

BABES-BOLYAI UNIVERSITY OF SCIENCE
INSTITUTE OF SOCIOLOGY AND SOCIAL WORK
DOCTORAL SCHOOL OF SOCIOLOGY

“HOW ARE YOU?”

- Experiences of lung cancer patients during healthcare

Summary

DOCTORAL STUDENT: PATAKI ERIKA

CONSULTANT: DR. HABIL DÉGI LÁSZLÓ CSABA PHD.MSW

CLUJ NAPOCA

2026

Content

1. SUMMARY	3
2. Introduction.....	5
2.1. Quality of life of patients	6
2.2. Developments in lung cancer treatment	7
3. The Patient as a Human Being, in a Holistic Approach	8
3.1. Understanding the disease.....	9
3.2. Lung cancer as a disease.....	9
3.3.Individual factors	10
4. Quality of care from the patient's perspective - PROMs and PREMs.....	11
4.1. Understanding diagnosis.....	12
4.2. Doctor-patient communication	13
5. Research plan, models	14
5.1. Research methodology	15
5.2. Research questions	15
5.3. Summary of research	16
5.4. Answering research questions	20
6. Conclusion	22
7.	23

1. SUMMARY

Introduction:

Lung cancer is the most common oncological disease in Hungary. Not only early diagnosis with extensive screening tests, but also subsequent high-quality and individualized therapy can help patients' condition. We know that in addition to the progression of the disease, the severity of symptoms and side effects, there are also financial and emotional burdens that can reduce the quality of life of patients. Although survival increases with the expansion of therapeutic options, we must focus not only on therapy, but also on the general well-being of patients. Lung cancer affects more people, and the experiences of those affected in the care system and during their patient journey (PED) can provide important feedback for the care system (PRO)

Objective:

To receive feedback on the treatment of lung cancer patients, thus helping to improve patient understanding. In addition, through the results of the research, stigmatizing reactions after diagnosis can be reduced (e.g. through sensitization) and the possibilities for processing distress can be explored, for the best quality of life. Another important goal is to motivate patients towards a better understanding of the disease, in which they can thus take a more active part in their own care process, regardless of its outcome. The experiences gained during the diagnostic process, knowledge of new innovative therapies, and mapping of support options after diagnosis, psychological burdens.

Methods:

The research uses a mixed methodology quantitative questionnaire cross-sectional study, which measured patients' self-reported clinical data and experiences during the patient journey, taking into account EQ 5-5D-5L and demographic, socioeconomic and medical variables. In two pre-selected pulmonology institutes, the National Korányi Pulmonology Institute in the capital and

the Pulmonology Department of the Szabolcs -Szatmár-Bereg County Hospitals and University Teaching Hospital - Jóna András Hospital. (n=122). The study took place in 2023-2024. The prerequisite for completing the questionnaire was some type of diagnosed lung cancer. The qualitative study was conducted with the involvement of a focus group sharing experiences regarding feedback on personal experiences. (n=7).

Conclusion:

The results provide information about the holistic condition of patients, not only about the tumor, but also about the multidisciplinary aspects of treatment in the complex therapy of lung cancer. We received information about the relationship with caregivers, the quantity and quality of communication. Self-assessed QoL levels can provide a basis for predicting survival later. Based on the study, the difficulties caused by patients in accessing primary care and early care, and the time until diagnosis seem to be long, which is partly a legitimate observation. Feedback on the work of the care team, information and quality of care is satisfactory. However, the quantity and quality of communication are not entirely reassuring. This may be due to the significant workload of the care staff.

Keywords: quality of life, lung cancer, holistic approach, PRO, PED

2. Introduction

Lung cancer is a highly stigmatized group of diseases, with a very poor prognosis and numerous prejudices. Compared to the “Morbus Hungaricus” of the 20th century, TB, its perception is very different.

"Lung disease is a disease of the soul. Cancer, as it is a disease of the body, can strike anywhere." (Sontag S.1983)

In public consciousness, cancer, unlike tuberculosis, is not a disease of the romantic nature. Perhaps this is because depression, which cannot be called romantic, has taken the place of melancholy....

"TB served the romantic worldview. Cancer today serves the simplistic worldview that teeters on the edge of paranoia."

While science has made significant progress in reducing TB, reducing lung cancer is now a challenge. We aim to provide the best possible opportunities to prevent it, and if prevention is not possible, to provide patients with the best possible diagnosis and treatment. This will become increasingly realistic with the advent of innovative therapies.

