Poster 1343P

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Understanding patient and caregiver perceptions of quality of life impacts in lung cancer through social listening

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KEY FINDINGS & CONCLUSIONS

- This analysis identifies emotional burden as the main quality of life impact of lung cancer, followed by physical impacts
- Feelings of stigma around smoking history were common; patients feel blamed for their condition, whereas others question whether they should receive treatment for what they perceive to be a self-inflicted condition
- Some patients felt abandoned by physicians because of a lack of empathy and communication
- Despite some limitations inherent to social listening, this study provides valuable insights into the lung cancer experience and highlights patients' desire to increase public awareness and for greater physician empathy

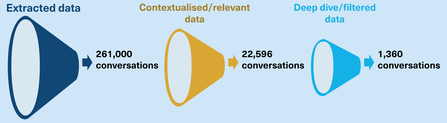
INTRODUCTION

- Patients and caregivers increasingly use social media to seek and share information around disease-related experiences[1]
- Lung cancer is one of the most common cancers globally, affecting the lives of >2 million patients[2]
- This observational study analysed social media trends, through social listening, to gain insight into quality of life (QoL) impacts and perceptions in advanced lung cancer

METHODS

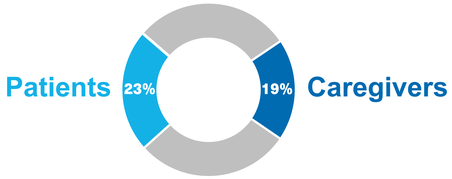
- Data were collected retrospectively (June 2019 to May 2020) across 14 European countries (UK, Spain, France, Switzerland, Belgium, Germany, Austria, Netherlands, Italy, Nordic countries, and Portugal) from open-access blogs, forums, and social networking sites (including Twitter, public Facebook, and YouTube). SocialStudio and Talkwalker were used for UK and non-UK data collection, respectively
- A three-tier technique (**Figure 1**) was used to identify relevant data, with random sampling procedures generating the final dataset for analysis. Conversations containing lung cancer and non-small cell lung cancer (NSCLC)-specific terms were extracted using social media aggregator tools. The information was filtered to a contextualised dataset by automated relevancy algorithms and manual review
- The final dataset was analysed for insights relating to burden of illness and quality of life (QoL)

Figure 1. Three-tier data analysis technique used to identify relevant data



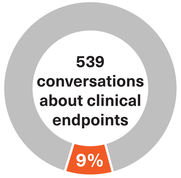
RESULTS

In this analysis, patients and caregivers were the main stakeholders



Quality of life

100 conversations concerned QoL



48 conversations discussed QoL as a treatment goal

Impact on QoL

- Emotional wellness was discussed in 70% of conversations across stages of the patient journey, including diagnosis, treatment, and relapse
  - After diagnosis, patients wanted to learn more about their condition, but were overwhelmed and intimidated by the volume and complexity of information
  - Nearly all patients were discouraged by survival statistics
  - Fear was common in patients awaiting test results, with increased anxiety at relapse
  - Patients with relapsed cancer sought advice and support on forums
- Physical challenges, mainly from long-term side effects of treatment (primarily chemotherapy), affected patients' physical well-being
  - Symptoms highlighted included muscle pain, breathlessness, and fatigue

> *"[...] Then she got the next chemo. Since then she has been so weak that she can only lie down, even walking on crutches no longer works. She also seems to find it difficult to speak. [...] she can no longer do anything alone."*
> Forum, caregiver, Germany

- Financial challenges were discussed in 9% of conversations, evident in countries such as Spain and France, where some patients and caregivers sought a solution in fundraising

> *"A friend's mother was diagnosed with lung cancer. His family needs all the possible help to cover the costs of the radiation therapy."*
> Twitter, friend, Spain

- Surprisingly, social wellness was mentioned in only 2% of conversations. Analysed conversations did not point towards an effect on patients' overall social life, or to any challenges with balancing career alongside disease management

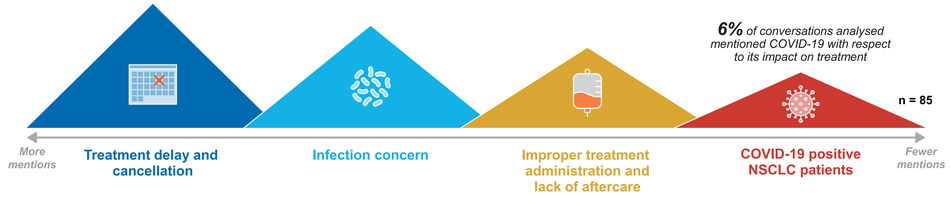
Stigma associated with lung cancer

- Feelings of stigma around smoking history were common, with patients feeling blamed for their condition. In most conversations, smoking status was not revealed, possibly as a result of this stigma
- In several countries, including France and Finland, questions were raised as to whether patients should receive healthcare support and treatment for what was perceived to be a self-inflicted condition
  - In the Netherlands, a young patient (aged 21 years) wanted to raise awareness of genetic mutations and the fact that anyone could get lung cancer, not just smokers
  - In Finland, patient support groups, experts, and healthcare professionals (HCPs) worked to raise awareness and remove stigma
  - In Nordic countries, never-smokers tried to raise awareness and remove the stigma, which might contribute to late detection and lack of funding for treatment

Key unmet needs

- Treatment delay and cancellation was the key effect from COVID-19, especially for patients receiving chemotherapy (**Figure 2**)
  - One patient in Germany preferred to postpone treatment to avoid further compromising her immune system
  - In the Netherlands, patients reported premature release from hospital and raised concerns of missed aftercare and inadequate home support
- Lack of effective treatments, poor communication, and lack of funding for treatments caused frustration among patients and caregivers
- Running out of treatment options weighed heavily on patients
  - In the UK, patients worried about immunotherapy not being available for 2 years, whereas in Italy and the Nordic countries, social disparity was perceived to affect treatment and cause late detection of cancer
- Some patients felt that HCPs could be insensitive and lack empathy. Additionally, insufficient information communicated by HCPs was highlighted as an unmet need by patients/caregivers, particularly in France, Spain, the UK, and Germany
  - Patients reported feeling "abandoned", "rushed", or "cold" during consultation, leading them to look for additional information online and, in the worst case, also resulted in patients doubting HCPs' competence and treatment decisions

Figure 2. Discussion around the impacts of COVID-19



NSCLC, non-small cell lung cancer.

Limitations

- **Only publicly available information** on digital platforms has been accessed and used for this research
- All social media research assumes that the information provided by patients is authentic and was **voluntarily shared** with other patients publicly
- Quality of insights gathered from the **analysis of digital conversations is dependent on the richness of patient conversations**, i.e., the details shared by patients about their health condition, treatment, medication, disease management challenges and quality of life
- Because of the **unstructured nature of social data,** it is **not always possible to find information for every business question**; the team has objectively determined if the available information supports a business question or not, and **accordingly reported the findings**
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- The nature of available digital content varies by platform, primarily owing to format (i.e., Twitter versus forums); during the sampling process, the research team has determined the **most appropriate platform to derive in-depth consultative insights**

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Disclosures

This study is sponsored by Novartis Pharmaceuticals Corporation. M.M. has nothing to disclose.

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