



Information need themes and their dynamics among people living with HIV/AIDS: an illness journey perspective

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DOI: <https://doi.org/10.47989/ir31356029>

Abstract

Introduction. It is crucial to identify the thematic information needs expressed by people living with HIV/AIDS across media platforms, and to analyse their dynamic evolution through different disease stages to facilitate targeted informational provision.

Method. Information need statements from people living with HIV/AIDS were collected (2022–2024) from Little Red Book, Baidu Knows, Haodf.com, and the Zhi Ai Jiayuan forum.

Analysis. BERTopic and dynamic topic modelling were used to identify themes, compare platform differences, and trace longitudinal changes over time.

Results. Information need themes differed significantly across platforms. On Little Red Book, individuals tended to emphasise information needs related to emotional support and social relationship adjustment; on Baidu Knows, they focused on disease management and maintaining life balance; on Haodf.com, they prioritised professional medical advice, and on the Zhi Ai Jiayuan forum, they sought comprehensive HIV-related information together with social support. The study also found dynamic changes in thematic information needs. During the early stage of HIV infection (stage I), individuals sought emotional support and foundational disease information. During the middle stage (stage II), their information needs diversified to include treatment strategies and family support. During the Advancing to AIDS (stage III), information needs became more specialised, emphasising treatment outcomes and complication management.

Conclusion. Both platform context and disease stage shape the expression of individuals' information needs. The findings underscore the value of platform- and stage-tailored information services that evolve from psychosocial reassurance to complex clinical guidance.

Introduction

HIV/AIDS is a chronic infectious disease that severely damages the human immune system and can lead to various opportunistic infections and malignancies. Because of its high transmission rate and mortality, it has become a significant public health issue threatening global health security (UNAIDS, 2025). The incurability of HIV/AIDS necessitates lifelong medication and health management, and this characteristic of the disease continuously affects and threatens quality of life, family relationships, and social participation (Cao, et.al., 2020; Domingues, et.al., 2018; Mujumdar, et.al., 2018; Nicholson, 2023). Therefore, providing timely, accurate, and easily accessible information has become a crucial strategy for improving the management of the disease (Coulson & Buchanan, 2022; Zeng, et.al., 2025; Zhang, et.al., 2023).

Providing informational support to patients first requires an understanding of their information needs. Information need can be conceptualised as an individual's self-perceived knowledge gap and the motivation to close that gap (Dervin & Naumer, 2009). It is highly contextual, stage specific, and is continually triggered and reconstructed as life circumstances and everyday practices evolve (Ruthven, 2022; Ruthven, 2025; Savolainen, 1999).

As they navigate the illness, patients develop diverse day-to-day information needs, which shift in a stage-specific manner over the course of the disease's progression (Bell, et.al., 2021; Chen, 2016; Jeske, et.al., 2024; Liu, et.al., 2025; Nicholson, 2023; Wittenberg-Lyles, et.al., 2011). As a chronic illness, HIV/AIDS involves a journey in which individuals progress from the early stage of HIV infection (stage I) through a middle stage (stage II) and eventually Advancing to AIDS (stage III) (National Health Commission of the People's Republic of China, 2007).

During the early stages of HIV infection, people face significant uncertainty associated with their diagnosis, which often leads to physical discomfort and psychological confusion. They require information related to scientific knowledge and pathology of HIV/AIDS to better understand it and cope with the initial symptoms (Lofgren, et.al., 2015; Reid, et.al., 2010).

During the middle stage of HIV infection (stage II), individuals need information on treatment processes, fertility, dietary health, social participation, and privacy protection to assist in choosing and adjusting treatment and life management strategies. This enables them to balance personal life and social roles while maintaining physical health (Carter, et.al., 2019; Hernando, et.al., 2015; Lofgren, et.al., 2015; Reid, et.al., 2010). As they advance to AIDS (stage III), they encounter more complex physiological and psychological challenges: they must manage disease-related complications and treatment outcomes, and require information on psychological adjustment, social support and end-of-life care to manage their health, improve quality of life, and prolong survival (Goodkin, et.al., 2018; Kanazawa, et.al., 2023).

Chronic illness management is often accompanied by profound life changes, shifts in worldview, and the reconfiguration of self-identity (Chen, 2018; Röing & Sanner, 2015). This contextual change is a critical precondition for understanding individuals' information needs (Cole, 2011; Huttunen, et.al., 2020; Wilson, 1981; Wilson, 1999). Understanding and meeting the dynamic information needs of people living with HIV/AIDS throughout their illness journey is therefore essential for supporting disease management and adaptation to life.

Online media platforms play an important role throughout the illness journey. By aggregating patients' digital traces, they not only help to explore patients' illness experiences but also help to meet information needs and interests in multiple ways (Chen, 2018; Lupton, 2021). The anonymity and interactivity of these platforms provide a relatively safe space for people living with HIV/AIDS to articulate their information needs and obtain the information they require. Increasingly, individuals are expressing and seeking information through social media, online health

communities, and specialised forums (Domingues, et.al., 2018; Farias, et.al., 2020; Stonbraker, et.al., 2017; Stonbraker & Larson, 2016; Taggart, et.al., 2015).

Each type of media platform plays a distinct role in meeting the diverse information needs of people living with HIV/AIDS (Taggart, et.al., 2015). Social media platforms, through their highly interactive communication environments, address needs related to emotional support and the sharing of peer-experiences (Dulli, et.al., 2020). Knowledge question-answer platforms offer personalised recommendations and meet specific information demands (UNAIDS, 2025). Online health communities, with their authoritative and scientific orientation, satisfy the need for fundamental medical knowledge (HIV.gov., 2025), and specialised forums provide a space for in-depth discussions on treatment options and shared experiential insights (Dudina & Tsareva, 2018).

The differences in content structure and interactive mechanisms across these platforms influence how individuals living with HIV/AIDS express their information needs and access support. A nuanced understanding of the specific information needs expressed in different contexts holds considerable theoretical and practical significance (Naumer & Fisher, 2010). However, existing studies predominantly rely on small-scale surveys and qualitative interviews, make limited use of objective data from online platforms, and have not systematically synthesised the overarching themes and subthemes of the information needs of people living with HIV/AIDS (Pian, et.al., 2020; Stonbraker & Larson, 2016). Research specifically addressing the information needs of people living with HIV/AIDS in China is even rarer; the few available studies focus mainly on health-education needs (Liu & Yuan, 2020). Consequently, there is a lack of systematic research on the information need themes expressed across different media platforms, the cross-platform differences, and how these themes evolve dynamically across the stages of the illness journey.

In China, different media platforms offer distinct forms of support for people living with HIV/AIDS. Little Red Book, as a representative social media platform, emphasises experiential sharing related to emotional adjustment and social relationships. Baidu Knows, a structured question-answer site, provides practical advice on concrete issues such as disease management and medication. Haodf.com, a professional medical services platform, offers physician-led consultations and recommendations for seeking care, and Zhi Ai Jiayuan, a specialised HIV/AIDS forum, provides comprehensive HIV knowledge and anonymous peer support. Building on the perspective of the HIV/AIDS illness journey, this study systematically identifies the information needs themes expressed by people living with HIV/AIDS across various media platforms.

This study examines the differences and dynamic changes in the information need themes expressed throughout the different disease stages. By exploring the relationships between information needs, platform environments, and disease stages, this study seeks to offer more comprehensive information tailored to the diverse needs of people living with HIV/AIDS, ultimately enhancing their quality of life.

Related literature

Theoretical background and framework of information need

Information need refers to the motivation to seek information that arises when individuals face an information gap or void (Wilson, 1981); it is the perceived discrepancy between the ideal and the actual state of one's knowledge (Case & Given, 2016). However, prior literature has not reached a clear consensus on the core concept of information need (Case & Given).

Within a problem-oriented tradition, Taylor's hierarchy of information need suggests that users' expressed needs are fundamentally aimed at answering concrete questions (Taylor, 1968). According to Atkin (1973), Belkin et al. (1982), and Kuhlthau (1991), information needs originate in uncertainty which individuals attempt to reduce through information seeking. This uncertainty-

centred view further explains the motivation behind information need. From Dervin's sense-making perspective, information need is understood as a desire to 'make sense of the situation' when individuals, situated in specific spatiotemporal contexts, confront problems, concerns, or choices (Dervin & Naumer, 2009). The process is continuous and contextual, progressing from *gap* to *bridge*, with one information need triggering another in the same chain (Case & Given, 2016; Shenton & Dixon, 2004; Shenton & Gibson, 2011). Building on this, Cole (2011) further argues that from a knowledge-formation perspective, information need is a constructive process: it is problem driven and aims to generate new knowledge that is integrated into existing cognition. Accordingly, this study conceptualises information need as a dynamic process triggered by a perceived knowledge gap in a particular context and externally expressed through interrogative or *help-seeking* utterances.

Although a unified definition remains elusive, research increasingly highlights context as a key factor shaping information needs: the external information environment both shapes and constrains how needs are expressed and met (Dervin, 1998; Savolainen, 2007). This environment includes fields such as social media, online health communities, and physician-patient consultation platforms (Fisher, et al., 2004; Johnson, 2006), as well as the digital traces generated by individuals' online activities. These traces can serve as temporal cues for retracing and reconstructing the trajectory of needs at different points in time (Chen, 2018; Cole et al., 2013).

