Living with hypertension: Data from patient perspectives on social media

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Table of Contents

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Abstract

Background: Hypertension is widely recognized as a clinically asymptomatic condition and often described as a “silent killer.” Despite this, growing evidence from research suggests that chronic conditions such as hypertension can significantly affect emotional well-being and disrupt daily life. In addition, whilst previous studies have highlighted that adherence to hypertension treatment is influenced by patients’ perceptions and quality-of-life impacts, these aspects remain underexplored, particularly outside structured clinical settings.

Objective: This study used social media listening (SML) to capture unprompted patient perspectives to examine how hypertension affects patients’ quality of life across countries and demographic groups, and to explore how emotional responses influence treatment adherence.

Methods: A social media listening study analyzed 86,400 anonymized posts from individuals with hypertension across 12 countries, collected between January 2022 and May 2024. Posts from 11 countries were translated and analyzed using artificial intelligence–enabled natural language processing to identify themes related to symptoms, care experiences, quality of life impacts, and treatment usage patterns. Posts from China were analyzed separately using a harmonized framework to comply with data transfer regulations. Quantitative and qualitative methods assessed variations by country, age, and gender, and to explore associations between emotional expression and treatment adherence.

Results: Patients with hypertension reported significant emotional burdens—particularly worry and anxiety—as well as disruptions to daily activities, work, social relationships, and finances. These impacts varied across country contexts. Patients in European countries more often described logistical burdens, such as the time demands of medical appointments, while those in Asian countries more frequently reported financial concerns.
Age-related differences were also observed: individuals under 40 years of age more commonly reported emotional strain and lifestyle disruption, whereas those aged 40 and above emphasized practical challenges, including treatment costs and access to care. Gender patterns further shaped the patient experience. Women more frequently described emotional impacts and frustrations with healthcare encounters, while men more often reported lower engagement with medical appointments and self-monitoring practices.
A link between distinct emotional reactions and treatment patterns was observed: patients who expressed more worry about their condition were more likely to consistently adhere to treatments and engage in other healthy habits, like monitoring their blood pressure or making lifestyle changes. In contrast, mentions of less consistent treatment adherence more often coincided with references to forgetfulness, side effects, cost concerns, sadness or depression.

Conclusions: The identified social media narratives reveal substantial psychological and practical impacts of hypertension, often underrecognized in clinical settings. Emotional engagement with the condition appears to influence treatment adherence, with

worry serving as a potential motivator and depressive symptoms acting as a barrier. Social media listening offers a valuable, patient-focused approach that complements traditional research in understanding the lived experience of hypertension.

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Living with Hypertension: Data from Patient Perspectives on Social Media

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A link between distinct emotional reactions and treatment patterns was observed: patients who expressed more worry about their condition were more likely to consistently adhere to treatments and engage in other healthy habits, like monitoring their blood pressure or making lifestyle changes. In contrast, mentions of less consistent treatment adherence more often coincided with references to forgetfulness, side effects, cost concerns, sadness or depression.

Conclusions:

The identified social media narratives reveal substantial psychological and practical impacts of hypertension, often underrecognized in clinical settings. Emotional engagement with the condition appears to influence treatment adherence, with worry serving as a potential motivator and depressive symptoms acting as a barrier. Social media listening offers a valuable, patient-focused approach that complements traditional research in understanding the lived experience of hypertension.

Keywords: Hypertension; Social Media Listening; Patient Experience; Emotional Impact; Treatment Adherence; Quality of Life; Real-World Evidence.

Introduction

Often described as a "silent killer" due to its frequent lack of noticeable symptoms (WHO, 2013), hypertension is the leading risk factor for death and disability globally.[1,2](Hypertension affects approximately one in three people worldwide,[2] and is expected to become increasingly prevalent as global populations age and certain risk factors, such as obesity, become more widespread.[1] Despite its high prevalence and severe health consequences, hypertension remains poorly controlled, with treatment non-adherence identified as a significant barrier to effective disease management.[3,4]

Traditional research methods, including qualitative interviews, quantitative surveys and data from clinical research, have provided invaluable insights into global hypertension epidemiology[5] and patient experiences. [3,6] However, these approaches may fail to fully capture patients' subjective experiences and the broader impacts of the condition. Noninterventional approaches are therefore crucial to developing a more holistic understanding of patient perspectives. Social Media Listening (SML)—the systematic analysis of unsolicited online conversations—is a powerful non-interventional research technique, enabling the study of authentic, unprompted, organic patient narratives at scale.[7-9] Recognized by regulatory bodies such as the US Food and Drug Administration

(FDA) as a valuable source of Patient Experience Data,[10] SML has proven effective in assessing quality-of-life impacts[9,11]and exploring treatment adherence across geographically and demographically diverse populations.[7,11] However, to date, no published SML studies have specifically investigated patient perspectives on hypertension experiences or management, highlighting a critical gap in current knowledge.

