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Lived experiences of dysphagia-related quality of life among esophageal cancer patients: a qualitative study

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Abstract

Introduction Esophageal cancer impairs basic functions such as eating and drinking frequently resulting in difficulty swallowing (dysphagia) and other problems such as weight loss, pain, fatigue, and taste alterations. There is still a research gap in understanding the impact of dysphagia on quality of life, as patients continue to bear significant physical and psychological burdens despite advances in treatment. This study attempted to address this gap by examining the lived experiences of dysphagia-related quality of life among esophageal cancer patients.

Methods A phenomenological study was employed to analyze the data provided by 14 patients with esophageal cancer at the Oncology Center of the University of Gondar Comprehensive Specialized Hospital from March to April 2023. An interview guide was employed to carry out in-depth interviews with purposively selected patients. The interviews were audio-taped, translated, transcribed, and analysed using thematic analysis.

Results Three main themes emerged from the analysis of the participant interviews: physical challenges related to difficulty swallowing, altered dietary habits, and struggle to maintain weight; psychosocial strain, including emotional distress and social isolation; and reliance on assistance, encompassing both dependency and financial burden.

Conclusion and recommendations This study underscores the significant physical, emotional, and social challenges experienced by esophageal cancer patients with dysphagia. To enhance support, healthcare providers should develop personalized care plans that address both the physical and emotional aspects of dysphagia, with sensitivity to cultural practices. Efforts should also be made to alleviate feelings of dependency and promote public awareness to reduce stigma and build a more supportive community.

Keywords Dysphagia, Esophageal cancer, Ethiopia, Experiences, Quality of life

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Introduction

By 2030, there will be an anticipated 85% increase in the cancer burden across sub-Saharan Africa, with the most significant increase in cancer incidence occurring between 2007 and 2017 in middle-income countries [1, 2]. Likewise, in Ethiopia, the prevalence of non-communicable diseases, including cancer, is on the rise [3]. Esophageal cancer is a frequently occurring malignancy of the upper gastrointestinal system. According to the GLOBOCAN 2020 findings, 604,000 new diagnoses and 544,000 deaths were diagnosed with esophageal cancer worldwide [4]. In 2018, esophageal cancer was the eighth most commonly diagnosed cancer and the seventh leading cause of death, with an estimated 1,752 new cases reported [5, 6].

Esophageal cancer affects vital bodily activities such as swallowing, eating, and drinking, as it develops in the esophagus, a critical part of the digestive system. The primary reason patients seek medical attention for esophageal cancer is dysphagia, which is the medical term for difficulty swallowing. Although dysphagia is a primary symptom of esophageal cancer, treatments often worsen the condition. Surgical procedures that remove essential structures, along with radiation and chemotherapy that damage the mucosal lining, can intensify swallowing difficulties and lead to unfavorable health outcomes, such as pain, fatigue, nausea, dry mouth, changes in taste, and weight loss, all of which severely impact patients' quality of life [7, 8].

Several studies have examined the quality of life of individuals with esophageal cancer in various settings, emphasizing the serious psychological and physical difficulties that the illness imposes. Patients who suffer from dysphagia frequently experience feelings of isolation, anxiety, and distress due to their inability to eat normally or engage in social meals, which has been demonstrated to impact not just nutritional intake but also social and psychological well-being [9, 10]. Research on esophageal cancer in Ethiopia has primarily concentrated on risk factors and epidemiological trends; minimal attention has been given to the difficulties these patients confront in their quality of life, particularly about dysphagia [11, 12].

Quality of life, as described by the World Health Organization (WHO) as an individual's perception of their position in life within the context of culture, values, goals, and expectations, is a crucial goal in contemporary healthcare, especially for chronic illnesses like cancer [13]. Cancer patients' quality of life is affected by a range of physical symptoms, emotional distress, and treatment side effects [14, 15]. According to studies, cancer patients in Ethiopia generally experience a low quality of life [16], which is caused by many variables that lead to a worse prognosis, including delayed diagnosis, limited healthcare access, financial barriers, and lack of insurance coverage [17].