To satisfy their information needs, individuals select from multiple information sources (Sonnenwald, 1999), and this selection is influenced by factors such as perceived source value, situational conditions, prior cognition, and usage experience (Kuhlthau, 1999; Savolainen, 2007). Platform-specific characteristics further affect how information needs are presented and what content is emphasised (Fisher, et al., 2004; Hirvonen, 2022; Park, et al., 2019). Understanding how individuals choose sources enables information providers to optimise service strategies, improve the efficiency of need-information matching, and better meet individuals' information needs and access (Ingwersen & Järvelin, 2005; Savolainen, 2007; Wilson, 1999). Therefore, analyses of information need should be grounded in concrete contexts and platform attributes, and by integrating diverse media environments with digital traces, should probe more deeply into differences in expression and dynamic changes over time.

The information needs of people living with HIV/AIDS across different media platforms

In the information age, various media platforms serve as key channels for information dissemination and social interaction. They influence how people living with HIV/AIDS express their information needs. Through diverse modes of communication, these platforms also provide avenues to access health information, share personal experiences, seek support, and engage in community activities (Aghaei, et.al., 2023).

Social media platforms offer people living with HIV/AIDS an efficient, real-time channel for obtaining information, enabling connection and interaction within their social networks (Genuis & Bronstein, 2017). They provide comprehensive medical information, including the latest research on HIV/AIDS, prevention measures, and treatment options (Genuis & Bronstein, 2017; Bazarova & Choi, 2014). Social media also provides emotional support (Bazarova & Choi, 2014), identity expression (Cunningham, et.al., 2018), and social interaction (McConnell, 2018), thereby helping to meet the diverse needs of people living with HIV/AIDS (Aghaei, et.al., 2023; Ibrahim, et.al., 2024).

Knowledge question-answer platforms, characterised by personalised recommendations and interactivity, address the specific information needs of people living with HIV/AIDS. The themes of expressed information needs on these platforms focus on individualised treatment information, such as treatment methods, medication selection, and side-effect management (UNAIDS, 2025).

Online health communities primarily supply the latest medical advice and professional treatment options, helping users understand treatment guidelines as well as the current health policies and research developments (Xu, et.al., 2023). Here, expressed information needs centre on diagnostic experiences, treatment approaches, and psychosocial support (Ayers, et.al., 2024).

Specialised forums dedicated to HIV/AIDS topics attract both healthcare professionals and people living with HIV/AIDS. They offer a space for exchanging experiences and obtaining insights into others' treatment courses and outcomes, as well as enhancing personal empowerment (Bussone, et.al., 2017; Coulson & Buchanan, 2022). On these forums, most users frequently seek information on treatment methods and medication information, symptom and side-effect management, and post-diagnosis coping strategies (Boyce, et.al., 2022).

Therefore, the various media platforms have accumulated substantial data on the information needs expressed across the illness journey. The discrepancies in information environments, interactive dynamics, and content presentation modalities across different platforms significantly shape the ways these needs are articulated. Identifying and analysing these variations is essential for a deeper understanding of the genuine information needs of people living with HIV/AIDS, and for developing more precise and contextually relevant information services.

Information needs of people living with HIV/AIDS at different disease stages

Information need themes refer to clusters of concerns repeatedly expressed in specific contexts that focus on particular information problems. These themes reflect both the focus of the content and the underlying need for information (Timmins, 2006). For people living with HIV/AIDS, such themes encompass knowledge of disease transmission, antiretroviral treatment, social support, and emotional adjustment, indicating an evolving attention to relevant information throughout illness management (Bekalu & Eggermont, 2013; Liu & Yuan, 2020). As individuals progress through the stages of the disease, their information needs change, becoming increasingly diverse and complex, and are influenced by multiple factors such as individual behaviour, the physical environment, and social context (Halman, et.al., 2013; Nokes & Nwakeze, 2005).

During the early stage of HIV infection, the information needs of people living with HIV/AIDS focus primarily on understanding basic disease knowledge, transmission routes, early symptom recognition, prevention, and treatment measures (Reid, et.al., 2010). Individuals at this stage are particularly concerned with information about HIV testing and urgently seek information on how to get tested and when to start treatment. As individuals move into the treatment stage, their information needs shift toward disease management, especially antiretroviral therapy monitoring and symptom relief (Reid, et.al., 2010). During this stage, they increasingly seek information on medical care, medication therapy, social work services, housing support, reproductive health, and overall disease management (Carter, et.al., 2019; Hernando, et.al., 2015; Lofgren, et.al., 2015; Reid, et.al., 2010). Although their understanding of treatment options and medication therapy improves, challenges remain in obtaining information on psychological support, emotional assistance and social services (Lofgren, et.al., 2015). In the later stages of infection, people living with HIV/AIDS confront more complex information needs involving multiple comorbidities, cognitive impairments, mental health issues, complex medication therapies and social isolation. Their needs centre on treatment methods, disease progression, cognitive function management, psychological support, social support, quality of life improvement and end-of-life care (Halman, et.al., 2013).

Although advances in HIV/AIDS treatment have extended life expectancy, the demand for comprehensive symptom management, psychosocial support and palliative care continues to increase, and existing treatment systems remain unable to fully meet these needs (Goodkin, et.al., 2018; Kanazawa, et.al., 2023; Karasz & Selwyn, 2003; Selwyn & Forstein, 2003). At every stage of the illness journey, people living with HIV/AIDS face social discrimination and stigma, creating a

continual need for timely and accessible information and guidance related to psychological resilience and emotional well-being to help them cope with societal pressures (Odimegwu, et.al., 2017).

A comprehensive and systematic understanding of these stage-specific information needs not only enhances individuals' ability to manage and cope with the disease but also fosters adaptation to life and social integration. Additionally, this understanding provides a practical foundation for developing personalised information services.

Research questions

Due to the stigma and discrimination associated with the disease, people living with HIV/AIDS often seek related information anonymously through online media platforms (Aghaei, et.al., 2023). The functional roles and interactive features of different media platforms influence, to a significant extent, how people express their information needs and the priorities they place on them. This, in turn, results in distinct forms and content of information expression across various platforms (HIV.gov, 2025; Xu, et.al., 2023). A deeper understanding of these differences in information need themes across media platforms can enable more targeted and effective information provision, thereby enhancing the health management skills of people living with HIV/AIDS and improving their quality of life. Accordingly, this study posits the following research question:

RQ1: What information need themes are expressed by people living with HIV/AIDS on each of the different media platforms?

Changes in personal life circumstances and routine behaviour often drive individuals to develop new information needs (Ruthven, 2022). As a chronic condition requiring long-term management, the information needs of people living with HIV/AIDS evolve dynamically and exhibit multidimensional characteristics across the various stages of the disease (Brashers, et.al., 2002). Because these needs evolve, providing personalised information tailored to their specific illness journey enhances their understanding and management of the condition and improves treatment adherence (Cao, et.al., 2020; Han, et.al., 2023; Marziali, et.al., 2021). A deeper examination of the dynamic evolution of information needs, particularly across different media platforms, will provide empirical support for the development of personalised information services for this population. Based on this, the second research question of this study is:

RQ2: How do the information need themes evolve dynamically across the different stages of the HIV/AIDS illness journey?

Methodology

Data collection

This study selected four platforms, namely Little Red Book (<https://www.xiaohongshu.com>), Baidu Knows (<https://zhidao.baidu.com>), Haodf.com (<https://www.haodf.com>), and the Zhi Ai Jiayuan forum (<https://www.120x.net>) as data sources. These platforms are important channels for people living with HIV/AIDS to express their information needs and obtain relevant information.

Data collection was completed using the Octopus Web-scraping software (<https://www.octoparse.com>), targeting posts published between 2022 and 2024. Because the social background during this period was relatively stable, the short-term impact of emergencies (such as epidemics) on information needs can be effectively reduced, thereby ensuring that the research focuses on long-term trends in information needs and their dynamic changes across the illness journey.

First, this study used 'HIV' and 'AIDS' as query terms to crawl relevant data. Second, to locate the information needs of people living with HIV/AIDS, this study employed interrogative and help-seeking markers as high-recall linguistic cues for an initial screening of the scraped corpus, including 'what should I do', 'is it/are', 'seeking help', '?', 'why', 'how', 'is there/any', and 'to ask'. These linguistic cues were used solely to identify sentence segments likely to contain information needs. They indicate the externalisation of a knowledge gap and an intention to seek solutions, thereby translating otherwise latent needs into operationalised questions (Belkin, 1982; Dervin & Naumer, 2009; Kuhlthau, 1991; Ruthven, 2019; Taylor, 1968).

The collected content included post titles, post details, publication time, and associated comments. Data were gathered from 26 September 2024 to 26 November 2024. In total, this study obtained 35,480 records from Little Red Book, 29,536 from Baidu Knows, 30,098 from Haodf.com, and 23,345 text records from the Zhi Ai Jiayuan forum. All data were drawn from publicly accessible pages; data collection and use strictly complied with each platform's accessibility rules and terms of use. Following collection, de-identification procedures were implemented (for example, removal of usernames and or IDs, contact information, and geolocation) and no identification, contact, or intervention was undertaken at the individual level. The technical workflow of this study is presented in Figure 1.

