

Patients with COPD and their resident loved ones

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Valorization



VALORIZATION

Knowledge valorization refers to ‘the process of creating value from knowledge, by making knowledge suitable and/or available for social (and/or economic) use and by making knowledge suitable for translation into competitive products, services, processes and new commercial activities’ (adapted definition based on the National Valorization Committee 2011:8). Therefore, this chapter will explain the possibilities and opportunities the results of this thesis gave for clinical purposes. Moreover, this chapter will build upon what is described in the paragraph ‘How should resident loved ones be involved in the patients’ treatment and disease management?’ in **Chapter 9**. Based on the guide to write this valorization addendum, all innovative ideas are described using the following headings:

Relevance: What is the social and/or economic relevance of the research results?

Target groups: To whom, in addition to the academic community, are the research results of interest and why?

Activities/products: Into which concrete products, services, processes, activities or commercial activities will the results be translated and shaped?

Innovation: To what degree can the results be called innovative in respect to the existing range of products, services, processes, activities and commercial activities?

Involving resident loved ones during the assessment of patients’ goals and problematic activities of daily life

Relevance

Resident loved ones are unable to identify patients’ most important problematic activities of daily life (ADL). This is, however, important because resident loved ones are faced with these limitations as well. Especially when the disease gets more advanced, it can be necessary that resident loved ones provide informal care to the patient, like helping them with washing or dressing. Knowing what ADLs are problematic and important for the patient creates understanding for each other’s situation. Moreover, when resident loved ones are involved in the assessment of the goals of patients’ treatment, difficulties can be taken care of on time (e.g. caregiver burden, or physical limitations in resident loved ones themselves).

Target groups

Findings from the current study are important for all resident loved ones of patients with COPD. Healthcare providers could be seen as target group as well, because they should request active participation from resident loved ones during the patients’ assessment.

Activities/products

The activity is that active participation of patients' resident loved ones during the assessment of patients' goals or treatment is requested. When asking patients to identify their most important problematic ADLs, active involvement of resident loved ones should be requested (e.g. together with the patient, or separate from the patient). For instance, when assessing patients' problematic ADLs at the start of a pulmonary rehabilitation program (to provide directions for treatment), these should be assessed in resident loved ones about the patients' problematic ADLs as well. Combining the results and discussing them together with the patient and resident loved one is important to make sure no possible treatment goals are missed.

Innovation

Active involvement of resident loved ones of patients with COPD is not necessarily innovative, however, it is innovative at this level. Because, this goes beyond allowing the presence of a resident loved one during a consultation with a healthcare professional or to give resident loved ones the opportunity to spend a day together with the patient in the health care facility or pulmonary rehabilitation centre. An active involvement is requested, in order to treat not only the disease, but the person who has the disease.

*Involving resident loved ones during education session(s)**Relevance*

Patients with COPD and their resident loved ones have low levels of general health-related and COPD-related knowledge. However, having sufficient levels of disease-related knowledge is important to self-manage the disease, to cope with the disease and to prevent deterioration. Resident loved ones might be able to support patients with their disease management when they have sufficient levels of knowledge.

Target groups

The target group includes all patients with COPD and their resident loved ones. Younger patients, with a higher level of education and better cognitive functioning, who participated in a pulmonary rehabilitation program previously, and who were diagnosed with COPD longer ago reported higher knowledge levels. Therefore, education should be provided to all patients and loves ones, but especially to patients and resident loved ones of patients who got the diagnosis recently, who are not (yet) eligible for a pulmonary rehabilitation program, or who are older, and with lower levels of education and cognitive functioning. Especially for the latter, more

vulnerable group, it could be important that resident loved ones take part in education sessions, together with, or perhaps on behalf of the patients themselves. In addition, patients who participated in a pulmonary rehabilitation program previously had higher levels of health and COPD-related knowledge compared to patients who did not attend a rehabilitation program before. However, the patients who participated in a pulmonary rehabilitation program previously still answered less than 70% of the statements correct. Therefore, the education provided during a pulmonary rehabilitation program should be evaluated to determine whether it can be improved.

Health insurance companies could also be seen as target group, because their goal is better and affordable care. It might be possible that providing education sessions involving resident loved ones prevents the use of other (more expensive) healthcare services (for instance prevention of hospital admissions). Nevertheless, intervention studies should prove this.

Activities/products

Education sessions for all patients with COPD and their resident loved ones. These sessions could be provided in a hospital or pulmonary rehabilitation centre (e.g. patient academy), but could also be viewed online. A major advance of bringing patients and resident loved ones together 'live' in an education session is that it could also result in a supportive feeling of meeting others in the same situation. Moreover, these sessions could be provided by knowledgeable lecturers/(para)medics, or by patients themselves. The latter because patients are experts in their own condition, and therefore able to spread useful knowledge. Additionally, the impact on patients and resident loved ones of the different ways in which knowledge could be transferred should be examined. For instance, providing education in a different way to patients with lower levels of cognitive functioning.