While quality-of-life research on esophageal cancer patients in Ethiopia is scarce, a few studies have addressed the topic, focusing on the physical symptoms, emotional distress, and the effects of treatments like chemotherapy. However, these studies do not fully capture the cultural and social aspects that shape the lived experiences of patients, particularly about dysphagia. This study seeks to address this gap by exploring the lived experiences of dysphagia-related quality of life among esophageal cancer patients.

Methods and materials

Study period and setting

The study was conducted at the Oncology Center of the University of Gondar Comprehensive Specialized Hospital from March to April of 2023. The hospital provides a variety of services and is situated in Gondar city, which is approximately 748 km northwest of Addis Ababa, the capital city of Ethiopia.

Study design

This phenomenological study explores the lived experiences of dysphagia-related quality of life among individuals diagnosed with esophageal cancer. Guided by the work of Max van Manen, the aim is to understand the individual perspective and the deeper meaning behind everyday experiences with dysphagia. Van Manen's phenomenological perspective was central to the research design, as it emphasizes capturing the essence of lived experiences through reflective analysis [18].

The population of the study

The study included adult esophageal cancer patients who underwent treatment during the research period and excluded those with dysphagia unrelated to esophageal cancer.

Sample size determination and sampling technique

The total sample size was 14, determined by reaching data saturation after the 11th interview. Three further interviews were performed to ensure that no new information emerged. To confirm comprehensive data collection, participants were chosen through the use of a heterogeneous purposive sampling technique.

Data collection tool and technique

An Amharic interview guide was used to gather the data. The guide was first prepared in English following a thorough review of the study objectives and relevant literature [19–21]. A fluent bilingual speaker translated it into Amharic to ensure its language and contextual authenticity. Three pilot interviews were conducted two weeks before the actual data collection time to refine the questionnaire; revisions included rephrasing complex questions for clarity, adding probing questions to elicit more detailed responses, and reorganizing the sequence of questions to improve the flow of the interview. The final questionnaire was divided into two sections: the first section included questions on the participants' clinical and socioeconomic characteristics, and the second section included open-ended and probing questions to elicit detailed answers.

The interviews were conducted by the principal investigator, a skilled qualitative data collector with more than seven years of research experience and a master's degree in clinical oncology nursing. Her experience guaranteed a high standard of professionalism throughout the data collection procedure and provided insightful information. To balance depth and consideration for the participants' time, each interview lasted between thirty and forty minutes, with an average of thirty-six minutes. The interviews were recorded on a Sony tape recorder; no repeat interviews were carried out, and the investigator took thorough field notes to capture further context.

Participants were selected for the study upon admission to the ward, where their dysphagia was identified through clinical assessments conducted by the oncology care team. The diagnosis was confirmed by a speech-language pathologist who evaluated the severity of their swallowing difficulties using standardized diagnostic procedures.

Informed consent was obtained before participants received any specific treatments as part of their medical care. Before the interview, participants were informed about the study's objectives, ethical approval, and the interviewer's credentials and affiliations. All volunteers signed informed consent forms, confirming their voluntary participation and consent for publication. Notably, none of the selected individuals declined to participate, demonstrating the success of the initial consent process and the clarity of the interview guide. To minimize bias, the principal investigator ensured that she did not treat the patients she interviewed, maintaining a clear separation between her clinical responsibilities and the research activities. The face-to-face interviews took place in a quiet, private room in the hospital's cancer center, which was chosen to safeguard privacy and limit unwanted influences.

All documents were securely archived, and digital material was password protected, allowing only the researchers to access important information. This robust data management strategy protected participant confidentiality while also ensuring the study's integrity.

Data processing and analysis

Before conducting the analysis, the interviewer transcribed the field notes and audiotape recordings from each interview. A native speaker of both languages verbatim translated it from Amharic to English. The researcher entered and saved the data as Microsoft Word documents. In the current analysis, we have used Colaizzi's six-step phenomenology process [22], These stages are: (1) familiarization with data through reading and re-reading; (2) identification of significant statements; (3) formulation of meanings; (4) clustering these meanings into themes; (5) developing an exhaustive description of the phenomenon; and (6) overall description of the experience.