Given hypertension's often asymptomatic nature and the potential stigma associated with treatment non-adherence, patients may underreport their true experiences or adherence challenges in clinical settings or structured research contexts.

To address these gaps, this study leverages SML and advanced Natural Language Processing (NLP) techniques to analyse patient perspectives on living with hypertension across twelve countries, examining cross-country differences, patient profiles and contexts, and the relationship between perceived impacts and treatment adherence.

Methods

Data Collection and preparation

Social media listening (SML) was used to listen to the voices of a global population of people with hypertension. Publicly available social media and forum posts from individuals living with hypertension, published between January 2022 and May 2024, were collected from global platforms such as Facebook, Reddit, X (formerly Twitter), and Instagram; Chinese platforms including Xiaohongshu, Weibo, Douyin, and Bilibili; and a range of country-specific patient forums for analysis.

Posts were identified using an English-language keyword query specifically developed for hypertension-related patient discussions, subsequently translated into eight languages (Portuguese, German, French, Italian, Spanish, Japanese, Korean, Mandarin Chinese), allowing data to be gathered from the United States (US), Canada, Brazil, the United Kingdom (UK), Germany, France,

Italy, Spain, Japan, South Korea, China, and Australia. All publicly accessible patient-generated posts meeting the keyword criteria within the specified timeframe and platforms were collected.

Posts published in languages other than English were systematically translated using Google Translate (version 2.0.14). Subsequently, multilingual expert analysts rigorously reviewed and refined translations to ensure accurate keyword rendering and overall semantic faithfulness.

Analysts manually reviewed and removed duplicate posts (e.g., cross-posts, retweets), metaphorical references to "high blood pressure" without clinical relevance, and posts which referred to the condition with no further detail on the patient experience. To approximate relative hypertension prevalence and national patient population sizes, the final dataset was refined by proportionally rebalancing posts per country. This was achieved by algorithmically removing excess posts removing (approximately 3,000 in total) at random from countries with disproportionately high digital verbosity. This sampling approach preserved the integrity of the overall global view while maintaining sufficient data from each country to support meaningful country-level analysis.

While the demographics within each country's sample were reviewed, they were intentionally not adjusted to preserve an accurate representation of individuals publicly discussing hypertension online.

Data anonymization complied strictly with the General Data Protection Regulation (GDPR) principles, involving automated removal of social media handles and manually checking for potentially identifying information (names, specific locations, or distinctive personal details). All analyses were performed on fully anonymized datasets.

As this study utilized existing, publicly accessible, and anonymized data, the ethics committee Pearl IRB determined that this study did not constitute human subjects research (ID 2024-0294) and was thus deemed exempt of IRB approval.

Language data analysis

Analysis utilized Luminoso, a commercially available artificial intelligence-driven NLP platform, for

analysis of all data except for that from China. Data from China were analyzed separately, following research frameworks and themes developed in the core analysis, to comply with China data transfer regulations. Luminoso was selected for its capacity to robustly explore semantic nuance in large-scale text data sets through inductive (bottom-up) thematic analysis.[12] Luminoso's effectiveness in capturing authentic patient experiences from unstructured online discussions has been previously shown in the study of patient experiences of Sjögren's disease.[13]

Following upload of the data to Luminoso, the research team initially explored the extensive unstructured text dataset and followed a bottom-up, inductive grouping approach to identify and define specific "concepts" in the patient language. These individual concepts (e.g., "anxiety") were iteratively grouped into broader thematic areas (e.g., "emotional impacts) and analytical domains (e.g., "QoL impacts") following thematic frameworks standard to patient experience research.[9] To ensure analytic rigor and reduce potential biases at this stage, all identified concepts and groupings were reviewed by separate analysts to those who created them before being finalized. In total, approximately 130 individual concepts — grouped into the analytical domains of disease terms and status, comorbidities, broader perceived causes, symptoms, life impacts, non-RX disease management, treatments, side effects, healthcare professional (HCP) types, and journey stages — were analyzed.

After defining and validating the concepts, the research team used Luminoso to conduct a thorough mixed-methods analysis of the data, examining both quantitative metrics (e.g., frequency of concept mentions, concept associations) and qualitative aspects (e.g., patient language patterns, illustrative examples). This integrated approach aligns with recommended best practices in SML research, maximizing both analytical scale and interpretive depth.[9]

Quantitative data from SML differ significantly from traditional survey data, as social media posts typically reflect patients' most immediate or significant concerns rather than exhaustive experiences. Thus, lower mention frequencies in social media data likely represent experiences more common

than equivalent percentages from structured surveys. Drawing upon previous experience with SML studies, including Perella et al. (2023), the research team recognized that experiences mentioned in approximately 50% of posts might indicate near-universal patient prevalence. However, mention frequencies varied substantially by topic; for example, symptoms were generally discussed more frequently than less immediately salient topics, such as comorbidities or treatment patterns.

