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ORIGINAL PAPER

Patients' perspectives on a nurse led self-management intervention after acute exacerbation of COPD

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Abstract

Aim: Patients living with chronic obstructive pulmonary disease (COPD) are challenged with managing the medical, social, and emotional consequences of the disease. Self-management of the disease plays a major role in actively preventing a deterioration such as an acute exacerbation (AECOPD). The aim of this study was to explore patients' perspectives on self-management, for both participants who received a complex multicomponent behavior-focused intervention (e.g., physical activity) after hospitalization (intervention group) and participants who did not (control group). *Design:* A qualitative descriptive study design was used. *Methods:* Semi-structured one-to-one interviews were conducted (n = 10). A newly implemented counselling program conducted by an Advanced Nursing Practice (ANP) care team was introduced as part of the study. Participants in the control group received standard treatment for hospitalized AECOPD, while the intervention group received counselling focused on patient self-management from the ANP care team over a 13-week period. Control and intervention group narratives were compared using framework analysis. *Results:* The predominant four topics in both groups were deducted from Lorig's conceptualization of self-management. These were: the management of burdensome emotions, the management of life roles, the management of medical regimen and recommendations, and the perception of self-management needs. The participants in the intervention group reported that counselling by the ANP team helped motivate them to sustain physical activity. They also found it reassuring to have a contact person they could easily reach out to in case of any queries or uncertainties, which provided them with a sense of security. *Conclusion:* There is a need for support in several areas of self-management after hospitalization for AECOPD. The newly introduced nurse-led self-management support was immediately well-received. Indeed, all participants appreciated the contact with their respective health professionals.

Keywords: Advanced Practice Nursing, COPD, exacerbations, nursing, self-management.

Introduction

Patients living with a chronic condition are challenged with managing the medical, social, and emotional consequences of the disease (Lorig & Holman, 2003). In chronic obstructive pulmonary disease (COPD), patients struggle to cope with the consequences of breathlessness in their daily lives (Sigurgeirsdottir et al., 2019). Patients' self-management, in particular health behaviors such as smoking cessation, physical activity, and exacerbation management influence the course of the disease (Global Initiative for Chronic Obstructive Lung Disease [GOLD], 2023). As a consequence, care models that support patient health behavior have been widely implemented and have demonstrated a positive impact on quality of life (QoL) and respiratory-related hospitalization (Schrijver et al., 2022). Through targeted promotion of self-management skills, affected individuals can be motivated and supported to feel confident in dealing with COPD and in recognizing the onset of an acute exacerbation of COPD (AECOPD) (Cravo et al., 2022). In this context, both

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the maintenance of exercise habits and the impact of COPD on social life are considered major challenges (Sigurgeirsdottir et al., 2019). As COPD progresses, symptoms and self-management needs may undergo change (GOLD, 2023). Therefore, self-management counselling should address the individual needs of the person affected (Barrecheguren & Bourbeau, 2018).

The existing evidence and knowledge regarding the significance of health behavior and its impact on patient outcomes in individuals with COPD needs to be made available to those affected. To transfer this knowledge to patients who are hospitalized due to an acute exacerbation of COPD, a hospital-initiated nurse-led integrated care program focusing on behavior change was developed and implemented using the Behavior Change Wheel (BCW) (Michie et al., 2014). The BCW is a practical resource used for developing behavior change interventions by considering the contextual factors that influence the behavior (Michie et al., 2011). The intervention is provided by an interprofessional team during hospitalization for AECOPD and then continued by an advanced nursing practice (ANP) care team with telephone or in-person contact every one to two weeks for at least three months (Schmid-Mohler et al., 2022).

Although a behavior-focused intervention is recommended, based on scientific evidence (GOLD, 2023), patients may experience it as challenging, particularly those with hospital-admitted AECOPD who are older, have a higher symptom burden (Hartl et al., 2016), and lower lung function (Hartley et al., 2020). Given these traits, this patient subgroup may find behavior change even more challenging than stable patients since their symptom burden, already high, may be further aggravated by implementing the behavior. For example, establishing a more physically active lifestyle may increase dyspnea or exhaustion in the beginning (Reijnders et al., 2019), or smoking cessation may initially affect psychological wellbeing (Paine et al., 2019). As a consequence, the program's focus on health behaviors may have undesired side-effects, including worry about making the behavior change or guilt or shame with regard to maintaining the behavior (Aumann et al., 2016).