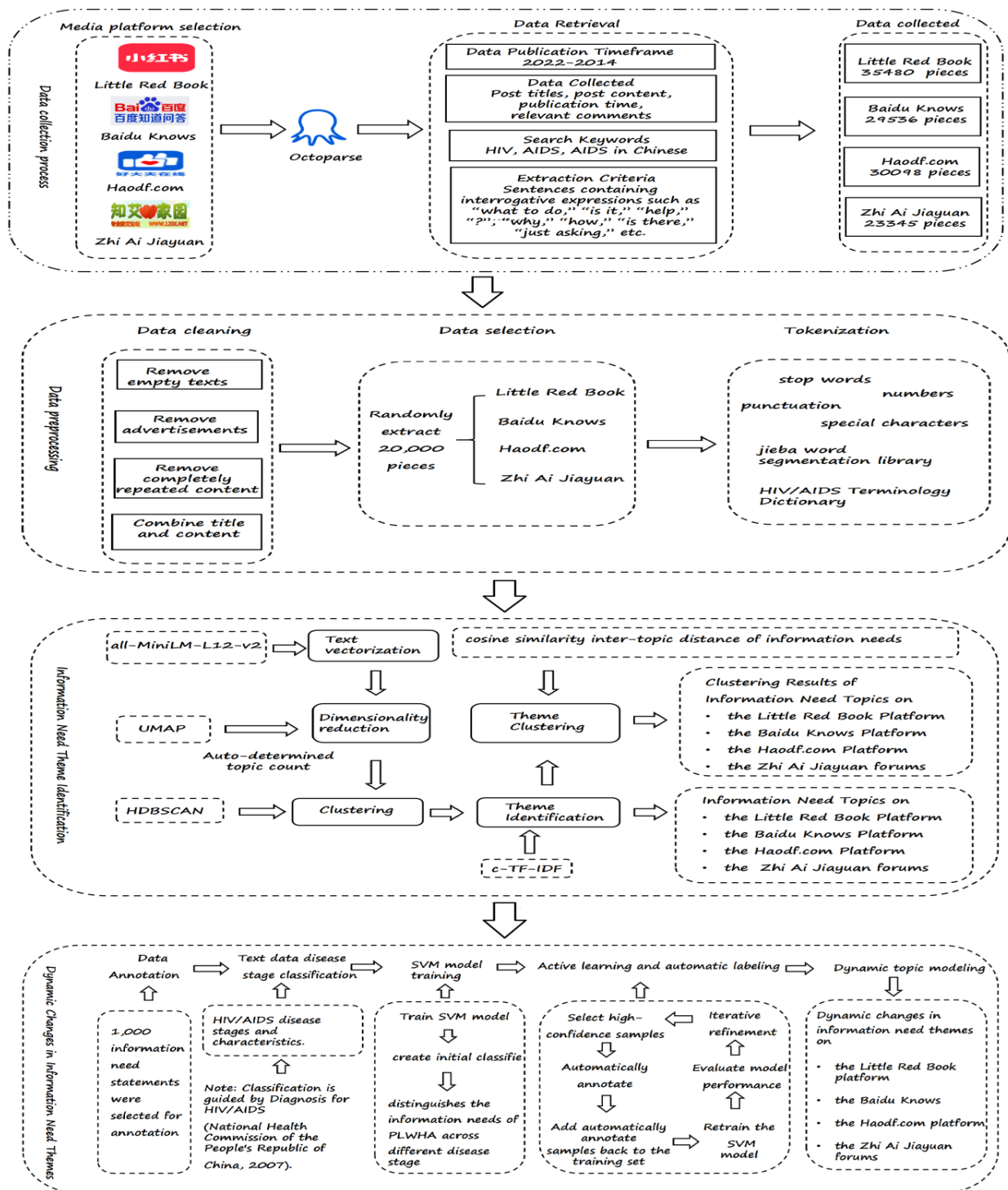


Figure 1. Research technology roadmap

Data preprocessing

In order to ensure the accuracy of the data, this study normalised the data from each platform after collection through data cleaning, selection, the removal of stop words, punctuation, numbers, and tokenisation.

- (1) **Data cleaning:** this involved removing empty text, advertisements, and repeated content.
- (2) **Data selection:** to ensure a balanced dataset across media platforms and to avoid analytical bias caused by large-scale data from any single platform, this study applied random sampling and selected 20,000 entries from each platform for analysis. This approach controls the sample size, reduces the dominance of high-volume platforms in the overall topic distribution, and enhances the comparability between platforms. However, a limitation of this method is the potential omission of low frequency but meaningful themes. Moreover, the study did not control for temporal or user-related variables, which may have affected the identification of dynamic changes in information needs.
- (3) **Removal of stop words, punctuation, and numbers:** the Harbin Institute of Technology (HIT) Chinese stop word list was used to remove some words that would have affected the topic extraction in the cleaned text. Punctuation and special characters were also removed.
- (4) **Tokenisation:** the jieba Chinese word-segmentation library in Python was used to segment the text data. Since the study involved using the specialised HIV/AIDS-related data, jieba's custom dictionary was supplemented with medical terms related to HIV/AIDS symptoms and medications extracted from *Diagnostic Criteria for HIV/AIDS* (National Health Commission of the People's Republic of China, 2007) to collect and supplement the medical terms that related to HIV/AIDS symptoms and medication.

Data analysis

Information need topic identification

This study used the BERTopic method for topic modelling to identify the themes of information needs collected across the four platforms. As part of the BERTopic method, text embeddings were obtained using a pre-trained language model; the uniform manifold approximation and projection (UMAP) algorithm was used to reduce the dimensionality; hierarchical density-based spatial clustering of applications with noise (HDBSCAN) was used for clustering; and class-based term frequency-inverse document frequency (c-TF-IDF) was used for topic representation (Alcoforado, et.al., 2022; Grootendorst, 2022). The following steps detail this procedure.

- (1) **Text vectorisation:** the text was converted into vector representations using the pre-trained language model all-MiniLM-L12-v2. This facilitated topic identification, clustering, and semantic analysis (Reimers & Gurevych, 2019).
- (2) **Dimensionality reduction:** to preserve the semantic structure while lowering computational complexity, the UMAP algorithm was applied to reduce the dimensionality of the vectorised documents, thus facilitating subsequent topic clustering and identification.
- (3) **Clustering:** the HDBSCAN clustering algorithm was used to conduct initial clustering and determine the number of information need themes on each platform. This algorithm does not require a predefined number of clusters and is capable of identifying topics with varying degrees of cohesion, making it well-suited for semantically uneven distributed text data.
- (4) **Theme naming:** keywords that represented the information need themes from each platform were extracted using c-TF-IDF. Themes were then assigned consistent and comparable names based on their core keywords.
- (5) **Clustering of information need themes:** the information need themes were clustered using topic vector representation, a distance metric, and hierarchical clustering.

- a) Topic vector representation. For each initial topic, the top-k representative keywords ranked by c-TF-IDF were selected. Their word embeddings were computed and averaged with c-TF-IDF weights to obtain the topic's semantic vector.
- b) Distance metrics. Cosine distances between all pairs of topic vectors were calculated to form a cross-platform topic distance matrix.
- c) Hierarchical clustering. Hierarchical clustering was applied to merge topics without pre-specifying the number of clusters, revealing the semantic hierarchy among topics and facilitating the cross-platform grouping of similar themes (Grootendorst, 2022).
- d) Cluster determination. By jointly considering the dendrogram, internal validity indices ($k \in [10, 20]$), and semantic interpretability, this study identified fourteen categories of information needs, as shown in Table 1. Due to space limitations, this study presents only the map of clustered information need themes from the Little Red Book platform (Figure 2).

Themes	Definition	Example topics
Causation knowledge	Themes related to disease aetiology	infection route; infection probability; contagion risk
Pathology knowledge	Disease progression and impact	early symptoms; opportunistic infections
Scientific knowledge	Public education and scientific outreach	survival time; research progress
Social security	Basic rights protection and service	hospital service guarantees; social service locations
Diet & health	Health practices and lifestyle guidance	health care methods; diet plans; nutritional needs
Fertility	Pregnancy precautions and preparation	pregnancy-related precautions; preparation
Future development	Long-term life planning	personal future development suggestions; career advice
Social interaction	Maintaining relationships and sharing experiences	family and social relationship maintenance; experience sharing
Treatment process	Treatment journey information	treatment methods; effectiveness; costs
Medication therapy	Medication use and related issues	efficacy; usage advice; purchase channels; prices; precautions
Psychological issues	Emotional and mental health needs	psychological resilience; comfort; counselling services
Test results	Interpretation of test outcomes	test results analysis; doubts about results
Diagnostic methods	Diagnostic inquiries	diagnostic criteria; diagnostic advice
Surgery consultation	Surgery-related consultation	surgery process; postoperative management

Table 1. Categories of information need themes and examples

(6) **Difference analysis:** based on the frequency of information need themes on each platform, a *chi-squared* test was used to detect distributional differences across platforms. Subsequently, a *z*-test was applied to analyse proportional differences among the themes.

