



Original Article



Association of Social Media Exposure and Information Credibility with Thalassemia Awareness and Community Participation among Urban Adults in Pakistan: A Cross-Sectional Study

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ABSTRACT

Pakistan has a 5-7% beta-thalassemia carrier rate, with thousands born annually requiring lifelong care. Awareness and community participation in screening and donation remain low. Social media offers a potential health communication channel, but its impact on thalassemia awareness and action in Pakistan is unclear. **Objectives:** To explore the association between social media exposure, thalassemia awareness, and community participation among Pakistani adults, and identify predictors of higher participation. **Methods:** This analytical cross-sectional study used simple random sampling to recruit adults (≥ 18 years) with at least one social media account via online links (December 2025 to March 2026), yielding 105 responses. A structured questionnaire assessed sociodemographic, usage, knowledge (0-7), and participation (0-7). Analyses included Mann-Whitney U, Kruskal-Wallis, Spearman's correlation, and multivariable logistic regression. **Results:** Most participants were aged 18-24 (66.7%), urban (100%), and held Bachelor's degrees (88.9%). Only 9.5% regularly saw thalassemia content, while 45.7% trusted it. Regular exposure was not associated with higher knowledge ($*p=0.445$), but trust was ($*p=0.012$). High participation (≥ 3 activities) occurred in 17.1%; none donated blood. Higher education predicted participation (aOR=9.48, $*p=0.020$), while female gender predicted lower odds (aOR=0.20, $*p=0.013$). Trust in social media was borderline (aOR=3.29, $*p=0.053$). **Conclusions:** In this urban, educated cohort, passive exposure does not translate to greater knowledge or action; content credibility and trust are more critical. The zero-donation rate highlights a knowledge-action gap requiring structural and cultural interventions. Campaigns should prioritize trust-building and women's engagement. Future research needs representative, longitudinal designs.

INTRODUCTION

Thalassemia is one of the most important monogenic disorders, which is a great health problem in Pakistan and the world at large [1]. Beta-thalassemia is present in the country, and the carrier rate is 5-7%, with thousands of babies being born with thalassemia major annually, who need supportive care throughout their lifespan [2]. Regular packed red blood cell transfusion every 2-4 weeks is required in these patients, which puts a significant financial and emotional burden on families and the health system [3]. While successful prevention models exist in

Iran, Cyprus, and Sardinia, Pakistan has a low rate of voluntary screening and donation services, and suffers from consistent blood shortages, despite being aware of the risks of blood transfusion [4, 5]. The complex problems of thalassemia in Pakistan require innovative and scalable solutions to address the existing knowledge-action gap. Digital technologies have transformed the field of health communication, and social media has become a powerful tool for reaching the masses in the field of health education and mobilization [6]. Social media platforms like Facebook,



Instagram, WhatsApp, YouTube, and TikTok can be used to deliver health information but also enable two-way communication so that individuals can share their experiences, engage in online communities, and organize community action [7]. The interactive character of social media platforms is very helpful for organizing blood donation campaigns, blood donation drives, fundraising campaigns, and advocacy programs, which is important for thalassemia care [8]. These digital platforms offer a cost-effective approach to reach people who are typically too geographically or socio-economically distant to access conventional health education methods, especially in rural or underserved areas in Pakistan, with a total number of internet users of more than 111 million [9-12]. Although the use of social media has been successful in the promotion of a range of healthy behaviors such as quitting smoking, chronic disease management, and pandemic response, its effectiveness in increasing awareness of thalassemia and encouraging participation in the community in South Asia is not well understood [9]. The Health Belief Model and Social Cognitive Theory propose that persuasive health messages, especially visual health stories and emotional stories, can increase threat appraisal and self-efficacy for prosocial behaviors such as blood donation [7]. The results will provide the health agencies, NGOs like Fatimid Foundation, and policymakers with evidence-based, culturally relevant, and resource-efficient digital health campaigns for thalassemia prevention and support in Pakistan.

