discrimination), and internalized stigma (i.e., incorporation of stigma into one's own beliefs about oneself) [16]. When these stigmas are pervasive in a society and begin to shape social policy, negative social control can also be described as "structural stigma." In any case, stigma gives rise to normal and non-normal patterns of behavior or identity-formation [17], and, in turn, these patterns have the potential to negate the effectiveness of otherwise promising prevention strategies such as PrEP [18, 19]. Each of these delineations highlight the ways that stigma can be manifest to the detriment of stigmatized populations, even when actual experiences of enacted stigma are rare. With respect to PrEP, the pervasiveness of social stigma has hindered the expansion of PrEP coverage by supporting evidence-neutral health policies (i.e., enacted and structural stigma) and by discouraging the widespread uptake of PrEP (i.e., internalized and felt stigma) [13].

Articulating the processes by which stigma is perpetuated, multiple related theories of stigma and risk perception highlight the role of the media (both the news media and social media) in initiating, perpetuating, and maintaining social stigma [20, 21]. These media-conscious approaches highlight how even minor risks have the potential to become embroiled in long-standing ideological controversies [22, 23] and play a role in communicating stigma within and between social networks and communities [24]. More broadly, the media has been shown to bear significant influence over what their audience is aware of, what their opinions are, and how they behave [25]. For example, successful mass media campaigns have resulted in changes to smoking behavior in jurisdictions across North America [26]. Other examples of the media's impact on health have been previously described with respect to its role in shaping the public's perceptions of HIV [27], mental illness [28, 29], vaccines [30], genetically modified foods [31], and climate change [32, 33]. Indeed, in each of these cases, the media has contributed to significant confusion, misunderstanding, and stigmatization even in the face of near-scientific consensus on these issues [34,35,36]. Furthermore, the media is understood to exert considerable political and ideological control by framing issues and setting policy agendas [37]—thus underscoring its importance to promoting new policy-based interventions, such as those regarding PrEP.

Ironically, the media also plays an important role in shaping social discourse about not only scientific innovations themselves but also the stigma surrounding these innovations. This is particularly important when considering the media's role in perpetuating felt and internalized stigma such as with respect to PrEP. Indeed, regarding HIV-stigma, research from as early as the 1990s shows that individuals are prone to overestimate the degree to which HIV is stigmatized [38]. Considering this, we hypothesize that media portrayals of stigma may have the unintended effect of reinforcing felt and internalized stigma. Therefore, we sought to identify news articles related to PrEP, with a focus in the present article on PrEP stigma.

Methods

Data Collection

To systematically sample Canadian media coverage of PrEP, two national news databases—Canadian Newsstream and Daily Xtra—were searched in January 2017 for key terms related to PrEP (i.e., PrEP, Pre-exposure prophylaxsis, Truvada, Tenofovir disoproxil, HIV medication, HIV drug, HIV treatment). Articles included in our search were published between 2008 and 2016, as this sampling frame was inclusive of the earliest mentions of PrEP in the media until the time the study was conducted. The selected sources were chosen to capture a systematic subset of both mainstream and gay news across Canada. From the keyword search, a total of 3020 search results were reviewed by three trained reviewers with the aim of identifying PrEP-related news articles. Most articles identified by our search strategy were not related to PrEP.

Thematic Coding

Aiming to identify themes covered in relevant articles, analyses were conducted using an inductive thematic approach (ITA) [39] wherein a code-book was collaboratively generated and validated against an iterative review of articles by paired coders. Inductive thematic analysis was selected as we expected that new coverage would cover a variety of themes not related to any

specific pre-established theory. As such, ITA is similar to so-called "grounded theory approaches" with the exception that the latter is applied in the context of theory development, while the present study was pre-occupied with identifying what role, if any, the media plays in originating, facilitating, and perpetuating stigma towards PrEP use. Consistent with ITA protocol [40], codes and coding practices were refined until consensus was reached between all three coders using a test-sample of ten articles. When finalized, the code-book contained nine codified themes focusing on PrEP portrayal, regulation, efficacy, awareness, side effects, accessibility, adherence, gender issues, and stigma. Final coding for each article was jointly reviewed and adjudicated to ensure consistency with the codified definitions for each theme. In the second stage of theme development, we reviewed articles with coded material (i.e., expressions) related to stigma. A subset of inductively defined themes was then developed examining (i) sources of stigma (e.g., friends and partners), (ii) the underlying rationale for stigma (e.g., personal responsibility), and (iii) rhetorical strategies to react to PrEP stigma (e.g., appeal to authority or data).