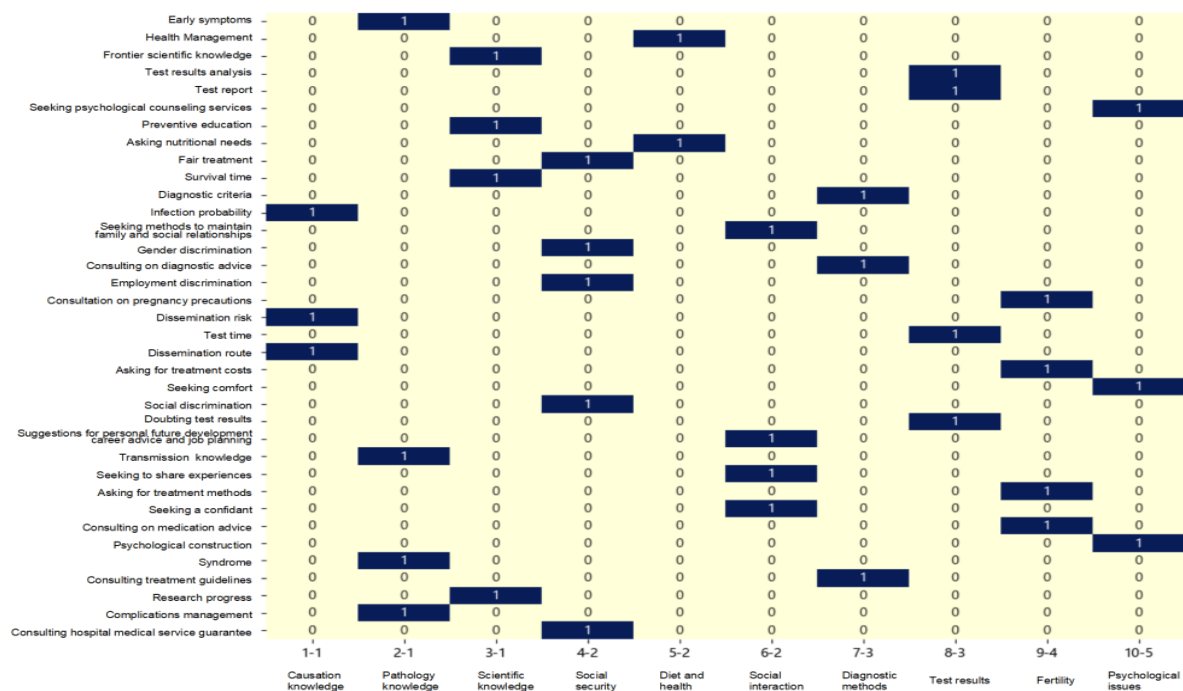


Figure 2. Thematic clustering of information needs expressed by people living with HIV/AIDS on Little Red Book

Stage-specific changes in information need themes

This study used the dynamic topic modelling tool in BERTopic to analyse the changes in the information need themes of people living with HIV/AIDS across four platforms using timestamps. The steps are as follows:

(1) **Text data disease-stage classification:** a set of 1,000 information need statements was manually labelled. Using the clinical symptoms and medical indicators of people living with HIV/AIDS from Table 2: HIV/AIDS disease stages and characteristics, the information need statements were classified into three disease stages: HIV infection early stage (stage I), HIV infection middle stage (stage II), and Advancing to AIDS (stage III).

Disease stage	Disease characteristics		
	Symptom	Medical indicators	Time description
HIV infection early stage (stage I)	similar to flu, acute HIV infection syndrome (fever, headache, sore throat, joint pain, diarrhoea, nausea, vomiting, night sweats, muscle aches, fatigue); persistent generalised lymphadenopathy; recurrent upper respiratory tract infections; herpes zoster; angular cheilitis; chapped lips, recurrent oral ulcers; nodular prurigo; seborrheic dermatitis; onychomycosis.	CD4+ T lymphocyte count > 500/mm ³ ; HIV serum antibody positive; HIV isolation test positive; high viral load and a temporary decrease in CD4+ cell count	recently infected; post-infection mild symptoms; acute phase; sudden onset; appearance of symptoms; within a short period; within 3–6 months; HIV antibody seroconversion within 1 year; early response; antibody generation phase; acute phase; primary infection phase
HIV infection middle stage (stage II)	long-term asymptomatic, stable condition; no symptoms displayed; gradual immune system destruction; gradual recovery of the body; slow control of viral load.	CD4+ T lymphocyte count ranging from 200/mm ³ to 500/mm ³ , low viral load, in a chronic state	asymptomatic period; long-term latency; stable state; maintenance phase; chronic phase; within 6–8 years; asymptomatic phase; latent phase; stable phase; antiretroviral treatment phase
Advancing to AIDS (stage III)	HIV-wasting syndrome; pneumocystis pneumonia; persistent oral candidiasis; oral hairy leukoplakia; symptomatic HIV-associated cardiomyopathy or nephropathy, accompanied by severe multiple opportunistic infections; complications; multiple opportunistic infections; malignancies; drug resistance; Kaposi's sarcoma, lymphoma; deep fungal infections; immunodeficiency; multisystem involvement.	CD4+ T lymphocyte count < 200/mm ³ , high viral load (greater than 100,000 copies/mL), more than 10% weight loss within 6 months	chronic infection; advanced stage; terminal stage; end-of-life stage; over 10 years; severe stage

Note. Classification is guided by *Diagnostic Criteria for HIV/AIDS* (National Health Commission of the People's Republic of China, 2007).

Table 2. HIV/AIDS disease stages and characteristics

(2) **Support vector machine model training:** a support vector machine model was trained using the labelled dataset (text, disease-stage labels, and information need labels) to create an initial classifier that then distinguished information needs across different disease stages.

(3) **Active learning and automatic labelling:** the trained support vector machine model was then used to label the data, optimising the training set. After model training and evaluation, the final results for each platform were summarised in Table 3. The evaluation metrics for each platform

demonstrate that the support vector machine model can effectively perform training and evaluation (Zhong, et.al., 2024).

Platform	Accuracy	Precision	Recall	F1
Little Red Book	0.75	0.78	0.72	0.75
Baidu Knows	0.72	0.75	0.70	0.724
Haodf.com	0.81	0.84	0.79	0.814
Zhi Ai Jiayuan forum	0.79	0.81	0.78	0.794

Table 3. Classification performance by platform

(4) **Dynamic topic modelling:** the data were classified by disease stage and input into the dynamic topic modelling tool. Changes in the themes of information need across different media platforms and through the stages of the disease were analysed.

Results

Distribution of information need themes of people living with HIV/AIDS across different media platforms

By training the BERTopic model, this study identified thirty-six information need themes on Little Red Book, twenty-four themes on Baidu Knows, thirty-eight themes on the Haodf.com, and nineteen themes on the Zhi Ai Jiayuan forum. Based on the clustering results of the information need themes, these themes were grouped into fourteen categories: causation knowledge, pathology knowledge, scientific knowledge, social security, diet and health, fertility, future development, social interaction, treatment process, medication therapy, psychological issues, test results, diagnostic methods and surgery consultation. The information need themes and clustering results for each platform are shown in Table 4.

Based on the frequencies of information need themes across platforms, the chi-squared test indicated significant differences in theme distributions among platforms ($\chi^2 = 39,396.98$, $df = 39$, $p < 0.001$, Cramér's $V = 0.41$). To further compare the proportional differences of specific themes across platforms, proportion z-tests were conducted for standardised comparisons. The results are presented in Table 5.

Media platforms				
Themes	Little Red Book	Baidu Knows	Haodf.com	Zhi Ai Jiayuan
Causation knowledge	infection probability; dissemination risk; dissemination route	early symptoms; transmission process	transmission risk; dissemination route; dissemination probability; infection process; infection conditions; viral load; infection probability; CD4 ⁺ T-cell count	-
Pathology knowledge	early symptoms; syndrome; complications management; infectious knowledge	complications management; relationship with other communicable diseases	clinical stage; early symptoms; opportunistic infection; tumour types; common symptoms; syndrome; symptom presentation; clinical manifestations	early symptoms; syndrome
Scientific knowledge	research progress; preventive education; survival time	survival hope; number of cases; prevention education; epidemic situation; promotion activities; family education; drug prevention propaganda	research progress; frontier scientific knowledge; survival time	frontier scientific knowledge; survival time
Social security	social discrimination; consulting hospital medical service guarantee; fair treatment; gender discrimination; employment discrimination	social information consultation and help; fair treatment; social discrimination; negative social impact	consulting hospital medical service guarantee	consulting social service location; consulting hospital medical service guarantee; free resource application process consultation
Psychological issues	psychological construction; seeking psychological counselling services; seeking comfort	psychological construction	seeking comfort	seeking comfort; seeking psychological counselling services
Medication therapy	consulting on medication advice	consulting on medication advice; consulting on medication efficacy	consulting on medication precautions; consulting on medication efficacy; consulting about the progress in new medication development; consulting on medication advice	consulting on medication advice; consulting on medication precautions

