

# Information needs of older patients living with chronic obstructive pulmonary disease (COPD) indicated for a specific geriatric rehabilitation programme: a prospective cohort study

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## Abstract

**Background:** Post-acute rehabilitation is recommended in the treatment of chronic obstructive pulmonary disease (COPD). It enhances the sense of control by education, which should focus on patient information needs. However, it is unknown whether a geriatric rehabilitation programme for older patients with advanced COPD and severely impaired health status (the GR-COPD programme) does fit these patient information needs. **Objectives:** The study aimed to identify the information needs of patients who were eligible for the GR-COPD programme, and investigated if health-related knowledge improved during rehabilitation. **Methods:** All patients indicated for the GR-COPD programme were eligible for this study. The information needs were measured with the Lung Information Needs Questionnaire (LINQ). **Findings:** The 158 patients (mean age 70.8 years; FEV1 %predicted: 35.5) showed relatively high baseline information needs (mean LINQ overall score: 8.6 [SD 3.1]), with the greatest need in the domains 'diet' and 'self-management'. After follow-up, the mean LINQ overall score significantly improved in patients who completed the GR-COPD programme ( $p=0.001$ ). **Conclusion:** Patients' knowledge showed a statistically significant improvement in some areas during the GR-COPD programme.

**Key words:** ● Advanced COPD ● Geriatric rehabilitation ● Pulmonary rehabilitation ● Self-management ● Health status

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Chronic obstructive pulmonary disease (COPD) is a progressive life-threatening lung disease that is characterised by persistent airflow limitation and chronic inflammation of the airways. The prevalence of COPD is rising and it is expected to become the third leading cause of death worldwide in 2030 (World Health Organization, 2002; 2013). Patients with COPD suffer from a high burden of symptoms, impairment of functional capacity and a declining quality of life (Yohannes et al, 1998; Wakabayashi et al, 2011; Chen et al, 2018).

Pulmonary rehabilitation (PR) is a recommended approach in the treatment of COPD (McCarthy et al, 2015). PR relieves symptoms, improves psychological wellbeing and enhances the sense of control that individuals have over their condition (Bourbeau et al, 2004;

McCarthy et al, 2015; Cannon et al, 2016; Vogelmeier et al, 2017). PR contains many components (Murphy et al, 2017), of which education and self-management interventions are an important part. It is important for patients to understand their disease and develop healthy behaviour patterns which can reduce their disabilities (Bourbeau et al, 2004), and increases their competence in managing their disease (Cannon et al, 2016). In contrast to an education programme, which assumes knowledge alone will lead to a behaviour change, self-management interventions focus on greater responsibility for healthcare decisions by increasing patients' confidence and competence in managing their disease (Bourbeau and van der Palen, 2009; Lavoie et al, 2015; Cannon et al, 2016). Providing a combination of education and self-management empowers the patient to partake in

the self-management intervention (Cannon et al, 2016). Without improvement of lung function, significant reductions in dyspnoea can still occur (Wakabayashi et al, 2011; Zwerink et al, 2014; Lenferink et al, 2017).

Successful self-management interventions can improve health status of COPD patients (Zwerink et al, 2014). However, successful use of self-management techniques is more likely in younger patients and those not living alone (Bucknall et al, 2012). In older patients with specific problems associated with ageing, such as multi-morbidity and the need to talk about end-of-life care, the impact of self-management on health status is less clear (Bachmann et al, 2010). These patients often suffer from concurrent diseases and complications interfering with the rehabilitation treatment, which raises the risk for dropout during PR (Cleutjens et al, 2017). Therefore, a geriatric rehabilitation (GR) programme, which integrates rehabilitation with palliative care aspects, specifically designed for older patients with advanced COPD and severely impaired health status (the GR-COPD programme), has been developed, implemented and evaluated (van Dam van Isselt et al, 2013; 2014; 2019).

Scott and colleagues (2011) conducted a study in older patients with moderate-to-severe COPD who received information about their disease. After education, there was still an expressed need for more information on salient self-management strategies. Patients differ in terms of depth and type of information they seek (Hyland et al, 2006). Patient information needs show the aspect of education that requires attention, whereas clinician-defined information needs provide a more limited focus (Hyland et al, 2006). Therefore, an education programme should focus on patient information needs. However, it is not known whether the GR-COPD programme addresses these patient information needs. The aim of the present study was to investigate:

- The patient information needs of older patients with COPD and severely impaired health status, who were eligible for a GR-COPD programme
- If the GR-COPD programme enhanced health-related knowledge in these patients.