Given these challenges and influencing factors, it was not clear how patients would experience the newly developed intervention focused on behavior change. To gain an initial insight, the implementation process was accompanied by an exploration of patients' experiences and needs regarding their self-management before and after the implementation of the complex multicomponent intervention.

Aim

The aim of the study was to explore patients' perspectives on self-management, for both participants who received a complex multicomponent behavior-focused intervention (e.g., physical activity) after hospitalization (intervention group) and participants who did not (control group).

Methods

Design

A qualitative descriptive design using individual semi-structured interviews was adopted. Patient narratives from the control and intervention groups were compared using Framework Analysis (Ritchie & Lewis, 2003; Ritchie & Spencer, 1994). The overarching objective of framework analysis is to systematically identify, describe, and interpret core patterns within individual cases and overarching themes within the phenomenon under investigation. In this study, we compared patient narratives across various characteristics (e.g., stage of COPD) and distinct groups (e.g., control and intervention).

The three core tasks in self-management (Lorig & Holman, 2003) were used as the theoretical framework for data collection and analysis. These tasks entailed management of burdensome emotions, life roles, and medical regimen and recommendations.

A further strength of framework analysis is that it allows a combination of deductive and inductive approaches (Gale et al., 2013). By merging deductive reasoning through use of the core tasks in self-management (Lorig & Holman, 2003) as a deductive framework, with inductive exploration, this approach not only validates existing theories but also facilitates the discovery of fresh insights, fostering a comprehensive understanding of the subject matter. Its adaptability enables a balanced evaluation that encompasses both predetermined frameworks and emerging themes, thereby shedding light on concealed intricacies within the data (Goldsmith, 2021).

The study was embedded in the study "Nurse-led integrated care to improve quality of life in COPD patients with a pulmonary exacerbation" (NICCO), which was approved by the Ethics Committee of the Canton of Zurich (www.kofam.ch, SNCTP000003402). Participants signed a consent form for the NICCO study, which included participation in the interview. Data collection in the NICCO study lasted from July 2019 until March 2023, with the implementation of the intervention in June 2020.

Study participants in the control group who were hospitalized with AECOPD before June 2020 received routine treatment, which did not involve any systematically implemented self-management support. In June 2020, participants in the intervention group were assigned to an ANP care team, in addition to their usual treatment. The ANP team visited the participants during their hospital stay and followed them up for three months, predominantly by telephone. At each visit, the ANP assessed the patient’s behavior, needs, and concerns regarding management of dyspnea, exacerbation management, physical activity, smoking, vaccination recommendations, medication adherence, long-term oxygen, healthy diet, and management of illness-related emotional distress. On the basis of the assessment, the APN provided education and counselling according to the intervention manual and by using Motivational Interviewing Techniques (Schmid-Mohler et al., 2022).

Sample

The study was conducted between October and December 2020 at University Hospital Zurich in Switzerland.

The sample included a subgroup of ten participants from the NICCO study before and after implementation of the newly developed intervention who had agreed to participate in an additional interview and were able to be interviewed in German. The sample for the intervention group had completed a three-month follow-up with the ANP team in the previous nine months.

Criteria for the NICCO Study were: hospitalization due to an AECOPD, diagnosed COPD (GOLD Stages 1 to 4), at least 18 years of age, and no cognitive impairment (Mini-Cog Assessment < 3) for participation in the interview.

For this qualitative study, which was embedded in the NICCO study, a purposive sample was selected using the following two criteria: a) group classification (intervention / control group) and b) assessment of quality of life during the first three months after AECOPD (improvement / stable / deterioration). For criteria b, health-related quality of life was assessed as part of the NICCO study using the Chronic Respiratory Questionnaire (CRQ) according to the procedure defined by the developers (Guyatt et al., 1987). The NICCO study used the self-administered version of the standardized questions on dyspnoea (SAS). The questionnaire was developed for patients with chronic airflow limitations and comprises 20 items assessing four domains: 1) dyspnea, 2) fatigue, 3) emotional function, and 4) mastery. The scoring scale ranges from 1 (extreme) to 7 (not at all) and was assessed with a recall period of the previous three months. To perform purposive sampling in this study, the score for each of the four domains (sum of items / number of items) was calculated. The differences between the scores at baseline and week 13 for each domain were then calculated. Participants were grouped into three categories based on these differences: improvement (higher QoL at week 13 in all four domains), stable (higher QoL in some of the four domains and lower QoL in the remaining domains), and deterioration (lower QoL at week 13 in all four domains).

