

The information needs of people with COPD—The holistic approach with special reference to gender and time since diagnosis

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Funding information

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Abstract

Aims: The aim of this study was to determine what kinds of unmet information needs people with COPD have and whether there are differences in information needs between genders or based on the time since COPD diagnosis.

Design: A descriptive cross-sectional study.

Methods: Data on people with COPD ($N = 169$) were collected from a two-part questionnaire distributed via website. On the first part, information needs concerning the medical aspects of self-management were measured by the Lung Information Needs Questionnaire (LINQ). On the second part, which was developed specifically for this study, a more holistic view of self-management counselling was sought. Statistical methods were used to analyse the data.

Results: The respondents had wide-ranging information needs in many areas of COPD self-management. The most often reported areas of unmet information needs included exacerbations, diet, fatigue, stress and anxiety, palliative care and sexual life. The information needs varied by gender and time since COPD diagnosis.

KEYWORDS

COPD, information needs, medicine, nursing, self-management counselling

1 | INTRODUCTION

Chronic obstructive pulmonary disease (COPD) is a persistent, life-limiting disease and is currently the fourth leading cause of death in the world (GOLD, 2020). Although COPD is incurable, its symptoms can be relieved and the quality of life of those with COPD can be improved. Because self-management is a crucial part of the lives of people with COPD, they need the requisite knowledge and skills to cope with this task. The disease's trajectory as well as the life situation of every person with COPD is unique. Therefore, the information needs of people with COPD vary between individuals

and as such counselling provided by healthcare professionals (HCPs) should be tailored accordingly.

2 | BACKGROUND

COPD is a progressive, incurable and debilitating disease. Smoking cessation is the most effective intervention to either reduce the risk of developing COPD or to stop its progression and improve long-term prognosis (GOLD, 2020). The progression of COPD can be very slow, and the symptoms can be misinterpreted as a normal

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part of ageing. Therefore, it may be difficult for people who suffer with COPD to recognize that they have the disease (Bragadottir et al., 2018; Disler et al., 2014). Moreover, many people with COPD do not understand that it is a life-limiting and ultimately terminal illness (Disler et al., 2014; Lippiett et al., 2019).

People with COPD usually have several symptoms (Christensen et al., 2016; Eckerblad et al., 2014). Breathlessness is the most common, debilitating and frightening symptom (Disler et al., 2014; Sigurgeirsdottir et al., 2019). Previous studies on patients with COPD have shown that the prevalence of anxiety, depression and dyspnoea is higher in women than in men. Furthermore, among women, quality of life is poorer and exacerbation frequency seems to be higher (Di Marco et al., 2006; Gut-Gobert et al., 2019).

Along with worsening symptoms, such as increasing breathlessness, mucus production and need for oxygen, social isolation among COPD sufferers becomes more evident over time (Marx et al., 2016; Russell et al., 2018). Living with COPD requires compromising and balancing demands, symptoms and energy levels on any given day (Johansson et al., 2019). An acceptance of restrictive life situations can be difficult and people with COPD may feel that they have lost their freedom (Sigurgeirsdottir et al., 2019) and essentially live at the mercy of the disease (Marx et al., 2016).

COPD affects people's physical and psychosocial well-being as well as their relationships with family and HCPs. Due to the perception that the disease is self-inflicted, people with COPD often have feelings of guilt (Lindqvist & Hallberg, 2010) accompanied by experiences of self-blame (Bragadottir et al., 2018) and shame (Lindgren et al., 2014). One potential consequence of shame among COPD sufferers might be the attempt to hide the disease from family members and HCPs (Bragadottir et al., 2018).

People with COPD have the burden of coping with the disease in their everyday life (Johansson et al., 2019; Sigurgeirsdottir et al., 2019). They have unmet information needs regarding COPD as a disease, including its aetiology, management and prognosis (Clari et al., 2018; Disler et al., 2014). Likewise, they have unmet physical, emotional, social and care needs (Clari et al., 2018).

Self-management is an integral part of COPD management. The International Expert Group's consensus (Effing et al., 2016) defines the goals of COPD self-management as "(a) optimizing and preserving physical health; (b) reducing symptoms and functional impairments in daily life and increasing emotional well-being, social well-being and quality of life; and (c) establishing effective alliances with healthcare professionals, family, friends and community" (Effing et al., 2016 p. 50). To successfully perform self-management and achieve the goals mentioned above, people with COPD need adequate and comprehensive information. It is recommended that counselling is provided at the time of diagnosis and then continued through to end-of-life care (Giacomini et al., 2012). Although adequate knowledge of COPD is the foundation, self-management skills, self-efficacy, health-literacy and motivation are likewise crucial for the self-management of people with COPD (Van de Velde et al., 2019).

