

Endobronchial valve treatment in chronic obstructive pulmonary disease: A qualitative study of patients' expectations

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Abstract

Objectives: Endobronchial valve (EBV) treatment is a treatment option for selected patients with severe chronic obstructive pulmonary disease (COPD) to reduce dyspnea and improve quality of life. However, the procedure is associated with risk of complications, and not all patients achieve the expected outcomes. The present study explores patients' expectations while waiting for EBV treatment.

Methods: Fifteen patients accepted for EBV treatment at Aarhus University Hospital in Denmark from October 2020 to June 2021 participated in a 30-min, semi-structured interview about (1) the experience of living with COPD and (2) expectations regarding EBV.

Results: Four themes were identified: a life of reduced quality; hopes and expectations; information about EBV; and perception of risks. Most patients described their lives as not worth living, and they hoped that EBV would give them their physical and social lives back, while also being aware that EBV would probably not work miracles. Patients' information seeking was influenced by their hopes and expectations to the treatment. They filtered out negative information, focusing on the hope for a positive outcome. This made them willing to run the risk of complications.

Conclusion: Living a life of considerably reduced quality, patients might have an increased focus on potential positive effects of EBV treatment while filtering out information about potential side effects. This might bias their decision-making process.

Keywords

COPD, emphysema, patient communication, decision-making, EBV

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Introduction

Chronic obstructive pulmonary disease (COPD) is a heterogeneous lung condition characterized by chronic symptoms (dyspnea, cough, sputum production) due to abnormalities of the airways (bronchitis, bronchiolitis) and/or alveoli (emphysema) that cause persistent, often progressive, airflow obstruction.¹ The destruction of lung tissue may eventually lead to hyperinflation and suboptimal gas exchange, resulting in breathing difficulties, hypoxemia, reduced energy levels, and deconditioning. Evidence-based management of stable COPD consists of pharmacological treatment with inhaled bronchodilators and sometimes inhaled corticosteroids, as well as behavioral initiatives in the forms of smoking cessation support and pulmonary rehabilitation.¹ Patients with emphysema often experience refractory breathlessness, resulting in impaired quality of life despite

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optimal treatment.² Lung volume reduction is first and foremost a symptomatic treatment option considered in cases with considerable breathlessness, reduced exercise capacity, and significant hyperinflation despite optimal treatment.³ Evidence has demonstrated that endobronchial valve (EBV) treatment can improve symptoms, exercise capacity, lung function, and quality of life in selected patients with severe emphysema.^{4–6} EBV is recommended in the recent Global Initiative for Chronic Obstructive Lung Disease (GOLD) report.¹

In spite of the potential benefits, the EBV placement procedure is associated with risk of complications, for example, pneumothorax that is seen in 4.2%–26.6% of the treated patients,⁷ and not all patients achieve the expected outcome.^{7,8} Moreover, patients are faced with the decision to receive EBV treatment at a point in their disease trajectory where there are only few remaining treatment options and an outlook toward worsening of life-limiting symptoms in the future. Healthcare providers play a significant role in patients' decision-making process. The concept of shared decision-making involves a process where patients and healthcare providers consider outcome probabilities and patient preferences and reach a healthcare decision based on mutual agreement.⁹ In shared decision-making, a central task of healthcare providers is to provide high quality information about the possible benefits and complications of the treatment, and to qualify the information that the patient has already received or sought by him- or herself.^{9,10} A web-based discrete-choice experiment survey among 294 patients with severe emphysema concluded that 71% would select EBV treatment, 6% would select lung volume reduction surgery (LVRS), and 23% would continue medical management,¹¹ but little is known about the expectations and considerations behind these choices.