Not only have therapies evolved in recent times, but patient engagement in healthcare processes is changing. One way to understand patients' experiences and needs is through the use of patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs). PROMs measure patients' perceptions of their symptoms, functional status, and health-related quality of life at a single point in time, and data collected using short, self-administered questionnaires. This information about health status indicates the outcomes of the quality of care. PREMs measure patients' perceptions of their personal experiences with healthcare provision. These questionnaire instruments ask patients to report on certain pre-defined processes that occurred during a given episode of care. (Churucca et al. 2021)

Incorporating these results and patient feedback into the licensing process, HTA, is now a European requirement.

Patient satisfaction has also received special emphasis in the care and clinical centers. Surveys are being prepared, but no survey has yet been conducted in our country examining the quality of life of lung cancer patients that assesses the understanding of the disease, experiences, the diagnostic journey and during treatment.

2.1. Quality of life of patients

“Now consider whether we still believe that we should consider not life but the good life as the supreme value?” (Socrates)

The concept of quality of life appears in the WHO (World Health Organization) definition, especially in relation to health-related quality of life (HRQoL). According to the WHO, quality of life is "an individual's perception of his or her situation in life, as influenced by the culture and value systems of his or her environment, as well as his or her own goals, expectations, patterns and relationships."

Quality of Life (QoL) is a complex and multifaceted concept, with no single, universally accepted definition, as it depends largely on individual values, cultural background and context. In general, however, it describes an individual's general well-being, satisfaction and zest for life, taking into account a number of factors. In terms of physical health, it is not only the absence of disease, but also good bodily functions, freedom from pain and vitality. It also includes psychological/mental well-being, including emotional stability, stress management skills and cognitive functions (memory, thinking).

In the social dimension, the quality of family and friendship relationships, the ability to integrate into society, community life, the ability to carry out everyday activities and make decisions.

It can affect the safety and comfort of the environment, access to the healthcare system, education, culture, financial resources, but also spiritual life, is influenced by personal faith, values, and finding meaningful goals.

According to the most accepted approaches, quality of life can be interpreted in two main dimensions:

- Subjective quality of life: This is an individual's own assessment of their life, how happy, satisfied they feel, how much they achieve their goals, and how much their expectations are fulfilled or how much they live with pain in their everyday lives. This can only be judged by

the individual themselves, and it largely depends on their personal values, on which areas of life they consider important.

-Objective quality of life: These are measurable, external factors that influence an individual's living conditions and well-being, such as housing, everyday living conditions, employment, education, and environmental impacts.

The examination and measurement of the concept of quality of life is gaining increasing importance; in medicine, the effectiveness of disease treatment is measured not only by alleviating symptoms, but also by its impact on the patient's quality of life (e.g., experiences gained during the treatment of cancer patients).

When introducing new technologies, patient feedback has an impact, and in the case of therapy with new techniques, their impact on patients' quality of life.

2.2. Developments in lung cancer treatment

In the past centuries There have been advances in the treatment of lung cancer. New diagnostic methods have been introduced to aid in early diagnosis (LDCT, PET CT, biomarker tests) and therapeutic methods (surgery, chemotherapy, radiotherapy, targeted therapy, immunotherapy) have emerged, improving the survival chances of patients.

The recognition of the harmful effects of smoking was a significant milestone in understanding the causative factors of lung cancer and in the fight against smoking, most importantly in its prevention. Primary prevention, the reduction of smoking, still presents many tasks for professionals, primarily in developing individuals' health awareness.

Protecting the environment and reducing air pollution can also contribute to reducing the development of lung cancer, a challenge we face.

In terms of age, patients are most often diagnosed between 55 and 70 years of age. Advanced age is often associated with a long smoking history. An unfortunate trend in recent years is that younger patients are being diagnosed, often without a smoking history, and the number of women affected is increasing.

Unfortunately, in many cases, those affected are not even aware of the symptoms, and many people postpone getting tested or participating in screening for a long time. The stigma surrounding cancer, which is very pronounced in the case of lung cancer, also makes early detection difficult.

3. The Patient as a Human Being, in a Holistic Approach

A major change in 20th and 21st century medicine compared to the previous, essentially curative treatments is that with the development of technology, and within this, medical technical possibilities, and biotechnologies, the disease has come to the fore as a process that transforms organs, tissues, and cells, which has transformed the host body, the patient's life and its prospects, down to genetics. The disease is being successfully mapped, and increasingly specific treatments are being developed and researched. Nowadays, such technical possibilities are available to the patient, which in many cases is not even understandable. The focus, however, has shifted - the person is not the center, the diagnosis is not the center, often only the treatment of the disease is what is taking place.

