Members' influence in COPD patient organizations
A comparative study of Norway and Austria

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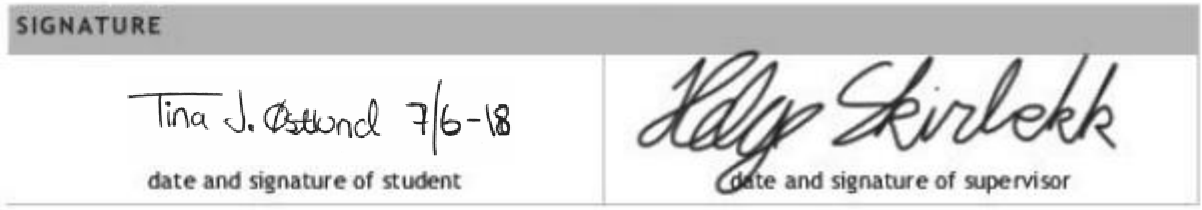

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Abstract

The aim of this thesis is to study how patients with chronic pulmonary obstructive disease (COPD) influence their patient organizations in Norway and in Austria. This is of interest as chronic diseases are a major challenge to the sustainability of healthcare services. As chronic disease management is of growing significance, the influence of patient organizations can play an important role when managing this burden. Based on the prevalence of COPD, the national legal framework, the aspect of culture and organizational structure, a comparative study of Norway and Austria has been carried out.

I will examine how patient organizations for people with the somatic disease of chronic obstructive pulmonary disease (COPD) in Norway and Austria are taking their members perspectives into consideration. I will also examine how these perspectives can influence their services. My research questions are:

1. How are patients with chronic pulmonary obstructive disease (COPD) organized in Norway and in Austria?
2. How are the patients' perspectives taken care of in these organizations?

In Norway, a qualitative study within the National Association for Heart and Lung Diseases (LHL) was conducted. In Austria, a content analysis of the homepage of the Osterreichische Lungenunion was conducted (ALU).

Compared to Norway, Austrian culture is perceived to be more liberal concerning smoking regulations and preventative measures. Patients with COPD do not have the same power with regards to influence and further political action compared to Norway. This may be due to the national legal framework implemented, where the external representation of patients in Austria is the Ombudsman. Patient organizations such as ALU are rather self-help groups. Concerning Norway, by using the theoretical framework of patient-centered care and experience-based co-design, members within LHL were found to have both internal and external influence. It was associated with organizational structure, personal initiative and the concept of democracy. Through these concepts, their perspectives were used as illustrations for further political action. ALU was seen to be more equivalent to the local groups of LHL, where information regarding members' influence was absent. Rather the aspect of self-help and empowerment of members was central.

Acknowledgements

I would like to express my gratitude to the study programme of European Health Economics and Management (Eu-HEM), who gave me the opportunity to do this study. Special thanks go to the Management Center Innsbruck and the University of Oslo. Furthermore, I would like to express my deepest gratitude to my supervisor Helge Skirbekk, for guiding me through the process of writing this master thesis, for useful comments and engagement from start to finish.

I would also like to thank all participants from the National Association for Heart and Lung Diseases in Norway (LHL) who took part of this study, providing me with valuable information through their willingness to share.

A special thank and appreciation goes to my friends and family who have willingly supported me with their abilities and their smiles through this two years of education, I will be forever grateful.

1. Introduction

Involving the patient in service improvement and responding to their demands and needs, has and will play a key role in the design of healthcare services. Good quality within healthcare requires that patients' experiences are considered and affecting the way healthcare are organized. The patient has first-hand information and is also the one the services are for. Therefore, to provide the best possible quality of care and involving patients in quality improvement is an important measure to take into account. Based on the demands and needs expressed, the goal would be to co-design and re-design the healthcare system together with the patients and not around them. Laws and regulations, favorable stakeholder relationships, as well as the healthcare system itself should lay the foundation for structuring this process[1] [2].

Within healthcare, there has been a change from a patient-passive care system towards a patient-participating care system where responding to a patient's uniqueness of experiences and preferences is a central aspect. Previous studies have reported that patient-centered care has decreased readmission rates to hospitals, average length of stay and prevalence of mortality. Also, it has led to improvement in chronic disease management and decreased costs. However, there are some possible barriers due to structural, - healthcare professionals and patient-related, - factors. A fragmented system or power imbalance may take the focus away from the patient as an individual and not a disease or statistic[3].

Few can argue the disadvantages of patient-centered care, however, it may be difficult to implement into practice. This means that general action must be involved to help promote the benefits of its implementation. Therefore, real life evidence from the organizations and its members is needed to tackle the possible barriers and to closer examine how the situation is pictured in reality[4].

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[1] Bate P, Robert G. Experience-based design: from redesigning the system around the patient to co-designing services with the patient [Internet] London: BMJ Quality & Safety; 2006 [Cited 2018 February 21]; 15: 307-310. Available from: http://qualitysafety.bmj.com/content/15/5/307

[2] Regjeringen. Brukermedvirkning [internet]. Oslo: Helse og Omsorgsdepartementet [updated 2009 May 26, cited 2018 Feb 21]. Available from: https://www.regjeringen.no/no/tema/helse-og-omsorg/sykehus/vurderes/prioriterte-utviklingsomrader/brukermedvirkning/id536803/

[3] Gluyas H. Patient-centred care: improving healthcare outcomes [Internet]. Pub Med: Nursing Standard; 2015 [Cited 2018 March 1]. Available from: https://www.ncbi.nlm.nih.gov/pubmed/26394978

[4] An independent panel commissioned by the Royal College of general practitioners. An inquiry into patient centred care in the 21st century, implications for general practice and primary care [Internet] Royal college of general practitioners: UK; 2014 [Cited 2018 February 21]. Available from: http://www.healthissuescentre.org.au/images/uploads/resources/Inquiry-into-patient-centred-care-in-the-21st-century.pdf

I will examine how patient organizations for people with the somatic disease of chronic obstructive pulmonary disease (COPD) in Norway and Austria are taking their members perspectives into consideration. I will also examine how these perspectives are implemented and influence their services. This will be conducted by a qualitative study within the national association for heart and lung diseases in Norway (LHL) and by a content analysis of the homepage of the Osterreichische Lungenunion in Austria (ALU).

My research questions are:

1. How are patients with chronic pulmonary obstructive disease (COPD) organized in Norway and in Austria?
2. How are the patients' perspectives taken care of in these organizations?

I will examine these questions through the theoretical framework of patient-centered care and experience-based co-design. By doing this, the categories derived from the qualitative data were organizational structure, challenges, legal framework, communication, influence and possible improvements. This will be further explained and compared to comparative data conducted from the homepage of ALU and discussed through the results and the discussion chapter.

1.2. Background

The reason for choosing chronic obstructive pulmonary disease is based on my experience from working at the emergency room at a local hospital in Norway. I observed the high prevalence of COPD patients that were admitted and that these were also to a high degree the ones that were readmitted. A history of previous hospital admissions may be due to disease severity, but psychological factors such as anxiety and depression are similarly related[5]. Also, during a study project in my last semester in Austria about non-communicable diseases, I was realising the relationship between lifestyle and chronic diseases and the opportunity we have to prevent the increasing prevalence. This is the reason for the choice of countries as well, for the aspect of comparison. After living in Innsbruck, Austria, I observed that drinking and smoking has more of a cultural influence and acceptance compared to Norway. Examples may be the Austrian liberal approach to indoor smoking and that alcohol is treated as a regular beverage and not strictly regulated. Also, the rules for advertisement differ, where beer and wine can be advertised

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[5] Ruparel M, Lopez-Campos J, Castro-Acosta A, Hartl S, Pozo-Rodrigues F and Roberts M C. Understanding variation in length of hospital stay for COPD exacerbation: European COPD audit. ERJ Open res; 2016 [Cited 2018 February 23]. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5005149/

in all channels of media[6]. This is of highly contrast to Norway in which the policy with regards to drinking and smoking is more restricted[7][8].

Within 2030, COPD is projected to rank third among all causes of death worldwide. This is largely due to the rise of an aging population and to the amount of people smoking which is seen to be risk factor number one. When this is the picture of today's reality and the disease is now considered preventable and treatable and can be hindered with change of lifestyle, this should be an incentive to turn the trend around[9].

The organization for economic co-operation and development (OECD) states that there is a deficit of information about the quality of the patterns and outcomes of care within primary care. There are some broad measures functioning, but little specific at local level regarding the micro quality of care[10]. This statement supports my interest for looking deeper the issue regarding patient organizations speaking the voice of their members. Therefore, getting in touch with the people who are working with the matter and the "expert patient" themselves is my way of approaching this study. This will be further explained in the results and discussion chapter.

2. Theoretical framework

2.2. Importance of study

Previous research has found that the importance of including patients is vital for their empowerment and for improving healthcare quality in general. In relation to the theoretical framework of patient-centered care, inclusion and shared decision making implies that the patient brings his or hers experiences forward. Using this as a valuable resource, the healthcare provider ought to explore this for developing cooperation in the process of treatment and care. Patient's expectations towards the healthcare system are based on deliberation of specific

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[6] Eisenbach-Stangl I, Alfred U, Karlsson T, Østerberg E. Alcohol policies in EU member states and Norway: A collection of country reports. Østerberg E, Karlsson, red. Chapter3, Austria. p. 76-100. Available from: https://ec.europa.eu/health/ph_projects/1998/promotion/fp_promotion_1998_a01_27_en.pdf

[7] Regjeringen. A tobacco-free future, national strategy for tobacco control [Internet]. Regjeringen: Oslo; 2013-2016 [Cited 2018 May 23]. Available from: https://www.regjeringen.no/contentassets/818bac68f5994a9181a0251032a8685a/national_strategy_tobacco.pdf

[8] Rentas R. The Borgen project, The blog [Internet]. Raven Rentas. 2017. The most common diseases in Austria: a result of lifestyle. August 20 2017 [Cited 2018 February 28]. Available from: https://borgenproject.org/the-most-common-diseases-in-austria/

[9] Adeloye D, Chua S, Lee C, Basquill C, Papana A, Theodoratou E, et al. Global and regional estimated of COPD prevalence: systematic review and meta –analysis [Internet]. Global Health Epidemiology Reference Group: The University of Edinburgh; 2015 [Cited 2018 March 1]. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4693508/

[10] OECD Health division. OECD Reviews of health care quality: Norway 2014– Raising standards [Internet]. OECD Publishing; 2014 [Cited 2018 March 2]. Available from: http://www.oecd.org/els/health-systems/ReviewofHealthCareQualityNORWAY_ExecutiveSummary.pdf p.24

elements such as treatment and health outcome. A combination of their expectations and experience will result in level of satisfaction where this can work as an important indicator for measuring quality[11]. This message is clearly stated through Donabedian's[12] writings on quality

> *Client satisfaction is of fundamental importance as a measure of the quality of care because it gives information on the provider's success at meeting those client values and expectations which are matters on which the client is the ultimate authority. The measurement of satisfaction is, therefore, an important tool for research, administration and planning* (12)

Over the past 20 years, patient satisfaction surveys have gained influence. However, how the results from these surveys are taken into consideration and have resulted in any improvements is not easy to measure. This supports the statement of OECD regarding the lack of information about patterns and outcomes in primary care[13].

There has been a change towards a patient-participating care system which has been followed by a replacement of the term discharge towards transition. This signals the increasing responsibility of healthcare organizations to maintain continuity and coordination of care for the benefit of the patient, which goes beyond discharge[14]. Lack of continuity is especially challenging concerning rehabilitation and follow-ups. Better coordination between primary and specialist care services is required, which will further have a preventative effect on a fragmented system[15]. Speaking of a patient-participating care system, some patient's wants to be involved in their own treatment process regarding inclusion and shared decision making. Others prefer to give all responsibility to the hands of the professionals. This can relate to the concept of the autonomous patient. Not

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[11] Brennan P F, Strombom I. Improving Health Care by Understanding Patient Preferences: The Role of Computer Technology [Internet]. Journal of the American Medical Informatics Association : JAMIA. 1998 [Cited 2018 March 5] 5(3):257-262. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC61299/

[12] Avis M, Bond M,Arthur A. Satisfying solutions? A review of some unresolved issues in the measurement of patient satisfaction [Internet]. Journal of advanced nursing; 1995 [Cited 2018 March 8]. Available from: https://onlinelibrary.wiley.com/doi/epdf/10.1046/j.1365-2648.1995.22020316.x?purchase_site_license=LICENSE_DENIED&show_checkout=1&r3_referer=wol&purchase_referrer=onlinelibrary.wiley.com&tracking_action=preview_click

[13] Al-Abri R, Al-Balushi A. Patient Satisfaction Survey as a Tool Towards Quality Improvement [Internet]. Oman Medical Journal; 2014 [Cited 2018 March 13]. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3910415/

[14] Harrison J. Patient-centered solutions for improving transitions of care [Internet]. Planetree; 2014 [Cited 2018 March 16]. Available from: http://planetree.org/planetalk/patient-centered-solutions-for-improving-transitions-of-care/

[15] Røsstad T, Garåsen H, Steinsbakk A, Sletvold O,Grimsmo A. Development of a patient-centred care pathway across healthcare providers: a qualitative study [Internet]. BMC health services research; 2013 [Cited 2018 March 16]. Available from: https://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-13-121

all members of a patient organization make use of the assistance it can provide. It depends on the individual and his or hers needs and their ability to make choices for oneself[16].

