Enhancing Understanding of Quality of Life in Multiple Sclerosis Through Social Listening: COMPLEMENTING TRADITIONAL HRQoL MEASURES

PCR75

Authors: Jackie Cuyvers[1], Abhinab Bhanja[1]
Convosphere Ltd[1], London, United Kingdom

INTRODUCTION

Multiple Sclerosis (MS) significantly affects patients' quality of life (QoL), with symptoms ranging from fatigue to physical disability.

Traditional tools like the FACIT-F and other PRO instruments are widely used in clinical trials and health economics and outcomes research (HEOR) to measure QoL.

However, these tools may not capture the full scope of the lived patient experience. Social listening offers a complementary method by uncovering unsolicited, real-world perspectives directly from patients and caregivers.

OBJECTIVE

To explore how retrospective social listening can surface quality of life impacts in MS that are often missed by structured HRQoL instruments and to assess its relevance as a complementary tool in HEOR.

METHOD

Data Source: Public posts from Twitter, forums, blogs, and YouTube

Geography: United States

Time Period: Jan 1 – Dec 31, 2019

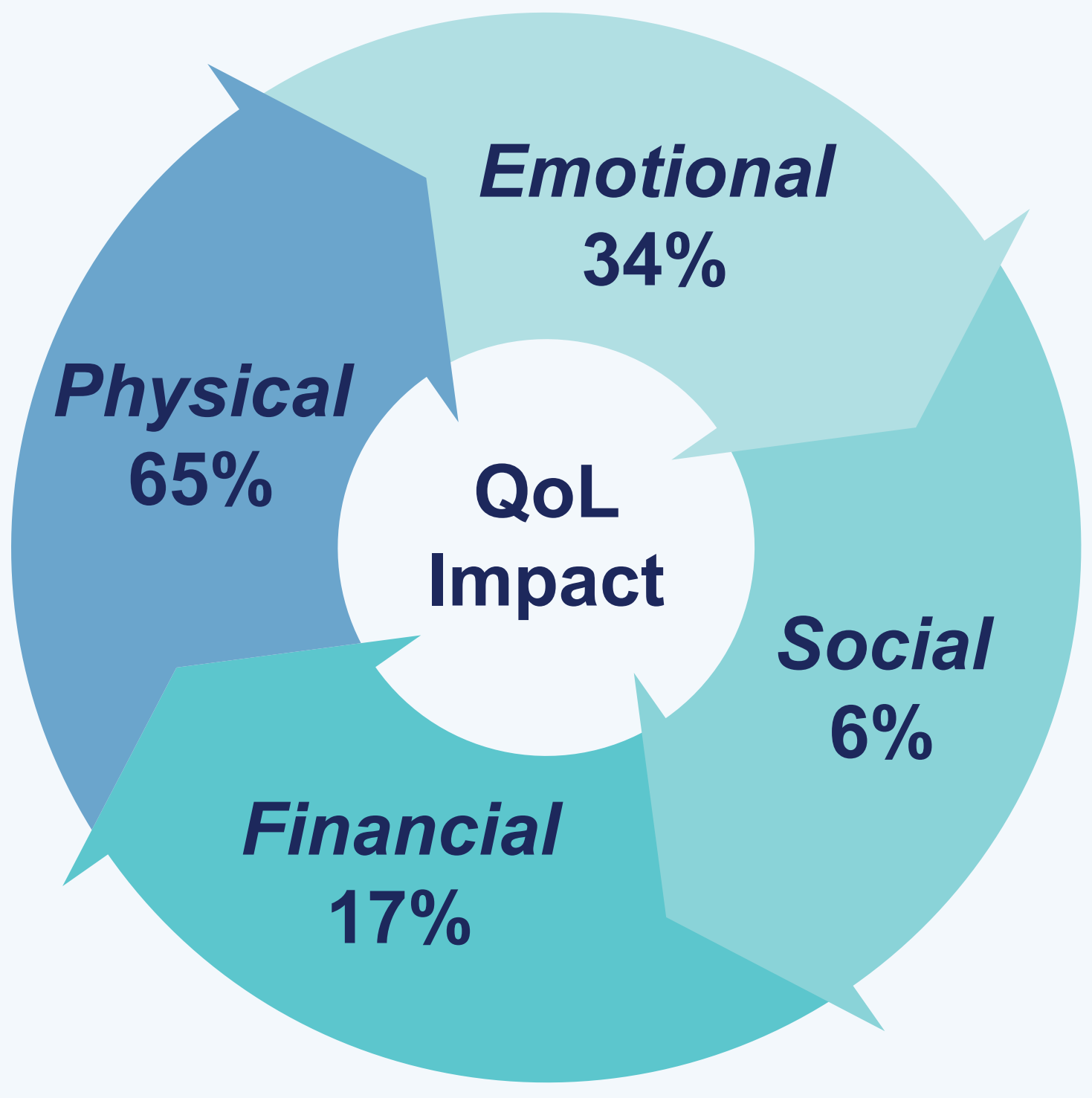
Sample: 500 manually selected patient/caregiver-centric posts