In healing, where the patient must be an active part of the healing team, success does not only depend on technique and innovative procedures. Possibility of partnership, the way the doctor/caregiver and the patient collaborate, along with relatives, nurses, specialists from many fields, such as dietitians, physiotherapists, psychologists, art therapists, can work together for the best outcome. This would be personalized medicine.

We talk about precision, personalized medicine, but it's truly individualized, when healing is not based on templates, but is tailored to the needs of the individual. Holistic healing involves thinking in terms of the unity of body, mind, and spirit. This approach can restore the patient's dignity and autonomy and make healing more human and meaningful.

3.1. Understanding the disease

Disease, as a pathological process with deviations from the norm, is what clinicians' study and what treatments are aimed at. *Disease* (biological illness) is described as a pathological process viewed from a third-person perspective.

illness- health experienced by patients, with all its symptoms and pains, is the patient's subjective, first-person experience, which is framed by the supportive or dismissive attitude of the immediate environment, the resources they have during coping, which is individual, but influences therapy with its effect.

Sickness is characterized as the social role or public status of *ill* health. Central to this framework is the diagnostic system, which serves as an interpretive bridge, translating the patient's subjective experience into the categories of the clinician's object. (Boyd 2000.)

The patient's social role and vulnerable state, which stems from stigmatization and protected social status, the patient role, which becomes part of the identity, is a third way of experiencing the disease, in which financial toxicity and vulnerability are also present.

The disease represents a significant burden for the healthcare system, as not all therapies are available, and access may only be the result of individual equity or a specially requested foundation decision, which in such cases may not be a transparent decision, but has a significant influence. During comprehensive treatment, all of these must be taken into account, in addition to the patient's priorities.

The next generation of oncopolitics is already examining the de-escalation of treatments, as costs cannot rise to unimaginable heights, and the effectiveness of therapies is also influenced by sustainability. Patient safety cannot be overridden, but drug manufacturers, developers, and health policy makers are engaged in significant conflicts in the background over financing issues. Medicalization, especially the treatment of chronic diseases, has become a big business. (Conrad 2007)

3.2. Lung cancer as a disease

Lung cancer is diagnosed in our country every year with nearly 9,000 new cases, and we lose almost the same number, 8-9 thousand people, to the disease. (Kiss et al. 2024)

The latest research (Bogos et al. 2024) draws attention to the differences in the recording of registers and statistical data. In our country, postmortem cases are also part of the statistics, while in other countries this is not included in the data, which may also be the reason for the high number of cases.

The 5-year age-standardized net survival rate for lung cancer patients is currently 18.4% (Kiss et al. 2025), meaning that only one in five patients is alive five years after diagnosis. One of the main reasons for the high mortality rate is that in half of the cases the disease is unfortunately diagnosed at an advanced, late stage, when it is no longer operable and treatment options are limited.

The diagnosis and treatment of lung cancer not only place a physical burden on patients, but also a significant psychological burden. Cognitive and emotional factors can influence how a patient copes with the disease and the extent to which they are able to maintain quality of life. Some patients may experience cognitive impairment, such as difficulty concentrating or memory problems, as a result of chemotherapy or brain metastases. Anger and frustration with disease and treatments can be a common reaction. Some patients may feel that they are responsible for their disease, which can lead to feelings of guilt, with a history of smoking being a significant factor.

Lung cancer patients use more common coping strategies to cope with their illness. Problem-focused coping allows for a reduction in stress-related emotions and a proactive approach to the therapeutic process. Researchers have confirmed the association between sense of coherence and coping styles with illness – higher levels of coherence limited emotion-focused coping and allowed patients to better cope with illness and illness-related limitations. (Polanski et al. 2016)

3.3. Individual factors

In addition to objective clinical indicators that describe the disease as a pathological process, the subjective reading of the disease as experienced by the individual, the exploration of personal feelings, symptoms, difficulties, well-being, i.e. the quality of life experienced from the patient's perspective, is of paramount importance.

The results of previous oncopsychological studies basically show that depression and negative life events are significant risk factors for cancer, in addition to traditional risk factors. (Dégi 2010.)

These are often accompanied by maladaptive stress management techniques such as smoking and alcohol consumption, which are proven to be pathogenic factors that can cause the disease.

