A Pilot Mixed-Methods Study of Malignant Pleural Mesothelioma Symptoms

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OBJECTIVES: To describe symptoms of malignant pleural mesothelioma (MPM), a rare cancer associated with a poor prognosis and significant symptoms, via a pilot mixed-methods study, because it is unclear whether MPM symptom assessment tools accurately characterize these symptoms.

SAMPLE & SETTING: Participants with MPM were recruited from a large northeastern U.S. academic medical center with an interprofessional MPM program.

METHODS & VARIABLES: A mixed-methods pilot approach was employed using the Lung Cancer Symptom Scale for Mesothelioma (LCSS-Meso) to quantitatively describe MPM symptoms and semistructured interviews to qualitatively capture these symptoms.

RESULTS: Seven participants with MPM completed the LCSS-Meso and qualitative interviews. The five symptoms evaluated by the LCSS-Meso were confirmed as symptoms of MPM in participant interviews. However, the presence and severity of some symptoms were either under- or overestimated by the scale. Two additional symptoms, distress and sleep disturbance, also emerged from the qualitative interviews.

IMPLICATIONS FOR NURSING: Nurses caring for people with MPM should have a thorough understanding of common symptoms, but they must also explore additional symptoms that are meaningful to each patient.

KEYWORDS LCSS-Meso; mixed methods; symptoms; malignant pleural mesothelioma

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Malignant pleural mesothelioma (MPM) is a rare but deadly cancer that arises in the pleural lining of the lung, is highly associated with asbestos exposure, and can have a lengthy latency period of approximately 40 years (Reid et al., 2014). People with MPM have a poor prognosis, with five-year survival rates of only 10.7% and median survival rates of fewer than six months if left untreated (Howlader et al., 2020; Saddoughi et al., 2018). In addition to poor survival, people with MPM have significant symptoms such as pain, dyspnea, fatigue, loss of appetite, and cough (Hollen et al., 2004; Mendoza et al., 2019).

Several quantitative tools have been adapted to measure MPM symptoms (see Figure 1). These tools are the Lung Cancer Symptom Scale for Mesothelioma (LCSS-Meso) (Hollen et al., 2004), the European Organisation for Research and Treatment of Cancer (EORTC) Quality-of-Life Questionnaire–Core 30 (QLQ-C30) (Aaronson et al., 1993), the EORTC Quality-of-Life Questionnaire for Lung Cancer (QLQ-LC13) (Nowak et al., 2004), and the MD Anderson Symptom Inventory Malignant Pleural Mesothelioma Module (MDASI-MPM) (Cleeland et al., 2000; Mendoza et al., 2019; Williams et al., 2018). The LCSS-Meso, which was modified from the Lung Cancer Symptom Scale (Hollen et al., 1993), measures general MPM symptoms as well as symptom distress, interference with activity level, and global quality of life (Hollen et al., 2004, 2006). The EORTC QLQ-LC13 is a lung cancer–specific supplement to the EORTC QLQ-C30, a general cancer symptom scale measuring various disease-related and treatment-induced symptoms, as well as global health and quality of life (Aaronson et al., 1993). The QLQ-LC13 assesses lung cancer symptoms as well as treatment-related side effects (Bergman et al., 1994). The MDASI-MPM is based on the MD Anderson Symptom Inventory cancer symptom measurement tool, and it is the only

MPM symptom tool incorporating qualitative inquiry. It consists of 13 core disease- and treatment-related symptoms from the original tool and six items specific to MPM. This tool also captures symptom interference, which together with symptoms describes the overall symptom burden (Williams et al., 2018).

Qualitative studies have also identified MPM symptoms by exploring the experiences of patients with MPM. In their study examining patient experience in the first three months following diagnosis, Arber and Spencer (2013) identified symptoms such as fatigue, pain, sweating, and dyspnea as significantly contributing to the experience of MPM. Clayson et al. (2005) also highlighted symptoms of fatigue, dyspnea, weight loss, and pain reported by patients with MPM. Another prominent theme in multiple qualitative studies is the significant emotional distress experienced by people with MPM (Arber & Spencer, 2013; Clayson et al., 2005; Girgis et al., 2018; Hughes & Arber, 2008).

