

Social Media, Grindr, and PrEP: Sexual health literacy for men who have sex with men in the Internet Age

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Abstract

Despite continued improvements to HIV/AIDS treatment and awareness, HIV transmission rates remain high among men who have sex with men (MSM). Online consumer health information targeting high-risk MSM through social media and geosocial networking (GSN) apps have shown to be successful HIV intervention strategies. This review article addresses (1) the efficacy and acceptance of delivering consumer health information about pre-exposure prophylaxis (PrEP) and HIV prevention through GSN apps, (2) the impact of online and social media communities in the discussion and delivery of information about PrEP and HIV interventions, and (3) on-going and possible future research and the role of information professionals.

Keywords: HIV, sexual health literacy, men who have sex with men, geosocial networking, social media

Social Media, Grindr, and Prep: Sexual Health Literacy for Men Who Have Sex with Men in the Internet Age

Throughout the ongoing struggle against the HIV/AIDS epidemic worldwide and with new advancements in treatment and prevention, higher incidences of infection and transmission of HIV continue to be reported among high-risk populations like men who have sex with men (MSM) (Goedel et al., 2019). Of the new HIV infections in Canada reported in 2018, 58% were among gay, bisexual, or other MSM (Public Health Agency of Canada, 2019). Health Canada reports an estimated 75,500 Canadians currently living with HIV and approximately 1/5 of whom are currently undiagnosed or unaware of their HIV status (2015). Despite the overall decrease in HIV cases among industrialized nations, MSM rates remain high even with targeted health interventions for high-risk groups, highlighting the difficulties in the transmission and propagation of credible and engaging consumer health information concerning HIV prevention and treatment (Goedel et al., 2019).

Within the past decade, new biomedical interventions have changed the reality of many who are at risk of HIV infection through reducing the rate of transmission with strategies of treatment as prevention. These strategies include the use of antiretroviral drugs to achieve undetectable viral loads in HIV-positive individuals and the use of once-daily oral pre-exposure prophylaxis (PrEP) to prevent new infections in HIV-negative individuals.

First approved by the American Food & Drug Administration in 2012, PrEP drugs like emtricitabine and tenofovir (commonly sold under the trade name Truvada) have the potential to be a turning point in the reduction of HIV transmission (Grover et al., 2015). Current Canadian health guidelines propose the use of PrEP by those deemed to be at high risk of HIV infection, including men or trans women who report condomless sex with men, those who have other

sexually transmitted infections (STI), those with high scores using risk assessment tools, anyone engaging in condomless sex with a non-treated HIV-positive partner, or those who share injection drug use equipment (Arkell & Harrigan, 2019). While clinical research about the effectiveness of PrEP is ongoing, current findings indicate a high degree of success (up to 99% effectiveness) in preventing the transmission of HIV when PrEP is taken daily. Despite the mounting scientific evidence about the effectiveness of PrEP, uptake rates of the drug are slow, with only 1,774 HIV-negative people reported taking the drug in the United States between 2011 and 2013 (Grov et al., 2015). Estimates by the AIDS Vaccine Advocacy Coalition place the number of PrEP users in Canada in 2020 at approximately 4,700-5,200 people (AVAC, 2020). Concerns about the efficacy of the drug, cost and availability, side effects, and risk compensation concerning sexual behaviour are possible indicators for the slow uptake in the drug. Effective consumer health information is required to help assuage fears, counter misinformation, and spread awareness to increase uptake and maintain effective drug administration.

