

# ADVANCED NON-SMALL CELL LUNG CANCER (NSCLC): PATIENTS' ILLNESS PERCEPTIONS AT DIAGNOSIS

## ABSTRACT

*Lung cancer is the leading cause of cancer-related death worldwide with non-small cell lung cancer (NSCLC) being the most common type. Advanced NSCLC is not curable and carries a poor prognosis. It also is associated with the highest burden on mental and physical health-related quality of life (HRQoL) of all patients with cancer. Patients' subjective experience with their illness and treatment (illness perceptions) may influence treatment decision making and health outcomes, including HRQoL. Illness perception studies with patients with lung cancer are reviewed. Using Leventhal and colleagues' Self-Regulation Model to better understand patients' experience and coping with their advanced-stage NSCLC (N=156) assessed illness perceptions (Illness Perception Questionnaire-Revised [BIPQ]) and HRQoL (EuroQol-visual analogue scale [EQ-VAS]). Patients reported high perceived consequences and stress (concern) at diagnosis along with moderate levels of symptoms (identity) and belief in their ability to manage their NSCLC (personal control). Patients reported low HRQoL compared to population norms. The illness perceptions of consequences, concern, and identity were negatively correlated with HRQoL, while personal control was positively correlated with HRQoL. Assessment of illness perceptions provides a nuanced understanding for patients as they cope with cancer diagnosis. To advance study, prospective longitudinal designs might study how illness perceptions might relate to HRQoL trajectories of patients with newly diagnosed advanced NSCLC as they receive first and later lines of cancer therapies.*

## KEY WORDS

NON-SMALL-CELL LUNG CANCER, ILLNESS PERCEPTIONS, STRESS, QUALITY OF LIFE, CANCER DIAGNOSIS

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## INTRODUCTION

Of all cancer types, advanced lung cancer is associated with the poorest quality of life, highest levels of clinical depression, anxiety, and patient risk of suicide.<sup>1-4</sup> Evaluating how patients with lung cancer perceive their illness may provide insight into their cancer experience.<sup>5</sup> Illness perceptions (ie, patients' subjective understanding of their disease) can influence important self-management and treatment decisions that affect survival and quality of life outcomes, among others. Despite the importance of patients' subjective beliefs, only recently has attention focused on illness perceptions of lung cancer patients.

Adding to the limited empirical research,<sup>6</sup> we report illness perceptions and health-related quality of life (HRQoL) from a single group of patients at the time of their diagnoses of advanced-stage non-small cell lung cancer (NSCLC; N=156). NSCLC is the most common form of lung cancer, representing approximately 85% of all diagnoses. Of all lung cancer patients, the majority have advanced-stage disease at diagnosis, with more than 57% having metastatic disease at diagnosis in the U.S.<sup>7</sup> Until recently, the overall survival for most patients was about one year,<sup>8</sup> although this is now substantially extended to 2 years or more with newer targeted and immunotherapies.<sup>9</sup> With these recent advances in treatment for NSCLC, there is a gap and need for new understandings of how patients cope with this disease. Before discussing patients'

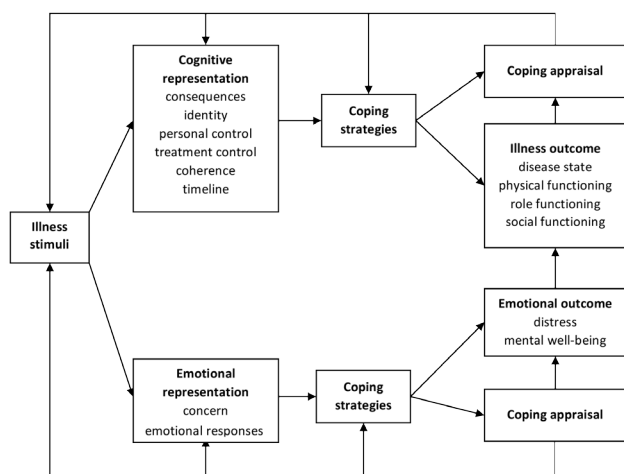
illness perceptions in the days following diagnosis, a theoretical framework for how individuals come to interpret and perceive “illness” is provided.

## SELF-REGULATION MODEL AND COGNITIVE AND EMOTIONAL REPRESENTATIONS OF ILLNESS

The Self-Regulation Model by Leventhal and colleagues<sup>5</sup> provides a framework to understand illness perceptions, describing how patients respond to health changes and illness threats, and how illness perceptions influence an individual's coping (see Figure 1 for detail).

Fig. 1 The Self-Regulation Model.

