



**THE SAHLGRENSKA ACADEMY**

# **Could Specialist Support Affect Patients' Adherence to COPD Treatment**

An original survey comparing disease knowledge, smoking habits and adherence to medication between current and new visits to the COPD-centre at the Sahlgrenska University Hospital in Gothenburg, Sweden.

Degree Project in Medicine

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Programme in Medicine

Gothenburg, Sweden 2018

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## **Abstract**

Chronic obstructive pulmonary disease (COPD) is increasing among the Swedish population. Today approximately one in ten in the ages 45 and 65 are affected by the disease but WHO predicts that COPD will become the third leading cause of death worldwide by 2030. Improved care could lead to less suffering for the individual and lower costs for society.

In September 2015, the Deputy Hospital Manager at Sahlgrenska University Hospital signed an order to create a clinic dedicated to the treatment of COPD. The order states that the clinic shall exist for 3 years until an evaluation should be made determining its continued existence.

This paper compares knowledge of the disease, smoking habits and adherence to therapy by comparing newly admitted and recurring patients at the COPD-centre using a questionnaire designed to measure these variables. Recurring patients has a better knowledge about their disease, a difference that is statistically significant, on the contrary, there is no statistical difference on adherence to medication even though a graphical difference can be seen. The information on smoking is effective. 34% of the newly admitted patients smoke regularly whereas only 15% of the recurring patients do so, a 56% reduction in active smokers.

A visit to the COPD-centre is positive for the patients. Their knowledge about COPD increases, which earlier studies has shown having a positive impact on adherence to therapy, and the share of active smokers is reduced significantly. Nonetheless, continued research is needed to more specifically target exactly what a visit to the COPD-centre does that causes this positive change.

## Background

Chronic obstructive pulmonary disease[1] (COPD) is increasing among the Swedish population.[2] Today approximately one in ten in the ages 45 and 65 are affected by the disease but WHO predicts that COPD will become the third leading cause of death worldwide by 2030.[3] Improved care could lead to less suffering for the individual and lower costs for society. The actions to improve care could be a complex mixture of change in attitude, the given information, technical support and improved medical therapy where adherence is a vital part.[4]

Improving a patient's adherence could benefit from having a much broader approach than just looking at how they adhere to their medication. The impact on adherence would benefit from having a more holistic view, where also other factors such as gender and level of education gets included.[5]

The adherence to medication may be defined as to the degree a patient takes their medical prescriptions and is one of the greatest challenges with drug development and therapies.

Adherence to long term treatment is on average less than 50 %, which indicates that there is a lot of untapped potential in drug therapies.[4] Increasing the effectiveness of all parts in the care by stressing the adherence may have a far greater impact on the health of the population than any improvement in specific medical treatments[6]. Nonadherence is complex and may be due to the life style, the patient, the regimen and the device, why the motivation, the support and the education is essential. Besides being less effective medical treatments, recent publications found that non-adherence to medications for the treatment of chronic conditions leads to annual loss of \$637 billion for pharmaceutical companies[7] and \$375 billion in treatment cost in the US[8].

The understanding of how visits to a specialist clinic may change the adherence in COPD patients could be essential in increasing adherence elsewhere.

Most patients get their diagnosis and first treatment of COPD at the family practice. Since only severe COPD, or severe symptoms caused by the disease, usually get treated at a specialty clinic[1], the understanding of causes to any possible increase in adherence gained by visits to a specialist clinic could be essential for improving treatment of the disease.

Since the disease is increasing worldwide and since patients usually have low adherence to long term medications, studies aimed at finding ways to increase adherence to the treatment of COPD is beneficial both from an individual as from a societal perspective.

## **The COPD-centre at Sahlgrenska University Hospital**

In September 2015, the Deputy Hospital Manager at Sahlgrenska University Hospital signed an order to create a clinic dedicated to the treatment of COPD. The order states that the clinic shall exist for 3 years until an evaluation should be made determining its continued existence.[9] The results of this paper support the Sahlgrenska Hospital Management in making an informed decision when determining whether or not the clinic should be made permanent.

## **Epidemiology**

COPD is more prevalent in communities with a higher percentage of smokers since smoking tobacco is the leading cause of COPD. It mostly affects older adults who either are active smokers or have been smoking earlier in life. The patients often also have one or several other chronic diseases, of which asthma and different cardiovascular diseases are some of the more prevalent ones.[10]

In 2010 COPD affected a bit less than 5% of the earth's population, about 330 million people.[11] In 2018 between 400,000 and 700,000 persons in Sweden have COPD and the

number of affected is expected to increase. In Sweden COPD is the main cause of death of about 2700 people per year.[10, 12]

## **Diagnosis**

Even though the common chest x-ray often shows signs of COPD, a confident diagnosis of the disease can only be made with spirometry. If a patient shows symptoms that correlates with classical symptom of the disease, such as shortness of breath, chronic cough, sputum and/or if the patient has exposure to, or have had exposure to, risk factors such as smoking, pollution or has genetic or habitual risk factors then the physician should order a spirometry for that patient.[13]