In practice, this started with the repeated reading of each interview transcript, identifying and highlighting important passages. These were then coded with specific labels, which were compared and grouped into preliminary themes. The initial coding and thematic organization were done by the first author, and the final themes and subthemes were developed in further discussion and refinement with three coauthors to reach an agreement. This iterative approach guaranteed an in-depth, thematic analysis. Quotes from each of the participants were used to supplement the research findings; minor adjustments in grammar and linguistics were made to make them clearer.

Data quality assurance

The study's credibility, dependability, confirmability, and transferability were all upheld, ensuring its trustworthiness [23, 24]. The maintenance of credibility involved open communication with participants to confirm the veracity of their experiences, while transferability was attained by emphasizing precise explanations over generalizations. Quotations were used to corroborate the findings, and thorough details regarding the location, date, and methods of data collection and processing were provided to establish dependability [25–27].

Results

Sociodemographic and clinical characteristics of the participants

Interviews were conducted with fourteen individuals, among whom 10 (71.4%) were male. The mean age of participants was 61.64 ± 11.68 years (mean ± SD), with a range from 42 to 79 years. More than half of the participants, 8 (57.1%), were either married or cohabiting with a partner. Regarding educational background, 4 (28.6%) had not received formal education. In terms of occupation, 6 (42.9%) were unemployed. Ten (71.4%) of the participants had medical insurance. Eight individuals (57.1%) were diagnosed at an advanced stage. Twelve participants (85.7%) underwent various treatment modalities. Half of the participants (50.0%) were categorized as having moderate dysphagia severity (Table 1).

The lived experiences of dysphagia-related quality of life among participants

Three themes were identified from participants' in-depth interviews. The first theme was physical challenges, which included subthemes such as difficulty swallowing, altered dietary habits, and struggle to maintain weight.

The second theme, psychosocial strain, encompassed subthemes of emotional distress and social isolation or stigma. Finally, the third theme was reliance on assistance, which was further classified into subthemes of dependency and financial burdens related to the illness (Fig. 1).

Theme I: Physical challenges

This theme discusses the physical difficulties of patients diagnosed with esophageal cancer. Specifically, it is the issue of dysphagia, as a result of the narrowing of the esophagus from the disease. This physical block in the throat makes people alter their way of eating because they are no longer able to swallow a wide range of foods. Participant 2 shared, *"Now every time I sit down to eat, my first thought comes to my mind: 'Will it go down or get stuck?' It's disturbing."*

Table 1 Sociodemographic and clinical characteristics of the study participants

Variable		Frequency	Percentage %
Sex	Male	10	71.4
	Female	4	28.6
Age (years)	Minimum	42	
	Maximum	79	
	Mean ± SD	61.64 ± 11.68	
Marital status	Single	6	42.9
	Married	8	57.1
Level of education	No formal education	4	28.6
	Secondary education	4	28.6
	Above secondary education	6	42.9
Working condition	Employed	8	57.1
	Unemployed	6	42.9
Medical expenses	Uninsured	4	28.6
	Insured	10	71.4
Time since diagnosis	Less than 6 months	2	14.3
	6–12 months	4	28.6
	More than a year ago	8	57.1
Stage	Early stage (I&II)	6	42.9
	Advanced stage (III& IV)	8	57.1
Treatment modality	Chemotherapy	2	14.3
	Chemotherapy & radiation therapy	6	42.9
	Radiation and surgery	2	14.3
	All	4	28.6
Dysphagia severity	Mild	5	35.7
	Moderate	7	50.0
	Severe	2	14.3

Beyond the fear resides the real struggle: the physical act of swallowing, a task that becomes progressively more painful and difficult as the esophagus becomes increasingly narrowed. This was best described by Participant 4, who said, *"It feels like I'm choking on my food,"* which identified physiological pain directly related to the esophagus' narrowing. These physical challenges are also evident, with most patients suffering from severe weight loss due to an inability to eat. It is the combination of the physical destruction of the esophagus with a restriction on eating that makes for a visible deterioration in their physical health.

The three subthemes that composed the physical challenge theme were difficulty swallowing, altered dietary habits, and struggle to maintain weight, all emphasizing some serious physical components of esophageal cancer in everyday life.

