

Advance care planning in life-limiting illnesses

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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). Given this definition, the societal value will be reflected on from five different perspectives: 1. Relevance - What is the social and/or economic relevance of the research results? 2. Target groups - To whom, in addition to the academic community, are your research results of interest and why? 3. Activities and products - Into which concrete products, services, processes, activities or commercial activities will the results be translated and shaped? 4. Innovation - To what degree can the results be called innovative in respect to the existing range of products, services, processes, activities and commercial activities?

RELEVANCE AND INNOVATION

The prevalence and mortality rate of life-limiting illnesses, such as chronic heart failure (CHF), chronic renal failure (CRF), and COPD are increasing worldwide. The disease trajectories of life-limiting illnesses are often characterized by uncertainty and are heterogeneous. The uncertainty of the disease trajectory makes it difficult for both physicians, patients and loved ones to timely start to talk about preferences for end-of-life care. However, patient-physician communication is an important prerequisite to deliver high-quality palliative care. Therefore, advance care planning (ACP), which enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate, is essential for patients with life-limiting illnesses. Indeed, active involvement in the process of ACP is important to maintain patient autonomy and improve quality of care near the end-of-life for both patients and their loved ones. Furthermore, ACP can contribute to the delivery of end-of-life care in concordance with patients’ preferences, which may reduce healthcare costs at the end-of-life. Indeed, previous research has shown that ACP-interventions have the potential to reduce high-intensity care and associated healthcare costs at the end-of-life. Despite the fact that patients with life-limiting illnesses are able to indicate their preferences for end-of-life care and ACP has proven to be effective in diverse adult patient populations, ACP is uncommon in patients with life-limiting illnesses. Therefore the main aim of the current thesis was to gain more insight into the quality of end-of-life care

communication in patients with life-limiting illnesses. In addition, we developed, executed and analyzed a structured, nurse-led ACP-intervention in order to improve ACP for patients with COPD and their loved ones.

TARGET GROUPS

Beside patients with life-limiting illnesses, especially patients with COPD, and their loved ones, also healthcare providers, the government and health insurance companies are important target groups of this thesis, because all of these target groups are involved in delivering optimal high-quality end-of-life care in concordance with patients' preferences.

Patients with life-limiting illnesses

ACP is an interdisciplinary process between patients, loved ones and healthcare professionals. The patient is the most important component in this triangle, as ACP is a process tailored to elicit patient's preferences for end-of-life care in order to ensure that clinical care is shaped by and in concordance with patient's preferences. ACP is an important element to achieving patient autonomy because it provides patients the opportunity to timely discuss their preferences for end-of-life care instead of waiting for a medical crisis. Therefore, ACP is especially important for patients with life-limiting illnesses, such as chronic organ failure, as those disease trajectories are often characterized by unpredictability and uncertainty. In addition, ACP can contribute to enhance the sense of control, as patients with life-limiting illnesses often perceive a low sense of control about their disease as a consequence of physical impairments. In this thesis we have shown that by having timely discussions about end-of-life care ACP can improve patient-physician end-of-life care communication without causing psychosocial distress in patients with COPD. Although the *ACP-study* was focused on patients with advanced COPD, the intervention could also be applied to other life-limiting illnesses, such as CHF or idiopathic pulmonary fibrosis (IPF). In fact, CHF is the leading cause of mortality worldwide and the prognosis of IPF is poor, which underlines the importance of timely ACP in those patients. Unfortunately, also in patients with CHF or IPF, ACP is uncommon, while both patient populations experience palliative care needs and are willing to discuss their future medical care.

In current healthcare there has been growing attention for personalized medicine. This patient-centered approach is focused on disease management tailored to indi-

vidual care needs of patients in order to improve quality of life. In fact, ACP can be seen as part of personalized medicine. Indeed, ACP-discussions have to be adapted to the patients' needs in order to deliver end-of-life care in concordance with patients' preferences. To achieve this goal the question 'what is important for this individual patient?' is essential.

Loved ones of patients with life-limiting illnesses

The designation of a surrogate decision maker is part of the process of ACP. Loved ones often act as surrogate decision maker and as a consequence have a pivotal role in ACP. Indeed, when patients are no longer able to make decisions about personal healthcare, the surrogate decision maker must provide direction in decision making. Surrogate decision-making can be emotional burdensome, especially when the loved one is not sure about the patient's preferences for end-of-life care. Therefore, it is important for loved ones to know the end-of-life care preferences of the patient and to be actively involved in ACP-discussions. In this sense, ACP may help loved ones in deciding about patient's end-of-life care and decrease the burden of surrogate decision-making. For this reason, we actively involved loved ones in the *ACP-study* by providing the ACP-session in the presence of the patient and his or her loved one(s).