## Methods

### Design

This prospective cohort study investigated the patient information needs of older patients with COPD and severely impaired health status, eligible for the GR-COPD programme. The study was conducted in the pulmonary department of two hospitals. After the required written

informed consent had been obtained, the baseline data (T0) were collected from questionnaires and from the patients' files during their hospital stay. After three months of follow-up (T1), the patient information needs and health status were measured again during a hospital visit. Data were collected between January 2015 and December 2017. The medical ethics committee of Leiden University Medical Centre approved the study (P14.248) and the study design was registered in the Netherlands National Trial Register (NTR6261). The effectiveness study has been recently published (van Dam van Isselt et al, 2019).

### Setting and participants

Patients with moderate (Global Initiative for Chronic Obstructive Lung Disease (GOLD) (Vogelmeier et al, 2017) stage 2) to very severe (GOLD stage 4) COPD, admitted to the pulmonary department of two hospitals in the Netherlands for an acute exacerbation, were indicated for the GR-COPD programme by a pulmonologist. Indication for the GR-COPD programme was considered appropriate when patients suffered from severely impaired health status due to high symptom burden and concurrent conditions, such as comorbidities, impaired nutritional and/or functional status and symptoms of anxiety or depression (Box 1). Due to these complex health issues, a multidisciplinary approach was required to achieve improvement in health status instead of physical therapy alone. All patients indicated for the GR-COPD programme were eligible to participate in this study. All participants signed a written informed consent. All patients

#### Box 1. Criteria for the GR-COPD programme

##### Major inclusion criteria

- Decline of functional status (ADL)
- Health status is severely impaired, as measured by CCQ, score  $\geq 2.0$
- Frequent exacerbations;  $\geq 2$  in the past 6 months (excluding the present exacerbation)

##### Minor inclusion criteria

- Hypoxaemia (excluding pre-existent chronic respiratory insufficiency)
- Impaired nutritional status: BMI  $< 21$  kg/m<sup>2</sup> and/or FFMI depletion
- Patients at risk for clinically relevant anxiety disorder or depression; HADS  $\geq 8$  on either subscale

##### Exclusion criteria

- Conditions interfering with rehabilitation, such as end-stage of disease
- Major psychiatric or cognitive disease

Indication for the GR-COPD programme: two major OR one major AND two minor criteria

Note: ADL=activities of daily living; CCQ=clinical COPD questionnaire; BMI=body mass index; FFMI=fat-free mass index; HADS=hospital anxiety and depression scale

included in the study were offered the GR-COPD programme. Patients who refused the programme received care as usual.

### *The GR-COPD programme*

The GR-COPD programme is organised as a structured care pathway in a skilled nursing facility (SNF) (van Dam van Isselt et al, 2013). In the Netherlands, these SNFs are usually situated in nursing homes (Holstege et al, 2013). The programme offers multidisciplinary patient-centred rehabilitation that also integrates palliative care aspects, to older patients with COPD and severely impaired health status, who have been hospitalised for an acute exacerbation. The individualised programme is provided by the multidisciplinary team of the SNF, which consists of an elderly care physician, a skilled nurse, a physiotherapist, a psychologist, an occupational therapist, a speech and language pathologist, a dietitian and a social worker. The programme contains several modules covering different aspects of rehabilitation and palliative care: optimising pharmaceutical treatment and inhalation techniques; supporting smoking cessation; adequate symptom control; endurance and strength training; inspiratory muscle training; breathing regulation skills and mucus evacuation techniques; improving nutritional status; psychosocial intervention; education focusing on self-management strategies; peer support contact; and advance care planning.

The education module of the programme consisted of 6-weekly organised carousel group sessions of 60 minutes. During these group sessions, education was provided concerning several aspects of successful self-management techniques, such as healthy diet, optimal activity levels and energy-saving techniques. The aim of the GR-COPD programme is to restore pre-existent functional level or to counteract and stabilise the gradual decline of health status, improve quality of life and prevent complications such as frequent hospital re-admissions (van Dam van Isselt et al, 2013; Paraschiv et al, 2015).