When examining self-management counselling, a patient-centred (i.e. the information needs expressed by the patient; cf. Hyland et al., 2006) or HCP-oriented (i.e. knowledge gaps among patients as detected by HCPs; cf. White et al., 2006) perspective can be taken. In this study, the choice was made to examine COPD patients' information needs as this approach was considered more patient-centred and thus more consistent with the principles of COPD self-management guidance (Effing et al., 2016).

In previous quantitative studies of COPD self-management, focus has been placed primarily on information needs tied to medical issues such as medication, smoking cessation and prevention of exacerbations (Cleutjens et al., 2017; Hyland et al., 2006; Jones et al., 2008; Sandelowsky et al., 2019; Scott et al., 2011). Thus, the psychosocial aspects of COPD self-management counselling, which are a crucial part of this study, remain mainly unexplored. Furthermore, studies on gender differences with respect to COPD patients' information needs are scarce, as are studies concentrating on how information needs change over time after diagnosis. Therefore, the aim of this study was to determine what kinds of unmet information needs of people with COPD have. The research questions were as follows:

1. What are the areas of COPD self-management counselling where unmet information needs appeared to be most prominent?
2. Are there differences in information needs by gender or depending on how much time has elapsed since COPD diagnosis?

3 | METHODS

3.1 | Design and participants

In this descriptive cross-sectional study, convenience sampling was used to gather data on the information needs of people with COPD. Information about the study, with the possibility of responding to a two-part questionnaire, was disseminated via Finnish respiratory patient organizations. The inclusion criteria were (a) having a self-reported diagnosis of COPD and (b) agreement to participate in the study.

3.2 | The questionnaire

The questionnaire consisted of two parts: (a) The Lung Information Needs Questionnaire (LINQ) which inquires about medical issues in COPD self-management, and (b) the complementary questions with a holistic approach to self-management.

The LINQ (<http://www.linq.org.uk>) is a valid and reliable self-completed questionnaire originally constructed for pre-interview assessment to prepare for clinical encounters (Hyland et al., 2006). It assesses the information needs of COPD patients from their own perspectives. It comprises 17 items and six domains: disease knowledge (4 items), medication (3 items), self-management (2 items), smoking (3 items), exercise (3 items) and diet (2 items). The response choices per question

as well as their format vary between the domains. The respondents' LINQ scores are summed for the total scores and domain scores. The total score ranges from 0 to 25, which provides an overview of the person's information needs. The individual domains are scored as follows: disease knowledge (0–4), medication (0–5), self-management (0–6), smoking (0–3), exercise (0–5) and diet (0–2). Higher scores indicate a greater information need (Hyland et al., 2006).

The LINQ also includes questions pertaining to year of birth, gender and living arrangements (Hyland et al., 2006). An additional question asking for the year of COPD diagnosis was added to the questionnaire to ensure that the respondents had indeed been diagnosed with COPD. Permission to use the questionnaire was received from Professor Michael Hyland (6 April 2017). The LINQ was double translated for this study by two translators.

Recent literature has demonstrated the importance of non-medical (psychosocial) issues for those living with COPD. Thus, due to the narrow perspective of the LINQ the questions with a more holistic approach were created for this study to examine where COPD self-management counselling patients' unmet information needs most often occur. Accordingly, the second part of the questionnaire consisted of a list of 33 items concerning the contents of self-management counselling widely regarded as essential for COPD patients' self-management (see Appendix S1). The items were developed for this study using previous systematic reviews (Stoilkova et al., 2013; Tan et al., 2012), a questionnaire (Bristol COPD knowledge questionnaire (BCKQ); White et al., 2006), clinical pathways (NICE, 2016) and the Finnish guidelines for COPD management (Kankaanranta et al., 2015). Moreover, a previous study of healthcare professionals' perceptions of counselling was used due to the holistic approach of the questionnaire employed in that study (Siltanen et al., 2020).

The respondents were asked to indicate whether they had been given information on the item in question and/or whether they required more information about it. The following response options were included: *I have received information; I have received information and want to receive more information; I have not received information and want to receive it; I do not want to receive information; and I cannot say.*

The complementary questions were pretested together with the translated version of the LINQ with a sample of 13 volunteers with COPD who had participated in a group meeting organized by the Finnish Lung Health Association. As a result of the pretesting, the response option *I have received information and want to receive more information* was inserted, and thus, the pretested volunteers' answers to the complementary questions were excluded from the study.

3.3 | Data collection

The link to the e-questionnaire, along with the study information, was published on the website of the Organisation for Respiratory Health in Finland between 6 November 2017 and 28 February 2018. Potential respondents were informed about the possibility of participating in this study via the website and Facebook page of the Organisation for Respiratory Health in Finland. In addition, the opportunity to use a

printed questionnaire was offered in Helsinki at an event organized by a local respiratory society for people with lung diseases. Those wanting to participate received the printed questionnaire, the study information sheet and a stamped addressed envelope.

