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EVERYDAY LIFE ACTIVITIES OF PEOPLE WITH CHRONIC OBSTRUCTIVE PULMONARY DISEASE: PERFORMANCE, MANAGEMENT AND EVERYDAY TECHNOLOGY USE

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Everyday life activities of people with chronic obstructive pulmonary disease: Performance, management and everyday technology use

THESIS FOR DOCTORAL DEGREE (Ph.D.)

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'The lungs will not improve – but daily life can'

Jeannette Pols, 2011 (1, p. 201)

ABSTRACT

Background: When a person is living with chronic obstructive pulmonary disease (COPD), his/her participation in everyday life activities is challenged due to a complex multitude of symptoms. Moreover, everyday technology utilised in daily life at home and in society also impacts on participation in everyday life activities. Knowledge of everyday life activities and everyday technology use of persons with COPD is sparse but is important to obtain for use in pulmonary rehabilitation.

The overall aim of this thesis was to evaluate and explore everyday life activities including everyday technology use in persons with COPD to generate knowledge that can be applied in COPD rehabilitation.

Methods: To evaluate and explore everyday life activities, both quantitative and qualitative studies have been conducted using a cross-sectional design (Study I, II, IV) and qualitative interviews (Study III). First, a reliability testing was performed to ensure the psychometric evidence of the Everyday Technology Use Questionnaire (ETUQ) (Study I) to apply in the following data collection. Data for Study I were collected among persons both with and without COPD. In Study II, the associations between health-related quality of life (HRQOL) and activities of daily living (ADL) performance, everyday technology use and demographic data were investigated. In Study IV, ADL performance was further explored, and the relationship between observed and self-reported ADL performance and everyday technology use was investigated. Statistical analyses such as Svensson's method for paired ordinal data, correlational and multiple regression analyses were applied in these studies. In Study III, the experiences and management of everyday life activities were explored through qualitative interviews, which were analysed using content analysis. All included participants in Study II-IV were diagnosed with COPD.

Findings: An overall finding was that, although different concepts, ADL performance and everyday technology use were related and they were associated with HRQOL among people living with COPD. The personal ADL (PADL) tasks found to be most affected among the participants were related to moving around inside and outside the home, bathing and lower dressing. The instrumental ADL (IADL) tasks most affected were related to cleaning, washing and transportation. The ADL motor skills most challenging for persons with COPD were Positions, Stabilizes, and Endures, and for ADL process skills they were Organizes, Accommodates and Benefits. Inter-rater and test-retest reliability of ETUQ was initially confirmed. The overall ability to use everyday technology was relatively high in relation to the difficulty presented by the technologies included in the ETUQ. However, some participants demonstrated lower ability scores indicating a potential need for support also in using everyday technology. Lastly, the participants experienced a complex juggling when managing their everyday life activities, being constantly aware of bodily symptoms and

limitations related to COPD, which meant that valued and pleasurable activities were not in focus and were not prioritised.

Conclusion: The participants in this thesis were affected by their disease while performing both PADL and IADL tasks in which everyday technology was involved. Moreover, they experienced a complex juggling seeking to manage their everyday life activities being constantly aware of bodily symptoms and limitations related to COPD. It is therefore important in pulmonary rehabilitation to address and support persons with COPD in choosing and performing everyday life activities of personal interest and value for them and to support them in using everyday technology. By evaluating and exploring everyday life activities through the dimensions of doing, and in natural and relevant settings, this thesis can contribute with new insights into the field of COPD.

Keywords: Activities of daily living, everyday technology, evaluation, health-related quality of life, occupational therapy, pulmonary rehabilitation

LIST OF SCIENTIFIC PAPERS

- I. Kaptain RJ, Kottorp A, Patomella AH, Helle T. Inter-rater and test-retest reliability of the Danish version of the everyday technology use questionnaire. *SJOT*. 2019; 26(3):226-234.
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LIST OF ABBREVIATIONS

ADL	Activities of daily living
ADL-I	Activities of daily living, Interview
AMPS	Assessment of motor and process skills
COPD	Chronic obstructive pulmonary disease
D	Measure of disorder
ETUQ	Everyday Technology Use Questionnaire
FEV	Forced expiratory volume
HRQOL	Health-related quality of life
IADL	Instrumental activities of daily living
MOHO	Model of Human Occupation
N	Number of participants
PA	Percentage agreement
PADL	Personal activities of everyday life
RC	Relative concentration
RP	Relative position
RV	Relative rank variance
SD	Standard deviation
SF36	The Medical Outcomes Study Short Form 36
SPSS	Statistical Package of Social Sciences

1 INTRODUCTION

1.1 PETER'S STORY OF EVERYDAY LIFE WITH CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD)

"I have COPD and it constantly challenges me in my everyday life. My lung capacity is down to 16%. My day always starts well, because waking up reminds me that I have been given another day alive, which has not always been a matter of course. Having enjoyed that for a while, the morning activities begin. After brushing my teeth, I need to regain my breath. Then I'm ready for the day's first challenge, namely the morning shower. The shower's steam is very troublesome for my lungs. Therefore, I should shower fast. But speed is incompatible with bad lungs. Things must go slowly with small movements. After shower, drying is the next struggle. First, I dry one part of the body. Then a few minutes break. Then the next parts. This includes longer breaks, leaning over the sink. The next challenge is dressing. Also a struggle with breaks.

Then I'm ready to go down to the kitchen for breakfast. The stairs is a true challenge. I need to stop for a break after having walked down 12 of the 16 steps. Just to catch my breath. The newspaper is usually in the letterbox. If it lands on the floor, I curse a little, because I must bend, which is not my favourite position. Preparing meals and eating involve several challenges. Owing to lacking space between the too large lungs and the stomach, breakfast is a piece of rye bread and a cup of coffee. On bad days, struggling to breathe, I can hardly eat. I must schedule my daily activities, and all movements should be well planned to manage the load on the lungs, especially when I am outside my home. Interruptions and surprises make me easily lose my breath, and I must stop completely to regain my breath. In windy weather, I am forced to consider the movement from the wind which I am unable to predict. Going to a café, I always choose one with toilets on the ground floor, because I am unable to rush. Grocery shopping is another chapter. I can only shop in stores located at a short distance from home. If I need milk and bread, I must set aside about one hour. Picking up more things will cost another hour.

My daily life is filled with strategies for how to get things done the easiest way. There is constant planning and wondering. Although I try to live smart, I also know that it is crucial to be as active as possible. I always fear that things will go wrong and an ambulance will be needed. The only way out of that situation is to fight, fight and fight." (Freely translated and adapted from newspaper article) (2)

Peter's story has many similarities with stories shared by the participants in this thesis. Although all stories and experiences are individual, Peter's story gives us a hint about his everyday life and how he manages his activities.

1.2 PERSONAL INTRODUCTION

As an occupational therapist, I have a special interest in everyday life activities. Within about 10 years as an occupational therapist in clinical practice and almost 10 years of teaching occupational therapy students, my professional interest in everyday life activities has been performed in various ways. This has, at times, been challenging in a setting focused on medical conditions; yet also very satisfying.

The daily life experiences in Peter's story are recognisable to most people living with COPD, I believe; an everyday life permeated in every aspect by COPD and by a constant struggle to adapt to the disease in the best possible manner. Occupational therapy seems so obviously relevant to this field; and, still, it is so remarkably underrepresented in practice and research. Through this thesis work, I have therefore also tried to understand how other professions reason about everyday life activities and explored how occupational therapy can contribute to the field of COPD.

The target group of this thesis is occupational therapists in clinical practice, education and research; as well as other healthcare professionals working within or interested in the field of COPD; and, naturally, people living with COPD and their significant others and caregivers. With this thesis and the four included studies, I hope to contribute to minimizing the knowledge gap within occupational therapy and to illuminate our way of reasoning about everyday life activities and thereby support people living with COPD in their independence and engagement of their everyday life activities.

2 BACKGROUND

A core belief within the profession of occupational therapy is that humans perform and engage in daily occupations (3) and that these occupations are central to human life and closely related to health and well-being (4). The focus of this thesis is to explore and evaluate the doing of everyday life activities of people with chronic obstructive pulmonary disease (COPD). Peter's story shows how he struggles to find strategies so that he can fulfil his need to do the things that are important and give meaning to him, not just managing some personal activities of daily living (ADL).

The need for studying people with COPD is immense as the prevalence of this devastating disease in Denmark is estimated to about 430,000 people of whom about half do not yet have the diagnosis (5). Worldwide the number of people with COPD is estimated at 251 million (6). This creates major health problems and a significant societal burden primarily because of health expenses and loss of working capacity (5,7–9). Moreover, co-morbidities such as cardiovascular diseases, depression or anxiety are common when living with COPD as also reflected in the poor health-related quality of life (HRQOL) often seen among people living with COPD (10,11).

COPD is primarily caused by smoking, but about one fourth of incident cases are caused by other factors such as pollutants, genetic factors and respiratory infections (12,13). Because of its link with smoking, there is a risk that COPD may be considered as self-inflicted by clinicians, researchers and healthcare providers (14,15). This may indicate the presence of a substantial issue with palpable consequences for the person who has COPD. In Denmark, all citizens are by law entitled to the same free healthcare through general practice, hospitals and municipalities. The management of COPD in Denmark is consistent with international evidence-based COPD guidelines (16,17).

2.1 THEORETICAL PERSPECTIVES OF EVERYDAY LIFE ACTIVITIES

Everyday life activities refer to a multitude of daily activities in which people engage (18). In this thesis, the concept everyday life activities is used synonymously with the term occupation as is in line with the Occupational Therapy Practice Framework: Domain & Process (18). Occupation is also defined as *“the everyday activities that people do as individuals, in families and with communities to occupy time and bring meaning and purpose to life. Occupations include things people need to, want to and are expected to do”* (19). According to the Model of Human Occupation (MOHO) (20), occupation includes three dimensions of doing: participation, performance and skills. These dimensions are mutually influenced by the person's volition, habituation and performance capacity, and the environment. A person's participation in occupations is conceptualised through the constant interaction of feeling, thinking and acting in and with the world. Performance refers to the units of doing that involve completing a series of steps that lead to a desired activity (20). The

smallest observable, goal-directed actions that make up occupational performance are referred to as occupational skills and they include motor skills, process skills and social skills (20,21). Examples of skills are to reach out for, grasp, lift and choose objects needed for completion of a specified task, move oneself within the environment using the appropriate amount of force and without bumping into things, or to keep attendance to the activity. In order to perform such actions, the underlying objective physical and mental components as well as subjective experiences are used, which in MOHO are collapsed into one concept defined as performance capacity (20). In this thesis, the three dimensions of occupations are explored and evaluated with a focus on doing and the experience of doing. Fisher (22) addresses the experience of doing as an occupational experience directly connected to occupational performance as observable aspects of the person's doing. When people then are doing and experiencing occupations through integration of their personal values, they are participating (22).

Comprised within occupation or everyday life activities are ADL (20), which can be divided into personal ADL (PADL) and instrumental ADL (IADL) (18,21). PADL are tasks relevant to perform on a day-to-day basis in order to cover basic needs such as eating, staying clean and being appropriately dressed (18,21); and they are the activities "*fundamental to living in a social world; they enable basic survival and well-being*" (23, p. 156). IADL include more complex interactions and support daily life within the home and community such as transportation, cooking, shopping, washing, maintaining home and integrating health management (18). In the literature, ADL is often positioned as one area among several within everyday life activities, e.g. work, productivity, education, leisure and play (18,20,21,24,25), but with variation in the classifications. The category primarily evaluated within this thesis is ADL. The division of PADL and IADL is useful, e.g. because it facilitates an overview of affected activities. Jonsson (26) and Hammel (27) suggest that the categorisation of occupation should rather be based on people's experiences of occupation. Moving the focus from objective to subjective categories with a focus on engagement may support occupational therapists in paying more attention to their clients' engagement in occupations.

As an objective of this thesis is to share its insights with colleagues, I have explicitly decided to use the concept of everyday life activities interchangeably with occupation, and use the concept of ADL as an underlying component of everyday life activities to clarify how the findings of the thesis and the included articles may inform multidisciplinary COPD rehabilitation. Some everyday life activities are not captured by the definition of occupation, but rather lead to imbalance such as, activities related to abuse or over- and underused capacities (4) by doing drugs, performing exaggerated exercise activities or underusing capacities by laying on the couch the whole day; however, those activities are not in focus in this thesis.

Several of the quoted papers describe the link between occupation and well-being from a theoretical vantage point; for example, the American Occupational Therapy Association states, "*the path to health and well-being is intricately linked to participating in daily*

occupations” (28). Furthermore, Wilcock and Hocking (4, p.1) express that “*occupation affects health and well-being at fundamental levels*”. Health is defined as “*the ability to adapt and self-manage in the face of social, physical and emotional challenges*” (29, p. 2) and Hammell (27, p. 106) refers to well-being as “*contentment – or perceived state of harmony - with one’s physical/mental health, self-esteem, sense of belonging, personal and economic security, and one’s opportunities for self-determination, meaningful occupation, maintenance of valued roles, and ability to contribute to others*”. However, to the author’s knowledge, these theoretical assumptions have not been investigated empirically among persons living with COPD.