To aid interpretation of the social media data, based on prior experience with social media listening data the research team defined the quantitative concept commonness data by thresholds, categorizing concept mentions as negligible (<2%), uncommon (2–6%), quite common (7–20%), common (21–40%), or very common (>40%). In addition, concept association scores were calculated to identify relationships between concepts. These scores reflect the conditional probability that a post mentioning one concept also mentions another—that is, the percentage of posts where the two concepts co-occur, relative to the total number of posts mentioning the first concept.

Results

Sample size and demographics

A final sample of 86,400 social media posts from 67,200 unique accounts were analyzed. The core sample used for Luminoso language analysis was 81,400 posts, comprising content from 11 countries (excluding China) and an additional 3,700 English-language posts Reddit that mentioned primary hypertension or hypertension with renal comorbidities (Table 1). An additional 5,000 posts from China were collected and analyzed separately to allow for comparable insights while complying with China's data transfer regulations.

Table 1. Social media listening sample distributions (n=86,400)[a]

Variables and categories	Participants, n (%)
Country Location samples[b]	
US	36,300 (44)
Brazil	11,200 (14)
Canada	2,500 (3)
UK	4,600 (6)
Germany	4,200 (5)

France	2,700 (3)
Italy	1,300 (2)
Spain	5,100 (6)
Japan	5,500 (7)
South Korea	3,500 (4)
China	5,000 (6)
Australia	900 (1)
Gender	
Female	11,300 (51)
Male	11,000 (49)
Age	
Under 40 Years Old	2,800 (35)
40 Years Old and Above	5,300 (65)
Ethnicity/ Race	
White	269 (34)
Black	240 (30)
Asian	153 (19)
Hispanic	132 (17)

[a]Sample sizesshown to nearest ’00.
[b]Non country coded samples: Boosts of samples for primary hypertension and hypertension with renal comorbidities gathered from Reddit in English language were also included: n=3,700.

Across the core 81,400 post sample (excluding China), gender was identifiable in 22,300 posts (51% male, 49% female), age group in 8,100 posts (65% aged 40+ years, 35% <40 years), and U.S. patient ethnicity in 800 posts (White 34%, Black 30%, Asian 19%, Hispanic 17% (Table 1). In all results reporting, unless China is explicitly referenced, values reflect the 11-market core sample excluding China, due to the need for separate analysis in line with data transfer regulations.

Terminology used by patients to describe their condition

Across the core sample, patient posts overwhelmingly used the lay term “high blood pressure” (86%) rather than the clinical term “hypertension” (14%) when describing their condition. Notable exceptions were patients from Spain (hipertensión) and France (hypertension artérielle, commonly abbreviated as HTA), who more frequently used these shorter, clinical terms. The clinical term “hypertension” was more commonly used by patients with severe conditions, comorbidities, who explicitly mentioned consultations with cardiologists, potentially reflecting their increased exposure to medical terminology. Patients explicitly referred to a diagnosis of “primary” or “essential”

hypertension in 10% of posts. The term “secondary” hypertension was rarely mentioned.

Condition status and comorbidities

In this study, 16% of all core sample posts mentioned condition status. Of these, 88% referred to a condition controlled by treatments whilst 12% described an uncontrolled or resistant condition.

Multiple comorbidities were mentioned by patients. Cardiovascular conditions and heart problems were mentioned most often, in 24% of all core sample posts. Metabolic conditions (19%) were also commonly mentioned; of these, diabetes (14%) and obesity (8%) were most common. Mental and neurological conditions (9%) were quite commonly mentioned, with anxiety disorders (6%) and depression (3%) mentioned most (Table S1 in Multimedia Appendix 1).

> “Probably linked to my obesity, I have been diagnosed with hypertension (180/90 without drugs) as well as prediabetes” - Patient, Primary hypertension, Male, 40+ age group, United States.
>
> “I have been struggling with anxiety, panic disorder and major depressive disorder for 14 years now. Over the years I have also developed hypertension.” - Patient, Hypertension with cardiac comorbidities, Female, <40 age group, United Kingdom.

An age-related pattern emerged: patients above 40 years more frequently mentioned cardiovascular issues and diabetes as co-occurring conditions, while patients below 40 years cited more commonly obesity (Table S2 in Multimedia Appendix 1).

Symptom mentions

This research found hypertension to be largely asymptomatic, with no single symptom commonly mentioned across patient posts. A long tail of 15 distinct physical symptoms was identified, though each was mentioned infrequently— appearing in no more than 5% of posts. The top individual symptoms that patients attributed directly to hypertension (rather than to treatment side effects) were joint or muscle pain (5%), headaches or migraines (4%), hearing issues (4%)—including tinnitus and

other sounds—and vision disturbances (3%) (Table S3 in Multimedia Appendix 1). Patients who mentioned their disease status (controlled, uncontrolled, or resistant) also discussed symptoms more frequently. Those with uncontrolled or resistant hypertension were especially more likely to report symptoms—particularly aches and pain (16% vs. 10%) and fatigue and sleep issues (11% vs. 5%)—compared to those with controlled hypertension (Table S4 in Multimedia Appendix 1).