3.4 | Ethical considerations

For this study, the ethical review statement was not requested by the Finnish National Board on Research Integrity TENK due to the ethical principles of research with human participants in the human sciences in Finland (TENK, 2012). In this study, the respondents were all adults, and their participation was voluntary. They agreed to participate by anonymously responding to the questionnaire via an open link or by post. At the beginning of the questionnaire, detailed information about the research was provided, including information about respondents' anonymity and the researchers' contact information. No personal data, apart from anonymous demographic data included in the LINQ, were gathered.

3.5 | Data analysis

Data analysis was performed using SPSS version 22.0. The descriptive statistics are presented as frequencies, percentages, means and standard deviations (SDs), or minimum and maximum values (range). The LINQ's mean (total and domain) score proportions of the maximum scores were calculated and presented as percentages ($\frac{\text{mean score}}{\text{maximum score}} \times 100$; Sandelowsky et al., 2019). A prerequisite needed to calculate the LINQ total scores was that the respondents had answered all the questions. Due to missing answers, it was possible to calculate the total scores of only 143 respondents. A *t* test was used to determine whether there could be significant differences in information needs between genders. A Kruskal–Wallis *H* test was used to determine whether there could be significant differences in information needs between different time periods (1–5, 6–10 and over 10 years) after diagnosis.

Before the data analysis of the second part of the questionnaire, the answers *I have received information and want more information* and *I have not received information and want to receive it* were combined. The authors' interpretation was that regardless of which response option was selected, the respondents had inherent information needs related to each item. A chi-square test was used to determine whether there could be significant differences in information needs between genders or between different time periods after diagnosis.

4 | RESULTS

4.1 | Demographics

Of the respondents ($N = 169$), 143 used the link to the e-questionnaire and 26 answered a printed questionnaire. In total,

169 people with COPD answered the LINQ. Concerning the complementary questions with a holistic approach, 156 people with COPD responded. The demographics of the respondents are presented in Table 1. On both parts of the questionnaire, the number of responses varied between the items due to the voluntary nature of answering.

4.2 | The information needs of people with COPD measured with the LINQ

The distribution of the respondents' LINQ total scores is shown in Figure 1. The mean total score was 9.4 (range 1–19, *SD* 4.0). Although the distribution of the respondents' LINQ total scores was determined, the share of respondents who had high information needs could not be calculated due to the lack of a validated cut-off level for the LINQ total score representing high information needs (cf. Sandelowsky et al., 2019).

The LINQ domain scores are presented in Table 2. When the mean domain scores were compared with the maximum possible domain scores and were presented as percentages ($\frac{\text{mean domain score}}{\text{maximum possible domain score}} \times 100$; cf. Sandelowsky et al., 2019), the specific information needs seemed to be especially in the LINQ domains of self-management and diet (Figure 2). The best-covered domains were smoking and medicines, followed by disease knowledge and exercise.

The self-management domain of the LINQ, in fact, concerns self-management of exacerbations, as it includes two questions: one about knowing what to do when breathing gets worse and one

about knowing whether to call an ambulance when breathing worsens. Nearly one-half of the respondents (42.5%; *N* = 71) reported that they had not been told what to do if their breathing became worse and 39.4% (*N* = 28) did not know what they should do in these situations. Furthermore, 83.6% of respondents (*N* = 138) had not been told when to call an ambulance if their breathing worsened, of whom 64.5% (*N* = 89) were uncertain about when to call an ambulance.

Almost two-fifths of the respondents (39.0%; *N* = 66) answered that HCPs had not been given any information on diet. Almost as many (30.2%; *N* = 51) had discussed eating healthy food with HCPs. One-fourth of the respondents (23.7%; *N* = 40) had received some advice to eat several small meals per day and 27.2% (*N* = 46) had been advised to lose or gain weight.

4.3 | The information needs of people with COPD measured with the complementary questions with a holistic approach

The results of the complementary questions revealed that the respondents (*N* = 156) had many unmet information needs concerning the content of counselling provided by HCPs (Figure 3). The results showed that over three-quarters of the respondents wanted information about palliative care or social security (Figure 3). An equal proportion of the respondents also needed information on how to recognize and self-manage typical COPD symptoms, such as fatigue, anxiety, depression or stress. Furthermore, subjects important for COPD management (e.g. rehabilitation alternatives) and