In a qualitative service improvement project by Buttery et al.,¹² patients, who received LVRS, EBV, or both, disclosed that they felt like they were in a fight to earn their chance to have an operation as they have consulted numerous healthcare providers before they were referred. They also expressed a lack of information about post-operative complications and the potential need for supplementary oxygen in the period after the treatment. However, only a minority of the included patients specifically received EBV, and they were interviewed between 1 and 8 years after treatment, increasing the risk of recall bias and negativity or positivity bias according to the perceived outcome. In another qualitative study by Baur et al.,¹³ patients and their caregivers were interviewed about their experiences with LVRS both before and after the surgery. An overarching theme in the patient and caregiver narratives was hope, and it was described how feelings of hope supported positive thinking about the surgery. Hope in the form of focusing on positive instead of negative possibilities may help patients through a challenging operation after their choice has been made,¹⁴ but might

also compromise the patients' susceptibility to less positive—and perhaps more realistic—pieces of information in the decision-making process. In the analysis by Baur and colleagues, data from pretreatment interviews were merged with posttreatment interview data, making it difficult to differentiate expectations prior to the treatment from experiences after the treatment.

A deeper insight into patients' expectations and considerations prior to EBV treatment may guide healthcare providers in covering factors of relevance when communicating with individual patients as part of the shared decision-making process. The aim of the present study was therefore to perform an exploration of patients' expectations and considerations prior to EBV treatment.

Methods

The study was conducted at the Department of Respiratory Diseases and Allergy at Aarhus University Hospital in Denmark. Ethical approval was waived by the Central Denmark Region Committees on Health Research Ethics. The processing of personal data was approved by the Central Denmark Region and listed in the internal record prior to the initiation of data collection (reference number: 1-16-02-676-20).

Participants

Danish-speaking patients with emphysema, who were accepted for EBV treatment at Aarhus University Hospital in the period from October 2020 to June 2021, were eligible for participation in the present study. Patients who were not cognitively able to take part in a telephone interview were excluded. Written informed consent was obtained from all subjects. Eligible patients who gave their informed consent to participate in the study were contacted by telephone with the purpose of scheduling a time for the interview. The exact sample size was not projected a priori. We continued to include participants as long as we were able to obtain additional new information, and until further coding did not add new insights to the themes.¹⁵

Data collection

Semi-structured interviews with a planned duration of 30 min were conducted based on an interview guide. The development of the interview guide was informed by other qualitative studies exploring patients' experiences of forthcoming health-related events^{13,16} and consisted of three parts: (1) the experience of living with COPD (e.g., "How is everyday life with COPD for you?"), (2) expectations regarding EBV treatment ("What thoughts have you had about EBV?"), and (3) additional comments ("Is there something you wish to add?"). Questions were generally open-ended and followed up by invitations to elaborate on

Table 1. Participant characteristics.

Participant	Age	Sex	Marital status	MRC	CAT	FEV1% pred.	Exa. >1 year
1	67	Male	Married	4	19	22	0
2	54	Male	Never married	4	16	20	1
3	73	Male	Married	4	21	31	2
4	62	Male	Never married	3	16	25	1
5	63	Female	Married	4	23	25	0
6	69	Male	Married	3-4	18	27	1
7	74	Female	Married	4	13	31	0
8	64	Female	Married	4	11	32	1
9	60	Male	Living with part	2	21	29	0
10	62	Female	Married	5	27	20	0
11	54	Male	Never married	4	25	18	0
12	72	Male	Married	4	20	37	0
13	59	Female	Married	4	27	31	0
14	70	Male	Married	4	16	26	0
15	71	Male	Married	4	12	29	0

CAT: COPD assessment test; Exa: Numbers of exacerbations; FEV1: forced expiratory volume in first second; MRC: medical research council dyspnea score.

individual experiences, for example, “Could you tell me more?” and “What does that mean to you?”. The interview guide was piloted in two interviews. The pilot interviews were included in the final dataset as no considerable changes were made to the interview guide. The final interview guide can be found as Supplemental Material. The interviews took place 1–3 months prior to the participants’ scheduled EBV treatment and were conducted via telephone in order to minimize the burden of participation for patients who did not have to travel to the hospital to take part in the interview. Patients were interviewed by two respiratory nurses, who were also clinically involved in the EBV consultations. Patients had therefore already met the interviewers face to face before doing the interview, minimizing the risk of patients feeling alienated by the telephone format. The nurses received supervision from a psychologist with previous experience in qualitative interviewing. The interviews were audio recorded and transcribed verbatim.