Quantitative Analysis

All quantitative analyses were conducted in R [41]. Descriptive statistics were stratified by the type of media (i.e., LGBT or mainstream) the article was published in, and linear and exponential regression models examined trends in frequency of themes over time. Regression coefficients were compared to assess differences in trends between LGBT and mainstream media sources [42]; and Student's t-tests were used to examine whether some themes were more likely in LGBT media than in mainstream media. Linear regression models tested whether the relative proportion of articles addressing each theme changed over time. Phi correlation coefficients were calculated to examine the intercorrelations between the coded themes.

Results

Descriptive Results

Out of an initial 3020 search results, a total of 101 media articles were coded. Descriptive statistics detailing the number and proportion of articles that had each theme are provided in Table 1 along with bivariate comparisons between LGBT and mainstream media sources. Most articles provided a description of PrEP (78.2%) and discussed regulatory implications (53.5%). Other important topics included efficacy (48.5%), accessibility (46.5%), and stigma (35.6%). Meanwhile, a relatively low proportion of articles discussed awareness (20.8%), side effects (25.7%), and adherence (28.7%). LGBT media articles were more likely than mainstream media articles to have included content coded as relating to awareness ($p < 0.01$), accessibility ($p = 0.02$), and stigma ($p = 0.02$). There were no other statistically significant differences between LGBT and mainstream media.

Table 1 Proportion of articles with each code

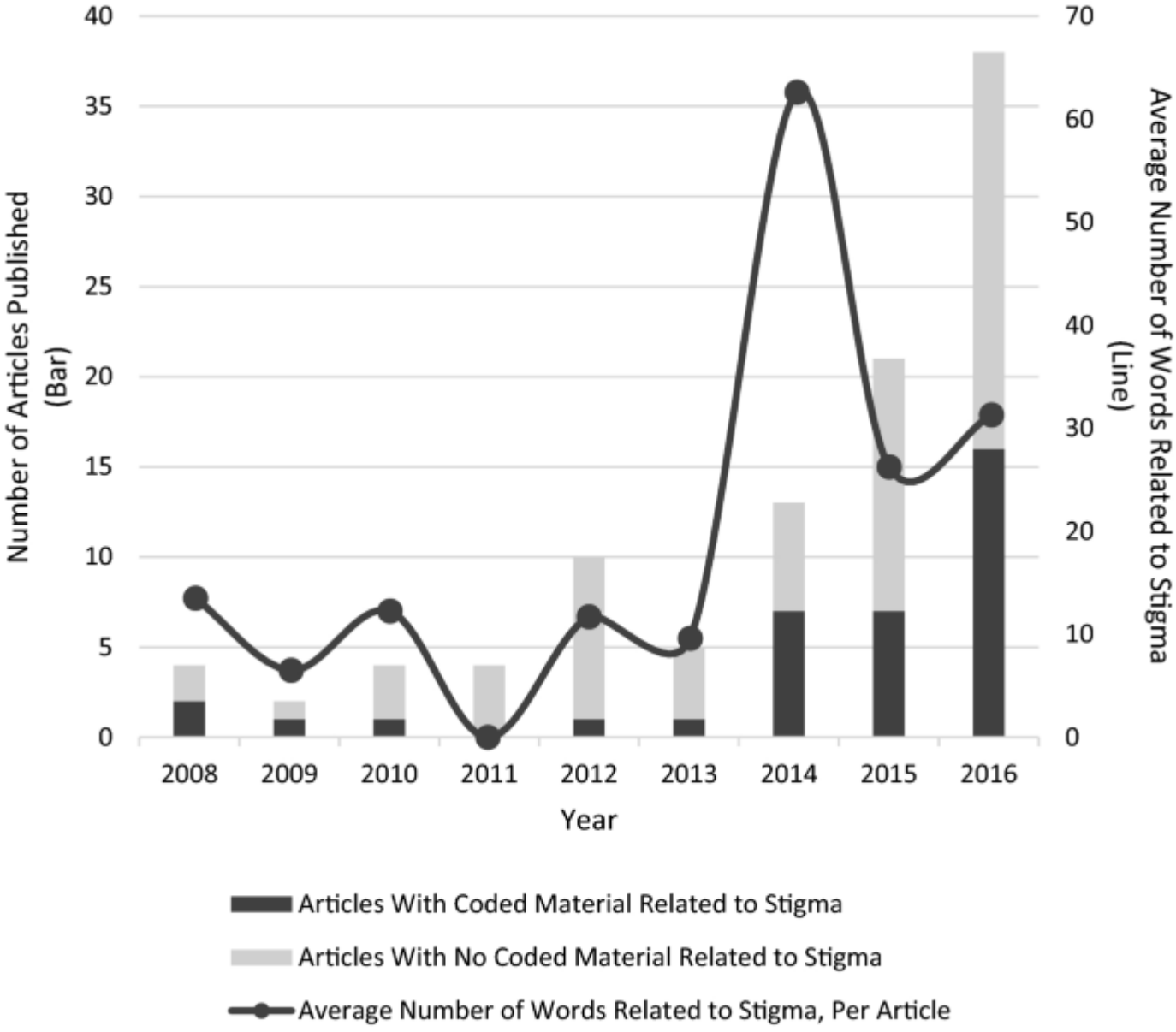
Inter-correlations between themes, stratified by media source, are provided in Table 2. Within LGBT media sources, themes for accessibility and regulation were correlated ($p < 0.01$), as were themes for adherence and side-effects ($p < 0.01$), and accessibility and awareness ($p = 0.01$). Within mainstream media articles, the description and awareness themes ($p = 0.03$), regulations and accessibility themes ($p = 0.03$), and side effects and stigma themes ($p = 0.04$) were correlated.