In relation to the growing importance of patient organizations and their role of speaking the voice of their members, I saw this as a natural theoretical framework for gaining insight of the matter. On the other hand, it is expressed that a patient-centered care approach is easier in theory than in practice[17]. However, my assignment is not to practice the work of art but rather to examine the performance of organizations in relation to taking care of its members' perspectives and experiences.

2.3. Patient organizations and the "expert patient"

I start off by defining what an organization is in the matter of this study. According to "The open university"[18]

> *An organization is a group of individuals working together to achieve one or more objectives. They are composed of individuals and groups of individuals, they are oriented towards achieving collective goals, they consist of different functions, the functions needs to be coordinated and last, they exist independently of individual members who may come and go* (18).

According to the World Health Organization (WHO), a healthcare system consists of all organizations, people and actions whose primary intent is to promote, restore or maintain health[19]. The rising trend of chronic diseases and an aging population is followed by a growing demand of healthcare services. Patient organizations are one type of initiative to tackle this burden through promoting, restoring and maintaining health. The influence and role of patient organizations can be seen as expanding the role of the expert-patient[20].

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[16] Habiba A M. Examining consent within the patient-doctor relationship [Internet]. Journal of medical ethics; 2000 [Cited 2018 March 21]: 183-187. Available from: http://jme.bmj.com/content/26/3/183

[17] Lavigne J M. Why patient centered care is here to stay [Internet]. Acceron; 2017 [Cited March 22]. Available from: http://www.accreon.com/why-patient-centered-care.html

[18] The Open University. What is an organization? [Internet]. Available from: http://www.open.edu/openlearn/money-management/organisations-and-management-accounting/content-section-1

[19] Ratnapalan S, Uleryk E. Organizational Learning in Health Care Organizations [Internet]. Toronto, Canada; Division of Emergency Medicine, The Hospital for Sick Children; 2014 [Cited 2018 March 24]. Available from: http://webcache.googleusercontent.com/search?q=cache:9VFTEKRAQHwJ:www.mdpi.com/2079-8954/2/1/24/pdf+&cd=3&hl=no&ct=clnk&gl=at

[20] Guillamon N, Armayones M, Hernandez, Gomez-Zuniga B. The role of patient organizations in participatory medicine: can virtual health communities help participatory medicine accomplish objectives? [Internet]. Journal of participary medicine; 2010 [Cited 2018 March 24]. Available from: https://www.medscape.com/viewarticle/737449_2

The definition of an organization embraces both internal relations within the organization and the external relationships between the organization and other stakeholders. Concerning the external relationships, patient organizations has had an increasing role with regards to influence and promoting patients experiences[21]. Micro level influence of patients within the organization can further have a greater social relevance. This brings me over to the concept of the expert patient. An observation made by health professionals is that patients are the ones that understand their disease the best. They are the ones with the knowledge and experience which could be used as a key decision-maker and a valuable resource for further political action and for promoting quality of health in general. Empowerment and increasing responsibility may strengthen the position of the patient and generate valuable relations and political action[22].

Patients with chronic diseases tend to seek information and social support in both formal and informal groups. Patient organizations are there to improve the quality of life for people living with a certain condition such as COPD. These organizations may also serve as a mediator between the patient and the professionals or speak their voice in relation to legal concerns. The main activities of patient organizations can relate to four areas of action: policy, capacity-building and education, peer support and research and development. The objective is usually raising public awareness, dissemination of information and promoting research[23]. Regarding external influence, it is said to be two bases of argumentation justifying participation of patient organizations in health policy making. The first is the political one, which implies the democratic value of transparency and accountability. The second argument is health-related and derived from the principle of equity and health promotion[24].

Concerning an organizations broad area of action, Peter Drucker argues that healthcare organizations are the most complex form of human organizations we have to manage. This statement is based on the fact that healthcare is a mixture of different professions such as physicians, administrators, patients and the government and is also influenced by politics and policy. All these different stakeholders and areas of action have seemingly different interests

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[21] Van de Bovenkamp M H, Trappenburg J M. Government influence on patient organizations [Internet]. Health Care Analysis; 2011 Dec 19 [Cited 2018 March 27] (4): 329–351. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3212690/

[22] The Expert patient, A new approach to chronic disease management for the 21st century. [Internet]. Department of health: UK [Cited 2018 March 28]. Available from: http://webarchive.nationalarchives.gov.uk/20120511062115/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4018578.pdf

[23] D Sienkiewicz, C van Lingen. The added value of patient organizations [Internet]. European patients forum: Brussels; 2017 [Cited 2018 March 28]. Available from: http://www.eu-patient.eu/globalassets/library/publications/epf_added_value_report_final.pdf

[24] K Souliotis, E Agapidaki, L E Peppou, C Tzavara, D Varavars, O C Buonomo et al. Assessing patient organization participation in health policy: a comparative study in France and Italy [Internet]. Int J Health Policy Manag. 2018 [Cited 2018 April 3] (1): 48–58. Published online 2017 Apr 15. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5745867/

which may not always harmonize. It is ought to be a well-functioning multi stakeholder relationship between the different levels, from micro to macro, such as individuals, clinics, hospitals, organizations and the government[25]. Barriers can arise with regards to a fragmented system or poor communication between the different levels which are stated about both the Norwegian and the Austrian healthcare system. Nevertheless, the structure and the processes of these systems have to be held accountable in relation to the legal framework implemented. The disease of COPD requires good coordination between various types of healthcare institutions. If not, such a fragmented system can lead to burdens on action and quality[26].

Another perspective regarding organizational culture is Peter Senge's theory about learning organizations which can be seen in accordance to Drucker. Senge states that the importance of organizational learning within healthcare systems is to provide a framework to structure this complex multi stakeholder system. It is essential to implement a foundation for mutual learning and provision of assigned functions to collectively improve patient care and outcomes. This may also lead to higher level of satisfaction. Internal organizational learning forms the base for weaving these diverse groups into a cooperative platform for the benefit of the expert patient, as Drucker stated. These perspectives can be seen in relation to the action and purpose of patient organizations derived from its definition and forms a well-suited basis for deeper examining the research questions.

2.4. Patient-centered care (PCC)

When researching and analysing the interviews, patient-centered care (PCC) was my main focus when looking into the topic of members influence within patient organizations. When evaluating health management, well-established relationships working together for the benefit of the patients ought to be the main goal. A patient-centered approach is one way of developing and managing a care system based on collaboration and a multi-stakeholder relationship[27].

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[25] Hagland M. Transformative quality: The emerging revolution in health care performance (E-book). CRC Press: 2008 (Cited 2018 May 12). Available from: https://books.google.no/books?id=zBHVg0xR548C&pg=PT57&lpg=PT57&dq=complex+form+of+human+organization&source=bl&ots=RCLv82bbKM&sig=DAM18-

[26] Hofmarcher M, Quentin W. Austria: Health System Review. Health systems in transition, vol 15 No7 [Internet]. European Observatory on health systems and policies: 2013 [Cited 2018 April 8]. Available from: http://www.euro.who.int/__data/assets/pdf_file/0017/233414/HiT-Austria.pdf

[27] Feigenbaum E. Theories of healthcare management [Internet]. Azcentral: 2017 [Cited 2018 May 8]. Available from: https://healthyliving.azcentral.com/theories-of-healthcare-management-12503617.html

The theoretical framework of patient-centered care focuses the role and influence of individuals and their patient representatives in healthcare policy and decision-making. This is done by using an adequate mix of instruments such as shared decision-making and experience-based co-design, both direct and indirect. Patient-centered care as a term has been used to describe an approach where healthcare providers *"see the situation through the eyes of the client"*[28]. There are various definitions of patient-centered care where the most common may be on the point of care concerning services and systems or broader policy considerations. The essence can be defined as *"in the broadest terms, patient-centered care is care organized around the patient. It is a model in which providers' partner with patients and families to identify and satisfy the full range of patient needs and preferences"*[29].

A misunderstood or unsatisfied patient usually has needs that requires to be met, either they are physical or emotional, which again results in their level of satisfaction. An unsatisfied patient could be seen as evidence of a service's failures or missing's. At the same time, patients are individuals and will vary in their capacity, experiences and demands. They will therefore require different types of services[30]. There are various ways of involving patients, but in this case, it is done by gathering patient experiences of healthcare services, using this as first-hand-information for improvement of quality. Healthcare organizations in general seek to increasingly improve quality by refocusing their policy and delivery towards and around the individual patient. By doing this, they are moving towards a patient-centered care system which can be seen in relation to both Drucker and Senge's theory about organizational culture[31]. A system using patient-centered care will aim to empower the expert-patient based upon personal experiences.

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[28] Wiig S, Storm M. et al. Investigating the use of patient involvement and patient experience in quality improvement in Norway: rhetoric or reality? [Internet]. BMC Health Services Research; 2013 [Cited 2018 April 13]. Available from: https://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-13-206

[29] Frampton S, Guastello S, Brady C et al. Patient-Centered Care Improvement Guide. 2008. Cited by: Kreindler A S. The politics of patient-centred care [Internet]. Health Expectations; 2015 [Cited 2018 May 8]. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5060841/

[30] Lewis S. Patient-Centered Care: An Introduction to What It Is and How to Achieve It, a Discussion Paper for the Saskatchewan Ministry of Health [Internet]. Saskatoon; 2009 [Cited 2018 May 8]. Available from: https://idainstitute.com/public_awareness/mythbusters/pcc_definitions/filedownload/Q2hhbmdlX0ZvdW5kYXRpb25fSW50cm9fdG9fUGF0aWVudF9DZW50ZXJlZF9DYXJlLnBkZg==/

[31] Luxford K, Safran G D, Delbanco T. International Journal for Quality in Health Care: Promoting patient-centered care: a qualitative study of facilitators and barriers in healthcare organizations with a reputation for improving the patient experience [Internet]. Oxford Academic; 2011 [Cited 2018 May 8]. Available from: https://academic.oup.com/intqhc/article/23/5/510/1864420

Empowerment is defined by WHO as *"A process in which patients understand their role, are given the knowledge and skills by their health-care provider to perform a task in an environment that recognizes community and cultural differences and encourages patient participation"…* which should be both an individual and community process[32].

2.5. Experience-based Co-design (EBCD)

The shift towards a patient-participating healthcare system has correspondingly resulted in a shift from a strong top-down approach towards bottom-up approach in how to structure the health sector more "user-centric". In relation to patient-centered care and the expert patient, experience-based co-design (EBCD) could complement the theoretical framework when looking into the research questions provided. Experience-based co-design has evolved around the world in the last decade and has been adapted to take account of local organizational context and processes, such as this study. As mentioned, there are little specific measures at the local level regarding quality of care; therefore this is a well suited complement to the theoretical framework. Experience-based co-design is an approach which aims to improve healthcare services by combining user experience design tools and processes to improve quality. This process includes both the patients, in this case the members, and the employees within the organization. It is an approach which is based on participatory action research, user-centered design such as patient-centered care, learning theory such as Senge's, and narrative-based approaches, to form change. Elements for implementing experience-based co-design within an organization can be patient-staff meetings, co-design groups or interviews which will be further explained within the discussion[33].