Difficulty swallowing For most, the challenge of swallowing becomes part of daily living and very much restricts their ability to take in food. Even small portions are exceedingly difficult to get down and frequently lead to efforts at vomiting, after which a person's overall health might be compromised. Many who manage to get some food down their throats describe it as feeling stuck or very painful, quite unlike before the illness. Participant 1 phrased this in the following words: *"Eating is much more difficult for me than for others; no matter how hard I try, the food refuses to go down. Swallowing really shouldn't be this hard. I have to fight my body every time, and fighting leaves me very tired."* Similarly, Participant 5 noted: *"My throat closes up; it lets no food in. When I eat, I vomit. I keep eating anyway, only to keep myself alive."*

Participant 6 further explicates significant physical challenges possessed by dysphagia as follows: *"Swallowing has been very difficult for me due to my illness, which has hurt my health and well-being. Nevertheless, I continue to see ways through which I can deal with the challenge."* The above quotation shows severe impairment in swallowing function and its consequent effects on physical health and quality of life. Despite all this, the participant expressed a seek for coping mechanisms; this might mean that it is indeed a very intricate interplay between physical limitation and psychological resilience.

The intensity of the condition has even extended to the basic functions, such as swallowing saliva, as explained by Participant 13: *"Even swallowing saliva is difficult for me. Hence, it becomes difficult for me to eat and talk. Swallowing should be easier, but it's constant war with my*

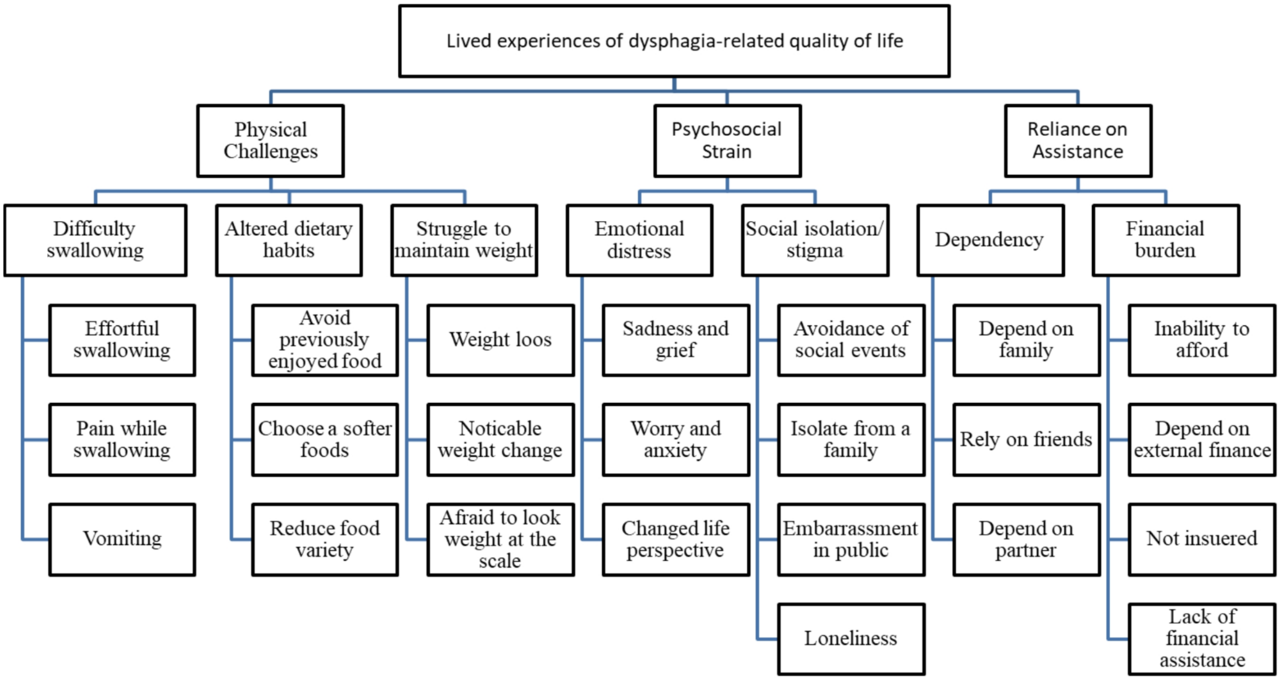

Fig. 1 Coding tree of theme analysis on lived experiences of dysphagia-related quality of life among esophageal cancer patients

body." The idea of a "constant war" with the body captures the ongoing struggle between physical limitations and the desire for normality. These narratives offer important insights into the everyday lives of people who have dysphagia, highlighting the significant impact on daily functioning and the need for adaptable coping mechanisms to deal with these difficulties.