Table 2 Intercorrelation between codes for mainstream (top) and LGBT media (bottom)

Full size table

Figure 1 shows the number of stigma-related articles across time, the share of these articles that included stigma coding, and the average word count dedicated to stigma-related themes across time. Summarizing these findings, we note that stigma has increasingly become a dominant topic in PrEP journalism and that the average number of words addressing PrEP stigma significantly increased in the wake of early media activism by PrEP skeptics [43]. Notably in 2014, there was a dramatic increase in the average word count related to stigma themes potentially coinciding with the endorsement of PrEP by the US Centers for Disease Control and Prevention [44].

Fig. 1

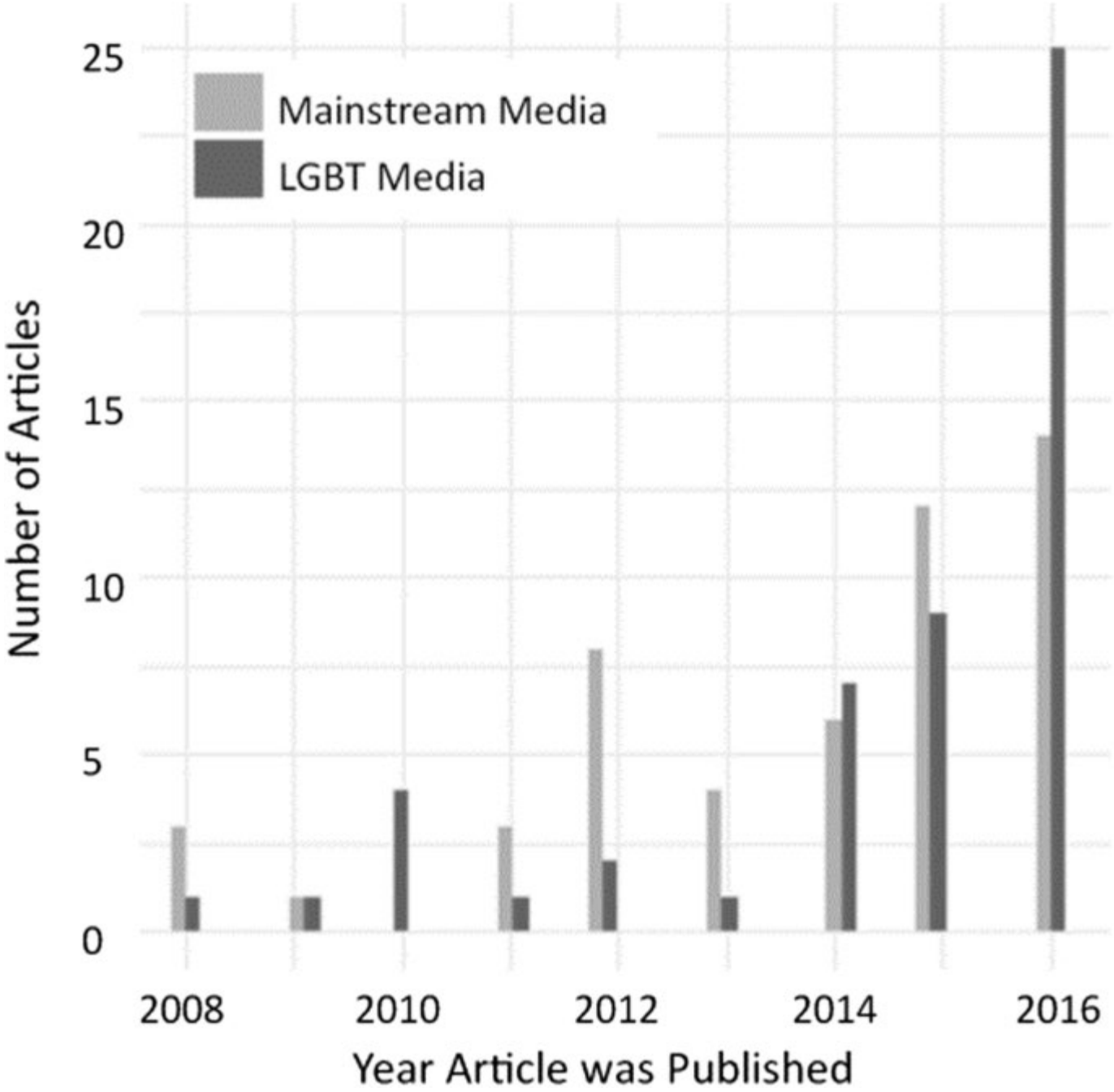


Prevalence of stigma coding over time

Full size image

Figure 2 shows the number of LGBT and mainstream media articles published each year. Overall, there was an exponential increase in the number of articles published over time ($p < 0.001$). However, comparing LGBT and mainstream media sources, there was no difference in trends ($p = 0.78$).