The spirometry is done after bronchodilators have been taken by the patient and the ratio between FEV1/FEV is calculated. A value of  $< 0.7$ , or  $< 0,65$  for ages  $> 65$ , determines if you have COPD. Thereafter the FEV1 gets compared to a predicted value, and the percentage of FEV1 to that value determines what stage of COPD the patient has.[14]

## **Treatment of COPD**

The treatment of COPD is very diverse. Even though smoking cessation is the most crucial factor in prolonging the prognosis, and the only factor that can stop the advancement of the disease, many factors are at play when determining the best treatment for a patient. The long-term treatment can include a better diet, physical exercise, medications, long-term oxygen therapy and sometimes prophylactic antibiotics. When talking about pure medical COPD treatments different inhalators, SABA and LABA (Short- and Long-Acting Beta-2-Agonists), LAMA (Long-Acting Muscarinic Receptor Antagonists) and ICS (Inhaled Corticosteroids), are the cornerstones. One of the goals of the long-term treatment is to reduce the number of exacerbations, sudden worsening of the symptoms, since these are associated with an accelerating progress of the disease and a shorter life-span. Many patients get hospitalized

during exacerbations since they are in need of short-term oxygen therapy, more effective inhaled medication and intravenous antibiotics. With smoking cessation and proper adherence to other recommended treatment progress of the disease can be slowed significantly, or even stopped altogether.[10, 14]

## Adherence

When writing or talking about adherence we often only mean how well the patient follows the prescribed regimen and how much they follow the caregiver’s advice. Adherence can be looked at from a broader perspective where more dimensions are observed.[6]

*Table 1. Adapted from Sabaté, Eduardo. [6]*

<b>Five Dimensions of Adherence</b>				
<b>Socioeconomic</b>	<b>Health care system</b>	<b>Condition - Related</b>	<b>Therapy - Related</b>	<b>Patient - Related</b>
Limited language	Patient-provider relationship	Lack of symptoms	Complexity of the medication regimen	Visual, hearing or cognitive impairment
Low health literacy	Long wait times	Severity of symptoms	Duration of therapy	Knowledge about disease
Unstable living conditions	Lack of care continuity	Depression	Frequent changes	Perceived risk/ susceptibility to disease
Lack of health insurance	Restricted formularies	Psychotic disorders	Actual perceived side effects	Perceived benefit of treatment
Medication cost				Motivation and confidence



## **Aim**

The aim of the project was to investigate the difference in and impact on both knowledge about COPD and adherence to medication between newly admitted patients or recurrent visits to the COPD-centre at Sahlgrenska University Hospital.

## **Research Questions**

1. Are the patients' perceived medical adherence unchanged between new and recurrent visits to the COPD-centre at Sahlgrenska University Hospital?
2. Are the patients' perceived basic knowledge about COPD unchanged between new and recurrent visits to the COPD-centre at Sahlgrenska University Hospital?
3. Is the proportion between actively smoking and non-smoking patients' unchanged between new and recurrent visits as stated to the COPD-centre at Sahlgrenska University Hospital?
4. Are there any specific demographic differences between groups in relation to questions 1-3, or more specifically, if there are any differences between patients' gender, socioeconomic status or age in relation to the questions above?

## **Medical Relevance**

Several of the medications used by COPD patients, particularly those acting in longer dosing intervals that don't have an immediate effect, are used less frequently than prescribed even though studies have shown clinically relevant benefits in sticking to the regimen.[15] It is therefore relevant to find connections between different levels of adherence to treatment between groups of patients since such finding could potentially benefit those individuals that does not get the best possible potential from their medications.

In this study the prime difference between the groups are whether they have specialized or non-specialized care for treatment of their COPD. If the study would show disparity between

the groups, then further studies will most probably be needed to specify which factors are the cause of it.

## Materials and Methods

To answer the research question about differences in adherence a tool, or method, to measure this was needed. Medication Adherence Rating Scale[16] (MARS), a validated tool for measuring adherence to medication, was chosen to measure adherence. MARS was chosen both because of its broad perspective and for its short length. Due to the nature of the survey the patients needed to fill out the form before their appointment with the physician which led to a time constraint that limited the number of questions in the form measuring adherence. The tool for measuring adherence also needed to be as broad as possible to include all kinds of medication. MARS is mostly used for measuring adherence for psychiatric medications, therefore slight changes have been made to a few of the questions to better fit the group surveyed, more specifically to question number 7 and 9. The questions have also been translated into Swedish.

A second tool measuring the patients' knowledge was also needed. This part was constructed by the author with input from physicians at the clinic. The tool measuring knowledge of COPD is a short questionnaire with seven questions about COPD and its treatment in Sweden[17].