Gelhorn et al. (2018) conducted a qualitative study using semistructured interviews to examine the content validity of the LCSS-Meso. The most commonly occurring symptoms in participants were consistent with those captured by the LCSS-Meso, including fatigue, dyspnea, loss of appetite, pain, and cough. A variety of other symptoms were identified by at least one participant in the study. However, these occurred less frequently than the five symptoms captured by the LCSS-Meso and were not emphasized as part of the major study findings (Gelhorn et al., 2018).

Although there is a small but growing body of MPM symptom research using quantitative, qualitative, or multimethod data collection, the investigators could not find dedicated mixed-methods research evaluating MPM symptoms. Mixed-methods approaches can offer an opportunity to comprehensively describe symptoms experienced by people with MPM by integrating quantitative data with qualitative accounts that would be missed by quantitative data alone.

FIGURE 1. Malignant Pleural Mesothelioma Symptoms Measured by Different Quantitative Tools

EORTC Quality-of-Life Questionnaire–Core 30
- Appetite loss
- Constipation
- Diarrhea
- Dyspnea
- Fatigue
- Financial impact
- Nausea or vomiting
- Pain
- Sleep disturbance

EORTC Quality-of-Life Questionnaire for Lung Cancer
- Alopecia
- Arm or shoulder pain
- Chest pain
- Cough
- Dysphagia
- Dyspnea climbing stairs
- Dyspnea resting
- Dyspnea walking
- Extrathoracic pain
- Hemoptysis
- Mouth sores
- Peripheral neuropathy

Lung Cancer Symptom Scale for Mesothelioma
- Appetite loss
- Cough
- Dyspnea
- Fatigue
- Pain

MD Anderson Symptom Inventory Malignant Pleural Mesothelioma Module
- Chest heaviness or tightness
- Coughing
- Difficulty remembering
- Distress or feeling upset
- Disturbed sleep
- Drowsiness
- Dry mouth
- Eye problems
- Fatigue
- Feeling of malaise
- Lack of appetite
- Muscle weakness
- Nausea
- Numbness or tingling
- Pain
- Sadness
- Shortness of breath
- Trouble with balance or falling
- Vomiting

EORTC—European Organisation for Research and Treatment of Cancer
Note. Based on information from Aaronson et al., 1993; Bergman et al., 1994; Cleeland et al., 2000; Hollen et al., 2004; Mendoza et al., 2019; Williams et al., 2018.

The purpose of this pilot study was to describe MPM symptoms through a mixed-methods assessment.

Methods

Mixed-methods research was employed in this pilot study because it offers a more comprehensive picture of MPM symptoms than qualitative or quantitative inquiry alone can provide. The study used a convergent design in which quantitative and qualitative data were collected concurrently and prioritized equally (Creswell & Plano Clark, 2018).

Sampling

Participants were purposively sampled from a population of people with MPM who were receiving care at a large university medical center with a dedicated interprofessional MPM program in the northeastern United States. The eligibility requirements were having a diagnosis of MPM, being aged 18 years or older, being English-speaking, and having the ability to give informed consent.

Data Collection

The quantitative and qualitative data collection occurred during a single in-person encounter. The qualitative interviews occurred first to minimize the influence of the LCSS-Meso tool on participants' responses (Hollen et al., 2004).

Qualitative data collection: Qualitative data collection of MPM symptoms occurred via semistructured, audio-recorded participant interviews lasting up to one hour based on a set of predetermined questions (see Figure 2). Each interview was conducted by the principal investigator or a trained nurse from the research team. Interviews were conducted in a private room, and participants were interviewed without family caregivers present to minimize bias.

Quantitative data collection: The LCSS-Meso was selected for the quantitative assessment of MPM symptoms because it has been tested in nearly 500 people with MPM and has a low burden of administration, with a mean completion time of just 10 minutes (Hollen et al., 1993, 2004, 2006). It has also been used as one of the primary measurement tools in contemporary MPM clinical trials (Baas et al., 2021; Zalcman et al., 2016). The LCSS-Meso consists of an eight-item patient scale and a five-item observer scale measuring symptoms of pain, dyspnea, fatigue, loss of appetite, and cough. The patient scale is scored from 0 to 100, with 0 representing the lowest score and 100 the highest score. The observer scale is a reverse-scored scale ranging from 100 to 0, with 100 corresponding to no symptoms and 0 indicative of severe symptoms.

