Breaking the Silence: How Online Forums Address Lung Cancer Stigma and Offer Support

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Abstract

Lung cancer remains a leading cause of cancer-related deaths, but public support for individuals living with lung cancer is often constrained by stigma and misconceptions, leading to serious emotional and social consequences for those diagnosed. Understanding how this stigma manifests and affects individuals is vital for developing inclusive interventions. Online discussion forums offer a unique opportunity to examine how lung cancer stigma is expressed and experienced. This study combines qualitative analysis and unsupervised learning (topic modelling) to explore stigma-related content within an online lung cancer forum. Our findings highlight the role of online forums as a key space for addressing anti-discriminatory attitudes and sharing experiences of lung cancer stigma. We found that users both with and without lung cancer engage in discussions pertaining to supportive and welcoming topics, highlighting the online forum's role in facilitating social and informational support.

1 Introduction

Lung cancer remains a leading cause of cancer incidence and mortality worldwide, accounting for approximately 2 million new diagnoses and 1.8 million deaths annually (WHO, 2022). Despite its prevalence, lung cancer is often heavily stigmatised due to its association with smoking, leading to the misconception that the disease is self-inflicted (Marlow et al., 2015). Individuals may encounter lung cancer stigma in three distinct but interconnected forms: *enacted stigma*, which involves perceived judgment or discrimination from others, such as friends, family, or healthcare providers; *anticipated stigma*, defined by the fear or expectation of being discriminated against; and *internalised stigma*, characterised by personal feelings of shame and guilt (Link and Phelan, 2001; Luberto et al., 2016; Webb et al., 2019). As a consequence, the burden of societal judgment and blame contributes to significant emotional distress, such as anxiety and depression, and can also deter individuals with lung cancer from seeking medical help or support for quitting smoking (Luberto et al., 2016; Scharnetzki and Schiller, 2021).

Social support is defined as the assistance available to a person through their connections with others, including individuals, groups, and the broader community (Lin et al., 1979). Research indicates that with more social support, individuals are less likely to internalise societal stigma as negative self-perceptions, thereby protecting their mental health (Birtel et al., 2017; Hamann et al., 2018). Additionally, individuals are encouraged to seek support via online forums (Taylor and Pagliari, 2019). These forums combat stigma by fostering supportive communities that offer companionship and empathy (Woo, 2017). Thus, online forums serve as valuable resources for analysing how lung cancer stigma is expressed and experienced. Natural Language Processing (NLP) techniques present a useful tool to better understand how lung cancer stigma and social support is addressed in online discussions.

This study applied NLP techniques to identify stigma-related posts and comments within a lung cancer forum. The primary objectives were to (1) identify content that challenges or reinforces stigma, (2) examine how lung cancer stigma is represented in online discussions, and (3) explore how the forum fosters support among individuals with lung cancer (IWLC) and individuals without lung cancer (IWoLC) through cross-collection topic modelling (Paul and Girju, 2009). The key findings corresponding to these objectives are as follows:

1. Anti-stigma narratives were observed in terms of calls for non-discrimination, emphasis on non-smokers developing lung cancer, and the need for anti-stigma support.

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2. Anticipated, enacted, and internalised stigma were present in the online discussions.

3. Support and welcoming-oriented topic were a major theme discussed among IWLC and IWoLC, highlighting the forum's role as a support network.

2 Related Work

Researchers have explored lung cancer discussions, revealing trends in discussion topics and support across platforms. Shah et al. (2024) applied topic modelling and time-series analysis to uncover trends and seasonal variations in lung cancer discussions, showing that curative and palliative care topics peak at different times. Zhao et al. (2019) explored the differences in lung cancer discussions across platforms like Twitter, Facebook, and Macmillan.org.uk, revealing that while all platforms were largely used to provide information, the nature of the interactions and support varied. For example, Twitter fostered more companionship support through hashtags, whereas Macmillan.org.uk had more emotional and informational support.