2.2 EVERYDAY LIFE ACTIVITIES WHEN LIVING WITH COPD

When a person is living with COPD, his/her participation in everyday life activities is affected and challenged by the complexity of symptoms as illustrated in Peter’s story in the beginning of this thesis. This complexity is captured in the characterisation of COPD as a progressive worsening of a person’s lung capacity; as the disease progresses, it gradually also affects the person’s physical, emotional and social functioning, causing a reduction in his/her perceived quality of life (30). The reduced physical functioning is due to muscle dysfunction, the consequences of dynamic hyperinflation, increased respiratory load or defective gas exchange (31,32), leading to symptoms of breathlessness, fatigue, pain, sputum production and cough (17,33). These physical restrictions can then affect, in various ways and to differing degrees, the performance of everyday life activities thereby hampering the person’s ability to get dressed, groom, do household activities and engage in mobility-related activities like moving around inside and outside the house and especially walking up and down stairs (34,35). Furthermore, the decreased mobility makes it difficult for the person to remain physically active (36) and may also limit his or her ability to leave the home (37), thereby affecting also participation in out-of-home activities, social and emotional functioning (37,38).

Social activities often contribute to a sense of belonging and a feeling of being useful; however, they are often reduced among people with COPD so that they include only the person’s spouse and close family when participation in and outside the home becomes too demanding (35). Perceived loneliness or insecurity in a person with COPD can evolve into emotional distress or anxiety in relation to handling breathlessness during everyday life activities (35,39). The lost ability to perform everyday life activities may then affect the person’s independence (38), resulting in a need to rely on support from formal and informal caregivers (40,41). Support may be needed to perform activities like dressing, bathing, cooking, cleaning and shopping (41). Furthermore, people who are living with COPD often give up leisure activities. A study found that almost half of the valued activities among persons with COPD were affected, and 42% of the group was unable to perform at least one valued activity (42). These negative effects may be caused by physical limitations or by the need to prioritise whatever time and energy is left after having performed the PADL (42,43).

Wilcock and Hocking (4, p. 140) describe the importance of everyday life activities in relation to health and development as follows:

“health and well-being are intimately connected with societal and environmental factors; what people do throughout their lives and day by day; how they interact with others and belong to families, communities, and places through what they do; and how, collectively and individually, they are in a state of continual transformation through what they do”.

Christiansen (44) argues that participation in everyday life activities helps create our identities, and MOHO further argues that occupational identity includes “one’s sense of capacity and effectiveness for doing” (20, p.117). Therefore, participation in everyday life activities, including both the ability to perform and the experiences of performing, is essential to who we are and how we perceive life.

The COPD literature agrees that everyday life activities are important for quality of life (30). However, this has not been further investigated empirically; and only a few studies focus on the performance or motivation of everyday life activities; instead, they focus on the underlying body functions (45–47). Therefore, more knowledge of performance and experiences of performance of everyday life activities is required to inform COPD researchers and decision-makers, and to design appropriate interventions within this field.

2.3 HEALTH-RELATED QUALITY OF LIFE AND COPD

It seems obvious that HRQOL is affected in those who are living with disease. Within the field of COPD, HRQOL is increasingly considered as one of the primary endpoints as it is generally recognised that COPD is associated with debilitating physical and emotional symptoms with a negative impact on HRQOL (48–51). HRQOL has been defined as an individual’s perception of physical and mental health (52). Furthermore, well-being has been linked to the positive and subjective aspect of a person’s life such as positive emotions and life satisfaction contributing to one’s overall HRQOL (53,54). Associations among HRQOL and variables such as lung function, physical impairment and ADL have been investigated to be able to better support people with COPD in the right areas. However, everyday life activities have been investigated only sparsely in relation to HRQOL; and, if evaluated, primarily then with ADL measured as physical functioning or simulated ADL (e.g. pretending to shower but without water and with clothes on) and not with a focus on the actual ADL performance (see examples in Barusso-Grüniger et al. (55) and Hu & Meek (56). Other variables affecting HRQOL could supposedly be the severity of the COPD diagnosis. A large study based on registrations from the Swedish COPD register of 7,810 persons with COPD showed that, as expected, people with more severe COPD also had lower HRQOL (45). However, other studies found no relationships between lung function and HRQOL (57–59). These varying results may be explained by HRQOL measuring the consequences of both physical, psychological and social factors. Therefore, a single physiologic predictor may not be enough to make associations significant (48,60).

Given the uncertainty characterising several HRQOL predictors, more knowledge of the relation between everyday life activities and HRQOL is needed to be able to support persons with COPD appropriately. This need is reflected in two of the main goals within pulmonary rehabilitation, viz. to increase participation in everyday life activities and enhance HRQOL among people with COPD (30).

2.4 EVERYDAY TECHNOLOGY USE IN PEOPLE WITH COPD

Everyday life activities involve everyday technology for various activities at home and in society (61–64). Everyday technology includes a variety of mechanical, electronic, and digital equipment that people encounter in their daily lives; e.g. microwave, washing machine, smartphone, ticket machines and self-scanners at the supermarket (64). The continuous and fast development of technology increases the impact the technologies have on everyday life activities, requiring users to have a certain level of digital competence (61). For people with COPD, who may be restricted to staying within their homes, the use of everyday technology through social media, online video calls or use of e-mails and chat is essential to remain socially active with friends or family. Furthermore, everyday technology use may also concern e-health, e.g. for monitoring the person's current state of health and sending data to healthcare professionals using a tablet or a cell phone (65), or consulting healthcare professionals via a video conference call (66).

Literature describing technology to support self-management is expanding (67–70); however, the ability to use technology may be influenced by lacking confidence, lacking skills or little motivation or interest in using the technology among people with COPD (68,71). Additionally, the likelihood of reduced cognitive functions as found among people with COPD (72,73) may affect their ability to use everyday technology (74,75). The technological development may therefore challenge persons in their everyday life activities as both performance of activities and participation in society may be influenced by the person's ability to use everyday technology (76,77). Furthermore, the physical and social environment may affect performance, either as a facilitator or a hindrance (76), as also in line with MOHO (20,78).

Environmental facilitators involve, e.g., reliance on guidance from children or grandchildren (68) or support from healthcare professionals in using the technology (71). Hindrances may also arise because of the design of the technology, making it challenging to use (79), and can surface as difficulties in using internet banking, opening electronic mail from the authorities as well as buying electronic bus or cinema tickets, leading to dependence on others. Such challenges have been referred to by people as hard to learn, taking up too much time and as difficulty in keeping up with changes in the technology (80). On the other hand, it has also been reported that using everyday technology comes with benefits such as saving time and being able to communicate in a more flexible way (80). Furthermore, greater technology use has been associated with less loneliness, better health, fewer chronic illnesses and lower

levels of depression (80), demonstrating that everyday technology is, indeed, an area relevant of attention also for people with COPD.

A few studies including diagnoses other than COPD have investigated the relationships between everyday technology and ADL. Among older adults with mild cognitive impairment and Alzheimer's disease, relations have been found between ADL ability and everyday technology use (81). Furthermore, participation in IADL outside the home was influenced by motivation and engagement in people with mild cognitive impairment (82). To the author's knowledge, comparable relations have not been investigated among people with COPD; nor have any studies focused on the ability to use everyday technologies like microwave, vacuum cleaner, self-scanner at the supermarket or use of home banking in people with COPD.

2.5 OCCUPATIONAL THERAPY IN THE CONTEXT OF PULMONARY REHABILITATION

The World Health Organization (WHO) has launched "*Rehabilitation 2030: a call for action*" to scale up rehabilitation globally (83). Ten action area priorities have been identified. Among these, Goal 3, Sustainable Development, is to strengthen 'good health and wellbeing' (84). Pulmonary rehabilitation is considered an interdisciplinary intervention encompassing several components; however, the results of such interventions have been inconsistent (85,86), indicating a need for further research in order to determine which interventions or recommendations are most efficient (17). Pulmonary rehabilitation is defined as "*a comprehensive intervention based on thorough patient assessment followed by patient-tailored therapies that include, but are not limited to, exercise training, education, self-management intervention aiming at behavior change, designed to improve the physical and psychological condition of people with chronic respiratory disease and to promote the long-term adherence to health enhancing behaviors.*" (17, p. 56).

This definition comprises elements such as exercise training, education and behavioural change, all of which are meant to improve physical and psychological conditions (30), though with exercise training being the foundation (86).

In the Key Concepts and Advances in Pulmonary Rehabilitation described by the American Thoracic Society and the European Respiratory Society (30), occupational therapy is an area for which this interdisciplinary team is responsible, although this is not explicitly described or stated in the document. However, in the overall goals of pulmonary rehabilitation, which are to be "*minimizing symptom burden, maximizing exercise performance, promoting autonomy, increasing participation in everyday activities, enhancing (health-related) quality of life, and effecting long-term health-enhancing behaviour change*" (30), participation in everyday life activities is mentioned. Furthermore, elements from self-management collaboration are relevant for occupational therapists. As an example, health professionals are encouraged to provide less advice and education but rather inspire persons with COPD to experiment with new adaptive behaviours and seek to integrate these behaviours into their daily life (30)

which is obviously an activity that falls within the profession realm of occupational therapists. However, evidence for occupational therapy among persons with COPD is sparse, as also highlighted in the Danish Health Authorities' National Clinical Guidelines for Rehabilitation of Patients with COPD (87). This guideline highlights the need for knowledge of whether the ability to perform ADL is improved through pulmonary rehabilitation. It is problematic that there are no descriptions of evidence-based practice within occupational therapy for people with COPD, not least since such descriptions are critical to informing clinical practice, ensuring the provision of well-documented, qualified and accurate occupational therapy. The literature describes how people with COPD are challenged to perform everyday life activities (34,88,89); it is therefore highly problematic if they receive no qualified support for managing their situation.

Self-management is part of pulmonary rehabilitation. According to Kaptein (86), this implies a stronger focus on the person than in general pulmonary rehabilitation where there may be a tendency to focus on the physical activity. Self-management includes personal goals that must be perceived as highly relevant for the person with COPD to increase the person's intrinsic motivation and take responsibility for own health and develop confidence in being able to manage effectively his or her own situation (90). An international expert group has proposed a consensus definition of COPD self-management intervention as a *"structured but personalised and often multi-component, with goals of motivating, engaging and supporting the patients to positively adapt their health behaviour(s) and develop skills to better manage their disease"* (89, p. 51). However, the contents of specific interventions vary concerning inclusion of exercise and physical activity (91,92), smoking cessation, education, guidelines for self-treatment of exacerbations, nutritional advice or dyspnoea management (93–97). Self-management interventions including communication with healthcare professionals have been found to improve COPD outcomes, whereas education alone has shown not be effective (17). Within self-management in pulmonary rehabilitation, focus is on making interventions that sustain behavioural change also after the intervention (90), even though people with COPD may have a high risk of relapse (86).

The definition of occupational therapy described by the World Federation of Occupational Therapists seems to integrate the self-management part of pulmonary rehabilitation:

"Occupational therapy is a client-centred health profession concerned with promoting health and well-being through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life. Occupational therapists achieve this outcome by working with people and communities to enhance their ability to engage in the occupations they want to, need to, or are expected to do, or by modifying the occupation or the environment to better support their occupational engagement" (19).

Still, evidence of interventions, and included evaluations, aimed directly at improving everyday life activities are deficient as are also guidelines to support occupational therapists within pulmonary rehabilitation. This thesis will provide a solid contribution that expands the knowledge base of occupational therapists working in pulmonary rehabilitation.

2.6 EVALUATION OF EVERYDAY LIFE ACTIVITIES

When evaluating the performance of everyday life activities, the constructs measured are evidently of great importance as is also the very environment where evaluations are performed. The literature shows that assessments evaluating ADL in people with COPD measure different aspects of ADL that are all relevant to move interventions in the right direction.

Especially two aspects are of interest; one aspect focuses on physical functioning or symptoms (55,98,99); the other on ADL performance (34,89). An example of ADL being evaluated with a focus on physical functioning is the use of simulated activities such as carrying a heavy backpack a certain number of laps (100) or simulate a shower performed with clothes on and no water; and lifting and lowering containers with a focus on lifting above or under pelvic girdle level (55). More examples are seen in a review focusing on performance-based ADL assessments using five ADL assessments (Glittre ADL Test, ADL Simulation Test, Monitored Functional Task Evaluation, Londrina ADL protocol, ADL simulation) in 23 different studies (39). As indicated by the title, all these assessments used either simulated tasks or functional tests and may have been generated using a definition of ADL as a physical activity subgroup (85). Functional tests here mean evaluation of functions like sit-to-stand, walking, lifting or carrying (39). In these evaluations, the outcomes are measured in terms of time used and number of shuttles or number of actions made (39). In contrast, ADL can be defined as a subcategory of occupations (18,20) leading to assessments measuring the concept of ADL performance (34,89) and addressing constructs like effort, efficiency, independence and safety (101).

These two different definitions and their use in evaluations of ADL may cause misunderstandings among healthcare professionals as there may be a tendency to think that the measurable concept of ADL means the same across all ADL evaluations. However, the concept is defined, applied and evaluated in different ways. When reviewing the literature of ADL evaluations among people with COPD, it appears that most evaluations apply the ADL definition referring to physical activity, leading to a gap in the literature of ADL evaluations referring to occupations.