Data collection

For all patients who met the study criteria, the change in quality of life over the past 13 weeks was calculated and they were grouped into one of three categories: improved, stable, or deteriorated. From each group (intervention and control), five patients were selected, ensuring at least one patient per QoL category.

Patients were contacted and asked by a research assistant if they were willing to be interviewed. By this means, verbal re-confirmation of the written informed consent was established. All patients re-confirmed their willingness to participate in the interview.

The researcher (first author), who did not know the patients beforehand, conducted the interviews at the respondents’ homes or by telephone, according to their preference. The interview guide was based on the three core tasks in self-management according to Lorig and Holman (2003), and the perception of self-management needs (Table 1).

Clinical data were retrieved from the hospital information system for the description of the study participants (age, sex, FEV1 [%], GOLD stage, O2 requirement, CRQ score, smoking status, and most recent hospitalization).

Data analysis

The audio-recorded interviews were transcribed verbatim. QSR NVivo 1.0© served as the qualitative software data program for analysis. The data were analyzed using framework analysis (Ritchie & Lewis, 2003). In the first step, the first author familiarized himself with the data by repeated reading of the transcripts. In the next step, transcript

Table 1 Interview guide

Introduction
- How did you experience your last hospital stay due to a 'lung attack'?

Management of burdensome emotions
- How did you experience the hospital stay? How would you describe it in one word?
- How did you experience the care of the treatment team in this situation? How supported did you feel in dealing with COPD?
- How did you feel after hospital discharge?

Management of life roles
- What specific challenges do you face in your daily life and surroundings because of your COPD?
- How does COPD affect your ability to participate in social activities? How are you supported by your environment in managing these challenges?
- How would you evaluate the support / advice you received from the treatment team in this area?

Management of medical regimen and recommendations

Knowledge regarding COPD
- What do you do or what do you pay attention to in everyday life in connection with COPD?
- How would you evaluate the support you received from the treatment team in this area?

Physical Activity
- How do you manage to be physically active? How would you evaluate the support / advice you received from the treatment team in this area?

Smoking cessation
- Do you smoke?
- If yes: Have you already tried or considered quitting smoking? What support do you think you would need to quit smoking?
- If no: Did you smoke in the past? If yes: What has helped you to quit smoking? How do you manage to be physically active? How would you evaluate the support / advice you received from the treatment team in this area?

Exacerbation management
- How informed do you feel about how to manage and prevent future lung attacks?
- How confident did you feel about early detection of a lung attack? What helps you to recognize it?
- How do you manage to be physically active? How would you evaluate the support / advice you received from the treatment team in this area?
- What else would you need to feel safer or more confident?

Perception of self-management needs

Control group
- Imagine you could receive counselling / care to help you deal with the disease in everyday life, what expectations would you have of this service?
- Which topics or questions would you want to see addressed?

Intervention group
- Which topics were addressed: according to your needs / too little / not at all? Which topics would you have liked to discuss in more detail?
- If you were to receive this support again, where do you see a need for action?
- What has particularly helped you?
- Would you recommend counseling to other people with COPD? If yes, why? If no, why not?

Conclusion
- What are your hopes for the future?

passages were aligned to the four deductively derived self-management categories (management of burdensome emotions, management of life roles, management of medical regimen and recommendations, and perception of self-management needs) and subcategories in the area of management of medical regimen and recommendations (knowledge of COPD, physical activity, smoking cessation, and exacerbation management). A framework matrix was created showing a row for each individual and a column for each category and / or subcategory. The respondents' statements associated with each category were summarized in the corresponding cell. The summarized statements of participants from the control group and the intervention group were compared and examined for similarities and differences. To increase reliability, independent segmental coding was performed by the last author, and differences were discussed.