2.6. Chronic obstructive pulmonary disease (COPD)

Chronic long term conditions are major challenges to the sustainability of healthcare services as its prevalence is increasing. In this regards, following the millennium, the healthcare system has been required to shift focus towards long term, patient-centered care[34]. Chronic obstructive

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[32] World Health Organization. WHO Guidelines on Hand Hygiene in Health Care: First Global Patient Safety Challenge Clean Care Is Safer Care. Chapter 2 Patient Empowerment and Health care (E-book). Geneva; 2009 [Cited 2018May 13]. Available from: https://www.ncbi.nlm.nih.gov/books/NBK144022/

[33] Donetto S, Tsianakas V,Robert, G. Using Experience-based Co-design to improve the quality of healthcare: mapping where we are now and establishing future directions [Internet]. London: King's College London: 2014 [Cited 2018 May 23]. Available from: https://www.kcl.ac.uk/nursing/research/nnru/publications/reports/ebcd-where-are-we-now-report.pdf

[34] Eaton, S., Roberts, S. Turner, B. Delivering person centred care in long term conditions [Internet]. The bmj: UK; 2015 [Cited 2018 May 13]. Available from: http://tvscn.nhs.uk/wp-content/uploads/2015/02/Personcentredcarein-LTCs.pdf

pulmonary disease (COPD) is projected to rank fifth in terms of disability-adjusted life years (DALYs) in 2020 and third among all causes of death worldwide in 2030. This is largely due to the rise in life expectancy. Also, the aspect of smoking is important, seeing that smoking is considered to be the single most important risk factor for developing COPD. At the same time, smoking has a cultural aspect in several countries, such as in Austria (6)[35]. When this pictures the reality and the fact is that COPD is now considered a preventable and treatable disease which can be slowed down or hindered with a change of lifestyle, this ought to be prevented. Lifestyle can have a cause and effect relationship for developing such a lung disease. Smoking over a long period of time may give permanent lung damage. Additional, other factors such as asthma and genetic predisposition or occupational exposure to hazardous gasses and chemicals can be triggers. COPD is a non-reversible disease, but it can be treated and its developing process can be dampened[36]. It is a chronic inflammatory lung disease that leads to obstructed airflow from the lungs which is then followed by breathing difficulties, cough, sputum production and wheezing. This will impact the daily life and activity of the individual diagnosed[37].

3. Aims: research questions

The aim of this study is to examine how patient organizations for people with the somatic disease of chronic obstructive pulmonary disease (COPD) in Norway and Austria are taking their members perspectives into consideration. I will also examine how these perspectives can influence their services. By using the theoretical framework provided, my research questions are:

1. How are patients with chronic pulmonary obstructive disease (COPD) organized in Norway and in Austria?
2. How are the patients' perspectives taken care of in these organizations?

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[35] Ludwig Boltzmann institute for COPD and pulmonary epidimiology. Annual Report 2014 [Internet]. Otto Wagner Hospital: Vienna; 2015 [Cited 2018 April 21]. Available from: http://copd.lbg.ac.at/sites/files/copd/Annual_Report_2014_LBI_COPD.pdf

[36] LHL. KOLS, den nye folkesykdommen [Internet]. Landsforeningen for hjerte- og lungesyke: Oslo [Cited 2018 May 23]. Available from: https://www.lhl.no/globalassets/hjerte--og-karsykdom/faktaark-sykdom/fakta_lunge_kols-okt-2014.pdf

[37] Mayo Clinical staff. COPD [Internet]. Mayo Clinic [Cited 2018 May 23]. Available from: https://www.mayoclinic.org/diseases-conditions/copd/symptoms-causes/syc-20353679

4. Research method

Based on a dual methodology, qualitative interviews with representatives from the national association for heart and lung diseases (LHL) were conducted in Norway. In Austria, for practical reasons and lack of informants, documents and the webpage-content of the Osterreichische Lungenunion (ALU) was analyzed. Through this process, comparable data in relation to the qualitative categories developed from the Norwegian informants was to some degree discovered. The results from these two studies will be analyzed separately and compared in the discussion chapter. The study has an explanatory design based on evidence to answer the research questions provided.

4.2. Qualitative research method

Qualitative research methods were developed within social and human sciences and refer to theories on interpretation and human experiences. By speaking with people in their natural setting, the goal is to investigate personal experiences by being an active participant in gaining knowledge about the research question. When doing qualitative research, the goal is not to find definite answers, but rather gain understanding. The choice of research method was grounded in the beneficial effect it has when exploring human and social experience, communication, expectations, attitudes and processes. Therefore, it appeared appropriate and useful concerning the aim of this study and it is highly valuable within healthcare in general[38].

The choice of research methodology depends mainly on the nature of the research question. Patients' experiences and perspectives are valuable to gain insight in how the organization is performing. This insight may provide information on how to achieve patient satisfaction through knowledge about which issues that ought to be crucial to confront and further, which changes this could involve[39]. Seeing this from a patient-centered perspective, including the members within the organizations is a crucial element and ought to be implemented. Qualitative studies generally investigate smaller groups of people compared to that of quantitative studies. However, qualitative studies examine the information obtained from the informants more deeply to understand how and why. When undertaking a qualitative study, there are no guidelines regarding how many informants is needed where one follows a process called saturation. Theoretical saturation is described as a process where the researcher continues to sample relevant

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[38] Malterud K. The art and science of clinical knowledge: Evidence beyond measures and numbers. Lancet 358:397-400; 2001.

[39] Reader T W, Gillespie A, Roberts J. Patient complaints in healthcare systems: a systematic review and coding taxonomy [Internet]. BMJ Quality and safety: UK; 2014 [Cited 2018 March 24]. Available from: http://qualitysafety.bmj.com/content/early/2014/05/29/bmjqs-2013-002437

information until there are no new theoretical insights being conducted from the data. This was reached within this qualitative study regarding LHL[40].

Stated by Malterud, a researcher should always reveal the style of analysis used in qualitative studies. The style of analysis used in this study was a mixture of an intuitive and theory-based style. This was done through the process of systematic analysis of data, coding and identifying categories within the data and finding patterns within the information provided. Concerning the intuitive style, data was first organized by high lightening the most important aspects which seemed relevant by intuition. Further, the aspect which was seen as most important in relation to the theoretical framework provided was further analysed and highlighted accordingly. In this way, the empirical data and the theory worked together when examining the research questions. A challenge may be to acknowledge the effect theory may have on the aspect of objectivity. Therefore, a mixture of style was used and a transparent description of the path from data to findings is necessary[41].

4.3. Limitations

Qualitative research can and is often criticized for being biased, of small scale and/or lacking rigor. On the other hand, when carried out properly it can be equally reliable and valid as quantitative research. Examining this, reliability and validity assesses the aspect of objectivity and credibility of the research. Concerning reflexivity, this relates to the reproducibility of data and the commitment to own angel of investigation. One way of improving reflexivity is taping and transcribing the data, which was performed within this study. Concerning validity, this relates to the honesty of data and to what degree the findings are an accurate representation of the matter investigated. It can be important to mention the concept of bias which cannot be eliminated, but rather taken into consideration. This can be relevant concerning the roles of the participants either they are employees or members. Further, the aspects of health of the informants, in this case primarily the members; can be seen as a limitation. When being sick and labelled by a diagnosis, your personal opinion can easier be affected by how you feel and the experience of how you are treated. This could be more relevant for some than for others in relation to disease severity and individual capacity. Human interactions cannot be studied or

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[40] Bryman A. How many qualitative interviews is enough? [Internet] Editors: Baker, E. S. & Edwards, R. National Centre for research methods review paper: University of Leicester [Cited 2018March 23]. Available from: http://eprints.ncrm.ac.uk/2273/4/how_many_interviews.pdf

[41] Malterud K. Qualitative research: standards, challenges, and guidelines. Lancet 358:483-488; 2001.

explained in simple terms, and understanding of it will be different amongst people where my understanding was one perspective[42].

The greatest limitation within this study was the barrier between what was intended to do and what was possible to do in practice. This made some changes necessary and resulted in a dual methodology. The biggest limitation was based on difficulties retrieving Austrian informants where I reached out to the organization, but did not get the response wanted. Drawn from the chosen methodology, comparable data was found to strengthen my comparative study. On the other hand, not to the degree wanted. The aspect of personal experience and attitudes is absent and not all categories had the information needed to compare. Furthermore, when trying to examine the situation of the prevalence of diagnosed COPD patients in Austria, this similarly challenging based on lack of data on the topic.

In Salzburg, Austria, the burden of lung diseases initiative (BOLD), was developed to measure the prevalence of COPD and its risk-factors in a standardized way. As this may be the only available research on the topic, it implied some limitations with regards to existing data and literature[43]. Although COPD is important and challenging on a worldwide scale, reliable data are lacking in most countries, such as in Austria[44]. This made me question the aim of study and made it unpredictable. Additional, it made me curious. Therefore, I continued with the study intended.

4.4. Study sample and data collection, LHL

The qualitative research is based on face-to-face semi-structured anonymous interviews over approximately a two months' time period. In the recruitment process of potential participants, email-invitations were sent out. There was a great variation of response, but the informants who took part of the study were very helpful and positive. This is a sample of people working in various areas within the same organization of LHL. Their viewpoints vary from a medical perspective to a political one. This benefits the validity of the study. At the same time, it is

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[42] Anderson C. Presenting and evaluating qualitative research [Internet]. American Journal of Pharmaceutical education; 2010 [Cited 2018 March 24]. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2987281/

[43] Schirnhofer L, Lamprecht B, Vollmer M W, Allison J M, Studnicka M, Jensen L E, et al. COPD Prevalence in Salzburg, Austria. Results from the burden of obstructive lung disease (BOLD) study [Internet]. Volume 131, Issue 1, Pages 29–36. Chest Journal: 2007 [Cited 2018 March 14]. Available from: http://journal.chestnet.org/article/S0012-3692(15)49877-0/fulltext

[44] Shahbab L, Jarvis M J, West R. Prevalence, diagnosis and relation to tobacco dependence of chronic obstructive pulmonary disease in a nationally representative population sample [Internet]. Thorax: UK; 2006 [Cited March 16]. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2117062/

important to emphasize that the sample of informants used in this study is not transferable to the population as a whole, and that the findings provided are not applicable for all organizations. The findings are rather a description applicable within this specific setting.

Additional, the study sample contains members of the organization diagnosed with COPD. This is to strengthen the aspect of the issue concerning the expert-patient. When contacting members, I accessed the homepage of LHL and reached out to several local groups. I spoke with five members that were also leaders within their local group located in their municipality. To reach more individual members, a request was sent out in the member-magazine of the organization, searching for people who wanted to take part of the study. Because of health information and patient confidentiality from the organizational side, they could not provide me with members. Therefore they assisted me with sending out a request where members could contact me instead of me contacting them. Four people reached out; two were willing to have a phone-interview while two wanted to answer a questionnaire over email.

This is an overview over the participants where their names, gender, role and locations are anonymous. There were 12 participants, five from the administration and seven that were members. Five of these members are also leaders within their local group.

Table 1:

Participant 1	Employee in the LHL administration
Participant 2	Employee in the LHL administration
Participant 3	Employee in the LHL administration
Participant 4	Leader local group
Participant 5	Leader local group (telephone interview)
Participant 6	Leader local group (telephone interview), contacted me based on note in the member-magazine
Participant 7	Leader local group (telephone interview), contacted me based on note in the member-magazine
Participant 8	Employee in the LHL administration
Participant 9	Leader local group
Participant 10	Member, accountant local group (answered a questionnaire via email), contacted me based on note in the member-magazine
Participant 11	Member, local group (answered a questionnaire via email), contacted me based on note in the member-magazine
Participant 12	Employee in the LHL administration

The choice of semi-structured interviews was due to the possible situation of sensitive information which should be taken into consideration when researching issues within healthcare. Furthermore, semi-structured interviews open for conversations that may stray out from some of the answers which may be interesting to further investigate. Also, open-ended questions give a degree of freedom to the informants[45]. An interview-guide was prepared, one for the employees in the administration and another guide for the members (*appendix*). This is a list of open-ended questions and topics wanted to uncover during conversation. As the interviewer, it was important to be as objective as possible and not lead the respondents' answers in any way. I felt this was especially important when communicating with the members and made every single interview different from the previous ones.

The interview-guide used when having face-to-face or telephone interviews was the same document that was sent out to those who wanted to answer a questionnaire over email. This therefore became a survey research with a questionnaire with both closed-ended and open-ended questions[46].

The interview guide covered topics such as challenges, legal framework, communication, rehabilitation, possible measures, top-down/bottom-up relations, degree of influence and some personal experiences and attitudes. The interviews lasted for about thirty to forty minutes. They were recorded and the informants were informed.

Transcripts are in Norwegian, but the important and useful statements are translated into English and provided in the results chapter.

4.5. Content-analysis of webpage, ALU

After conducting qualitative interviews within LHL and deriving categories from the transcripts, some aspects of organizational structure of ALU was central to explore. The procedure for conducting information from the homepage of ALU was done via three steps. First, categories from the qualitative data were used as a starting point for finding comparative Austrian data. Through a translating programme, information was conducted, sorted and noted in relation to these categories. Then an analysis was done to compare similarities and differences. The data is presented in the result chapter and is further discussed alongside the data conducted from the qualitative interviews of LHL.