Quality of Life (QoL) impact mentions

Quality of Life impacts were mentioned very commonly (45% of all core sample posts) spanning the areas of everyday life (21%), emotional balance (20%), work/education (10%), social connections (6%), and financial health (5%) (Table 2). Patient posts frequently contained references to more than one impact area; therefore, the sum of mentions of specific life impacts are typically higher than the total percentage of posts mentioning the broader life impact area.The single most common individual impact was worry/anxiety (11%), an emotional balance area impact, which was mentioned across the patient journey and especially at diagnosis (15%).

Table 2. QoL impact areas and individual impacts mentioned (in 2% or more posts) across core sample (n=81,400) [a]

Life Impact Area Mentions	Total (%)	Individual Life Impact Mentions	Total (%)
Everyday Life	21	Time spent on medical appointments	9
		Sleep disruption	6
		Time spent researching online	5
		Functional limitations	3
		Household task difficulties	2
Emotional Balance	20	Worry and Anxiety	11
		Sadness and depression	4
		Fear	2
		Shock and disbelief	2
Work/ Education	10	Impact on job performance	9
Social Connections	6	Impact on family & friendships	3
		Ability to maintain a social life	2
Financial Health	5	Expense cost concerns	3

Insurance coverage	2

[a]Core sample excludes China due to country data transfer regulations. Samples sizes shown to nearest ’00.

Differences in QoL impacts by patient profile

Country

Clear differences in QoL impact mentions by country emerged. Patients in five countries - Spain, France, Germany, South Korea and Japan - reported impacts with higher frequency than the global average (Table 3).

Table 3. QoL impact area mention volume percentages (%) by country across total sample (n=86,400)[a]

Market	Total Life Impacts (%)	Everyday Life (%)	Emotional Balance (%)	Work & Education (%)	Social Connections (%)	Finances (%)	Total Posts (n)
Global Sample	45	21	20	10	6	5	86,400
South Korea	64	28	29	18	10	8	2,236
France	60	33	25	11	11	6	2,686
Spain	55	34	17	11	10	6	2,768
Germany	51	25	27	11	7	3	2,126
Japan	48	20	21	10	7	7	2,608
United Kingdom	45	21	19	10	5	4	2,078
Canada	45	21	19	13	6	3	1,103
Australia	44	20	21	11	4	6	403
United States	42	19	19	10	5	5	15,151
China	41	10	15	10	7	7	3,450
Brazil	38	12	21	5	5	4	4,198
Italy	31	20	17	5	7	4	396

[a]Total sample includes China which was analyzed separately to core sample due to country data transfer regulations. Sample sizes shown to nearest ’00.

In Europe, patients from Spain (34%), France (33%), and Germany (25%) frequently highlighted impacts related to everyday life, emphasizing practical challenges such as the inconvenience, time burden, and disruption to leisure or personal activities caused by frequent medical appointments. Specifically, these patients cited lengthy wait times and difficulties accessing specialists, potentially

reflecting regional healthcare system limitations and clearly connecting healthcare delays to personal QoL impacts.

In Asia, patients from South Korea (8%), Japan (7%), and China (7%) expressed particular concern about the financial health impacts associated with managing hypertension. These financial concerns were more prominent among patients above 40 years of age, who described increased anxiety regarding healthcare costs following retirement. This difference by age aligns with the broader global pattern observed in older age groups (Table 4).

> *"When I was diagnosed at a cardiology clinic, I paid nearly 10,000 yen (approximately $70 USD), including for my medication. And the prescriptions change every time I visit, so the costs keep coming"* - Patient, Male, 40+ age group, Japan.

In the US, patients more frequently self-identified their race or ethnicity in posts and a sample of 800 posts from patients with race or ethnicity data was qualitatively analyzed (Figure S1 in Multimedia Appendix 1). Notable differences in experiences with HCPs were identified: Patients self-identifying as Black more frequently describing negative HCP experiences, including being dismissed, and inadequately informed or cared for. These patients mentioned attending medical appointments less often than other patients and referred to conducting their independent online research more, potentially suggesting more self-reliance to compensate for lower quality HCP care.

> *"I was discharged from the hospital with no support with what's classified as Level 2 high blood pressure. We need more black doctors for black patients."* - Patient, Female, Black ethnicity, Unknown age, United States.

In contrast, White and Hispanic patients reported more positive experiences with HCPs and their care frustrations focused on the logistical burdens of care more, such as the time and effort needed to attend specialist appointments.

Age

Within the 8,100 core sample posts that could be categorized by age, patients self-identifying as

below 40 years of age more frequently reported impacts on their Emotional Balance (28%), Work/ Education (17%), and Social Connections (9%) than their older counterparts (Table 4).