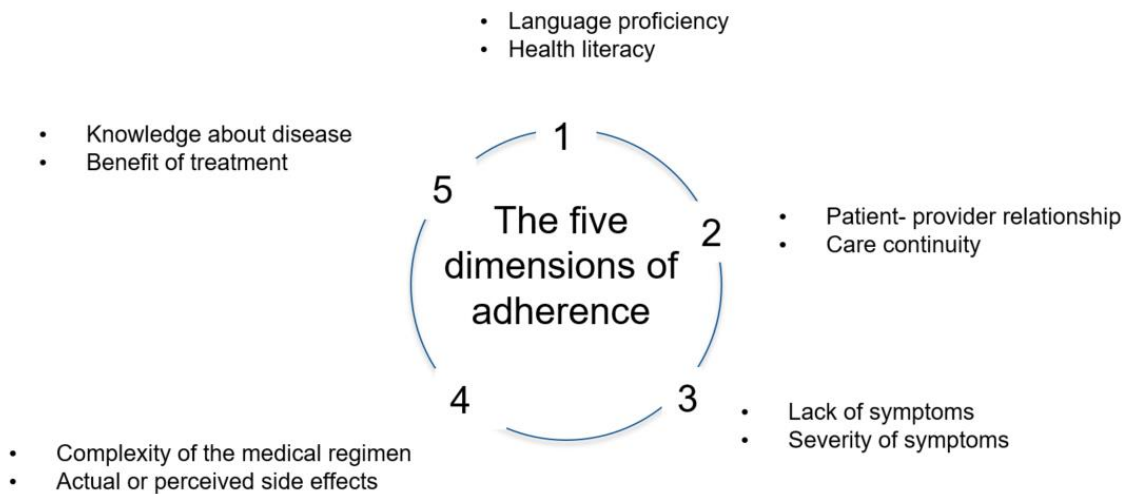
The survey also included questions about gender, age, which neighbourhood or district they lived in, smoking habits and how much the disease affected their daily life.

The questionnaire was handed out to visiting patients for five weeks at the clinic, between the 16th of October and the 17th of November in 2017, a period that the author had calculated would include more than one hundred patients.

116 patients had an appointment at the clinic during the period. More than 90% of those patients answered most of the questions on the questionnaire. The number of included

respondents vary when comparing data. These variations stem from what data the respondent have excluded when filling out their form.

The questionnaire contains as much of the complexity of adherence as could be fitted in to the limited time that the patients had when filling out the forms. In *Figure 1* you can see what parts are included.



*Figure 1 - Adapted from Sabaté, Eduardo. [6]*

## **Ethics**

The patient could feel uncomfortable answering questions about adherence to medicine since it can make them feel accused of not doing what the caregivers has ordered. They could also get uncomfortable answering a form about COPD. Both problems are met by having a neutral page at the top of the questionnaire that both hides their replies from the staff as well as explains that only the one person doing the study will see their individual questionnaires.

Since the questionnaire was anonymous an approval of conducting the study without having an ethical review board's approval was given by the head of the clinical department.

There are no issues contrasting the Universal Declaration of Human Rights[18] or the World Medical Association's Declaration of Helsinki[19].

## Statistical Methods

SPSS 25 was used to calculate data and to generate graphs and tables.[20] Prior to importing the data to SPSS the data was compiled and sorted in Microsoft Excel (2016).

Knowledge about COPD was calculated with a Mann–Whitney *U* Test.

Adherence was calculated by an independent-samples T-test where equal variances weren't assumed. The same was done when looking for a correlation between how much the disease affected daily life and their result on the adherence scale.

Smoking habits between the groups was calculated with a Fisher's Exact Test.

# Results

## Demographic Data

Most patients were above the Swedish age of retirement and none were younger than 45 years of age. Almost two thirds of the patients were women. 87% were born in Sweden, which is slightly more compared to the population average of 83%.[21]

Table 2. The age distribution among patients.

	Years of Age								
	45-49	50-54	55-59	60-64	65-69	70-74	75-79	80-85	>85
Male, n= 41	0%	2%	5%	7%	22%	10%	27%	20%	7%
Female, n= 70	1%	1%	3%	14%	14%	21%	10%	19%	16%
Total, n= 111	1%	2%	4%	12%	17%	17%	16%	19%	13%

Table 3. Gender distribution and share of immigrants.

	Gender			Born in Sweden	
	Male	Female	Total	Yes	No
First visit, n= 29	35%	65%	73%	86%	14%
Recurrent visit, n= 80	45%	55%	27%	90%	10%
All Visits n= 109 (116)	38%	62%	100%	87%	13%

Table 4. Distribution of background by comparing if parents are immigrants or not.

	Parents born in Sweden		
	Yes	One	None
First visit, n= 28	82%	3%	15%
Recurrent visit, n= 79	86%	4%	11%
All Visits n= 107 (116)	83%	3%	14%

## Knowledge of COPD

103 out of 116 patients did both the questionnaire about COPD and answered the question about whether it was a first or recurring visit to the clinic. The maximum value on the knowledge questionnaire was 7. The recurring patients had a 0.72-point higher mean, at 3.49, than the new patients at 2.77 points. A Mann–Whitney *U* test showed a significant p-value of 0.033.