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[45] Cohen D, Crabtree B. Qualitative research guidelines project, semi-structured interviews [Internet]. Robert Wood Johnson Foundation; 2006 [Cited 2018 March 24]. Available from: http://www.qualres.org/HomeSemi-3629.html

[46] Child care & early education: Survey research and questionnaires [Internet]. The regents of the University of Michigan [Cited 2018 March 24] Available from: https://www.researchconnections.org/childcare/datamethods/survey.jsp

4.6. Ethical measures and confidentiality

When doing empirical studies, it ought to be clearly stated that the data cannot be used to trace recognizable information unless the informant has obtained prior consent. Regarding the issue of sensitive information, ethical considerations had to be taken pre interviews, such as confidentiality clause, informed consent and anonymity. The reason for having anonymous interviews is based on the fact that identity is not relevant, but rather the message that is told. However, it is relevant if they are working within the organization or if they are members. Their diagnosis, name or title is not relevant in relation to the aim of this study.

When conducting any type of research, it would be unethical to gather information without informing the informants and expressing the aim of the study, explaining their role. Therefore a document of information and consent was made for the Norwegian part of study. The document was prepared for the reason to make clear to all participants that participation was on a voluntary basis and that they were free to withdraw from the interview at any time.

The research project was approved by NSD, the Norwegian centre for research data (project no: 59143).

Concerning the information gathered through the content analysis of the homepage of ALU, this is information taken from the internet which is available to the general public. Therefore, no ethical considerations or issues of anonymity were taken into account.

5. Results

As a starting point, it is beneficial to examine the differences between Norway and Austria concerning the prevalence of chronic obstructive pulmonary disease and the legal framework which is implemented. I will continue with presenting the results conducted from the Norwegian informants and the information conducted from the Osterreichische Lungenunions homepage.

5.2. COPD: a comparison of Norway and Austria

The legal restrictions on alcohol and smoking are stricter in Norway than in Austria. Examples are access, advertising and smoking regulations. The legal age for buying tobacco and alcohol in Norway is 18 for tobacco and beverages containing less than 21% alcohol and 20 for spirits containing more than 21% alcohol. In Austria however, the legal age is in contrast 16 and 18. Also, the cultural aspect concerning drinking and smoking is more commonly accepted in Austria than in Norway[47] [48] [49]. In 2015 22,4% of the Norwegian population aged from 15 and upwards smoked daily, where in Austria, 35,5% of the adult population were smokers. Another very interesting aspect in relation to smoking culture is the legal framework regarding where it is permitted to smoke. For the sake of comparison, in Austria in 2015, these areas were not smoke free: healthcare facilities, universities, government facilities, indoor offices, restaurants, pubs and bars and public transport. This is highly contrasted to Norway, where all these areas were to be smoke free[50] [51].

In Austria, hospital admission rates for chronic diseases such as COPD are considerably higher than the OECD average. Drawn from data provided by European patient associations which participated in the EFA survey, Austria was one of the countries with the highest prevalence of COPD with a number of more than 10% of the population[52]. Additional, more than 30% of the population suffers from some sort of a respiratory disease such as allergy, asthma or COPD[53]. High admission rates may be an indication of poor quality of primary care based on the fact that most symptoms could be handled without need for hospitalisation. However, it is important to state that there are different types of diagnosis and a varying degree of severity which may require intense treatment[54]. In contrast to Austria, a more recent study states that approximately 150 000 people have COPD in Norway which is estimated to be about 6% of the Norwegian population[55].

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[47] Monsen Ø, Siem H, Weibust B E. Norway and health, and introduction [Internet]. Norwegian directorate of health: Oslo; 2012 [Cited 2018 May 25]. Available from: https://helsedirektoratet.no/Lists/Publikasjoner/Attachments/302/Norway-and-health-an-introduction-IS-1730E.pdf

[48] Chartsbin. Statistics collector team 2012: Minimum legal age for buying alcohol around the world [Internet]. Chartsbin [Cited 2018 May 21. Available from: http://chartsbin.com/view/l7kn

[49] Snowdon C. The nanny state index. Austria 2017 [Internet]. Epic center: Brussels; 2017 [Cited 2018 May 21]. Available from: http://nannystateindex.org/austria-2017/

[50] Drope J, Schluger N, Cahn Z, et al. The Tobacco Atlas, Austria [Internet]. Atlanta: American Cancer Society and Vital Strategies; 2018 [Cited 2018 May 19]. Available from: https://tobaccoatlas.org/country/norway/

[51] Drope J, Schluger N, Cahn Z, et al. The Tobacco Atlas, Norway [Internet]. Atlanta: American Cancer Society and Vital Strategies; 2018 [Cited 2018 May 19]. Available from: https://tobaccoatlas.org/country/austria/

[52] OECD. Health at a glance. 2015 – How does Austria compare? [Internet]. OECD: 2015 [Cited May 28]: p.9. Available from: https://www.oecd.org/austria/Health-at-a-Glance-2015-Key-Findings-AUSTRIA.pdf

[53] Wer ist die osterreichishe lungenunion? [Internet]. Lungenunion [Cited 2018 12 may]. Available from: http://www.lungenunion.at/index.php/ueber-uns/wer-ist-die-oelu

[54] OECD. Health at a glance 2009, OECD indicators [Internet]. OECD publishing; 2009: 116 [Cited 2018 May 12]. Available from: http://www.oecd.org/health/health-systems/44117530.pdf

[55] Nafstad P. Folkehelserapporten: kronisk obstruktiv lungesykdom (kols) i Norge [Internet]. Folkehelseinstituttet; 2014 [updated 2018 January 24: Cited 2018 May 12]). Available from: https://fhi.no/nettpub/hin/ikke-smittsomme/kronisk-obstruktiv-lungesykdom-kols/

Association surveys argue that access to an early diagnose of COPD in Austria is “very difficult” and are often made too late. Regular check-ups do not focus on lung diseases and does not include spirometry which can easily identify this type of diseases. On the other hand, access to treatment is seen to be “very easy”[56]. Based on this, a study called the LEAD study aims to investigate which triggers and backgrounds that are common for lung diseases in Austria. This is done to offer treatments for possible patients and to prevent future prevalence. The letters in LEAD stems from Lung, Heart, sociAl, and boDy. It is a team which consists of medical specialist which are working for the future Austrian pulmonary health. They aim to make a change based on the calculation that COPD is the fourth most common cause of death in Austria with an increasing number of infections. The study provides valuable and extensive insights into the health status of the Austrian general population through different examinations where the participants return every fourth year. The results are stored within an anonymous database, and more than 11 000 Austrians have already taken part[57].

Routine check-ups for COPD do not exist in Norway either. COPD develops slowly and is not always as easy to discover. This also leads to a predicted high number of people living with the disease, but is not aware of the fact because of lack of check-ups and ignorance[58]. From the information provided by a medical informant from LHL, approximately 300 000 people have COPD in Norway without knowing. This is seen to be a crucial issue to challenge.

5.3. Legal framework: a comparison of Norway and Austria

Studying the prevalence of COPD and organizational influence, the national legal framework can be seen as a foundation for structuring this and is therefore crucial to examine.

Healthcare in Norway is organized nationally through the ministry of health and is based on a universal coverage system. The four regional health authorities have the responsibility of handling specialist care, while primary care is handled by the 428 municipalities where general practitioners act as gatekeepers. Overall, the Norwegian healthcare system is performing well,

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[56] Franchi M. Book on Chronic obstructive pulmonary disease in Europe – sharing and caring [Internet]. European Federation of Allergy and airways diseases patients associations; Brussels: 2009 [Cited 2018 May 28]. Available from: http://www.efanet.org/images/2012/07/EFACOPDBook.pdf

[57] Ludwig Boltzmann institute. The Austrian LEAD Study, A longitudinal study investigating health challenges in pulmonology [Internet]. Ludwig Boltzmann institute for COPD and respiratory epidemiology: 2018 [Cited 2018 March 24]. Available from: http://copd.lbg.ac.at/en/research-program-austrian-lead-study/austrian-lead-study

[58] Astma og allergiforbundet. Fakta om kols [Internet]. NAAF; 2006 [updated 2018 February 16: Cited 2018 March 26]. Available from: https://www.naaf.no/fokusomrader/kols/fakta-om-kols/

but is meeting the same challenges as several other countries with regards to chronic diseases, aging population and coordination problems[59]. Concerning the disease burden, it is now the non-infectious diseases such as COPD, cancer, mental health disorders and substance abuse that comprise the major challenges. As a result and in relation to the concept of transition as mentioned, there is a need for other types of interdisciplinary follow-ups and rehabilitation over time while the patient can still live at its own home[60]. This is where patient organizations can be an important resource to take advantage of, and use to help managing this burden on chronic disease management.

Efforts for improving coordination between different healthcare providers and better the quality of care have increased in Norway recent years. During the 1970s the main focus of improvement was equality, in the 1980s it was cost containment and decentralizing healthcare services and in the 1990s the focus was on efficiency. Following the millennium, the focus has shifted towards structural changes and policies intended to empower patients, while at the same time improving coordination between the healthcare providers (59). One example of response to this is the coordination reform which was implemented in 2012. This reform ought to promote coordination between the primary and secondary healthcare grounded on the lack of mediating structure[61]. Point 1.2.2.2 within this reform outlines a recommendation for a binding system of agreements between municipalities and health authorities. By this, they underline the point of user involvement and how to include non-governmental organizations, such as patient organizations. This will be further discussed[62].

When communicating with the employees of LHL, they provided me with information regarding which legal framework that is implemented to assist their members and patients in general. Also, what a patient’ rights and obligations are in relation to their own treatment process was useful information given. The relevance of this study is based on this existing legal framework and the theoretical framework provided.

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[59] Ringard Å, Sagan A, Sperre Saunes I, Lindagl A K. Norway: Health System Review. Health systems in transition, vol 15 No 8 [Internet]. European Observatory on health systems and policies: 2013 [Cited 2018 May 9]: p. 119. Available from: http://www.euro.who.int/__data/assets/pdf_file/0018/237204/HiT-Norway.pdf

[60] Meld. St. 26 (2014-2015). The primary health and care services of tomorrow – localized and integrated. Oslo: Norwegian ministry of health and care services; 2015. Available from: https://www.regjeringen.no/contentassets/d30685b2829b41bf99edf3e3a7e95d97/en-gb/pdfs/stm201420150026000engpdfs.pdf

[61] Romøren I T, Torjesen O D, Landmark B. Promoting coordination in Norwegian health care [Internet]. International journal of integrated care; 2011 [Cited 2018 May 9]. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3226017/

[62] Regjeringen. Report no.47 (2008-2009) The Coordination Reform, proper treatment – at the right place at the right time [Internet]. Norwegian ministry of health and care services; Oslo [Cited 2018 May 10,9. Available from: https://www.regjeringen.no/contentassets/d4f0e16ad32e4bbd8d8ab5c21445a5dc/en-gb/pdfs/stm200820090047000en_pdfs.pdf

Your rights as a patient are described in *the act of 2 July 1999 No. 63, the patients' rights act*. This act provides the framework for the relationship between the patient and healthcare providers. It also sets focus on the needs and demands of the patients relating to the principle of autonomy[63]. Based on this act, users of healthcare services have the right to influence and it is the duty of these services to include them[64]. This is the aspect of "user-influence" which is included in chapter three, the right to participation and information. According to the informants in LHL, in every council and committees, there is required to have a user representative where the members are in this way represented.

Within LHL, there are regulations and action on municipal level, county level and organizational level where the patient has rights to care and where the organization is there to assist the patient if not satisfied. This also raises the aspect of specialist healthcare which is provided through the patient's rights act, chapter two. As a patient in Norway you have the right to free choice of hospital, which is also stipulated in the patients' rights act. On the other hand, free choice of type of treatment or specialized care is restricted (63). LHL has now built a new specialist hospital which takes part of this arrangement by some treatments.

Concerning the Austrian healthcare system, it differs in both the structural and cultural aspect from the Norwegian one. Similarly, there is a high level of satisfaction. The Austrian healthcare system provides near universal coverage for the population and the share of people reporting unmet needs for health services is the lowest in the European Union (EU). However, there is some dissatisfaction regarding the lack of coordination, as also reported in Norway. In contrast to Norway, the Austrian system is based on the Bismarckian model of statutory health insurance (SHI), free choice of provider, unrestricted access to all levels of care and no gate-keeping system. It is decentralized between the federal and the regional level (Lander) with a high degree of self-governing bodies and independent states. This is stated to have led to fragmentation and inadequate coordination, as previously mentioned (26)[65].