Altered dietary habits As dysphagia progresses, food preferences change, leading individuals to avoid foods they once enjoyed because these items exacerbate their symptoms. Concerns about dietary intake and maintaining energy levels become prominent as meal preparation becomes increasingly difficult, often resulting in a preference for a simpler, softer diet. This adjustment is aimed at improving swallowing ability and reducing discomfort. Participant 4 highlighted this shift by saying, *"Before, I used to love a wide range of meals, but these days, I find that I have to keep to a simpler, softer diet to stay comfortable. Although I do not like it, I have to do it in order to manage."* This narrowing of food choices is echoed by Participant 10, who remarked, *"I used to enjoy eating peppers, but now I have not been able to because they aggravate my illness. I have resorted to consuming very small, soft foods, almost like a baby, which is causing me to lose energy."*

This condition changes a lot of their dietary habits, as they need to adapt to these physical challenges. Participant 13 gave an example of this change, saying: *"For me, eating at mealtimes has become a whole new challenge. I used to enjoy cooking and trying different recipes, but these days I tend to stick to a small number of simple, easily digested dishes. Although I do not appreciate it as much as I used to, it is what keeps me going."* The meaning behind this response creates a distinction between what has become a restricted diet from the earlier, more varied, and enjoyed, culinary experience of the participant. This adaptation of the participant has reduced the enjoyment of food but represents a practical approach toward dealing with the physical demands their condition imposes.

Struggle to maintain weight Participants who experience dramatic declines in weight due to restrictive eating habits face serious concerns about weight loss. Maintaining a healthy weight becomes a constant struggle, raising worries about dietary deficits and overall health. Participant 3 expressed the frustration of this ongoing battle by stating, *"No matter how hard I try, my condition causes me to lose weight, so trying to maintain my current weight is like trying to hold on to something that is constantly sliding away."* This is an extremely physical demand that participants make, and they do report noticeable effects on their overall condition.

Participant 10 further reported the impact of weight loss, stating, *"To see myself noticeably lighter than my peers served as a blunt reminder of the severity of my* *condition."* This exemplifies the impact of weight loss on their perception of health and condition severity. Participant 11 expanded on the frustration with, *"I am continuously losing weight, and it's disheartening to watch the scale."* Such narratives underscore the relentless fight to maintain weight. These narratives have wider overtures toward everyday and persistent problems associated with their bodily health and condition management.

Theme II: Psychosocial strain

The challenges associated with dysphagia significantly impact the psychosocial well-being of individuals with esophageal cancer, creating a considerable emotional and social burden. Difficulties in swallowing often lead to heightened psychological distress, manifesting as anxiety and depression. These emotional challenges can result in social withdrawal, as patients may find it difficult to cope with the embarrassment or discomfort of eating in public or participating in social gatherings. Participant 7 stated: *"I am often filled with sorrow and fear, so much so that I have ceased going to family things. It's easier to withdraw rather than to face people feeling this way."* This statement illustrated that the emotional cost of the illness may lead to stopping going to social engagements and family things, which is an illustration of a larger pattern of social isolation. Participant 5 also said, *"The constant anxiety with my condition makes me avoid social events. I don't want to be around others when I'm feeling so low."*

Moreover, eating together from the same plate, especially in large groups comprising people from the same family or community, is culturally symbolic, especially during key events like holidays. If the ability to engage in this practice is taken away by dysphagia, then such people feel that a part of their social identity and personhood is lost. Participant 14 shared, "*Eating together from one plate is our way of life. Now I have to eat alone or with special food. It's as if I've lost a part of who I am.*" An identity loss that intertwines deep into their cultural practices and personal identity further adds the psychosocial strain. This quotation illustrates how there is a massive avoidance of social interaction due to continual anxiety about one's condition.

The theme of psychosocial strain again can be divided into two subthemes, emotional distress, and social isolation.