If, with today's comprehensive approach, the healing professional does not cure the disease, the diseased organ or body part, but the sick person, even if he cannot restore it, but would like to maintain a treatable good condition, the human behavior and lifestyle that pose an increasing risk to the individual, adverse effects, and certain personality factors must also be taken into account.

4. Quality of care from the patient's perspective - PROMs and PREMs

It is now widely accepted that the outcome of cancer treatment is not only influenced by the timing of diagnosis, initiation of treatment, or general physical condition, but also by psychosocial or personality factors. In the healing process, it is essential to understand how the patient relates to their illness, themselves, and their relationships, what coping strategies they have, and what psychological reactions they experience during therapy (Holland, 2002, Riskó, 2015).

Health outcomes can be influenced by an individual's experience of symptoms, motivation, values, preferences and psychological state, as well as their social and economic environment. Ideally, to obtain a holistic picture of the impact of new health technology, all of these aspects should be taken into account and incorporated into the adoption processes of new therapeutic technologies. This is possible through multidimensional measures reported directly by patients, PRO's, -(patient reported outcomes) - of which there is a wide range. They differ in the reporting approach, the constructs measured and the characteristics of the person that researchers want to capture, and individual feedback is very important. A subset of PROMs aims to measure health-related quality of life and includes aspects related to health status, such as physical, mental and biological functioning. (Facey, Holford et al. 2026)

For patients, the quality of healthcare is of paramount importance in the treatment of disease and the preservation of quality of life. Patients' subjective experiences and expectations greatly influence the quality of care they perceive, ideally - this is a dynamic process that is reflected back and measured by their quality of life (EORTC QLQ-LC13 / QLQ-LC29 or FACT-L) questionnaires or health gain indicators (QALY -DALY)

The quality of care for lung cancer patients depends on many factors, and the subjective experiences of patients can often lead to significant quality improvements. Regular surveys of patient opinions and improvements based on these results are needed to ensure that patients receive the best possible care in the long term.

4.1. Understanding diagnosis

When the diagnosis is announced, the patient has been waiting for this moment for many months, which makes him anxious, because the next period has arrived at a moment that will affect every aspect of the rest of his life. About this moment and the shock that followed, a patient told me the line quoted by Hungarian poet Endre Ady: “Everything is completely broken.” There are long months behind the affected person, the patients feel desperate, tense, anxious, and confused. Here, finally, there is a stated certainty, it means the bottom of the river, but it is also a starting point for starting therapy.

The announcement of the diagnosis is an extremely difficult moment for both the patient and the oncologist. It is good if the patient's immediate family member can be present if possible. The doctor's task is to assess at the moment of diagnosis how much information the patient is able to absorb about their condition and how they can provide reassuring support appropriate to the situation (Riskó, 2017).

The concept of distress was linked by JC Holland (1992) to the natural, i.e. “normal” reaction triggered by cancer. The diagnosis *of cancer* itself induces distress, and biological, psychological and social factors can all influence the variability of anxiety (Andreotti et al.,

2015). Therefore, the term distress is a collective term used in psychosocial oncology, and its level can vary from normal to pathological (Rohánszky et al., 2014).

4.2. Doctor-patient communication

In the patient-doctor relationship, doctors were attributed an authoritarian and paternalistic role, who would send back: “trust me and don’t worry!”. The doctor, as a professional expert on life, health, illness and death, could demand obedience from patients, relatives and subordinates alike. There are emergency situations when there is no room or opportunity for anyone else. The development of the hospital hierarchy and its rigid, authoritarian nature, its almost military atmosphere, have unfortunately reinforced this in recent times and have not alleviated it. There is a great lack of time, from which doctors also suffer, since the information communications with which they can best inform patients would take much more time than they have at their disposal. With the development of technology, communication has been lost, while for centuries communication was the number one means of healing. The increased burden of administration takes away resources from here.

The treating physician - oncopulmonologist - is the link between the oncoteam and the patient, who reports the patient's results, forwards the team's decisions, and supervises the treatment.

Patients, as those affected in this situation, cannot be objective with the data, they cannot hear anything with the curves, which they hear during a consultation. There are many non-intellectual reasons for this, they are unable to abstract themselves from their current situation, and often the "brain fog" that occurs during therapy also affects their intellectual state. Often they are only able to approach their own illness and life situation emotionally. They need support in all respects, not only physically, but also from a spiritual and social aspect.