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[63] The act of 2 July 1999 No. 63 relating to patients' rights. Helse og omsorgdepartementet: Oslo; 2009. Available from: http://app.uio.no/ub/ujur/oversatte-lover/data/lov-19990702-063-eng.pdf

[64] Helsedirektoratet. Utredning, behandling og oppfølgning av personer med psykolidelser, brukermedvirkning som lovfester rettighet [Internet]. Helsedirektoratet: Oslo [Cited 2018 May 12]. Available from: http://www.helsebiblioteket.no/retningslinjer/psykoselidelser/brukermedvirkning/brukermedvirkning-som

[65] Nolte E, Knai C. Hofmarcher M, Conklin A, Erler A Elissen A, et al. Overcoming fragmentation in health care: chronic care in Austria, Germany and The Netherlands; Health economics, policy, and law [Internet] p. 125-46: 2012 [Cited 2018 May 9]. Available from: http://researchonline.lshtm.ac.uk/146725/1/Nolte_et_al._2012_HEPL.pdf

In Austria, patients' rights are not regulated in one special act, but are based on the provisions of civil, criminal, administrative law and professional codes. This is due to the fragmented system with different levels of responsibilities. From 1999, agreements on patients' rights according to article 15a are provided by the Lander through the so-called Patient's Charter (PatientCharta). This article also aims to improve the corporation between individual actors and between the different levels of healthcare services, such as the goal of the Norwegian coordination reform. However, this has more of political significance than legal[66] [67]. On the other hand, the content of the Charter held two aspects out: representation of patient's interests and enforcement of claims for loss or damage. With respect to this, the concept of a patients' Ombudsman was introduced to investigate complaints[68].

Responsibility within most areas of healthcare in Austria lies in the federal government while the hospital sector lies in the responsibility of the Lander. Every Lander has patients' Ombudsman offices of representatives that are in place to protect patients' rights and interests. The Ombudsman system is in place to provide an institution which has the rights and powers to speak on behalf of someone else, in this case, on behalf of patients. The Ombudsman system is independent and not subject to any other external direction or any similar private service. Within the field of public health, this was the emergence of "patient's representatives" (PA-s, peoples attorneys) and a strengthening of patients' role and rights. The responsibilities of the PAs are mainly safeguarding and securing the rights and interests of the patients. The functioning of a PA is to be an instrument for patients who are not able to make themselves understood sufficiently, providing external feedback to hospitals, safeguard quality and create willingness to enter into discussion. Further, they are an extrajudicial institution, enforcing legal claims in an un-bureaucratic way. PAs has a wide range of patient-oriented activity, but they were primarily established in order to provide patients with specialist and qualified representation, free of charge[69]. Within the Austrian healthcare system, there are also self-help groups and associations where the biggest organization for COPD is the Osterreichische Lungenunion which will be further explained.

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[66] Leischner A, Zeinhofer C, Linder C, Kopetzki C. Medical law in Austria [E-book]. The Netherlands: Kluwer Law International; 2011 [Cited 2018 May 9] p. 174-75.

[67] Habl C, Bachner F, Klinser D, Ladurner J. The Austrian Health Care System, key facts [Internet]. Austrian Federal Ministry of Health: Vienna; 2010 [Cited 2018 May 2]. Available from:
https://www.bmgf.gv.at/cms/home/attachments/2/7/1/CH1602/CMS1475570873153/the_austrian_health_care_system.pdf

[68] De Gooijer W. Trends in EU Health Care Systems [e-boo]. The Netherlands: Springer; 2007 [Cited 2018 May 2].

[69] Mackenney S, Fallberg L. Protecting Patients' rights? a comparative study of the ombudsman in healthcare [E-book]. Bachinger, G., Chapter 1, The patient ombudsman system in Austria. United Kingdom; Radcliff Medical Press: 2004 [Cited 2018 May 4].

In relation to the disease of COPD and tobacco restrictions, in Norway, Act No. 14 of 9 March 1973 relating to the prevention of the harmful effects of tobacco; the tobacco control act, is the primary law with regards to the issue. Nevertheless, the law has been amended several times. In 2004, Norway introduced legislation that prohibited the advertising of tobacco products and limited the areas where residents are permitted to smoke, where it was implemented a total ban on smoking in restaurants and bars. In 2005, Norway took part of the WHO framework of the Convention on Tobacco Control. This law prohibits smoking in most indoor public places and by some outdoor areas for preventive reasons. The law also has direct and indirect forms of tobacco advertising and restricts the packaging and labelling[70].

In Austria, the tobacco act of 1995 was amended in 2004 to include a general ban on smoking in indoor public places and included a far-reaching ban on advertising tobacco products. The amendment in 2008 extended to include restaurants and bars, but still allowed smoking in separate rooms under certain conditions. Further, the tobacco act was amended in 2015 to introduce an even more far-reaching smoking ban in restaurants and bars that was said to come into effect on May 1, 2018. Current smoking legislation in Austria involves a compromise and compared to other European countries – is very permissive. According to Eurobarometer survey on Tobacco, Austrians were some of the populations that seemed least supportive of implementing smoking restrictions in public places, strongly influenced by individual emotions and other interest groups. The reason for the liberal approach towards tobacco could be difficult to explain but some experts believe it has to do with the aspect of personal choice and freedom[71].

With regards to the smoking ban introduced by the previous government which was to be implemented in May 2018, this ban was scrapped due to the argument of restricting the “freedom of choice”. A petition was organized based on the willingness and wishes of the public, collecting over 500 000 signatures for implementing the smoking ban. When this was ignored, it put the current government in a tricky position through challenging the concept of direct democracy which was weakened[72].

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[70] Act no. 14 of march 1973 relating to prevention of the harmful effects of tobacco. Ministry of health and care services. Available from: http://www.tobaccolabels.ca/wp/wp-content/uploads/2013/12/Norway-2004-Prevention-of-the-Harmful-Effects-of-Tobacco-Act.pdf

[71] Ladurner J, Gerger M, Holland W W, et al. Public health in Austria, an analysis of the status of public health [Internet]. Observatory studies series; 2011 [Cited 2018 May 2]. Available from: http://www.euro.who.int/__data/assets/pdf_file/0004/153868/e95955.pdf

[72] “Ashtray of Europe”: Austrian MPs vote to scrap smoking ban [Internet]. The Guardian; 2018 [Cited 2018 May 20]. Available from: https://www.theguardian.com/world/2018/mar/22/austria-mps-vote-to-scrap-smoking-ban-despite-petition

5.4. Presentation of funds

Once the data was conducted, it was transcribed, coded and analysed, looking for similarities and differences amongst the informants. The reason for the chosen categories developed was based on the main discussions derived from the interviews in relation to the theoretical framework provided. It was topics that were repeated from several of the informants which together lead me to the funds presented.

The sample of employees of LHL pictured various perspectives grounded in their roles and experiences within the organization. This was similar for the members who also had different perspectives in relation to if they were leaders within the local member-groups speaking on behalf of several, or an individual member speaking on behalf of themselves. When analysing the interviews, some similarities and differences were found, probably based on role, work tasks, personal experiences, but also individual attitudes and expectations.

In this chapter, the main findings will be presented. They stem from the interviews and the process of data analysis where quotes and statements are presented to exemplify. The relevant information provided is mostly based on data conducted from the informants together with information found on the homepage of the organizations as explained in the methodology chapter.

Organizational structure

Norway: the National Association for Heart and Lung Diseases (LHL)

As a basis for understanding the informants' statements, some basic knowledge about the organization and its structural design is crucial. LHL is the national association for heart and lung-patients in Norway. It is an ideal health-organization with over 52 000 members where they are joining on a volunteer basis. This year, LHL is celebrating their 75 year anniversary. This represents a 75 year long development within healthcare from what was the starting point to what LHL is today. In relation to being ideal, the business of the organization is private and not controlled under any public administration. It is rather controlled by its own structure and activity. The national meeting held every third year is the central decision-making body and is where the employees from the administration, individual members from the local groups and various politicians are meeting to form the agenda based on a traditional democratic structure.

LHL consists of approximately 250 local groups, clinics, rehabilitation and a hospital. This is the foundation for relations with their members, from pre-, during and post- treatment. This is performed through the assistance from professionals, but also through the concept of peers. LHL works with different types of diseases such as heart, lung, muscles, stroke, asthma, allergy and obesity where they have experts within the diverse fields that can provide information and services. This year (2018), LHL opened a new hospital, also known as the patients' hospital. Some of the previous working clinics have moved their medical operation to this hospital to gather the amount of knowledge into one institution, while still having several other operational clinics located other places. Some of the treatments at this hospital are part of the Norwegian regulation of free choice of hospital within the coordination reform[73].

In accordance to LHLs strategy for 2018-2020, their goal is to supplement the public services by being an ideal alternative through their strength of being a member-organization who is also providing health services. LHL is central in the media and pushes relevant issues on the public agenda by being one of the strongest influencers within the area of heart, lung and brain (73).

Austria: the Osterreichische Lungenunion (ALU)

The Osterreichische Lungenunion is a nationwide self-help group for people suffering from COPD, allergy, asthma, pulmonary fibrosis, lung cancer, neurodermatitis and urticarial. The concept of the union is the goal of self-help and an informed patient through working for public awareness. When the public is informed, those affected will have easier access to the fast-growing offer that is operating. In this way, they can take advantage of the benefits which follows. Similar to LHL, it is a non-profit organization dependent on members, volunteers, partners and sponsors. ALU provides information about several aspects of disease, such as medical, practical, prevention and coping strategies.

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[73] LHL. Strategi 2018-2020 [Internet]. LHL; 2018 [Cited 2018 June 2]. Available from: https://www.lhl.no/globalassets/brosjyrer-og-dokumenter/dokumenter/strategi-2018-2020_web.pdf

The burdens that respiratory illness brings are several. Therefore, ALU offers various services such as:

- Education and information, rich information material for those affected
- Lectures and discussions with experts on relevant topics every 3rd Wednesday
- Patient training
- Functional breathing and voice training
- Consultation hours for patients of children with respiratory diseases
- A newsletter, published 5 times a year
- Consultation and answering questions
- Informal gathering of those affected
- Hikes[74]

This is quite similar to the activities of LHL concerning distribution of information, ensuring lectures and discussions with experts on relevant topics – where this is usually done within the local groups of LHL. Both have consultation hours and training, where LHL has clinics and a hospital where this is practiced. Both have newsletters and channels for answering questions from patients and members and for providing information. Moreover, they both have informal gatherings for those affected and additional physical activity. Again, within the structure of LHL, this is usually done and arranged within and by the local groups.

At the homepage of ALU, under the category of "diseases", you can learn about the various diseases they are working with through informing yourself. The page provides you with topics such as what is COPD, how to treat it, living with it, diagnosis, questions and answers from others, rehabilitation and home workouts, etc. These pages of information are not simply for the ones diagnosed, but also for the family, friends and carers, to include the concept of dependents.

The Osterreichische Lungenunion has patient education for asthma and COPD where they offer a training centre. The centre is medically accompanied by doctors and professors from other instances that have great competence on the matter. Within the patient training course of COPD, the patients learn to understand their illness and how to manage it in a responsible way. There are discussions of COPD drugs and the use of medical treatment. Members can learn about self-control, how to deal with respiratory infections, how to travel safe, and learn about behaviour in

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[74] Uber Uns: Was Wollen Wir? [Internet]. Østerreichische Lungenunion [Cited 2018 June 2]. Available from: http://www.lungenunion.at/index.php

case of emergency. Further, they have oxygen therapy, exercise, technique training and relaxation exercises[75].

Comparing LHL and ALU, it was found that the similarities were primarily between ALU and the local groups of LHL, rather than LHL in its full range of action and influence.

Challenges

When diving into the categories drawn from the interviews of LHL, challenges were one of the first topics discussed. Both the members and the employees within the administration of LHL expressed that it was physical and psychological pain that was the most common challenges members are experiencing. All members mentioned in relation to this that meeting with the local groups were highly beneficial grounded on the aspect of both physical activity and the social community it provides. As previously stated, hospital admissions may be due to both physical and psychological factors such as anxiety and depression. Therefore, such a social measure appears preventative and as stated, highly beneficial.

In addition to the physical and psychological aspect, other issues were stated during the qualitative interviews derived from various questions asked. These were follow-ups and rehabilitation after hospitalization, the transition between hospitalized and home, re-admissions, distribution of information, awareness and disease relating to work-life. It was also mentioned the issue of ownership towards the organization and the fact that the local groups vary in their size. This can impact the opportunity for individual members to participate in their local area.