When encountering a health threat (illness stimulus), individuals form mental representations of the threat (illness perceptions). These representations inform individuals' thoughts and beliefs of the illness (cognitive representations) and emotional response to the illness (emotional representations), which influence their selection of coping strategies and appraisals of their coping and health outcomes. Illness perceptions are dynamic, informed by current and prior experiences with the illness and can change with new experiences and information about the disease (eg, symptom change, success or failure of the treatment).<sup>5</sup>



When encountering a health threat, patients form mental representations (illness perceptions) that guide coping behaviors to manage the consequences of the illness, which then influence physical and emotional health.<sup>10</sup> Specifically, illness perceptions can be subdivided into cognitive representations (ie, thoughts and beliefs of the consequences of the illness, the symptoms experienced, how long the illness will last, whether or not the illness can be controlled, and the extent of understanding the illness) and emotional representations (ie, emotional responses to the illness such as fear and concern).<sup>11</sup> Illness perceptions are informed by current and prior experiences with the illness and can change over time as a consequence of having new experiences and information about the disease (eg, symptom change, success or failure of the treatment).

Illness perceptions among patients with cancer appear to influence decision making and co-vary with negative psychological responses and symptom reports.<sup>12-14</sup> Illness perceptions appear to influence decision-making for end of life care.<sup>15</sup> Additionally, maladaptive illness perceptions have been associated with worse physical and mental health and diminished functioning in patients with head and neck<sup>16</sup> and breast cancer,<sup>13</sup> higher levels of cancer-specific stress, depression, and fatigue interference in chronic lymphocytic leukemia patients,<sup>17</sup> and greater distress in patients with breast cancer.<sup>13</sup> Illness perceptions informed by the experience of

cancer can influence these important health outcomes. For example, negative perceptions that one's cancer will last for a long time, is a serious condition, is associated with many symptoms, and is difficult to understand have been associated with greater distress in patients with breast cancer.<sup>18, 19</sup> The role of illness perceptions in patients with newly diagnosed advanced-stage NSCLC is less well-characterized.

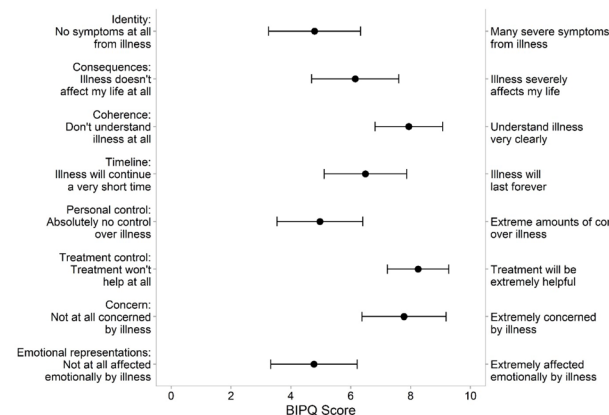
## ILLNESS PERCEPTIONS OF PATIENTS WITH NEWLY DIAGNOSED LUNG CANCER: AN EXAMPLE FROM THE U.S.

From June 2017 to March 2019, 156 patients with newly diagnosed stage IV NSCLC were consented and enrolled in an observational study from a single comprehensive cancer center. They were to receive treatment at a National Cancer Institute designated comprehensive cancer center in the US. This study was approved by the institutional review board in accordance with federal regulations and the Declaration of Helsinki. Patients were predominantly male (55.8%; n=87), white (85.9%; n=134), older (mean [M]=62.9 years; standard deviation [SD]=11.6; range=27-92), married (58.3%; n=91), retired (51.3%; n=80), and had at least a high school education (85.3%; n=133). Patients were diagnosed recently before completing their baseline questionnaires (median=42 days). The majority (80.8%; n=126) had not begun treatment, while the rest (19.2%; n=30) started treatment within a month prior to consent. Most of the patients had a history of smoking (91.0%; n=142) and 27 (17.3%) were current smokers. Patients completed illness perceptions and HRQoL surveys with a trained telephone interviewer after consent. Patients also had a copy of the measures to view as they were interviewed.

The Illness Perception Questionnaire-Revised (BIPQ) is a self-report measure used to assess 8 mental representations of illness (consequences, timeline, personal control, treatment control, identity, concern, coherence, and emotional response), with one question for each.<sup>11</sup> Patients responded to each item using a 0 - to 10 - point Likert scale, with higher scores reflecting stronger endorsement of the illness representation. Figure 2 lists the items along with the anchors for 0 - and 10 - point responses. As there are no cutoff scores for this measure, variations in illness perception scores are summarized by tertiles, with scores 0.00-3.33 as viewed as low, 3.34-6.66 as moderate, and 6.67-10.00 as high.