Respondents	LINQ		The complementary questions	
	Mean/ <i>N</i>	Min-max/%	Mean/ <i>N</i>	Min-max/%
Age at the time of reply (years, mean, min-max)	68.3	29–83	66.3	29–83
Age classified by time since diagnosis (years, mean, min-max)				
1–5 years			65.0	29–83
6–10 years			66.9	52–83
Over 10 years			67.0	48–83
Gender (<i>N</i> , %)				
Men	78	46.4	73	46.8
Women	90	53.6	83	53.2
Living arrangement (<i>N</i> , %)				
Alone	61	37.2	59	37.6
With others	103	62.8	93	61.2
Smoking status (<i>N</i> , %)				
Never smoked	11	6.5	10	6.4
Former	135	79.9	126	80.8
Current	23	13.6	20	12.8

TABLE 1 Demographics of the respondents who answered the LINQ (*N* = 169) and the complementary questions with a more holistic approach (*N* = 156)

FIGURE 1 The distribution of the respondents' LINQ total scores (N = 143)

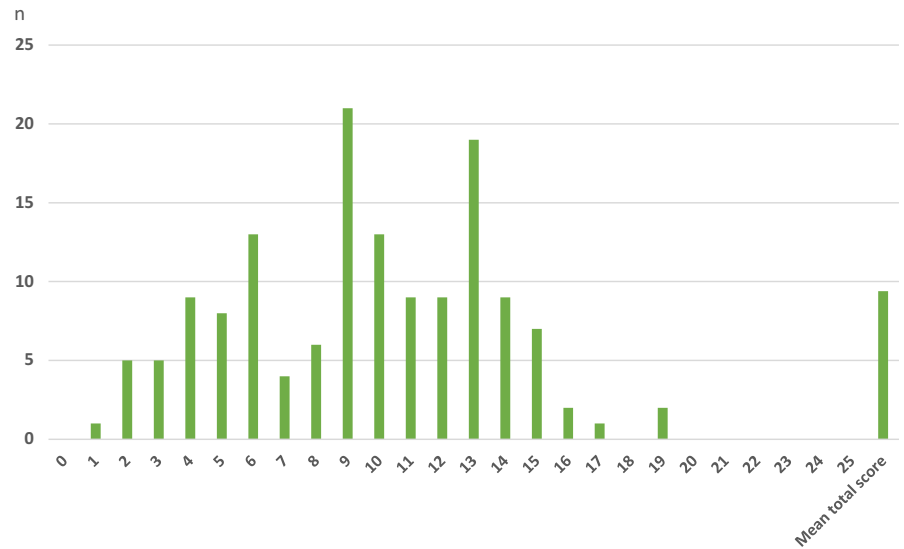
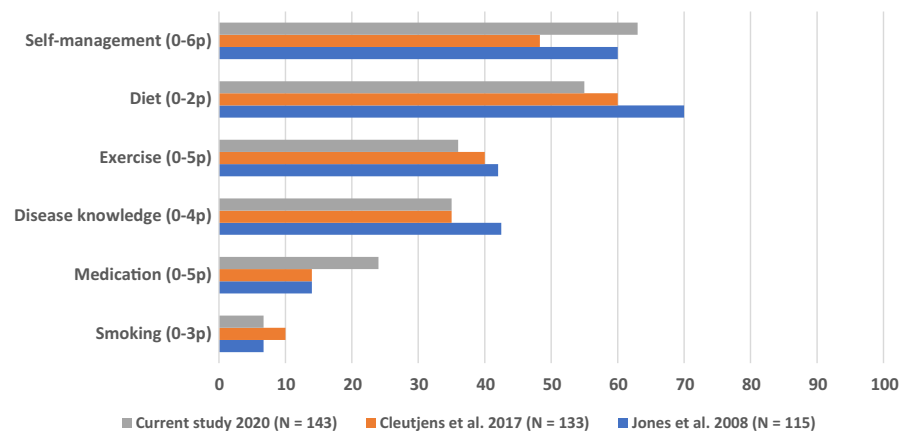


TABLE 2 The mean LINQ total scores and domain scores in the current study and in two previous studies (Cleutjens et al., 2017; Jones et al., 2008)

	Current study (N = 143)		Jones et al. (2008; N = 115)		Cleutjens et al. (2017; N = 133)	
	Mean	SD	Mean	SD	Mean	SD
Disease knowledge (0–4p)	1.4	1.0	1.7	1.0	1.4	0.7
Medication (0–5p)	1.2	1.0	0.7	0.9	0.7	1.1
Self-management (0–6p)	3.8	1.5	3.6	1.6	2.9	1.6
Smoking (0–3p)	0.2	0.7	0.2	0.5	0.3	0.9
Exercise (0–5p)	1.8	1.3	2.1	1.4	2.0	1.1
Diet (0–2p)	1.1	0.8	1.4	0.7	1.2	1.1
LINQ total score (0–25p)	9.4	4.0	9.6	3.6	8.5	3.3

FIGURE 2 The percentages of the mean LINQ domain scores of the maximum possible domain scores $(\frac{\text{mean domain score}}{\text{maximum possible domain score}} \times 100; \text{cf. Sandelowsky et al., 2019})$ in the current study and in two previous studies (Cleutjens et al., 2017; Jones et al., 2008)



daily life (e.g. relaxation, energy conservation, sleep and rest and management of daily tasks) were areas of high information needs. Noteworthy, although almost two-thirds of the respondents wanted to receive information on living in a relationship and having a sex life, one-tenth of the respondents expressed that they did not want to receive information on these issues.