Results

As part of this study, ten semi-structured individual interviews were conducted with seven men and three women. Three interviews were conducted at individual subjects' homes (KG1, KG2, IG5) and seven by telephone (KG3, KG4, KG5, IG1, IG2, IG3, IG4). The interviews lasted between 31 and 85 minutes (a mean of 49 minutes). During the interviews, participants were offered short breaks and asked questions about their respiratory well-being. In the intervention group, all patients had end-stage COPD (GOLD 4), while the GOLD stage of the patients in the control group varied across all four stages. Further characteristics of the respondents are described in Table 2.

Table 2 Sample characteristics (n = 10)

ID	Age	Sex	FEV1 [%]	GOLD	Long-term oxygen	Change in QoL over 3 months (CRQ)[a]	Smoking status	Group assignment	Last hospitalization due to AECOPD
KG1	72	w	39	3	no	deterioration	no	control	October 2019
KG2	70	m	65	3	no	improvement	no	control	December 2019
KG3	60	m	31	4	yes	deterioration	no	control	February 2020
KG4	68	m	92	1	no	stable	no	control	January 2020
KG5	64	m	57	2	no	stable	no	control	October 2019
IG1	69	w	18	4	yes	deterioration	no	intervention	July 2020
IG2	49	m	27	4	yes	deterioration	no	intervention	August 2020
IG3	79	w	34	4	yes	stable	no	intervention	March 2020
IG4	67	m	18	4	yes	stable	no	intervention	March 2020
IG5	69	m	12	4	yes	improvement	no	intervention	June 2020

Note: (CRQ)[a] score comparing CRQ scores at time of hospitalization due to AECOPD to scores three months after hospitalization. Improvement: improvement in one to 4 scores and stable in the others. Stable: part of the scores improves and part of the scores worsens. Deterioration: deterioration in one to all 4 scores and stable in the others.

Management of burdensome emotions

All participants reported that living with COPD involved burdensome emotions. They reported feelings of helplessness, loss, and not feeling safe, as well as fear due to dyspnea.

Three respondents in the control group and one in the intervention group mentioned fear of contracting another respiratory infection, including COVID-19. They feared a rapid deterioration in health and not being able to recover if they experienced another AECOPD. One respondent in the intervention group expressed fear of shortness of breath when walking unaccompanied. Consequently, the individual rarely left the house alone. Four respondents in the control group and two in the intervention group expressed uncertainty about the course of COPD. One respondent in the intervention group with end-stage COPD experienced feelings of powerlessness because he could not do anything to maintain a stable condition: *"Not quite helpless, but somehow, still kind of powerless. I don't expect it to get any better and that's why I have to see that what I still have still kind of works for me"* (IG4). He saw no option but to accept his condition.

In sum, burdensome emotions arose mainly from fear of infections and uncertainty about the future and were mentioned more often by patients from the control group.

Management of life roles

Three respondents in the control group and five in the intervention group mentioned that COPD had an impact on their participation in social events. Spontaneous outings or appointments were especially difficult since they needed breaks during the activity or were dependent on a slow pace of activity. Two respondents in the control group stated that they were no longer able to pursue activities in their leisure club as a result: *"I had to say that I simply couldn't do it anymore. I no longer have the strength to do that. I no longer have the breath to do it"* (KG3). One respondent in the control group spoke of feelings of shame when people on the street stared at him because of his oxygen device. Only two people in the control group said that COPD did not have a major impact on their social life since they already lived a secluded life. Nevertheless, they tried to stay in touch with their social circle by actively initiating contact from their side. Four individuals in the intervention group reported that the impact of COPD on their social life was discussed in the ANP counselling session.

All bar one respondent from the intervention group stated that they received help regularly from their partners or relatives in managing everyday life. This support was perceived as valuable. At the same time, two respondents in the control group and one in the intervention group reported that they did not want to be a burden on their relatives and sometimes denied having complaints or tried to keep them hidden: *"I always say I'm fine. Even when I'm feeling bad"* (IG5). All respondents in the intervention group stated that possibilities for support in everyday life were discussed during the care consultation, which was perceived as reassuring. Three individuals in the intervention group indicated that they learned of new sources of support, which they would consult in future, if necessary.