Analysis

The analysis process was carried out using manual data management. Data were analyzed using thematic analysis as described by Braun and Clarke¹⁷ for identifying, analyzing, and reporting themes within data. An inductive approach was used to understand the patients’ expectations and considerations. Through repeated readings of the dataset, we searched for meanings and patterns in the first phase. After familiarizing ourselves with the data, we, in the second phase, began to produce initial codes. We manually organized the data into meaningful groups. In the third phase, we sorted the different codes into potential themes. In this phase, we also considered the relationship between codes, between themes, and between different levels of

themes. In the fourth phase, we refined the themes and generated a thematic “map” of the analysis. In the following phase, phase five, we defined and named the themes. We conducted and wrote a detailed analysis for each theme. The last phase had to do with producing the present article. In this case, we have provided a concise, coherent, and logical account of the data.

To enhance the quality of the analysis, the two first authors were deeply involved in the analysis process. The analysis was later presented and further discussed in the overall research group.

Results

A total of 15 patients were included in the study and took part in qualitative interviews prior to their scheduled EBV placement. Participant characteristics can be found in Table 1. The mean age of the included patients was 65 years and their lung function ranged from 18% to 37% of predicted at their individual age (forced expiratory volume in 1 s). Five of the included participants were female. Eleven patients were married/living with a partner, and the remaining patients were non-married/living alone. The audio recordings of the interviews had a mean duration of 20.5 min (range: 9–33 min). The audio recordings excluded the general intro and outro of the interview and therefore had a shorter duration than the complete interviews.

Additional patients were included until data saturation was achieved. Data from several of the patients had essential characteristics in common, which according to Morse¹⁸ can be understood as replication.

The analysis revealed four themes. An illustrated overview of the themes and their proposed interrelation can be found in Figure 1.