Nevertheless, there is a serious lack of evidence if the mere exposure to thalassemia content on social media translates to real-life community action in Pakistan, where genetic disorders often have social stigma attached and where the knowledge-action gap is stark. In this study, the link between exposure to social media, awareness about thalassemia, and community involvement among adults who use social media in Pakistan has been investigated to fill the identified research gap. This study aimed to evaluate the relationship between social media consumption patterns and the level of knowledge about thalassemia. To identify the most effective social media platform and content format to promote awareness and mobilize action, and to identify factors independent of the social media content that predict high social media participation in terms of knowledge and action.

METHODS

The study was an analytical cross-sectional study to examine the impact of social media on awareness of thalassemia and community involvement among Pakistani social media users. This study was conducted with the supervision of the University of the Punjab (PU), Lahore, Pakistan. The study was carried out in compliance with the

principles of the Declaration of Helsinki. All participants gave informed consent electronically before data collection. All participants were voluntary and could drop out of this study at any time without any consequences. These responses were anonymous and confidential, with all data collected kept confidential. Data were only used for research. Data were gathered by means of an online survey from December 2025 to March 2026. The study population included adults (age 18 years and above) using at least one social media platform and who could read and understand English/Urdu. The participants were recruited by simple random sampling through social media available on the internet, such as Facebook, Instagram, WhatsApp, and X (previously Twitter). People under 18 years old, people who did not complete the questionnaire, and duplicate responses found during the data cleaning were not included in the analysis. The minimum sample size was calculated using the standard cross-sectional proportion formula: $n = Z^2P(1-P)/d^2$. Assuming a conservative thalassemia awareness prevalence of 50% ($P=0.50$) at a 95% confidence level ($Z=1.96$), a sample of 105 participants provides a margin of error of $\pm 9.6\%$ ($d \approx 0.096$). This is acceptable for exploratory research in a hard-to-reach digital population [13, 14]. For the primary two-group comparisons (Mann-Whitney U tests), a sample of 105 provides approximately 80% power to detect a moderate effect size (Cohen's $d \geq 0.55$) at $\alpha=0.05$. However, for multivariable logistic regression, the sample was underpowered (18 events for 7 predictors; recommended ≥ 70 events), so the regression findings should be interpreted as exploratory. The final analytic sample of 105 represented complete cases after listwise deletion of missing data. The number of samples was deemed sufficient for providing a reasonably accurate estimate of the study findings and for evaluating the relationships between exposure to social media, thalassemia awareness, and community involvement. 150 participants were recruited and included in the final analysis. A structured self-administered questionnaire was used to collect these data, designed following a thorough literature search on thalassemia awareness, health communication, and social media. The questionnaire was divided into four parts. The first part gathered data on sociodemographic factors such as age, gender, education level, occupation, residence, and marital status. The second section examined social media usage behaviors such as preferred social media platforms, time spent using social media daily, frequency of social media use, and exposure to thalassemia-related content. The third section assessed knowledge about thalassemia disease etiology, inheritance, clinical presentation, diagnosis, treatment, transfusion needs, screening for carriers, and prevention. The fourth part evaluated the community's participation in blood donation campaigns, fundraising, volunteer work,

awareness campaigns, advocacy, and support for thalassemia patients/thalassemia organizations. A pilot test of the main survey was conducted, and the questionnaire was reviewed by subject experts to ensure content validity. Changes were made as a result of expert input and pilot study results. The Cronbach's alpha coefficient was used to measure the internal consistency of the awareness scale and the community participation scale. The questionnaire was transformed into an online survey through a web-based platform and sent via social media. Study information and an electronic informed consent form were given to participants before accessing the questionnaire. Only participants who gave consent were allowed to fill out the survey. Exposure to thalassemia-related information on social media (frequency of exposure and type of information seen) was the main independent variable. Thalassemia awareness was measured by a knowledge score based on the awareness-related items, and participation in a community was measured by an engagement score based on the participation-related items.