Fig. 2 Illness perceptions reported by newly diagnosed NSCLC patients (N=156).

The Illness Perception Questionnaire-Revised (BIPQ) was used. Each item (8) was rated on a 0 to 10-point scale. Anchors for each item are provided. The mean values with standard deviations bars are depicted.



For HRQoL, the EuroQol-visual analogue scale (EQ-VAS) was used. The EQ-VAS is a single item for patients to rate their overall health on a vertical visual analogue scale ranging from 0 (“the worst health you can imagine”) to 100 (“the best health you can imagine”).<sup>20</sup> Spearman’s rho correlations were computed to examine associations between illness perceptions and HRQoL using SPSS version 22.0.

## PATIENTS’ ILLNESS PERCEPTIONS

Person-centered care as a concept and a measure is central to modern care now places emphasis on the person and shows how everyday experiences living with cancer can change patient and family needs and wants.

In summary, despite ongoing challenges with resource allocation, building partnerships, geographical distance between investigators and policy alike, the goal for Canada to create new knowledge and to build national capacity in cancer survivorship research, is achieving its objectives. This Canadian experience incites new ventures in international collaboration for better research and practice in the next decade.

## COGNITIVE REPRESENTATIONS

### Consequences: Does NSCLC affect patients’ lives?

Patients viewed having lung cancer as moderately consequential for their lives (ie, *consequences*,  $M=6.15$ ;  $SD=2.91$ ), reflecting the disease’s considerable burden on quality of life and functional capacity. Results are consistent with patients with lung cancer reporting quality of life disruption<sup>1</sup> and high symptom burden concurrently.<sup>21</sup> Poor functional status is common in lung cancer with an estimated 30-50% of patients having performance status limitations (ie, at best being capable of all self-care but unable to work).<sup>24, 25</sup> Interestingly, medical professionals may not appreciate patients’ poor functional capacity. Prevalence of poor functional capacity was 34% when assessed by medical professionals, yet 48% when self-assessed by patients in a sample of 503 patients with lung cancer.<sup>24</sup> Indeed, lung cancer is one of the largest contributors to disability worldwide<sup>26</sup> and causes significant economic burden via productivity lost and health-care costs (ie, lung cancer cost the European Union €18.8 billion in 2009 alone<sup>27</sup>).

### Coherence: Do patients understand NSCLC?

Patients’ high reported *coherence* ( $M=7.94$ ;  $SD=2.26$ ) suggests they understand their cancer well. Importantly, this is a report of patients’ subjective global understanding of their disease. Due to the limited specificity of the coherence item of the BIPQ, it is not known what information patients ‘understand’ nor if it is accurate. Nevertheless, patients’ knowledge of treatment and NSCLC may influence patients coping and behavioral and health outcomes.<sup>15, 28</sup> However, the timeline and controllability items of the BIPQ provide additional detail on how patients understand their illness.

### Timeline: Do patients appreciate that NSCLC is a terminal illness?

Life expectancy for advanced NSCLC is improving. However, it is still considered a terminal illness. Interestingly, the *timeline* ( $M=6.49$ ;  $SD=2.76$ ) data indicates that patients with newly diagnosed NSCLC believe their disease will last a moderately long time but not “forever.” Although patients’ reported cognitive representations reflect a level of optimism at diagnosis, this may also suggest an unawareness of the disease severity or a failure to acknowledge such if known.<sup>29</sup>

Also, whether or not such perceptions are helpful to mental or physical health is not well-characterized.<sup>14</sup> Prior research demonstrates that providers communicating to patients that lung cancer was incurable were associated with higher hospice utilization rates, suggesting that conveying accurate information about the disease and prognosis may play a role in patients’ treatment or supportive care choices.<sup>28</sup>

### Personal and treatment control: Do patients believe they can control their NSCLC?

Patients report at least moderate control over their disease (ie, *personal control*;  $M=4.97$ ;  $SD=2.86$ ). Viewing the self as in control is important, as less personal control has been found to relate to more depressive symptoms in a sample predominantly consisting of patients with lung cancer.<sup>30</sup> Patients reported personal control can be contrasted with their stronger perceptions that treatment will help (ie, *treatment control*;  $M=8.25$ ;  $SD=2.06$ ). This may reflect hope enabling a sense of control over their advanced NSCLC.<sup>31</sup> Notably, other longitudinal data show personal and treatment control to decrease with time for patients with lung cancer, suggesting a greater recognition of the limits of one’s own control as well NSCLC treatments.<sup>32</sup>

Prior studies of illness perceptions in lung cancer have indicated that patients hope to be cured from lung cancer with treatment.<sup>33</sup> Hope for cure is consistent with a survey of patients primarily diagnosed with metastatic lung cancer that had over two-thirds of patients reporting to believe chemotherapy to be curative.<sup>28</sup> This view of treatment may provide hope to patients. It might also move patients to choose aggressive treatment pathways with detrimental effects on quality of life and unrealistic expectations of the survival benefits. As such, further research is needed to understand the nuances of patients’ understanding of their disease and treatment in advanced NSCLC.