In both groups, participants described the significant impact of COPD on their daily lives and social activities and highlighted the importance of social support in daily life. Participants in the intervention group mentioned the positive effect the care consultation had had on their emotional state and their knowledge regarding resources available.

Management of medical regimen and recommendations

Knowledge regarding COPD. All respondents felt well informed about COPD. This knowledge had developed over the years through living with COPD. Discussions with various health professionals, training courses on COPD, and their own searches on the internet increased this knowledge.

In the intervention group, all respondents reported that they had received additional information on COPD during the ANP care consultations. In addition, challenges of everyday life had been discussed, which the participants considered helpful and beneficial.

Physical activity. All respondents – in the intervention and control group – reported an ongoing struggle with integrating exercise training into daily life. Respondents found it difficult to sustain motivation to exercise or go for a walk. COPD-related fluctuations in well-being, as well as the fear of developing a dyspnea attack, also affected exercise training. All patients in the intervention group reported restrictions in physical activity outside the home, in terms of time or distance. One reason for these restrictions was their dependence on oxygen. They reported that the ANP care team provided ongoing support and motivation by suggesting ways to increase activity. All patients perceived this as beneficial. Two respondents in the intervention group mentioned being able to keep up their training thanks to exercises demonstrated by the physiotherapist or ANP and the material provided online – both features of the NICCO-intervention. Two interviewees from the control group and two from the intervention group were supported by their relatives in exercising: *"Every day I go for a walk with my wife for at least an hour"* (KG4).

All participants reported difficulties in incorporating exercise into their daily routine, while the participants in the intervention group perceived the ongoing care counselling to have assisted them in maintaining motivation.

Engaging in discussions and being able to talk openly about the difficulties with the ANP while exploring strategies and receiving comprehensive explanations and various exercise options benefited the participants in the intervention group. Participants stated that the exercises demonstrated and taught to them could be applied in their daily lives. Using this knowledge to self-motivate was effective, and the patients felt encouraged to undertake more activities.

Smoking cessation. All respondents had smoked in the past but were no longer smoking at the time of the interview. No participant quit smoking during the program.

Exacerbation management. All respondents in the intervention group and three in the control group felt confident in recognizing an AECOPD. Recognition was described as a learning process, primarily based on experience gained from previous exacerbations: *"Actually just experience. Yes, because I've already had a few major and minor exacerbations"* (IG3). Some patients reported that they had assessed the AECOPD as less severe than the health professionals. In some cases, the symptoms were perceived as not serious enough, therefore initiation of action was delayed: *"Yes, I noticed that I just wasn't feeling that well, but I didn't see it as meaning I needed to go to the hospital right away"* (IG4). Three respondents in the control group and two in the intervention group reported that their relatives had also noticed the onset of an AECOPD. In two cases, the relatives had initiated the necessary steps.

Five respondents in the intervention group and three in the control group reported having a written exacerbation action plan. They felt confident about using it. It conveyed a sense of security and gave them the feeling that they were equipped to react promptly if an exacerbation occurred. Respondents with action plans felt confident in their ability to contact a health professional if they were unsure or unclear about how to handle AECOPD. For the participants of the intervention group, support in reacting in an adequate manner was predominantly provided by the ANP care team. It filled them with pride when they initiated actions independently and a consultation was thus prevented: *"Then I took these tablets, i.e., according to this plan, and then I didn't have to go to the doctor and didn't have to go anywhere and it went well again afterwards"* (IG1). Two individuals in the control group reported not having an action plan and contacting a health professional when they had a complaint.

Participants from both groups reported that an action plan provided them with a sense of security, which they described as a feeling of safety and confidence in managing COPD. In contrast to the control group, all participants in the intervention group received a written action plan. They stated that they appreciated the opportunity to have a low threshold contact person who could evaluate their symptoms.

To summarize, as regards COPD management, all respondents in the control group and three in the intervention group expressed confidence in dealing with COPD and in their own abilities to manage COPD. Two respondents in the intervention group reported having little confidence in their own abilities and were therefore glad of the support they received. All respondents in the intervention group reported that the care advice and guidance received had been motivating and had helped them to feel more confident in dealing with COPD: *"Yes, this advice simply gives you motivation"* (IG5).