Despite progress in understanding lung cancer discussions online, there is still a lack of research specifically on lung cancer stigma in these forums. A European social media study touched on stigma briefly, noting that platforms often emphasise that anyone can get lung cancer (Straton et al., 2020). Another text analysis study, based on phone interviews transcripts, found that both patients and caregivers experience stigma (Occhipinti et al., 2018). While Roesler et al. (2024) used a RoBERTa model, in conjunction with handcrafted features, to identify internalised, anticipated, and enacted stigma related to substance use, similar work on lung cancer stigma is still limited.

Research also indicates that public attitudes may vary across different demographics and groups, such as posts made between patients and family members (Andy and Andy, 2021). To our knowledge, no prior research has examined forum discussions between IWLC and IWoLC using unsupervised text analytics.

3 Methodology

3.1 Data Collection

We used an English dataset collected in May 2024 from the lung cancer online discussion forum Lungevity.org[1], including all posts and comments.

[1]https://forums.lungevity.org/

We acquired the entire dataset of 332,261 entries from 2003 to 2024 consisting of 292,901 comments and 39,360 posts. For analysis, we selected a subset ($D_{Labelled}$) of 66,264 entries: 50,196 from IWLC and 16,068 from IWoLC. This subset was chosen because each entry is pre-labelled by the platform, indicating whether it was posted by an IWLC or IWoLC, based on registration information. Users are also labeled as members, moderators, or administrators by the platform. Further details about $D_{Labelled}$ are provided in the Appendix, Table 2.

3.2 Stigma Related Content Identification

Our goal with this work was to utilise unsupervised methods to identify specifically stigma-related content for further thematic analysis. Details of the stigma identification process are shown in Figure 1.

To identify stigma-related content within our dataset, we first split each entry into individual sentences. We then computed cosine similarity scores between $D_{Labelled}$ and the Stigma Items from the Cataldo Lung Cancer Stigma Scale (CLCSS) (Cataldo et al., 2011), as well as with representative participant quotations from an interview study (Hamann et al., 2014). Details of the scale are included in Appendix Tables 3.

For example, the post sentence "Nevertheless, I am not so upfront with my lung cancer" had a similarity score of 0.77 with the statement "I feel guilty because I have lung cancer" from the CLCSS. We used a pre-trained SBERT model all-MiniLM-L6-v2 to embed $D_{Labelled}$ and CLCSS entries and calculate similarity score between each entries.

Subsequently, we conducted manual annotations to determine whether a post sentence was stigma related. Annotators MC and JL analysed the first 200 post sentences with the highest cosine similarity scores. A sentence was labelled as stigma-related if it contained elements of anticipated, enacted, internalised stigma, or anti-stigma content. We achieved Cohen's Kappa score of 0.74, indicating substantial agreement between annotators (McHugh, 2012).

For sentences annotated as stigma-related, we applied a qualitative thematic analysis approach, consisting phases of: familiarising ourselves with the data, coding, generating initial themes, reviewing and developing themes, refining, defining, and naming themes (Clarke and Braun, 2017).

3.3 Cross-Collection Topic Modelling

The purpose of applying cross-collection topic modelling was to identify support-related topics