When ADL is defined by occupational therapists, the concept of ecological relevance (22) activities should also be considered. Being ecologically relevant means that the activities are contextualised, which is explained as follows: *“to engage in ‘real’ task performances, in ‘real’ places, with ‘real’ objects, with the ‘real’ people usually present, when they would ‘really’ do it, and they are doing it the way they ‘really’ do it”* (22, p. 72). Occupational therapists do not intend to improve time or number of laps but to modify any inefficiency, safety or effort issues pertaining to relevant everyday life activities (21), making the persons performing the activities feel engaged and motivated during performance (20). Therefore, it is important to evaluate constructs relevant to performance of everyday life activities as seen from the perspective of the person with COPD within the context of his or her everyday life and in the environment where the activity in question is actually performed. Knowledge from

occupational therapy evaluations also needs to be incorporated into pulmonary rehabilitation to bridge the current gap in interdisciplinary evidence. Even for people with COPD suffering from a chronic lung condition, everyday life activities harbour potential for improvement.

Evaluations of the ability to use everyday technology are likewise important as part of pulmonary rehabilitation to support people facing limitations in everyday technology use at home and in society. Evaluations of telehealth or e-health include measures of the effect of an intervention within pulmonary rehabilitation (102), but the ability to use these technologies is usually not evaluated among people with COPD.

2.7 RATIONALE OF THIS THESIS

Participation in everyday life activities of persons living with COPD are affected and challenged due to the complexity of symptoms and their related consequences. This complexity is contained in the characterisation of COPD as a progressive worsening of a person's lung capacity. As the disease progresses, it gradually also affects the person's physical, emotional and social functioning, thereby further reducing his/her perceived quality of life. The character and magnitude of everyday life activities are still insufficiently investigated and the role of occupational therapy is also only vaguely described within clinical guidelines of pulmonary rehabilitation. Moreover, everyday technology has become an intertwined part of all our everyday lives, but how this affects everyday life activities and quality of life among people with COPD is insufficiently explored. Therefore, the purpose of this thesis is to expand the knowledge base for occupational therapy practice and research and to inform the clinical guidelines within pulmonary rehabilitation by generating new insights into how persons with COPD experience and manage participation, perform everyday life activities and use everyday technology. In addition, evaluations, measuring aspects of the doing of everyday life activities and everyday technology use, that are performed in relevant and natural environments must be valid and reliable, and must be used to generate detailed information about strengths and weaknesses in skills and performance. Knowledge derived from these evaluations and the experiences of people with COPD can then be applied in pulmonary rehabilitation and the field of COPD, potentially enhancing health and well-being for persons with COPD.

3 RESEARCH AIMS

The overall aim of this thesis was to evaluate and explore everyday life activities including everyday technology use in persons with COPD to generate knowledge that can be applied in the field of COPD.

The specific research aims were to:

- Investigate the inter-rater and test-retest reliability of the Danish version of the Everyday Technology Use Questionnaire (ETUQ) when used with older adults with and without COPD (Study I)
- Investigate if HRQOL was associated with quality in ADL performance and everyday technology use. Moreover, a secondary aim was to examine whether lung function, years with COPD, living status or educational level affected HRQOL (Study II)
- Describe how people living with COPD experience and manage activities of everyday life (Study III)
- Explore the quality of ADL performance; and to investigate the relationship between observation and self-report when evaluating ADL performance and the ability to use everyday technology in people living with COPD (Study IV)

4 METHODS

4.1 OVERVIEW OF RESEARCH DESIGNS

To evaluate and explore everyday life activities and everyday technology use among people living with COPD, a combination of quantitative (Studies I, II, IV) and qualitative (Study III) research designs was used. Combining these designs ensures both depth and breadth of the knowledge base generated from the thesis (103).

Table 1. Overview of the purpose and research methods in the four studies.

	Study I	Study II	Study III	Study IV
Purpose	Investigate inter-rater and test-retest reliability of Danish version of the ETUQ	Investigate associations between HRQOL and ADL performance, everyday technology use and demographic data	Describe the experience and management of activities of everyday life	Investigate and explore ADL performance and the relationship between observed and self-reported ADL performance and everyday technology use
Design	Quantitative, cross-sectional study	Quantitative, cross-sectional study	Qualitative study	Quantitative, cross-sectional study
Data collection	Questionnaire in semi-structured interview	Questionnaire in semi-structured interview and self-assessment, observation of ADL task performance	Individual, semi-structured interviews	Questionnaires in semi-structured interview, observation of ADL task performance
Participants	N=47 with and without COPD	N=80 with COPD	N=8 with COPD	N=84 with COPD
Instruments	ETUQ	ETUQ, SF-36, AMPS	---	ETUQ, ADL-I, AMPS
Data analysis	Descriptive statistics, Svensson's method and Rasch analyses	Descriptive statistics and multiple regression analyses	Qualitative content analyses	Descriptive statistics, Rasch analyses, correlational analyses

Note: The sample is the same in Study II and Study IV. **Abbreviations:** ADL-I: Activities of daily living, Interview; AMPS: Assessment of Motor and Process Skills; COPD: Chronic obstructive pulmonary disease; ETUQ: Everyday Technology Use Questionnaire; SF-36: 36-Item Short Form Survey.

4.1.1 Quantitative study design

The quantitative studies in this project have all been conducted using an observational design within a cross-sectional study design (104). The cross-sectional study design is characterised by measuring the participants only once, which is useful when investigating prevalence (105) like in the present studies where current ADL performance, everyday technology use and HRQOL were investigated (within Study I measures were repeated for evaluation of stability in everyday technology use). The cross-sectional design allowed us to obtain a multitude of findings by using different samples (varying in size and with or without diagnosis) and different analyses such as multiple regression analysis, correlation analysis or Svensson's method for paired ordinal data.

4.1.2 Qualitative study design

Qualitative interviews were performed using content analysis applying an inductive approach (106). Induction is characterised as searching for patterns by retrieving similarities and differences in the data and hence move from the concrete and specific level to the abstract and more general level (106). Efforts have been made to ensure a consistent level of abstraction and interpretation, albeit the overall theme has been more abstract and subject to more interpretation than the subcategories as also suggested by Graneheim et al. (106,107).

4.2 PARTICIPANTS

The participants in this thesis were related to two study samples. In Study I, the sample consisted of N=47 adults with and without COPD. Participants both with and without COPD were included to get a broad sample for testing the reliability of the first Danish version of the ETUQ. In Study II-IV, all participants' main diagnosis was COPD; this was confirmed by simple spirometry using the Vitalograph copd-6 (Vitalograph Ltd, Buckingham, United Kingdom) and through participation in the e-health project TeleCare North Trial (108). In the e-health project, participants were given a tablet for weekly reporting of data on their current state of health, including blood pressure, pulse, blood oxygen saturation and weight (65).

The participants' age was 47-87 years. The participants' characteristics are shown in Table 2. For further details, please see the original articles.

Table 2. Characteristics of participants in Study I-IV.

	Study I (N=47)	Study I With COPD (n=23)	Study I Without COPD (n=24)	Study II (N=80)	Study III (N=8)	Study IV (N=84)
Age, mean (SD)	71.09 (8.07)	71.39 (7.43)	70.79 (8.63)	70.05 (9.38)	73.25 (7.76)	69.94 (9.42)
Gender n (%):						
Male	15 (32)	7 (30)	8 (33)	30 (38)	4 (50)	31 (36.9)
Female	32 (68)	16 (70)	16 (67)	50 (62)	4 (50)	53 (63.1)
Education n (%):						
Primary school/skilled worker	27 (57)	15 (65)	12 (50)	60 (75)	1 (12.5)	64 (76.2)
Student/higher education	20 (43)	8 (35)	12 (50)	17 (21)	7 (87.5)	17 (20.2)
Living conditions n (%):						
Living alone	20 (43)	13 (56)	7 (29)	37 (46)	3 (37.5)	34 (40.5)
Cohabiting	27 (57)	10 (44)	17 (71)	43 (54)	5 (62.5)	50 (59.4)
Classification of COPD, n (%):	-	-	-	78 (98)	8 (100)	82 (98)
Normal				4 (5)	0	4 (4.8)
Stage I				17 (21)	1 (12.5)	17 (20.2)
Stage II				50 (62)	3 (37.5)	54 (64.3)
Stage III				7 (9)	2 (25)	7 (8.3)
Stage IV				0	2 (25)	0

Note: The sample is the same in Study II and Study IV. **Abbreviations:** COPD: Chronic obstructive pulmonary disease.

4.2.1 Sampling in Study I

Participants in Study I were recruited purposively through healthcare centres, activity centres, patient organisations and organisations of older adult (109). We aimed to attain a sample sharing the characteristic of being elderly and for some participants also having COPD. Furthermore, snowball sampling (103) was used. Inter-rater reliability and test-retest reliability were each tested on a sample of 30 participants with equal representation of persons with and without COPD. With some participants agreeing to participate in both the

inter-rater test and the test-retest evaluations, the overall number of participants was N=47. Inclusion criteria were >55 years of age and living in ordinary dwellings; and exclusion criteria were people with major cognitive, physical, hearing or visual functional limitations.

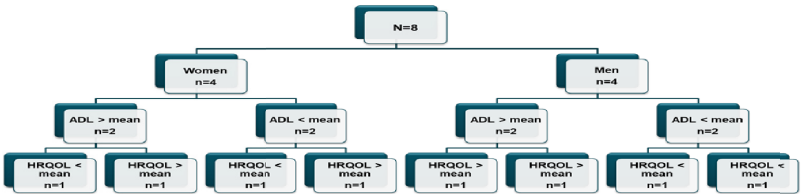
4.2.2 Sampling in Study II and IV

Participants were recruited through healthcare centres in the Northern Denmark Region through convenience sampling (103). The target sample was N=100. However, since evaluations were not completed in all cases, the final sample was N=80 for Study II and N=84 for Study IV. Included were persons registered with a COPD diagnosis in primary healthcare. Exclusion criteria were (i) being unable to understand Danish sufficiently to answer the questionnaires in Danish, (ii) living in a nursing home, (iii) being diagnosed with cognitive impairment or (iiii) having a visual or hearing impairment that could not be compensated for by technical aids. Nurses at the healthcare centres were introduced to the inclusion and exclusion criteria by the author of this thesis. When in contact with potential participants, the nurses asked them if they would agree to receive a telephone call inviting them to participate in this project. The inclusion and exclusion criteria were verified by the author or the co-supervisor (TIH) when contacting the participants. Excluded participants were not registered.

4.2.3 Sampling in Study III

For Study II and IV, participants were asked if they would agree to be contacted on another occasion for participation in an interview study. The invitation was accepted by 55 participants (65%). Using criterion sampling (110), we purposively selected participants for interviewing (103) to ensure variety in terms of gender, living status, ADL performance and HRQOL measures (Figure 1). Eight participants were contacted by telephone and they all agreed to participate in interviews.

Figure 1. Flowchart of criterion sampling procedure according to gender, ADL performance^a and HRQOL^b.



Notes: ^aMeasured by ADL Interview. ^bMeasured by the Medical Outcomes Study Short Form 36 (SF36).
Abbreviations: ADL: Activities of daily living; HRQOL: Health-related quality of life.

4.3 DATA COLLECTION

During data collection and subsequent individual interviews at the participants' homes, assessments were based on four instruments: ADL-I, AMPS, ETUQ and SF36. The selected ADL assessments were focused on occupation and deemed to be ecologically relevant, and both self-report and observation were represented. SF36, though generic, is well established within the field of COPD and has been used in other studies in the Northern Denmark Region. Using the SF36 made it possible to compare the results across samples and diagnoses where relevant.

4.3.1 Instrumentation

4.3.1.1 *ADL-Interview (ADL-I)*

The ADL-I is a semi-structured interview measuring the self-reported quality of ADL task performance (111,112). ADL-I is based on the ADL taxonomy which, in turn, is based on the categorisation of activities from the MOHO as well as aspects of persons habits, roles and needs within the environment (113). The taxonomy is organised into levels of occupational forms, activities and actions inspired by Lawton (113). Forty-seven ADL tasks related to PADL and IADL are rated by the participants using a seven-category (a-g) rating scale. The scores reflect effort/fatigue, efficiency, safety and independence ranging from (a) the task is performed independently without use of extra time or effort and without risk to (g) the task is performed by others – he/she cannot participate. The task is marked “not relevant” if the participant finds the task irrelevant in daily life. ADL-I is a standardised assessment found reliable and valid (111,114,115), also in persons with COPD (34).

4.3.1.2 *Assessment of Motor and Process Skills (AMPS)*

The AMPS (21,101) is an instrument measuring the observed quality of ADL performance. It was developed for occupational therapists or occupational therapy students who completed a training course and subsequently were calibrated as raters (21). The AMPS is a conceptual model of the relation between performance and participation with the person, the environment, the task, society and culture (21).