FIGURE 2. Interview Questions

- What would you tell someone you just met what it is like to have mesothelioma?
- Can you describe how it felt when you were diagnosed with mesothelioma?
- What are some of the physical functioning issues you have experienced?
- What are some of the symptom issues you have experienced?
- What are some of the emotional issues you have experienced?

Ethical Considerations

Prior to participant enrollment, the study received institutional review board approval from the affiliated university where the study was conducted. Written informed consent was obtained from each eligible candidate prior to participation.

Data Analysis

Quantitative data analysis used descriptive statistics from the observer and patient scales of the LCSS-Meso. Qualitative data analysis occurred through content analysis as described by Elo and Kyngäs (2008). The investigators and the qualitative research collective, a committee of clinical nurses under the guidance of a PhD-prepared nurse researcher that have a special interest in qualitative research, completed three rounds of data review. Symptoms were coded, counted, and categorized before being developed into common symptom themes. Two of the investigators reached final consensus on these themes. These were reviewed, paired with matching symptom categories from the quantitative data, and illustrated in joint display tables (Fetters et al., 2013). Themes for which there were no related quantitative categories were also included in the display tables. Symptom severity from the quantitative scales was then compared to the qualitative symptom data to determine whether there was congruence between the quantitative and qualitative data.

Results

Seven participants were enrolled and completed the study (see Table 1). Mean symptom scores from the LCSS-Meso paired with representative quotes from the qualitative interviews for each symptom are illustrated in Table 2. All five symptoms measured by the

LCSS-Meso featured prominently in the qualitative interviews. Two new symptoms, sleep disturbance and distress, were also identified.

Dyspnea

Dyspnea received the highest mean score on the LCSS-Meso ($\bar{X}$ = 64.4, SD = 20.82) and was a universally experienced symptom for all participants in the qualitative interviews. However, dyspnea scores sometimes appeared incongruent with the dyspnea severity perceptions expressed in the qualitative interviews. Descriptors such as "severe," "hard to breathe," "really tight," and "torture" were used to characterize this dyspnea. One participant (02) described these struggles with dyspnea: "I was very short of breath. I mean, I was really panting."

Pain

Pain elicited the second lowest mean score on the LCSS-Meso ($\bar{X}$ = 27.57, SD = 31.35), but it was the most frequently discussed symptom in the qualitative interviews. It was commonly described as being severe in nature and occasionally episodic, but frequently constant. Pain occurred throughout the MPM trajectory, with the source of pain attributed to the underlying cancer as well as treatments. The pain associated with MPM became a persistent reminder of the disease for many participants, as evidenced by one participant's (01) perspective: "This whole right side is a constant, constant, painful area. . . . Pain is constant. It's a question of degree at times." Some participants had a fatalistic attitude toward the pain, believing that it was an expected part of the MPM experience, and some participants worried that the pain was an indicator of the life-threatening nature of their disease.

TABLE 1. Participant Characteristics (N = 7)

Characteristic	$\bar{X}$	SD	Range
Age (years)	71.57	7.18	58–79
Time since diagnosis (months)	27.86	27.29	2–84
Characteristic			**n**
Race			
White			7
Gender			
Male			4
Female			3
Mesothelioma subtype			
Epithelioid			4
Biphasic			2
Sarcomatoid			1

Fatigue

Another symptom that was troubling for participants was fatigue, which received the second highest mean score on the LCSS-Meso ($\bar{X}$ = 50.57, SD = 30.09) and was described as a significant burden. Fatigue was characterized either as generalized tiredness or more specifically as muscular fatigue, physical deconditioning, or loss of endurance. Although this study did not include an examination of symptom burden, interviews indicated that fatigue was linked to activity level for many of the participants, such as one participant (07) stating, "Take a break. Have to sit down for a few minutes. Go and do laundry. Then I get tired. Around 2 or 3 [pm], maybe I'll lay down. Sometimes I'll make it until 4 or 5 [pm]." Participants universally sought ways to adapt to fatigue and changes in activity level.