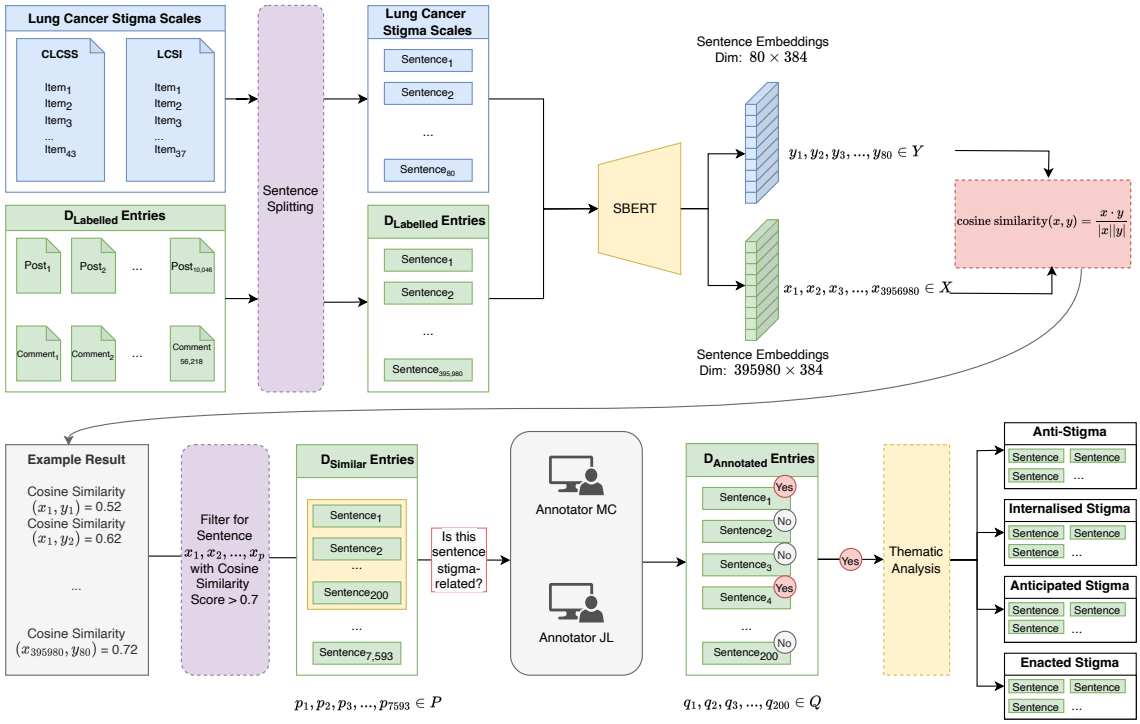

Figure 1: Key Steps for Identifying Stigma-Related Content

and gain insights into the support dynamics between IWLC and IWoLC. For pre-processing, we removed stop words and personal names from all datasets. Additionally, we applied NLTK's lemmatizer to enhance coherence in the results. To capture word co-occurrences and differences between IWLC and IWoLC in $D_{Labelled}$, we employed cross-collection Latent Dirichlet Allocation (ccLDA) (Paul and Girju, 2009). The ccLDA model was executed for 2,000 iterations, with both gamma 0 (the prior for topics common across collections) and gamma 1.0 (the prior for collection-specific topics) set to 1.0. We provided two sets of distributions: one representing the topic word distribution shared by both groups, and another highlighting the word distribution unique to each group. Experiments were conducted with 10, 20, and 30 topics, and "Support and Welcoming" emerged as a common topic across all three. The results presented in this paper are based on the 30-topic model, as it provided the most coherent and interpretable topics according to human analysis.

4 Results

4.1 Anti-Stigma Content

The complete set of themes derived from $D_{Labelled}$ related to anti-stigma is presented in Table 1. Four overarching themes are discussed: (1) Call for non-discrimination, (2) Statements emphasising that non-smokers can also get lung cancer, (3) Personal experiences of lung cancer due to factors other than smoking, and (4) Expectations regarding anti-stigma support.

Theme	Illustrative Quotes
Call for non-discrimination	• "Lung cancer doesn't discriminate, and neither should society." • "While some may think I deserved to die of lung cancer, I disagreed."
Statements emphasising that non-smokers can also get lung cancer	• "Among those diagnosed with lung cancer, about 15% of females and 5% of males have never smoked." • "I have lung cancer, and I've never smoked."
Personal experiences of lung cancer due to factors other than smoking	• "My lung cancer is believed to have been caused by the toxic dust we inhaled without masks." • "As a Vietnam Veteran exposed to Agent Orange, my lung cancer was presumed to be linked to it, but my 35 years of smoking was all that mattered at MD."
Expectations regarding anti-stigma support	• "Pat expected the same support that people diagnosed with other cancers receive." • "Don't ask if they smoked; instead, show that you care." • "Instead of placing blame, we need to focus on finding a cure."