First, the person assessed by the AMPS chooses at least two standardised ADL tasks with which he/she is well acquainted, that are relevant to everyday life and reasonably challenging to perform for the individual person. Then, the occupational therapist observes the ADL tasks being performed. The occupational therapist evaluates the quality of the performance, scoring 16 ADL motor skills and 20 ADL process skills, using a four-point criterion-referenced scale according to physical effort, efficiency, safety and independence ranging from (4) Competent to (1) Unacceptable (101). Measures of ADL motor and ADL process ability (logits) are generated through the AMPS software by the use of a Rasch analysis model and based on established cut-off values; the need for assistance to be able to live in the community can also be predicted using the AMPS (21,116). The AMPS is a standardised and internationally recognised assessment. It has been found valid and reliable in numerous studies and has been

utilised in persons with and without diagnoses, including COPD, and across ages and genders (see Fisher & Jones (21)).

4.3.1.3 Everyday technology use questionnaire (ETUQ)

The ETUQ is used to evaluate the amount of relevant everyday technologies and the perceived ability to use these technologies at home and in public places (117). The ETUQ is completed through a structured face-to-face interview first assessing which of the 93 everyday technologies included in the ETUQ are relevant for the person's current life situation. A technology is considered relevant if it is (a) available to the person and is (b) currently used by the person or has been used in the past by the person or is intended to be used in the future by the person. If so, the ability to use the everyday technology in question as perceived by the person him or herself is marked by the interviewer on a five-category rating scale, ranging from (5) No perceived difficulties to (1) Not using the technology anymore (117).

The ETUQ was originally developed for use in elderly people with cognitive limitations (118,119) but has since been used among adults with mental retardation (120), acquired brain injury (121) and older adults without known cognitive impairments (122). The ETUQ draws on the same theoretical foundation as the MOHO (78) and on Lawton's theory (123) on the balance and interplay between a person's ability and the pressure and norms within the environment. The ETUQ has been shown to be a unidimensional construct with good validity based on internal structure, individual response processes and precision in the generated measures among older adults with and without cognitive impairment, mental retardation and acquired brain injury (124–126). The ETUQ was translated into Danish in Study I, and the instrument demonstrated excellent test-retest and inter-rater reliability in older adults with and without COPD (127).

4.3.1.4 Medical Outcomes Study Short Form 36 (SF36)

The SF36 is a well-established generic questionnaire measuring self-reported HRQOL (128). The SF36 contains eight subscales: physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional and mental health; combined the scores produce two summary scores indicating the measure of physical and mental HRQOL. The SF36 has been validated in Danish (129) and in populations with COPD (130,131). The development of the SF36 was accomplished to achieve accepted standards of representation of multidimensional health concepts, and a measurement of health status that included levels of well-being as well as personal evaluations of health (131).

4.3.2 Data collection Study I

For Study I, data were collected by four raters who were registered occupational therapists (the author included). They had completed an ETUQ course conducted by the developers of the instrument. When investigating inter-rater reliability, the raters were paired in different combinations with rater 1 performing the ETUQ interview including the scorings and rater 2

only performing the scorings. The scorings were made independently during the interview based on the participant's responses. To investigate the test-retest reliability, rater 1 repeated the ETUQ interview within 1-4 weeks. This was considered sufficiently long time to avoid responses being remembered by the participant while still obtaining as small variations in health status and everyday technology repertoire as possible (132).

4.3.3 Data collection Study II and IV

Data for Study II and IV were collected simultaneously. Five occupational therapists (including the author of this thesis) were trained in using the ADL-I and the ETUQ by the developers of the instruments. Moreover, an expert from Aalborg University instructed us in using the Vitalograph copd-6 (Vitalograph Ltd, Buckingham, United Kingdom). Data were collected at two visits to the participants' home one to three weeks apart. First, data were collected by one of the five occupational therapists; second, the AMPS was performed by one of ten occupational therapy students attending the University College of Northern Denmark. During their education, they are trained and calibrated in performing the AMPS, and they were thoroughly introduced to the procedures before data collection. During the first visit, participants were orally informed about the study and they received an information letter and provided written consent. Thereafter, a simple, up-to-date measurement of lung function (forced expiratory volume (FEV) 1% predicted) was obtained using the Vitalograph copd-6. Then, sample characteristics were collected, and the ETUQ was administered. Using the information gathered, two AMPS tasks were chosen that were to be performed at the second visit. Lastly, the participant was introduced to the SF36 and handed a form to be completed before the second visit. At the second visit, the AMPS evaluation was completed and filled-in SF36 forms were collected. The second visit was conducted by the occupational therapy student one to three weeks after the first visit.

4.3.4 Data collection Study III

Using an interview guide (133), data for Study III were collected through semi-structured interviews conducted in the participants' home. The interviews were performed during a 6-week period by the author, and some of the participants were therefore known to the author from prior data collection. The visits started by giving verbal and written information of the study aim, and written consent was obtained. Only a few demographic data were gathered as most information had already been obtained in Study II. However, lung function (FEV 1% predicted) was measured again to get an up-to-date measurement. The interview questions were asked to obtain knowledge of how the participants experienced and managed activities of everyday life. They were invited to describe a typical day and which activities such a day would include. If they experienced challenges, they were encouraged to explain the reasons for these challenges and how they would manage. To get a thorough understanding of their experiences, follow-up questions were asked about their activities of everyday life. All eight

interviews were recorded on tape with a digital voice recorder. The interviews lasted between 36 and 54 minutes.

4.4 DATA ANALYSIS

4.4.1 Data analysis Study I

For investigating the inter-rater and test-retest reliability of the ETUQ, Svensson's method for paired ordinal data was used (134–136). Svensson's Micro Soft-Excel file for six categories was used to calculate the statistical measures of the ETUQ data (134). First, the percentage agreement (PA) was calculated for each item and evaluated using a commonly accepted definition of agreement: <40%, poor agreement; 40-60%, fair agreement; 60-75%, good agreement; >75%, excellent agreement (137). Then, four additional statistical measures were calculated to make a thorough analysis of the reliability of the ETUQ: relative position (RP), relative concentration (RC), relative rank variance (RV) and measure of disorder (D) (136). RP indicates systematic shifts in position between the pairs, whereas RC indicates the systematic change in the concentration of the scores. RP and RC thereby become measures of systematic disagreement in the group and have possible values from -1.00 to 1.00 (136,138). RV indicates the difference between the paired ranges, and D is a measure of disorder among possible combinations of the pairs. D and RV were calculated to evaluate individual sources of disagreement (135,139,140).

To investigate the stability of how a specific everyday technology was considered relevant to the participants, a relevance score of 0 was added to the 1-5 category scale. Thereby, the combinations of pair-wise data from the six-category rating scale yielded a total of 36 (6x6) possible combinations (134). Additional reliability analysis was performed to explore the relationships on a more generic person level instead of item level. The ETUQ data were therefore transformed into interval measures using a Rasch rating scale model (141), as described in the analysis of Study II and IV. A preliminary validity test in relation to response processes was performed as the ETUQ had not been validated among older people with and without COPD in Denmark. None of the participants demonstrated unacceptable goodness-of-fit to the model, and all Rasch-generated interval measures from the participants were used as valid estimations of everyday technology use according to a cut-off of infit Mean Square residual less than 1.4 associated with a standardised *z* value of less than 2.0 (142,143). Pearson's correlations were then used to explore the relationships between measures regarding raters and time points.

4.4.2 Data analysis Study II and IV

4.4.2.1 Preparatory analysis

The raw scores of ADL task performance were prepared for analysis by categorising the lowest rating within each response category on a four-point ordinal scale ranging from

competent to unable, in line with earlier studies analysing and presenting data from ADL-I (111,115). Data on quality of ADL performance were utilised for descriptive analysis of the ordinal scores of the 16 ADL motor skills and 20 ADL process skills. Furthermore, Rasch rating scale models (141) were applied to convert the raw scores from ADL-I, ETUQ and AMPS into individual interval measures of ADL task performance and ability to use everyday technology using WINSTEPS computer software program version 3.69.1 (144) and ADL motor ability and ADL process ability using AMPS computer-scoring software (21). These procedures are further described elsewhere (21,111,114,118,125). The measures of HRQOL were calculated using SF36 statistical software.

Categorical variables were presented as frequencies and percentages (%), while continuous variables, expressed in logits or amount (ADL task performance, ADL motor ability, ADL process ability, use of everyday technology, amount of relevant everyday technologies), were tested and met criteria for normality and were presented as mean, SD and minimum/maximum scores. For completing the statistics, the Statistical Package for the Social Sciences (SPSS) Statistics Version 26 was utilized (IBM Corp., New York, United States).

4.4.2.2 Primary analysis

Associations with HRQOL were investigated using multivariable linear regression analyses (145). Initially, the data were investigated to determine if they met the underlying assumptions (linearity, normality, multicollinearity, homoscedasticity) (145). As all assumptions were met, the regression analysis continued. The hierarchical regression model was used in three steps (145). In the first two steps, variables were entered, that have earlier been predicted would affect the participants' HRQOL (34,146), whereas variables that had not been investigated previously were added to the regression analysis in the third step, leading to the following order: firstly, data on level of education and living conditions; secondly, lung function (FEV1% predicted) and years since COPD diagnosis; thirdly, the amount of relevant everyday technologies and the Rasch-generated measures reflecting the perceived ability to use these technologies, ADL motor ability and ADL process ability. Additionally, an interaction variable between ADL motor ability and ADL process ability was calculated and entered (145) since a relation exists between these aspects of ADL performance (21). HRQOL has both a physical and a mental summary score, and either score was used as the dependent variable in the multivariable linear regression analyses. P-values < 0.05 were considered statistically significant.

To indicate the level of ADL skills challenge within the sample, the ADL motor and ADL process skills were sorted according to calculated mean and SD of each skill for each task. As all participants performed two ADL tasks for observation, two raw scores represented each skill, resulting in a total of 168 skills scores.

To further investigate ADL performance, the potential need for assistance to live in the community was predicted by matching the ADL motor ability and the ADL process ability

according to the evidence-based cut-off measures by Merritt (116) and Fisher (21) of 1.5 logit and 1.0 logit, respectively. If both measures are above the cut-offs, the person is likely to live independently in the community. If both measures are below the cut-offs, the person is likely to need assistance for community living (21). When a match in relation to the cut-off criteria is not possible, the cut-off of ADL process ability is suggested to determine the potential need for assistance (21).

The self-reported ADL task performance was presented according to the ordinal 4-point scale by frequencies of each of the 47 ADL tasks. The Rasch-generated measures of ADL performance from ADL-I were used for analysis of relationships.

To investigate the relationship between ADL performance and everyday technology use, Pearson's correlation coefficient (r) (145) was applied. The following measures were investigated: ADL task performance, ADL motor ability, ADL process ability and ability to use everyday technology. The strength of the correlation coefficient was considered according to Munro, cited by Domholt (147) (0.00–0.25 = little, if any correlation; 0.26–0.49 = low correlation; 0.50–0.69 = moderate correlation; 0.70–0.89 = high correlation; 0.90–1.00 = very high correlation). For further interpretation, the shared variance (R^2) was calculated and expressed in percent (%) (145). P-values < 0.05 were considered statistically significant.

4.4.3 Data analysis Study III

The first interview was transcribed verbatim by the author of this thesis. The following seven interviews were transcribed by three occupational therapy students trained in transcribing and according to procedures described by the author. The first transcription received from each student was reviewed while listening to the recording to ensure its accuracy, yet also acknowledging that transcription is an interpretive process (148). The transcriptions took place in parallel with the data collection.

The transcripts were analysed using inductive qualitative content analysis (106,149). This involved moving from the specific and concrete data toward an abstract and general understanding by using open coding and creating categories and themes. To perform the open coding, firstly, the text was read thoroughly several times and lines relevant to the aim were marked. Then, the marked sentences were transferred to a coding sheet and condensed into meaning units. Subsequently, codes were assigned to the meaning units. The codes were then arranged in clusters based on similarities and differences shaping sub-categories, categories and later the overall theme. This process was performed in the original language (Danish) in order to preserve the contents maximally, as recommended by van Nes et al. (150). Themes, categories and sub-categories were later translated into English, taking the findings to another level of abstraction. Data analysis was mainly conducted by the author of this thesis. At different stages of the analysis, the emerging codes, sub-categories and categories were critically discussed and reflected upon within the research group until a common understanding was achieved.

4.5 ETHICAL CONSIDERATIONS

The four studies within this thesis complied with the ethical principles of medical and social science research according to the Declaration of Helsinki (151) and the formal requirements for research on humans in Denmark (152). Pursuant to the principles of the Declaration of Helsinki, all data were treated confidentially, participation was voluntary and written informed consent was obtained. Confidentiality was upheld by following the General Data Protection Regulation (GDPR) with respect to collecting, processing and storing personal data (153). GDPR reference numbers from the University College of Northern Denmark: FOU-UU-2018-03 (Study II and IV), FOU-PHD-2018-70 (Study III). Study I was approved by the Danish Data Protection Agency: 2014-41-3078; because this study was initiated before the 2018 Data Protection Act, regulation No. 502 was applied. Moreover, the study was conducted in accordance with the principles for Responsible Conduct of Research to increase research integrity and to honour principles of honesty, transparency and responsibility.