Having the opportunity to ask questions and have them answered helps them feel safe. In a foreign world that they didn't want to enter, it's also difficult for them to find their way around. Patients have no choice but to turn to treating physicians with the utmost trust, a trust that can sustain them in this extremely difficult life situation.

During communication with patients, various aspects come to the fore, from the clinician's side, the main aspect is the objective, professional approach. Knowledge of data related to disease is to be able to interpret these data, be it laboratory, histological, radiological results, in a complex way, and use them in determining the stage, in planning therapy. Taking into account and adhering to the protocols during treatment and the objects that are available during healing or treatment. The fact that these therapeutic decisions are not made by the treating physician alone indicates the complexity of this area and modern oncological care in the case of cancer patients. Knowledge of prognoses, the knowledge and responsibility that they have during treatment, is often coupled with a distance, since their task is also to maintain their own mental health and avoid burnout.

5. Research plan, models

The aim of the research was to obtain feedback on the treatment of lung cancer patients, thus helping to improve patient understanding. In addition, through our research results, stigmatizing reactions after diagnosis can be reduced (e.g. through sensitization) and distress can be processed, which helps to achieve the best quality of life.

Both qualitative and quantitative approaches can be useful tools for examining the quality of life of lung cancer patients, and help to create a comprehensive, nuanced picture that allows for subtle feedback and opinions that would be difficult to express in other ways.

Despite the growing population of lung cancer survivors, we have limited knowledge about the survival path. Quality of life studies are being conducted, which is essential for each therapy, and manufacturers' protocols require it, but regardless of the product and therapy, no research has been conducted that addresses physical, oncopsychological, social, and communication issues related to the involvement.

5.1. Research methodology

The research uses a mixed methodology quantitative questionnaire cross-sectional study, which measured the patients' self-reported clinical data and experiences during the patient journey in two pre-selected pulmonology institutes: the National Korányi Pulmonology Institute in the capital and the Pulmonology Department of the Szabolcs -Szatmár-Bereg County Hospitals and University Teaching Hospital - Jósza András Hospital. (n=122). The study took place between 2023-2024. A prerequisite for completing the questionnaire was a diagnosed lung cancer of some type. The qualitative study was conducted with the involvement of a focus group regarding feedback on personal experiences (n=7).

The quantitative questionnaire was completed on paper by the patients independently or, if necessary, with assistance. The research plan was approved by the Scientific Ethics Committee under file number BMEÜ/4270-1/2022/EKU. The study, which was conducted at the Pulmonology Department of the Jósza András Hospital in Nyíregyháza, was approved by the local Institutional Ethics Committee.

The sample size included in the analysis was 122 people with the inclusion of the two hospitals mentioned above. Both institutions are high-traffic, non-problematic or moderately problematic institutions. Thus, very problematic and low- or average-traffic hospitals were underrepresented in the research. The data are presented in valid unweighted form. The base of the basic distributions (100 percent) is the number of valid answers to the given question. The bivariate relationships were checked with chi-square statistics, and the “p” values were evaluated at 95 percent. In characterizing the factors, their average values were examined and compared in the different demographic groups.

5.2. Research questions

A significant amount of clinical data and statistics are produced, and significant attention and development is directed towards improving the therapy of the disease, but the lived experiences of patients do not receive sufficient attention.

Lung cancer has the highest incidence among all cancers, but unfortunately the prospects, life expectancy and late symptoms are still not very good, and the time available to those affected is short due to the prolonged diagnostic process. Due to the already described stigmatization, it is not easy for patients to open up and share their experiences.

The following questions arose during the research:

How informed are patients and in what aspects would they need more information?

Are the care staff attentive to the psychosocial needs of patients and do they receive sufficient support in this regard?

Do patients have sufficient knowledge about innovative therapies?

5.3. Summary of research

The quantitative sample includes data from lung cancer patients between the ages of 42 and 92, with balanced gender representation.

The quantitative research was conducted whilst the patients were still undergoing treatment.

Half of the participants were diagnosed with complaints, half were diagnosed during screening, 90% of them were diagnosed with lung screening and only 10% through LDCT.

The majority of respondents self-reported having no serious physical or mental health problems. problem, and their general health status can be considered good. For more than three-quarters of the respondents, public information, good relationships between patients and doctors, and doctors' knowledge of lung cancer would have been key to early diagnosis of lung cancer. These

aspects could be the areas for development that deserve more attention in the future, according to the respondents.