The current ubiquity of online information use and mobile phones has led electronic health (eHealth) and mobile health (mHealth) to be seen as viable and important vectors for the distribution of consumer health information in order to change behaviour, enhance treatment efficacy, increase patient knowledge, and improve clinical outcomes (Schnall et al., 2014). While smartphone applications have been developed with the goal of offering information about HIV and other STI transmission, they often have infrequent app downloads, inability to reach large numbers of high-risk people, and overall poor reception and reviews (Sun et al., 2015). Social media platforms and popular geosocial networking (GSN) apps, which allow MSM to connect through an online social platform to find sexual partners based on geographic proximity (e.g., Grindr, Jack'd, Scruff, Growlr, etc.) (Fields et al., 2020), have been used by

public health campaigns to address these shortcomings. The most popular of these services, Grindr, has reported over 2 million daily users worldwide (Goedel et al., 2019) and due to their influence in interpersonal and sexual relationships among MSM, these apps present fruitful opportunities for communication and knowledge transfer concerning HIV prevention (Buttram & Kurtz, 2019). Likewise, the widespread use of social media platforms like Facebook, Twitter, and Instagram present possible mediums for the spread of HIV health information to MSM groups that are more difficult to reach, allowing repeated exposure to messaging and offering the possibility to disseminate information to large numbers of people at once (Cao et al., 2017).

This review article will discuss (1) the efficacy and acceptance of delivering consumer health information about PrEP and HIV prevention through GSN apps, (2) the impact of online and social media communities in the discussion and delivery of information about PrEP and HIV interventions, and (3) on-going and possible future research and the role of information professionals.

Literature Review

The search strategy for this review included a survey of literature from the medical, information technology, and information science disciplines. The focus included HIV/AIDS treatment and prevention, consumer health information, internet health research, and evaluation of health information literacy. Inclusion of articles in the review required a focus on the use or implementation of PrEP for high-risk populations, a study of GSN apps, or social media-based health information interventions, as well as a recent publishing date within the past 10 years. Specific search terms used included: geosocial networking apps (and related trade names), social media (and specific platforms), pre-exposure prophylaxis (and trademarked drug names), men who have sex with men, risk management and HIV/AIDS.

Discussion

Geosocial Networking Apps and Sexual Health Information

Indications show the use of the internet by a large portion of the sexually active population, including rates as high as one third of adults looking for sexual partners online and also those using the internet tending to be more sexually active (Smith et al., 2018). The use of GSN apps for MSM is also high, with some rates found as many as one in three MSM having used a GSN app, 85% of users logging on with daily frequency (Abuelelam et al., 2019) and apps like Grindr having as many as two million daily active users globally (Goedel et al., 2019). Due to the multifunction use of GSN apps as methods of interpersonal interactions (both social and sexual), the frequent and often daily use by MSM, and their potential to reach traditionally underserved or hard-to-reach populations, they have been identified as useful mediums for the conveyance of health information and targeted sexual health interventions (Fields et al., 2020). This includes targeting particularly important populations like MSM who are uncertain of their current HIV status or those with low self-efficacy in STI testing (Sun et al., 2015). Additionally, GSN apps have been used as effective tools assessing the need for and interest in the implementation of PrEP programs in new regions (Hampel et al., 2017), further strengthening the argument for their ability to reach high risk MSM and those interested in targeted consumer health information for HIV prevention.

Acceptability of Sexual Health Information Dissemination Using GSN Apps

The reception of sexual health information for MSM using GSN apps has been positive, with high overall acceptability (Czarny & Broaddus, 2017; Sun et al., 2015). Other encouraging trends show that these interventions are generally well received regardless of sociodemographic variables like race, ethnicity, age, income, education, or geographic location (Czarny &

Broaddus, 2017; Gilbert et al., 2013). Community feedback describes favourably the incorporation of sexual health sections and advertisement banners within GSN apps, with the frequency of information delivery including both information actively sought out and weekly push alerts (Czarny & Broaddus, 2017; Fields et al., 2020). Information concerning PrEP is among the most accepted types of information offered through the apps, which offers encouraging evidence to continue health messaging through GSN apps in an effort to increase PrEP uptake, especially in rural or less centralized urban centres (Czarny & Broaddus, 2017).

