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Research Paper

The development and evaluation of a social media-based HIV knowledge dissemination platform in China



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ABSTRACT

Objective: This study aimed to introduce the development of a social media-based HIV knowledge dissemination platform and evaluate its dissemination effects, users' feedback, and preferences. Methods: A social media-based HIV knowledge dissemination platform ("Lihui Space") was developed as a WeChat Official Account (WOA) to disseminate HIV-related information and knowledge to the public and answer subscribers' questions. A cross-sectional study was conducted on 784 platform subscribers between July 2021 and September 2021 to evaluate users' experiences with and preferences for the platform. This platform included three content levels about HIV-related information and knowledge: individual level (health self-management), community level (social function), and society level (news and policy), and dissemination information through texts, pictures, videos, and websites. A descriptive analysis was conducted to estimate the dissemination effects of the platform and evaluation scores. Results: As of September 16, 2021, this platform's WeChat Communication Index (WCI) score was 923.60, the total number of users was 100,008, and the total views in one month was more than 724,000. Participants reported a high level of satisfaction with this platform in terms of overall evaluation (23.36 \pm 3.06), readability (18.46 \pm 2.63), function evaluation (13.93 \pm 1.92), design and structure (22.96 \pm 3.36), and interactivity (12.56 \pm 2.69).

Conclusion: This social media-based platform is currently available in the WeChat application. It is a promising tool for HIV knowledge dissemination and addressing disparities in accessing health care resources.

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What is known?

- Persons living with HIV (PLWH) need continuous, integrative, and dynamic information support to confront lifelong disease management.
- HIV-related discrimination may discourage PLWH from asking for help from medical professionals face-to-face.
- WeChat Official Account (WOA) has become an acceptable and popular method to disseminate health knowledge in China.

What is new?

- We developed a WOA platform to disseminate HIV-related information and knowledge and provide personalized consultations for users.
- The platform showed influential dissemination effects, which ranked first within HIV counseling and services.
- Users reflected satisfied evaluations of this platform regarding overall evaluation, readability, function evaluation, design and structure, and interactivity.

1. Introduction

The development and popularization of antiretroviral therapy (ART) have made HIV infection a chronic disease that can be treated and managed. The life expectancy of persons with HIV (PLWH) has

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largely been extended [1]. However, due to its nature of being infectious and chronic, HIV infection brings great challenges to the long-term care of PLWH [2]. HIV infection is lifelong and may affect many aspects of daily life for PLWH, such as other treatments for complications and comorbidities [3], lifestyles [2], interpersonal relationships [4], education and career development [5], marriage, and fertility [6]. Furthermore, due to the misconceptions and stereotypes about HIV transmission modes and contagiousness, PLWH commonly experiences perceived discrimination and internalized discrimination, which may discourage PLWH from asking for help from medical professionals face-to-face [7–9]. Therefore, to meet these daunting challenges, applying effective methods to meet PLWH's continuous, integrative, and dynamic information support needs is urgent.

The rapid development of mobile health (mHealth) technology has reduced geographical, temporal, and even organizational barriers and provided more access to healthcare information and services [10]. Specifically, in the Web 2.0 era, characterized by data interconnection, the boom of the smartphone and social media networks has become a new channel and promising tool for information acquisition and communication. For instance, Dulli et al. [11] organized social media-based support groups through Facebook for youth living with HIV to improve their HIV knowledge, adherence, and retention and provide social support. Guo et al. [12] provided psychological knowledge for PLWH through a self-designed program delivered by WeChat. Social media caters to people's lifestyles, so social media-based health education and knowledge dissemination may be more acceptable, especially among young people.

WeChat is a mobile app with over 1.25 billion active users in 2021 and is China's most popular social media platform [13]. WeChat Official Account (WOA) was launched in 2012. It transmits messages to users and has become one of the main functions of WeChat [14]. Because of the convenience of information dissemination, the WOA has become an acceptable and popular method to disseminate health knowledge in China [14,15]. Our research team developed a social media-based HIV knowledge dissemination platform in 2014, currently available in the WeChat application. We visualized and realized the functions of this platform through the WOA. Anyone subscribing to this platform will have free access to HIV-related articles and can communicate with medical professionals. Although several other existing WOAs aim to disseminate HIV knowledge, none have reported evaluation data for their platform. This study aimed to introduce the development of our social media-based HIV knowledge dissemination platform and evaluate its dissemination effects and users' feedback and preferences.