The content areas about which the respondents most often reported having received enough information included vaccination, peer support, care of mouth, long-term oxygen therapy and searching for further information (Figure 3). However, the need for information was evident in these areas as well, as over one-half of the respondents had information needs concerning these items too, apart from vaccination.

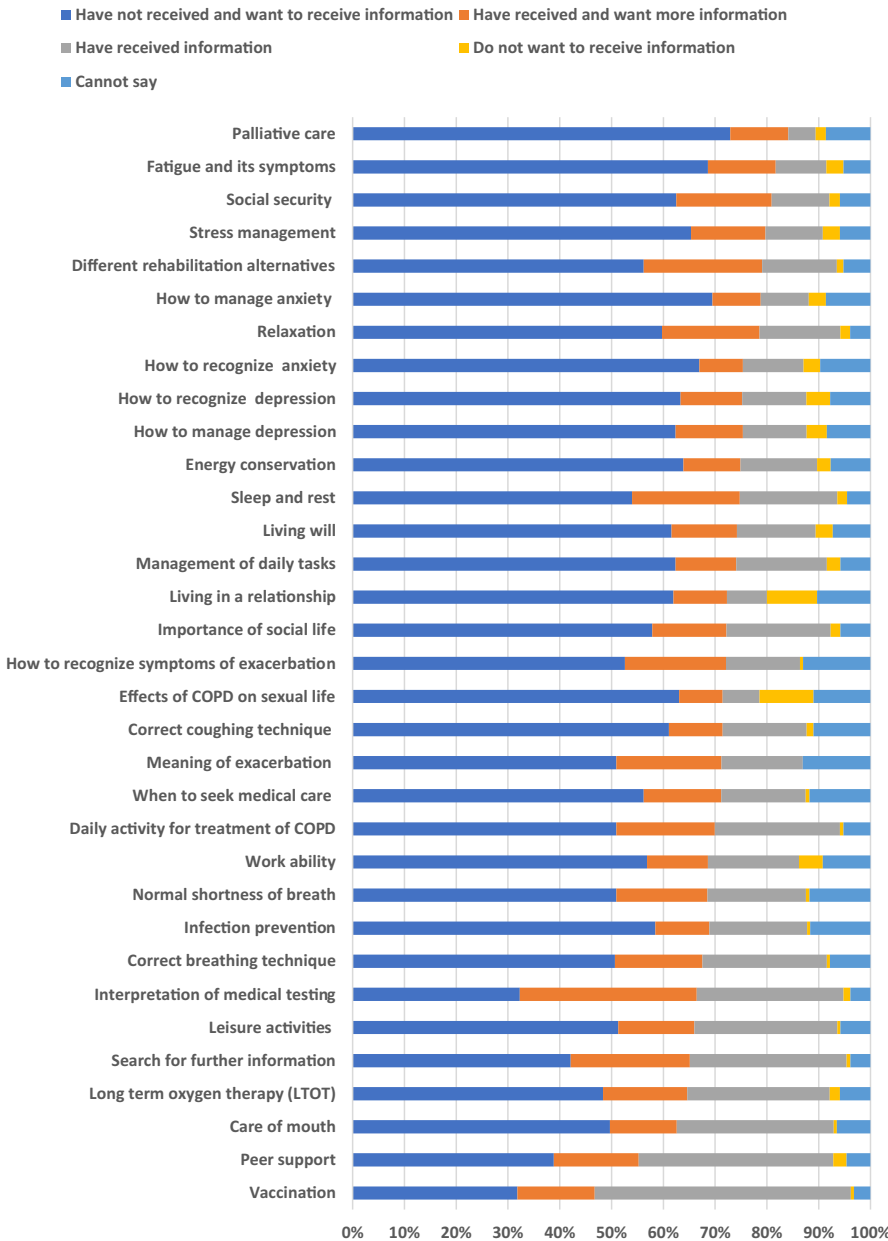


FIGURE 3 The COPD patients' perceptions of receiving information and their desire to receive more information (N = 151-156)

4.4 | Information needs by gender

No difference in LINQ total scores between genders was detected. The mean LINQ total score of women was 9.64 (range 2-19, SD 4.1), while that of men was 9.21 (range 1-17, SD 3.9; $p = .53$). Regarding the mean domain scores, there were no gender differences except in the domain of smoking, where women reported a significantly higher need for information than men. The mean domain score of smoking was 0.38 (SD 0.76) among women and 0.10 (SD 0.47) among men ($p = .007$). Clinically, however, this difference was still small. The minimal clinically important difference (MCID) on the LINQ is one point (www.linq.org.uk).