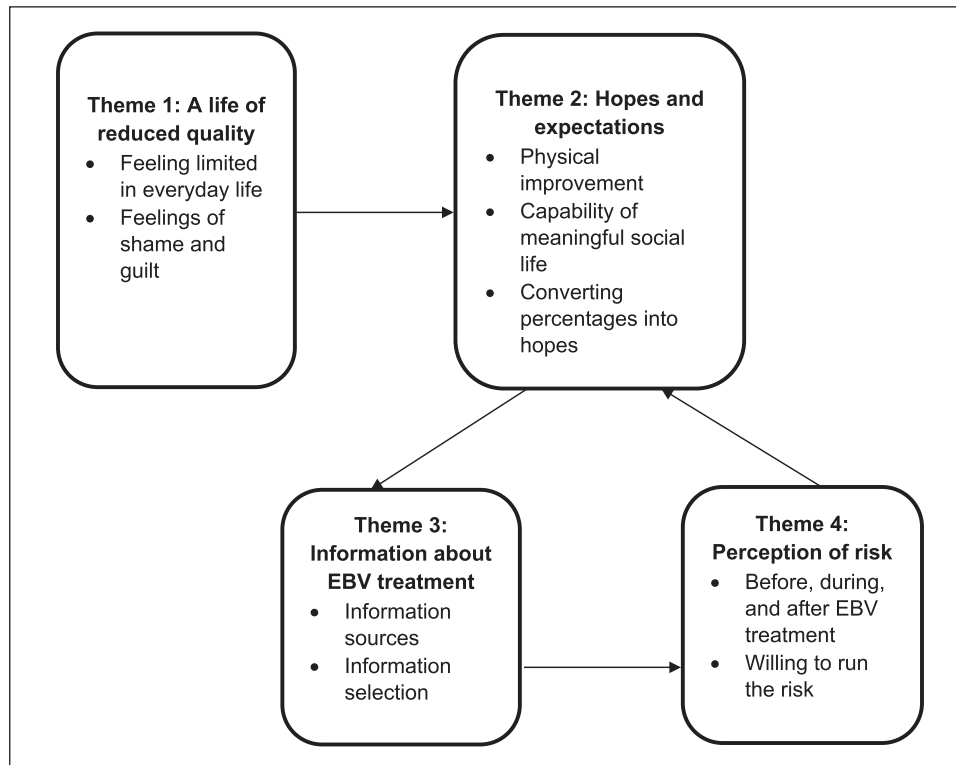


Figure 1. Overview of themes describing patients' expectations and considerations prior to EBV treatment.

Theme 1: A life of reduced quality

The patients described their lives before approval for EBV treatment, as a life of reduced quality. Their shortness of breath and other symptoms kept them trapped in an everyday life full of limitations and deprivation:

Right now I don't think it's a life [. . .] it makes me feel like I'm trapped in a prison. . . actually. . . I can't move freely

Living with COPD for many years had meant continuous loss for the patients, which also impacted the quality of life and thoughts about the future:

So it's been a process where I've had to give up more and more. . . and that's also the fear I have. . . that is, that I'm looking into a future that's not very pleasant

Feeling limited in everyday life. The patients found that their lung disease limited their opportunities for both physical and social activities, for example, ordinary everyday tasks such as taking care of personal hygiene, shopping, cleaning, and gardening:

. . . so I can't do the same everyday things as I used to, and things take longer, right. . . I can't just take the grandchildren to the playground or anything. I have to plan my daily life (. . .) it all has to be planned in a completely different way [compared to before the illness]

The fact that there was no room for spontaneous activities, and that everyday life had to be planned, largely repeated itself in the patients' stories. Patients expressed that they had to save up energy and air, and that all tasks took longer.

Likewise, the more social activities such as walks, hobbies, and spending time with family and friends were experienced as insurmountable tasks. The patients often had to say no to social activities and hobbies:

. . . I have to give up things that I have loved. . . and that I can no longer do. In the end, I had to give up playing golf [. . .] this means that my opportunities down the road will be limited

Giving up on hobbies, such as hunting, bowling, golf, cycling, traveling, etc., also meant that many patients experienced a loss of social relationships.

Some patients felt more and more isolated as the disease progressed. The feeling of isolation could arise from not being able to endure what they used to and thus not being able to nurture social relationships in the same way as before. Withdrawing from social relationships was also described as a conscious act, either because they were not physically or mentally capable of the activities and relationships or because they thought they could no longer contribute in a meaningful way to the relationship. Regardless of the reason, whether it was self-chosen or not, the lack of social relationships appeared as a serious consequence of the disease—and the feeling of isolation was associated with both sadness and deprivation:

What is the worst? It is the isolation, I think. . . [. . .] well, I haven't had much social interaction because I isolate myself deliberately, because I don't have the energy. . .

Feelings of shame and guilt. Patients found it shameful to live with COPD. This was connected to the fact that they placed a great deal of guilt on themselves for having contracted the disease. They could not help worrying about what others might think. Therefore, the patients put effort into hiding the disease and pretending to be "normal":

. . . when I see people walking by on the street. . . well, I pretend I'm normal. Just standing there and taking a break [. . .] it's not fun to feel that way, where you constantly have to go and hide how you feel. . . because you're embarrassed about it. I'm actually embarrassed that I have COPD. . . because I could have avoided it if I had stopped smoking a little earlier [. . .] . . . it's shameful. . . yes. . . it is

Some patients stated that it is difficult to live with an invisible illness, and they experience that others do not understand how bad it feels:

but sometimes I also have the feeling that they think it's just nonsense. . . they don't think it's as bad as it sometimes is [. . .] yes, because you can't see that the person has COPD if they just sit still. . .

