The 65th ASH Annual Meeting Abstracts

ORAL ABSTRACTS

904.OUTCOMES RESEARCH-NON-MALIGNANT CONDITIONS

Understanding the Experiences of Patients with Sickle Cell Disease and Their Caregivers By Social Media Listening in the UK

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INTRODUCTION: Sickle cell disease (SCD) is a life-long hereditary condition associated with reduced life expectancy and quality of life. [1] Long-term complications include high infection risk, stroke, severe anemia, organ damage, and vaso-occlusive crises. [1-2] In the United Kingdom (UK) there are ~20,000 patients with SCD. [3] Online conversations involving patients with chronic conditions can provide insight into their health-related concerns, caregiver experiences, and other stakeholder perspectives. [4] Here, we explore online conversations surrounding SCD to gain valuable information regarding real-world experiences and unmet needs.

METHODS: A qualitative netnographic social media listening (SML) study was conducted in the UK using a search term syntax containing disease and treatment keywords, hashtags, and relevant website addresses. A 12-month historical search (1 Jun 2022-1 Jun 2023) was conducted using a third-party SML tool (TalkWalker), capturing all relevant SCD-related conversations across publicly accessible social media/digital channels including Twitter, Instagram, TikTok, forums, blogs, YouTube, and Facebook public pages. A sample of randomized data was sifted to isolate posts referencing the patient/caregiver experience for further analysis. Topics were identified from the sifted data using artificial intelligence (AI)-powered theme detection in natural language processing (NLP), manually grouped into common themes and quantified for prevalence and sentiment. Human-led qualitative analyses using keyword filtering and manual trawling were performed to contextualize and validate the findings.

RESULTS: A total of 45,864 online posts with 687,302 engagements (i.e., likes, shares, comments, etc.) were captured. The sifted results yielded 513 posts (1.1%). Of these, 93% were from patients with SCD, and the remaining 7% were from caregivers and other sources. The largest number of posts came from Instagram (173 posts), followed by forums (123 posts), TikTok (123 posts), and Twitter (94 posts). NLP and qualitative sentiment analysis identified six overall themes: the experiences with management of SCD within the National Health Service, UK (72.5% [372/513] posts: 8.6% positive, 34.1% negative, 57.3% neutral), living with SCD and understanding the condition (70.8% [363/513] posts:13.2% positive, 41.3% negative, 45.5% neutral), the importance of community, support and family planning (60.6% [311/513] posts: 19.0% positive, 21.9% negative, 59.2% neutral), understanding the burden of SCD through accounts over lifetime (45.4% [233/513] posts: 17.6% positive, 26.6% negative, 55.8% neutral), talking about and raising awareness of SCD (40.9% [210/513] posts: 14.3% positive, 17.1% negative, 68.6% neutral), and access to/experiences with treatment (27.1% [139/513] posts: 6.5% positive, 29.5% negative, 64.0% neutral) (**Figure**). The patient experience in accessing healthcare was striking, highlighting a lack of empathy from healthcare professionals (HCPs) and prejudice from those in primary/emergency care in providing care. Patients share their experiences of pain crises, their attempts to understand triggers, and the underestimation by HCPs of the real-life impact, leading to symptom dismissal and stigmatization associated with the need for painkillers. Importantly there is a strong outcry from patients with SCD and their community that current treatments are unsatisfactory, burdensome, or difficult to access.

CONCLUSIONS:SML forms a valuable, novel, and quantifiable method of identifying challenges, unmet needs and capturing the patient's digital voice in SCD, adding to the evidence base in an under-researched area. Limited access to emergency care, low levels of empathy from HCPs, racial bias, and stigmatization reported by patients further highlight the presence of health inequity within this population. There is a pressing plea for the development and accessibility of improved treatments for this population.