Emotional distress The patients undergo psychological suffering as they learn to survive with dysphagia, leading to profound feelings of sadness, anxiety, and a change in perspective toward life. Participant 1 described the depth of this emotional pain: *"Thinking about all the problems I faced in my life and dealing with another issue also is very depressing."* This quote reflects the feeling of being overwhelmed by living with a chronic and life-threatening condition, where each additional burden, such as difficulty swallowing, becomes increasingly challenging.

Participant 6 pointed out that the concern expressed by others can exacerbate his emotional pain: *"People's concern for my condition adds to my distress and makes me very disturbed."* This experience illustrates that social support, intended to provide comfort, can instead amplify awareness of one's vulnerability, leading to increased anxiety and emotional pain.

Participant 8 elaborated on the transformative impact of dysphagia on his perception of life: "*Before, I used to cherish every moment and put great regard on my health. The disease has, however, made me look at life differently now, where I realize how fragile it is.*" This statement reflects how dysphagia compels individuals to reevaluate their values, shifting from a sense of invulnerability to an acute awareness of life's fragility.

Besides, Participant 9 emphasized the relational impacts of living with dysphagia, stating, *"One of the most challenging aspects of living with this condition is how bad it is for my relationships. It is tough watching your loved ones worry and struggle with you."* That further reinforces intricate emotional dynamics, including feelings of guilt, sorrow, and helplessness when a serious condition burdens not only the individual patient but also his social and familial network.

Social isolation Chronic illness can profoundly affect social interactions, leading individuals to withdraw from activities and events they previously enjoyed. This withdrawal often results in feelings of loneliness and alienation, intensified by social anxiety and discomfort in social settings. Participant 2 provided a touching example of social isolation: "*My difficulty in swallowing caused an unplanned episode of vomiting during a meal, leaving me feeling even more alone. The strange atmosphere of the restaurant and other patrons' looks made me feel uncomfortable and more isolated.*" This account highlights how physical symptoms of the illness can trigger social discomfort and intensify feelings of isolation.

Participant 3 shared his reluctance to participate in social activities, saying: "*I am invited to weddings, but I prefer not to go to any because I find it difficult to eat meat dishes that are usually served. While everybody else is celebrating and eating and drinking, I am not able to participate.*" For some participants, not being able to partake in communal eating on important cultural occasions, for example, holidays, added to their sense of social isolation. Participant 12 expressed this: *"I used to celebrate holidays with my family. I used to have meals with my family. "Now I am scared of taking solid food, so I always stay alone in my room while they celebrate."* The other participant 5 shared, *"During holidays, we used to gather to eat doro* *wot, but now I can only see them eating. It is like I am no longer part of my family."*

These experiences underline how, in this kind of cultural context, social isolation is not only about physical separation but also about the emotional and cultural disconnection engendered by the inability to share in traditional communal eating practices. This adds depth to the picture of social isolation that is experienced by these individuals living with dysphagia. In particular, this is relevant to cultures where communal eating takes on centrality to belong to social identity.

Theme III: Reliance on assistance

Individuals with esophageal cancer often experience dysphagia, which leads to increased dependence over time on a relative, friend, or caregiver for support in daily activities such as preparing food and personal care. This dependency extends beyond physical dependence; it profoundly impacts emotional well-being and alters the perception of life value. The loss of independence exacerbated by difficulties in swallowing creates significant emotional stress, resulting in feelings of frustration, helplessness, and a diminished sense of identity, despite the presence of a supportive network. Participant 2 expressed the internal conflict faced when grappling with the effects of dysphagia on independence: *"I had to leave my job because of my condition. Today, for everything, even the small things, I have to depend on my family. It is frustrating, but what other choice do I have*?" This statement reflects more of the internal conflict associated with the inability to manage daily tasks due to swallowing difficulties.

In addition to emotional distress linked to dysphagia, the continuous need for specialized care and dietary adjustments imposes a financial burden. The costs associated with medications, special diets, and transportation to medical appointments become overwhelming. One of the participants, Participant 6, elaborated on how these financing challenges impacted his sense of independence. *"The costs for my medications and the special food I need are so high. My savings are gone, and I don't know how much longer I can keep asking my family for help."* The quote resonates with double burden of financial strain and reliance on others for support. The theme of reliance on assistance can be further divided into two subthemes: dependency and financial burden, both of which are closely intertwined with the challenges posed by dysphagia.