R version 4.6.0 was used to enter and analyze data. Demographic characteristics of the participants were summarized using descriptive statistics: frequencies, percentages, means, standard deviations, medians, and interquartile ranges (IQR). Mann-Whitney U tests were used to compare the knowledge and participation scores between two groups, and the Kruskal-Wallis test was used in the comparisons between several groups. Spearman's correlation was used to evaluate the correlation between social media exposure variables and knowledge scores. Variables that might be confounding the relationship between rates of high community participation and anticipated variables were included as potential confounding variables in a multivariable logistic regression analysis to determine independent predictors of high community participation. The odds ratios (ORs) were adjusted and reported with 95% confidence intervals (CIs) and were considered to be statistically significant at p -value < 0.005.

RESULTS

The majority of the sample were young adults, aged 18 to 24 (66.7%), with slightly more females (52.4%) than males. 100% of the participants lived in urban areas. The majority of them had a Bachelor's Degree (88.9%), and 80.2% indicated that they did not have any personal or professional association with thalassemia. Instagram (39.0%) and 3 or more hours a day (74.3%) were the most popular platforms and amount of time spent on social media, respectively. The percentage of people who always read thalassemia content was less than 10% (9.5%), and less than 45.7% of people trusted information about thalassemia. Although there was still low participation

(17.1%) regarding a high level of community involvement, 28.6% indicated that they felt they were directly encouraged to take action by social media. Interestingly, all the subjects had never donated blood for thalassemia patients (Table 1).

Table 1: Sociodemographic, Social Media Use, and Thalassemia-Related Characteristics of Participants (n=105)

Variables	Category	n (%)
Age Group	18-24 Years	70 (66.7%)
	25-34 Years	24 (22.9%)
	35-44 Years	4 (3.8%)
	45-54 Years	5 (4.8%)
	55+ Years	2 (1.9%)
Gender	Male	50 (47.6%)
	Female	55 (52.4%)
Residence	Urban	105 (100.0%)
	Rural	0 (0.0%)
Education	Intermediate / FA / FSC	12 (11.1%)
	Bachelor's Degree	93 (88.9%)
Personal Connection to Thalassemia	Thalassemia Patient	2 (2.0%)
	Family Member Has Thalassemia	8 (7.9%)
	Healthcare Worker in Thalassemia	10 (9.9%)
	No Connection	85 (80.2%)
Most Used Social Media Platform	Facebook	9 (8.6%)
	Instagram	41 (39.0%)
	YouTube	12 (11.4%)
	WhatsApp	24 (22.9%)
	TikTok	16 (15.2%)
	X (Twitter)	2 (1.9%)
	LinkedIn	1 (1.0%)
Daily Hours on social media	<1 Hour	7 (6.7%)
	1-2 Hours	20 (19.0%)
	3-4 Hours	35 (33.3%)
	5-6 Hours	19 (18.1%)
	>6 Hours	24 (22.9%)
Frequency of Seeing Thalassemia Content	Yes (Regularly)	10 (9.5%)
	Yes (Occasionally)	15 (14.3%)
	Yes (Rarely)	40 (38.1%)
	No (Never)	40 (38.1%)
Trust in Thalassemia Info on social media	Completely Trustworthy	13 (12.4%)
	Mostly Trustworthy	35 (33.3%)
	Neutral	41 (39.0%)
	Mostly Untrustworthy	5 (4.8%)
	Completely Untrustworthy	11 (10.5%)
High Community Participation (≥3 Activities)	Yes	18 (17.1%)
	No	87 (82.9%)
Social media Directly Motivated Action	Yes	30 (28.6%)
	No / Not Sure	75 (71.4%)
Ever Donated Blood for Thalassemia	Yes (Once or Multiple)	0 (0.0%)
	No (Intend or Not)	105 (100.0%)

Higher scores of knowledges were significantly associated

with trust in thalassemia information on social media (median = 5.0 vs 4.0, $p=0.012$). However, participation ($p=0.878$) and knowledge ($p=0.445$) scores did not significantly differ for those who were regularly exposed to content about thalassemia's. There was also no significant association of personal experience with thalassemia with respect to knowledge ($p=0.385$). There was no correlation between participation scores and preference for emotional videos ($p=0.994$) (Table 2).