Table 4. QoL impact area mention volumes by age group across core sample (n=8,100)[a]

Life Impact Area Mentions	<40 years old (%)	40+ years old (%)	Individual Life Impact Mentions	<40 years old (%)	40+ years old (%)
Everyday Life	26	26	Time spent on medical appointments	12	10
			Sleep disruption	9	8
			Time spent researching online	5	6
			Functional limitations	5	5
			Household task difficulties	3	3
Emotional Balance	28	22	Worry and Anxiety	19	13
			Sadness and depression	4	3
			Fear	6	4
			Shock and disbelief	2	2
Work/ Education	17	12	Impact on job performance	13	11
Social Connections	9	5	Impact on family & friendships	6	5
			Ability to maintain a social life	3	2
Financial Health	8	10	Expense cost concerns	4	5
			Insurance coverage	3	4

[a]Core sample excludes China due to country data transfer regulations. Sample sizes shown to nearest ’00.

Worry/anxiety, which was the top individual impact, was disproportionately mentioned by patients below 40 years old (19% vs. 11% overall). Whilst many patients of 40 years old or above tended to describe hypertension in resigned terms, it was common for patients below 40 years old to express very high levels of concern about the implications of their diagnosis for their broader health and lifestyle.

> *“When they told me I had HBP I said nope, I’m too young for this, this will drastically change my life”* - Patient, Male, <40 years age group, Canada.

Additionally, patients below 40 years of age more frequently mentioned individual impacts such as

negative effects of hypertension on their job performance (13% vs 11%) and the disruption of medical appointments (12% vs 10%) to their daily life than older patients. Patients of 40 years old or above more frequently highlighted financial health concerns (10% vs 8%) related to medical expenses (5% vs 4%), insurance coverage (4% vs 3%) and financial security in retirement.

"After retiring at 60 I had to face reduced healthcare access and higher costs of treatment" - Patient, Hypertension with cardiac comorbidities, Male, 40+ age group, China.

Gender

Across the 22,300 core sample posts that could be categorized by gender, differences in the frequency of reported QoL impacts were minor, though distinctions appeared within the areas of *emotional balance* and e*veryday life*. Men were less likely to mention experiencing worry or anxiety about their diagnosis (9% vs 11%) and reported attending medical appointments less frequently (6% vs 9%) than women. Women, who were less likely than men to mention conducting independent online research (3% v 5%), described more negative experiences with healthcare providers—particularly around the time of diagnosis – than men (Table S5 in Multimedia Appendix 1).

"I couldn't convince local doctors that my high blood pressure wasn't just stress." - Patient, Female, Unknown age group, United States.

Comorbidities

When analysts examined the impact of additional cardiovascular and renal conditions on QoL, they found that patients with co-occurring cardiovascular conditions more frequently cited everyday life impacts (28%)—particularly time burdens from medical appointments and online research, as well as activity limitations—compared to the general hypertensive population (Table S6 in Multimedia Appendix 1). No other major differences in QoL impacts were observed across the comorbidity groups, suggesting that hypertension alone can substantially affect quality of life, independent of other chronic conditions.

Treatment adherence

Analysis identified divergent patterns in hypertension treatment adherence. Among the 8,000 core sample posts (9% of total) explicitly referencing treatment adherence, 54% described strict adherence, whereas 46% indicated inconsistent treatment adherence. These findings with a global meta-analysis of 25 previous research studies, which reported an adherence rate of 45.2% (Abegaz et al., 2017).

More adherent patients emphasized consistent routines and frequently highlighted structured monitoring methods.

> *"I focus on taking my meds and going for daily walks – I try not to let the good habits slip"* – Patient, Hypertension with cardiac comorbidities, Unknown gender, 40+ age group, France.
>
> *"I have an app on my phone. Just to keep an eye on it."* – Patient, Primary hypertension, Unknown gender, <40 age group, Japan.

Conversely, patients who did not consistently adhere to treatments described a range of factors including missing doses due to forgetfulness, fluctuating use of medication based on perceived symptoms, and deliberate discontinuation or avoidance of treatment without medical guidance.

> *"I have been on blood pressure medication for years but often forgot to take it or run out. Even when I ran out of pills before, I didn't go to the hospital"* – Patient, Hypertension with renal comorbidities, Unknown age & gender, Japan.
>
> "*I have been prescribed blood pressure meds but I'm going to experiment to see if I actually need them. I have made some changes to my diet."* - Patient, Hypertension with cardiac comorbidities, Unknown age & gender, United Kingdom.
>
> *"Then I experienced the tablet side effects, like impotence… dizziness, fatigue. I stopped taking my tablets on my own, without consulting the doctor."* - Patient, Unknown gender, <40 age group, Germany.

In profiling patients who reported strict adherence to treatment compared to those who did not consistently manage their condition, clear associations emerged between adherence and a range of

proactive self-management (Table 5). When patients mentioned strict treatment adherence, these mentions were strongly associated with mentions of following structured daily routines and habits (79% associated), at-home monitoring of their condition (77% associated), dietary changes (77% associated), and physical exercise (71% associated). These posts mentioning treatment adherence also frequently mentioned proactive online research (69% associated) and regular contact with healthcare providers (68% associated).