Fig. 2

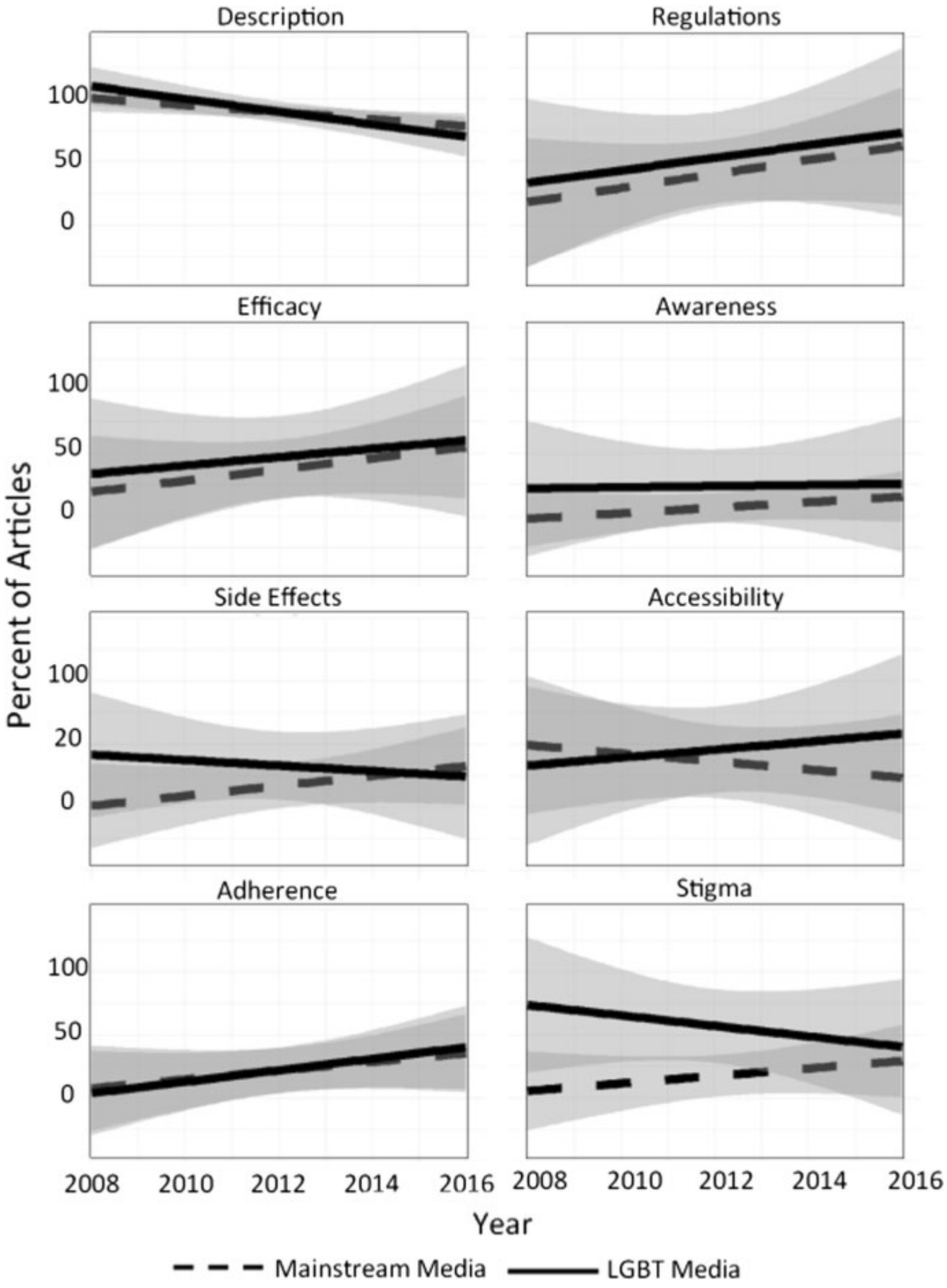


Number of PrEP articles published each year, by media source

Full size image

Figure 3 shows the proportion of articles coded with each theme, by year, for LGBT and mainstream media. Overall, the relative proportion of articles addressing each theme was stable. Indeed, only the description theme decreased in frequency over time ($p = 0.012$).

Fig. 3


Description
Regulations
Efficacy
Awareness
Side Effects
Accessibility
Adherence
Stigma
Percent of Articles
100
50
0
20
2008
2010
2012
2014
2016
Year
Mainstream Media
LGBT Media

Proportion of articles published each year, by code

Full size image

Thematic Focus: PrEP Stigma

Sources of PrEP Stigma

Overall, stigma was primarily discussed in generic terms (n = 6), though specific sources of stigma included health care providers (n = 4), friends and partners (n = 4), and the media itself (n = 1). For instance, health care providers were characterized as being "disappointed" in their patients who had "given up on condoms," opting for PrEP instead [45,46,47]. Regarding PrEP access, one advocate commented that

"the process of getting a prescription for Truvada as PrEP can seem stigmatizing because it's only made available to men who identify themselves as people who don't use condoms systematically and have more than one sexual partner." [45]