Concerning the importance and the wish of enlightening and increasing distribution of information about the topic of COPD, participant seven expressed his concern through a story saying

> *"I got a phone through LHL from a journalist who had participated a meeting for a rehabilitation-group for people with lung diseases. It was not one person who wanted to come forward and talk about themselves or their disease, so they contacted me for the purpose of writing an article. They were looking for people who dare coming forward and say that they are diagnosed with COPD. This is the problem".*

Better cooperation between healthcare services, distribution of information and informing the public seem like an important aspect to take into account. Also decreasing the aspect of taboo

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[75] Serviceleistungen: Patientenschulung Asthma und COPD [Internet]. Østerreichische Lungenunion [Cited 2018 June 2]. Available from: http://www.lungenunion.at/index.php/serviceleistungen/patientenschulung

around the topic of COPD is crucial. This may be due do the fact that COPD is related to lifestyle and the feeling of guilt. On the other hand, it is important to think about the fact with regards to preventative measures and culture which can also impact lifestyle and culture.

With regards to influence, one of the employees of LHL mentioned the distance between the members and the administration and the issue of lack of feeling ownership towards the organization. Participant three stated *"they are members of the organization and they feel some sort of ownership, when the administration buys clinics and builds new ones, it can be hard to follow. This has been a challenge lately"*.

Participant eight supports this statement by saying

"The process concerning the building of the new hospital has taken a lot of our time and attention, so there is a small degree of guilt within several of us. We haven't had much time to focus on the local groups. I think everyone could be more active and use the strength of the organizational structure that is there. We are dealing with heart and lung-patients. They are the ones that know where the shoe pinches".

For the sake of comparison and regarding the main challenge of physical activity mentioned by several, like LHL - ALU has lectures, patient training and hikes. This embraces both the social and the physical aspect to tackle the shared challenge of COPD patients. There was an example from the homepage of ALU which enlightens the benefits of physical activity which is crucial for better health. The story was about a patient diagnosed with a severe degree of COPD in 2007. When diagnosed, he had to adjust his whole life to manage and adapt towards a new lifestyle in accordance with his disease. Through being involved in sports, his physical and mental health improved. Regular exercise and staying active is even more important for people living with a chronic disease than for an average healthy person. For patients with lung diseases, regular activity is the key to survival. This information and his personal spirit helped him manage his health in a positive way, which also hindered worsening of his disease[76].

Additional, by ALU having a strong focus on self-help, this may be seen as a challenge for some. Enlightening this is done through using an example of a person living with COPD from the homepage of ALU. She used to smoke regularly when she was younger and didn't stop even though diagnosed, but limited her cigarette consumption to some degree. Before being

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[76] Neuigkeiten [Internet]. Osterreichische Lungenunion [Cited 2018 June 2]. Available from: http://www.lungenunion.at/index.php/aktuelles/neuigkeiten

diagnosed, she thought her symptoms were age related and she suffered regularly from chest infections with a severely decreasing lung-capacity. After being diagnosed and started inhalation therapy, she didn't suffer in the same degree as previously[77].

Through the concept of self-help, ALU wants to address that although a physician can help make the life of the patient as easy as possible, they will not be present in their home around the clock. Therefore, living with a disease such as COPD is correspondingly called self-control, self-treatment and self-management. To manage this is up to the initiative of the individual patient, taking responsibility for personal health. Based on this, ALU offers the opportunity to learn about the disease through their channels of providing information.

Legal framework

In relation to laws and regulations discussed, the informants of LHL were asked if there is any legal governmental influence or restrictions on the organization. Furthermore, if there are any laws and regulations which order them to include the members in some way.

The statues that is decided upon at the national meeting every third year sets the framework for the whole organization and their political aims for that three-year-period. This framework also lay out the ethical baseline for the members such as a no-smoking policy and the concept of respect.

Participant eight expressed

"We are very independent. We have the Norwegian Public Health Act and alike, which is relevant in relation to the processes of the hospital and other clinical business. We also have the Working Environment Act. In addition, we adopt statues at our national meetings which are our own rules, framing the organization – what to work with and how to do this. How should the democratic process be organized and how can you as an individual member have a channel for influencing the organization?"

Participant one further stated *"organizations are so-called, legally speaking - autonomous. There are very little overregulating legal framework to control the organizations".*

Regarding the statement provided on LHLs homepage, *"LHL influences the government and the society in the battle for patients' rights"*, the members were asked if they knew what their rights

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[77] Leben mit COPD [Internet]. Osterreichische Lungenunion [Cited 2018 June 2]. Available from: http://www.lungenunion.at/index.php/erkrankungen/atemwege/copd/leben-mit-copd

as a patient and as a member were[78]. A common statement within most members was that it is up to the activity and initiative from the individual member to accumulate such information. The information is present, the homepage is good and the opportunities are there. However, information doesn't come without giving an effort yourself. Additionally, the local groups arranges meetings for discussing various topics, where patients' rights has been a common subject, teaching the members about the different aspects.

The members were also asked if they felt that this was taken into practice trough political organizational action. This will be further explained with regards to communication, but the common statement was yes, that LHL was good at fighting the case of the members. Participant one stated

"The experience we have from advising and managing cases on individual level aims to be transformed into interest policy; hence, we use this as illustrations when expressing our policy and viewpoints towards the decision makers".

When it comes to the Austrian system, information about legal rights and structure was not provided at their homepage. Nevertheless, with regards to patients' rights in Austria in general, this is the responsibility of the Ombudsman. Lawyers and courts offer legal representation but not the aspect of communication and mediation, as mentioned. For a patient with COPD, this may be of higher significance. This was the basis for the establishment of the independent Ombudsman system, also called PAs. Its independence is insured by constitutional laws separately in each state with the main goal of safeguarding the rights and interests of all patients (69). In this regards, ALU seems to be an independent association promoting information and self-help, where it is the legal system on a national and regional level which ensures the patients' rights. On the other hand, this needs to be confirmed.

Communication

The organizational structure of LHL is a traditional structure based on democracy with little bureaucratic influence. The communication process is directed both internally and external, vertical and horizontal. The system is based on three levels and to some degree, the government. The organization consists of the different local groups organized within the municipalities. Next level is the county-committees. At the organizational level, there is the administration which is located at the new hospital at Gardermoen. The administration is also communicating external

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[78] LHL: Bli medlem [Internet]. LHL [Cited 2018 June 2]. Available from: https://www.lhl.no/bli-medlem/

towards the government and politicians. At the same time, they are also communicating towards the media to influence and inform the public. This study hasn’t investigated the county-level other than the information provided by the participants. It was expressed a small degree of activity within this level.

Looking into the local level, the way the local groups can communicate upwards is based on individual initiative and the structural foundation that is implemented. The most important channel for communication and influence is seen to be the national meetings where the local groups, the administration and politicians are gathered. This is where the political framework, interest policy, statues and goals are decided upon. Decisions here are based on the concept of democracy where the majority rules.

The majority of the members stated that the communication process within the system is good, supported by participant six *“I think, basically, that there is a very good communication process”.* On the other hand, there were also some local groups that were not pleased with how the communication process is performed. Participant four stated

> *“There is some sort of slowness within the system when trying to contact the administration - if we want something or we have questions about courses or lectures. They have many experienced employees that are lecturing, but they are difficult to reach. They have meetings etc. and they don’t always reply, it is difficult … “*

Within the local groups of LHL, the concept of peers are also taken into action where some have the working title as an equal or a peer and has the aim to be *“a partner for conversation, someone who has the same diagnose and in worst case, be a shoulder to cry on”.* On the other hand, another participant expressed the feeling that the concept of peers supported the aspect of the lack of communication were it was expressed a feeling of writing off responsibility, letting the local groups taking care of themselves.

It can be important to mention the aspect of time investigating the system and activity of LHL, with the building of the hospital which has led to many busy employees. This was also mentioned in the challenges-part, stated by participant eight. Their availability and capacity could to some degree have been weakened within the time-period of study. Based on the interviews, there was some irritation concerning the perception that the organization was working commercially, thinking about business in contrast to medical action on behalf of their members. However, several of the employees expressed that they were familiar with this being a concern within the members and they were conscious about the situation.

Speaking of the external communication from the administration towards the politicians, one of the features of a patient organization is applicable – speaking the voice of their members. As participant three stated*, "LHL as an organization represents both users and professionals. Even though a physician is speaking, they speak on behalf of the members".* This also relates to the organizations initiative to invite and show face at the relevant hearings, communicating on behalf of the members. Participant one stated

> *"We do not have our own channel towards the politicians. We can try to get meetings with government officials, but we have to work hard for this. Further, we try to be present at all arenas where decisions are to be taken or where there are discussions about topics that are relevant for the ones we are representing. We try to be updated! We are one of the country's biggest patient organizations so we are often inviting inn. We have been better to invite the big organizations into processes, especially with regards to user-involvement at system-level"*

Another aspect in relation to communication is cooperation and influence between different organizations at a horizontal level, both national and international within the Nordic countries. One example is where LHL allied with the Norwegian Confederation of Trade Unions (LO) during a smoking campaign, communicating towards the public to inform and prevent.

In relation to the mentioned legal framework for tobacco, there has been collaboration also within this field of policy. Participant one stated

> *"LHL, together with the association for cancer, has been very committed to prevent the damage of tobacco. We have been working with this in recent years. At this field, we feel we have contributed to a properly strict tobacco act. We had a specific strategy and used a lot of time and resources, but this is not only LHL alone".*

This is important in relation to the fact that smoking is seen as the number one risk factor for developing COPD as explained previously, where LHL is a strong influencer for preventative action.

Concerning ALU and national collaboration, one example that was provided through the homepage was collaboration between ALU and the pharmacy business. A pilot project was started in 2009 in collaboration with the pharmacist chamber Vienna. Based on the increasing number of chronic lung patients and the number of people who uses pure oxygen as medicine, the pilot project called “the oxygen filling station pharmacy”, was initiated. The concept was to increase the mobility of the patients where they can find large oxygen tanks in pharmacies.

No information was found about the structure of ALU concerning how members can communicate upwards within the union and in this way have any influential effect. There is no information about to what degree the organization is speaking through the media or having any external communication. However, there are articles with statements from the ALU concerning topics that is relevant, such as LHL which is engaged in relevant issues. ALU aims towards a great responsibility on the individuals. While being self-managing, a network of people such as medical professionals, doctors, physiotherapists, psychologists and nurses can all help and support when dealing with such a disease, making a network of stakeholders. Again, these groups of stakeholders have to work together towards the same goal based on mutual learning and communication.

Influence

This category is closely related to the category of communication where influence similarly has both an internal and an external aspect. Historically, LHL has had great influence within the health sector by developing healthcare services where clinics and international relations have been founded. LHL has at the same time been pushing for change related to politics and policy on behalf of patients. One example is the patients’ rights act previously explained, where LHL was a frontier for implementation by having a petition resulting in some thousands signatures, explained by participant one.

Concerning influencing the government on behalf of members, the organization has to play an active part in working towards politicians fighting for patients’ rights as mentioned. In this way, what is taken forward by the members can further be taken into political action. This is one way the members are influencing. How you as an individual member can have a channel to influence internally within the organization is decided upon at the national meetings. Participant eight stated

> *“... so that a member which is concerned about an issue within the local environment can come forward with solutions. They may further be adopted at the national meeting and included in our interest policy programme which becomes mine or ours – mandate to work political”.*

Furthermore, participant eight stated

> *"The members have a great power of influence. They will get the organization they deserve. The more active they are, the more they can form the organization. You can probably find local groups who do not feel that things are working as good as it should, but how active have they been themselves?"*

The informants were asked if they meant that the members were heard and if they had any influential power. The majority of all the participants answered yes, both members and employees. Moreover, it seemed as the employees responded faster in contrast to the members who thought more carefully about the question before answering. This may have to do with their role and influence in relation to the matter.

The organizational culture and system is based on a democratic process which means that the majority rules, as mentioned. The administration can't overrule the majority of members. Participant nine supported this concept by expressing that *"it is the democracy that rules, but it depends how engaged the people who are present is, that's how a democracy works".*

With regards to the ALU, there was no information about members' internal influence or the external influence of the organization to be found.

Possible improvements

One of the questions provided through the qualitative study of LHL was if there were some measures that would be beneficial to implement or if there were some missing's within the organization concerning communication and influence. The members were followed up with, if necessary, if there were some measures they felt was needed to improve the organizational structure.

With regards to the structural design, it was a common saying that the structure is well functioning, where participant eight stated

> *"I haven't seen the need to do something with the structure, but what could be done better is that both members, representatives and us within the administration, can be more active to use the opportunities that lie within this structure. Maybe be better to travel around, visiting the local groups, attend more annual meetings and be attentive".*

Participant four expressed another measure to be taken into account

> *"… visibility and the feeling of fellowship. We should know who are sitting in the central board. They should be easy to contact, but they are themselves the closest, that's a common thing within LHL. It is not easy to cooperate with the other local groups either. Everyone is themselves the closest. We have little contact with them. Little contact with the county-committee as well".*

The question is then how to tackle this and how to develop measures and solutions for taking better use of the structure that is already functioning. On the other hand, participant nine expressed that *"much of the criticism comes from ignorance"*, where information and awareness seems essential.