The education modules of the programme are considered an important tool to achieve these goals (Bourbeau et al, 2004; Cannon et al, 2016) by improving adequate self-management (Zwerink et al, 2014).

### *Measurements*

The information needs of both the patients who received the GR-COPD programme, and patients who received the usual care (UC), was measured with the Lung Information Needs Questionnaire (LINQ). The LINQ is a validated self-complete

tickbox questionnaire with 16 questions (Hyland et al, 2006), that has a good retest reliability (Jones et al, 2008). It is divided into six domains: understanding COPD; medication; avoidance of exacerbations; smoking; exercise; and nutrition. Total possible scores range from 0 to 25; a lower LINQ score indicates a lower need for information on that domain of the disease (Reed and van der Does de Bye, 2011).

Health status was measured using the Dutch version of the Clinical COPD Questionnaire (CCQ) (van der Molen et al, 2003). The CCQ is a validated and reliable self-administered questionnaire and is responsive to changes in patients with all stages of COPD (van der Molen et al, 2003). It consists of 10 items in three domains: symptoms; functional state; and mental state. A seven-point Likert scale from 0 to 6 is used for each item, with lower scores indicating better outcomes. A total score of  $\geq 2.0$  is considered as impaired health status.

The Barthel index (BI) score was used to assess the functional capacity of the patients at baseline. The BI is a valid, reliable and widely used instrument to indicate the need for assistance in care (Collin et al, 1988). Total possible scores range from 0 to 20, with lower scores indicating increased disability.

### *Statistical analysis*

All data were processed using Statistical Package for the Social Sciences (SPSS) 23. Descriptive analyses were used for general baseline patient characteristics, disease characteristics and data from measurements on admission. To compare the mean outcome measurements on admission (T0) and after three months follow-up (T1), the paired sample t-test was used. Pearson's correlation coefficient was calculated to determine the strength of linear correlations between pairs of variables of interest. We defined statistical significance at  $p \leq 0.05$  (two-sided level of significance).

## **Results**

A total of 275 patients fulfilled the inclusion criteria during the specified period, and 158 participants were enrolled into the study. The GR-COPD programme was accepted by 78 (49%) participants (GR group), while 80 participants chose to refuse the programme and received usual care (UC group). Of these, follow-up could not be performed in 8 (10%) patients (three [4%] of whom died) in the GR group and in 21 (26%) patients (five [6%] of whom died) in the UC group. A total of 70 (90%) and 59 (74%) subjects in the GR group

and UC group, respectively, completed the study (Figure 1).

The baseline characteristics for the 158 patients, stratified between those who followed the GR-COPD programme and those who did not, are summarised in Table 1. Indicated by the mean BI score of 17 ( $\pm$  0.3) and mean CCQ score of 3.7 ( $\pm$  0.1), the study population consisted of patients with moderate care dependency and severely limited health status. The vast majority of subjects had severe to very severe (GOLD stage 3 to 4) COPD, and 44 (27.8%) patients were on long-term oxygen therapy.

### Patient information needs at T0

On admission, the overall mean LINQ score was 8.6 ( $\pm$  3.1). Neither the use of long-term oxygen therapy, nor the GOLD stage of patients, affected this baseline LINQ overall score. As judged by the LINQ domain scores, the greatest need for information, within this study population, was in the area of diet and self-management. In Table 2, the results of all measurements at baseline (T0) and after 3 months follow-up (T1) are presented. Compared with the UC group, the GR group had a not significant higher overall LINQ score ( $p=0.48$ ), with higher information needs on disease knowledge ( $p=0.92$ ), medicines ( $p=0.25$ ), smoking ( $p=0.01$ ) and diet ( $p=0.79$ ).

### Changes during the GR COPD programme

From T0 to T1, the mean LINQ overall score of the GR group significantly improved ( $p<0.01$ ), while the UC group failed to reduce its overall patient information needs. Improvements were seen in the following specific domains: smoking ( $p<0.01$ ), diet ( $p=0.07$ ) and exercise ( $p=0.09$ ). However, the self-management domain score, which scored the greatest need for information at T0, showed no significant improvement in either group.