2. Methods

2.1. Study design and participants

A cross-sectional study using convenience sampling was conducted between July and September 2021 to evaluate users' feedback and preferences about the platform. This study was reported according to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement [16]. Eligible participants were users who had followed the platform for more than two weeks and voluntarily participated in this study.

The total number of users was 97,462 (population) when the questionnaire was released. The recommended minimum sample size was 382, with a two-sided alpha level of 5% and a power of 80% [17].

2.2. Procedure

2.2.1. Development of the social media-based HIV knowledge dissemination platform

The "Lihui Space" (https://mp.weixin.gq.com/s/s5DhsN6Ui02YBY

3hAYnalQ) WOA was created by Hui Li to isseminate HIV-related information and knowledge to the public. Target users of the platform included PLWH, caregivers of PLWH, medical professionals, and key populations vulnerable to HIV infection. Every WeChat user who searches "Lihui Space" in WeChat can find this WOA and freely receive HIV knowledge articles after subscription. These articles (posts) on the "Lihui Space" WOA disseminate HIV-related information and knowledge through texts, pictures, videos, and websites. All these posted articles are from credible sources.

At the launch of this platform, the administrator only posted HIV-related knowledge-based articles, such as an introduction to HIV and acquired immure deficiency syndrome (AIDS) and the treatment of AIDS. Over time, we have collected an increasing number of users' preferences and feedback on the content of the articles through messages left after reading the articles and personalized consultations. We have expanded the contents of the articles and formed the content framework (Fig. 1).

2.2.1.1. Functions. Knowledge dissemination and personalized consultations are the two main functions of the platform. Appendix A shows that users can see the previously posted articles after opening the "Lihui Space" WOA. Users can browse the specific content by clicking on one of the articles (Appendix B). By clicking on the three-dot button at the top right of the posting page, users can send the article to their WeChat friends, share the post with all their WeChat friends using the "Moments" function and review the articles anytime through the "Add to Favorites" function (Appendix C). On the home page, users can search for articles they are interested in through search catalogs (Appendix D) or enter keywords in the dialogue box (Appendix E). The platform will recommend articles to users by matching keywords with the previous posts' titles. The "Query tool" button provides several quick links to search for information on HIV-designated hospitals, Centers for Disease Control and Prevention (CDCs), community organizations, medication interactions, and kidney function (Appendix F).

If users still have questions after reading the articles on the platform, they can leave messages in the dialogue box. Medical staff will answer their questions within 24 h (Appendix G). Some of the answers to frequently asked questions are collected and compiled into future articles. We also update the framework if the content framework does not cover these frequently asked questions. Specifically, medical staff can only see users' avatars and WeChat virtual names in the dialogue boxes. There is no risk of privacy exposure for personalized consultations.

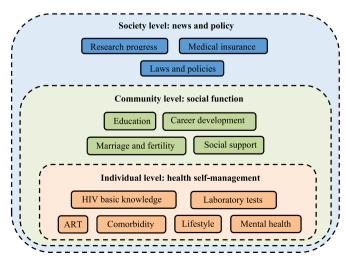


Fig. 1. Content framework of the platform. ART = antiretroviral therapy

2.2.1.2. Management and maintenance. The platform is managed and maintained by Hui Li, a full-time medical staff with 18 years of working experience focusing on HIV-related consultation and knowledge dissemination at a local CDC office. She posts 2-3 articles each day on the "Lihui Space" WOA and responds to all daily messages. The articles' topics prioritize HIV-related news, the latest research progress, laws, and policies. For instance, several recent articles introduced whether PLWH can be vaccinated, research progress on HIV vaccines, and medical insurance policy about ART. In other cases, articles are posted according to the content framework. Usually, the medical staff follows the following sequence: basic HIV knowledge, ART (medication plan, medication adherence, side effects, etc.), laboratory tests (results interpretation, coping strategies, etc.), healthy lifestyles, common commodities (tuberculosis, sexually transmitted disease, etc.), psychological interventions, marriage and fertility, and human rights (education, career development, medical insurance, etc.).

As introduced above, the platform can recommend previously posted articles by matching the keywords in the questions and the titles of the articles. If there is no recommendation, after the user leaves a message, the medical staff will respond to questions herself.

2.2.2. Evaluation of the platform

We evaluated this platform regarding dissemination effects data and user feedback and preferences. Dissemination effects data could be directly obtained from Qingbo big data [18] and the WeChat platform. User feedback and preference data were collected through self-report questionnaires.

2.3. Ethical considerations

This study was conducted according to the World Medical Association Declaration of Helsinki and approved by the Peking University Biomedical Ethics Committee (IRB00001052-21055).