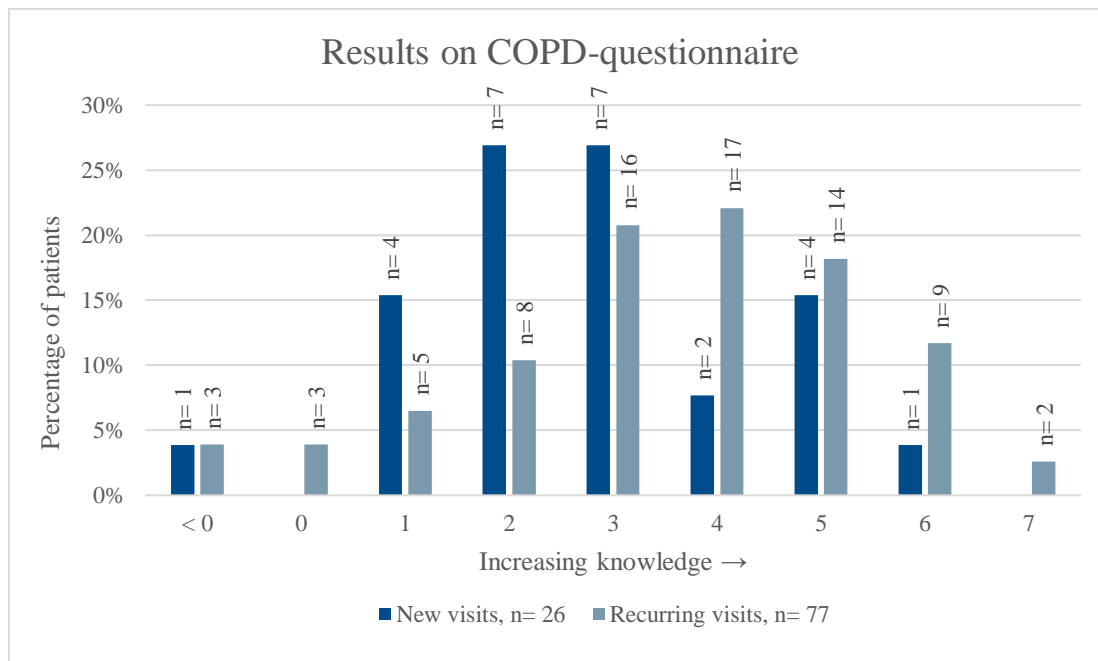


Figure 2 – The patients' knowledge of COPD

When comparing male and female respondents and including everyone, both new and recurring visits, there is a difference of 0.52-points between genders with a maximum test score of 7. The difference is not significant.

Table 5. The gender difference in knowledge.

Gender	N	Mean
Male knowledge	39	3.00
Female knowledge	65	3.52



## Smoking Habits

Out of 116 respondents 109 answered both the question about smoking and about being a new or recurring visitor to the clinic.

*Table 6. How many participants that were included when measuring smoking habits.*

	Included		Excluded		Total	
	n	Percent	n	Percent	n	Percent
Patients on smoking habits	109	94%	7	6%	116	100%

When comparing the results on the proportion of smokers between first and recurring visits to the clinic we get a 56% reduction, from 34% for first visits down to 15% for the patients that have visited the clinic and met a specialist at least once before. Fisher's Exact Test showed a P-value of 0.033 when comparing the groups.

*Table 7. Percentages of active smokers comparing first and recurring visits.*

	Active Smokers
Recurrent visit, n= 80	15%
First visit, n= 29	34%
Total, n= 109	20%

We could follow the smoking habits and the origin of the patients. The sample sizes turned out to be too small to draw any conclusions from these statistics.

*Table 8. Shows the distribution of home-address among the participants.*

	First visit			Recurrent visit		
	n	Smokers	%	n	Smokers	%
Outside Gothenburg	8	2	25%	20	3	15%
Hisingen	6	4	67%	10	2	20%
Downtown + Western Goth.	14	4	29%	44	6	14%
Eastern Gothenburg	1	0	0%	5	1	20%

# Adherence

105 out of 116 patients filled out both the form on adherence and answered the question about whether it was a first or recurring visit to the clinic. There was a slightly higher mean for the patients on MARS, with a maximum of 10, but the data is not normally distributed, and the difference is not significant with a p-value of 0.588.

Table 9. Comparison of the mean self-reported adherence on a scale from 0 to 10 between first and recurrent visits.