Table 2: Comparison of Knowledge and Participation Scores by Social Media Exposure, Trust, and Personal Connection Using Mann-Whitney U Tests

Comparisons	Group	n	Median (IQR)	U	Z	p-value
Knowledge Score						
Regular Exposure	No (n=95)	95	4.0 (3.0 - 6.0)	543.5	-0.76	0.445
	Yes (n=10)	10	4.5 (2.75 - 5.25)			
Trust in SM Info	No trust (n=57)	57	4.0 (3.0 - 5.0)	988.0	-2.51	0.012
	Trust (n=48)	48	5.0 (3.0 - 6.0)			
Personal Connection	No (n=85)	85	4.0 (3.0 - 6.0)	746.0	-0.87	0.385
	Yes (n=20)	20	5.0 (3.25 - 6.00)			
Participation Score						
Regular Exposure	No (n=95)	95	0.0 (0.0 - 2.0)	462.0	-0.15	0.878
	Yes (n=10)	10	0.0 (0.0 - 2.0)			
Content Preference	Other (n=61)	61	0.0 (0.0 - 2.0)	1343.5	-0.01	0.994
	Emotional Videos (n=44)	44	0.0 (0.0 - 2.0)			

The difference between the participants who did not trust thalassemia information on social media and those who did was statistically significant, with a difference of 0.85 points (mean of 4.69 points for those who trusted the information, and a mean of 3.84 points for those who did not trust). For regular exposure ($p=0.484$) and personal connection ($p=0.442$), respectively, there were no significant differences (Table 3).

Table 3: Kruskal-Wallis Test Comparing Knowledge Scores Across Most Used Social Media Platforms

Platform	n	Median (IQR)	Mean Rank
TikTok	16	5.0 (3.25 - 6.00)	61.0
X (Twitter)	2	4.5 (3.00 - 6.00)	52.5
WhatsApp	24	4.0 (3.00 - 6.00)	51.0
Instagram	41	4.0 (3.00 - 6.00)	54.4
Facebook	9	4.0 (2.50 - 5.50)	49.1
YouTube	12	3.5 (2.25 - 5.00)	44.5
LinkedIn	1	2.0 (2.00 - 2.00)	5.0

Kruskal-Wallis $H=6.81$, $df=6$, $p=0.338$

No significant correlation was found between thalassemia content on social media ($\rho = -0.077$, $p=0.436$) or the time spent on social media per day ($\rho = 0.040$, $p=0.683$) and thalassemia knowledge scores. The near-zero coefficients imply that there is little meaningful linear relation between the social media exposure patterns and awareness level in this sample (Table 4).

Table 4: Spearman's Rank Correlation Between Social Media Exposure Variables and Knowledge Score

Variable 1	Variable 2	ρ (rho)	S	p-value
Knowledge Score	Frequency of seeing that content ¹	-0.077	207749	0.436

Knowledge Score	Daily hours on social media ²	0.040	185144	0.683
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¹Higher value = less frequent exposure (Regular=1, Occasional=2, Rare=3, Never=4). ²Higher value = more hours (1= <1hr, 2=1-2hr, 3=3-4hr, 4=5-6hr, 5= >6hr). Model fit: Null deviance 96.21, Residual deviance 80.64, AIC 96.64, Nagelkerke $R^2 \approx 0$

After adjusting for all predictors, female gender was associated with 80% lower odds of high community participation compared to males (aOR = 0.20, $p=0.013$). Higher education (Bachelor's degree or more) increased the odds by almost 9.5-fold (aOR = 9.48, $p=0.020$). A borderline positive relationship was found between trust in social media information and aOR (aOR = 3.29, $p=0.053$). The other variables (age, personal connection, familiarity with emotional videos, preference for emotional videos) were not significant. The model had good fit (Hosmer-Lemeshow $p=0.303$); however, the Nagelkerke R^2 value was low (≈ 0.19), and this indicated that there are some factors other than what was measured that influence the model (Table 5).