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Figure. Emergent themes and breakdown of respective sentiments (N=513)
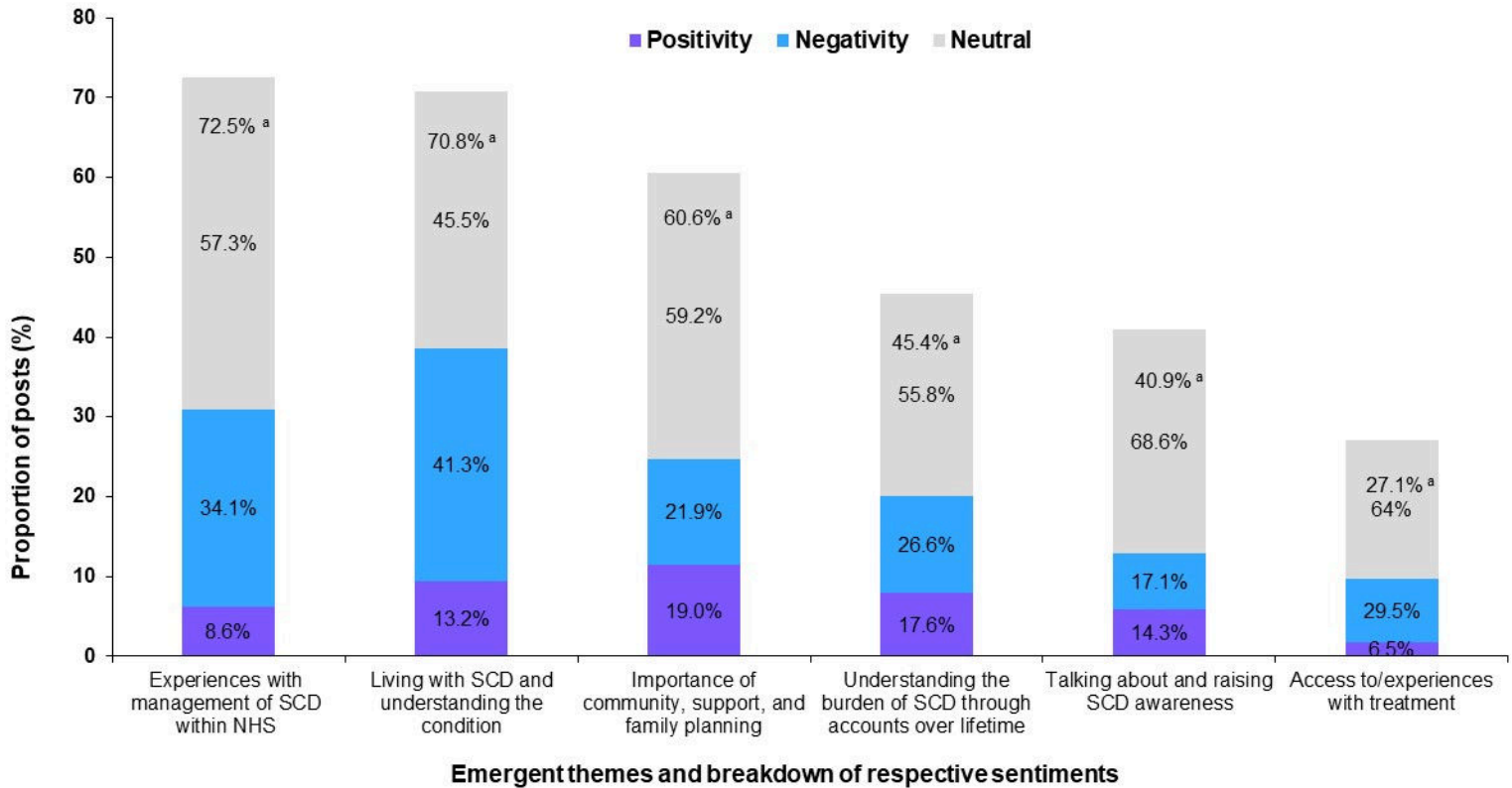
aProportion of posts for the respective theme out of total 513 posts.
NHS, National Health Service; SCD, sickle cell disease

Figure 1