Perception of self-management needs

All respondents were in regular contact with a health professional. For all of the patients, this was their pulmonologist or general practitioner. The respondents in the intervention group also had contact with the ANP care team. All respondents valued the contact with the relevant health professional. They reported that the counselling provided them with a sense of security. The proactive phone calls of the ANP care team also helped to check the effectiveness of the self-management. The information was perceived as credible, since it came from a specialist: *"It is also reassuring because these are people who know what they are talking about"* (IG1).

All those in the intervention group regarded the regular contact with the ANP care team and the exchange of information about their condition very positively. They appreciated the nursing care team being aware of their health situation and felt that they were taken seriously. The respondents also liked the fact that professionals had taken the time to listen to their concerns and that the measures and decisions were taken jointly. The ease of contact and the possibility of being able to ask questions at any time increased the confidence of those affected: *"That is reassuring. Yes, I say that. Because you have someone who cares about you, who is interested in you"* (IG5). All respondents in the intervention group stated they would recommend the care consultation to others.

In addition, participants in the control group mentioned having trust in their pulmonologist or general practitioner and felt well supported in their self-management needs. They felt that they could discuss the topics with the specialists and did not mention the need for additional action or counselling.

Discussion

The study describes the patients' experience of their self-management before and after the implementation of a self-management intervention and reveals that patients with COPD experience all three core tasks of self-management as described by Lorig and Holman (2003): management of burdensome emotions, life roles, and medical regimen and recommendations.

When the narratives of the intervention and control groups were compared, notable distinctions emerged in the particular experiences of managing COPD-related challenges: more individuals in the control group reported experiencing burdensome emotions, notably fear of infections and uncertainty regarding the future, while the intervention group faced similar challenges but with less frequency. Moreover, the intervention group actively sought new sources of support and discussed the impact of COPD on social life during ANP counselling sessions. Two individuals in the control group had not received a written action plan for exacerbations and relied primarily on general healthcare providers without seeking further support or counselling. In contrast, all those from the intervention group had structured action plans, received ongoing personalized support from the ANP care team, and found the care consultations beneficial in managing COPD effectively. These distinct patterns between the groups underscore the influence of personalized support and tailored interventions in enhancing COPD management and emotional well-being.

The concern that patients may be additionally burdened by the self-management intervention with negative feelings of fear, shame or guilt was not confirmed. One reason may be that the patients perceived the behavior change intervention they received as having been modelled on their everyday situation, integrating the individual choices and obstacles faced by patients. Acknowledging the patients' feelings and providing them with sufficient time may have positively affected patients' acceptance of the behavior-focused intervention (Baker & Fatoye, 2019; Giacomini et al., 2012; Mousing & Lomborg, 2012; Russell et al., 2018). Another reason may be that all participants in the intervention groups were no longer active smokers. A previous study indicated that in smokers with COPD the prevalence of psychological comorbidities is 23.6% compared to 9.3% in smokers without COPD (van Eerd et al., 2015). Consequently, a future observation of the effect of the intervention on smokers is required.

An important finding was that patients in the control group did not have the impression of lacking any kind of support. All patients who received routine care reported having regular and trustful contact with their pulmonologist or general practitioner. Straightforward and low-threshold access to a health professional is generally of great importance for people with COPD (Stokes et al., 2019), and was already provided by their usual care team. This may indicate that such patients have less or no need for additional support from an ANP care team. Nevertheless, it is notable that all patients in the intervention group valued the additional support of the ANP team. The predominant feeling regarding the counselling was the sense of security it provided. One reason may be that all patients in the intervention group suffered from GOLD 4 and were partially house-bound, although able to leave the house spontaneously, albeit with an oxygen device. A proactive phone call may therefore serve as a connection to the outside world, providing a sense of being cared for and not forgotten (Early et al., 2019; Hoaas et al., 2016). This may indicate that patients with progressed COPD in particular have emotional needs that can be met by ANP care counselling, providing a sense of safety (Leine et al., 2017).