Table 1: Anti-Stigma Content (Synthetic Examples Derived from Original Quotes)

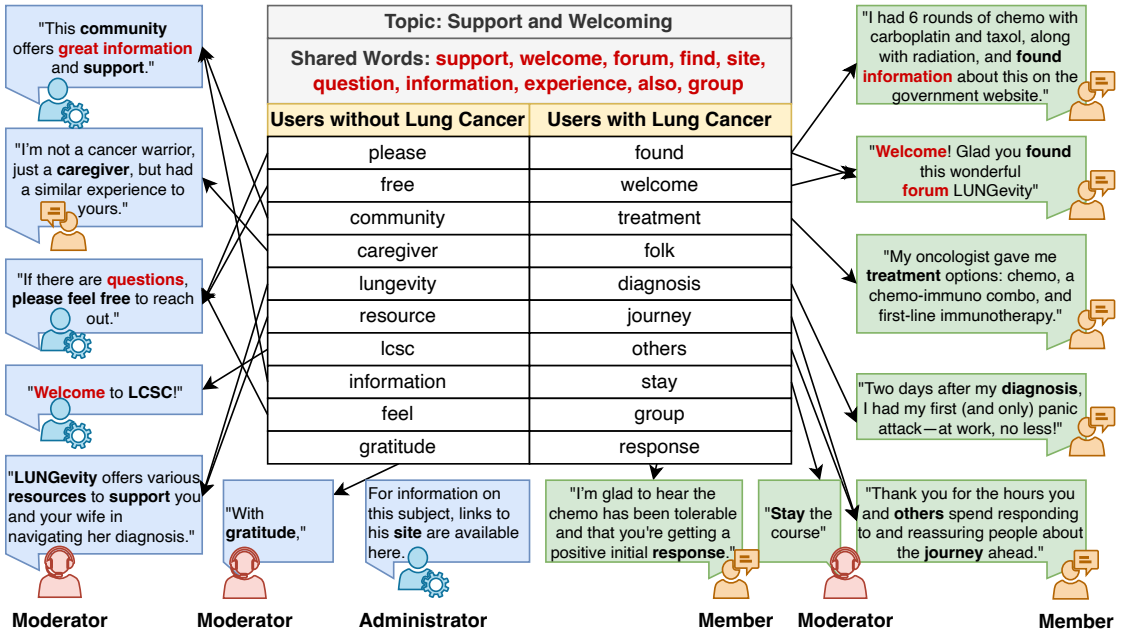

Figure 2: A topic focused on "support and welcoming" among users with and without lung cancer, demonstrated with rephrased examples from $D_{Labelled}$. User's roles include forum administrator, moderator, and member.

4.2 Anticipated, Enacted, and Internalised Stigma

The analysis of lung cancer forum discussions revealed various forms of stigma experienced by patients, including internalised, enacted, and anticipated stigma. Appendix Table 4 includes the complete thematic analysis result.

Internalised stigma was evident in feelings of guilt, as one user reflected, "Sometimes I wonder if the initial irritation I feel when people ask if I smoked is actually hiding the guilt I have for having smoked for so long."

Enacted stigma was frequently encountered in public attitudes, particularly in the assumption that lung cancer is self-inflicted due to smoking. One participant remarked, "Whenever I tell people I have lung cancer, the first question is always, 'Did you smoke?'" Additionally, others noted stigma from healthcare professionals by stating that "I just wonder about why so many doctors assume smoking is the cause. This can't be true since we have many who have never smoked at all."

Anticipated stigma was reflected in the fear of being pitied or misjudged, leading some individuals to selectively disclose their diagnosis. As one participant explained, "I want to avoid seeing pity in people's expressions... It's as if they immediately perceive you as being on the brink of death." This anticipation of stigma prompted another to "keep it mostly to me at work, confiding only in a few close friends." Not upfront is another reflect as one user suggested that "Nevertheless, I am not so upfront with my lung cancer."

4.3 Topics Related to Support

Through the use of ccLDA, we identified topics related to Support and Welcoming that were shared among both IWLC and IWoLC. Figure 2 highlights the shared and distinct vocabulary used by both groups when discussing support. The illustration also includes synthetic examples with highlighted key terms, indicating whether the post was made by an administrator, moderator, or member.