Cough

Cough was a commonly reported symptom on the LCSS-Meso ($\bar{X}$ = 39.57, SD = 32.51), with all participants exhibiting the symptom on the observer scale and all but one participant on the patient scale reporting it, although only three participants identified issues with cough in interviews. Of these three participants, only two identified cough as a significant symptom. For these individuals, cough not only interfered with daily activities and socialization, but also became an outward manifestation of their disease, with one participant (07) reporting that she often felt obligated to offer an explanation for it: "I'll say, 'Oh, it's from radiation.' Which it is. That's the original cough."

Loss of Appetite

Loss of appetite produced the lowest mean scores on the LCSS-Meso ($\bar{X}$ = 26.14, SD = 28.62), and it was perceived as a mild problem for participants in the qualitative data. Only two participants focused on eating and appetite in the interviews, with appetite clearly linked to weight for these participants. One participant (04), who had not lost weight, was diligent about manipulating his diet to prevent weight loss: "Now, my objective is to keep weight on. I'm eatin' muffins and bacon. I haven't had bacon in 20 years. I'll have breakfast. I'll record my weight."

New Symptoms

Two new symptoms were identified in the qualitative interviews: distress and sleep disturbance. Distress,

TABLE 2. Visual Display of Data for MPM Symptoms

	LCSS-Meso Patient Scale			LCSS-Meso Observer Scale			
Symptom	**$\bar{X}$**	**SD**	**Range**	**$\bar{X}$**	**SD**	**Range**	**Representative Quotes**
LCSS-Meso symptoms							
Cough	39.57	32.51	0–81	75	23.15	25–100	■ "When I was totally quiet I was fine, but the first time that I would start to talk, I would be coughing a dry cough that got progressively worse over the evening." (participant 02)
Dyspnea	64.43	20.82	27–81	67.86	17.5	50–100	■ "The shortness of breath . . . there was a period of time where my chest was really tight and it was hard to breathe. . . . What happens is, I guess the lung gets really hard or whatever from that problem." (participant 06) ■ "I think the biggest physical issue is the shortness of breath. If I can overcome that, I'll feel like a million dollars, other than I got the cancer." (participant 04)
Fatigue	50.57	30.09	0–82	71.43	20.82	50–100	■ "I said to him that I was tired and that I thought I would just lay low, because we had talked about meeting up with friends of ours and I just didn't feel up to it." (participant 02) ■ "By the third day, you just wanna lock yourself in a room and lay in bed and don't wanna talk to nobody. You don't wanna hear anybody. You don't wanna say anything. You just wanna be there to sleep and it brings you down." (participant 06)
Loss of appetite	26.14	26.62	0–80	78.57	24.74	25–100	■ "The odd thing is, I don't mind the fact I lost the weight, it's more a question of how I happened to lose the weight. . . . I don't miss it, I don't get hungry per se." (participant 01)
Pain	27.57	31.35	0–75	75	23.15	50–100	■ "Riding in the car is painful because of the bumping, the jostling of this huge roundness I have on the left side of my abdomen and up my chest to some extent. Movement is restricted. Once I get into a chair, I'm comfortable, but getting up and down can be painful." (participant 03) ■ "I had been having pain in my left side, and it would kind of change position, like right under my ribs towards my back, towards my front, and, at times, I could not even lie on that side." (participant 02)
New symptoms							
Distress	–	–	–	–	–	–	■ "Well, it's depressing, and the depression has remained, you know, three months now, I guess?" (participant 03) ■ "Well, you're forced to confront death and expect that it's going to happen. You don't know when, and you're just grabbing. Envision yourself grabbing with your nails trying to hold on to anything you can get." (participant 05)
Sleep disturbance	–	–	–	–	–	–	■ "Being in the hospital is torture. You can't get a good night's sleep." (participant 03) ■ "I have to sleep higher. I'm more comfortable with my head elevated." (participant 01)

LCSS-Meso—Lung Cancer Symptom Scale for Mesothelioma; MPM—malignant pleural mesothelioma
Note. The LCSS-Meso measures MPM symptoms and distress. The patient scale is scored from 0 to 100, with 0 representing no symptoms and 100 severe symptoms. The observer scale ranges from 100 to 0, with 100 representing no symptoms and 0 severe symptoms.