Emerging Recommendations and Best Practices for GSN App Health Messaging

Ongoing research on the acceptability and effectiveness of GSN app sexual health messaging has highlighted several emerging trends and best practices which could be of use to consumer health providers and those designing similar targeted public health interventions. These recommendations include the ability to distinguish legitimate health information from spam or fraudulent messages, a focus on reaching populations outside the traditionally predominant gay social spaces and avoiding stigmatization of groups by solely targeting higher risk demographics like young MSM or racial or ethnic minorities (Fields et al., 2020; Jones et al., 2019). Timeliness of information delivery is a noted benefit of GSN apps, though information should not hinder the experience and enjoyment of meeting sexual partners through apps to maintain favourability among users. Information offered should remain both engaging and sex positive, avoid overly clinical language, work to build a culture of precautionary social norms, and should be delivered by authoritative and trusted information sources (Kesten et al., 2019).

The geolocation functionality of the apps offers great potential for providing geographically tailored information about local resources and HIV testing, though caution should be exercised to avoid the perception that too much personalization is intrusive and violates the

privacy of users, especially in regions where public disclosure of same-sex sexual activity carries individual risk or could be dangerous or impact personal wellbeing (Kesten et al., 2019).

The encouraging feedback from users along with the emergence of recommended best practices for GSN sexual health messaging suggests the continued use and development of these HIV intervention strategies and further refinement of messaging and information tailored to this medium. Behaviour concerning HIV status and use of PrEP between app users is another consideration. Disclosing PrEP use or serostatus is an increasingly common practice among GSN app users and this information exchange factors into risk analysis concerning HIV transmission. This increase in app user PrEP use, awareness, and communication strengthens evidence that GSN apps offer an impactful intervention point to provide accurate and relevant consumer health information (Newcomb et al., 2016).

Social Media and Sexual Health Information for MSM

While GSN apps have a significant reach and impact among high risk MSM, they do not have the universality and ability to reach a broader range of people as does social media. The ubiquity of platforms like Facebook, Twitter, and Instagram allow sexual health information to reach more diverse populations while being cost effective and easily scaled-up, allowing repeated exposure to information with built-in user feedback, and to encourage direct engagement between information seekers and providers. Possible communication mechanisms include crowd sourcing, pop-up ads, establishing virtual communities, online counselling, education and frequently asked questions (FAQ) forums, and referral for STI testing (Cao et al., 2017). There are also existing online communities centred around popular and online meme culture for the lesbian, gay, bisexual, and transgender community with millions of followers,

demonstrating the large-scale possibilities for consumer health information dissemination when addressing the appropriate audiences (Grov et al., 2019).

Social media has also been highlighted by users as a medium of interest for delivery of sexual health information, especially among youth as it allows the exchange of information with peers and helps foster an interest in and engagement with their own sexual health (Magee et al., 2012). The potential held by social media is important not only for the dissemination of sexual health information but also as a possible source of study and data for researchers looking to understand the information behaviour of those searching for, consuming, and sharing health information online.

Facebook, Twitter, Instagram: How is the Information Used?

Of the popular social media platforms available, Facebook, Twitter, and Instagram are commonly used in sexual health and HIV interventions online, with Instagram, Twitter, and Snapchat cited as of being particular use in reaching younger people (Jones et al., 2019). Gaining an understanding of the content of the health information shared on social media can be of value to consumer health providers, showing how communities at high risk are engaging in HIV and PrEP-related communication. This includes if and how the information and sentiments being shared are aligned with those of public health priorities, as well as identifying unique and beneficial messages that could be amplified and propagated with support from health information professionals (Nobles et al., 2020).