Living with severe COPD changed the self-perception for many of the patients. They went from being autonomous, self-reliant individuals to being patients with COPD. The new self-perception implied an undesirable situation, where they often found themselves dependent on the help of others.

Several patients referred to themselves as being a burden to both close relatives and friends:

And then I'm also embarrassed that my husband, who is the sweetest, nicest person, that he has to help me in the shower. I can't even manage to take a shower by myself—I need help for that

Theme 2: Hopes and expectations

Most patients conveyed a sense of doubleness when describing their thoughts about the outcome of EBV treatment. On the one hand, they described the realistic expectation that EBV would not work miracles, and that the effect would be relatively limited. On the other hand, they also expressed hopes of being able to live their lives more fully after the treatment. It appeared that patients balanced hopes and expectations with the purpose of not feeling too disappointed if the outcome of EBV treatment was limited.

Well, I thought, I should try and give it a go. You know, I am not expecting anything, but I am hoping for the best. . . You know, I can't get disappointed . . .

Physical improvement. Patients hoped for physical improvement after EBV treatment, including less breathlessness and more energy. Some reported this as an end goal in itself, whereas others emphasized that "better breathing" would result in better exercise capacity, which could improve physical capacity through a more active lifestyle.

I would like to be able to walk longer distances. Perhaps without the walker for the shorter walks, right? But you know, just being able to walk longer and perform better. . . having more air to perform better.

I would be more physically active [after EBV treatment]. I would simply do more to get my lungs back on track, if I could just get some help to breathe. I think that [EBV treatment] would expand my breathing capacity a little. . . I think so.

Some patients hoped that the increased physical capacity after EBV treatment would make them able to resume old hobbies such as horse-back riding, golf, traveling, and spending time in nature, as well as practical tasks such as gardening, grocery shopping, and house cleaning. Such activities would increase quality of life and a sense of normality:

My hope is to be able to take long walks and pick mushrooms. There are lots of them in the forest at this time of year. Being outside is something that means a lot to me. [. . .] I'm hoping to be able to do more by myself. Moving around and taking a shower without help. Feeling some degree of. . . or a high degree of normality.

Capability of meaningful social life. Patients also hoped that they would be able to take part in social activities and spending more time with family and friends after EBV treatment:

I want to be able to have a dance with my husband. . . Just being able to take part in events where there is a lot of people, and not having to just sit there and gasp for air after one hour, only wanting to go home. Yeah. . . I wish I had a more social life.

Many patients described how social activities, physical capacity, and mental well-being were closely related, and that they hoped for improvement in all aspects after the treatment.

It's both physical and mental, right. We know that. It [physical activity] works and it keeps depression and melancholy away, for example. And also, being something for other people.

Some used metaphors to describe their hopes of a more active and meaningful life after the treatment. EBV treatment was described as "a gift," "a blessing," "a prize," "a liberation," and "winning the lottery." One patient described the treatment as an expected personal turning point in life:

I really hope these valves will work [. . .] It will be my personal New Year's Eve. . . that's how I feel. . . If they really work

[. . .] I can get my life back. I know that my lungs will never be completely healthy. But if they could just get a little better. That would mean a lot. I am looking forward to that day.”

Converting percentages into hopes. When expressing their hopes and expectations to the outcome of EBV treatment, patients tended to convert the expected percentage of improvement directly into the performance of meaningful activities.

Well, I have told my family and my kids that if I get 30% more air [. . .], then I would be able to spend more time with them. . . my children and grandchildren. If we went on a trip, I could come with them.

Being so restricted in everyday life, patients described that, after EBV treatment, every gained percent count in their hopes for more quality of life.

I hope I'll get better. . . and every percent it gets better is a blessing.

Theme 3: Information about EBV treatment

Data showed that patients get information about EBV treatment from many different sources. The analysis also showed that patients often experienced having received different information. Patients can take on different roles—passive or active—in relation to information seeking. The analysis also showed that patients are selective with regard to the information they receive.