Table 5: Multivariable Logistic Regression Analysis of Factors Associated with High Community Participation

Predictors	aOR	95% CI	p-value
Age (≥ 25 years)	1.87	0.38 - 8.93	0.429
Gender (Female vs Male)	0.20	0.05 - 0.66	0.013
High Education (Bachelor+)	9.48	1.74 - 85.02	0.020
Personal Connection (yes)	1.34	0.25 - 5.88	0.712
Regular Exposure (yes)	0.51	0.05 - 3.79	0.531
Trust in SM Info (yes)	3.29	1.01 - 11.63	0.053
Prefer Emotional Videos (yes)	0.73	0.22 - 2.29	0.597

DISCUSSION

The study aimed to explore the association between social media exposure, awareness of thalassemia, and community engagement among adult users of social media in Pakistan, and found that the frequency of social media use is high despite the relatively low level of meaningful community engagement around thalassemia and adult users' limited awareness of thalassemia. The findings illustrate that knowledge is strongly linked with trust in the information posted on social media ($p=0.012$), but that mere exposure to thalassemia information doesn't necessarily equate to more knowledge or greater participation in the community, thus dispelling the notion that the more information on health-related topics available online, the more they will be trusted and impact health. It may be more effective to build trust by engaging trusted sources and experts, and/or by ensuring content is transparent and curated, than to just have more content posted, particularly in a context like the Pakistani market where there is lots of misinformation about health [14, 15] and the content about thalassemia may be intermittent or inadequately curated. The alarmingly low level of community participation (17.1% of the participants scored high in participation, and no one had ever donated blood for the thalassemia patient) echoes the results of Bossman *et al.* [16] in other LMICs, where a lack of knowledge does not always result in prosocial behavior because of structural, cultural, and motivational barriers. Results showed that 28.6% of them felt directly motivated to take action through social media. Similarly, in social media-based blood donation campaigns in Punjab found that the lack of trust, perceived blood donation as inconvenience, and cultural reservations regarding the blood donation for genetic conditions were major challenges [17, 18]. In Pakistan, women are more restricted in their mobility, have higher caregiving responsibilities, and face greater social barriers to public participation [19]. The high level of correlation between education and participation suggested that education equips individuals with the skills, confidence, and social capital to participate in community health initiatives, whereas the marginally significant link between trust in social media information and high levels of community participation ($aOR = 3.29$, $p=0.053$) showed that perceptions of credibility may help individuals move from awareness to participation. The finding of a non-significant association between emotional video preference and community participation ($p=0.597$, $aOR = 0.73$) calls into question the notion that emotional content is more successful at mobilizing action, and presents an opportunity for health organizations to invest in more complex campaign designs incorporating emotional content with practical guidance to increase community

engagement and participation [20]. As expected, the top used platforms were Instagram (39.0%), WhatsApp (22.9%) and TikTok (15.2%) with no significant association between platform use and knowledge or participation scores, indicating that platform use is not as important as the quality of content and the levels of trust and knowledge [21] as seen in other social media usage trends in Pakistan where visual and video-based social media platforms are also highly preferred by youth in urban areas [22]. The current findings exclusively reflect the awareness, social media behaviors, and community participation patterns of a young, highly educated, urban, digitally connected stratum of Pakistani adults.

However, there were several limitations in this study, such as being cross-sectional, relying on convenience sampling, a highly educated urban sample which limits the ability to make generalizations to rural and less educated populations, and self-reported data with the possibility of social desirability bias, as well as insufficient power for multivariable logistic regression and the lack of content quality assessment. Moving forward, further studies should use probability sampling, involve a diversity of geographical and socioeconomic groups, include a longitudinal design to capture the temporal nature of the problems, and use qualitative approaches to gain an understanding of the experiences of thalassemia patients, their families, and community members in Pakistan.

CONCLUSIONS

In this urban, educated cohort, social media exposure does not automatically translate into thalassemia awareness or community participation; trust in information is more critical than exposure volume. The zero blood donation rate highlights a knowledge-action gap requiring structural and cultural interventions. Campaigns on Instagram and WhatsApp should prioritize credibility, actionable calls, and women's engagement.

Authors' Contribution

Conceptualization: AM

Methodology: AM

Formal analysis: AM, TAH

Writing and Drafting: HS, HY

Review and Editing: AM, HS, TAH, HY

All authors approved the final manuscript and take responsibility for the integrity of the work

Conflicts of Interest

The authors declare no conflict of interest.

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