Approach: Qualitative content analysis with manual thematic coding and sentiment analysis

Domains Analysed: Physical, emotional, financial, and social impacts

RESULTS

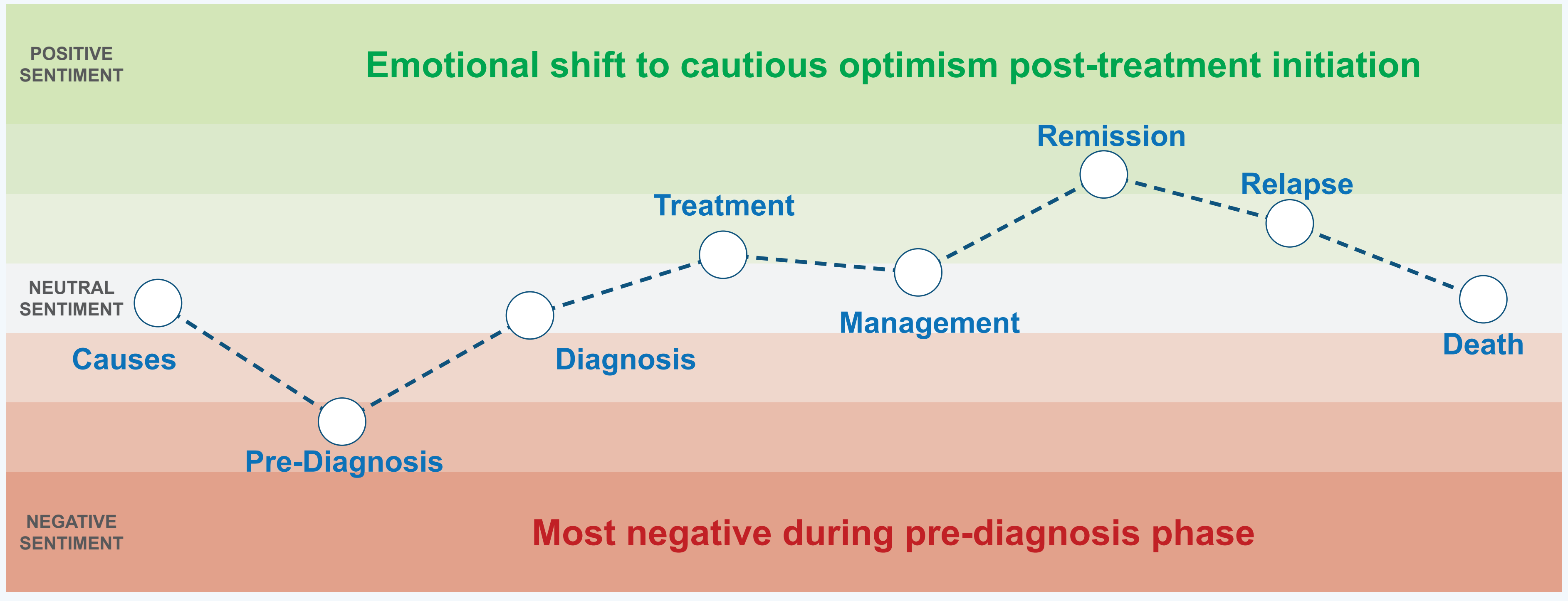
BREAKDOWN OF QoL MENTIONS



UNMET NEEDS

- Lack of awareness and understanding
- Mistrust in healthcare professionals
- Medication side effects vs. efficacy trade-offs
- Financial strain and access barriers