Eight respondents in the study felt able to recognize an AECOPD. The literature recommends a plan of action to encourage early intervention in the case of AECOPDs, which has been shown to reduce the impact of an exacerbation on the health status of the affected person and to accelerate recovery (Hegelund et al., 2020; Howcroft et al., 2016; Lenferink et al., 2017). Eight respondents in this study reported having a plan of action which they valued and felt gave them the confidence to initiate measures independently. Two patients in the control group had no action plan and did not express a need in this regard. One explanation for this may be that the patients had a very low-threshold approach to the pulmonologist and therefore did not experience any further needs. Or alternatively, it might be that the patients did not know that a written action plan is recommended as standard care and thus did not require one. The creation of a written exacerbation action plan is recommended regardless of the patient's relationship with healthcare professionals (GOLD, 2023). This is important since the pulmonologist or general practitioner is not usually available at night or on weekends. Patients' independent self-management is important and promotes safety, as has been highlighted narratively in this study and confirmed by quantitative research (Lenferink et al., 2017).

The patients in this study describe the extensive impact of COPD on their social lives. In line with earlier studies, relatives were a resource for those affected and provided support in coping with everyday life and self-management (Korpershoek et al., 2016; Sigurgeirsdottir et al., 2019). However, the affected individuals in this study, as well as in a study by Johansson et al. (2019), did not want to be a burden on their relatives. Therefore, it is necessary to include these issues in counselling to support the affected individual in dealing with these aspects of the disease. As counselling continues to be further developed, consideration should be given to the inclusion of relatives. In line with Tumilty et al. (2020), our participants also described social withdrawal primarily occurring due to functional symptoms, with the COVID-19-pandemic and the threat of infection further aggravating withdrawal (McAuley et al., 2021; Mousing & Sørensen, 2021).

Anxiety and uncertainty often follow after AECOPD (Martínez-Gestoso et al., 2022), which can result in low confidence and can affect self-management negatively (Rahi et al., 2023). In earlier studies, nurse counselling was experienced as helpful in promoting self-confidence in the ability to manage COPD (Baker & Fatoye, 2019). Therefore, additional support after an AECOPD may be especially important. Patients perceived the support of physical activity as motivating. As studies of people with COPD have described, maintaining regular exercise training after AECOPD also posed a major challenge for respondents in this study (Janaudis-Ferreira et al., 2019; Thorpe et al., 2014). In line with earlier studies, the participants in the present study appreciated the benefits of professional guidance in maintaining physical activity (Janaudis-Ferreira et al., 2019; Stewart et al., 2014; Thorpe et al., 2014). This perception is promising and indicates that care counselling, such as that received by the intervention group, may effectively support affected individuals in continuing exercise training in the future (Baker & Fatoye, 2019; Wang et al., 2020).

The study has certain limitations: no participant was an active smoker, consequently this perspective is lacking. Secondly, the GOLD stage between the intervention and control groups differed, resulting in a control group with less progressed COPD – this may have led to additional differences in the narratives. Thirdly, in order to safeguard the study participants from contracting COVID-19, certain interviews were conducted via telephone. On the other hand, data collection through telephone interviews did not reveal any degradation in data quality or discernible impact on respondents' willingness to provide responses. Generally, it should be noted, that all participants of this study participated in the NICCO study and are fairly well motivated patients. The results may have been different if patients who declined study participation had been included. Despite the limitations, the study provides an initial insight into how patients experience a nurse-led intervention.

Conclusion

Patients with COPD find self-management tasks challenging. The low-threshold nurse-led intervention was well received, providing patients with end-stage COPD with a sense of security. They felt more confident in coping with COPD and initiating measures in the event of an AECOPD. Patients who suffered from less progressed COPD and who already had trustful and regular contact with a pulmonologist or general practitioner did not express a need for additional support. Further research is needed to investigate more closely the benefits of this type of care advice.

Ethical aspects and conflict of interest

This study was embedded in the study "Nurse-led integrated care to improve quality of life in COPD patients with a pulmonary exacerbation" (NICCO), which was approved by the Ethics Committee of the Canton of Zurich (www.kofam.ch, SNCTP000003402). The authors declare there are no conflicts of interest.

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Author contributions

Conception and design (LU, GSM), data analysis and interpretation (LU, GSM), manuscript draft (LU, GSM, CH), critical revision of the manuscript (DHS, CH, CFC), final approval of the manuscript (LU, GSM).

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