## EMOTIONAL REPRESENTATIONS

### Concern: How concerned are patients about NSCLC?

Patients report a high level of NSCLC *concern* ( $M=7.78$ ;  $SD=2.80$ ), likely indicative of the high stress accompanying diagnosis. Typically, stress of patients with cancer peaks at diagnosis and initiation of treatment.<sup>34, 35</sup> Stress has biobehavioral effects and when highest is associated with concurrent depressive, anxiety, and physical symptoms, immune dysregulation, and quality of life disruption.<sup>36</sup>

### Emotional responses: Does NSCLC affect patients’ emotions?

In addition to concern, patients reported a moderate level of emotional distress (ie, *emotional response*;  $M=4.77$ ;  $SD=2.89$ ). Emotional representations are important for medical professionals to consider as the emotional experience of lung cancer significantly affects HRQoL.<sup>37</sup> Negative affect (ie, fear, anger, sadness, stress) has been shown to be associated with poorer functioning, pain, and general health. Although reducing negative affect may have HRQoL benefits, maintaining positive affect (ie, happiness, interest, optimism) is also associated with benefits.

Conversely, depressive symptoms are of particular importance, though the neurovegetative (ie, fatigue, sleep disturbance, cognitive impairment) and emotional (ie, depressed mood, guilt, hopelessness) indications of major depressive disorder are often unrecognized or underestimated in severity when recognized.<sup>2, 3</sup> Evidence of the needs of patients with comorbid depression being unmet is the elevated suicide incidence in advanced lung cancer.<sup>4</sup> Lung cancer has

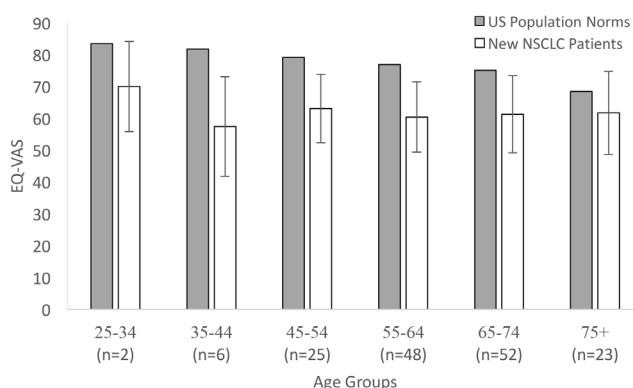
psychiatric comorbidity 2-3 times that of other cancer types, with rates of clinical depression ranging from 18-38% and anxiety estimated around 26%, and still others (15-48%) with subclinical disorders.<sup>2, 3</sup> Importantly, depression and anxiety negatively impact treatment adherence and survival in patients with advanced NSCLC.<sup>37-39</sup>

## HEALTH-RELATED QUALITY OF LIFE

Figure 3 provides the patients' HRQoL rating, within age groups, compared to U.S. population HRQoL normative data by age.<sup>40</sup> Collectively, patients reported HRQoL to be low ( $M=61.4$ ;  $SD=23.4$ ;  $range=0-100$ ) compared to the population norm ( $M=80.0$ ;  $standard\ error=0.1$ ). Correlational analyses were completed to examine the associations of illness perceptions with HRQoL. Greater perceived consequences of NSCLC (consequences;  $\rho=-0.286$ ;  $p<0.001$ ), symptoms attributed to NSCLC (identity;  $\rho=-0.419$ ;  $p<0.001$ ), stress (concern;  $\rho=-0.185$ ;  $p=0.022$ ), and emotional distress (emotional response;  $\rho=-.189$ ;  $p=0.020$ ) were correlated with worse HRQoL, while greater belief in having the ability to manage NSCLC (personal control;  $\rho=0.340$ ;  $p<0.001$ ) and belief that treatment will help (treatment control;  $\rho=0.249$ ;  $p=0.002$ ) were correlated with better HRQoL. Interestingly, timeline and coherence were not significantly correlated with HRQoL ( $ps>0.279$ ). Investigating illness perceptions can enable a better understanding of how patients may respond to their illness and why patient-reported health outcomes including HRQoL are poor in advanced NSCLC patients. Examining patients' subjective experience to help maximize quality of life may be especially important while medical professionals balance survival and HRQoL benefits when making treatment decisions.