SENTIMENT TRENDS



GOING BEYOND FACIT-F

FACIT-F

FACIT-F measures the direct impact of fatigue, while social listening reveals its broader emotional and social consequences, offering a more holistic view of quality of life.

The 13-item scale:

- ✓ I feel fatigued.
- ✓ I feel weak all over.
- ✓ I feel listless ("washed out").
- ✓ I feel tired.
- ✓ I have trouble starting things because I am tired.
- ✓ I have trouble finishing things because I am tired.
- ✓ I have energy. (reverse scored)
- ✓ I am able to do my usual activities. (reverse scored)
- ✓ I need to sleep during the day.
- ✓ I am too tired to eat.
- ✓ I need help doing my usual activities.
- ✓ I am frustrated by being too tired to do the things I want to do.
- ✓ I have to limit my social activity because I am tired.

SOCIAL MEDIA

Social media conversations reveal QoL burdens that standard tools often miss, highlighting not just physical symptoms, but also social isolation, financial strain, healthcare access issues, and emotional impacts on patients and caregivers.

Financial Strain:
Inability to work due to symptoms results in job and income loss, compounding the financial burden alongside challenges with healthcare access and insurance coverage.

> *"Choosing which bills to skip for my healthcare."*
> *"Lost my job, waiting and hoping for disability."*

Social Isolation & Stigma:
Physical limitations and reduced work participation restrict social interaction, leading to missed social opportunities and heightened feelings of isolation.

> *"MS is invisible, people don't believe what they can't see."*
> *"Using a cane, still getting judged for it."*
> *"She was always smiling, and now she can't even work."*

Emotional Toll on Patients and Caregivers:
The emotional burden extends beyond patients,as caregivers face continuous stress, mental fatigue, and the psychological strain of supporting a loved one through the condition.

> *"#MultipleSclerosis comes with anxiety, every day is unpredictable."*
> *"Feels like my world is falling apart around me."*

DISCUSSION & CONCLUSION

DISCUSSIONS:

Social listening reveals a rich, patient-driven narrative of MS that is often missing from structured QoL instruments. It captures complex, intersecting challenges that patients face in their daily lives, from stigma to financial instability. While not a replacement for PROs, it provides a continuous, unsolicited, and ecologically valid view into real-world QoL impacts.

CONCLUSIONS:

Social listening offers a complementary lens to structured QoL measures such as FACIT-F. By incorporating unsolicited patient voices, HEOR frameworks can be enriched to better reflect patient-centred value and inform decision-making in treatment access and support.

IMPLICATION FOR STAKEHOLDERS

Payers: Access richer insights on real-world patient burden

Pharma: Tailor patient-centric strategies and communications

Researchers: Supplement PRO instruments with digital ethnography methods

FUTURE DIRECTIONS

Extend methodology to other chronic or rare conditions

Integrate real-time social data into RWE dashboards

Develop ethically grounded patient involvement protocols in social listening studies

DISCLOSURE:

This analysis builds on prior data presented at the World Congress of Neurology 2023, but with a distinct methodological and HEOR-oriented framing not previously presented.

REFERENCES

1. Facit.org. FACIT-F Functional Assessment of Chronic Illness Therapy – Fatigue: overview. https://www.facit.org/measures/facit-fatigue. Accessed October 14, 2025.

CONTACT INFORMATION

Address: Saint Martins House
1 Lyric Square
Hammersmith
London W6 0NB

Email: info@convosphere.com

Phone:
UK +44 (0)203 8580235
US +1 332 6001419