



BEYOND THE PAIN: UNDERSTANDING CANCER TREATMENT-RELATED ORAL MUCOSITIS THROUGH PATIENT EXPERIENCES



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BACKGROUND

Oral mucositis (OM) is a common, painful, and life-altering side effect of cancer treatment, frequently disrupting eating, speaking, sleeping, and social interactions. Capturing real world patient experiences and insights can help to identify patient priorities and co-create solutions to support prevention and management of OM and enhance quality of life (QoL).

The MCLS initiative aims to shine a light on the challenges of cancer treatment and the need to improve supportive care therapies, resources, and access. Unfortunately, the prevalence of supportive care delivery continues to remain low. A recent study found that up to 79% of cancer survivors had unmet supportive care needs and reported dissatisfaction with current supportive care services (Penedo et al., 23)

The MCLS program acknowledges the rigors of both short-term and perpetual treatment, and we do not believe any cancer therapy-related side effect, whether it is extreme fatigue, debilitating diarrhea, hair loss, chronic pain, or others, should ever be viewed as ‘acceptable’ or ‘tolerable.’

METHODS AND MATERIALS

Ambassadors for Make Cancer Less Shitty (MCLS), an advocate-led initiative to highlight realities of cancer treatment and survivorship, circulated a digital survey to a pan-cancer patient audience, designed to capture perceived severity of OM, treatment experiences, and QoL.

All survey respondents were asked if they would be interested in participating in a virtually hosted, follow-up focus group

Six individuals were asked to participate in a 3-hour follow-up focus group to further discuss physical and emotional impact, effectiveness and accessibility of supportive care, gaps in existing OM management strategies, and recommendations.



“I didn’t even know oral mucositis was a thing until I had it.”

“I thought it would just be uncomfortable, not impossible.”

RESULTS

ORAL MUCOSITIS DIGITAL SURVEY RESULTS n=59	
SEVERE AND PERSISTENT SYMPTOMS	
Difficulty eating	38 / 64%
Difficulty speaking	25 / 42%
Difficulty sleeping	21 / 36%
Difficulty swallowing	23 / 39%
GAPS IN TREATMENT EFFICACY	
Current treatments are adequate	21 / 36%
Current treatments “somewhat worked” but are inconsistent	18 / 31%
Current treatments do not work	13 / 22%
Not sure whether current treatments work	6 / 10%
no response	1 / 1%
LACK OF EARLY INTERVENTION AND COMMUNICATION GAPS	
Received adequate intervention / adequately informed on possibility of experiencing OM	31 / 53%
Did not receive adequate intervention / adequate information on possibility of experiencing OM	25 / 42%
Not applicable (did not experience OM)	3 / 5%

RESULTS

Among survey respondents, difficulty eating, speaking, and sleeping were common (64%, 42%, and 36%, respectively), and 31% of patients required opiates for OM pain relief.

Only 36% of respondents felt current treatments were adequate, and 31% said treatments “somewhat worked” but inconsistently, pointing to gaps in treatment efficacy. Lack of early intervention and communication was also an issue, with 42% of patients reporting not receiving adequate education on risk or prevention.

The focus group validated these findings. Additionally, participants reported:

- malnutrition,
- weight loss,
- isolation,
- and inconsistent or inadequate symptom relief.

The lack of education on OM risk was associated with:

- delayed symptom management,
- and increased distress.

Participants described trial-and-error self-management, often relying on peer support after receiving conflicting provider advice. Priorities among focus group participants included early education on risk/avoidance of OM, better oncology-dental coordination, and accessible supportive care therapies.

CONCLUSIONS

Conversations about risks of OM and appropriate interventions are not happening consistently. Current OM strategies fail to meet all patient needs and individuals are often left to navigate OM on their own. Despite many available products, no single solution provides consistent relief. Making patients co-creators in designing personalized, durable care solutions may improve quality of life and long-term clinical outcomes.

“I wish they had said, ‘This can get bad, Here’s how to deal with it.’”

“This is the worst kind of thing you could ever have in your life. The worst feeling in your mouth.”

Reference: Penedo, F. J., Natori, A., Fleszar-Pavlovic, S. E., et al. (2023). Factors associated with unmet supportive care needs and emergency department visits and hospitalizations in ambulatory oncology. *JAMA Network Open*, 6(6), e2319352. <https://doi.org/10.1001/jamanetworkopen.2023.19352>