Table 5. Association scores of concepts linked to treatment adherence behaviors across core sample (n=8,000)[a]

Adherence Drivers	Association Score (%)[b]
Consistent Treatment Adherence	
Structured daily routines and habits	79
At-home condition monitoring	77
Dietary changes	77
Physical exercise	71
Independent online research	69
Worry/ anxiety	62
Severe condition	54
Less Consistent Adherence	
Forgetfulness	79
Treatment side effects	73
Sadness / depression	71
Cost/ insurance issues	65
Milder condition	65

[a]Core sample excludes China due to country data transfer regulations. Sample shown to nearest ’00.
[b]Association scores represent the conditional probability that two concepts co-occur within the same post, expressed as a percentage—specifically, the proportion of posts mentioning the first concept that also mention the second.

When examining the potential drivers of these patients’ emotional responses—particularly worry and anxiety—were strongly associated with positive disease management and treatment adherence. Worry and anxiety were frequently co-mentioned with strict adherence (62% association), as well as with other proactive measures such as lifestyle changes, home monitoring, and self-education. This suggests that emotional engagement with the condition may play a central role in motivating consistent adherence and self-care.

Importantly, this emotional engagement appeared independent of clinical status. Mentions of a more

severe or complex condition showed a lower association with adherence (54%), indicating that perceived risk or emotional concern—rather than objective disease severity—may be a more influential factor in treatment adherence.

However, the analysis also highlighted several key barriers to adherence (Table 5). In addition to general forgetfulness (79%) and the perception of having a mild condition (65%), patients commonly cited treatment side effects (73%) and cost or insurance-related issues (65%). Notably, the emotional impact of sadness or depression was also associated with less consistent treatment adherence (71%), suggesting that not all emotional responses are activating; some may inhibit consistent management.

These findings suggest that patients often weigh concern about long-term health risks against the emotional and practical burdens of strict treatment adherence, resulting in a complex balance that influences adherence to treatment.

Discussion

The burden of Hypertension

Although hypertension is frequently described as a clinically "silent" or asymptomatic condition, this large-scale analysis of social media narratives revealed that patients consistently experience notable disruptions in daily life and emotional balance. These findings align with broader evidence showing that chronic illnesses, even those with minimal or no overt symptoms, can substantially affect patients' psychological well-being and daily functioning.[14–16] Prior research similarly reports extended periods of poor mental health in individuals managing chronic conditions, highlighting that uncertainty around disease progression and the continuous demands of self-management contribute significantly to psychological distress.[17]

For example, research in diabetes has documented how persistent anxiety about the need to maintain optimal blood glucose levels and uncertainty about future complications generates significant psychological strain.[18] Similarly, this study suggests many patients with hypertension experience a high emotional toll from managing a condition characterized by hidden but significant health risks.

As Theofilou (2011) found, chronic diseases, regardless of symptom severity, are associated with decrease in health-related quality of life from both physical and psychological factors.[16]

Notably, our findings show that patients without any additional comorbidities still reported substantial Quality of Life (QoL) impacts—particularly in emotional and everyday life areas—at similar levels to those with other chronic conditions. This suggests that hypertension alone imposes a meaningful psychological and practical burden, independent of broader multimorbidity. Such findings challenge assumptions that QoL impacts arise primarily from comorbidities and reinforce the need to view hypertension itself as a condition with significant standalone impact on patients' lives.

These insights emphasize the necessity of explicitly acknowledging and addressing the psychological and emotional impacts associated with chronic conditions traditionally considered asymptomatic, reinforcing the value of a holistic approach to patient care. Patient associations could play a valuable role in this, raising awareness of patient needs, tackling potential stigma around psychological and emotional impacts, and providing education and support to patients to improve their QoL.

Variance by patient demographics and country contexts

This analysis revealed important variations in patient experiences of hypertension across geographic and demographic subgroups.

Patients across countries reported different types of QoL impacts, with European patients more often describing time burdens, and Asian patients highlighting financial concerns—particularly among older adults. Patients in the US showed patterns linked to racial and ethnic identity, with notable disparities in care experiences, reflecting systemic and cultural influences on care. The findings highlight the importance of designing interventions and communications that are responsive to local health system contexts and patient expectations, enabling more relevant and equitable hypertension care across markets.

Patients below 40 years of age more frequently reported significant emotional impacts, including anxiety, worry, and social disruption, compared to older patients. Although literature specifically examining age differences in hypertension is limited, this finding aligns with broader evidence from other chronic conditions, which suggests that younger individuals typically experience greater distress, partly due to the unexpected nature of chronic illness early in life.[19] Our findings further suggest patients below 40 years of age face distinct challenges related to work performance, social engagement, and anxiety about future health. These patterns point to the need for age-specific support strategies that address both emotional and lifestyle-related impacts. Patients aged 40 years old or above, by contrast, placed greater emphasis on financial concerns related to healthcare expenses and retirement security, suggesting older patients may benefit from more practical care access and financial planning support.