### Relationship between patient information needs and health status

The health status (CCQ) of all study participants showed a significant improvement after 3 months ( $P <0.01$ ). To determine if there might be a relationship between patient information needs as measured by the LINQ and the health status (CCQ), we calculated the correlation coefficients between these variables. No relationship was found between the LINQ overall score and the CCQ on T0 ( $r=-0.11$ ,  $p=0.28$ ) and T1 ( $r=0.06$ ,  $p=0.61$ ). Improvement in LINQ overall score also showed no relationship to the CCQ or the improvement in CCQ ( $r=0.14$ ,  $p=0.25$ ).

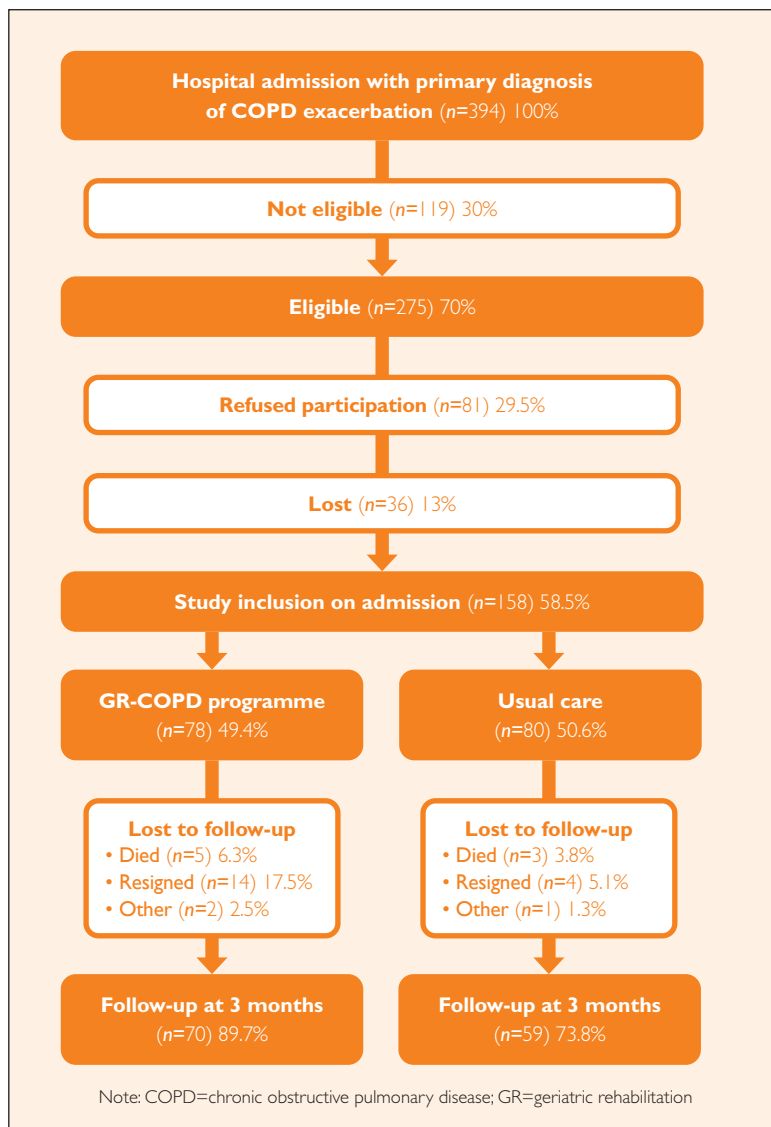


Figure 1. Flowchart of study design

Table 1. Patient and disease characteristics at baseline

Characteristic	GR-COPD		Usual care		Total	
	n	%	n	%	n	%
Number of patients	78	(49.4)	80	(50.6)	158	(100.0)
Sex	Male	33 (42.3)	45 (56.3)	78 (49.4)		
	Female	45 (57.7)	35 (43.8)	80 (50.6)		
Living status	Alone	33 (42.3)	32 (40.0)	65 (41.1)		
	Together	45 (57.7)	48 (60.0)	93 (58.9)		
COPD severity	GOLD 2	12 (15.4)	21 (26.3)	33 (20.9)		
	GOLD 3	36 (46.2)	44 (55.0)	80 (50.6)		
	GOLD 4	30 (38.5)	15 (18.8)	45 (28.5)		
Smoker	33 (42.3)	17 (21.3)	50 (31.6)			
	<b>Mean</b>	<b>SD</b>	<b>Mean</b>	<b>SD</b>	<b>Mean</b>	<b>SD</b>
Age in years	70.2	(8.5)	71.3	(7.6)	70.8	(8.1)
Health status (CCQ)	3.8	(0.1)	3.6	(0.1)	3.7	(0.1)
Barthel index	16.3	(0.4)	17.7	(0.3)	17.0	(0.3)