	N	Mean
Recurrent visit	79	8.49
First visit	26	8.31

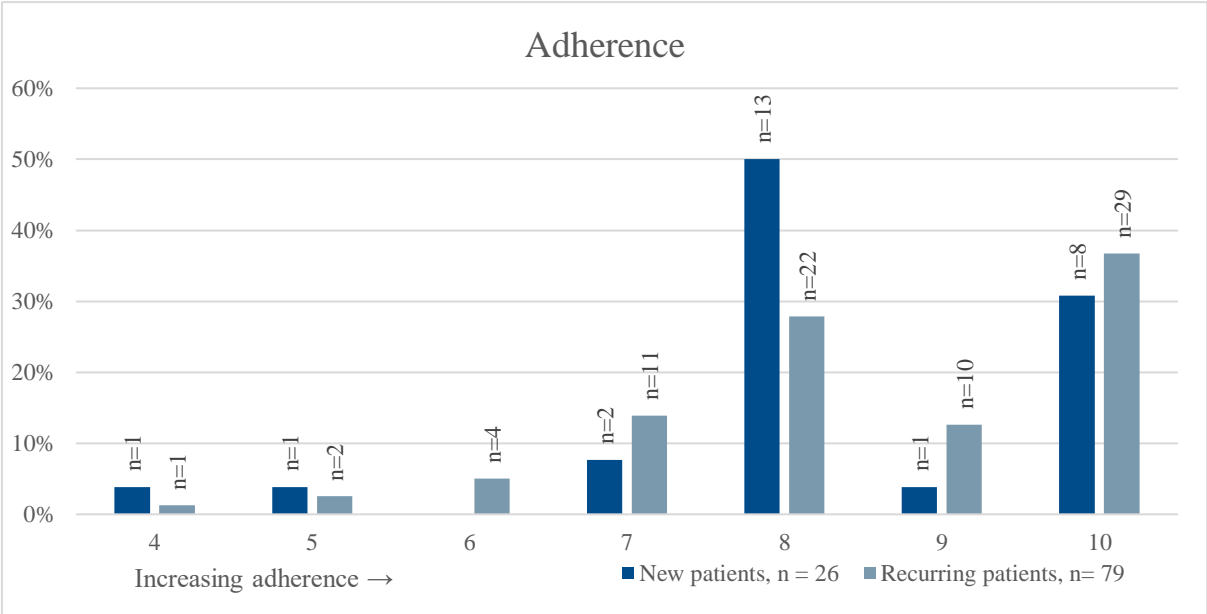


Figure 3 - The patients' self-reported adherence to medication.

The patients' self-reported adherence compared with how much COPD affects the patients' daily life shows a decrease in how much they are affected with increasing adherence. This difference in means is seen both when comparing those that have maximum 10 in adherence compared to the rest, and when comparing those with 8 or higher with those lower than 8. These correlations are not significant with high p-values. How much the patients were

affected was measured on a scale from 0-10 where a lower score equals a lesser impact from the disease on their daily life.

*Table 10. The diseases effect on daily life compared to adherence.*

	Adherence	N	Mean
How COPD affects daily	= 10	32	5.813
life	< 10	56	6.196

*Table 11. The diseases effect on daily life compared to adherence.*

	Adherence	N	Mean
How COPD affects daily	>= 8	70	5.957
life	< 8	18	6.444

## **Discussion**

### **Material and Methods**

A confidential survey might have been more optimal but due to time constraints, having the survey anonymous was chosen since it might have increased response rates, a factor valued when planning this report. Even though anonymity might increase response rates and the difference of disclosing sensitive information between an anonymous and a confidential survey are unclear[22], a confidential survey would probably have been preferable. One clearly negative aspect of having it anonymous is the lack of control; there is no way of looking up patients and double-check when things are unclear, and it is impossible to look for further data that is not included in the questionnaire. The research gets clearly limited to the data you get from the questionnaire, which puts a lot of weight on constructing a survey that includes everything essential and making the questions easily understood without room for interpretation.

### **Knowledge of COPD**

A larger sample might have made a difference, especially when measuring knowledge between new and recurring visits since a p-value of 0.033 shows a correlation.

When comparing genders, results are had that suggests women being treated for COPD have a higher health literacy. A study on adults done by the U.S. Department of Education's National Center for Education Statistics, shows a higher general health literacy among women.[23] It is interesting to note that this gender difference also shows up in this limited study done in Sweden and where the women also have a slightly higher mean age. This suggests that men in general need more support if their adherence as a group is to be increased.

The importance of educating patients about their disease and its management is crucial in getting a higher adherence. Also important is the care-givers skill in assessing the level of education needed by individual patients.[24] This paper shows that the patients admitted to the COPD-centre at Sahlgrenska University Hospital do increase their knowledge. It is unclear if the increase in knowledge is due to better care and education from the staff and physicians or if being admitted to a specialist clinic has a direct influence in patients taking their disease more seriously and the increase thus being a product of this revelation.

## **Smoking habits**

When comparing means on smoking habits they show an effective result in the survey. There is a 56% reduction in active smokers between new and recurring visits. This is a huge decrease in active smokers and it is significant. The same applies here as in the section above: What part of this decrease is due to having been treated by specialist physicians and nurses and what part of the decrease is due to other factors?

Since earlier studies have shown that higher education can lead to higher adherence, in this case a lower percentage of smokers, one could assume that an appointment with a specialist would be more beneficial for patients from lower socioeconomic areas, in this study Hisingen and Eastern Gothenburg.[25, 26] This study failed to show this correlation even though it shows a larger reduction in number of smokers from the parts of the city that have a lower median income and a lower level of people with degrees from higher education, no conclusions can be had from these statistics since the sample sizes are too small.

## **Adherence**

The comparison on adherence to therapy was not statistically significant, however it was graphically visible. The form analyzing adherence could be improved with more questions specifically about COPD medication. Using the MARS as the tool for measuring adherence

gave a validated tool, but since two questions were modified and the questions were translated into Swedish from English, one could instead have constructed a tool specifically aimed at the target population which might have given different results.[16]

Education is vital and self-management skills are very important in gaining higher adherence.[27] Even though this study have shown an increase in patient knowledge and a decrease in active smokers, which is a sign of increasing adherence, it fails to show an increase in adherence to their medicine regime.