When the nurses from the healthcare centres asked eligible persons if they could be contacted by one of the researchers, the pressure for participation potentially eased for the persons with COPD as compared to being asked directly by the researcher; hence increased the level of voluntary participation. The participants were also all introduced to the purpose of the study and informed that they could withdraw at any time without any personal consequences and they were informed that the data would be anonymised and treated confidentially. Verbal and written consent was obtained before data collection. Potential risks or burdens were considered in relation to breathlessness and fatigue and incorporated into the data collection by paying attention to signs indicating if participants needed to rest, both during interviews and observations.

According to the National Committee on Health Research Ethics in Denmark, an ethical permit is only required in questionnaire surveys and interview research projects if the project also involves human biological material (154). Therefore, no additional formal ethical approval was required for any of these studies in Denmark.

Data collection was planned according to the participants' preference to avoid any inconvenience. For people living with COPD, mornings were often characterised by cough and a slow start and little energy would be left in the afternoon. Therefore, most visits were planned around noon and performed with structure to minimise the time spent, though breaks were included when indicated by the participants. When data collection took place in the participants' homes, the researcher strived to balance taking responsibility for obtaining quality data against still being humble and respectful when visiting the persons in their homes and asking about how they lived their lives. Furthermore, the data collectors were transparent about the information being used only for the research project and they guaranteed that any information given would not be shared with the municipality. As an example, when a participant demonstrated how demanding it was for him to get in and out of the bathtub and told how he would like to contact the municipality to have the bathtub removed, the author of

this thesis made clear that she could not pass on that specific information, but instead supported him in finding the relevant contact information of a person he could contact.

The occupational therapists as well as the occupational therapy students were all introduced to the role and responsibilities of collecting data for research by the author of this thesis. They were also informed about giving the participants a short feedback summary after their observations/interviews of their observed and self-perceived evaluations to create a natural atmosphere. Furthermore, all data collectors met a few times during the data collection for short meetings to catch up on their experiences, and they were encouraged to contact the project coordinator (RJK) if they had any questions or concerns. They were also instructed to inform the participants of their scores when performing the spirometry testing, and that the spirometry test was only an indication not necessarily a true measure of lung function.

A general reflection among data collectors was that participants were very open-minded and willing to share their perceptions and experiences of everyday life activities with us. This could be explained by the fact that all participants had been involved in another research study and were used to sharing their perspectives in research. Moreover, the significant others could also be very enthusiastic wanting to respond and give their view on the questions, which could conflict with the purpose and the gathering of unbiased answers from the participants, since significant others were not meant to contribute to this specific data collection. Therefore, a few times, it was necessary to explain to the significant others that the participants' answers were important to gather first, and then their reflections could follow after the formal evaluations had been completed.

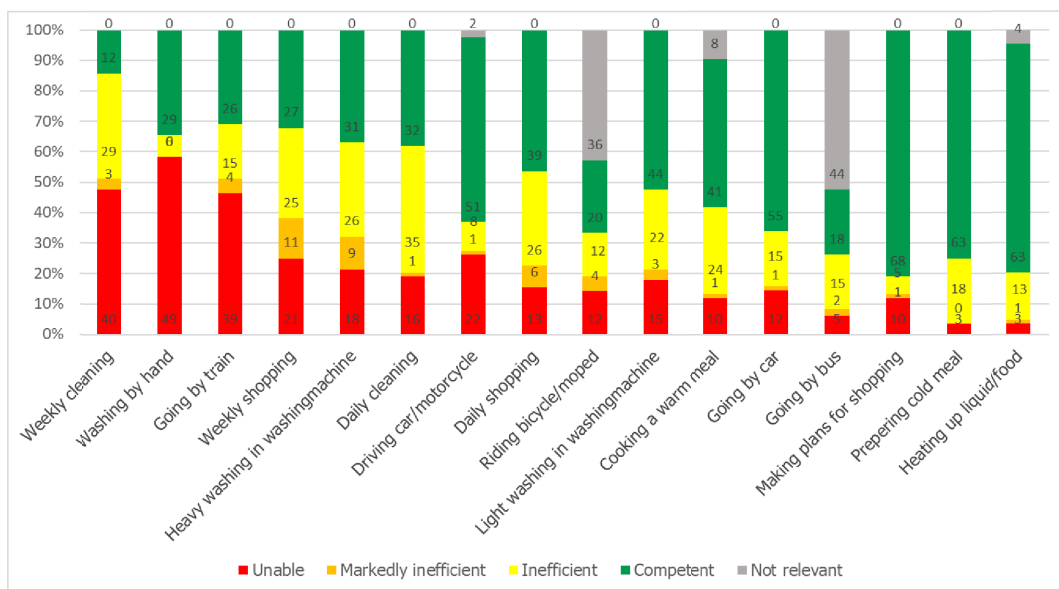
Everyday life activities in people with COPD have been explored and evaluated using a variety of methods and assessments. The findings will be presented in three sections the order of which does not mirror the order of the studies: first, the statistics presenting participation, performance and skills displayed when performing everyday life activities and using everyday technology when living with COPD will be presented; second, the analysis of the qualitative interviews presenting the participants' experiences of managing everyday life activities will be detailed; and third, the relations between different variables of ADL, everyday technology use and HRQOL will be presented.

5.1.1 ADL task performance

Figure 2. PADL tasks from most to least affected in performance among people with COPD (N=84).




Figure 3. IADL tasks from most to least affected in performance among people with COPD (N=84).



5.1.2 Challenges in ADL performance skills among people with COPD

The distribution of ADL performance skills according to mean measures of the observed raw scores are presented in Table 3. The higher means of ADL motor skills indicate the ADL skills that participants performed with more ease, and the higher means of ADL process skills indicate more efficient, safe and independent performance. The lower means indicate the ADL skills observed to be more challenging, requiring more effort and being more inefficient, with less safety or requiring assistance (21,101).

Table 3. Distribution of ADL motor skills and ADL process skills according to mean measures based on raw scores. Each participant completed two ADL tasks, meaning that each measure is based on n=168 scorings.

ADL motor skill	Mean (SD)	ADL process skill	Mean (SD)	Less challenging skills
Lifts	3.21 (0.99)	Uses	3.88 (0.47)	
Aligns	3.20 (0.99)	Inquires	3.86 (0.51)	
Walks	3.20 (0.99)	Attends	3.64 (0.73)	
Grips	3.18 (0.99)	Searches/Locates	3.61 (0.79)	
Moves	3.15 (1.02)	Chooses	3.61 (0.84)	
Transports	3.12 (0.99)	Heeds	3.40 (1.00)	
Flows	3.01 (1.01)	Sequences	3.55 (0.83)	
Manipulates	2.93 (1.00)	Terminates	3.39 (0.95)	
Coordinates	2.84 (1.00)	Adjusts	3.39 (0.94)	
Paces	2.71 (1.05)	Restores	3.32 (1.07)	
Calibrates	2.58 (0.92)	Initiates	3.18 (1.05)	
Bends	2.55 (0.90)	Handles	3.14 (1.00)	
Reaches	2.49 (0.87)	Gathers	2.95 (1.01)	
Endures	2.48 (1.06)	Continues	2.79 (1.00)	
Stabilises	2.32 (0.75)	Notices/Responds	2.73 (1.01)	
Positions	2.07 (0.38)	Paces	2.71 (1.04)	More challenging skills
		Navigates	2.60 (0.95)	
		Organises	2.27 (0.71)	
		Benefits	1.99 (0.44)	
		Accommodates	1.82 (0.42)	

Abbreviations: ADL: Activities of daily living; SD: Standard deviation.

5.1.3 Overall measures of ADL performance, everyday technology use and HRQOL

The overall measures (logits, amount or summary scores) of ADL performance are presented in Table 4 for the following variables: ADL task performance, ADL motor ability, ADL process ability, ability to use everyday technology, amount of relevant everyday technologies and HRQOL. These measures are used in Study II and/or Study IV.

The mean ADL motor ability (1.14 logit) is below the cut-off for both independence (1.5 logit) and competence (2.0 logits); and the mean ADL process ability (1.03 logit) is just above the cut-off for both independence and competence (1.0 logit) (Table 4), indicating increased clumsiness, physical effort or fatigue and likelihood of inefficient use of time, space or objects (21).

For the ability to use everyday technology, the sample mean was 56 (Table 4), which exceeded the item mean difficulty (by default set at 50.0 logits). This indicates that the perceived ability to use everyday technology was higher than the overall challenge encountered when using the everyday technologies included in ETUQ.

The mean HRQOL-mental was just above the expected level. The mean HRQOL-physical was just below a summary score of 50 expected for the general population. There was a large range in the minimum to maximum scores in HRQOL both physical and mental (Table 4).

Table 4. Measures of ADL task performance, ADL motor ability, ADL process ability, ability to use everyday technology, amount of relevant everyday technologies and HRQOL (N=84) and (N=80).

	Mean ± SD (N=80)	Min./Max. (N=80)	Mean ± SD (N=84)	Min./Max. (N=84)
ADL task performance ^a (logits)	-	-	2.46 ± 1.71	-1.17/6.80
ADL motor ability ^b (logits)	1.18 ± .59	-.4/2.6	1.14 ± .66	-1.20/2.70
ADL process ability ^b (logits)	1.01 ± .43	0/2.2	1.03 ± .46	-.80/2.20
ET ability ^c (logits)	56.58 ± 5.79	46.86/80.02	56.21 ± 5.48	46.86/80.02
ET relevance ^c (amount)	45.46 ± 11.82	14/67	-	-
HRQOL – physical ^d (sum score)	37.45 ± 9.17	16.74/57.42		
HRQOL – mental ^d (sum score)	51.68 ± 11.42	17.16/72.01		

Notes: ^aMeasured by the ADL-Interview (ADL-I). ^bMeasured by the Assessment of Motor and Process skills (AMPS). ^cMeasured by the Everyday Technology Use Questionnaire (ETUQ). ^dMeasured by the Short Form 36 (SF36). **Abbreviations:** ADL: Activities of daily living; ET: Everyday technology; HRQOL: Health-related quality of life; SD: Standard deviation; Min.: Minimum; Max.: Maximum.

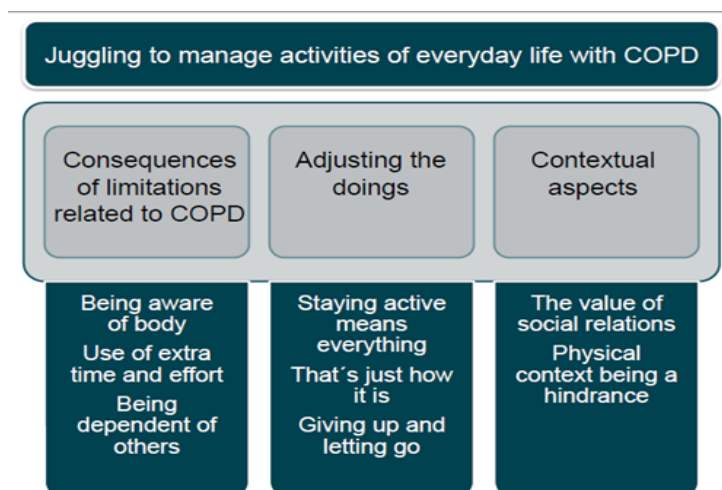
5.1.4 Need for assistance for community living

The results for ADL motor ability and ADL process ability predicting the need for support for community living indicate that $n=23$ (27.4%) of the participants in Study IV would potentially be independent and able to function in the community with both ADL motor and ADL process ability measures above cut-off. A group of 36.9% ($n=31$) was in need for assistance to be able to live in the community as both ADL measures were below the cut-off. Two persons (2.4%) had an ADL motor ability above the cut-off and an ADL process below the cut-off, indicating that they were likely to need assistance to live in the community. Finally, 33.3% ($n=28$) were likely to be independent in the community; but obtaining additional evidence for this is essential as their ADL motor ability was below the cut-off and their ADL process ability was above the cut-off. Overall, 70% of the participants in this sample had a motor ability below the expected level.

5.2 MANAGING EVERYDAY LIFE ACTIVITIES WITH COPD

The findings of Study III comprised the overall theme “Juggling to manage activities of everyday life with COPD” and three categories representing the elements of the juggle: “Consequences of limitations related to COPD”, “Adjusting activities” and “Contextual aspects”. Each category also had sub-categories (Figure 4). The juggling occurred both between the three categories and within each category, reflecting the complexity of managing everyday life activities.

Figure 4. Results of Study III represented by theme, categories and sub-categories.



5.2.1 Juggling to manage activities of everyday life with COPD

To manage everyday life activities, the participants were considering the consequences of the bodily limitations related to COPD, how to adjust their activities by applying strategies and the contextual aspects involving social relations and the physical hindrances. While participating in everyday life activities, the participants needed to be aware of how their symptoms developed and consider if they needed to apply a strategy to manage their situation. On the one hand, the participants had accepted the disease and adapted so much to their situation that they did not always notice their symptoms. On the other hand, the disease was experienced as frustrating, affecting their ability to manage their everyday life activities.

5.2.2 Consequences of limitations related to COPD

COPD-related symptoms like breathlessness, cough and fatigue were experienced as limiting the everyday life activities of people with COPD, forcing them to constantly juggle between their bodily signals and whatever time and effort they could muster. Moreover, the need for assistance from others was part of the juggle and could positively affect time and effort, but at the same time dependence was experienced as frustrating.