Studies analysing HIV-related hashtag trends on Twitter highlight that platform as being used primarily for the sharing of general health information and news rather than personal expression and discussion, as well as the limitations of targeting specific high-risk groups due to the character limits of Tweets forcing a trade-off between target specificity and how information-

rich the communication can be (McLaughlin et al., 2016; Schwartz & Grimm, 2017). A similar analysis of visual content on Instagram found that most social media posts and discussion concerns infographics and stigma reduction about HIV and little about clinical interventions, PrEP use, or general public sexual health priorities (Nobles et al., 2020). Facebook is perhaps the most successful in both delivering and sharing sexual health information due to its participatory features and networking capability that helps foster solidarity and community, with great success found through the use of popular opinion leaders and peer-mentoring in online Facebook communities (Ko et al., 2013; Patel et al., 2018; Young et al., 2013).

Social Media and Sexual Health Discussion

When dealing with information concerning sexual health, and HIV especially, the sharing of experiences through traditional channels can be difficult for individuals due to a reluctance to disclose sensitive personal information (Christine et al., 2019; McLaughlin et al., 2016). The perceived anonymity offered by social media allows users to discuss sexual health issues within online social circles with less fear of stigma (Christine et al., 2019; Hannaford et al., 2018; Taggart et al., 2015). Understanding the different kind of personal sexual health information that is shared online compared to in-person with clinicians and practitioners can serve as a valuable data source for tailoring future consumer health initiatives for HIV (McLaughlin et al., 2016).

Studying social media trends allows discovery of factors useful in designing and implementing sexual health interventions that may be missed by traditional research (Hannaford et al., 2018). An example of this includes determining the barriers to the increase in PrEP use among high risk MSM. Examples of the kinds of barriers discovered through analyzing social media discussion includes online ordering of PrEP, HIV and gay stigma, issues of perceived promiscuity of PrEP users, side effects of the medication, sexual risk compensation, experiences

with poorly informed healthcare practitioners, and opinions on the pharmaceutical industry (Franks et al., 2018; Hannaford et al., 2018; McLaughlin et al., 2016).

Understanding online trends in sexual health and HIV discussions can allow researchers and consumer health providers to move beyond merely using social media as a way to disseminate information and instead leverage the interactive capabilities of the platforms to encourage participation and self-motivated interest in HIV prevention and sexual health among high risk MSM. Encouraging active contribution of social media posts, compared to simple observation and endorsement, has shown to be an effective strategy in increasing HIV testing and sexual health awareness online (Cao et al., 2017). Social media posts encourage people to share experiences and information and can trigger others to do the same, which in turn can increase the use of medication, help reduce anxiety, and to share rapid solutions to problems through impromptu virtual support groups (Hannaford et al., 2018).

An online presence from consumer health information providers delivering accurate and relevant information in response to these online expressions of need highlights the potential for powerful impacts on how online social networks of high risk MSM discuss, understand, and engage with sexual health information and HIV prevention tools like PrEP.

On-going and Possible Future Research & the Role of Information Professionals

This review has uncovered numerous on-going and possible future research directions and the ways information professionals may be implicated in the improvement of online HIV consumer health information.

Challenges of Tailoring Community-Level Interventions for Specific Geographic, Racial or Social Groups

Further research can be conducted into best practices concerning targeted HIV health information and the information behaviour and preferences of minority groups of MSM. There are indications that MSM of colour tend to be the most assortative in their sexual partners when using GSN apps and require more specific geographic and community-level interventions to achieve the best results (Abuelezam et al., 2019). Conversely, the explicit targeting of groups like young black MSM through GSN apps leads to potential stigmatization of an already high-risk sub-group of MSM (Fields et al., 2020; Jones et al., 2019). Further study should be conducted to uncover the best messaging and information delivery strategies of online health information for specific vulnerable minority populations. This also includes those involved in transactional sex work, who tend to be at higher risk and are less likely to be reached through GSN apps or social media (Eaton et al., 2015; Patel et al., 2016).

Application of Information Behaviour Models to Understand Low PrEP Uptake

The slow uptake in PrEP use by high-risk MSM has revealed a knowledge-behaviour gap between awareness & willingness to use PrEP compared with how many individuals actually take the drug regularly; studies range with results from one third to as high as 3 in 4 MSM being aware or willing to take PrEP, but with actual regular prescribed use of the drug being much lower (between 6-12%) (Frankis et al., 2016; Goedel et al., 2016; Schueler et al., 2019; Strauss et al., 2017).