characterized as cognitive, emotional, social, spiritual, physical, or behavioral in nature, can include feelings of sadness or fear as well as more severe issues such as depression and anxiety (National Comprehensive Cancer Network, 2021). Distress was a common theme in the patient experience of MPM, frequently occurring at the time of diagnosis and persisting across the disease trajectory. Distress manifested for participants in a variety of ways, such as feeling shocked, scared, or sad, or exhibiting anxiety or depression. The emotional impact of MPM was particularly troublesome for many participants. One participant (04) noted:

> Well, the pathology report came back, and it's not epithelioid. It's biphasic. That was a major, major setback for me. That was devastating. I said, "Wow, now what?" So, mentally, that was crushing. . . . For me, so far, it's been more psychological. . . . It's just a life-changing experience.

For many of the participants, uncertainty about the future framed these feelings of distress across the MPM trajectory.

In addition to emotional distress, cognitive changes also contributed to distress for some participants who had received chemotherapy. These changes were primarily represented by short-term memory loss and problems with focusing. One participant (01) said, "I call myself 'chemo brain' because there's a lot of things I have completely forgotten. . . . I have no clue." One participant (04) lost his train of thought during the interview, blaming it on the cognitive side effects of the chemotherapy.

Sleep disturbance was another MPM symptom described by several participants. Sleep patterns were affected by a variety of factors, including prior surgery and chemotherapy treatments. One participant (05) reported, "When I was on some of the earlier chemo, the nights were long because I had trouble sleeping." Sometimes sleep routines were chronically altered, with participants noting that they had to permanently change their sleep habits, such as sleeping with their head elevated or altering their sleep location.

Discussion

This pilot study confirmed that people with MPM experience the symptoms represented in the LCSS-Meso. These findings align with a qualitative assessment of content validity of the LCSS-Meso by Gelhorn et al. (2018). This pilot study also showed that the LCSS-Meso alone did not fully capture the range of symptoms and symptom severity experienced by people with MPM. One explanation is that the LCSS-Meso tool assesses symptoms that have occurred within the past 24 hours. However, participant interviews indicated that symptoms of MPM may evolve over time, be experienced intermittently, or be precipitated by specific triggers such as cancer treatments or exertional activities. In addition, participants were still deeply affected by symptoms that had occurred in the past, even months and years prior. Participants also feared the development or worsening of symptoms that would indicate terminal progression of the disease, which may have contributed to their perceptions of symptom presence or severity in the qualitative interviews.

Although limited literature is devoted to the evolving nature of symptoms in MPM, symptom presence and severity have been shown to change over time for some cancers, particularly in response to treatments such as chemotherapy and radiation (Li et al., 2021; van Beek et al., 2020; Williams et al., 2018). Williams et al. (2018) noted that although 75% of people with MPM reported dyspnea around the time of diagnosis or disease recurrence, only 35% reported dyspnea or worsening of dyspnea during cancer treatment. In the lung cancer setting, cough was found to be the most prevalent symptom before chemotherapy, but fatigue became more common during chemotherapy. Symptom severity was also seen to change over time, with sleep disturbance being the most severe symptom prior to starting chemotherapy and loss of appetite being the most severe symptom during chemotherapy (Li et al., 2021). Fatigue was also found to occur more frequently and be more severe during radiation treatment for breast cancer rather than before or after treatment (Hofsø et al., 2013). Conversely, perceptions of "being worried" or emotional distress became less common and severe over time (Hofsø et al., 2013).

Some symptoms may persist long after cancer therapies have been completed. Chronic symptoms such as depression, pain, fatigue, and sleep disturbance are common in survivors, and they may last for months or even years post-treatment, as can depression (Bennett et al., 2010; Hofsø et al., 2013; van Beek et al., 2020). Symptoms can also be more likely to occur at end of life, with pain, dyspnea, and loss of appetite more common within the final three months of life than earlier in the cancer trajectory (Seow et al., 2021).

Although some of these symptoms may occur continuously, others, such as pain, may occur on an intermittent basis, or they may occur continuously but with periodic breakthrough "spikes" in intensity (Lasheen et al., 2010). Similarly, symptoms may be

contextualized. A study by Arber and Spencer (2013) found that no participants with MPM experienced shortness of breath at rest, but there were many reports of shortness of breath with exertion.