Outside the medical establishment, people using PrEP were also characterized as facing stigma from their friends and sexual partners [45, 48,49,50]. For instance, one gay man was quoted as saying that his friends called him a "sex addict" and "a whore" when they found out he was taking PrEP [45] and another PrEP advocate stated that he believed "negative media coverage of the drug" contributed to low PrEP uptake [51]. Providing evidence for PrEP stigma, four articles made note of the term "Truvada whore" which was initially used to critique PrEP, but quickly became a badge of honor: "#TruvadaWhore" [46, 52,53,54]. Six articles also cited instances of PrEP being referred to as a "party drug" [44, 55,56,57,58,59,60]—a reference to mixing Truvada with traditional sex drugs—"a combo known as 'MTV'" [61].

Writers also represented PrEP skepticism as being primarily concerned with worries that PrEP would encourage "risky and irresponsible behaviour" such as condomless anal sex [56]. Indeed, 26 of the studies related to PrEP stigma referenced, either directly (n = 4) or indirectly, the phenomenon of risk compensation. Of primary concern was the impact that PrEP would have on condom abandonment (n = 22) and promiscuity (n = 7). In a context with an overwhelming focus on behavior, only 5 articles linked stigma specifically to worries that PrEP would contribute to increased HIV or STI infections. Other PrEP skeptics went so far as to say that "Truvada is for cowards"—emphasizing a priori judgments about the moral character of people on PrEP [54]. Indeed, questions like "Why can't people behave themselves?" [emphasis added; 47], provide an example of the implicit and explicit assumptions made about promiscuity and behaviors which prioritize personal pleasure.

Impact of PrEP Stigma

The most commonly reported impact of PrEP stigma was its role as a barrier to PrEP uptake. This was despite a common acknowledgement that PrEP stigma was an implicit sub-category of HIV-stigma or sex-negativity. Illuminating the negative impact of stigma, one health care provider questioned why he would prescribe PrEP when his patients already have "highly effective tools" available to them [58]. Another man on PrEP noted that stigma not only meant his partners were more willing to engage in condomless sex, but that sometimes there was an

"expectation" for it—leading to "some awkward situations" [49]. Finally, PrEP was also framed as divisive in the gay community, forcing individuals to choose "for PrEP or against," as one advocate put it [48].

Responses to PrEP Stigma

Seeking to address PrEP stigma, writers and PrEP advocates alike sought to undermine PrEP skepticism through the media [62]. For instance, one PrEP skeptic was quoted as saying that he felt PrEP was "irresponsible" but could not explain why beyond "it's just what he feels" [63]. This framing of PrEP skepticism as naïve or values-driven was widespread. For example, one PrEP advocate was quoted as likening the battle for PrEP to the battle for birth control: "There was a value judgement attached," he concluded [64]. PrEP advocates, on the other hand, were often depicted as separating "feelings from the actual facts" and were poised to call out "false arguments" against PrEP [50, 65]. For instance, in the following excerpt a writer backs up a PrEP advocate's urging for evidence-based PrEP policy:

"'It is critical that PrEP access be governed by science and not by personal values,' Calabrese rightfully claims. This is particularly true when the goal should be to end the epidemic." [Emphasis added, 30].

However, despite an overwhelming majority of the included articles being supportive of PrEP and despite the general acknowledgement that "we cannot be judgmental [about PrEP] " [66], many of the arguments supporting PrEP skepticism were left unanswered or were even subtly reinforced. For instance, one writer commented,

"Most of the Canadians I spoke to for this story—on and off the record, inside and outside the AIDS establishment—are to some degree hesitant" [67].

More specifically, when writers represented the positions of academics and clinical professionals, experts were often portrayed as cautious regarding the potential impact, limitations, and side-effects of PrEP. This was particularly true when considering the role that PrEP might play in risk compensation. For instance, health care providers were said to be concerned that prescribing PrEP would contribute to "unsafe sex" or that it would give "patients a false sense of confidence" [47]. Further, writers and experts alike sought to provide fair and balanced coverage, often leading them to rebut their own rebuttals to PrEP skepticism. For instance, in the following example a writer notes that one group of researchers did not find evidence for risk compensation, but in the next sentence they use a direct quotation from these researchers to undermine their own argument:

"Goicochea says some critics have expressed concern that people taking the drug will have sex more often and freely and engage in unsafe sex leading to higher instances of other sexually transmitted infections. But, he says, condom use actually increased during the study. 'But of course, this is under the conditions of the clinical trial with monthly visits. So participants were consulted and given condom supplies on a monthly basis,' he says" [68].