Media platforms				
Themes	Little Red Book	Baidu Knows	Haodf.com	Zhi Ai Jiayuan
Treatment process	asking for treatment costs; asking for treatment methods	asking for treatment costs	consulting on medication advice; asking for treatment methods	consulting on medication advice; asking for treatment effectiveness
Test results	test results analysis; test report; test time; doubting test results	test results analysis	test results analysis; test time; test report	test results analysis
Fertility	consultation on pregnancy precautions	consultation on pregnancy preparation information	consultation on pregnancy preparation information	-
Diet and health	health management; asking nutritional needs	consulting diet plan	-	health management; consulting health care methods
Social interaction	seeking methods to maintain family and social relationships; seeking to share experiences; seeking a confidant	seeking a partner	-	seeking a partner; seeking methods to maintain family and social relationships; seeking fellow sufferers
Diagnostic methods	consulting treatment guidelines; diagnostic criteria; consulting on diagnostic advice	-	consulting on diagnostic advice; diagnostic criteria	-
Future development	suggestions for personal future development	-	-	-
Surgery consultation	-	-	surgery process; postoperative management	-

Table 4. Information needs themes expressed by people living with HIV/AIDS on different media platforms

As shown in Table 5, the distribution of information need themes expressed by people living with HIV/AIDS varies significantly across media platforms. In particular, themes such as causation knowledge, pathology knowledge, scientific knowledge, social security, psychological issues, medication therapy, treatment process, and test results exhibit large inter-platform differences. In contrast, themes of fertility, diet and health, social interaction, diagnostic methods, future development and surgery consultation show smaller differences and relatively high consistency. On Little Red Book, people living with HIV/AIDS search for information on emotional support and social adaptation, especially peer-to-peer experience sharing. On Baidu Knows, their focus is on disease management and balancing everyday life, with a strong demand for pathology knowledge. On Haodf.com, they predominantly seek professional medical opinions and advice on treatment methods, medication efficacy, and complication management. Finally, on the Zhi Ai Jiayuan forum, their information needs centre on social security and related social support resources.

Themes	Little Red Book ^a		Baidu Knows ^b		Haodf.com ^c		Zhi Ai Jiayuan ^d	
	Proportion	95% Confidence interval, Wilson	Proportion	95% Confidence interval, Wilson	Proportion	95% Confidence interval, Wilson	Proportion	95% Confidence interval, Wilson
Causation knowledge	0.082 ^{bcd***}	[7.8,8.6]	0.053 ^{acd***}	[5.0,5.7]	0.183 ^{abd***}	[17.5,18.5]	0.003 ^{abc***}	[0.0,0.0]
Pathology knowledge	0.101 ^{bcd***}	[9.7,10.5]	0.064 ^{ac}	[6.0,6.7]	0.296 ^{abd***}	[29.4,30.6]	0.067 ^{ac}	[6.4,7.1]
Scientific knowledge	0.110 ^{bd}	[10.6,11.5]	0.294 ^{acd***}	[28.7,30.0]	0.114 ^{bd}	[10.6,11.4]	0.095 ^{abc***}	[9.1,9.9]
Social security	0.140 ^{bcd***}	[13.5,14.5]	0.225 ^{acd***}	[21.9,23.0]	0.015 ^{abd***}	[0.9,1.1]	0.209 ^{abc***}	[20.4,21.5]
Psychological issues	0.072 ^{bc}	[6.9,7.6]	0.050 ^{acd***}	[4.7,5.3]	0.014 ^{abd***}	[0.9,1.1]	0.073 ^{abc*}	[6.9,7.6]
Medication therapy	0.020 ^{b*cd}	[1.8,2.2]	0.103 ^{ac}	[9.9,10.8]	0.147 ^{abd}	[14.5,15.5]	0.097 ^{ac*}	[9.3,10.1]
Treatment process	0.075 ^{bd}	[7.2,7.9]	0.062 ^{acd***}	[5.8,6.5]	0.077 ^{bd}	[7.6,8.4]	0.102 ^{abc***}	[9.8,10.6]
Test results	0.104 ^{bcd***}	[10.0,10.9]	0.078 ^{acd**}	[7.4,8.1]	0.051 ^{abd***}	[4.7,5.3]	0.070 ^{abc**}	[6.6,7.3]
Fertility	0.026 ^{bcd***}	[2.4,2.8]	0.037 ^{acd***}	[3.4,4.0]	0.019 ^{abd***}	[1.8,2.2]	0.007 ^{abc***}	[0.0,0.0]
Diet & health	0.045 ^{bcd***}	[4.3,4.8]	0.035 ^{acd***}	[3.3,3.8]	0.005 ^{abd***}	[0.0,0.0]	0.136 ^{abc***}	[13.1,14.1]
Social interaction	0.103 ^{bcd***}	[9.9,10.7]	0.002 ^{ad}	[0.0,0.0]	0.003 ^{ad}	[0.0,0.0]	0.152 ^{abc***}	[14.7,15.7]
Diagnostic methods	0.075 ^{bcd***}	[9.9,10.7]	0.001 ^{ac}	[0.0,0.0]	0.036 ^{abd***}	[3.7,4.3]	0.004 ^{ac}	[0.0,0.0]
Future development	0.046 ^{bcd***}	[4.3,4.9]	0.003 ^{a***}	[0.0,0.0]	0.002 ^{a***}	[0.0,0.0]	0.005 ^{a***}	[0.0,0.0]
Surgery consultation	0.004 ^{c***}	[0.0,0.0]	0.002 ^{c***}	[0.0,0.0]	0.246 ^{abd***}	[4.7,5.3]	0.004 ^{c***}	[0.0,0.0]

Note: In this table, the letters a, b, c, and d represent the four media platforms. Each letter indicates that the proportion for that theme on the focal platform differs significantly from the proportion on the platform indicated by that letter. For example, for the pathology knowledge theme on Little Red Book (a), the entry 0.101^{bcd***} means that the proportion on platform (a) differs significantly from those on Baidu Knows (b), Haodf.com (c), and the Zhi Ai Jiayuan forum (d), all at $p < 0.001$. The scientific knowledge theme on the Little Red Book platform (a), the entry 0.110^{bd}, means that the proportion on platform (a) differs significantly from those on the Baidu Knows platform (b) and the Zhi Ai Jiayuan forum (d) after Holm-Bonferroni correction ($p < .05$). $p < .05$, $** p < .01$, $*** p < .001$ (all Holm-Bonferroni adjusted).

Table 5. Differences in the proportion of information needs themes expressed by people living with HIV/AIDS on different media platforms

Thematic changes in information needs across HIV/AIDS stages and media platforms

During the early stage of HIV infection (stage I), people living with HIV/AIDS express information needs related to social interaction, social security, pathology knowledge, scientific knowledge, psychological issues, and test results. During the middle stage of HIV infection (stage II), these themes become more diverse: they continue to seek social interaction, social security and scientific knowledge, but also search for information on diet and health, treatment process, medication therapy, fertility and future development. During the Advancing to AIDS stage (stage III), they continue to express needs for information on diet and health, treatment process and medication therapy, but in addition require pathology knowledge, scientific knowledge, test results, psychological issues, and surgery consultation. Figure 3 depicts the dynamic evolution of these information need themes across the stages of the disease.

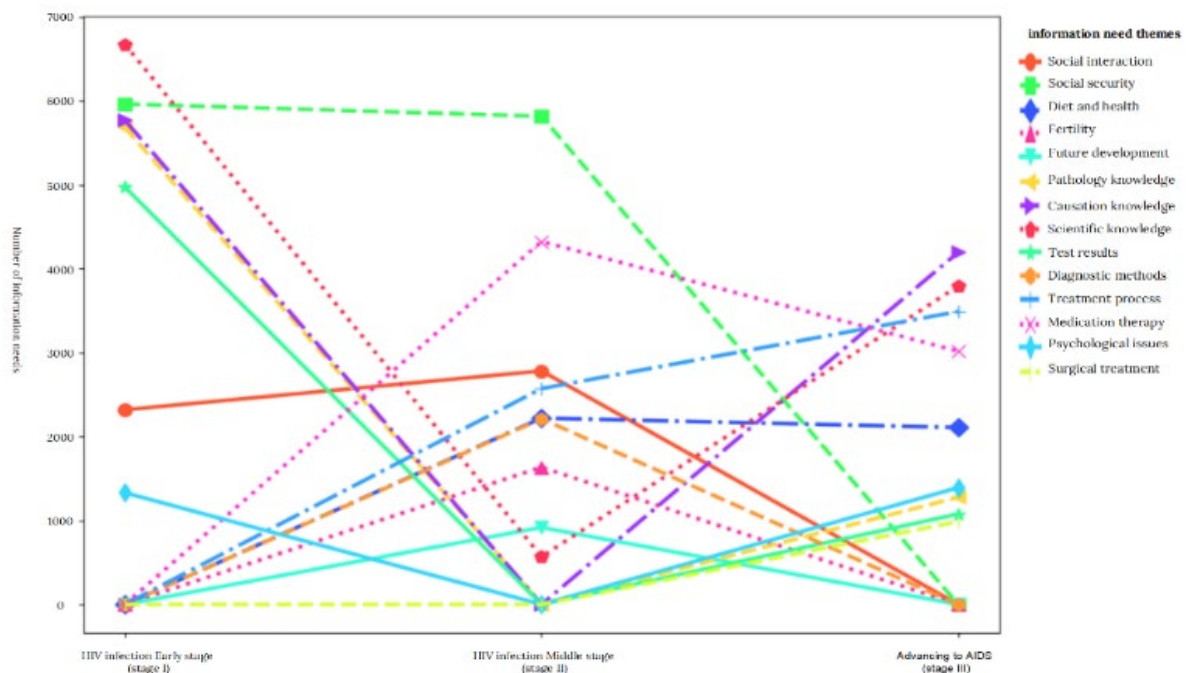


Figure 3. Dynamic changes in information need themes expressed by people living with HIV/AIDS across different stages of disease

The changes in information need themes of people living with HIV/AIDS during different disease stages across media platforms are illustrated in Figures 4–7.