In addition to changing symptom patterns, the meaning ascribed to a particular symptom or symptoms may also evolve. In a qualitative study on patient perspectives of MPM, some participants felt more empowered to take charge over their symptoms as time passed, but others became more distressed as they recognized symptoms associated with disease progression (Clayson et al., 2005).

Symptom evolution, intermittent experience, changes in context, and changes in meaning may all contribute to explaining the discordance in symptom prevalence and severity between quantitative and qualitative data in this study. Quantitative assessment tools offer a snapshot in time of cancer symptoms and may over- or underestimate symptom severity within a longer time frame. In addition, assessment scales that only measure cancer-specific symptoms and not treatment-related side effects may miss key patient experiences of MPM. The LCSS-Meso tends to measure disease-specific symptoms, in contrast to other scales such as the MDASI-MPM, the QLQ-C30, or the QLQ-LC13, which incorporate treatment-related side effects. Quantitative scales may also miss symptoms that represent important experiences for individual patients with MPM. This study's qualitative interviews helped to identify two additional symptoms, sleep disturbance and distress, that affected participants and are not measured by the LCSS-Meso.

Although there is little research on sleep disturbance in the MPM setting, this symptom is incorporated into other assessment tools that have been used to assess patients with MPM, including the MDASI-MPM and QLQ-C30. Qualitative interviews conducted during development of the MDASI-MPM found sleep disturbance to be a disease- and treatment-related symptom in people with MPM (Williams et al., 2018). The QLQ-C30 and QLQ-LC13 were key symptom assessment tools in a study that found that sleep disturbances were higher in people with MPM receiving chemotherapy than in a population without MPM (Bottomley et al., 2007).

In addition to sleep disturbance, this study highlighted the significant distress experienced by people with MPM. Distress is a common theme in other qualitative MPM research. Hughes and Arber (2008) described high levels of distress intertwined with the overall experience of MPM in study participants. Distress in the form of anger and stress was also prominent within the initial three months of diagnosis in a study of people with MPM (Girgis et al., 2018). Distress was identified as a symptom experienced by people with MPM in a qualitative assessment of symptoms for the development of the MDASI-MPM tool (Williams et al., 2018). A meta-analysis by Ball et al. (2016) also found that distress was a common occurrence in people with MPM, with physical symptoms representing one source of this distress. Reasons for distress in the MPM population were found to be different than in people with lung cancer (Ball et al., 2016), reinforcing the need for dedicated MPM symptom assessment tools.

KNOWLEDGE TRANSLATION

- Dyspnea, pain, fatigue, cough, and loss of appetite are symptoms experienced by people with malignant pleural mesothelioma (MPM).
- Additional symptoms experienced by people with MPM may include distress and sleep disturbance.
- Quantitative symptom assessment tools alone may not accurately capture MPM symptoms.

Strengths and Limitations

The major limitation of this pilot study is its small sample size. However, this study's sample size is consistent with sample sizes in other qualitative MPM studies and pilot studies. Sampling participants with MPM is challenging because of the rarity of this disease and a high symptom burden that prevents travel for, or lengthy participation in, in-person interviews. This is consistent with research on other rare diseases with small patient populations (Hee et al., 2017). The major strength of this study is that it is the first known research using mixed methods to evaluate MPM symptoms, which therefore contributes a new perspective on these symptoms.

Implications for Nursing

MPM is an often-fatal cancer for which there is no viable cure. A significant emphasis for nurses caring for patients with MPM should therefore be on symptom assessment. People with MPM may either under- or overreport symptoms on symptom assessment tools, and these tools may miss other individually relevant symptoms. Nurses caring for patients with MPM should not only have a thorough understanding of common MPM symptoms, but also the flexibility to explore symptoms that may be

meaningful to each patient. Nurses occupy a key position on the healthcare team and can make significant contributions to improving symptom assessment in the MPM population.

Conclusion

Findings from this mixed-methods pilot study offer a more comprehensive picture of MPM symptoms than could be captured through a single methodology. Future research should focus on confirming these findings in larger studies, further refining MPM symptom assessment tools such as the LCSS-Meso, and exploring the patient experience of MPM symptoms.

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Walker and Cacchione contributed to the conceptualization and design and completed the data collection. Walker provided statistical support. All authors provided the analysis and contributed to the manuscript preparation.

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