5.2.2.1 Being aware of the body

The constant awareness of the bodily signals was described as demanding for people with COPD. However, their ability to “read” their body and adapt their everyday life activities accordingly gave them a feeling of security and confidence. They described how they had prevented severe pneumonia and avoided hospitalisation several times by using relevant procedures. However, exacerbations occurred even when trying to avoid them, and the negative effects of these exacerbations on their everyday life activities would last several weeks, requiring much energy and perseverance.

5.2.2.2 Use of extra time and effort

Another consequence of COPD-induced limitations was experienced notably in relation to everyday life activities requiring extra time and effort. The participants needed to apply strategies to manage daily activities through adaptation, planning and taking breaks. Personal ADLs were highly prioritised, and preferably performed independently, such as getting out of bed, getting washed and dressed even though it took extra time and effort. Less strength and time were then left for other activities such as shopping, doing laundry and especially leisure activities, also leading to no longer being impulsive in choice of activity.

5.2.2.3 Being dependent on others

Dependence on others was experienced as unwanted and frustrating, making daily life less flexible. However, help was also recognised as necessary, and the participants felt grateful and safe when others were around to support them whenever needed. Help and support were provided by their partner, their children, neighbours and by the municipality; and sometimes,

private help was booked, for example, to do gardening or shovel snow in the winter. For several participants, an important resource was to have their spouse nearby when taking a shower or for support in periods with exacerbations, which also made them feel safe.

5.2.3 Adjusting activities

The participants adjusted their activities by juggling between deciding which strategies to apply in order to stay as active as possible. It was experienced as frustrating to adapt all the time, needing to have a slow start of the day and to take breaks during shower and dressing. Depending on the severity of their COPD, they adapted to their situation and found themselves challenged because they had no alternative: “That’s just how it is”.

5.2.3.1 Staying active means everything

It was a common perception among the participants that they should stay as active as possible in daily life. During pulmonary rehabilitation, they had learned that exercise prevents deterioration, and they described feeling proud when managing to exercise, attend swimming classes or do gymnastics, or go for their daily walk. However, the participants tended to focus on performing activities to stay active rather than to be engaging, which affected their general level of motivation. Some activities were performed because the person felt obliged to perform them.

5.2.3.2 That’s just how it is

The limitations caused by the disease permeated their everyday life activities by determining which activities could be performed, how and when. The disease was described as an annoying disadvantage that had invaded their lives, but there was nothing to do about it.

5.2.3.3 Giving up and letting go

Some everyday life activities required so much time and effort that they were too fatigued and breathless to perform these activities and therefore gave up. At first, giving up on an activity was experienced as a failure, but when it was finally accepted, there was no longer a need to consider the activity, and letting go was experienced as a relief.

5.2.4 Contextual aspects

As part of the context, social relations in different everyday life activities were highly valued by the participants, leading to feelings of being secure and/or loved. The context also comprised physical hindrances, especially stairs, bathtubs or different weather conditions making everyday life activities even more challenging.

5.2.4.1 *The value of social relations*

Even though social activities were highly valued by the participants, leaving the house was too demanding for some and they did not have the possibility to participate in social relations or in leisure activities where they could share their experiences of how to manage the disease. On the other hand, disease would also often be the focus of every conversation, meaning that participating in groups where nobody knew of the disease could be liberating.

Another opportunity to maintain social relations without demanding transportation was by using the internet for interactions through media like Messenger, Snapchat or FaceTime.

5.2.4.2 *Physical context being a hindrance*

The physical context was experienced as full of hindrances, making everyday life activities challenging. In particular, stairs were described as a major challenge, requiring extra time and effort or being completely impossible to use, resulting in participants not being able to visit their children or friends anymore. Also, climbing the bathtub was a severe hindrance involving a high risk of falling.

A few participants expressed being challenged in using different kinds of everyday technologies due to lack of motivation, decreased memory or diminished ability to use it correctly.

5.3 RELATIONS BETWEEN ADL, EVERYDAY TECHNOLOGY AND HRQOL

5.3.1 Associations between HRQOL, ADL performance and everyday technology use

The associations between physical and mental HRQOL, ADL performance and everyday technology use were also investigated. The overall measures used for the multivariable linear regression analyses are presented in logits in Table 4.

Four variables were statistically significantly associated with HRQOL – physical: ADL motor ability ($p<0.01$), ability to use everyday technology ($p=0.006$), amount of relevant everyday technologies ($p=0.015$) and years since COPD diagnosis ($p=0.023$). The interaction variable between ADL motor ability and ADL process ability was not statistically significant but was close ($p=0.051$). Step 3 in the regression model explained 50.6% ($R^2=0.506$) of the variation in HRQOL– physical. Step 1 ($R^2=0.003$) and step 2 ($R^2=0.230$) indicated that step 3 was essential to explain HRQOL - physical. Only one variable, ability to use everyday technology, was statistically significantly associated with HRQOL – mental ($p=0.009$). Step 3 in the regression model explained 22.80% ($R^2=0.228$) of HRQOL – mental, whereas Step 1 ($R^2=0.018$) and step 2 ($R^2=0.085$) only explained an inconsiderate part.

Table 6. Multivariable linear regression analyses for HRQOL - physical (Step 3).

	<i>R</i> ²	B	SE B	B	<i>p</i>	VIF
	.506					
Educational level		-1.037	2.051	-.047	.615	1.087
Living status		-2.138	1.802	-.113	.240	1.118
FEV1 % predicted		.003	.059	.005	.959	1.119
Years with COPD		-.308	.132	-.223	.023	1.129
ET ability^a		.456	.160	.284	.006	1.229
ET relevance^a		.194	.077	.242	.015	1.144
ADL Motor^b ability		8.155	2.046	.499	.000	1.935
ADL Process ability ^b		-1.905	2.750	-.084	.491	1.815
Interaction variable (ADL motor/ process ability)		-5.677	2.848	-1.253	.051	-----

Notes: ^aMeasured by Everyday Technology Use Questionnaire (ETUQ) (logits), ^bMeasured by the Assessment of Motor and Process Skills (AMPS)(logits). Statistically significant results are highlighted in bold.

Abbreviations: FEV1: Forced expiratory volume in 1 sec.; COPD: Chronic obstructive pulmonary disease; ET: Everyday technology; ADL: Activities of daily living.

Table 7. Multivariable linear regression analyses for HRQOL - mental (Step 3).

	<i>R</i> ²	B	SE B	B	<i>p</i>	VIF
	.228					
Educational level		1.679	2.931	.067	.569	1.087
Living status		-1.748	2.575	-.081	.500	1.118
FEV1 % predicted		.086	.085	.120	.317	1.119
Years with COPD		.317	.189	.201	.099	1.129
ET ability^a		.622	.229	.339	.009	1.229
ET relevance ^a		.052	.110	.057	.636	1.144
ADL motor ability ^b		.904	2.923	.048	.758	1.935
ADL process ability ^b		2.237	3.928	.086	.571	1.815
Interaction variable (motor/process skills)		2.555	4.189	.493	.544	---

Notes: ^aMeasured by Everyday Technology Use Questionnaire (ETUQ)(logits), ^bMesasured by the Assessment of Motor and Process Skills (AMPS)(logits). Statistically significant results are highlighted in bold.

Abbreviations: FEV1: Forced expiratory volume in 1 sec.; COPD: Chronic obstructive pulmonary disease; ET: Everyday technology; ADL: Activities of daily living.

5.3.2 The relationships between observed and self-reported ADL performance and use of everyday technology

The relationships between observed and self-reported ADL and use of everyday technology were investigated using Pearson's correlation coefficients. A statistically significant, moderate correlation was seen in three cases: (i) ADL performance and ADL motor ability with a shared variance of 29.8% ($r=.546, p < .001$); (ii) ADL performance and ability to use everyday technology with a shared variance of 27.5% ($r=.524, p < .001$); and (iii) ADL motor ability and ADL process ability with a shared variance of 41.7% ($r=.646, p < .001$). The Pearson correlation coefficients revealed statistically significant but low correlations in two cases: (i) ADL motor ability and ability to use everyday technology with a shared variance of 7.5% ($r=.273, p=.012$); and (ii) ADL performance and ADL process ability with a shared variance of 8.8% ($r=.297, p=.006$).

The correlation coefficients between the last set of variables indicated "little, if any" relationship and were not statistically significant for ADL process ability and ability to use everyday technology.

5.3.3 Test-retest and inter-rater reliability in ETUQ

The inter-rater reliability demonstrated a percentage agreement of 87–100% based on all items (100%), which is considered excellent agreement (140). Concerning the RP and RC for inter-rater reliability, Table 8 demonstrates values varying between -.14 to .10 (RP) and -.50 to .08 (RC) for all ETUQ items. Both RP and RC were relatively close to .00, indicating only minor inter-rater differences. RV was from .00 to .01 across ETUQ items, indicating minor individual variability in accordance with the measure of disorder (D).

Regarding the percentage agreement for the test-retest reliability, a variation from 53% to 100% was found, demonstrating excellent agreement for 84 items (90%), good agreement for eight items (9%) and fair agreement for one item (1%) (see Table 9 for specific items and exact PA). For the test-retest reliability, the RP varied from -.16 to .17 and the RC from -.14 to .10, indicating minor systematic shifts in position and concentration within the group. The RV for test-retest reliability varied from .00 to .18, reflecting a wider distribution of the percentage agreement across items. These findings are also reflected by D (ranging from .00 to .18), representing a possibility of disorder of up to 18% within the pair. When investigating the test-retest results of the ETUQ items with a PA below 75%, we noticed a tendency to shift between the scale steps 'No difficulty' and 'Not relevant'. The correlation coefficient between ETUQ measures related to raters on the same occasion was $r=.87$ ($p<.01$), indicating a variance of 75.7%, whereas the correlation coefficient between ETUQ measures related to different time points was $r=.76$ ($p<.01$) with a variance of 57.8%. These results were in line with the findings obtained when using Svensson's method based on item level.

Table 8. Inter-rater reliability results of the frequency of items, relative position (RP), relative concentration (RC), relative rank variance (RV) and measure of disorder (D) in relation to level of percentage agreement (PA) for scores of the 93 items of the Danish version of the ETUQ using Svensson's method.

Level of agreement	PA(%)	Frequency of items (%)	RP	RC	RV	D
Excellent	100	47 (51)	.00	.00	.00	.00
	97	26 (28)	-.04 - .04	-.04 - .04	.00	.00 - .01
	93	13 (14)	-.06 - .06	-.02 - .05	.00 - .01	.00 - .02
	90 ²	4 (4)	-.08 - .10	.00 - .08	.00 - .01	.00 - .02
	87 ¹	3 (3)	-.14 - -.01	-.05 - -.01	.00 - .01	.00 - .04

Notes: ¹Smoke detector, DVD, Radio; ²Alarm clock, TV w. remote, Stereo, Mobile phone top on money.

Abbreviations: PA: percentage agreement; RP: relative position; RC: relative concentration; RV: relative rank variance; D: measure of disorder.

Table 9. Test-retest reliability results of the relative position (RP), relative concentration (RC), relative rank variance (RV) and measure of disorder (D) in relation to level of percentage agreement (PA) for scores on 93 items of the Danish version of the ETUQ when using the Svensson's method for analysis.

Level of agreement	PA(%)	Frequency of items (%)	RP	RC	RV	D
Excellent	100	17 (19)	.00	.00	.00	.00
	97	12 (14)	-.03 - .04	-.04 - .03	.00	.00 - .04
	93	17 (18)	-.16 - .10	-.09 - .05	.00	.00 - .01
	90	12 (10)	-.07 - .10	-.10 - .09	.00	.00 - .02
	87	6 (7)	-.04 - .07	.00 - .05	.00 - .02	.00 - .06
	86	1 (1)	-.08	-.09	.00	.00 - .02
	83	8 (8)	-.16 - .10	-.09 - .05	.00 - .03	.00-.06
	80	7 (7)	-.06 - .12	-.08 - .09	.00 - .02	.00 - .04
	79	1 (1)	-.15 - .16	-.29 - -.02	.00	.00 - .01
	77	3 (3)	.04 - .17	-.05 - .07	.00 - .04	.00 - .05
Good	73 ⁴	3 (3)	-.09 - .03	-.08 - .00	.00 - .04	.00 - .06
	70 ³	3 (3)	.06 - .12	-.08 - .08	.00 - .05	.00 - .07
	63 ²	2(1)	-.04 - .16	-.10 - -.03	.00 - .08	.00 - .10
Fair	53 ¹	1(1)	-.14	-.01	.18	.18

Notes: ¹Tape player; ²Pedometer, Flushing mechanism; ³Camera digital, Automatic ticket machine, Automatic check-in at airport; ⁴Import digital data, Remote control, Computer game.

Abbreviations: PA: percentage agreement; RP: relative position; RC: relative concentration; RV: relative rank variance; D: measure of disorder.

6 GENERAL DISCUSSION

In the Introduction, a knowledge gap was identified related to how people with COPD manage their everyday life activities, including everyday technology use, and how this relates to their HRQOL. Furthermore, a lack of knowledge was identified in relation to the sparse evaluations focused on how persons with COPD actually perform everyday life activities, although this dimension is highly relevant to pulmonary rehabilitation and may critically inform occupational therapy practice, research and clinical guidelines.