2.4. Data collection

2.4.1. Questionnaire data collection

All users evaluation were collected through online data collection. The platform administrator (the medical staff) released the questionnaire as an article on the WOA. The informed consent was put on the first page of the questionnaire. Participants started to fill out the questionnaire after clicking "agreement" of the informed consent. To guarantee data quality, incomplete questionnaires, and questionnaires from duplicate IP addresses were deleted from the system.

2.4.2. Measures

All dissemination affects data from the WeChat platform were collected on September 16, 2021. The primary indicator of the dissemination effects is the WeChat Communication Index (WCI). The WCI is a comprehensive and transparent disseminating power indicator, and it has become one of the most rigorous standards for measuring the dissemination effects of WeChat [14,19]. The WCI score (V14.2) consists of 4 dimensions (overall communication power, average dissemination power, headline communication power, and peak dissemination power) and is calculated by a complex formula (Appendix H) [20]. Higher WCI scores indicate larger dissemination effects.

Other descriptive indicators of dissemination effects include the total number of users, the total number of delivered articles, the

total number of readings in the past month, the average daily readings in the past month, the average reading number for each article in the past month, and the highest reading number for a single article in the past month. The WeChat platform only kept a data record for messages in the past five days, so we only reported message response data between September 12 and September 16.

We designed a 29-item questionnaire to collect participants' demographic information, motivations and preferences, and platform evaluation data regarding the overall evaluation, readability, function evaluation, design and structure, and interactivity, according to Zhu et al.'s study [21]. Of the five evaluation dimensions, all the items applied a 5-point Likert scale score. Higher scores indicate better outcomes. The Cronbach's α coefficient of the overall evaluation (5 items), readability (4 items), function evaluation (3 items), design and structure (5 items), and interactivity (3 items) were 0.899, 0.933, 0.943, 0.963, and 0.847, respectively, in our study.

2.5. Data analysis

Descriptive analysis was adopted to analyze the information and dissemination effects of the platform. We used SPSS 24.0 for user evaluation data analysis. The mean and standard deviation (*SD*) were estimated for continuous variables, and the frequencies and percentages were calculated for categorical variables.

3. Results

3.1. Dissemination effects of the platform

As of September 16, 2021, the WCI score of this platform was 923.60. According to the GS data, this score ranked at 4,333 among over 1.3 million WeChat subscription accounts, a third-party platform that offers public dissemination of big data on social media [20]. Within the field of HIV counseling and services, this platform ranked first.

This platform had a total of 100,008 users and delivered 2,295 articles. The total views in the past month (August 16 to September 16) was 724,000. The average daily views in the past month was 24,133. A single article's highest number of readings in the past month was 24,136. The top 10 most-viewed posts in the past month are shown in Table 1. Between September 12 and 16, the platform administrator provided consulting services for 425 users, with an average of 85 users per day.

3.2. Sample characteristics

Of the 784 participants, most were male (92.22%), and 7.78% were female. The majority of the respondents were adults aged between 18 and 60 years, with 141 (17.98%) between 18 and 25 years, 13.47% between 26 and 30 years, 35.59% between 31 and 40 years, 125 aged between 41 and 50 years, and 48 (6.12%) aged between 51 and 60 years. Two (0.26%) participants were teenagers under the age of 18. Five (0.64%) participants were older adults over 60 years old. The number and percentage of participants who reported their education level of senior high school or below, college, a bachelor's degree, and a master's degree or above were 168 (21.43%), 202 (25.77%), 344 (43.88%), and 70 (8.93%), respectively. More than 80% of the participants reported being PLWH (636, 81.12%). Other participants included caregivers (46, 5.87%), medical professionals in the HIV field (29, 3.7%), medical professionals in different fields (22, 2.81%), volunteers or social workers (39, 4.97%),

Table 1 Top ten most-viewed posts.

Rank	Title	Classification	Views
1	Antibody BilA-SG may become the first immunotherapy in the world to cure AIDS	Research progress	25,067
2	How to visually distinguish whether your sexual partner has an STD	Comorbidity	22,670
3	What if my sexual partner forces me to take HIV test?	Laws and policies	22,178
4	Six steps to achieve a healthy life after HIV infection	Lifestyle	18,759
5	What? It is safer to date with PLWH?!!	Lifestyle	17,850
6	The moderna AIDS vaccine will start human trials this Thursday, using mRNA technology that is similar to the COVID-19 vaccine	Research progress	17,217
7	Real story My major is usually to be a public servant after graduation. Is it meaningful to get the degree?	Career development	16,101
8	What are the stages of HIV infection?	HIV basic knowledge	15,908
9	Be careful of "super spreaders" in the AIDS epidemic	HIV basic knowledge	15,889
10	New research progress of CAR-T cell therapy in curing AIDS	Research progress	15,015

Note: AIDS = acquired immune deficiency syndrome. STD = sexually transmitted disease. PLWH = people living with HIV. CAR = chimeric antigen receptor.

and others who paid attention to HIV (62, 7.91%).