Information sources. Some patients appeared very active in terms of searching for information. They looked for information on the internet, television, through patient organizations, in private networks, and from the health service (general practice and hospital doctors/nurses). These actively information-seeking patients often used the information obtained to inquire about treatment options when they were in contact with the healthcare system. Several patients thus gave the impression that their own active efforts contributed to the initiation of initial investigations and EBV treatment approval:

I read a bit on Doctor Google [. . .] and I participated in lung rehabilitation a few years ago [. . .] and talked to a doctor about it, and he said: “it’s not something you can get—it’s too expensive”. . . but uh. . . then I had a good doctor at the pulmonary clinic. . . and she thought it might be interesting if I could be recommended for such an EBV

Other patients took a more passive role, where the information about EBV treatment was given by the doctor in connection with hospitalization or planned consultations in the healthcare system. The analysis showed that several patients felt they had received different information

depending on who or where they asked about their options for treatment:

. . . I was offered it [EBV treatment] in [city name 1]. . . and then the doctor calls and tells me that I was approved. But then she suddenly says that I wouldn’t benefit from it anyway. And then they send me to [city name 2], and then I go in and talk to the sweet young doctor, and then he says: “I’m sure you’ll benefit from it”

Many patients therefore had the experience that not all doctors had the right knowledge about treatment options and the criteria for EBV treatment.

Information selection. Patients often tended to be selective about the information they received. It seems that they craved the type of information that fed their hope for improvement, whereas more negative information was pushed to the background or even “skipped”:

. . . well, I’ve read a bit about it. . . and some feel really well after the procedure, and others feel badly. And then I skip over [the information about] those who feel bad. . .

It seemed that the optimistic information “sticked to” the patient and continued to nurture both hope and expectations for the future after EBV treatment:

I heard about someone who had it done, but it was my ex-son-in-law who came and said it. He had heard that the person had got 40% better. . . so uh. . . [. . .] . . . if I could get like that [40% better], I would fly around. . .

On the contrary, it appeared that the patients neglected the more negative stories or information. They may have heard them, but the information “did not stick,” and their desires and hopes for effect downplayed the significance of the negative information:

I go to gymnastics with someone who has had it [EBV treatment] done. . . and it hasn’t helped him. . . but I still hope

A factor that appeared to be important in the patients’ considerations about EBV treatment was their trust in the healthcare professionals that were in charge of the treatment. Patients conceived that the mere fact that a trained and experienced healthcare professional had labeled them ready for treatment was synonymous with limited risk of the invasive procedures:

Well, I actually think that they wouldn’t do this operation on me if they thought it was life-threatening. . . then they probably wouldn’t do it. . .

Knowing that they would be accompanied by a competent healthcare professional with whom they had a strong alliance appeared to influence patients’ risk perception.

Theme 4: Perception of risks

Most patients considered potential risks as part of their decision-making, and as part of their reflections and preparations in the time between decision and treatment. A few patients mentioned risk considerations spontaneously, while most of the patients did not mention worries until prompted by the interviewer.

Before, during, and after EBV treatment. Patients brought forward several specific worries about EBV treatment. Worries concerned issues that were feared to take place either before, during, or after the treatment. Specific worries *before* the treatment included worries about the procedure being cancelled due to organizational factors such as a shortage of staff or being rejected in the minutes prior to the invasive procedures. Patients also worried about not being physically fit for treatment:

Well, I am not as physically fit as I was a year ago. . . I'm really not. I feel more breathless. . . and I can feel that my muscle mass is not what it used to be

Worries *during* the treatment included fear that the specialist in charge of the treatment procedure would cancel due to findings that could not be stated in the assessment phase:

I really hope that it will be successful. . . because I know that I can get all the way to the operating table and then be told that it's not going to work after all.