There are also other methods besides patient education, skillful physicians and care-givers that can contribute in increasing adherence to therapy in the chronically ill. Some we might start seeing soon as technological advances start to facilitate patients' self-management. One study from 2017 shows how technology could provide such positive impact on adherence: Text messages that reminds patients to take their medications.[8]

## **Conclusion and Implications**

If the patient's knowledge of the disease truly increases by having an appointment at a specialist clinic, then that difference in knowledge probably also increases the patient's adherence to medication and counsel given by the physician.[27, 28] A family doctor could screen patients knowledge with just small questionnaires' and then either provide additional information or refer to a specialist clinic those that lack basic knowledge of COPD. This would be an extremely cheap way of increasing adherence among this huge group of patients which as a result could lead to less suffering and lower costs for society.

The caregivers knowledge makes a difference[25], and it is therefore important for family doctors to keep up to date with guidelines to give good counsel. If all family practitioners were up to date on the basic guidelines of COPD treatment, a specialized clinic focusing on COPD is probably still needed for referrals for more advanced stages or those with high

comorbidity. The clinic might also be essential in helping other clinics and family practices in implementing guidelines and perhaps helping in the job needed to spread information to colleagues when new treatments and new guidelines surface. Lastly the clinic is perfect for scientific research advancing the knowledge and treatment of COPD.

Having visited a specialist clinic focused on COPD should not create a drop from 34% to 15% in active smokers, as the results of this report show. Family doctors should have knowledge of this widespread disease and more knowledge and better adherence to guidelines from physicians would most likely reduce the number of smokers and delay the more severe stages of the disease. In Sweden, COPD is estimated to cost 14 billion SEK annually[10]. Since the more severe stages of the disease are more costly and smoking cessation is the only factor stopping the progress of COPD, focusing on the family practices, who are the ones that usually treat COPD at the initial stages, would be the most cost-effective way of reducing that cost. Even a few percent fewer active smokers among COPD patients would probably save billions.

## Populärvetenskaplig sammanfattning

Kroniskt obstruktiv lungsjukdom, KOL, ökar i Sverige. KOL, som ofta drabbar rökare, är en kronisk sjukdom som leder till sämre lungkapacitet och vid fortsatt rökning krävs ofta syrgas och sjukhusvård. Sjukdomen ökar i Sverige och i världen så tror Världshälsoorganisationen, WHO, att KOL kommer att bli den tredje vanligaste orsaken till död år 2030. Att förbättra KOL-sjukvården skulle kunna leda till minskat lidande och det skulle spara samhället stora pengar.

I september 2015 så togs det på Sahlgrenska sjukhuset ett beslut om att inrätta en klinik som fokuserar på sjukdomen KOL. Kliniken är det KOL-centrum som idag finns på Sahlgrenska. Enligt beslutet så ska KOL-centrum utvärderas och senast hösten 2018 ska beslut tas om kliniken ska göras permanent.

Den här uppsatsen jämför nya och återkommande patienter till KOL-centrum vad avser deras följsamhet till medicinering, deras rökvanor och deras kunskap kring KOL-sjukdomen.

Patienterna fick fylla i en enkät konstruerad att mäta dessa variabler. Återkommande patienter har en bättre kunskap kring sin sjukdom och skillnaden mellan grupperna kan visas statistiskt, däremot visar resultaten inte någon skillnad på följsamhet till medicinering även om en grafisk skillnad kan ses. Andelen rökare minskar från 34% för nybesöken till 15 % för återkommande patienter, vilket ger en reduktion av rökare på 56%.

Ett besök på KOL-centrum är positivt för patienten. Kunskapen kring sjukdomen ökar, något som tidigare studier visat har en positiv verkan på följsamhet till terapin, och andelen rökare sjunker markant. Det krävs dock fortsatta studier för att få reda på mer exakt vad i behandlingen och mötet på KOL-centrum som leder till dessa positiva resultat.



## **Acknowledgements**

I want to thank the nurses at the COPD-centre for having done the time-consuming job of handing out, collecting and explaining the questionnaire to the patients. Thank you!

I also want to thank my supervisors, Associate Professor Boo Edgar, who have helped me by giving me much appreciated feedback on most everything, and Specialist Physician Anita Nordenson, for being my clinical contact and supervisor at the COPD-centre where she has helped me come up with relevant questions for the questionnaire and helped me understand how the patients are treated. Thanks to both of you and I hope you appreciated working with me!

Lastly, I would like to give special thanks to all the amazing patients who invested their time in filling out the questionnaire. Many thanks!