On Little Red Book, people living with HIV/AIDS express different information needs during each stage of the disease. During the early stage of HIV infection (stage I), they primarily express different information need themes related to social interaction, pathology knowledge, scientific knowledge, psychological issues, and test results. During the middle stage of HIV infection (stage II), their information needs broaden to include social interaction, scientific knowledge, social security, fertility, diet and health, future development, treatment process, medication therapy, and diagnostic methods. During the Advancing to AIDS stage (stage III), their focus shifts markedly toward pathology knowledge, treatment process, diet and health, test results, psychological issues, and scientific knowledge, as shown in Figure 4.

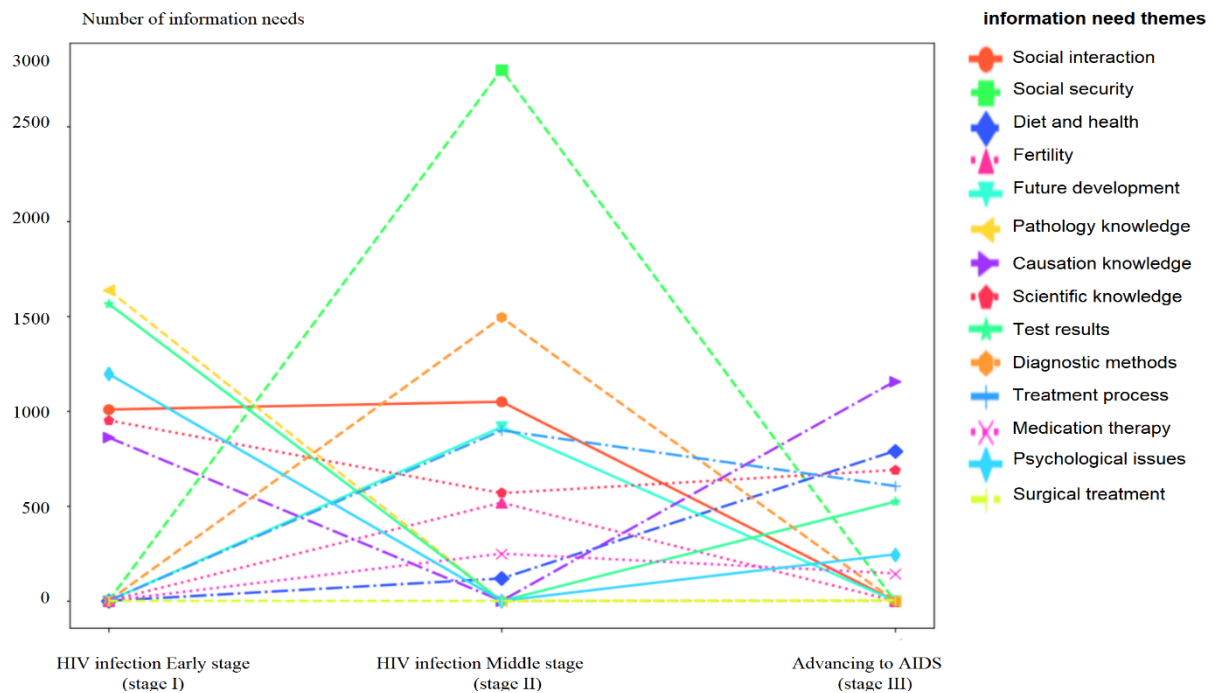


Figure 4. Dynamic changes in information need themes expressed by people living with HIV/AIDS on Little Red Book

On Baidu Knows, people living with HIV/AIDS during the early stage of HIV infection (stage I) search for social security, pathology knowledge, scientific knowledge, psychological issues, and test results. During the middle stage of HIV infection (stage II), in addition to ongoing interest in social security and scientific knowledge, their needs expand to include fertility, diet and health, treatment process, and medication therapy. During the Advancing to AIDS stage (stage III), their information needs become more concentrated on diet and health, treatment process, medication therapy, pathology knowledge, scientific knowledge, test results, and psychological issues, as shown in Figure 5.

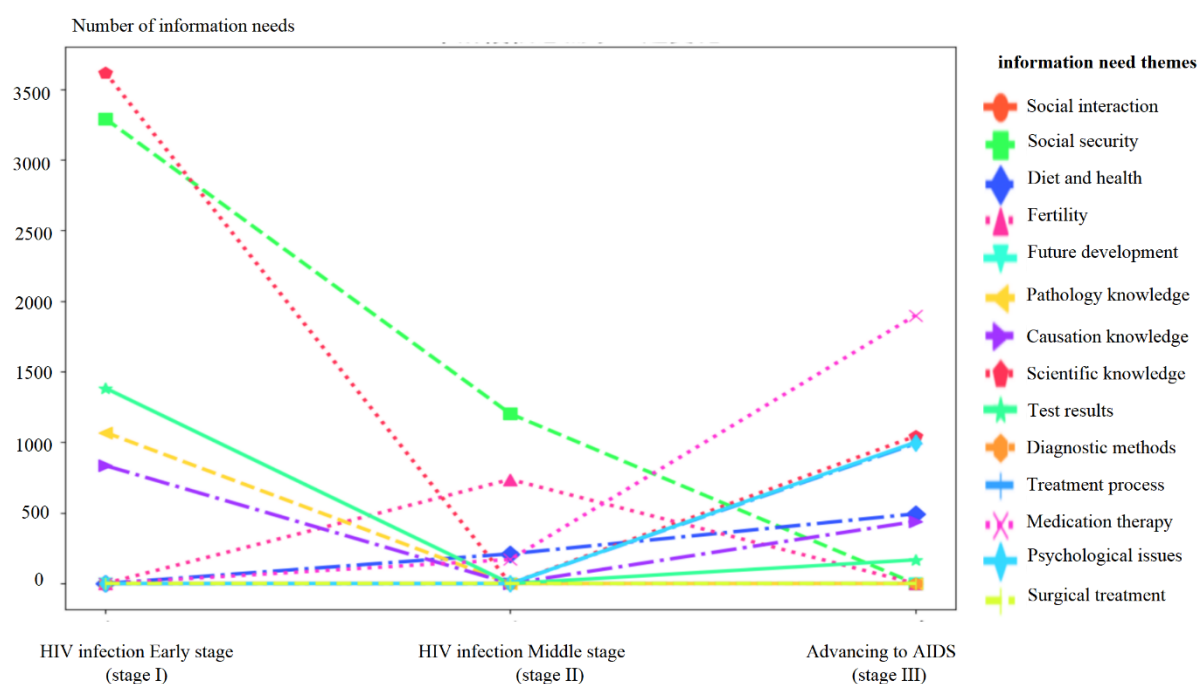


Figure 5. Dynamic changes in information need themes expressed by people living with HIV/AIDS on Baidu Knows

On Haodf.com, people living with HIV/AIDS during the early stage of HIV infection (stage I) focus on causation knowledge, pathology knowledge, scientific knowledge, psychological issues, and test results. During the middle stage of HIV infection (stage II), their expressed needs shift to social security, fertility, treatment process, medication therapy, and diagnostic methods. During the Advancing to AIDS stage (stage III), their needs concentrate on treatment process, medication therapy, pathology knowledge, causation knowledge, scientific knowledge, psychological issues, and surgery consultation, as shown in Figure 6.