However, there were also several examples where writers did make use of forceful quotations, such as the one below, in an attempt to resolve ambiguity and doubt:

“You can worry all you want, but once the evidence is in, you cannot deny it. This is based on science, and the science says that Truvada taken as prophylaxis is effective, it’s safe, and complications are extremely rare” [47].

Discussion

Primary Findings

In the present study, we reviewed a systematically sampled subset of news media articles related to stigma throughout the early emergence of PrEP in Canada and inductively developed three themes which identified sources of stigma, the underlying rationale for stigma, and the rhetorical strategies imbedded within the media’s portrayal of stigma. In doing so, we note that our findings are easily contextualized within a growing body of literature that highlights the media’s role in shaping not only their audience’s awareness and knowledge of given health topics, but also their attitudes towards the subject matter covered [69,70,71]. Within this literature, it has become apparent that the media has, at times, become, even if unwittingly, instrumental to the spread of stigma and prejudice [72]. Examples of this include the media’s role in the development of stigma towards mental illness [29], body weight [73], sexuality [74, 75], and HIV [76].

Consistent with these findings, we found that even though our news articles framed stigma as problematic and identified common sources of PrEP-related stigma, these articles did not necessarily work to undermine PrEP stigma. This is particularly worrisome given that negative portrayal can contribute to stigma and stigma can, in turn, negate the efficacy of PrEP by tying it to rejected stereotypes, behaviors, or identities [17, 24]. In the present study, the most commonly identified rationale for stigma was scientific uncertainty regarding the effectiveness of PrEP and the potential for risk compensation. This is consistent with previous research which has shown that scientific uncertainty was a common theme in US news coverage, especially prior to the endorsement of PrEP by the US Centers for Disease Control and Prevention [77]. So, while writers provided persuasive rebuttals to many commonly reported worries of PrEP skeptics, the out-sized focus on dissenting voices gave considerable weight to these arguments, even if unintentionally. By doing so, news media coverage of PrEP provides subtle reinforcement of arguments that do not necessarily represent informed scientific consensus. Indeed, this problem has been regularly documented with respect to other scientific topics such as vaccines, genetically modified foods, and climate change [30]. Given previous misreporting in the media regarding PrEP [78, 79] and risk perception theories that emphasize the difficulty of disseminating politicized findings [21, 22], our assessment of historical and current media coverage supports the need for greater cooperation between academic researchers and news writers to correct common misconceptions and negative assumptions about PrEP. In practice, this means that researchers should (a) invest time in working with journalists to communicate findings and participate in public conversations, (b) make themselves available to work with journalists by building relationships with the respective writers and editors covering their research area, (c) gain sufficient training to communicate effectively with lay audiences, and (d) understand and support the journalists duty to ensure that content is both relevant to readers and newsworthy [80].

More broadly, our study highlights how the emergence of new prevention strategies presents academic, policy, and journalistic institutions with a serious challenge—especially in the face of

already inflicted damage. Primarily, our review raises the question of how to promote potentially controversial interventions while hoping at the same to communicate caution with respect to emergent scientific and biomedical innovations. This challenge of communicating uncertainty and risk while at the same time not destabilizing public confidence in scientific consensus is an increasingly important area of research—one that requires the support of academics, clinicians, policy leaders, and journalists [81].

Underscoring this challenge, policy makers are increasingly subjected to democratized decision-making and must, therefore, navigate public policy decisions with careful attention to the mediating influence of news coverage and commentary [37]. This is particularly true given the media's documented influence over agenda-setting, framing, and priming—leading some political scientists to describe media outlets as bona fide policy actors [82, 83]. Thus, media coverage plays a central role in determining the policy implications for stigmatized and politicized public health interventions, such as PrEP [84].