**Fig. 3** Health-related quality of life reported by patients with newly diagnosed NSCLC ( $N=156$ ) and age-adjusted U.S. general population norms.<sup>40</sup>

The EuroQol-visual analogue scale (EQ-VAS) was used (range 0-100). Age-adjusted data from U.S. population norms are provided (grey bars). Means and standard deviations of participants' EQ-VAS data are reported (white bars) using the EQ-VAS normative age groupings. NSCLC subgroup sample sizes ranged from 2 (ages 25-34) to 52 (ages 65-74).



## SUMMARY AND IMPLICATIONS

Illness perception data illustrate the serious ramifications of a diagnosis of advanced NSCLC in a newly diagnosed, predominantly treatment-naïve sample. A review found a broad range of consequences associated with the diagnosis of lung cancer including patients' feeling little control over

their disease and high emotional distress.<sup>6</sup> Consistent with our findings, other studies revealed that negative illness perceptions associated with worse mental and physical HRQoL over and above relevant demographic and clinical characteristics (eg, age, brain metastasis, performance status, and treatment<sup>41</sup>)—highlighting the importance of subjective patient experiences in understanding how patients respond to cancer.

Importantly, prior meta-analyses consistently find illness perceptions to have moderate to large effect sizes with health outcomes such as psychological distress, functional status, and quality of life—suggesting that these experiences are critical to understanding how patients respond to cancer.<sup>14, 42</sup> In this study, we described that patients' HRQoL was influenced by the experience significant symptoms from NSCLC (identity) that affect their lives (consequences) and cause distress (concern). Indeed, meta-analyses found moderate to large effect sizes (Fisher's z transformations [ $r_z$ ] ranging from 0.309 to 0.607) were found in the relationship between identity and functioning as well as quality of life outcomes in patients with cancer, such that higher reports levels of identity were associated with lower levels of functioning and quality of life. Although only a moderate relationship between consequences and psychological wellbeing were found ( $r_z=0.355$ ), large effect sizes between emotional representations and mental health (anxiety, depression, psychological distress;  $r_z$  ranging from 0.517 to 0.738) have been also previously demonstrated.

According to the Self-Regulation Model, illness perceptions influence both health outcomes and coping behaviors in response to the illness such as making treatment decisions that ultimately influence health outcomes. This insight into the patient experience offered by evaluating illness perceptions can provide potential targets of clinical intervention by medical professionals. For example, identifying patients' source of concern that is emotionally affecting them throughout treatment may help inform patient education or referral for psychological care. How patients understand their illness and treatment is important; consistent with research on patients' accurate understanding of the purpose of chemotherapy for terminal cancer affecting treatment decisions,<sup>28</sup> patients with advanced NSCLC receiving early palliative care were less likely to proceed with aggressive treatment (ie, chemotherapy) near end of life if they reported accurate perceptions of their prognosis—potentially limiting patient morbidities and escalating cost of care.<sup>15</sup>

Illness perceptions may also have a role in treatment acceptability and adherence. Although some patients never receive treatment due to poor performance status, others do not receive treatment due to a lack of knowledge about treatment options.<sup>43</sup> Patients that do not receive treatment may benefit from conventional treatment as their clinical characteristics at diagnosis (eg, performance status, clinical presentation, and tumor markers) are similar to patients who receive treatment.<sup>44</sup> Additionally, an early clinical trial of cisplatin ( $N=215$ ) found that only half of patients completed the 4 planned cycles, with patient refusal to continue accounting for 29% of those with less than 4 cycles—double the number of patients withdrawing due to toxicities.<sup>45</sup> For patients deciding which treatments to accept, HRQoL decisions and a better understanding of the role of treatment may be essential.

Due to the importance of subjective experiences of advanced NSCLC, evaluating illness perceptions can provide insight into these experiences. For medical oncology, this may be particularly informative as new treatments are emerging at a rapid pace. As survival time improves with new targeted therapies and immunotherapies, understanding the subjecti-

ve experience of patients related to HRQoL is vital to patient care. Future research is needed to understand which specific components of illness perceptions influence important health outcomes and treatment decisions, with the hope of developing impactful clinical applications (ie, support programs to promote adaptive coping with NSCLC).<sup>46</sup> Since illness perceptions can have a profound impact on important patient-reported outcomes, prospective quality research on patient experiences should occur simultaneously with new clinical trials in advanced NSCLC.

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