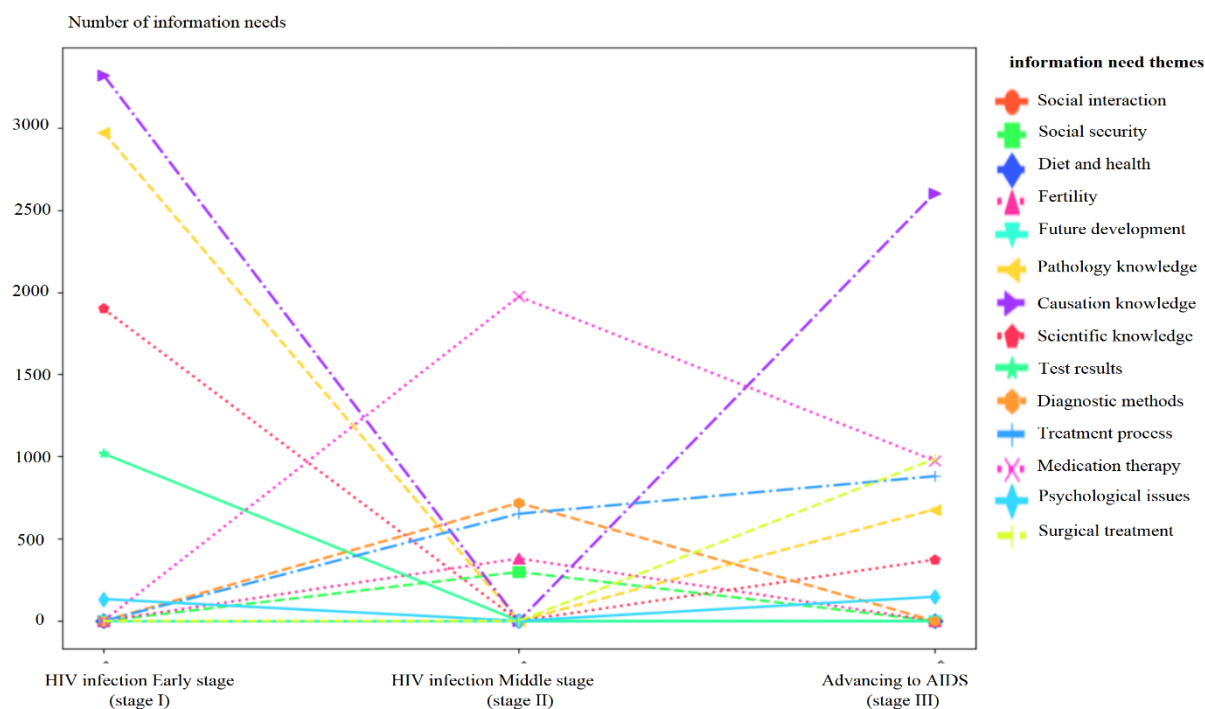


Figure 6. Dynamic changes in information need themes expressed by people living with HIV/AIDS on Haodf.com

On the Zhi Ai Jiayuan forum, people living with HIV/AIDS during the early stage of HIV infection (stage I) express needs centred on social interaction, social security, pathology knowledge, scientific knowledge, and test results. During the middle stage of HIV infection (stage II), their information needs expand to include social interaction, social security, diet and health, treatment process, and medication therapy. During the Advancing to AIDS (stage III), their needs focus on diet and health, treatment process, pathology knowledge, scientific knowledge, and test results, as shown in Figure 7.

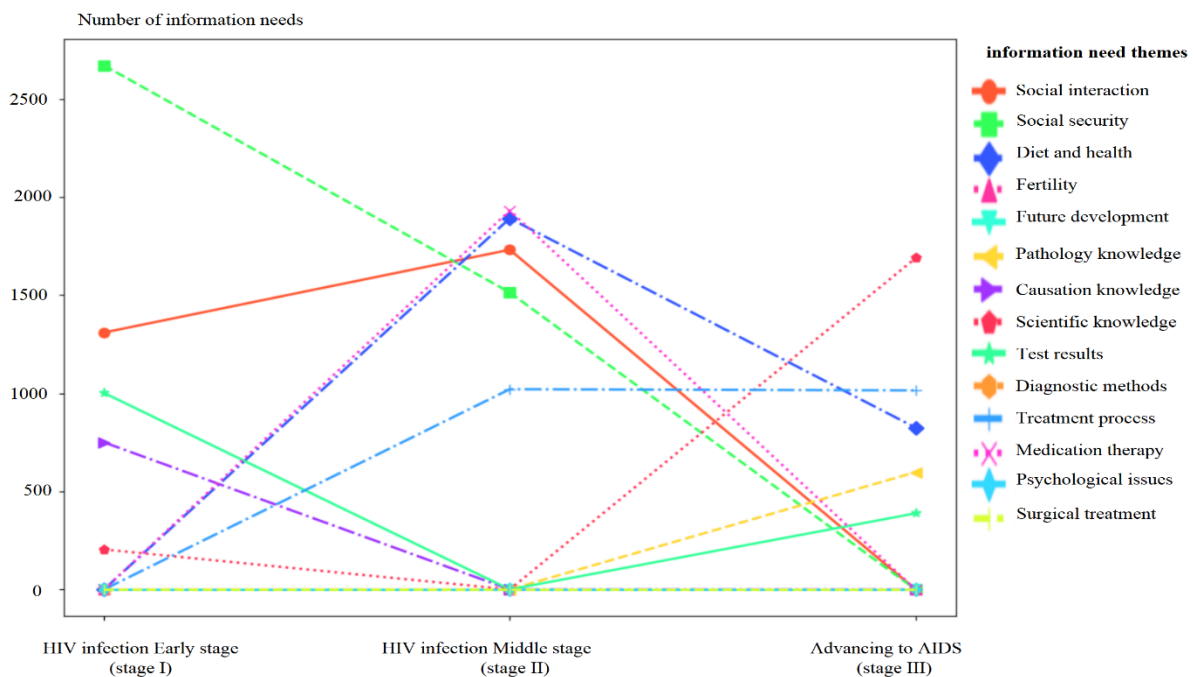


Figure 7. Dynamic changes in information need themes expressed by people living with HIV/AIDS on the Zhi Ai Jiayuan forum

Discussion

Analysis of information need themes

This study found significant differences among the themes of information needs expressed by people living with HIV/AIDS across various media platforms. These differences were closely related to each platform's functional positioning, information presentation style, and interactive mechanisms. Specifically, the Little Red Book platform is a lifestyle-oriented platform centred on visual and textual content and social interactions that encourages users to engage in emotional expression and exchange life experiences. Influenced by its social nature, people living with HIV/AIDS primarily express needs for social interaction-related information, including seeking a confidant, maintaining family and social relationships, and exchanging causation knowledge. This finding aligns with prior studies examining information needs expressed on social media platforms (Ayers, et.al., 2024; Jindal & Liao, 2018).

In contrast, Baidu Knows functions as a structured knowledge question-answer platform, leveraging its robust search capability to provide precise and practical solutions to specific problems (Bazrafshani, et.al., 2022). On this platform, people living with HIV/AIDS predominantly focus their information needs on causation knowledge, interpretation of test results, and social security issues. This differs from previously studied topics such as HIV virology, epidemiological trends, transmission routes, clinical diagnoses, and preventive measures (Liu & Yuan, 2020). These differences indicate that users on the Baidu Knows platform prefer information directly relevant

and practically useful to their personal health situations. Their preference may stem from perceptions of Baidu's search efficiency and information accuracy, positioning it as a preferred platform for obtaining practical and solution-oriented information.

Haodf.com, a professional medical service platform, emphasises content generated by healthcare professionals, including health articles and online consultations, thereby offering authoritative and specialised medical information (Liu & Lu, 2018). Previous research has shown that online health communities provide emotional support and social companionship for people living with HIV/AIDS (Liu & Yuan, 2020; Zhong, et.al., 2024). The findings from this study further illustrate that, owing to its strong emphasis on medical professionalism, users on the Haodf.com platform primarily express information need themes related to medication advice, medication efficacy, and management of complications.

Zhi Ai Jiayuan, a specialised forum for HIV/AIDS-related discussions, traditionally provides emotional and companionship support for users (Hu, 2018; Yu, 2015). This study further reveals that the platform has developed a more comprehensive organisational structure of information and content. Its content covers diverse aspects, including causation knowledge at the initial diagnosis, the treatment process, and medication therapy, to psychological issues, social security, diet and health, and fertility. With consistent topic continuity and strong community cohesion, the platform offers a stable information environment, enabling users to access comprehensive information spanning medical, daily life, and social dimensions. Thus, it constitutes an integrated information support system capable of meeting diverse needs across both disease stages and daily living.

Differences in how information needs are expressed stem from uncertainty within information behaviour and from individuals' choices of information sources (Case & Given, 2016). When a knowledge gap is perceived, needs are typically voiced as questions or help-seeking requests and become progressively specified within concrete contexts (Belkin, 1982; Dervin & Naumer, 2009; Kuhlthau, 1991; Taylor, 1968). On this basis, individuals choose from multiple sources according to criteria such as relevance, timeliness, usability, and reliability (Kuhlthau, 1999; Sonnenwald, 1999; Wilson, 1999). Meanwhile, the affordances of different media also shape the modes of expression, and the relative weighting of information need themes (Hirvonen, 2022; Park, et al., 2019).

Across media platforms, the information services currently offered could be optimised based on the information need themes expressed by users on each platform. The Little Red Book meets the emotional support needs of people living with HIV/AIDS. However, to strengthen this, the platform could add dedicated columns such as *Psychological Adjustment Guides* and *Patient Stories*, encouraging users to share personal experiences via images, text, or short video. The Baidu Knows platform could refine platform tags and improve question categorisation by adding discussion areas for core themes such as *Social security* and *Disease management*. It may also consider establishing an *Urgent help* rapid-response mechanism to help patients find relevant solutions quickly. The Haodf.com platform could add specialised modules on *Treatment effectiveness* and *Disease management*, offering clear information on *Treatment methods*. Charts and flowcharts could help patients understand the treatment options across different disease stages. Lastly, the Zhi Ai Jiayuan forum could add dedicated sections on *Treatment costs* and *Social security*, providing detailed explanations of social security policies and cost-management guidelines. By setting up navigation tags for *Insurance reimbursement* or *Financial assistance*, the forum could ensure that users can find the existing social security resources to alleviate economic burdens.

Analysis of the dynamic changes in information need themes

This study indicates that people living with HIV/AIDS express information need themes that evolve over the course of their illness journey. These changes not only reflect how people adjust their information needs according to disease progression but also reflect the shifts in their daily

routines. Different disease stages constitute key turning points in the illness journey (Genuis & Bronstein, 2017; Loveys, 1990). Prior to HIV infection, individuals' lives correspond to the routine, controllable daily patterns described by Savolainen (1995).