Differences in the quality of HCP experiences were observed by gender globally, and by race and ethnicity in the US, reflecting known disparities in healthcare interactions documented in prior research.[20] Women, and Black patients in the US, more frequently described negative HCP encounters, such as dismissal or poor communication, than other groups, consistent with broader findings on medical mistrust and communication gaps.[21] SML was particularly effective in uncovering these sensitive experiences, including perceptions of bias and mistrust, which may not be fully captured in structured surveys or clinical interviews. The findings reinforce the importance of culturally responsive and equitable communication strategies that can help close persistent trust and care gaps across patient populations.

The link between emotions and adherence to treatment

A key finding from our analysis was the strong association between patient-reported worry or anxiety and consistent treatment adherence and other forms of proactive self-management measures. Patients expressing concern were more likely to describe structured routines, home monitoring, dietary

changes, and self-education, and emotional engagement appeared to be a stronger predictor of adherence than clinical severity.

This aligns with health psychology literature, which indicates that patients' emotional responses and perceived illness threat can significantly influence treatment and management factors—particularly in chronic conditions requiring ongoing self-care.[22,23] Studies have shown that when patients perceive a condition as asymptomatic or low-risk—as is often the case with hypertension—they may struggle to maintain adherence due to a lack of urgency.[24–26]

Findings from this study highlight the need for a nuanced approach to emotional impact assessment in hypertension management. While worry and anxiety were associated with more consistent adherence and proactive measures in our analysis, we also found that sadness or depression correlated with less consistent treatment adherence—reflecting patterns observed in previous research.[27] This reinforces the idea that different emotional states can shape treatment adherence in distinct and sometimes opposing ways. It also suggests that emotional responses cannot be assessed in binary terms of 'positive' or 'negative,' but must be understood in relation to their effects and patient context.

Further research is needed to explore how constructive emotional engagement can be supported without triggering counterproductive stress responses, which have been shown to worsen blood pressure outcomes.[28,29] The dual role of emotion—as both a motivator and a potential barrier—underscores the complexity of addressing psychological factors in chronic disease care.

Emotional tensions that complicate treatment adherence must also be considered. Whilst patients may be motivated to manage their condition by concern about their condition to adhere to condition management practices, they may also be affected by competing emotional pressures—such as frustration with side effects or anxiety over cost and insurance coverage. Prior research has similarly identified economic strain and adverse treatment experiences as major contributors to non-

adherence.[30,31] These counter concerns may blunt the motivational effect of worry, leading some patients to be less consistent in their condition management.

Together, these findings emphasize the importance of understanding and considering patient's full emotional and practical context to support consistent, effective hypertension self-management.

Limitations and further research

While social media listening (SML) provides valuable insights into patient experiences, several limitations warrant consideration. A primary concern is selection bias: social media users typically skew younger, more technologically adept, and more actively engaged in health discussions, potentially underrepresenting older adults or those less inclined to publicly share health information. This bias may impact the representativeness of our findings as noted in prior SML studies.[11] Although efforts were made to include diverse platforms and demographics, our sample likely overrepresents individuals experiencing heightened health concerns or unmet healthcare needs.

Another limitation involves reliance on self-reported data, which introduces potential inaccuracies regarding demographics and clinical details. Interpreting social media content inherently limits our ability to seek clarification or explore context, which may reduce interpretive accuracy. Despite these constraints, qualitative insights derived from SML remain highly valuable for understanding authentic patient experiences.

While broad in scope, this study was geographically limited to hypertensive patient experiences across 12 economically developed countries, excluding perspectives from regions significantly impacted by hypertension, such as Southeast Asia and African countries. Given hypertension’s global health burden, future research should expand geographic representation to include these regions, enriching our understanding of diverse cultural and socioeconomic factors influencing patient experiences and adherence to treatment.

Importantly, while initial findings suggested disparities in HCP experiences by race and ethnicity, our

analysis was limited to US data, where these attributes were reported at sufficient volume. Ethnicity data were not consistently available across other markets, limiting global comparisons. Additionally, our study did not assess biological factors, including the impact of race on treatment response, which may be relevant to understanding patient outcomes and should be explored in future research.

In addition, further research should specifically explore the optimal balance between fostering sufficient patient concern to motivate adherence and mitigating excessive worry or anxiety, which can negatively affect overall health outcomes. Understanding how best to leverage emotional responses constructively without inducing harmful stress will be crucial for advancing comprehensive patient care and adherence strategies.[28,29]

Ultimately, our research underscores how SML complements traditional patient-experience methodologies by capturing extensive, unmediated patient perspectives at scale.[7,11] While SML effectively identifies unmet patient needs and generates valuable hypotheses, regulatory bodies such as the FDA advocate a mixed-methods approach, emphasizing the importance of triangulating insights from structured surveys, clinical studies, and qualitative analyses to strengthen the validity and applicability of patient-centered healthcare strategies.[10] Indeed, it is increasingly acknowledged that SML should not replace established research tools but rather function as a complementary data source, providing unique insights that enrich traditional methodologies.[9] Like all forms of real-world evidence, SML inherently carries biases, yet it remains an invaluable component within a comprehensive, multidimensional research framework.