The participants in the qualitative focus group were not affiliated with an institution. This was not expected of them. The majority of the participants involved here were no longer in active treatment.

The qualitative study showed that in the early diagnosis of lung cancer, the participants considered screening programs to be the most important, so that examinations could be carried out as soon as possible before complaints occur, and an appointment could be made as soon as possible, e.g. for a CT scan, since in this situation time is of the essence, both from a health and psychological point of view, and quick action is paramount. The rural and urban participants reported very different experiences with regard to waiting times for examinations.

Patients considered the provision of expedited services to reduce waiting times and specific information about diagnostic processes to be of utmost importance in terms of patient journey transparency. The research participants were aware of their tumor type and stage of disease, but very few of those surveyed were aware of their own biomarker involvement, despite this being the basis for subsequent treatments.

During the quantitative study, almost half of the patients were informed about the surgery.

The most difficult aspects of lung cancer surgery were the anxiety before surgery and the recovery period in the hospital. In the case of radiotherapy and drug therapy, weakness and fatigue were the most common complaints. The latter was particularly true for women.

The research showed that during the patient journey, a trusting relationship with the treating physician is of paramount importance for lung cancer patients, and that the treating physician can provide patients with not only professional support, but also, if possible, psychological support. Unfortunately, this is not always realistic given the current workload of clinicians. There were differences between rural and Budapest participants, as well as between female and male participants, in terms of their reliance on psychological help.

A smaller proportion of those in Budapest, lacked support for emotional and social issues.

In treatment decisions, those under 65 years of age needed information about clinical trials and available supportive care more than the older age group.

Almost 70% of those with primary education lacked information on patient rights, while this was the case for 34% of those with secondary education and 20% of those with higher education.

Information about treatment was on average the most important for men, the elderly, residents of villages and those with higher education. The same can be said about information about lifestyle, which was on average more important for the under-65 age group.

When comparing the two institutions, it turned out that the patients in Nyíregyháza were more likely to lack emotional support, information on patient rights and information about end-of-life care, while the patients in the capital institution were more satisfied. We therefore created factors from the questions related to the need for certain forms of support provided to people receiving drug therapy. The result of the factor analysis is that the questions used were grouped into two significantly different information-content factors (new variables), which in our case are the following:

- Lifestyle information: Information on catheter care, lifestyle, breathing exercises, pain relief, smoking cessation, nutrition, and psychosocial support
- Treatment information: Information about medical treatment, management of side effects, reducing the risk of complications

Examining the averages of the factors, the following can be said (Figure 1). Lifestyle-related information is on average more important for women. On average, those under 65 years of age consider lifestyle-related information to be important, while those older than them require information about treatment. On average, those living in the capital consider lifestyle-related information to be the least important. Residents of villages consider both to be more important, but treatment-related support to be less important. Those with higher education consider both information to be very important. Those with secondary education are on average more neutral in their opinion, but lifestyle-related information is more important. Those with primary education consider lifestyle-related information to be more important, while those with secondary education consider information about treatment to be less important.

AVERAGE IMPORTANCE OF LIFESTYLE AND TREATMENT INFORMATION FOR DIFFERENT DEMOGRAPHIC GROUPS



Participants in the qualitative research agreed that it is very important to have appropriate, receive comprehensive professional information about treatments, side effects, and necessary lifestyle changes, because there is a lot of different information online that can mislead patients. Participants considered it essential for recovery that individual or group oncopsychological support be available to patients diagnosed with lung cancer. This is particularly true during supportive and palliative care.

The qualitative research reveals that the patients involved use conscious coping strategies used in combating disease, among which psychological support, the importance of sports, meditation, the sustaining power of family, and everyday humor. The participants mentioned learning about the diagnosis and the side effects of chemotherapy as the most difficult moments. They formulated an important message for those who are just starting their journey as patients to trust their doctor, not to get information from unreliable online sources or statistics, and to trust themselves and their recovery.

The final questions in the research also asked about experiences with COVID 19 care.

The direct effects of the pandemic on patients' treatment processes limit long-term conclusions but cannot be drawn within the scope of this research.

5.4. Answering research questions

1.

Question:

What unmet physical, social, emotional, and health needs do patients with lung cancer have, regardless of diagnosis or treatment status?

Certificate:

During the patient journey, patients provided feedback on different experiences at different times.

The most difficult and uncertain period is the diagnostic period and the period before starting treatment. They have little knowledge about the symptoms and their recognition, and side effects.