Healthcare providers

ACP is not only important for patients with life-limiting illnesses and their loved ones, but also for healthcare providers, since they are involved in the process of decision-making and delivering the actual end-of-life care. Indeed, some patients prefer to leave final decisions regarding end-of-life care to the physician. Furthermore, healthcare providers have to collaborate with loved ones to make surrogate decisions when the patient lacks decisional capacity. In fact, healthcare professionals can only adequately fulfill this task when they are aware of patient's preferences. Therefore, timely communication about preferences for end-of-life care in terms of ACP is important for healthcare professionals in order to deliver end-of-life care in concordance with patient's wishes. Here too, ACP should not be limited to the discussion and documentation of preferences for life-sustaining treatments, but should also include comprehensive discussions about different scenarios which could occur in patients with life-limiting illnesses during the disease trajectory. Indeed, when ACP is limited to the documentation of life-sustaining treatment preferences those preferences are often not applicable to the clinical situation at hand.

Government and health insurance companies

The economic burden of life-limiting illnesses, as for example COPD, is substantial by a high burden of healthcare consumptions. The prevalence of COPD is expected to increase in the next years and as a consequence the health care costs will rise further. Although the cost-effectiveness of ACP was not assessed in this thesis, it is possible that early ACP can improve those healthcare costs by preventing unwanted life-sustaining treatments, ICU admissions or hospitalizations at the end-of-life. Indeed, as a consequence of continuous improvements in healthcare technology people with life-limiting illnesses live longer. However, it can be questioned how treatments aimed at life extension will affect a patient's quality of life. ACP is of particular importance in a constantly developing world of medicine to answer the question: "Would you want everything possible to be done?".

ACTIVITIES AND PRODUCTS

As part of the *ACP-study* we have developed a two-day training for respiratory nurse specialists, during which end-of-life care communication skills and the structured ACP session during the study were taught and practiced. This training can be used to teach ACP to other healthcare professionals, such as chest physicians, general practitioners or medical students. In addition, the training can be adapted to be used to teach ACP to nurses working in outpatient settings, such as homecare organizations, or other departments, such as cardiology or oncology.

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 were published in professional scientific journals, they were also presented during symposia and congresses. The results published in Chapter 2 were presented during the 'Junior Research Symposium Centres of Expertise for Palliative Care' in 2014. The results of Chapter 3 were presented as a poster during the 4th International Seminar of the PRC/EAPC in 2014 and in Dutch during the 'Vlaams-Nederlands Onderzoekforum Palliatieve Zorg' in 2015. The results of Chapter 4 were presented during the International Society of Advance Care Planning and End-of-Life Care (ACPEL) conference in 2015. In addition, for the presentation about the results published in Chapter 2 the award for 'best oral presentation' was received in 2014. Moreover, the 'NRS Travel Grant' was received in 2015 and provided the opportunity to present the results published in Chapter 4 during the ACPEL conference. Furthermore, data of the *ACP-study* about preferences for end-of-life care (not included in this thesis), were presented

during the European Respiratory Society (ERS) Congress in 2016. Finally, presentations about the importance of ACP in patients with COPD were presented during several other events

INNOVATION AND IMPLEMENTATION

The lack of communication about end-of-life care in patients with COPD is well described in the current literature. However, adequate, structured and individualized ACP-interventions aimed at improving this quality of end-of-life care communication were lacking. The *ACP-study* has proved that the developed structured nurse-led ACP intervention adapted to specific needs for ACP in COPD is an adequate facilitator for patient-physician communication about end-of-life care without causing psychosocial distress in both patients and their loved ones. However, changes found in the *ACP-study* were small and there is still room for improvement. In our opinion future ACP-studies should therefore not only focus on behavior change in one healthcare professional, but should also include patient empowerment. For example, online personalized ACP education platforms could be developed for patients with life-limiting illnesses in order to induce behavior change regarding initiation of ACP-discussions by increasing awareness in patients and loved ones of the importance of ACP; addressing ACP education needs; and empowering of patients to start an ACP-discussion with a healthcare professional. We believe that those education platforms could be a desirable addition to our developed and in this thesis described ACP-intervention. Indeed, this thesis provided directions for implementation of ACP in regular clinical care. For example, ACP can be implemented in the hospital setting or in other clinical care settings which care for patients with life-limiting illnesses, such as general practice and rehabilitation centers. Furthermore, this thesis offered clues to include ACP in guidelines on the treatment and management of life-limiting illnesses, in order to make ACP as a routine and standard part of care. In addition, the intervention can possibly be implemented for other patients with advanced chronic life-limiting illness, such as CHF or IPF.