## References

1. National Heart, L., and Blood Institute (NHLBI). *COPD*. [cited 2017 30/12]; Available from: <https://www.nhlbi.nih.gov/health-topics/copd>.
2. Nationella KOL-registret Luftvägsregistret/RiksKOL, *Årsrapport 2011*. 2011.
3. World Health Organization, *World Health Statistics 2008*. 2008.
4. Arbetsgruppen för bättre läkemedelsanvändning, *Abla II mindre sjukdom och bättre hälsa*. 2001.
5. McKinsey&Company, *A 360-degree approach to patient adherence*. 2017.
6. World Health Organization, *Adherence to long-term therapies: Evidence for action*>. 2003.
7. Health Prize Technologies and Capgemini Consulting, *Estimated Annual Pharmaceutical Revenue Loss Due to Medication Non-Adherence*. 2017.
8. Car, J., et al., *eHealth in the future of medications management: personalisation, monitoring and adherence*. BMC Medicine, 2017. **15**(1): p. 73.
9. Lars Grip, S.U., *Bildande av KOL-centrum på Sahlgrenska Universitetssjukhuset*, S.U. Hospital, Editor. 2015.
10. Socialstyrelsen, *Nationella riktlinjer för vård vid astma och KOL*. 2018.
11. Vos, T., et al., *Years lived with disability (YLDs) for 1160 sequelae of 289 diseases and injuries 1990&#x2013;2010: a systematic analysis for the Global Burden of Disease Study 2010*. The Lancet. **380**(9859): p. 2163-2196.
12. Socialstyrelsen, *Dödsorsaksregistret*. 2015, Socialstyrelsen Stockholm.
13. Global Initiative for Chronic Obstructive Lung Disease (GOLD), *Global strategy for diagnosis, management, and prevention of COPD – 2017 report*. 2017.
14. Alf Tunsäter, D., överläkare. *KOL, Kroniskt obstruktiv lungsjukdom*. 2017 [cited 2018 2/25]; Available from: <http://www.internetmedicin.se/page.aspx?id=231>.

15. Restrepo, R.D., et al., *Medication adherence issues in patients treated for COPD*. Int J Chron Obstruct Pulmon Dis, 2008. **3**(3): p. 371-84.
16. Fialko, L., et al., *A large-scale validation study of the Medication Adherence Rating Scale (MARS)*. Schizophrenia Research, 2008. **100**(1): p. 53-59.
17. Socialstyrelsen, *Vård vid astma och KOL*. 2015.
18. Assembly, U.N.G., *The Universal Declaration of Human Rights*. 1948.
19. World Medical Association (WMA), *WMA Declaration of Helsinki – Ethical principles for medical research involving human subjects*. 2017.
20. IBM Corp, *IBM SPSS Statistics for Windows*. 2017: Armonk, NY: IBM Corp.
21. Statistiska centralbyrån, S. *Befolkningsstatistik*. 2016 [cited 2018 Feb 18]; Available from: <https://www.scb.se/hitta-statistik/statistik-efter-amne/befolkning/befolkningens-sammansattning/befolkningsstatistik/>.
22. Murdoch, M., et al., *Impact of different privacy conditions and incentives on survey response rate, participant representativeness, and disclosure of sensitive information: a randomized controlled trial*. BMC Medical Research Methodology, 2014. **14**(1): p. 90.
23. Mark Kutner, *The Health Literacy of America's Adults 2006*, National Center for Education Statistics, U.S. Department of Education.
24. Stromberg, A., *The crucial role of patient education in heart failure*. Eur J Heart Fail, 2005. **7**(3): p. 363-9.
25. Bourbeau, J. and S.J. Bartlett, *Patient adherence in COPD*. Thorax, 2008. **63**(9): p. 831-838.
26. stadsledningskontor, G., *Samhällsanalys och Statistik*. 2015.
27. Bodenheimer, T., et al., *Patient self-management of chronic disease in primary care*. Jama, 2002. **288**(19): p. 2469-75.

28. Anna, S., *The crucial role of patient education in heart failure*. European Journal of Heart Failure, 2005. 7(3): p. 363-369.

# Appendix

## The Questionnaire Used in the Study



**SAHLGRENSKA AKADEMIN**

### **Enkät för patienter på KOL-centrum Sahlgrenska sjukhuset**

Enkäten används som en del i ett examensarbete (30hp) på läkarprogrammet.

Syftet med enkäten är att undersöka om det finns skillnader mellan gruppen som tidigare varit på KOL-centrum och den grupp som är här första gången vad avser följsamhet till medicinering och kunskap kring KOL-sjukdomen. Förhoppningen är att studier som denna kan leda till insikter som kan förbättra KOL-sjukvården inom regionen.

Enkäten är anonym och de enskilda svaren kommer endast att läsas utav den personen som sammanställer alla svaren.

Vi är mycket tacksamma för er medverkan.

Med vänliga hälsningar  
Läkarkandidat Väinö Lilja med handledare  
Sahlgrenska akademien  
Göteborgs universitet

Exempel		Ja	Nej
X	Detta är en anonym enkät.	X	

		Ja	Nej
A	Är det ditt första besök på KOL-centrum som patient?		

		Kvinna	Man
B	Kön		

		Ja	Nej
C	Röker du?		

Hur fick du kontakt med KOL-centrum?		
D1	Egen vårdbegäran (Egenremiss).	
D2	Remiss från vårdcentral.	
D3	Remiss från annan klinik på ett sjukhus.	
D4	Remiss från en akutmottagning.	
D5	På annat vis eller vet ej (skriv):	

Stadsdel		
E1	Hisingen	
E2	Centrum, Majorna-Linné, Örgryte-Härlanda	
E3	Östra Göteborg (Angered, Gamlestaden, Bergsjön m.m.)	
E4	Västra Göteborg (Askim, Frölunda-Högsbo, Långedrag m.m.)	
E5	Kranskommun till Göteborg	
E6	Utanför Stor-Göteborg	

		Ja	Nej
F	Är du född i Sverige?		

		Ja, en	Båda	Ingen
G	Är någon av dina föräldrar född utomlands?			