There is uncertainty at the beginning of the patient journey, communication about the available options is lacking, just as the care system is lacking at the basic care level, many home medical practices are unfilled, and it would be most important to be able to accurately find out about the risks and provide information based on one's own and family medical history.

When the diagnosis is communicated, they already have sufficient accurate information in terms of prognosis, treatment options, complications, and risk factors. Here, the complaining individual becomes a patient, and the patient journey is already carried out according to protocols.

During and after the surgical procedure, complications and rehabilitation are discussed. 56% of patients say they are well informed and 27% very well informed. Here, the medical team stands by the patient and the patient's path becomes clearer.

They are able to share all aspects of the disease 54% completely, but 7% reported not being able to share at all.

Overall, 89% found the care to be reassuring.

When defining patient-centered care, empathy, compassion, and information are of paramount relevance.

During follow-up care, only 25% of patients are satisfied with their experiences, which may also be influenced by the narrowness of individual perspectives.

Overall, we found unmet needs. This was most evident at the beginning and end of the patient journey, and information and active involvement in the process can alleviate these regardless of the individual's condition. I think this will always be the case, as it is not always possible to imagine a positive outcome in comprehensive and general results.

2. Question:

Do patients have sufficient knowledge about innovative therapies?

Certificate:

Among the traditional treatment modalities, surgery represents the best future perspective for patients, but this was a realistic plan for 18% of the patient population studied. This is consistent with the results of other larger studies. In addition to traditional therapy, neoadjuvant and adjuvant chemotherapy and radiotherapy, innovative, immune and targeted therapies have brought great breakthroughs and great perspectives in recent times, which are unfortunately not available to everyone.

This availability is determined by the patients' test results and disease stage.

The results of molecular pathology examinations and biomarker tests can represent a very important milestone during the patient's journey.

Unfortunately, those affected do not have enough information about this. They know what stage and type of their tumor is. However, very few people know what mutation this means and what therapy is associated with it. Only 3-3% were able to give feedback on which subtype their tumor belongs to, and in the end, 65% of the patients received treatment for adenocarcinoma, so the test was definitely determined from their samples.

A lot of clarification and more precise information is needed here.

In summary:

Patients do not have enough information about innovative therapy.

6. Conclusion

Quantitative and qualitative research conducted among lung cancer patients revealed that patients participating in the research reported uncertainty mainly in the early stages of the patient journey. Inequalities between institutions and lack of information indicate significant gaps in care. Professional and psychological support is essential for successful coping.

From the perspective of patient journey management, the time factor is of great importance during the diagnostic journey, as the shortest possible time between early diagnosis and further examinations would be of paramount importance. Regional inequalities can be experienced between Budapest and Nyíregyháza in waiting times and quality of care. Transparency is needed, which can even speed up the process of care during the patient journey.

Patients have difficulty accessing information, apart from the main type and stage, patients have difficulty accessing information, their knowledge of the pathological results is no longer sufficient, even though this would determine the subsequent treatment and life prospects. During the therapeutic journey, they are well informed during surgical preparation, but not in all cases in the case of radiation and drug treatment. This treatment-related information would be more for older people and men.

Lifestyle-related information is more important for women and those under 65. Education also improves awareness, but authentic official information is important for patients, as they find it more difficult to navigate the online space, which may be due to differences in age and digital literacy.

In terms of psychological and social support, the confidential relationship established with doctors is key, but there is a great need for psychological support and oncopsychological support, since the workload and role of clinicians in this area cannot be expected alone. Regionally, half of the patients in Nyíregyháza lacked emotional support, while those in Budapest were more satisfied. There is a strong need for expert psychological support, especially in palliative care.

In terms of coping strategies and difficulties, the critical points are -Learning about the diagnosis, pre-operative anxiety and the side effects of chemotherapy (fatigue, weakness – especially in women) are the most difficult stages. If we consider the available resources, sports, meditation, family and social support, but also humor, are helpful, according to the participants' reports.

Overall, it can be said that lung cancer patients face several challenges, regardless of diagnosis and treatment method. They have unmet physical, social and emotional needs, which manifest themselves with varying intensity in each phase of the patient's journey.

7.