Innovation

Education for patients is already part of a pulmonary rehabilitation program and transferring knowledge to patients by a general practitioner or a chest physician is already done in primary and secondary care. However, providing education sessions to groups of patients and targeting (especially) their resident loved ones, is the innovative part of this activity.

*Involving resident loved ones during individual treatment sessions of patients**Relevance*

Resident loved ones of patients with COPD have many (undiagnosed) morbidities themselves. Moreover, some resident loved ones suffer from health related problems due to the fact that they have a relative with COPD. For instance, having symptoms of anxiety and depression or physical limitations due to providing informal care to the patient.

Target groups

Resident loved ones of patients receiving individual treatment sessions. Healthcare providers could be seen as target groups as well, because they provide care and should invite patients' resident loved ones during the treatment.

Activities/products

Treating not only the disease of the patient, but the whole client system of the patient with the disease, during individual treatment sessions. When resident loved ones are actively involved during the patients' individual treatment, they gain knowledge in when and how they could help the patient, but also when patients are able to do activities by themselves. So patients are supported adequately by their resident loved ones, and resident loved ones receive advice and skills to support the patients. Another advantage could occur during the explanation of the use of a bronchodilator or other medication. Active involvement of resident loved ones during such a treatment can ensure that the medication is taken the right way and it could increase the likelihood of patient compliance.

Innovation

The involvement of resident loved ones at this level requires a new vision of the individual treatment of the person with COPD and its social system. Including/'treating' the resident loved ones' health or health related problems, in order to increase the patient's wellbeing, during the patients' treatment is innovative.

*Involving resident loved ones during patients' lifestyle change**Relevance*

Resident loved ones of patients with COPD are often current smokers themselves. In addition, yet unpublished data analysed by a colleague showed that only 30% of the resident loved ones were physically active (defined as spending ≥ 30 min in moderate-to-vigorous physical activity on at least 5 days per week).

Target groups

The target group includes all patients with COPD who have a resident loved one. Patients with a loved one, but not living together, might be a target group as well. However, additional research is needed to investigate the consequences for patients with COPD who have a (resident) loved one with an unhealthy lifestyle.

Activities/products

Resident loved ones' lifestyle should be addressed when aiming at a behavioural change in patients with COPD. For instance, when patients with COPD are advised to quit smoking, they need support from their resident loved ones in order not to start smoking again, after a successful smoking cessation. This will be counteracted by resident loved ones when they continue smoking themselves, especially when they smoke inside the house. Another example is to stimulate physical activity in patients with COPD when their resident loved ones are sitting on the couch during a large part of the day.

So, when aiming at behavioural change in patients with COPD, the social system of the patient should be included. First, the resident loved one's lifestyle should be part of assessing the patient's lifestyle. Second, the resident loved one should be involved during every step of behavioural change. So, starting with the step 'pre-contemplation' until the step 'maintenance'. Thus, resident loved ones should be included in the patients' treatment regarding behavioural change (and be advised as well) because they are part of the patients' lifestyle.

Innovation

Nowadays, an advice for behavioural change is most often provided to the patient only. This makes sense, because the assessment includes only the patient's lifestyle. Including the resident loved ones' lifestyle within the assessment of the patients' lifestyle and within all steps of behavioural change for the patient is innovative.

Other activities and/or products

The findings presented in this thesis have led to several activities in the field of expertise. Besides the fact that the results of this thesis are published in professional scientific journals, they are also presented during symposia and congresses. The results published in Chapter 2 were presented in Dutch during the 'Vlaams-Nederlands onderzoeksforum palliatieve zorg' in 2015. The results of Chapter 4, 5 and 7 were presented during the European Respiratory Society (ERS) Congress in 2015 and 2016. A poster about Chapter 5 was presented during the patient organi-

zation networking day at the ERS Congress 2016, organized by the European Lung Foundation. In addition, for the abstracts of Chapter 4 and 5 the 'ERS Young Scientist Sponsorship' and the 'ERS/ELF Travel Grant for best abstract in Patient Centered Research' were received in 2015 and 2016, respectively. Moreover, parts of Chapters 1, 4, 5 and 7 were presented in Dutch during the "Longdagen 2016", organized by the Netherlands Respiratory Society (NRS), 'Nederlandse Vereniging van Artsen voor Longziekten en Tuberculose' (NVALT), and Lung Foundation Netherlands.

The remaining data obtained from this study could be analysed and published in scientific journals. Furthermore, the remaining data and the data obtained in this thesis could provide the basis for further studies on the home environment of patients with COPD.