Some patients feared lethal effects of the anesthesia, knowing that their limited lung function makes them vulnerable to anesthetic procedures. Fear of the risk of infection during the invasive procedures was also mentioned. These were, in some cases, based on experiences from previous invasive procedures. Finally, patients mentioned the fear of pneumothorax during treatment and the complications afterwards.

Several patients described how their primary concern was that there would be no effect *after* the treatment. That their hopes and expectations would not be fulfilled. Some patients also expressed worries about having foreign objects (the valves) within their bodies and a fear of the valves breaking loose:

They showed me how the little valve looks like. Well, what happens when they loosen. . . what then? . . . Is it dangerous? . . . I think about that a little bit.

I am afraid to cough up the valves. . . or something like that"

Willing to run the risk. When talking about the perceived risks, some patients described EBV treatment in line with any other choice in life.

Everything in life comes with a risk

Others described EBV treatment as the most radical and risky treatment they had ever received for their COPD. However, they were willing to run this risk as the last chance of winning their lives back. One patient expressed the seriousness of making such an existential and paramount decision in the following way:

I have arranged that my whole family is gathering on the Sundays before the surgery. Things can happen during surgical procedures, but that's how it is. I expect to wake up again, but of course I am worried about it. [. . .] Things can happen, right. But this is something that I want to do, so that's the way it has to be.

Discussion

In this exploration of patients' expectations and considerations prior to EBV treatment four themes were identified: a life of reduced quality; hopes and expectations; information about EBV treatment; and perception of risks. As illustrated in Figure 1, there was a tendency for patients' hopes and expectations (Theme 2) to mirror their perception of the reduced quality of their life with emphysema (Theme 1). Patients described their lives as not worth living and as being "trapped in a prison" with shame and guilt as companions. Their hopes and expectations were described as a way of living their physical and social lives more fully and as "a liberation." At the same time, patients appeared to be aware of the more realistic expectation that EBV treatment would not work miracles, and that the effect most likely would be relatively limited. Patients' way of seeking and receiving information about EBV (Theme 3) appeared to be colored by their high hopes to the treatment. They filtered out negative information about EBV and chose to focus on the hope for a positive outcome. This influenced their risk perception (Theme 4) and made them willing to run the risk with the purpose of winning back their lives, despite knowing the possible complications before, during, and after the EBV treatment.

The hopes for physical improvement in our study is in line with the most frequently reported personal goals by patients prior to EBV treatment in the study by Hartman and colleagues,¹⁹ that is, "Walking," "Shower etc.," "Household," "Exercise," "Cycling." When comparing the findings from our study with studies of patients' expectations to other evidence-based interventions in COPD, it is remarkable that the patients' hopes for a positive outcome of EBV treatment are so high. Other non-pharmacological interventions in COPD, such as smoking cessation and pulmonary rehabilitation, require continuous effort, self-management, and engagement in lifestyle and behavior changes from patients,²⁰ making many patients feel that they are left to themselves and that "nothing could be done for them."²¹ When patients with COPD are then offered to be "passive receivers" of invasive treatment with competent healthcare professionals directing their treatment, they might set up their hopes and expectations for a positive outcome.^{20,22}

The findings of the current study showed that patients were hopeful about this new invasive treatment option. Their hope for a better life—a more normal life—after EBV treatment appeared deep-felt. Hope enables people to deal with difficult situations, loss, loneliness, and suffering.²³ It is future-oriented, related to choices and wishes, just as hope is associated with trust, perseverance, and courage.²³ The analysis showed that the patients waiting for EBV treatment had a future-oriented hope. They wanted a change in their current life situation. The patients perceived the EBV treatment as an alternative to their current situation—an escape route. Our findings indicated that many patients who are approved for EBV placement might have unrealistic wishes for major changes. They tried to downplay their hopes by saying that of course they hope but do not expect anything. The patients expressed a trust in the healthcare professionals, as someone who can help them in their difficult life situation, and the patients showed courage in different ways, for example, to undergo examinations and later treatment in the hope of achieving a desired result. It is important to support hope and avoid hopelessness in patients living with life-threatening illness.²⁴ It requires thorough and caring communication to gain insight into the patient's life situation, in order to be able to feed hope and at the same time gently express what is realistic and what, on the other hand, might be "wishful thinking."²⁵