The three dimensions of doing everyday life activities identified in MOHO, i.e. participation, performance, and skills (20), have been explored and evaluated among people with COPD within this thesis. This has generated new insights that may be applied within the field of COPD in general and within occupational therapy as part of pulmonary rehabilitation in particular. The focus of this thesis has been on the doing rather than the person, albeit it has also included the individuals' perceived subjective experiences of performing everyday life activities and using everyday technology, as well as some objective measures reflecting performance capacity, and how these dimensions are associated with HRQOL. Furthermore, the thesis has explored the interaction between the persons' doing everyday life activities and the ecological dimension, i.e. how the environment either supports or hinders their doings.

The majority of evaluations within the field of COPD have appraised performance capacity (20) from the individual person's perspective while focusing on elements such as musculoskeletal and cardiopulmonary functioning (85,155,156). Some have explored how COPD and the reduced performance capacity have affected the experiences of the lived body (43,60,157,158), focusing on the "*experiences of being and knowing the world through a particular body*" (20, p. 77). The evaluation of both performance capacity and experiences of the lived body are important for understanding persons with COPD. Further theoretical assumptions are that also the dimensions of doing everyday life activities are valuable because they contribute to the person's health and well-being (20,159,160). These assumptions derived from theory and earlier research were tested empirically in persons with COPD in the present thesis. The research within this thesis fully acknowledges the need for assessing the physical dimensions of the person, yet it supplements this important perspective by offering a broader perspective and assessments not previously systematically used within the field of COPD. Thereby, it is hoped, to contribute with new insights and add to the existing body of knowledge of persons with COPD. Incorporating these novel theoretical perspectives also allowed to suggest potential additional target areas for pulmonary rehabilitation interventions to support the participation in relevant everyday life activities of people living with COPD.

The findings will be discussed in relation to the current knowledge gaps and how the findings can contribute to the field of COPD.

6.1 EVERYDAY LIFE ACTIVITIES AND EVERYDAY TECHNOLOGY USE IN PEOPLE WITH COPD

An overall finding in this thesis is that ADL and everyday technology use are associated with HRQOL among people living with COPD; hence, the findings empirically support the theoretical assumptions described above. Furthermore, the findings substantiate that based on their ADL performance level at least one third of this sample may need support to live in the community. Together, these findings strengthen the rationale for interventions aimed at improving everyday life activities in people with COPD.

ADL skills mirror the quality of interaction between a person and his/her environment (21). Therefore, the one third of the participants whose ADL motor ability was affected and who had a higher ADL process ability may likely be able to improve their overall ADL performance by changing their current strategies. Adaptations in the environment may also help those persons performing the task to improve specific ADL skills such as reaching, bending and organising, even if these adaptations do not specifically target the person's underlying performance capacities. For example, a person who is challenged when performing the ADL motor skill reaching during a task in the kitchen can manage this skill with better quality if the utensils used for the task are placed more appropriately and he or she does not have to use the same effort when reaching for the utensils needed.

The overall findings show that the ADL motor ability is more affected (mean 1.14 logit for the group as a whole and the cut-off for competence is 2.0) than the ADL process ability (mean 1.03 logit, cut-off for competence is 1.0) (Table 4). The ADL motor ability demonstrated in the performance of ADL tasks is likely to be affected by the breathlessness or fatigue people with COPD often experience (17). The demanding and challenged ADL motor skills can also affect the overall ADL performance resulting in slow and inefficient performance, also reflected in the ADL process skills (101). People with COPD may also be challenged in terms of their ADL process skills because they have cognitive limitations (72,161). ADL motor and ADL process skills are hierarchically organised (Table 3) as further discussed in Study IV; and being conscious of this hierarchy when planning and targeting interventions through relevant everyday activities may be useful.

The PADL tasks found to be most affected among the participants were Pedicuring, Moving around inside and outside the home, Bathing, Washing hair, and Putting on socks and shoes. The IADL tasks most affected were Cleaning, Washing, Going by train and Shopping. These most affected ADL tasks are also reported by others to be the most affected tasks for people with COPD (34,89). However, in Bendixen et al. (34), evaluations were performed just before discharge following hospitalisation due to exacerbations, which is also reflected in the fact that the tasks were performed slightly more inefficiently than among the included participants in this thesis. Furthermore, Annegarn et al. (89) found that 30% of the sample was unable to perform the problematic ADLs and 44% were not satisfied with their performance. Despite this diminished ability to perform ADL tasks, the ADL performance has been targeted directly for intervention only in a few studies (162–165).

6.2 NEED FOR SUPPORT WHEN LIVING WITH COPD

People living with COPD often need physical, psychological and social support (166). These elements were all described in Study III, where dependence on others was experienced as unwanted and frustrating; still, at the same time, participants felt grateful and safe when others were around providing help and support whenever needed, e.g. in PADL or in relation to having exacerbations. However, support from relatives has some disadvantages worth considering (40,41,167). Relatives supporting people with COPD as caregivers without being educated to perform care often have other perceptions of the person's ADL than has the person with COPD him or herself (167). These different perceptions were found in the estimation of capabilities, among others. Thus, the person with COPD and the supporting person did not perceive the capabilities in the same way, which led to misunderstandings of the assistance needed (41). It was therefore suggested to include caregivers in self-management and ask them to help identify problematic ADL (41,167).

Including relatives in self-management may also seem relevant since many relatives provide extensive and multifaceted support for people with COPD. A study by Weinreich et al. (168) found that half (52%) of the participants received help from relatives in their everyday life activities, often several times a day (168). A quarter of the sample (22%) received help through private housekeeping or home care service, once a week or every second week. Close to half of the sample with COPD were living alone (168), indicating that when living with someone, support is received in everyday life activities. However, this raises the question whether persons living alone need less support for everyday life activities or whether having someone around is tantamount to receiving more support. The findings in Study IV showed that about one third of the participants may need assistance to live in the community, one third may function independently and one third is likely functioning independently. Overall, these findings of need for assistance seem relatively well to match the 52% receiving help for their everyday life activities reported by Weinreich et al. (168). However, whether the persons in need of support are those actually receiving it has not been investigated in depth in this thesis. This unresolved issue is particularly important to consider in future studies as about half of the sample investigated in the present studies were living alone (Table 2). Still, considering the disadvantages of being in need of support and the extent of diminished ADL in persons with COPD, the ideal would be to focus on optimally reducing the need for assistance by increasing the independence of everyday life activities through pulmonary rehabilitation. This may also be a perspective worth considering in relation to the economic burden of COPD previously mentioned (7).

6.3 PARTICIPATION IN VALUED EVERYDAY LIFE ACTIVITIES IN PEOPLE WITH COPD

The findings in Study III indicate that valued and pleasurable activities were not in focus and prioritised by the participants. Helle et al. (88) studied the amount of time spent on work, daily living tasks, recreation and rest among 74 participants with COPD. Their sample partly overlaps with the sample in Study II-IV of this thesis. Compared with a healthy American

population with the same mean age, the participants spent two hours more on everyday life activities per day and two hours less on recreational activities (169). This shift in time used from recreational to everyday life activities is further supported by findings in Study II, which showed that people living with COPD are more challenged in their performance of both PADL and IADL. This may, indeed, explain why they spend more time on these activities than healthy populations. The larger amount of time spent on daily tasks may moreover explain the reduced time left to be spend on valued activities undertaken out of interest and for pleasure. Considering the fatigue and breathlessness that COPD causes, this is understandable but also a concern as these types of activities are valued and important to the person's psychological well-being (20).

The volitional system in MOHO aims to describe aspects shaping our choices when engaging in various activities and includes the values and interests as earlier mentioned. It also includes personal causation, i.e. the perception of one's capabilities and how to use one's capabilities to influence one's life situation. Hence, personal causation may be an additional component causing people with COPD to stop doing everyday life activities. Participants in Study III expressed that they could no longer participate in leisure activities they had previously enjoyed, e.g. social gatherings, playing golf or doing gardening. Making an effort to try out new leisure activities may be quite demanding, influencing personal roles. According to Study II, more than 90% of the participants perceived that they were either inefficient or could not perform the activities of moving in and out of the house (Figure 2), which seriously restricted their possibility of participation outside the home. However, Genoe and Zimmer (170) found that even though leisure activities caused breathlessness, they also contributed with richness and meaning to life, which was vital for coping with COPD.

In pulmonary rehabilitation, it is therefore important to address and support this group of persons in choosing and performing activities of personal interest and value for them because this may help them retain their role, continue living according to their preferences and achieve their goals (20). Health professionals need to be aware of these needs since persons with COPD may not see themselves, and often they do not ask for this kind of support but rather spend their days at home (171).

6.4 EVERYDAY TECHNOLOGY USE IN PEOPLE WITH COPD

The ability to use everyday technology is a part of ADL performance among people with COPD as indicated by the statistically significant moderate relationship found between measures from the ETUQ and ADL-I in Study IV. As expected, this relationship is not complete as the constructs differ and the ability to use everyday technology among the participants varies less for ETUQ measures than for ADL performance. Table 4 shows a sample mean of the ability to use everyday technology (mean 56.21, SD 5.48) that is just above the item mean difficulty (by default at 50.0 logits), indicating that the overall group level of perceived ability to use everyday technology fits relatively well the difficulty presented by the technologies included in the ETUQ. However, some participants have scores below the mean, and they may therefore potentially need support in using everyday

technology. Some of the participants in Study III also explained how they did not remember and understand how to use everyday technology e.g. for social contacts, although they valued social contacts highly. In such cases, an introduction to and subsequent support in how to write a text message or use FaceTime would be relevant as it would allow the persons with COPD to benefit from the possibilities offered by participation in valued occupations that everyday technology can promote (61).

The theoretical foundation of the ETUQ is based on the balance and interplay between a person's perceived ability and motivation on the one hand and the pressure and norms within the environment on the other hand (inspired by MOHO (78) and Lawton (172)). In their ecological model, Lawton and Nahemow (173) described pressure from the environment had to be carefully balanced as excessive pressure could be counterproductive, whereas positive, mild pressure could increase the everyday technology competence of people with COPD. Even a small improvement in the environment was described to have a positive effect on a person with less competence and to positively affect the person's self-perception (172). Peine and Neven (174) broaden these perspectives with an awareness of the intertwined relation between the world of ageing people and the design world of technology. Technology is designed with a purpose. Older people may then *"adapt, circumvent, use selectively or decide not to use a technology at all. But the technology can be subsumed in the life-world of older people. Once there, it also starts to re-shape the forms and practices of ageing"* (173, p. 6).

Seen in relation to the participants in this thesis, these perspectives emphasise the importance of people being aware of themselves in relation to the everyday technology use. For example, one participant in Study III felt proud when her grandchildren told her that she was "cool" when she used technology in communication with them. This gave her a positive perception of herself and her competence in relation to the technology. Other participants in Study III expressed being challenged in using different kinds of everyday technologies due to lack of motivation, decreased memory or diminished ability to use it correctly. Still, they could not just ignore that technology was present. Consequently, if the technology is not adapted or circumvented, it will affect the persons, which may lead to a feeling of being excluded from part of society when not being able to integrate the technology. These feelings do not support health and well-being among people with COPD; still, according to Lawton (172), these feelings may be changed with minor improvement from the environment, for example in the form of help from healthcare professionals who may teach the person with COPD how to use everyday technology.

Although everyday technology is an important part of everyday life, it still has not been fully integrated into pulmonary rehabilitation. This may generate gaps between persons who are able to use the technology and those who are not (61). In other words, the ability to use different kinds of everyday technologies may be an increasingly important prerequisite for facilitating both health management and everyday life activities for people with COPD (80). This is also supported in the findings of everyday technology use being associated with HRQOL (Study II). However, everyday technology is complex to integrate and its integration

requires that health professionals stay updated and dare embrace new challenges (61). Therefore, it can be crucial to evaluate systematically the ability to use everyday technologies as outlined in the ETUQ and to apply a version in national language that demonstrate evidence of stability and precision in the generated measures (Study I). Moreover, the ETUQ can support the planning of individually targeted interventions. Interventions using everyday technology could consist of adapting the environment, integrating relevant strategies to compensate for motor or process limitations and identifying how to match the user's capabilities with the environment (175). The design of the technology as described by Patomella et al. (176) should encompass concrete suggestions for how to make everyday technology less difficult to use. In order to evaluate the outcomes of interventions involving everyday technology use, precise and reliable outcomes are important. The outcomes of Study I provide evidence of such measurements generated from the ETUQ.