According to the complementary questions with a holistic approach, the proportion of women who needed more information on the items presented seemed to be slightly larger than that of men (Table 3). However, the only statistically significant differences

between genders appeared in the areas of palliative care, with higher information needs among women ($p = .043$) and living in a relationship, with higher information needs among men ($p = .018$).

The set and order of priority of the 10 most often mentioned items of unmet information needs varied between genders (Table 3). The women's information needs more often concerned the areas of psychosocial well-being (social security, stress, anxiety and depression) and end-of life issues (palliative care and living will), whereas in terms of order of priority, the information needs of men were associated more with issues of daily living (relaxation, rehabilitation and management of daily tasks), living in a relationship and sexual life. Some issues were equally important for both men and women. Fatigue was the second most often mentioned item of unmet information needs by both men and women, while palliative care was also among the five most often mentioned items for both genders (Table 3).

TABLE 3 The 10 most often mentioned items of unmet information needs by gender.* The results of complementary questions with a holistic approach (N = 148–155)

Women (N = 79–83)		Men (N = 69–72)	
Items of self-management counselling	%	Items of self-management counselling	%
Palliative care	90.1	Relaxation	80.3
Fatigue and its symptoms	86.4	Fatigue and its symptoms	77.5
Social security	85.1	Different rehabilitation alternatives	77.5
Stress management	83.9	Living in a relationship	77.5
How to manage anxiety	83.5	Palliative care	77.2
Different rehabilitation alternatives	80.2	Effects of COPD on sexual life	76.1
How to recognize depression	79.0	Stress management	76.1
Relaxation	78.1	Social security	76.0
How to recognize anxiety	78.0	Daily activity for treatment of COPD	75.3
Living will	77.2	Management of daily tasks	74.7

*p-values: palliative care ($p = .043$) and living in a relationship ($p = .018$), others non-significant.

TABLE 4 The 10 most often mentioned items of unmet information needs by time since diagnosis. The results of the complementary questions with a holistic approach (N = 148–156)

1–5 years since diagnosis (N = 58–62)		6–10 years since diagnosis (N = 40–42)		Over 10 years since diagnosis (N = 50–52)	
Items of self-management counselling	%	Items of self-management counselling	%	Items of self-management counselling	%
Palliative care	85.2	Relaxation	87.5	Stress management	86.6
Social security	81.6	Sleep and rest	87.5	Fatigue and its symptoms	86.3
Meaning of exacerbation	78.7	Fatigue and its symptoms	85.4	Relaxation	84.7
How to recognize symptoms of exacerbation	77.4	Stress management	85.0	How to manage anxiety	84.6
Different rehabilitation alternatives	77.1	Palliative care	82.9	Social security	84.4
How to manage anxiety	75.8	Management of daily tasks	80.5	Palliative care	84.0
Living in a relationship	75.8	Living will	78.6	How to manage depression	82.7
Effects of COPD on sexual life	75.4	Energy conservation	78.1	How to recognize anxiety	82.7
Fatigue and its symptoms	75.4	Different rehabilitation alternatives	78.1	Different rehabilitation alternatives	82.4
Importance of social life	73.8	How to manage depression	75.6	Management of daily tasks	80.8

4.5 | Information needs by time since COPD diagnosis

When measured by the LINQ (the mean total and domain LINQ scores), there were no significant differences in information needs between different time periods (1–5, 6–10 and over 10 years) after COPD diagnosis.

According to the complementary questions with a holistic approach, the 10 most often mentioned items of unmet information needs remained fairly similar regardless of how long it had been since COPD diagnosis (Table 4). The only statistically significant difference existed in the area of recognizing anxiety ($p = .047$), which appeared on the list of top 10 items of unmet information needs only

at the time point of more than 10 years after diagnosis. However, the managing anxiety item was also on this list at both the 1–5 and over 10 years since diagnosis time periods.

However, the set and order of priority of the 10 most often mentioned items of unmet information needs varied by time since COPD diagnosis. During the first five years after diagnosis, information needs pertained more to managing exacerbations, social security, rehabilitation and living in a relationship than in subsequent years. Interestingly, palliative care was also considered to be more important as a subject in the first five years after diagnosis than later on in life. Even later, emphasis was increasingly placed on psychological well-being and managing daily life with COPD.