One strategy to help lay audiences make accurate judgements about PrEP is to address the heuristic processes that govern the way information is perceived and processed. One of the common heuristic devices used in media coverage is to appeal to expert opinion [35]. However, communications research shows that such appeals can be executed on a sliding scale of effectiveness, especially with respect to already controversial topic areas. This is because individuals distinguish between so-called expert opinion and their own personal views when forming judgements [85]. With that said, a growing number of studies suggest that the weight-of-evidence (i.e., the certainty of consensus in the scientific community) does in fact persuade individuals to agree with expert opinion [35]. This suggests that, whenever possible, expert opinion should be presented within the broader context of existing evidence—and that lay readers should not be asked to rely on only the viewpoint of a single practitioner (a common practice in person-driven pieces).

A second strategy to improve lay judgement of scientific coverage is to minimize false equivalencies. While there is an obvious and well-meaning desire for journalists to give equal weight to each perspective, available research suggests that this style of reporting effectively undermines scientific consensus and distorts lay people's ability to accurately understand what is being conveyed [86]. Similarly, a number of studies have shown that contrasting-view narratives increase uncertainty in lay readers—highlighting single-view narratives as more effective in conveying important health information [87]. With that said, writers should not attempt to resolve scientific issues before scientific consensus is reached. Communications research has shown that providing evidentiary balance (e.g., acknowledging limitations of current research, avoiding personal predictions, and explaining next steps to fill in knowledge gaps) increases lay trust in the scientific process [88, 89]—thus strengthening the weight of consensus once it is achieved.

While not common practice for all media outlets, linking to scientific articles and providing measures of uncertainty (e.g., margins of error) can also improve trust and increase the perceived credibility of news articles [81]. As noted earlier, researchers should also seek to develop working relationships with policy makers and journalists who regularly discuss and report on

their research areas. This allows for smoother dissemination and facilitates better reporting practices, relieving journalists and policy makers of the burden for developing appropriate error estimates and providing accessible content such as lay summaries or infographics [90, 91]. However, journalists should be cautious when conveying news on behalf of researchers in areas where broader scientific consensus has not been achieved, and policy makers should take care to minimize the political function of emerging scientific research until sufficiently broad evidence is available to support policy action. Doing so will reduce the political utility of interventions by resigning scientific uncertainty to the appropriate academic and scientific channels where it can best be adjudicated [92, 93]. Conversely, when scientific consensus has been reached, it is important to identify such consensus as news-worthy, particularly if previous reports conveyed doubt. Applied beyond PrEP, such action might be taken with respect to preventing stigma against people living with HIV by accurately portraying the scientific consensus surrounding viral load suppression and undetectability—namely, that people living with HIV cannot pass on the virus if their viral load is suppressed or undetectable [94, 95].

Limitations

Regarding the limitations of the present study, readers should be aware that some relevant media articles may not have been captured in our sampling process. Indeed, while news databases provide an expansive and powerful source for examining new coverage, indexing limits make it difficult for any single database to accurately and completely catalog relevant news media. Further, as social media has come to play an increasingly important role in media dissemination [96,97,98], research is urgently needed to assess how traditional media and scientific research is disseminated via these media and how public health leaders can influence these newly democratized outlets for knowledge translation.

Conclusions

In conclusion, the present study demonstrates the relationship between scientific uncertainty in emergent prevention strategies (e.g., PrEP) and the stigmatization that occurs as the public attempts to incorporate scientific innovation into existing ideological frameworks. Considering this with respect to communications research, we argue that reporting standards developed for knowledge translation must account for the heuristic processes of readers—especially with respect to the presentation of expert opinion and scientific consensus. This is the responsibility of both academics, who provide source quotes and scientific guidance, and journalists, who convey these messages to the public. We, therefore, conclude that enhancing cooperation between these two actors is paramount to reducing stigma and misinformation in scientific reporting.

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Ethics declarations

Conflict of interest

All authors declare that they have no conflict of interest.

Ethical Approval

This article does not contain any studies with human participants or animals performed by any of the authors.