Dependency The development of dysphagia due to esophageal cancer often leaves individuals heavily dependent on others for their day-to-day needs. This dependency not only reflects the level of care required from family and friends but also imposes a significant psychological burden on the individuals themselves. Relying on others can lead to feeling of inadequacy, guilt, and loss of self-esteem. Participant 3 described the emotional toll of this dependency as follows: *"My husband feels overwhelmed with the burden of meal preparation because of my condition, which makes me realize how dependent I am on others."* This indicates the underlying internal conflict of acknowledging the burden placed on loved ones versus intensified feelings of guilt and helplessness.

Participant 4 further expressed this internal struggle, noting: *"I'm grateful that friends offer to help do chores, but not being able to help because of the illness really points out how dependent I am on others."* This reflection thus focuses on the conflicting emotions that exist between thankfulness toward the supporting parties and distress over the loss of independence. Participant 7 noted the almost total nature of his dependency *"Apart from meal preparation, I depend on my partner for a lot of daily tasks, and this really makes me realize how much this condition has made me dependent."* This recognition emphasizes the reality of living with dysphagia, where dependence on others becomes an unavoidable aspect of everyday life.

Financial burden The financial burden associated with managing dysphagia, primarily due to medical care, special diets, and long-term care, is significant. This strain can create considerable stress for patients and their families. Limited financial support and insufficient insurance coverage often aggravate this burden, complicating the already challenging circumstances for those affected. Participant 1 exemplified the seriousness of this financial strain: *"I currently live with my teenage daughter, who has no income, and we are not receiving any financial assistance."* This quote resonates with feelings of anxiety and pressure resulting from a lack of financial security and the day-to-day pressure of managing core needs amid serious swallowing difficulties.

Participant 6 shared the challenges of affording key health-related items: *"I have had problems with the purchase of necessary diets and nutritional supplements important for my health treatment."* The added financial strain of maintaining treatments further contributes to the overall burden of living with dysphagia. Participant 9 expressed the challenge of asking for financial help; *"My younger sister helped pay a few of my bills, but it was a big burden because it was too much money. Asking for financial help was one of the lowest points in my life."* This quote symbolizes the deep feelings of vulnerability and discomfort that come with financial dependence, even upon relatives and loved ones. Participant 14 emphasized the limitations of insurance coverage: *"Insurance didn't cover the cost of special foods, especially those that are easier to swallow, which added more financial pressure* *and made me even more worried about my health and financial situation."* This sentence reveals how the financial burden together with health problems has a great impact on the patient's overall quality of life.

Discussion

The findings from this study yield an in-depth exploration of dysphagia-related quality of life among esophageal cancer patients' perspectives and encompassing a three core dimensions: physical difficulties, psychosocial strain, and reliance on assistance. These outcomes outline the multidimensionality nature of dysphagia, are consistent with conventional frameworks of health-related quality of life (HRQoL), particularly the EORTC QLQ-C30 and the EORTC QLQ-OES18, which are designed for cancer and esophageal cancer patients, respectively [28, 29]. The EORTC QLQ-C30 evaluates physical, emotional, cognitive, and social domains, while the EORTC QLQ-OES18 focuses on esophageal cancer-specific symptoms such as dysphagia, reflux, and eating difficulties, which are reflected in the study's core themes. Consistent with existing literature, the diverse and complex nature of the challenges faced by individuals experiencing dysphagia is evident [30–32].

The study revealed that physical issues such as difficulty swallowing, changes in dietary habits, and weight loss, were the most common concerns, with a major impact on many aspects of participants' everyday lives. These problems are in line with important elements of the EORTC QLQ-OES18, including dysphagia, eating restrictions, and weight loss. To address these issues, participants altered their diets in terms of texture and consistency. Despite their best efforts, they frequently struggle to maintain a healthy weight. These findings are consistent with prior research on dysphagia and esophageal diseases, which clearly highlights the enormous burden of managing eating difficulties and negotiating dietary changes [33–36].