An HIV diagnosis, however, represents a major life transition. To cope with this shift, people living with HIV/AIDS require information that meets their needs and maintains continuity in their daily lives. This aligns with previous findings that they need ongoing informational support to navigate the turning points of their illness journey (Brown & Powell-Cope, 1991; Han, et.al., 2023).

In the early stage of HIV infection (stage I), people living with HIV/AIDS experience physical discomfort and confusion due to the uncertainty surrounding diagnosis (Liu, et.al., 2023; Reid, et.al., 2010; Zhang, et.al., 2016). To alleviate this distress, they need scientific knowledge and pathology knowledge, as well as guidance for test result analysis, to build a preliminary understanding and reduce uncertainty. Simultaneously, the psychological burden of social stigma and related emotional stress drives a strong need for emotional support and counselling information. People living with HIV/AIDS seek resources on psychological counselling and social support to help them cope with emotional distress and adapt swiftly to the diagnosis.

Providing timely education on basic disease information, along with emotional comfort and reassurance, is therefore critical in helping individuals manage early-stage challenges and prepare for subsequent treatment.

During the middle stage of HIV infection (stage II), people living with HIV/AIDS have begun and adapted to standardised antiretroviral therapy and accumulated some experience in disease management (Supodo, 2020). At this point, the expressed information need themes shift from early-stage concerns to optimising treatment effectiveness. They increasingly seek information on medication precautions, medication efficacy, and personalised health management guidance based on treatment effectiveness. Such information enhances their disease management capacity, quality of life and strengthens their sense of control during long-term treatment, enabling more proactive lifestyle adjustments.

To adapt to new social and family roles, they also express needs for information and guidance on increasing social participation and protecting personal privacy in workplace and social settings (Goodman, et.al., 2022; Marellapudi, et.al., 2021). Interventions during the middle stage (stage II) should therefore align with these evolving information needs by promoting healthy lifestyles, fostering social engagement and supporting psychological adjustment, thereby enabling individuals to use information effectively to adapt to new environments and roles for long-term disease management.

As people progress to the Advancing to AIDS stage (stage III), people living with HIV/AIDS face more complex health challenges, including opportunistic infections and various complications. Their information needs become highly specialised and context-specific (Rangaraj, et.al., 2022; Zeng, et.al., 2025). They express needs for in-depth information on pathology, dietary and health recommendations, treatment effectiveness, and medication efficacy to manage their health, improve quality of life, and prolong survival. They also express needs for content on psychological adjustment, social support and palliative care to address emotional stress and relieve psychological burden, ensuring that social interaction and psychosocial needs are met (Zeng, et.al., 2025). Therefore, at this stage, people living with HIV/AIDS require personalised informational support that offers comprehensive medical guidance and holistic psychosocial assistance, guaranteeing that they receive adequate support and care in their final life phase.

Different media platforms possess distinct strengths in meeting these information needs. As the illness journey progresses, the uncertainty surrounding these needs is reconstructed in a stage-

specific manner (Belkin, 1982; Dervin & Naumer, 2009; Kuhlthau, 1991; Ruthven, 2022). Accordingly, users are advised to select and adjust platforms in line with their current disease stage and the types of information required. During the early stage of HIV infection (stage I), they may prioritise Little Red Book for emotional expression and experience sharing. For concrete ‘how-to’ questions, Baidu Knows can provide structured answers, while Haodf.com offers physician advice and guidance when individualised medication or risk assessment are involved.

Upon entering the middle stage (stage II), people living with HIV/AIDS can combine Baidu Knows and Haodf.com to obtain actionable responses and verify knowledge to support treatment and daily life adjustments, while using Zhi Ai Jiayuan to supplement information on social security and provide peer support. During the Advancing to AIDS stage (stage III), they can focus their use on Haodf.com to obtain clinical decision making and referral recommendations, supplemented by Zhi Ai Jiayuan to provide social support and help build a sustainable support network. Table 6 further illustrates the relationships among information need themes, disease stages, and platform characteristics.

Disease stage	Themes	Recommended platforms	Platform advantages & features
HIV infection early stage (stage I)	Social interaction; Psychological issues; Basic AIDS knowledge	social media platforms (e.g. Little Red Book); online health communities (e.g. Haodf.com)	Supports emotional expression and peer experience sharing, combined with access to professional health knowledge, to help patients in the initial HIV infection stage alleviate psychological stress and acquire foundational disease knowledge.
HIV infection middle stage (stage II)	Diet and health; Treatment process; Fertility	knowledge question-answer platform (e.g. Baidu Knows); online health communities (e.g. Haodf.com)	Combines real-time answers from knowledge Q&A platforms with professional guidance from online health communities to help HIV patients manage treatment processes, medication efficacy, and complication management.
Advancing to AIDS (stage III)	Medication therapy; Complications management; Psychological construction	online health communities (e.g. Haodf.com); specialised forums (e.g. Zhi Ai Jiayuan)	Integrates professional medical consultations with peer support, assisting AIDS patients in handling complex medication regimens, complication management, and end-of-life care needs.

Table 6. Mapping information needs across disease stages and platforms

Conclusion and limitations

From an illness journey perspective, this study integrates BERTopic with dynamic topic modelling to conduct cross-platform and stage stratified comparisons of the information need themes expressed by people living with HIV/AIDS on different media platforms during 2022–2024. The results indicate marked cross-platform differences in theme distributions and reveal dynamic shifts in focal themes as the disease progresses. Social media platforms and specialised forums emphasise emotional support and the exchange of lived experiences; question and answer platforms foreground actionable, problem-solving responses; and online health platforms provide professional verification and clinical advice. These findings underscore the need for cross-platform collaboration to meet the comprehensive information needs of people living with HIV/AIDS. In practice, informational support should therefore match information types and delivery channels to disease stage and commonly used platforms, thereby providing targeted and context-sensitive services.

Overall, this study adds to the thematic understanding of the information needs of people living with HIV/AIDS along temporal and contextual dimensions. It demonstrates the applicability of topic modelling and dynamic analysis techniques for uncovering changes in information needs and offers a new technical pathway for information needs research. The findings furnish a structured basis for cross-platform coordination and targeted referral, enabling individuals to select appropriate media platforms in line with stage-specific needs and obtain tailored informational support more efficiently. In addition, the study proposes operationalisable evaluation dimensions, providing a quantitative foundation for translating descriptive insights into testable, practice-oriented interventions.

This study has several limitations. First, interrogative sentences were used as high-recall cues in the initial screening to locate texts expressing information needs. This strategy favours explicit, solution-seeking needs but insufficiently covers needs articulated in non-interrogative forms (for example, narrative statements), leading to possible omissions. To broaden coverage, future work could incorporate intent detection for non-interrogative texts at the pre-screening stage and conduct validation analyses comparing alternative screening strategies.

Second, the disease-stage labels used in this study were not native to the platforms; rather, they were assigned by referencing the *Diagnostic Criteria for HIV/AIDS* and segmenting texts accordingly. Misclassification is more likely near stage boundaries (for example, transitions from HIV infection middle stage to AIDS). To mitigate this risk, a closed-loop pipeline was adopted, comprising manual annotation, support vector machine training, and active learning with second-pass calibration for low-confidence cases. Even so, residual error may persist. To improve labelling quality and result stability, future research could refine decision rules, expand the labelled sample, and quantify consistency (for example, inter-annotator agreement).

Third, the use of multiple platforms, numerous themes, and a stage-stratified framework the study required a large number of statistical tests. With a large sample size, this may yield statistically significant yet substantively trivial findings. To reduce this risk, Holm–Bonferroni corrections were applied to pairwise platform comparisons, and alongside the overall chi-squared test, effect sizes (Cramér's V) and 95% confidence intervals for platform-specific proportions were reported. To strengthen substantive interpretation, future research should reduce the number of tests, emphasise effect sizes, and pre-specify a small set of key contrasts and minimum important effect thresholds. Supplementing analyses could include absolute differences and their confidence intervals, equivalence testing, and bootstrap resampling.

Fourth, this study relies on publicly available social media texts and did not conduct face-to-face interviews; consequently, it may not capture latent information needs or allow probing of

individual motivations and contextual details. Future research will adopt a mixed-methods design, conducting semi-structured interviews grounded in the thematic framework developed here to refine the thematic taxonomy and propose platform-specific support strategies.

Fifth, data were collected for 2022–2024. The public health and healthcare context during this period (including COVID-19-related care environments) may have influenced how information needs were expressed on social media. Because the study focused on platform- and stage-based theme differences rather than identifying the effects of specific events, no causal inference is being made regarding COVID-19 or similar shocks. The observed differences primarily reflect the contextual features of this period, limiting generalisability across time and settings. Moreover, the relatively short observation window may not capture long-term trends or deeper shifts in information needs. Future research could extend the time span to analyse long-term trajectories and assess the impact of sudden events on thematic structures.

Acknowledgements

The authors wish to thank the participants for generously sharing their experiences, and the research assistants who supported the data collection and transcription. They also wish to thank the reviewers and editors of the journal for their valuable feedback and insightful comments.

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