The shared words, such as *support*, *welcome*, and *group*, suggest that both IWLC and IWoLC interact in ways that foster inclusiveness and community belongings. However, there are also differences in the specific terms used by each group, reflecting their distinct experiences and needs. For instance, users with lung cancer more frequently mentioned terms related to *treatment*, *diagnosis*, and *journey*, indicating their focus on medical aspects and personal experiences of living with the disease. On the other hand, users without lung cancer, such as caregivers, moderators, or administrators, often used words like *caregiver*, *community*, and *gratitude*, underscoring their supportive roles and expression of appreciation.

5 Discussion

This study examined how online forum discussions address lung cancer stigma and provide support by analysing 66,264 entries from Lungevity.org. The findings indicate that the online forums may serve as platforms for sharing anti-stigma information. Forum administrators and moderators were instrumental in promoting anti-discriminatory content through educational posts and articles to raise public awareness. These results align with the study of Seering et al. (2019) highlighting the important role of community moderators in online spaces.

We identified stigma-related content in the forms of anticipated, enacted, and internalised stigma. In line with previous study (Chambers et al., 2012), the forum reflected internalised stigma, often seen as guilt and reluctance to discuss one's condition, particularly among former smokers. Enacted stigma was associated with public attitudes viewing lung cancer as self-inflicted, and users with lung cancer reported discomfort sharing their diagnosis, highlighting how questions about smoking history may reinforce stigma (Williamson et al., 2020).

Our study highlights differences in the language used by IWLC and IWoLC, providing a view to understand the support and welcoming dynamics within Lungevity.org forum. IWoLC include administrators, moderators, and members, while IWLC include of moderators and members. The keyword "caregiver" in IWoLC posts suggests that caregivers use the forum to seek information and share their experiences. Additionally, keywords such as "please feel free", "community", and "lcsc (lung cancer support community)" are more commonly used by moderators and administrators, highlighting their focus on organising, offering support, and providing information and resources.

In contrast, IWLC tend to use more illness-related terms like "treatment", "diagnosis", and "journey", reflecting their focus on navigating their condition and seeking information. Words like "welcome", "stay", and "group" emphasise the emotional connection and sense of belonging within the community.

These findings align with research by Andy and Andy (2021), who observed that IWLC more often discuss hospital visits and health concerns, reflecting a need for practical and emotional support. However, the support from IWoLC, such as moderators, appears less emotionally charged. This could be due to the fact that nearly half of IWoLC's posts and comments are made by administrators and moderators, whose main responsibility is to maintain a positive, inclusive environment for safe user interaction. As part of their role, their language is often more neutral and informational, using phrases such as "Welcome to LCSC", "Please feel free to", and "Lungevity offers various resources to support". This helps establish a sense of order and structure within the forum. Research also supports this, suggesting that while moderators provide valuable resources and guidance, their communication tends to reflect a neutral tone, which aligns with their responsibilities in managing the forum and ensuring balanced discussions (Barak et al., 2008; Seering et al., 2019).

Building on this, our findings also highlight that moderators and administrators play a central role in fostering a safe and supportive space within the forum. Consistent with previous studies, we found that their primary responsibility goes beyond providing emotional support. Instead, moderators focus on promoting engagement by facilitating discussions and ensuring community interaction. They may reframe posts to encourage responses and act swiftly to address harmful content, safeguarding the well-being of users, as seen in the work of Deng et al. (2023).

6 Conclusion and Limitation

This study shows how online forums can help address lung cancer stigma and provide support for IWLC and IWoLC. By analysing discussions on Lungevity.org, we found that these platforms not only facilitate the sharing of personal stigma experiences but also promote anti-discriminatory attitudes. The distinct language used by IWLC and IWoLC highlights the community's supportive dynamics, with caregivers seeking information, moderators and administrators offering guidance, and IWLC navigating their conditions. However, the dataset is derived from a single forum and may not reflect the broader lung cancer community. Additionally, manual annotation and thematic analysis may not necessarily yield generalisable results and may not capture the full scope of lung cancer stigma manifestations. Future research would benefit from utilising more diverse data sources and exploring more fully automated methods for stigma detection, including leveraging large language models (LLMs) to enhance thematic analysis.

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A Appendix

Ethics Statement This study was approved by the LNR 3A Ethics Committee of The University of Melbourne (No. 2024-29891-56821-3). All demonstrated examples were rephrased to protect participant privacy.