Taking part of the social aspect based on peers can be an essential measure to emphasize. This is one aspect of where the local groups of LHL plays an important part of rehabilitation and disease management[79].

I observed that concerning possible improvements and measures, the members had more to express whereas the employees were quicker to say that they couldn't think of any.

An example of activity/measure the Osterreichische Lungenunion has provided is breathing and voice training through singing. Together with associates, they developed the concept "voice and vocal training for patients with respiratory diseases". 16 participants took part of the pilot project, mainly asthma and COPD patients resulting in them feeling more balanced and more conscious about their breathing. Through singing, you can strengthen the respiratory muscles and your breathing similar to physical exercise. Physicians often recommend their patients to participate or develop a gradual physical exercise program as part of their lung rehabilitation, where such activities can also have an important effect. This is designed to improve overall physical condition which can have positive influence and impact on their quality of life at the same time as being a social place[80].

Personal attitudes

The local groups of LHL differs in size and activities, but the ones represented in this study were rather active and of a larger size varying from 200-700 members. The amount of active members was regularly smaller, approximately 10%. The work of the local groups are based on a

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[79] Leader D. The importance of COPD support groups [Internet]. Inogen; 2016 [Cited 2018 May 22]. Available from: https://www.inogen.com/blog/importance-copd-support-groups/

[80] Atem- und stimmtraining [Internet]. Osterreichische Lungenunion [Cited 2018 June 2]. Available from: http://www.lungenunion.at/index.php/serviceleistungen/atem-stimmtraining

volunteer basis, therefore some of the members felt that it was up to the administration to engage, not the volunteer members. The informants which were speaking on behalf of the local groups were generally very organizational active individuals and had been doing this through several memberships with a long experience.

It is up to the local groups to recruit new members, but if this wasn't done, which reactions and sanctions that would be practiced were uncertain. Participant four stated

"We are here ... we are LHL. We are the ones who keep the members going. We are the ones who get new members. Can they get members themselves? Can they adapt to what we are doing? (...) it shouldn't be like this, but it is".

Further, the aspect of age can create a barrier in relation to this, where every single individual member do not always have the opportunity or knowledge to find their way to the relevant information, such as by using the internet. It was stated that the average age was around 70 years within the local groups. At the same time, not everyone have the willingness and capacity to be active.

Another concern mentioned by several was the issue of public vs. private, especially with regards to the newly build LHL hospital. There was a concern expressed in relation to the fact that the hospital is part of the organization and not an individual instance. The concern was therefore if the hospital would have economic or other operating set-backs, if this could affect the work and performance of the organization, and the other way around.

6. Discussion of findings

In the discussion part, the main goal is to discuss and answer the research questions through use of the findings in light of the theoretical framework provided. At the same time as exploring this, cause and effect relationships can correspondingly have an impact on the member's influence concerning all aspects mentioned, together aiming to answer the research questions.

To my knowledge, there isn't any previous qualitative research that has examined the aim of this study.

The categories identified and derived from the qualitative interviews were structure, challenges, legal framework, communication, influence and possible improvements, whereas the additional personal attitudes isn’t considered relevant to discuss.

Structure

In relation to the category of the organizational structure of LHL, the local groups, clinics, rehabilitation and the hospital, structures the organizational foundation from pre-, to post-treatment. The concept of peer support implies a role and an arena where peers can provide knowledge, share experiences and offer emotional, social or practical support for each other. In this way, the local groups are training the individuals for empowerment. All stakeholders should recognize their role and be provided with the knowledge and skills to further increase patient participation and influence (32). In the light of Peter Senge’s theory about learning organizations, an organization is a place for mutual learning and for collectively improving patient care and outcomes. As mentioned, there are both homogenous and heterogeneous teams such as peers and the administration. They are all working towards a shared goal where partnerships and relations for support are emerging, where members influence may be a key resource (19). As provided through the findings and the majority of LHL, this was stated to be functioning. However, where some felt a weak ownership and influence. Furthermore, regarding patient-centered care and health management, the managers, in this case the employees of the LHL administration have to work hard to keep these relations stable and satisfied. As provided through the results, there was expressed some lack of visibility and fellowship. Through the functioning structure, a patient-centered approach can be one way challenging this (27).

Patient-centered care focuses on the role and influence of individual patients and patient representatives in healthcare policy and decision-making. Increasing members influence is done by using an adequate mix of instruments such as shared decision-making and experience-based co-design. Responding to the members desires for information and participation is one way of approaching the matter which will require a good communication process and greater visibility. As mentioned, patient-centered care as a term has been used to describe an approach where healthcare providers “see the situation through the eyes of the client” (28). Based on the information provided by the informants of LHL, this is done through the concept of the expert-patient and the local groups where they can raise their case through the functioning structure and take part of the meetings where decisions are made.

Looking into the Austrian situation, there are some lack of information and data. It was observed that the organization based on self-help is more comparable to the local groups of the Norwegian comparable. It appears as the structural foundation of ALU and LHL differs, where LHL has the administration communicating and influencing externally on behalf and based illustrations of their members. Further, as LHL has the national democratic meetings as an arena for members to influence, information about a comparable was absent concerning ALU. This limits the aspect of patient-centered care and experience-based co-design. On the other hand, the Ombudsman system is in place for providing an institution which has the rights and powers to speak on behalf of someone else, in this case on behalf of patients (69). At the same time, in contrast to PCC and EBCD, the concept of self-help can be seen in the light of empowerment of individuals to strengthen the concept of the expert-patient.

Challenges

Patient satisfaction is an important indicator for measuring quality within healthcare (11). Looking into this can give an insight to the members' demands and needs emphasized by Donabedian (12) and his writings on quality. In relation to LHL and influence and the statement provided about a distance between the members and the administration, the issue of members' lack of feeling ownership can be seen directly in the light of patient-centered care and the expert-patient. By this, the goal should be to redesign or co-design the healthcare system together with the patients and not around them. According to Donabedian, the success of the provider can be seen in the satisfaction of the client, which in this case is the organization and its members. This brings me to the approach of experience-based co-design which aims to improve healthcare services through implementing user experience into quality improvements. Using the beneficial effect of EBCD, PCC and/or learning theory such as Senge's has, can together help tackle those challenges mentioned and increase patient satisfaction.

Several of the challenges mentioned are in some way interconnected. A challenge mentioned was with regards to the lack of continuity of care concerning rehabilitation and follow-up which requires better coordination between primary and specialist care services. The previous statement about a fragmented healthcare system was supported by OECD which identified that high hospital admission rates may be an indication of poor quality within primary care. On the other hand, it is important to acknowledge that there are various types of diagnosis, sickness history and varying degrees of severity which may in fact require hospitalisation (55). Patient organizations could decrease the burden related to a fragmented healthcare system through making the transition-process easier and providing support and information. At the same time, grounded in the definition of an organization, tackling these challenges ought to be done through working collectively towards achieving the objectives of the organization in the light of PCC and EBCD.

It could be an important aspect to mention that several of the challenges, such as rehabilitation and re-admissions is not all up to a patient organization such as LHL and ALU to solve, but rather the government through politics, policy and the healthcare system. On the other hand, external influence through the media could be one way of approaching these challenges, speaking on behalf of the expert-patient, expressing their needs.

Kundt et al. conducted guided focus interviews on the topic of chronic obstructive pulmonary disease care in Austria. They explored the challenges and approaches which were also relevant for the aim of this study based on the lack of Austrian informants[81]. Derived from that qualitative research, they concluded that although COPD are widely common in Austria, prevention and disease education is weak and awareness of the topic is lacking. This supports my concern and the effect this had on this study. Health education and correct use of treatment is a major issue in Austria, where the focus is on treatment rather than prevention. There is said to be an absence of structured COPD management programs and coordination relating to a fragmented system. This is where ALU is providing self-help to empower the patients with knowledge. At the same time, is was also stated that patients who took part of physical activity, social gatherings and seeking specialist help, perceives their own health to be better than those patients who didn't take part of such measures. It was concluded that patient support groups was demonstrated to be helpful through the concept of peer support and receiving the updated information needed about the disease and treatment, as within both ALU and LHL through their activities (79).

Legal framework

Patient organizations are there to improve the life quality of people living with a certain condition such as COPD. The necessity for this is increasing based on the estimation that within 2030, COPD is projected to rank third among all causes of death worldwide (9). Through raising public awareness, preventive measures, dissemination of information and promoting research, patient organizations can support the aim of turning this trend around (23).

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[81] Kundt F S, Enthaler N, Dieplinger A M, Studnicka M, Knoll A, Flamm M et al. Multiprofessional COPD care in Austria, challenges and approaches: Results of a qualitative study [Internet]. The Central European Journal of Medicine: Salzburg; 2018 [Cited 2018 June 8]. Available from: https://www.researchgate.net/publication/325410378_Multiprofessional_COPD_care_in_Austria-challenges_and_approaches_Results_of_a_qualitative_study

In relation to the concept of autonomy and patient-centered care in Norway, your rights as a patient are described in the patients' rights act where it provides the framework for the relationship between patients and healthcare providers. Furthermore, it directs focus towards the role of the patient based on the principle of autonomy. The individual has the right to make decisions about their own care without any other external influence. However, healthcare providers are free to educate and inform the patient[82]. With regards to LHL and this concept, LHL is a so-called ideal and volunteer autonomous organization. Comparable to a patient's autonomy and seen in relation to Senge's learning organization, LHL is dictated by its own structure and culture. And thus, it relies on its own internal regulations and statues where they can act independently based on its founded objectives[83]. Moreover, within the organization of LHL, the members are autonomous individuals on a volunteer basis for membership.

Point 1.2.2.2 (62) in the Norwegian coordination reform outlays the recommendation for a binding system of agreements between municipalities and health authorities. This recommendation can be seen in the light of the theoretical framework of PCC and EBCD. It supports the point of user-involvement and how to include non-governmental organizations such as LHL, into the process. Nevertheless, the concept of "user-influence" imposes the requirement of a member-representative present in all councils and committees. In this way, the health and care services are influenced by the expert-patients own experiences and needs. This relates to the goal of co-design through the assistance and relationship with non-governmental organizations. Primary, the message is that patient organizations should be heard. This is done through meetings and hearings where they can influence on topics which touch their area of action. In this way, organizations such as LHL can influence on behalf of its members before decisions are taken into policy, as provided through statements of informants.

Concerning the statement provided at the homepage of LHL *"LHL influences the government and the society in the battle for patients' rights"* (78), it was largely expressed that the organization was in fact fighting the case of their members. The patients' rights act was to some degree brought forward by the initiative of LHL where they saw it necessary to fight for the rights of their members, strengthening the concept of PCC. Before this act came into force it was little legal jurisdiction on the topic. It was therefore a symbol of a new focus towards the health of individuals and their right to healthcare.

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[82] Entwistle A V, Carter S M, Cribb A, McCaffery K. Supporting patient autonomy: the importance of clinician-patient relationships [Internet]. Journal of general internal medicine; 2010 [Cited 2018 June 8]. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2881979/

[83] Simmering J M. Autonomy. Reference for business [Internet]. No date [Cited 2018 April 18]. Available from: http://www.referenceforbusiness.com/management/A-Bud/Autonomy.html

When discussing PCC and a patient's autonomy in general, this raises some conflicting aspects. Initially, PCC involves the principle of strengthening the role of the patient which can be seen in the light of a patient's autonomy. Meaning, they can independently choose treatment and take part of the process. On the other hand, respect for autonomy also indicates respect for a patient's individual choice of not making own decisions, but rather follow the recommendations of the professionals. Some wants to be guided rather than being the guide themselves. This can be seen as the decisional capacity of the individual[84].

Communication

In accordance to Drucker's statement about healthcare as a mixture of various stakeholders that may have conflicting interests (25), a well-established stakeholder relationship is crucial to manage these relations and to retain satisfied members and external communication. The majority of informants from LHL stated that this is in fact the case. On the other hand, some stated that the relationship is not as good as it ought to be and that the communication process was slow, as stated in the results.

This brings back the aspect of individuals and individual initiative and engagement as stated in the results, from both parts of the network of communication within LHL. However, with regards to Senge's theory about learning organizations and the importance of organizational learning within healthcare systems, to structure this complex multi stakeholder relationship and to lay a foundation for mutual learning in general, good communication is the key. Internal organizational learning forms the base for weaving these diverse groups into a cooperative platform for the benefit of the expert-patient, which in this case is also the member (25). Organizations such as LHL and ALU, consists of various teams who are learning and working together towards a shared goal. This process should be used beneficial through the structure of the organization and through the concept of democracy, using all stakeholders as valuable resources. As provided in the results, this is how the members of LHL communicate within the organization, which again gives them a channel for influencing.

