

# Toward partnership in care for patients with COPD

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## VALORISATION





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## Valorisation

### What is the problem?

Chronic obstructive pulmonary disease (COPD), although preventable not a curable disease, causes high levels of disability and it is an increasing public health problem worldwide. COPD is characterised by irreversible airflow limitation in the lungs. Active smoking is the main risk factor for developing COPD; however second-hand smoking, frequent respiratory infections, dust, and air pollution in the workplace or the environment are also contributing factors. As well, there are genetic disorders that predispose to develop COPD. According to estimates by the World Health Organisation, approximately 65 million people worldwide are affected by COPD, and with the ageing population, this burden is bound to increase and impose great demands to public health care and society. Moreover, COPD tends to be underdiagnosed and undertreated by healthcare professionals. In the Netherlands 1 in 50 people are diagnosed with COPD, while almost one quarter of the Maastricht population aged  $\geq 40$  years had COPD.

The tremendous distress that COPD poses on the quality of life of those who suffer is obvious. However, the psychological impact of COPD goes far beyond the individual, as patients become heavily dependent on family members and professional caregivers. This underlines the magnitude of the burden that COPD has on our society and the urgent need to develop effective treatments. The paradoxical issue about the current management of COPD is that pharmacologic strategies are being selected based on COPD severity to reduce symptoms and prevent COPD exacerbations. On the contrary, it is known that the symptom burden is not simply a consequence of the underlying physiological disorder. Thus, interventions targeting only physiological parameters may not lead to improved patients' adaptation to their illness, treatments and comorbidities.

Pulmonary rehabilitation (PR) has been shown to enable patients with respiratory diseases to improve their day-to-day activities and restore the highest level of independent functioning. Indeed, as defined by the American Thoracic Society/European Respiratory Society statement, this non-pharmacological comprehensive intervention should contain *patient tailored therapies* designed to improve the physical and psychological condition of people with chronic respiratory disease and to promote the long-term adherence to *health-enhancing behaviours*. Nonetheless, individual responses to PR are variable, highlighting the importance of discerning this complex concept.

## How do we contribute?

The current thesis significantly adds to the understanding of coping styles present among COPD patients entering, as well as undergoing PR. In addition, critical evidence was provided about the role of coping styles as predictors of change in clinical outcomes following PR, such as symptoms of anxiety, depression and exercise tolerance. Further exploration of the effects of PR on coping behaviour of patients who respond very well, and those patients with a moderate or no response to PR is of crucial importance. The results reported in this thesis suggest that PR *per se* can influence the coping of good responders. Furthermore, the present research sheds light on the content and delivery of educational programmes integrated in the current COPD management interventions and on the attitudes of PR healthcare professionals toward partnership in care. Cumulatively, these insights may support in adapting the treatment programme to the patients' needs with an aim of improving patients' benefit from PR; and may trigger greater attention and provide the basis for further study of the complex relationship between healthcare professionals and their patients. Moreover, this dissertation provides recommendations on how to motivate patients to achieve their goals by proposing the Kaleidoscope Model of Care, as well as how to individually tailor interventions for a holistic COPD care by suggesting the novel KALMOD – Behaviours for Health intervention. Consequently, the research described in this thesis has substantial societal impact.

## What do we know now?

### *Insights in coping styles*

One of the main findings of this research was that majority of the patients entering PR use medium and high levels of the maladaptive *passive reaction pattern* coping style, whereas they rarely report high levels of the beneficial *active confronting* coping style. In addition, a lower use of *active confronting* coping style and an increased use of *avoidance* and *passive reaction pattern* coping style are specific for the patients with symptoms of anxiety and/or depression compared to those patients without this symptomatology. Thus, this present research shows a relationship between coping styles and psychological distress in patients with COPD entering PR. Another main finding described in this thesis is that coping styles are predictors of change in clinical outcomes such as exercise intolerance, anxiety and depression of PR. As well as, that a comprehensive PR not containing a coping intervention, may result in change in coping styles of COPD patients by increasing the level of the coping style referring to better adjustment to the disease, while consequently, decreasing the levels of maladaptive coping styles associated with worse health outcomes. In fact, the research among patients with a very good response in exercise tolerance and/or disease-specific health status, patients with a moderate response and patients with no

improvement in these two outcomes after PR, demonstrated that changes in coping styles after PR occurred among good responders, whereas PR did not change the coping among moderate and non-responders. Furthermore, the results suggest that good responders significantly decreased their *passive reaction pattern* coping style in contrast to non-responders after a PR programme. Altogether, the studies on coping styles of patients with COPD which are part of this dissertation, yield new findings which implicate that coping styles may be important factors to consider and they may be influenced by coping interventions incorporated in PR.

### *Insights in education in COPD*

Findings from the systemic review shed light on the educational topics frequently included in the educational programmes integrated in current COPD management interventions. These are: smoking cessation, medication use, exercise, breathing strategies, exacerbation prevention, and stress management. Importantly, in minority of the current interventions, the education was tailored to the patient. Nevertheless, this review underscored the inconsistent approach to teaching patients with COPD, highlighting the need of more in-depth recommendations on the content and structure of educational programmes in the practice guidelines and statements.

### *Insights in attitudes of healthcare professionals providing PR*

Finally, the findings in this thesis suggest that although healthcare professionals providing PR support active patient's behaviour in the consultation, place value in patient's self-management and express positive attitudes toward patient's participation – patient's competencies related to "*patient as member of a care team*" and "*patient should be an independent information seeker*" were considered as less important. Healthcare professionals' attitudes might reasonably be considered to be among the important predictors of patient's enablement, thus these insights may draw attention to the potential impact of healthcare professionals' role on patient's self-management behaviours and health perceptions.