Conclusion

This large-scale social media listening analysis—the first to focus specifically on hypertension—sheds light on patient experiences often overlooked in traditional clinical research. While hypertension is clinically considered as largely symptomless, patient narratives reveal substantial disruptions to daily routines and emotional burdens such as worry and anxiety. Notably there is

strong link between how patients emotionally perceive hypertension as a health threat and their adherence to treatment. Future studies should build on these findings and specifically examine the complex interplay between patient perceptions, emotional experiences, and adherence to treatment to inform more effective patient-centered support strategies.

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Data availability

The datasets generated during and analysed during the current study are not publicly available due to legal and privacy considerations.

Abbreviations

HCP: Healthcare Professional

SML: Social Media Listening

QoL: Quality of Life

Multimedia appendix

Additional analysis and results.

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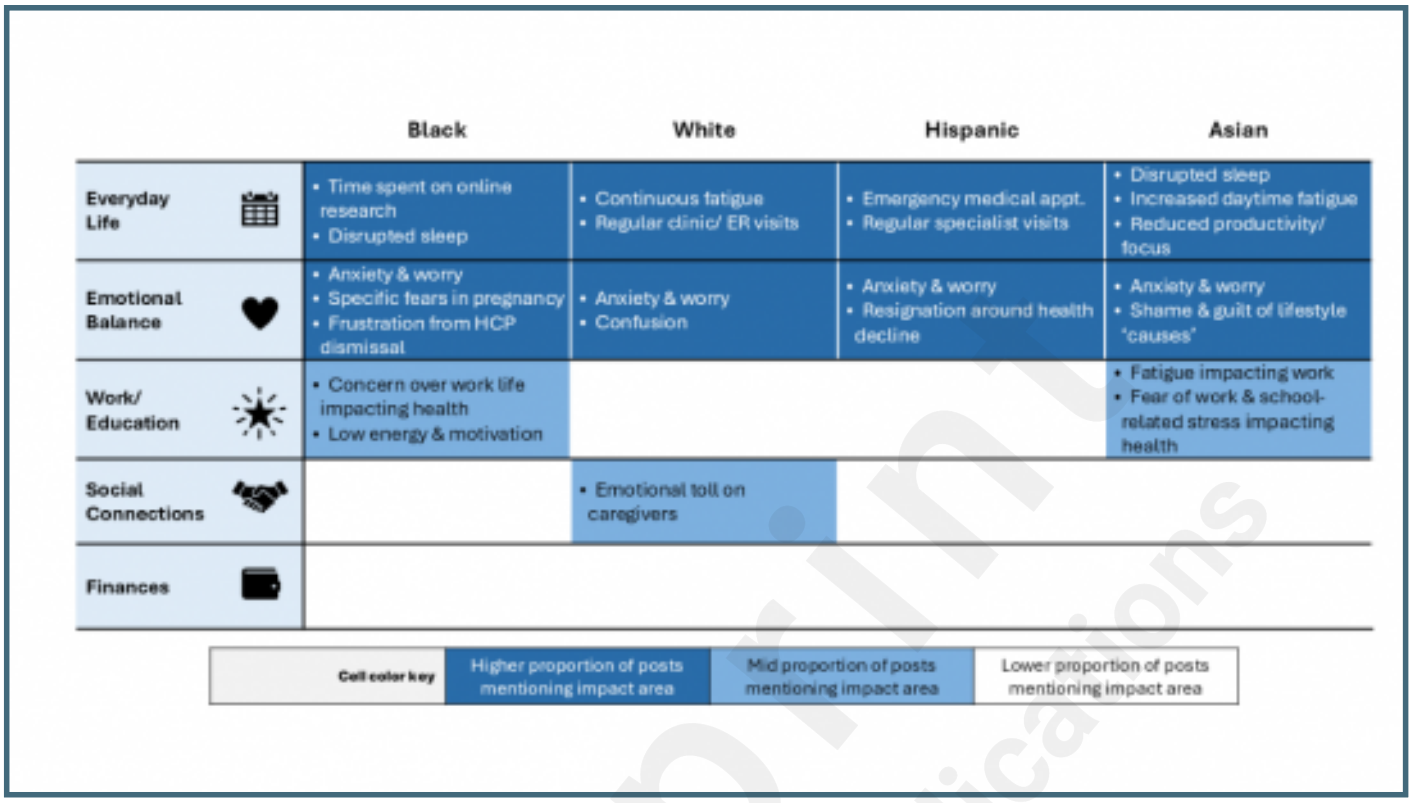
Supplementary Files

Figures

Supplementary figure 1.



Multimedia Appendixes

Additional analysis and results.
URL: http://asset.jmir.pub/assets/d8de6cb2210e041f64c9b05595514d39.docx