

Elephant in the Room: Gap Between the Awareness and Need for Psycho-Social Support for Czech Lymphoma Patients as Captured Through the Analyzes of Social and Traditional Media

Jakub Novák^{1*}, Jakub Smutný², Veronika Bačová¹, Jan Popluhár¹, Martin Pour¹
1 ROCHE s.r.o., Prague, Czech Republic
2 Newton Media, a. s., Prague, Czech Republic
*jakub.novak@roche.com

Background & Objectives

- Social, as well as traditional media are omnipresent in our existence and influence all aspects of our daily lives.
- Online space has also become extensively used by (prospective) patients and caregivers to ask questions and discuss their health, disease, or treatment-related experiences and concerns.
- Together with traditional media they thus shape patient disease awareness, patient journey, quality of life and this way, they might even affect treatment outcomes.
- In this study, we combined media analysis (both social and traditional) to gain insights into the lymphoma patients' and caregivers' sentiments, the unmet needs, blind spots, and system bottlenecks in Czechia.

Conclusions



Therapy side effects and distress are among the main drivers in decreased quality of life in lymphoma patients.



Information about the Importance and availability of psychological support is rare and with narrow outreach.



Better mental health is related with better quality of life and might improve the outcome of the therapy.



Social media listening might help to guide policies needed to better support psychosocial status of all patients.

MAPPING THE PATIENT JOURNEY FROM SYMPTOMS TO THERAPY

The symptoms most commonly reported in the media are those associated with the stories of "ordinary" people. Besides the classic B-symptoms these also include more frequent infections, nose bleed, 'alcohol pain' (pain in the nodule after drinking alcohol), fatigue or depression, diarrhea or constipation, bleeding from teeth cleaning or cough. The same symptoms are also discussed in Facebook groups and discussion forums.

Patients provide unmoderated recommendations on diagnostics (e.g. on un/reliability of blood tests).

Treatment advances over the last few years are covered by the most relevant Czech media (e.g. increase in mean survival, blood cancers as a chronic diseases).

Treatment is the most common topic discussed - mostly chemotherapy, sometimes also biological treatment or bone marrow transplantation (CAR-T rarely).

There is absolute minimum of information about the possible prevention in the media.

Method

- Media analysis was conducted by using the archive of media coverage from Newton Media, including press, online sources, TV and radio broadcasting based on the keyword "lymfom" (Czech expression for "lymphoma") and covering the period between October 2022 and October 2024.
- Social media listening (SML) analysis was based on a data retrieved using the social media monitoring tool from Newton Media a.s. and the data collection was conducted based on keywords relevant to the topics of "Hemato-oncology" and "Lymphoma." SML analysis covered the same time period as media analysis.
- The data sources included social media platforms such as Facebook, X (formerly Twitter), Instagram, YouTube, TikTok, and Reddit, as well as Czech discussion forums and user discussions on news portals.
- Non-systematic literature review was performed to inform the discussion of the results.
- Review of local guidelines was conducted in order to check the local legislative framework.

Limitations

- Local focus might limit the transferability of the results to other countries.
- Closed groups and forums were not analyzed to comply with privacy issues.
- Patient interviews and focus groups would be needed to better understand the results.

PATIENTS' & CAREGIVERS' NEEDS AND CONCERNS

PATIENT/CAREGIVER EXPERIENCE AS COVERED BY TRADITIONAL MEDIA

- In the media, poor tolerability of the treatment (chemotherapy), long time to return to relatively good condition or fatigue syndrome were mentioned.
- (Late) relapse presented as "fight on another front."
- The whole patient experience is enormously psychologically demanding.
- Fertility concerns of female patients.
- Dependence on family assistance when it comes to care, food preparation or transport to doctors are mentioned among other issues.
- Isolation during the therapy.
- Transportation for the treatment mentioned as one of the issues.

Overall, while significant fears, concerns, and economic challenges are prevalent, advancements in treatment and help from support groups provide hope and comfort for lymphoma patients.

PATIENT/CAREGIVER EXPERIENCE SHARED ON SOCIAL MEDIA

CONCERNS

Impact of the therapy and how to handle it (parents, elderly, etc.).

HOPE

- Progress in treatment options & hope for recovery.
- Support groups provide relief and psychological comfort.

FEAR

- Significant negative modifier of patient's quality of life.
- Different stages, different fears:
 - Diagnosis phase - initial symptoms lead to fear of a cancer diagnosis.
 - Treatment phase - patients fear that treatment may not be effective and worry about the possibility of death.
 - Post-treatment phase - even after successful treatment, there is a pervasive fear of relapse.

“INVISIBLE” ISSUES & REAL IMPACT

OBSERVED UNMET NEED

- Czech treatment guidelines include psychological support as a part of (early) palliative care in order to improve patient's quality of life, minimize stress, enable better patient participation in therapy & compliance.¹
- Despite their needs, patients won't find sufficient information about the available psychological support and its importance in the media.
- In the relevant media, any remarks about patient organizations (POs) and what do they offer are generally missing.
- Implementation of psychiatric reform² and National Action Plan for Mental Health 2020-2030³ is slow and behind expectations.⁴

Patients with blood cancers in the Czech clinical practice would benefit from better awareness about psycho-social awareness and support. NGOs and POs might be leveraged here, at least temporarily, as state fails to provide necessary psychological services. SML might serve as a tool in navigating the unnecessary changes.

MENTAL HEALTH DISORDERS MIGHT AFFECT TREATMENT ADHERENCE AND SURVIVAL

- Distressed patients with lymphoma could have tendencies for harmful coping mechanisms, incl. risky alcohol consumption.⁵
- Among patients with blood cancers, depression was associated with a reduced overall survival.⁶
- In patients with diffuse large B-cell lymphoma, pre-existing mental health disorders can predict survival outcomes.⁷ Having a mental health disorder predicts poorer overall survival also in patients with Hodgkin lymphoma.⁸

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