## **For whom is it of interest and how to proceed?**

### *Scientific community*

We have undertaken various efforts to ensure that the knowledge obtained from our studies reaches this target group. First of all, I have presented most of our findings at several international conferences which are frequented by researchers and clinicians from all over the world. In addition, we aimed to publish the research articles that constitute this thesis, in various international scientific journals that target scientific, as well as clinical audiences. Therefore, researchers in the field of collaborative self-

management or PR in general, can benefit from the new information we have added to the existing knowledge in this field. For example, we have shed a new light on the potential contributing factors to self-management and partnership in care for patients with COPD. Although our findings do not lead to a full and complete understanding of all factors contributing to successful partnership working, we have made a contribution to disentangling this complex relationship. Researchers could build on these findings, as well as the paradigms we have used when designing new studies in the field. Our increased knowledge about these processes can eventually lead to better PR interventions.

### *Patients*

Findings offered by this dissertation put the individual patient at the centre of the COPD care, thus they strongly advocate for a patient-driven care. It stands to reason that incorporating interventions tailored to the individual patient's coping styles into PR, can further improve patient's health and reduce healthcare costs. It is crucial to translate these findings into behavioural observations and also, to correctly interpret behavioural changes in a meaningful way. Moreover, our research emphasise that in the world of participatory medicine, patients are no longer a target group and passive recipients of care, but crucial and active members of the care team, involved in the decision-making process at every step.

### *Healthcare professionals*

The results of this thesis, which may help to optimise the COPD therapy and improve patients' quality of life, are of interest for general practitioners (GPs), lung physicians, nurses and all healthcare professional providing PR. GPs are in position to recognise symptoms of COPD in an early stage and to contribute in counteracting patients' maladjustment to COPD already in its early stage. Furthermore, our research demonstrated that nurses are the most involved healthcare professionals in delivery of educational programmes integrated in current COPD management interventions. Therefore, the insights shared in this dissertation may influence their day-to-day approach to individual patients. Analyses by the American Thoracic Society and European Respiratory Society indicate that PR in COPD is cost-effective: hospitalisations are of shorter duration and lower frequency in the years following PR. Exploring the attitudes and beliefs of PR healthcare professionals on the importance of supporting the patient as an active partner, as it was done in this thesis, may indeed be necessary for improvement of the effectiveness of self-management programmes incorporated in PR. Moreover, findings offered by this dissertation, potentially suggest that clinicians should do their best to collaborate with patients, to understand their needs and desires and to jointly design plans of care that are as

consistent as possible with those needs and desires. Simple? No. But the upside may be huge, for both, if they can learn how to do it.

### *Industry*

The idea that physiological parameters and data analysis is not enough, but that integrated solutions need to address chronic diseases much more comprehensively, is understood by the leading medical companies on the market. Thus, most major medical devices and pharmaceutical companies, especially the ones in diabetes care, are claiming personalised treatment plans, prevention and “selling outcomes” vs. “selling hardware”, as stated strategic goals. In fact, the vision of medical technology companies is increasingly focused on integrated solutions to empower patients and drive behaviour change. Hence, motivation (to optimise disease control) has been promoted by these companies as one of the most crucial factors contributing to treatment success. Therefore, promotion and maintenance of motivation is a declared goal in the development of their new medical products. Subsequently, medical companies strive to provide patient’s services with reimbursement related to patient’s outcomes, which will be more holistic and personalised vs. population management. They plan to achieve this through education, coaching and adherence support, which in turn, will result in patient engagement characterised with enhanced health literacy and therapy adherence. Care coordination across stakeholders, remote patient monitoring and tele-consultation are also the ways, which will eventually, empower patients and drive behaviour change. Partnership networking between patients, healthcare professionals and (food, care) providers has been also highlighted.

Cumulatively, these aforementioned concepts strongly resonate with the findings and recommendations provided in this dissertation. Hence, this makes our research contextually relevant and highly attractive for industrial players involved in bringing innovative solutions, not only to COPD, but to any chronic disease. In fact, adapted versions of both, Kaleidoscope Model of Care and KALMOD – Behaviours for Health, already applicable to patients with diabetes, have been proposed in this thesis with an aim to prevent long-term COPD related complications and escalating healthcare costs. These models of care, applicable and adaptable to different chronic diseases, may also have an impact on mHealth, patient safety and patient empowerment.

Mobile self-management applications and innovative technologies that can: enhance health literacy on clinical condition and the roles of dietary choices, lifestyle and therapy; track and compare daily data vs. guidelines provided by the healthcare professionals; facilitate the dialog between patients and their specialists to better manage the disease; help monitor and record disease evolution; follow tailored exercise programme; find trustworthy information on the disease and treatment options are warranted. Additionally, integrated solutions with feedback loop (patient and/or healthcare professionals receive alerts and coaching), as our suggested



adapted KALMOD – Behaviours for Health internet intervention for COPD management, will facilitate treatment support for high-value therapies. Therefore, collaboration with medical technology companies is paramount to achieve this goal as soon as possible.

On the other hand, we are moving toward a New Cognitive Era defined as: Cognitive “internet of things“ which involves infusing connected devices with the ability to understand, reason, learn, and generate their own hypotheses and confidence levels to help people make data-driven decisions. Cognitive computing may drive the field forward.