Note: CCQ=Clinical COPD Questionnaire; COPD=chronic obstructive pulmonary disease; GOLD=Global Initiative for Chronic Obstructive Lung Disease; GR=geriatric rehabilitation

**Table 2. Outcomes of measurements on admission (T0) and after 3 months (T1) for patients who did and did not follow the GR-COPD programme**

Scale	Tests	Admission	3 months	Improvement	P-value
Scale/subscale	Range	n=	Mean SD	Mean SD	Mean SD
<b>Admission (T0)</b>					
CCQ		56	3.8 (1.1)	2.4 (1.1)	1.4 (1.2) <0.05
LINQ	0–25	27	8.5 (2.9)	6.4 (3.5)	2.1 (3.0) <0.05
Disease knowledge	0–4	30	1.2 (0.9)	1.2 (1.0)	0.0 (0.9) 0.84
Medicines	0–5	31	0.4 (0.8)	0.5 (1.0)	-0.1 (0.2) 0.58
Self-management	0–6	32	2.8 (1.7)	2.3 (1.7)	0.5 (2.1) 0.19
Smoking	0–3	33	0.6 (0.7)	0.2 (0.4)	0.5 (0.8) <0.05
Exercise	0–5	30	1.9 (0.8)	1.5 (1.0)	0.4 (1.4) 0.09
Diet	0–2	32	1.4 (0.8)	1.1 (0.7)	0.3 (0.9) 0.07
<b>Follow-up at 3 months (T1)</b>					
CCQ		56	3.6 (0.9)	2.8 (1.0)	0.7 (1.1) <0.05
LINQ	0–25	44	8.1 (3.3)	8.0 (3.6)	0.1 (2.9) 0.88
Disease knowledge	0–4	48	1.3 (1.2)	1.0 (1.0)	0.3 (0.9) 0.05
Medicines	0–5	49	0.5 (0.6)	0.4 (0.8)	0.1 (1.0) 0.57
Self-management	0–6	49	3.0 (1.8)	3.1 (1.7)	-0.0 (2.1) 0.89
Smoking	0–3	51	0.2 (0.5)	0.2 (0.6)	0.0 (0.6) 1.00
Exercise	0–5	49	2.0 (1.3)	2.0 (1.4)	-0.1 (1.1) 0.61
Diet	0–2	51	1.3 (0.7)	1.3 (0.7)	0.0 (0.9) 0.88

Note: CCQ=Clinical COPD Questionnaire; COPD=chronic obstructive pulmonary disease; GR=geriatric rehabilitation; LINQ=Lung Information Needs Questionnaire (high score=high information need)

### Discussion

This study focused on the course of patient information needs within older patients, who were eligible for the GR-COPD programme. The first main finding of this study revealed that this population had the greatest need for information in the area of diet and self-management. Second the overall patient information needs improved during the GR-COPD programme. However, despite this improvement, the specific score of the self-management domain still shows a clear knowledge gap. Inferring from this, we conclude that the GR-COPD programme probably enhances health-related knowledge, although improvement of the self-management domain was not achieved.

Our results are in line with previous literature on this subject, also indicating inadequate education in patients with COPD (Nakken et al, 2017), with an expressed need for more information in the area of diet and self-management (Hyland et al, 2006; Jones et al, 2008; Scott et al, 2011). Data on the effect of rehabilitation programmes and education in patients with COPD show positive outcomes of these programmes on functional status, health status, psychological wellbeing, disease knowledge and information needs (Griffiths et al, 2000; Bourbeau et al, 2004; Hyland et

al, 2006; Wakabayashi et al, 2011; Zwerink et al, 2014; Cleutjens et al, 2017; Nakken et al, 2017). Studies on the effect of specifically designed geriatric rehabilitation programmes for older patients with advanced COPD are scarce, making interpretation of our results difficult. The patient information needs in this study appear to show a similar enhancement in health-related knowledge, after participating in a GR-COPD programme. However, the programme did not sufficiently meet information needs in the self-management domain. Offering patients with COPD self-management strategies, such as an exacerbation action plan, appears to be important in improving healthcare utilisation, helps with retention of information and reduces the encountered disability (Bourbeau et al, 2004; Bucknall et al, 2012; Cannon et al, 2016). Then again, studies specifically focusing on self-management demonstrated that fewer than half of patients with COPD became successful self-managers (Bucknall et al, 2012; Cannon et al, 2016).