5 | DISCUSSION

This study demonstrated that people with COPD may have reasonably high information needs concerning a broad range of topics even after attending consultations with HCPs. The findings of previous studies suggest that many people with COPD neither receive timely and sufficient information (Russell et al., 2018) nor necessarily understand what their HCPs tell them about COPD (Disler et al., 2014). This indicates the need for COPD self-management counselling to be further developed in a more patient-centred direction.

The LINQ assessed the information needs of COPD patients regarding medical issues. The most important domain about which the respondents wanted more information was self-managing exacerbations. This is consistent with those of previous studies using the LINQ (Cleutjens et al., 2017; Jones et al., 2008; Sandelowsky et al., 2019; Scott et al., 2011). The need for information on self-managing exacerbations is understandable because breathlessness is one of the most common (Christensen et al., 2016; Eckerblad et al., 2014) and frightening symptoms of COPD (Disler et al., 2014; Hynes et al., 2012; Sigurgeirsdottir et al., 2019). Furthermore, breathlessness is associated with hospitalization and the fear of death (Russell et al., 2018).

In the present study, almost two-fifths of the respondents reported that they had not received any information about diet. Likewise, other studies have found that people with COPD face challenges when they attempt to receive relevant and understandable information about nutrition (Cleutjens et al., 2017; Hakami et al., 2018; Sandelowsky et al., 2019). This may be explained by the fact that many HCPs may not themselves possess sufficient knowledge about the links between diet and COPD and thus tend to avoid the topic. Additionally, HCPs' understanding of self-management has been described as narrow and primarily focused on exacerbations and medications rather than on promoting, for example, a good diet (Russell et al., 2018; Verbrugge et al., 2013). Counselling COPD patients on a healthy diet is important because many suffer from malnutrition or other nutrition problems (Collins et al., 2019). In addition, a healthy diet is beneficial with respect to comorbidities of COPD, such as metabolic and cardiovascular diseases (Schols et al., 2014).

Regarding the medical domains of self-management assessed by the LINQ, no clinically relevant differences in information needs by gender were found. Likewise, no differences in information needs by time since COPD diagnosis were detected. Furthermore, the authors were not aware of any previous studies looking at such differences in information needs assessed by the LINQ.

According to the complementary questions with a holistic approach, the need for information seemed to be high especially in terms of the psychosocial issues in COPD self-management. The proportion of respondents with unmet information needs remained high regardless of gender or how much time had elapsed since diagnosis of COPD. However, the set and order of priority of the issues about which respondents needed information did vary by gender and time.

Although there is a wealth of knowledge about gender differences concerning COPD as a disease and also a few studies about COPD patients' information needs, there is a paucity of published research on gender differences with respect to the information needs of COPD patients. To the authors' knowledge, the current study might be among the first in this field. The authors believe that the awareness of gender differences with regard to information needs is vital to ensuring the person-centredness of counselling.

In the current study, both men and women wanted to receive more information on fatigue. According to previous literature, almost one-half of both men and women who have been diagnosed with COPD suffer from chronic fatigue (Theander & Unosson, 2011; Todt et al., 2014). Due to its prevalence and extreme physical and mental burden on the daily lives of people with COPD (Kouijzer et al., 2018), fatigue is an important issue to be covered in COPD self-management counselling.

Palliative care was also among the five most often mentioned issues of unmet information needs among both men and women and even the most important issue among the women. Women also more often had information needs about other end-of-life issues, such as a living will. This may be explained by the greater symptom burden among women as compared with men, as women are more likely to experience severe dyspnoea at a younger age and are also more likely to have exacerbations than men (DeMeo et al., 2018; Di Marco et al., 2006).

Psychological issues like managing stress, anxiety and depression were among the most often mentioned areas of unmet information needs among women. This is in line with previous studies where female COPD patients were found to have higher levels of anxiety and depression than males (Di Marco et al., 2006; Jenkins et al., 2017). There has also been a stronger correlation between dyspnoea and depression in women than in men, likely contributing to worse symptom-related quality of life in women (Di Marco et al., 2006). The findings of the current study highlight the importance of covering the psychological aspects of living with COPD, especially in the self-management counselling of women. This is demonstrated by the elevated risk of suicide among people with COPD, especially among women (Sampaio et al., 2019).

The areas of self-management counselling about which men more often had unmet information needs included living in a relationship and sexual life. In spite of the importance of sexual life, especially for men with COPD (Collins et al., 2012), HCPs seem to be unprepared for dialogue. For example, it has been stated that nurses find it uncomfortable to speak with patients about their sexual health (Fennell & Grant, 2019). The need for COPD-specific teaching for HCPs, including regarding sexual activity, has been recognized (Blackmore et al., 2017).