Also, in the context of shared decision-making, it is important for the healthcare provider to pay close attention to the patients' hopes and expectations to EBV placement in order to understand the reasons for declining or accepting treatment. Based on the results of the present study, it may not be enough to provide basic information on what patients can expect from the treatment, as many patients appear to believe that the expected percentage of improvement (e.g., 5% improvement in lung function) can be directly converted into an equivalent increase in the performance of meaningful activities (e.g., spending 5% more time with family and friends). It is the healthcare providers' responsibility to check what information the patients base their decision on. Patients might have sought information from multiple sources and have a tendency to filter out negative information in order to keep up the hopes for a positive outcome. This is consistent with theories and evidence of cognitive dissonance and biased information-seeking, suggesting that after a decision has been made, people generally tend to select additional information supporting rather than conflicting with their choice.²⁶ In addition, patient-directed online information is frequently incomplete, inaccurate, and/or outdated, as exemplified by a study in idiopathic pulmonary fibrosis.²⁷ Patient decision aids are clinical tools that have been developed to support communication about specific treatment choices with the purpose of minimizing decision-related bias and maximizing patient involvement.²⁸ Development of tools to support EBV decision-making in the future should be based on a systematic and evidence-based methodology.²⁹

Strengths and limitations

The present study is among the first to perform an exploration of patients' expectations and considerations prior to EBV placement. While existing studies are predominantly retrospective, the prospective design of the present study reduces the risk of recall bias, as well as negativity or positivity bias according to the actual outcome of the EBV treatment. A strength of the present study is the sample of participants from a population that are severely ill, who were recruited within a limited time window from referral to EBV treatment. Both males and females are represented in the group of participants, and the age range of the included participants are relatively wide (54–74 years) and fairly representative of the age range that is generally considered relevant as candidates for EBV treatment.³⁰

Among the limitations are that the nurses who interviewed the patients were also partly responsible for the clinical consultations. Their views on EBV treatment, and their wish for a strong alliance with the patients during the course of treatment, might have constituted a bias in the data collection. On the other hand, the already existing alliance between the nurse and the patients may also have resulted in richer and more trustworthy patient narratives. Another important limitation is that only patients who accepted referral to EBV treatment were included in the present study. Hence, we did not gain insight into the considerations of patients who were not referred to the hospital. Reasons for non-referral of relevant candidates for EBV treatment can possibly be attributed both to the referring physician, for example, lack of specific knowledge about EBV among general practitioners, or to the patient, for example, negative attitudes and expectations toward invasive treatment.

Conclusion

Living with considerably reduced quality of life, patients with advanced emphysema appear to have high hopes prior to EBV treatment, which may influence the way they perceive information about potential effects and risks of the treatment. These results suggest that there is a need for adjusting shared decision-making tools to support clinicians in balancing hope and realistic expectations when communicating with patients about EBV treatment. Longitudinal studies are needed to explore patient experiences and narratives of the actual outcome of EBV, as well as studies exploring the experiences and considerations of patients who did not accept referral to EBV treatment.

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Author contributions

Data collection: LHKJ and KLK. Study design: IF-V, EB, TDC, KB, MB, AL, LHKJ, and KLK. Analysis of data: IF-V, and CAM. Manuscript preparation: IF-V and CAM. Review of manuscript: All.

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Ethical approval

Ethical approval for this study was waived by the Central Denmark Region Committees on Health Research Ethics because studies collecting data exclusively via questionnaires does not need approval from an ethical committee, according to Danish legislation (the Act on Research Ethics Review of Health Research Projects §14, Section 2).

Informed consent

Written informed consent was obtained from all subjects before the study.

Trial registration

Not applicable.

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Supplemental material

Supplemental material for this article is available online.

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