As the GR-COPD programme integrates rehabilitation with palliative care aspects, the relation between (effective) self-management and (the effect of) palliative care elements of the GR-COPD programme might be of interest.

However, our study aimed to investigate the patient information needs, not the effect of the palliative care elements of the programme, or the relation between self-management and palliative care elements. One could argue that health status might indirectly reflect the effect of palliative care elements of the programme, as it also reflects symptom burden. Symptom burden can be seen as an important domain of the palliative care needs of patients with advanced COPD (Janssen and McCormick, 2014). However, we did not find any significant relationship between the LINQ (domain) scores and health status, measured by the CCQ. Furthermore, changes in LINQ (domain) scores also showed no significant relationship with improvement in health status, indicating that information needs do not directly epitomise the effect of a rehabilitation programme on health status. Information needs assess the effect of the educational process (Jones et al, 2008), which contributes to the persistent and meaningful benefit of the programme (Bourbeau et al, 2004). Further research is needed to find and understand the relationship between increased knowledge, improved self-management and change in health status within this specific population.

### Strength and limitations

To the best of our knowledge, this is the first study that describes the patient information needs of older patients with COPD and severely impaired health status. Furthermore, this study describes the course of these needs during the GR-COPD programme, measured by the LINQ. However, there are some limitations to our study. First, sampling bias might have affected the results. There might be differences between participants and eligible patients refusing participation, such as higher motivation. Highly motivated patients with COPD may have been more willing to participate in the study; however, we were unable to collect information on patients who were selected for the study but refused to participate, so we are unable to explore this further.

### Key points

- **This is the first study that investigated patient information needs of patients admitted for post-acute geriatric rehabilitation for chronic obstructive pulmonary disease (GR-COPD)**
- **Patients admitted for post-acute GR-COPD have the greatest need for information in the area of diet and self-management**
- **The overall patient information needs improved during the GR-COPD programme, but the self-management domain still showed a knowledge gap**
- **Education modules in post-acute GR-COPD should focus more on patient information needs**

Second, we compared results from patients who followed the GR-COPD programme with those of patients who refused the programme. So, there is a risk that selection bias has occurred. However, this selection is probably in accordance with real-life clinical practice.

Third, the completion rates for study questionnaires were disappointing, especially in the intervention arm of the study. This might be due to competing interests, by the fact that the participants had to provide a lot of information in the different questionnaires, because this study is part of a larger study.

Last, no conclusions can be drawn from our result about long-term effects.

### Conclusions

This study shows an improvement of patients' health knowledge during the GR-COPD programme. More specifically, we found a reduction of patient information needs regarding smoking, diet and exercise. However, this study also showed that the information needs in the self-management domain were insufficiently met, before and even after the GR-COPD programme. Further studies are needed to prove the added value of geriatric rehabilitation for patients' health knowledge in this specific population. Furthermore, research will also have to be

### Continuing professional development: reflective questions

- **To what extent are education modules in post-acute (geriatric) rehabilitation focused on patient information needs, instead of clinician-defined information needs?**
- **What are effective interventions to improve self-management in these patients?**
- **What are effective interventions to improve knowledge about healthy diet in these patients?**
- **How can we better understand the relationship between (increased) knowledge, (improved) self-management and change in health status in these patients?**

conducted into the effect of the specific education modules, and to what extent they are aimed at improving patient self-management. **IJPN**

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**Contributions:** TJW designed the study, processed and analysed the collected data and wrote the manuscript. EFvDvI participated in the design of the study, reviewed and helped writing the manuscript, and assisted with the statistical analysis; WPA reviewed the manuscript. All authors have given final approval of the version to be published

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