Charissa Andreotti, James C. Root, Tim A. Ahles, Bruce S. McEwen, Bruce E. (2015) *CompasCancer, coping, and cognition: a model for the role of stress in cancer-related reactivity and cognitive decline* <https://doi.org/10.1002/pon.3683>

Boyd M. Kenneth(2000) *Disease, illness, sickness, health, healing and wholeness: exploring some elusive concepts* <https://doi.org/10.1136/mh.26.1.9>

Bogos, K., Kiss, Z., Gálffy, G., Tamási, L., Ostoros, G., Müller, V., Urbán, L., Bittner, N., Sárosi, V., Vastag, A., Polányi, Z., Nagy-Erdei, Z., Vokó, Z., Nagy, B., Horváth, K., Rokszin, G., Abonyi-Tóth, Z., Barcza, Z., & Moldvay, J. (2020). Lung Cancer in Hungary. In *Journal of Thoracic Oncology* (Vol. 15, Issue 5, pp. 692–699). Elsevier Inc. <https://doi.org/10.1016/j.jtho.2019.11.001>

Churruca , K., Pomare , C., Ellis , LA, Long, JC, Henderson, SB, Murphy, LED, Leahy , CJ, & Braithwaite , J. (2021). Patient-reported outcome measures (PROMs): A discussion of generic and condition-specific measures, trends, and issues. In *Health Expectations* (Vol. 24, No. 4, pp. 1015–1024). John Wiley and Sons Inc. <https://doi.org/10.1111/hex.13254>

Conrad Peter Medicalisation Book Editor(s): [J. Michael Ryan](https://doi.org/10.1002/9781394260331.ch52)
<https://doi.org/10.1002/9781394260331.ch52>

Dégi, Cs., L. (2010). *Psychosocial analysis of cancer: a theoretical introduction for caregivers*. Presa Universitara Clujena.

Holland, JC (1992). Psycho-oncology: an overview, obstacles and opportunities. *PsychoOncology*, 1(1), 1-13.

Holland, JC (2002). The history of psycho-oncology: overcoming attitudinal and conceptual barriers. *Psychosomatic Medicine*, 64(2), pp. 206–221.

Kiss, Z., Berki, TL, Maráz, A., Horváth, Z., Nagy, P., Fábián, I., Kovács, V., Rokszin, G., Surján, G., Barcza, Z., Kenessey, I., Wéber, A., Wittmann, I., Molnár, GA, Szabó, TG, Buga, V., Karamousouli, E., Darida, M., Abonyi-Tóth, Z., ... Vokó, Z. (2025b). Overall Survival of Hungarian Cancer Patients Diagnosed Between 2011 and 2019, Based on the Health Insurance Fund Database. *Cancers* , 17 (10). <https://doi.org/10.3390/cancers17101670>

Kiss, Z., Berki, TL, Maráz, A., Horváth, Z., Nagy, P., Fábián, I., Kovács, V., Rokszin, G., Surján, G., Barcza, Z., Kenessey, I., Wéber, A., Wittmann, I., Molnár, GA, Szabó, TG, Buga, V., Karamousouli, E., Darida, M., Abonyi-Tóth, Z., ... Vokó, Z. (2025b). Overall Survival of Hungarian Cancer Patients Diagnosed Between 2011 and 2019, Based on the Health Insurance Fund Database. *Cancers* , 17 (10). <https://doi.org/10.3390/cancers17101670>

Kiss, Z., Szabó, TG, Polgár, C., Horváth, Z., Nagy, P., Fábián, I., Kovács, V., Surján, G., Barcza, Z., Kenessey, I., Wéber, A., Wittmann, I., Molnár, GA, Gyöngyösi, E., Benedek, A., Karamousouli, E., Abonyi-Tóth, Z., Bertókné Tamás, R., Fürtös, DV, ... Vokó, Z. (2024). Review of the incidence of cancer in a Central European country: a Hungarian, national study between 2011 and 2019, based on the health insurance fund database | <https://doi.org/10.3389/fonc.2025.1446611>

Riskó, Á. (2017). Prevention of malignant tumors, psychosocial risk factors. *Oncopsychology in practice*. Ed. Horti J, Riskó Á. 2. On-line edition , Volume I-II.

M, Rohanszky ., Thege Barna, K., György, B., László Hospital, S., Department, O., Foundation, T., University, S., & Institute, M. “Those who survived the disease” - *Quality of life of cancer patients in the light of a retrospective study* . Hungarian Oncology 55:193–198, 2011

Polanski, J., Jankowska-Polanska, B., Rosinczuk, J., Chabowski, M., & Szymanska-Chabowska, A. (2016). Quality of life in patients with lung cancer. *OncoTargets and Therapy* , 9 , 1023–1028. <https://doi.org/10.2147/OTT.S100685>