6.5 OCCUPATIONAL IDENTITY AND OCCUPATIONAL COMPETENCE RELATED TO PERFORMANCE OF EVERYDAY LIFE ACTIVITIES IN PEOPLE WITH COPD

MOHO (20) describes that occupational identity is created through participation in occupations and by integrating elements such as the person's experiences of doing, one's role identity in doing and by doing what one finds interesting and pleasurable to do. Interrelated with occupational identity is occupational competence, which captures the skills and the ease with which identity is transformed into action. The participants in Study III experienced this complex juggling when managing their everyday life activities while being constantly aware of their bodily symptoms and limitations due to COPD. In other words, they had evolved an occupational competence by applying strategies of doing things slowly, taking breaks, using the atomiser or medication to prevent pneumonia and by staying active despite their disease. These competences supported their well-being, as also found by Stridsman et al. (43). The participants had also integrated support from the environment into their daily lives and were able to participate in social activities, which affected the occupational identity by making them feel on top of the disease, supporting them in the role as a person managing the COPD. However, their occupational identity was also affected by the severely reduced or completely absent ability to perform activities out of interest or for pleasure, since performing necessary everyday activities consumed all their effort and energy. Instead, they described having stopped performing several activities out of interest or pleasure such as leisure activities outside the home, social gatherings or gardening, as also found in other studies (35,170,177). The participants showed a great anticipation within their occupational competence when managing their symptoms; however, in regard to their occupational identity, they expressed resignation as far as valued activities were concerned, which could influence their quality of life in an undesirably way according to MOHO (20). Stridsman et al. (43) found that participants' well-being improved because they adjusted to the life with a chronic condition by accepting their limitations, learning how to handle variations in their illness and relied on their ability to manage the disease. These findings may not be completely compatible with the

participants in this thesis (Study II) where an overall low mean of HRQOL-physical was found (mean 37.45, SD 9.17) (Table 4) as was also a wide range in perceived HRQOL, especially in some participants. The statements from several participants in Study III representing the sub-category *That's just how it is* show that their well-being was not as desired. In this sub-category, the disease limitations were described as annoying disadvantages that had invaded their everyday lives without leaving them with any possibilities to change this unwanted situation as they had no tools for doing so.

6.6 EVALUATIONS OF ADL PERFORMANCE IN PEOPLE WITH COPD

An Expert Review of Respiratory Medicine that states, "*In the near future, proper ADL evaluation should rank among the most important outcomes to be assessed in this population*" (38, p. 588). When evaluating ADL performance, the person's interaction with the environment in the doing of a relevant and meaningful task, either the person's level of participation, performance or skills (within the dimensions of doing) (20), should be evaluated. However, earlier studies of people with COPD have mainly evaluated physical capacity in relation to a person's performance, e.g. how much weight the person in question is able to lift and how many times; or what distance the person is able to walk, run or bike and the time used for this activity. However, these measures may be divorced from meaningful doing. They may be useful for obtaining a comprehensive evaluation of a person's functional capacity, but they do not give a full picture in the sense stated in the above-mentioned Expert Review: "*functional tests evaluate functional capacity, not ADL performance*" (38, p. 581). However, it can be difficult to determine exactly when the construct of ADL performance is evaluated and when the construct of functional capacity is evaluated since the two concepts overlap in various evaluations. Such overlaps may cause misunderstandings between different health professions because they use evaluations differently. It is, however, important to state that the relevance of evaluations is not the focus of this thesis, but rather the definition and the operationalisation of the constructs measured.

In the American Thoracic Society/European Respiratory Society Statement of pulmonary rehabilitation, ADL evaluations are recommended because it is necessary to evaluate if physical exercise has an effect on ADL performance (30). It is, of course, relevant to learn if the physical exercise does affect ADL performance; however, doing physical exercise may not increase ADL performance as expected (178). A systematic review examined the effects of physical rehabilitation on independence in ADL and found only small effects (179). However, to the author's knowledge, this has not been further investigated among persons with COPD. When occupational therapists perform evaluations of the dimensions of doing, they focus on occupation. Fisher & Marterella (22) described this as being occupation-focused, where occupation-focused is at the one end of a continuum and body functions, environment or other contextual factors are at the other end. The reason for working in an occupation-based manner is that focus and attention should be on the occupation in which the person is engaged rather than on bodily functions (22). Furthermore, when evaluations are

also ecologically relevant (22) as described in the Background section, the person's engagement becomes stronger because "real" tasks are performed in "real" places, meaning that the occupation becomes contextualised. At the opposite end of this continuum is decontextualised or simulated activities (22). Therefore, occupational therapists are recommended to perform occupation-focused and ecologically relevant evaluations; the more so as they may contribute with new perspectives on the field of COPD. One such perspective is the evaluation of ADL performance; another is to target interventions through ADL performance and performance of everyday life activities.

Another important issue to consider when reflecting upon evaluations are the psychometric properties of the specific tools. In this thesis, the evaluations are all standardised and they have demonstrated psychometric utility. Only the ETUQ was not earlier tested for reliability and validated in a Danish context among persons with COPD before this study was conducted. This was therefore done in Study I before using the ETUQ in the subsequent studies forming this thesis.

6.7 METHODOLOGICAL CONSIDERATIONS

6.7.1 Sampling

In Study I, participants both with and without COPD were included to ensure a wide distribution in both inter-rater and test-retest reliability testing. Moreover, recruitment through different healthcare and activity centres, patient organisations and organisations of elderly adults through purposive and snowball sampling increased sample heterogeneity. However, even though the participants were rather heterogeneous in terms of age, gender, living status and education, they were relatively homogeneous in terms of technology functioning, which minimises the variation in the ETUQ scores. The sample size within this study is also rather small, which could also affect the variation in the ETUQ scores. Still, in some larger studies, a relatively small sample has also been used to investigate reliability issues (180), supporting the size of the present study.

In recruitment of participants for Study II and IV, the inclusion and exclusion criteria were presented by the author of this thesis to nurses at healthcare centres who were in weekly contact with potential participants through follow-up calls in relation to the TeleCare North Project (108). The nurses then approached potential participants fitting the inclusion criteria and asked them if they were willing to be contacted by telephone. In this selection, the researcher had no influence on the process but received only names and telephone numbers of participants who could be contacted. This selection could explain the low representation of participants with severe COPD. The nurses may not have asked persons with severe COPD whether they wanted to participate, unconsciously trying to "protect" them. This could have been modified during the data collection, but no analysis of this aspect was performed until data collection was complete; therefore, the authors were not aware selection bias could have affected recruitment. Selection bias may also exist if more persons with more severe than milder forms of COPD declined the invitation to be contacted. Still, the sample distribution

according to lung function did reflect the general population in regards to being heterogeneous in terms of age, gender, living status and educational attainment.

The sample size in the studies on which this thesis is based was too small to allow for studying subgroups stratified by lung function, living status or otherwise. However, practical and ethical considerations also had to be made in relation to recruitment as we were reluctant to impose further burdens on persons already struggling with breathlessness and fatigue.

The criterion sampling applied in Study III can be viewed as a strength in ensuring participant heterogeneity in terms of gender, ADL ability and HRQOL. This variety may also mirror the variety in participants' statements about how they managed their everyday life activities, which may have led to saturation of data after the eight interviews.

6.7.2 Data collection

A methodological strength of this thesis is the use of well-established psychometric measures for the assessments. The ADL-I, AMPS and SF36 have all been applied in a Danish context and among various samples including but not limited to people with COPD (22,34,129,131,181). Furthermore, the reliability and validity of the ETUQ in a Danish context was investigated as part of this thesis. Expected relationships have also earlier been found between the generic SF36 and the disease-specific Saint George Respiratory Questionnaire (SRGQ) (182–184). However, the SRGQ has been found to be more sensitive in relation to severity measures of lung function and breathlessness than the SF36 (48). The major constructs evaluated in the applied assessments were primarily within the dimension of doing (20), and the present thesis therefore contributes new knowledge about people with COPD in this respect.

The AMPS is a sensitive tool for measuring quality when interacting with the environment while performing ADL tasks, and it could therefore be used also to detect changes in ADL performance. Study II and IV may be the first studies where AMPS is used exclusively among people with COPD, and are the first studies presenting how the raw scores can be integrated into the implications of the study outcomes. By looking into both the challenged and less challenged ADL skills, it is possible to identify which skills to address in interventions, viz. either compensation through adaptation or development through enhanced ADL performance.

Data were collected in the participants' homes. For the participants, this had the advantage that they did not have to leave their home, which was often very challenging. On the other hand, they had a visitor and may have felt a need to clean up or make coffee for the data collector, even though they felt that this was a strenuous activity. Being in the home environment for data collection, the participant was in his/her natural environment while the interview was conducted and ADL tasks were performed. This supported the ecological relevance of the present studies.

Having the possibility of employing occupational therapy students as data collectors meant that they were introduced to doing research and had a chance to apply their AMPS calibration skills in a relevant setting while still being students.

6.7.3 Data analyses

Different methods of analysis have been applied for investigating and exploring the statistical data in the three quantitative studies of this thesis. Svensson's method for paired ordinal data (134) was the primary analysis applied in Study I. This method was chosen to be able to investigate the changes in the distribution between the pairs of test-retest and pairs of inter-rater scores at an item level using a conservative approach to the original data. In Study II and Study IV, parametric statistics (using measures generated by means of Rasch analysis (141)) like Pearson's correlation statistics and multivariable linear regression analysis (145) were applied, giving opportunities for more in-depth investigation of relationships. Besides, descriptive statistics were also applied in Study IV where raw scores from the AMPS (21) were analysed to explore which skills were most challenging among persons living with COPD. By investigating and exploring both the Rasch-generated measures and the original ordinal data from the AMPS, opportunities for adding new perspectives to the results were provided. Furthermore, by applying the content analysis in Study III further possibilities occurred of adding more nuanced perspectives of the participants own experiences in managing everyday life activities.

7 CONCLUSIONS, CLINICAL IMPLICATIONS AND FUTURE STUDIES

The conclusions and clinical implications in this thesis are based on the evaluation and exploration of everyday life activities including everyday technology use in persons with COPD.

- The participants in this thesis found that their ability to perform PADL and IADL tasks was negatively affected by their COPD. This was demonstrated using valid and reliable ADL assessments (the AMPS and the ADL-I), which provided detailed information about strengths and limitations in ADL performance. Moreover, the participants experienced a complex juggling when managing their everyday life activities while being constantly aware of bodily symptoms and limitations related to COPD. On the one hand, they managed to apply effective strategies and adaptations into their everyday life activities that helped them better manage their disease and positively affected their occupational identities. On the other hand, findings also indicate that valued and pleasurable activities were not being focused on and prioritised by the participants. Instead, resignation towards several activities of interest or pleasure was described. Disease limitations were described as annoying disadvantages that had invaded their everyday lives and robbed them of opportunities for change. In pulmonary rehabilitation, it is therefore important to address and support persons with COPD in choosing and performing activities of personal interest and value for them. This may further support them in defining their roles, living according to their preferred lifestyles and achieving personal goals.
- Everyday technology is an intertwined part of the everyday lives of people with COPD. However, some participants perceived limitations in using everyday technology which affected their ability to perform and participate in valued everyday life activities that technology might otherwise promote. They may therefore benefit from support in integrating everyday technology into their daily life. Everyday technology is still not fully integrated into pulmonary rehabilitation which is complex and requires that health professionals stay updated and accept the challenges of introducing everyday technology to people with COPD. Therefore, it can be crucial to use a valid and reliable questionnaire like the ETUQ to evaluate the ability of people with COPD to use everyday technologies. The ETUQ can also support the planning of individually targeted interventions.
- Theoretical assumptions about the importance of everyday life activities for the health and well-being of persons with COPD have been supported empirically by this thesis. Moreover, the relationship between everyday life activities and everyday technology has been illuminated, and everyday life activities and everyday technology have been found to be related but different constructs. Considering the disadvantages of needing support and the extent to which persons with COPD experience a reduction in their

ability to do ADL, the ideal would be for pulmonary rehabilitation and self-management to be focused on increasing the levels of efficiency, ease, safety and independence in their everyday life activities. This approach would also clearly be the most cost-effective approach seen from a personal as well as societal perspective.

- By evaluating and exploring everyday life activities through the dimensions of doing in natural and relevant settings, this thesis can contribute with new insights into the field of COPD. Occupational therapists are recommended to apply evaluations that are occupation-focused and ecologically relevant and thereby contribute to the strengthening of the multidisciplinary knowledge base of how these perspectives shape everyday life activities of people with COPD. Important is also to choose evaluations with demonstrated validity and reliability to ensure optimal quality in the evaluation process.
- Future research should explore how interventions focused on relevant ADL performance and everyday technology use can be designed and implemented in order to contribute to current pulmonary rehabilitation strategies that may impact on the HRQOL and well-being of persons living with COPD. This could be performed through careful design of intervention plans following feasibility and pilot testing.

7.1 COVID-19 REFLECTIONS

The majority of people living with COPD belong to the group at heightened risk of running a serious COVID-19 disease course, and their participation in society is currently very limited or impossible. The overwhelming amount of information that has come into our daily lives can scare us all (185). Even before the advent of the COVID-19 pandemic, feelings of vulnerability could further exacerbate anxiety and isolation, which highlights the need for healthcare professionals to do whatever they can to reduce anxiety among people with COPD in the primary COVID-19 risk groups (185). In this situation, the ability to use technology becomes even more essential. Findings in this thesis show that whereas most of the participants do have smartphones or similar technologies, they may need support in using them optimally. Moreover, findings show that there is room for improvement in participants' everyday technology performance and that they are capable of integrating adaptive strategies to improve their performance. These resources therefore need to be further facilitated by occupational therapists to avoid that this vulnerable group foregoes opportunities from participation in meaningful and relevant everyday life activities.

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