Research has been conducted to apply information behaviour modelling techniques (i.e. theory of planned behaviour; information-motivation-behavioural skills model) to analyze ways to improve consumer health information surrounding PrEP in order to increase uptake of the

drug and improve HIV testing (Meadowbrooke et al., 2014; Walsh, 2019). This research incorporates how information exposure, use of sexual health information, and experience accessing health care are influenced by personal perceptions of information relevance and contextualization of information through social interactions to motivate health decision making (Meadowbrooke et al., 2014). Use of information behaviour models, modifying existing models or the creation of new ones is an important direction for future research in addressing areas of concern in HIV prevention and treatment with appropriate consumer health resources and interventions.

Development of Information Technology Tools to Support Online HIV Information

The development of novel information technology tools in order to support online HIV consumer health is another research path holding great potential. Current research in this area includes: the development of an ontology-based FAQ query system for HIV/AIDS information (Ayalew et al., 2019), future versions of which could potentially be incorporated into GSN app sexual health information sections; continued research into social media data mining and monitoring to help make informed decisions and strategies concerning online HIV information materials (Christine et al., 2019; Grov et al., 2019; Hannaford et al., 2018); and the creation of automated text summaries from health social media posts (Liu et al., 2019).

Long Term Research

Research gaps have been identified, including: a lack of large-scale longitudinal studies examining and clarifying the relationship between information behaviour changes and shifts in HIV/STI incidence in high risk MSM populations; a need for more comparative studies between MSM using GSN and those who are not and their differing information needs and behaviours; and the continuation and replication of existing studies in more diverse geographic and cultural

regions (Zou & Fan, 2017). Continuing collaboration between researchers, health information providers, and GSN app developers is essential in the ongoing evolution and success of this consumer health information medium (Zou & Fan, 2017). Monitoring of changes in social media use and internet, mobile phone, and telecommunication technologies will also help ensure sexual health information professionals can most effectively deliver the highest quality and most useful information to high HIV-risk populations.

Conclusion

This article has presented an overview of the efficacy and acceptance of distributing HIV prevention and sexual health information through geosocial networking apps, the impact of social media networks on discussion around and dissemination of sexual health information, and highlighted areas of new or continuing research surrounding these topics.

Information professionals hold a unique position in the promotion of sexual health information to high-risk populations. Librarians, in particular, are often seen as trusted sources for reliable information and when concerning sexual health, this privileged position could have meaningful impacts. Sexual health discussions can be sensitive and information seekers who have had negative experiences with clinicians due to the stigma of HIV and same-sex sexual activity are still in need of accurate, timely, and non-judgemental health information and information professionals are well positioned to fill this role.

Within the on-going research on GSN and social media delivery of sexual health information, there is an important role to be played by information professionals, especially regarding the use of information behaviour models. The geographic specificity and community-tailored requirements for the highest efficacy of GSN and social media information campaigns requires research on local populations to discover the most effective messaging to reach those at

highest risk. This evaluation of information seeking, use, and sharing is at the core of the work of information professionals which places them in the unique position to support the on-going efforts of sexual health providers to fight the spread of HIV. This information behaviour analysis is especially important in helping to assess and close the knowledge-behaviour gap between those who are aware of treatments like PrEP and the number of sexually active men who have sex with men who are regularly taking the drug.

The effectiveness and availability of PrEP as a preventative treatment for HIV and the ubiquity of social communication online offers an important opportunity to make major strides towards eliminating HIV as a threat to public health, especially among populations that are most at risk. This opportunity creates an imperative for continuing and timely research towards this goal and the expertise of information professionals through research in human-computer interaction, knowledge management, data science, and librarianship have important roles to play.

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