3.3. Users' motivations and preferences

Of all the participants, more than 70% had followed this platform for more than one year, including 361 (46.05%) reporting 1–3 years and 214 (27.3%) reporting more than three years of use. In addition, 89 (11.35%) participants reported their following period between 7 and 12 months, 92 (11.73%) reported their next period between 2 and 6 months, and 28 (3.57%) reported their next period for less than two months and more than two weeks. Most read articles on the platform frequently, 485 (61.86%) reported reading articles daily, and 233 (29.72%) reported reading articles every two or three days. Only 46 (5.87%) participants reported that they read articles once a week, and 20 (2.55%) reported a frequency of reading articles less than once a week. The reasons reported by users for following this platform were as follows: acquiring HIV-related knowledge and information (737, 94.01%); being aware of HIV-related news, policies, and laws (637, 81.25%); getting timely help in emergent and special situations (467, 56.57%); communicating with medical professionals (453, 57.78%); getting peer support (157, 20.03%); and other reasons (9, 1.15%). Table 2 shows that users preferred to know about more on treatment (free ART, self-paid ART, side effects, physical examinations); CD4+ T-cell, viral load, and medial resistance; and functional cure.

3.4. User evaluations

Participants showed generally satisfied evaluations of this platform. High scores were received in terms of overall assessment $(23.36 \pm 3.06, \text{ range } 5-25)$, readability $(18.46 \pm 2.63, \text{ range } 4-20)$,

function evaluation (13.93 \pm 1.92, range 3–15), design and structure (22.96 \pm 3.36, range 5–25), and interactivity (12.56 \pm 2.69, range 3–15).

4. Discussion

This study introduced the development of a social media-based HIV knowledge dissemination platform and evaluated users' feedback and preferences. This platform has been available for seven years and actively posts articles according to a user-codesigned content framework daily. To our knowledge, this is the first study to evaluate an HIV knowledge dissemination platform through both objective dissemination effects data and subjective user feedback data. This platform showed effective dissemination outcomes and good user feedback.

Maintained and managed by a full-time, experienced medical staff, this platform posts HIV knowledge articles daily, providing continuous information support for users. We also summarized a content framework according to professional knowledge and users' feedback to guide future posts. Contents of three different levels covered many aspects of PLWH's daily life, which might provide integrative information support for users. The medical staff browsed every message left by users and provided personalized consultations when necessary. Therefore, this platform also provides dynamic information support for users.

This platform effectively disseminated, with a WCI score of 923.60, near No.10 WCI of the top tertiary hospital (949.48) among 668 WOAs in China [14]. It is estimated that there were approximately 1.25 million PLWH in China by the end of 2018 [3]. Given the large proportion of PLWH among the participants in the survey, we estimate that most of our 100,000 users are PLWH. This means that

Table 2 Users' content preferences (n = 784).

Content	Prefer to view	Hope for more posts on
Cognition (HIV basic knowledge)	507 (64.67)	321 (40.94)
Lifespan (lifespan-, smoking-, and death-related factors)	383 (48.85)	269 (34.31)
Treatment (free ART, self-paid ART, side effects, physical examinations)	636 (81.12)	482 (61.48)
CD4 ⁺ T-cell, viral load, and medial resistance	564 (71.94)	425 (54.21)
Fertility (Fertility knowledge, key points of interruption)	244 (31.12)	223 (28.44)
Daily life (nutrition supplements, pets, drugs, protection of family and friends)	307 (39.16)	232 (29.59)
Functional cure	535 (68.24)	447 (57.02)
Rights (medical insurance, marriage, medical treatment, career development, education)	358 (45.66)	334 (42.60)
Psychological problems (fear of AIDS, depression, homosexuality)	305 (38.90)	254 (32.40)
Sexually transmitted diseases (syphilis, condyloma acuminatum)	261 (33.29)	190 (24.23)
Real stories	344 (43.88)	267 (34.06)
$Query \ tools \ (national\ HIV\ designated\ hospitals, national\ CDC, community\ organizations, medication\ interactions, kidney\ function)*$	364 (46.43)	322 (41.07)

Note: Data are n (%). *The platform provides a query tool button with five links, which can help subscribers lookup information. ART = antiretroviral therapy. AIDS = acquired immune deficiency syndrome. CDC = Center for Disease Control and Prevention.

users of this platform may cover a proportion of Chinese PLWH that must be considered. The platform may have reached a broad range of audiences because the administrator consistently posted articles daily for a long period, and the users codesigned the content. Since participants gave positive survey feedback, this platform will continue attracting increasing users. Moreover, nearly 60% of our participants reported that they followed the platform to obtain timely help in emergent and special situations and to communicate with medical professionals, which indicated that the communication function also played an important role in attracting users continuously.