H	Din ålder. Markera en ruta nedan.									
	0-44	45-49	50-54	55-59	60-64	65-69	70-74	75-79	80-85	85+

Hur mycket påverkar din KOL-sjukdom dig i din vardag? Markera med ett kryss.

Inte alls	0	1	2	3	4	5	6	7	8	9	Mycket
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Svara nedan angående all förskrivna medicinering, inte enbart den för din KOL-sjukdom. Svara efter hur du upplevt det den senaste tiden.

	Fråga	Ja	Nej
1	Glömmer du ibland att ta dina mediciner?		
2	Slarvar du ibland med att ta dina mediciner?		
3	När du mår bättre, slutar du då ibland att ta dina mediciner?		
4	Om du mår sämre då du tar en medicin, slutar du då ibland att ta den?		
5	Jag tar mina mediciner endast då jag är sjuk.		
6	Det är onaturligt för min kropp och mitt sinne att vara beroende av medicinering.		
7	Mina mediciner får mig att må bättre.		
8	Genom att fortsätta min medicinering kan jag förebygga sjukdom.		
9	Min medicinering påverkar min mentala hälsa negativt.		
10	Mina mediciner gör mig trött och slö.		

Nedan följer sju påståenden om KOL som antingen är sanna eller falska. Välj vet ej om du är osäker. Chansa inte då det försämrar resultatet.

	Påståenden om KOL	Sant	Falskt	Vet ej
I	Bokstäverna i förkortningen KOL står för Kroniskt Obstruktiv Lungsjukdom.			
II	Sjukdomen KOL delas in i 5 grader.			
III	Rökstopp är den enda åtgärd som hejdar sjukdomsprocessen.			
IV	Läkemedel är mycket viktigare än att röra på sig.			
V	Influensavaccin bör tas årligen om man har KOL.			
VI	Diagnosen KOL ställs med hjälp av spirometri.			
VII	Lungröntgen vid KOL är alltid onormal.			

## The Questionnaire Used in the Study Translated to English



**SAHLGRENKA ACADEMY**

### **Questionnaire for patients at the COPD-centre at Sahlgrenska University Hospital**

The survey will be used as part of a master thesis for a student studying medicine at Sahlgrenska.

The purpose of the questionnaire is to look for differences between newly admitted and recurring visits to the COPD-centre in reference to the patients' adherence to medication and to their knowledge of COPD. Hopefully surveys like this one could lead to knowledge that could improve the treatment of COPD.

The questionnaire is anonymous and the responses will only be seen by the person collecting the data.

We are grateful for your participation.

Kindly  
Medical Student Väinö Lilja  
Sahlgrenska Academy  
Gothenburg University



Exempel		Yes	No
X	This questionnaire is anonymous.	X	

		Yes	No
A	Is this your first visit to the COPD-centre as a patient?		

		Female	Male
B	Gender		

		Yes	No
C	Do you smoke?		

How did you get in contact with the COPD-centre?		
D1	You made your own referral ("Egenremiss" in Sweden).	
D2	Referral from a family doctor.	
D3	Referral from another clinic at a hospital.	
D4	Referral from a doctor after visiting the emergency room.	
D5	Some other way (write):	

District		
E1	Hisingen Island	
E2	Downtown, Majorna-Linné, Örgryte-Härlanda	
E3	Eastern Gothenburg (Angered, Gamlestaden, Bergsjön)	
E4	Western Gothenburg (Askim, Frölunda-Högsbo, Långedrag)	
E5	Crane municipality to Gothenburg	
E6	Outside of the greater Gothenburg region	

		Yes	No
F	Were you born in Sweden?		

		One	Both	None
G	Were your parents born abroad?			

H	Your age. Highlight a box below.									
	0-44	45-49	50-54	55-59	60-64	65-69	70-74	75-79	80-85	85+

How much does COPD affect your everyday life? Highlight below.

Nothing	0	1	2	3	4	5	6	7	8	9	A lot
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Answer below for all of your prescribed medications, not just the ones you have due to COOPD.

Question		Yes	No
1	Do you ever forget to take your medicine?		
2	Are you careless at times about taking your medicine?		
3	When you feel better, do you sometimes stop taking your medicine?		
4	Sometimes if you feel worse when you take the medicine, do you stop taking it?		
5	I take my medication only when I am sick.		
6	It is unnatural for my mind and body to be controlled by medication.		
7	My medications makes me feel better.		
8	By staying on medication, I can prevent getting sick.		
9	My medication makes me feel weird.		
10	Medication makes me feel tired and sluggish.		

Below you have 7 statements about COPD that are either true or false. Highlight the “?” if you are uncertain. Guessing will lower the overall results.

True or False		True	False	?
I	The letters COPD stand for Chronic Obstructive Pulmonary Disease.			
II	COPD is categorized in to 5 stages.			
III	Smoking cessation is the only proven way of slowing down disease progression in COPD.			
IV	COPD-medication is a lot more effective than exercise.			
V	Each year, all persons with COPD should be vaccinated against the influenza infection			
VI	A confident diagnosis of COPD can only be made with spirometry.			
VII	A chest x-ray is always abnormal if a patient has COPD.			