Psychosocial strain, another core theme identified in this study, which has been extensively fit well within the HRQoL frameworks, particularly the QLQ-C30, which examines emotional and social functioning. Participants stated that a grief and sadness over theirs new circumstances, coupled with worries about the future leads a detachment in their interpersonal connections.

The subtheme of emotional state is also consistent with earlier research that addresses the significant emotional cost that people with comparable diseases [30, 31, 37]. Another emerged subtheme, social isolation illustrating the challenges individuals face in public and at home. Participants often reported a range of issues starts from decline of dining invitations, through worsening feelings of social isolation to a lack of sense of community. This finding is consistent with several studies, which has shown that dysphagia has a major impact on social engagement and interpersonal interactions [30, 38, 39]. This study adds an additional component unique to the Ethiopian cultural context, where traditional dishes with a firm texture, spicy, and peppery are important at social gatherings like weddings and festivals. Feelings of isolation and identity loss are exacerbated by the inability to participate in culturally meaningful foods, underscoring a gap in current HRQoL frameworks which may not fully account for cultural elements affecting social engagement.

Within the theme of reliance on assistance, this study explored the need for support from family, friends, and caregivers in managing daily tasks, overcoming emotional challenges, and addressing financial hardships associated with dysphagia. While previous studies have focused on the financial burdens of chronic conditions and emphasized the importance of comprehensive support systems [37, 40–42], this study extends those findings by highlighting the psychological strain that comes from depending on others for basic needs, such as eating and swallowing. These insights align well with the EORTC QLQ-C30 tool, particularly in the areas of role functioning, emotional functioning, and financial difficulties. However, the study also reveals a significant gap in existing frameworks, including the EORTC QLQ-C30, which may not fully capture the psychological toll of dependency, especially in cultures where self-reliance is highly valued. Therefore, care plans for individuals with dysphagia should not only focus on financial and emotional support but also include strategies to mitigate the psychological burden of relying on others for assistance, creating a more comprehensive approach to managing the condition.

Limitations

While the study provided valuable insights, there are several limitations to consider. Firstly, focusing on a single oncology center may not fully capture the diverse experiences of individuals from different cultural or socio-economic backgrounds. Secondly, despite using heterogeneous purposive sampling methods, the study encountered a gender imbalance, which could have influenced the findings and limited the understanding of how gender differences may impact individuals' lived experiences.

Conclusion and recommendations

The findings of the study shed light on the complex challenges faced by individuals with dysphagia in the context of esophageal cancer. The study highlighted three main areas of difficulty: physical challenges; such as swallowing issues, dietary adjustments, and weight loss; psychosocial strain, including emotional distress and social isolation;

and reliance on assistance, characterized by dependence on caregivers and financial struggles. A unique aspect revealed was the cultural dimension, where traditional Ethiopian foods and social events exacerbated feelings of exclusion and identity loss.

To enhance care for individuals with dysphagia, healthcare providers should develop personalized care plans that address both the physical and emotional aspects of management. Culturally sensitive interventions are essential in addressing practical and emotional challenges, while public education and awareness efforts can help reduce stigma and create a more supportive community environment.

Future research should expand to multiple oncology centers and ensure gender balance in participant sampling to capture a broader range of experiences. This approach will improve understanding of how gender, culture, and socio-economic status influence the lived experiences of individuals with esophageal cancer and dysphagia.

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Author contributions
TA: Writing of the original draft, writing- review and editing, conceptualization, methodology, investigation, data curation, formal analysis, supervision, validation, and project administration. WT: Writing- review and editing, writing of the original draft, methodology, data curation, formal analysis, resources, and validation. GB: Writing- review and editing, data curation, formal analysis, software, resources, visualization, and validation. HT: Writing- review and editing, methodology, conceptualization, formal analysis, resources, visualization, and validation.

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Data availability
The data will be available from the corresponding author upon reasonable request.

Declaration

Ethics approval and consent to participate
Ethics approval was granted by the Institutional Review Board of the University of Gondar, with protocol number 051/23/SN. Additionally, formal permission was obtained from the University of Gondar Comprehensive Specialized Hospital. Prior to participation, all individuals in the study provided written informed consent for voluntary participation and publication of the study. All methods were performed in accordance with the relevant guidelines and regulations.

Competing interests
The authors declare no competing interests.

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