Participants' information and functional preferences also provide valuable insight and references for future work by the platform. Of all the preference options, the top three topics that participants recommended to have more posts on are all related to HIV treatment-related medical knowledge. In addition, of the top ten articles ranked for reading number, three were about research progress on functional cures, including the one with the highest number of readings. Therefore, most users need medical knowledge, especially about ART, laboratory tests, and treatment progress. Moreover, 44.52% of the participants wished the platform increases interactive communication functions. Therefore, improving the social support of PLWH through this platform is also an important future goal. The study results also showed that other topics are of relatively low preference and need. This may indicate that these topics may not be common problems of PLWH. For instance, PLWH who are homosexual men, have already married, or have offspring, may not be interested in articles related to marriage and fertility.

This platform has the following strengths in terms of HIV knowledge dissemination. First, the platform tailors PLWH's preferences for using social media daily. WeChat is a common app among the Chinese population. As one of the main functions of WeChat, WOAs are also widely used by WeChat users. In 2019, over 76% of WeChat users followed more than ten WOAs [22]. Therefore, this platform is promising for attracting more users and expanding health education access. Second, this platform covers a wide range of HIV-related topics that are highly relevant to the daily lives of PLWH. Importantly, the platform administrator posts articles about the latest research progress, news, and policies, which are helpful for PLWH. Third, this platform reaches a wide range of potential target users. This rich HIV knowledge can improve the selfmanagement of PLWH, enhance care abilities among caregivers of PLWH, enhance the HIV knowledge of medical staff, and reduce HIV discrimination by the public. Fourth, this platform provides a communication channel with medical professionals and thus can help users solve their problems. Fifth, this platform has low management and maintenance costs, which makes it feasible for its sustainability. Sixth, the online acquisition of information may help to reduce the resistance of PLWH due to HIV-related discrimination.

Several limitations of this study should be noted. First, all the articles posted on the platform are presented in simplified Chinese. The platform administrator, responsible for responding to messages, must improve in English. To meet more potential users' needs, we will include members skilled in English on the management and maintenance team in the future. Second, we applied convenience sampling to evaluate users' feedback and preferences. The results of this study may need to be more generalizable to the general user population. Third, although 784 participants are larger than the minimum sample size (382), it is much smaller than the average number of daily readings of the platform (24,133), which indicates the online questionnaire has a low response rate.

In conclusion, this social media-based platform provides professional, comprehensive, readable, and real-time HIV-related knowledge to PLWH, caregivers of PLWH, medical professionals, and others who are focused on and interested in HIV. Anyone who follows this platform can read all the articles and communicate with medical professionals for free. This platform has attracted many users and shown positive feedback and evaluations. It may become a promising tool for HIV knowledge dissemination and relieving inequality issues for medical resources. The experience of this platform can also provide a practical reference for other knowledge dissemination platforms and disease management. Given WeChat is also an internationally popular social media app, this model of knowledge dissemination mode may also benefit patients in other countries. Furthermore, improving patients' health outcomes is the ultimate goal of knowledge dissemination. Future studies can establish a cohort from the platform users to evaluate the long intervention effects of this platform.

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CRediT authorship contribution statement

Shuyu Han: Conceptualization, Methodology, Validation, Formal analysis, Investigation, Data curation, Writing - original draft, Writing - review & editing, Funding acquisition, Project administration. **Hui Li:** Conceptualization, Methodology, Validation, Formal analysis, Investigation, Resources, Data curation, Writing - review & editing, Supervision, Project administration. **Ke Li:** Conceptualization, Methodology, Validation, Formal analysis, Investigation, Resources, Data curation, Writing - review & editing. **Zhiwen Wang:** Conceptualization, Methodology, Validation, Formal analysis, Investigation, Resources, Supervision, Writing - review & editing.

Data availability statement

The datasets generated during and/or analyzed during the current study are available from the corresponding author upon reasonable request.

Declaration of competing interest

The authors have declared no conflict of interest.

Appendices. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ijnss.2023.06.003.

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