Forum	Sub Forum	IWoLC	IWLC	Number of Entries
Discussion Forums	General	2936	11384	14320
	NSCLC Group	1148	4319	5467
	Caregiver Resource Centre	1317	1873	3190
	SCLC Group	641	1282	1923
	LC Survivors	366	1384	1750
	US Veterans	4	37	41
	NHS Treatment	0	1	1
Living Well	Just For Fun	2159	8248	10407
	Hope	937	3161	4098
	Healthy Living Recipes	156	75	231
Welcome New Members!	Introduce Yourself	2784	11094	13878
Grief	Grief	1715	3226	4941
Treatment Forums	Chemotherapy	164	864	1028
	Immunotherapy	140	488	628
	Surgery	52	360	412
	Radiation	44	304	348
	Supportive Care	4	7	11
News / Advocacy	Lung Cancer News	903	703	1606
	Advocacy	229	385	614
Stories Of Survivorship	Share Your Story	281	825	1106
Lung Cancer Navigator	Navigator	56	143	199
Support	Support Resources	28	9	37
Terms of Use	Features and Support	4	24	28
Total		16068	50196	66264

Table 2: Distribution of Entries by Forum, Sub-Forum, and User Status

No.	Statement
1	I feel guilty because I have lung cancer.
2	I work hard to keep my lung cancer a secret.
3	Having lung cancer makes me feel like I'm a bad person.
4	I'm very careful whom I tell I have lung cancer.
5	I feel I'm not as good as others because I have lung cancer.
6	I worry people who know I have lung cancer will tell others.
7	Having lung cancer makes me feel unclean.
8	In many areas of my life, no one knows I have lung cancer.
9	I feel set apart, isolated from the rest of the world.
10	I told people close to me to keep my lung cancer a secret.

Table 3: 10 Example Items from Lung Cancer Stigma Statements from CLCSS (Cataldo and Brodsky, 2013)

Stigma Type	Category	Illustrative Quotes
Internalised Stigma	**Guilty**	"Sometimes I wonder if the initial irritation I feel when people ask if I smoked is actually hiding the guilt I have for having smoked for so long." "After a biopsy confirmed a diagnosis of non-small cell squamous cell lung cancer, I felt both fear and guilt about my history of smoking." "I regret having smoked for as long as I did, but I'm deeply grateful that I eventually quit."
	Not upfront	"However, I'm not as open about my lung cancer."
Enacted Stigma	**Public's Attitude: Asking about Smoking History**	"Whenever I tell people I have lung cancer, the first question is always, "Did you smoke?"" "Maybe I'm more sensitive than others, but I can't stand it when people hear I have lung cancer and immediately ask if I smoked."
	Public's Attitude: Viewing Lung Cancer as Self-Inflicted	"She faced an ongoing battle against the stigma that lung cancer is a self-inflicted condition." "Even though lung cancer rates among lifelong non-smokers, especially women, have been mysteriously rising, the prevailing attitude remains that smokers get what they deserve."
	Stigma from Healthcare Professionals	"I just wonder about why so many doctors assume smoking is the cause. This can't be true since we have many who have never smoked at all." "Despite quitting smoking long before my cancer diagnosis, some medical professionals still focus on my smoking history, seemingly to blame me."
	Questioning Why Other Incidences Are Not as Stigmatised	"We wouldn't ask a breast cancer patient if they nursed their babies, so why is it socially acceptable to ask if I smoked? The implication is that if I smoked or sunbathed, then I could be blamed for my lung cancer or melanoma." "If smokers supposedly deserve to get sick, then the same logic should apply to those who are overweight, inactive, or engage in risky behaviors—factors that contribute to other illnesses that receive far more sympathy and research funding."
Anticipated Stigma	**Fear of Pity and Misjudgment**	"I want to avoid seeing pity in people's expressions... It's as if they immediately perceive you as being on the brink of death."
	Selective Disclosure and Minimisation	"When I was initially diagnosed with possible lung cancer, I kept it mostly to myself at work, confiding only in a few close friends. Before my surgery, I informed more people but downplayed the situation as much as possible."

Table 4: Thematic Analysis Results