Previous literature on changes in COPD patients' information needs over time is limited. The studies that do exist have concentrated mainly on the period of time during which diagnosis of COPD is made (Disler et al., 2014), with few—if any—studies having been conducted on potential changes in patients' information needs during the years thereafter. Although previous knowledge about COPD patients' unmet information needs with respect to

time since COPD diagnosis is accordingly limited, some comparisons can be made with what is known about information needs in different stages of the disease (GOLD stages I–IV). However, care must be taken when making such comparisons, as the concepts in question do not fully correspond, albeit to some extent, are parallel.

In the present study, the need for information on managing exacerbations was clearly evident, especially during the first five years after diagnosis. Part of the explanation for this is that one-third of COPD patients are diagnosed for the first time during the most severe stages of the disease (GOLD 2013 categories C/D; Raluy-Callado et al., 2015). Based on previous studies, it is also known that people with mild or moderate COPD have often experienced at least one exacerbation (Welte et al., 2015).

Regardless of the severity of COPD itself, being diagnosed has been described as “a breakdown of life” (Lindgren et al., 2014) or as a turning point of life (Bragadottir et al., 2018). During this time, many patients reflect on their future, on disease progression, on the possible need for long-term oxygen and of course on their mortality (Arne et al., 2007). With this in mind, it is understandable that in the present study, palliative care was the first among the 10 most often mentioned areas of unmet information needs within the first 5 years of diagnosis. Furthermore, the other areas of unmet information needs, within the first 5 years of diagnosis, such as social security (livelihood), rehabilitation and living in a relationship, were all representative of a scenario where a person is newly diagnosed with a chronic illness and is attempting to adapt to living with it.

Based on the results of this study, it seems that after 10 years have elapsed since COPD diagnosis, the need for physical and psychological adaptation to the restrictions caused by the disease begin to play a larger role. Fatigue and having adequate rest, on the one hand and the attempt to maintain physical functioning and independence through, for example rehabilitation, on the other, were key areas of unmet information needs. Maintaining psychological well-being seemed to be particularly challenging and more often information on stress, anxiety and depression was needed. Similar results have been obtained in studies on the severe or very severe stages of COPD, where people with COPD have described their lives as being limited by restrictions on leisure and social activities and fears of COPD progression (Gabriel et al., 2014). At these stages of the disease, people with COPD and their relatives have been reported to experience unmet psychosocial and existential needs (Ek et al., 2015).

The results of this study reinforce the notion that while initial information is important, self-management counselling should be continued throughout the lives of COPD patients in consideration of their changing information needs.

5.1 | Strengths and limitations

This study has two strengths. Along with the validated LINQ, complementary questions based on an extensive literature search were

used in the study to cover non-medical issues in COPD self-management counselling in addition to medical ones. Also, the study used self-reported data, which is valuable in that it provides information from the viewpoint of the patients. As a result, the perspective taken by the study was patient-centred and more holistic than that selected by previous studies.

This study also had some limitations. First, the recruitment of participants via a webpage may have been biased in favour of people who use the Internet and thus presumably the younger ones. In Finland, however, three-quarters of people at the age of 65–74 use the Internet (Statistics Finland, 2018). In this study, 64% ($N = 103$) of the respondents were more than 65 years old and the age of the oldest respondent was 83 years. Hence, we can suppose that age has not been an obstacle to participation for people with COPD. Second, as the data were self-reported, the question remains as to whether all the respondents really had a diagnosis of COPD. However, it was assumed that the proportion of participants without a physician-confirmed COPD diagnosis was small, as the results of the LINQ in the current study were very much compatible with those in previous studies (see Table 2) where the diagnosis of COPD among the participants was confirmed.

6 | CONCLUSIONS

COPD self-management counselling should be based on the information needs of the individual patient and should also consider the patient's gender and the time since diagnosis. Particular attention should be paid to the often neglected psychosocial areas of living with the disease. A holistic instrument for the measurement of the information needs of people with COPD is therefore needed.

ACKNOWLEDGEMENTS

The authors want to thank all the respondents for participating in this survey. H.S. is funded by Tampere Tuberculosis Foundation, Tampere, Finland.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

AUTHOR CONTRIBUTIONS

Study design: HS, MK, EP. Data collection: HS. Data analysis: HS, HH. Data interpretation: HS, TA. Draft of the manuscript: HS, TA, EP. Manuscript revision and approval of the submitted version: HS, TA, HH, MK, EP.

DATA AVAILABILITY STATEMENT

Research data are not shared because permission for sharing is not requested from those people with COPD who participated in this study.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

How to cite this article: Siltanen H, Aine T, Huhtala H, Kaunonen M, Paavilainen E. The information needs of people with COPD—The holistic approach with special reference to gender and time since diagnosis. *Nurs Open*. 2021;00:1–11. <https://doi.org/10.1002/nop2.773>