Looking at the greater picture and the social relevance of the matter, it was said to be two lines of argumentation justifying participation of patient organizations in health policy making, implying an external relationship towards the government. The expert-patient is a valuable resource which can and should be used as a key to valuable and reliable information for further

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[84] Frank L. Person-centered care, autonomy, and the definition of health [Internet]. The American journal of bioethics: City University of New York; 2013 [Cited 2018 June 3]. Available from: http://ethicsandtechnology.eu/wp-content/uploads/downloadable-content/Person-Centered_Care_Autonomy_and_the_De.pdf

political action. Participation in patient organizations in general allows the members to take part of health policy decision making. Through internal communication and influence upwards within the organization, the members can influence their own health based on further external representation by the organization towards the government and the public. Existing research indicates that patients influence and participation within healthcare is linked to enhanced quality of healthcare services and better efficiency of the healthcare system. This can imply better health within the population in general (23). One example provided from LHL was the influence the organization had on the implementation of the patients' rights act, and additional on tobacco restrictions and preventative measures.

Influence

Concerning the research questions, this is the category with the highest degree of impact directly related to the aim of this study, together with the category of communication. Nevertheless, all the categories are in some way linked together and lead to how patients are influencing and how patient organizations are taking care of their members' perspectives. Hence, the choice of categories presented.

The theoretical framework of patient-centered care focuses on the role and influence of individual members and patient representatives in healthcare policy and decision-making. This is done by using an adequate mix of instruments such as shared decision-making and patient participation co-design. Previous research has stated that the importance of including patients within healthcare services is vital for improving healthcare quality and for empowering the patients themselves, as mentioned. In relation to the theoretical framework of patient-centered care, inclusion and shared decision making implies that the patient brings his or hers experiences forward. Further, the healthcare provider, in this case the organization, has to explore this as a basis for developing cooperation in the process of care (3). Regarding LHL, this was stated to be done through the formal meetings within the organization and through the statues decided upon. In the light of an EBCD approach within a patient organization, using measures such as patient-staff meetings, co-design groups or interviews is one way of how this could be done. Influence can be seen both internally and externally, towards the public on behalf of the members as provided through the discussion on communication.

Influence should be seen in relation to the structural design of the organization, at the same time as personal experience and the feeling of fellowship – or the lack of it. The qualitative informants had some different viewpoints on this matter, but the overall message was that the members do have an influential effect within LHL, based on the principle of democracy.

When examining the structural design of an organization, its architecture, goals, structure, relations and the coordination of this, is in focus. This is further related to the management and personal initiative of the members and their representatives. The legal framework, policies, procedures and the hierarchy lay down some sort of a framework for how this is organized[85]. In relation to the aspect of relations as mentioned, individual initiative and engagement is crucial, where information doesn't come falling into your hands. If playing a passive part in the communication process, involvement is hindered. Being a proactive member, the tendency to effect environmental change increases. At the same time, the ones with a proactive personality are positioned to grasp opportunities to influence and change. Contrary, if trying but not receiving response – that raises another barrier which may due to structural or personal capacity[86].

Members of LHL have an open line for communicating with the employees in the administration, allowing them to ask questions regarding different aspects of diseases in relation to the challenges mentioned. This can also be seen in relation to influence where the employees can get an insight of which challenges that is relevant for their members. Based on the findings, there was corresponding data from the members and the employees on the topic. The expert-patient can in this way influence the aims and objectives of the organization. This can further lead us to the aspect of communication where the messages of the members are taken into action etc. As read from the results, individual cases and experiences are put into action as evidence-based illustrations. Further, this is what the organization is working for with regards to interest politics and communicating towards the politicians and the public.

The members of LHL expressed some various perspectives concerning influence. Some expressed a high degree of influence, others did not. In this regards, some expressed at lack of influence where they were missing the feeling of being seen and expressed a slow process of communication. Consequently, use of ECDB measures could be used more actively. The

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[85] Defoe, D. Understanding organizations using the four frame model: factories or machines (structure), family (human resources), jungle (politics), and theatres, temples or carnivals (symbols) [Internet]. Psycolawlogy; 2013 [Cited 2018 May 25]. Available from: https://www.psycholawlogy.com/2013/05/31/understanding-organizations-using-the-four-frame-model-factories-or-machines-structure-family-human-resources-jungle-politics-and-theatres-temples-or-carnivals-symbols/

[86] Fay D, Frese M. The concept of personal initiative: an overview of validity studies [Internet]. University of Giessen: Germany; 2001 [Cited 2018 May 25]. Available from: http://www.evidence-based-entrepreneurship.com/content/publications/063.pdf

elements which seemed to emphasize influence were communication, structure, visibility and initiative.

The aspect of media gives the members some kind of external influence where these evidence-based illustrations can further impact the public and politicians. This can also be related to the goal of self-help within ALU, working for an informed patient and an informed world through public awareness. When the public is informed, those who are affected can have easier access to the fast-growing offer and take advantage of the benefits which follows. However, as mentioned with regards to Austria and the public, the concept of direct democracy has been weakened through the scrap of the intended smoking ban. In general, this shows some lack of public influence on the government.

Possible improvements

It was stated that a patient-centered care approach is easier in theory than in practice (17). The question is then to challenge this and develop and implement measures to take better use of the structure that is already in place to increase the influence of the members. Some measures can derive from the results provided for improving the influence of the members. Taking greater advantage of the structure, increase visibility, fellowship and cooperation with other health instances, and informing the public were some. Doing a qualitative study helped increase insight and provided information about how to gain patient satisfaction, which challenges were present, or which changes should be implemented. As mentioned, an unsatisfied patient, or in this case a member, can be seen as evidence of a service's own failures or missing's (30). On the other hand, such a study is limited to the informants participating, where others could have provided other perspectives. This can further relate to personal initiative, expectations and satisfaction.

Concerning the social aspect within both organizations, studies show that depression and anxiety can decrease your health status and increase the risk for flare-ups. Physical restrictions with regards to the disease of COPD can take control over the patient's well-being. In this regards, research shows that a social measure and peer support can protect the person's health status, which can also lead to better eating habits, increased physical activity and smoking cessation. Taking part of the social aspect where there are peers, can be seen as an essential measure to take into account which is provided through the activities of both organizations (79).

With regards to disease burden, it is now the non-infectious diseases such as COPD, cancer, mental health disorders and substance abuse problems that comprise the major challenges in both Norway and Austria. As a result, there is a need for other types of interdisciplinary follow-ups over time (60). COPD develops slowly and is not always easy to discover. There is lack of routines for check-ups of COPD where thousands of people are living with the disease without knowing. Such routine check-ups are not included in either Austria or in Norway. This leads to a higher predicted number of people living with COPD than previously provided (58). The general awareness of COPD should increase, especially in Austria, where preventative measures concerning tobacco and lifestyle could be some specific measures to target. Furthermore, this could maybe challenge the issue of a fragmented system, not only focusing on the inpatient sector, but also focusing on the patient after discharge. This could again decrease the burden of re-admission and hospitalization, which in Austria are high (26).

Patient satisfaction is an important indicator for measuring quality within healthcare. A combination of their expectations and their experience will give result in their level of satisfaction. Over the past 20 years, patient satisfaction surveys have gained influence. However, there are no clear relationship between the results of these surveys and if they have caused any improvements in satisfaction and quality (13). Taking this into account, dissatisfaction ought to be considered. Therefore, a measure to suggest for patient organizations could be to implement some kind of measurement for patient satisfaction, such as an annual survey. In this way, patient organizations could easier, if necessary, restructure and co-design the organizational structure based on the needs and experiences provided from their members.

7. Conclusion

Derived from a dual methodology and embracing the lack of Austrian qualitative data, differences were found between Norway and Austria concerning the prevalence of chronic obstructive pulmonary disease, national legal framework, culture and the organizational structure. It was observed that the Norwegian healthcare system is more preventative and has a greater allowance for patients influence within health care policy making compared to Austria.

The importance of hindering the growing prevalence of COPD in Austria seems to be weak, where it is primarily organized through empowerment and self-management. The focus is rather on treatment than on preventative action. The legal and cultural aspect in Austria was nor to be seen as either preventative or favourable in relation the prevalence of people suffering from COPD. Regarding areas of action of patient organizations, it is the legal framework which provides the external representation of patients in Austria, relating to the Ombudsman and where patients’ rights are not regulated in a special act. Within the Austrian healthcare service, there are rather self-help groups and associations where the biggest organization for COPD was the Osterreichische Lungenunion. Based on the content analysis of the homepage of ALU, the structural design and the goal of the organization, differ from the Norwegian comparative of LHL, whereas the activities were highly similar. It was observed that ALU could be seen as equivalent to the local groups of LHL in relation to empowerment of the expert-patient rather than influencing further political action. In contrast to LHL, it was observed that the aspect of members influence was absent.

Concluded from the information conducted by informants and the statements provided, the main findings within LHL were that the members’ perspectives were taken into consideration. Their perspectives and experiences were taken care of and worked as illustrations for possible further political action. Within the organization, influence was associated with personal initiative, organizational structure and the concept of democracy which corresponds to the theoretical framework of patient-centered care and experience-based co-design. Nevertheless, some possible measures can derive from the results provided for improving influence. These are; taking greater advantage of the structure, greater visibility and fellowship and stronger cooperation with other health instances and the public. I also want to mention the importance of implementing routine check-ups for COPD and the value it could have on the prevalence of undiagnosed patients. This concerns both Norway and Austria and healthcare systems in general. Additional, as mentioned, implementing annual surveys for gaining insight of members’ satisfaction could similarly be an important measure to implement in patients organizations.

Regarding the social importance of this study, the expert-patient can and should be used as a valuable resource for additional further political action where participation in patient organizations can allow members to take part of health policy decision making. Through members’ internal influence and further external organizational representation, they can impact healthcare in general, such as the goal of LHL. As mentioned, this is based on legal framework, the aspect of culture and the activity and performance of the organization, such as pictured in this study.

7.2. Further studies

In relation to the previous statement about the lack of data on this subject, I believe further studies are needed in order to generalize and understand the importance of members' influence within patient organizations and the social impact this can have. This study implies efforts to increase data about COPD patients' experiences, especially in Austria. Furthermore, the study would have benefited from a larger study sample of informants, primarily with regards to members from both organizations.

Any generalization of the findings from this study should be done with caution based on major organizational differences in healthcare across countries with regards to structure, possibilities, legal framework and culture. On the other hand, some of the challenges provided can point to general challenges in other areas and for other equivalent organizations. This can imply some degree of transferability beyond this study setting. The findings could work as descriptions or notions applicable to a specific setting where the concept of generalization should not be the goal.

Concerning the Austrian perspective, it will be interesting to follow the development of the LEAD study and its scope of research on the area.

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9. Appendices:

Interview-guide:

Employees:

1. How does a regular day look like for you? What are your main duties?
   Do you have any personal contact with members? How?
2. What are the main challenges members are experiencing? Has this changed with time?
3. The homepage states “LHL influences the government and the society in battle for patients’ rights” – How is this done in practice?
4. Do you feel the government takes you seriously?
5. What is the organizations routine for following up information provided from members?
6. Do you feel the members have any influence on the work of LHL? How?
7. Are there any structural changes you see necessary to implement? - Structure, communication, personal abilities?
8. Patients has rights on their side (patients’ rights act), is the organization influenced by any laws or regulations? Which?
9. Are there any laws or regulations which imply the organization to include the members in some way?
10. To what degree do you mean the organization is working political? – Or commercial?
11. How is the communication-process with the government working?
12. Do you have any examples where change has happened based on the influence of members? – Or where the organization has had external political influence?

Members:

1. Why did you become a member of LHL? Why did you want to take part of a local group?
2. How does the local group work? Which activities do you have?
   How many members are you? And how many are active?
3. Do you feel you are followed up by the administration? If yes – how?
4. Do you feel there are any distance between members and the administration? If yes – how? Do you feel the administration takes you seriously?
5. What are the main challenges you as a member are experiencing? Where do you need assistance from the organization?
6. The homepage states "LHL influences the government and the society in battle for patients' rights" – Do you feel this is done in practice? How?
   Do you know what your rights are?
7. Are there any changes that should be made - with regards to structure, communication or others? – Why and how?
8. Are the local groups influenced by any laws or regulations?
9. Do you feel user-influence is important and used within the organization?
10. In what degree do you mean the organization is working political? – Or commercial?
11. Do you have any examples where changes had happened based on pressure from individual members or the local teams?

Additional for both employees and members:

OECD stated that an indication for better healthcare quality could be to decrease the high number of hospital readmission for COPD-patients, how do you think this could be done?