From guideline to practise

VALORISATION ADDENDUM

In this chapter, the valorisation and the societal value of this thesis: '*Between guideline and practice: the organisation of multidisciplinary heart failure care in three European regions'* are addressed. In particular, the relevance of heart failure (HF) for health care organisation and members and training of the multidisciplinary team, more specifically the role of HF-nurses and primary care nurses within this team are addressed. This includes the training as a mean to improve HF-care in primary care and the use of technology as mean to support both health care providers and patients.

Currently, the prevalence of known HF in the developed countries is estimated at 1% to 2% of the adult population, and up to 10% of the elderly population over 75. It is expected that this number will further grow since the baby boom generation born between 1945 and 1965 is ageing fast. Moreover, the treatment options for HF have improve significantly, resulting in more patients surviving with HF. This also leads to an increased use and the complexity of care and an increasing burden on an already congested health care system. Due to the increasing complexity of HF care, the risk of suboptimal treatment is substantial. The European HF-Guidelines are developed to improve care, but also to alleviate the challenges of HF care for the health care systems, the health care providers and the HF-patients. However, notwithstanding these guidelines and better treatment options, HF-care remains suboptimal. It is therefore important to get more insight into the implementation of the HF-guidelines in daily practice in order to identify barriers and facilitators for guideline adhered care.

One of the main findings of this thesis is that HF-care remains to be improved in participating centres. To some extent, the differences in health care organisation contribute to different implementation of recommendations and differences in the way how HF-care is delivered, For example, in Belgium and Germany, HF-nurses are not considered to be part of the multidisciplinary team by government and by health care insurance companies. This leads to a limited number of HF-nurses in both countries although the European guidelines strongly advises the multidisciplinary approach of HF-care. Our study also showed that national HF-nurse education does not necessarily correspond to a significant extent with the Heart Failure

Association curriculum for the continuous education of HF-nurses and that the focus varies between countries. Nevertheless, it may prepare nurses to act within the limitations of their own health care system to provide optimal care within the possibilities of each system.

Despite the fact that HF is a complex disease, in which diagnosis and treatment are usually initiated in hospital, most patients receive their follow-up and treatment in primary care. Unfortunately, primary health care providers have limited knowledge of HF, its detection and management and HF-education principles, leading to missing early diagnosis of HF, inadequate up- or down titration of HF-medication, missing early deterioration of symptoms, and lacking of HF-education to patients and self-care support. Primary care HF-clinics, in which a combination of HF-nurse and HF-cardiologist provide follow-up and treatment in primary care, can be a means to manage this shortcoming. However, this thesis shows that in none of the investigated regions such primary care HF-clinics are present. Therefore, it is important to increase the awareness of primary care health care providers with respect to HF and its management, highlighting the large impact on outcome if done properly. GPs should be trained to diagnose and treat HF in order to acquire sufficient knowledge and confidence to start, up- or down titrate HF medication if required, but also to seek contact with HF specialists (both physicians and nurses) in case of uncertainties. Realistic estimation of what is possible but also what is not possible in the primary care setting should be made. The local agreements on collaboration between primary and secondary care including also patients need to be made. Although guidelines do not consider primary care nurses to be part of the multidisciplinary team, in in fact they are and should be. Consequently, they should be trained to enable them to provide evidence based HF education, to monitor patients during their follow-up and to recognise early HF signs and symptoms in order to timely refer patients to the GP or HFN. This training can be included in regular training programmes for GPs and nurses, yet this education can also be organised in continuing education programmes.

The congested health care system as a result of too many patients and a shortness of professionals is a challenge where patient empowerment may help to reduce professionals' interference. The results of this thesis contributed to design the digital 'DoctorME' application

developed within the INTERREG-NWE PASSION-HF project. This application interacts regularly with patients about their wellbeing, symptoms and vital signs on a regular basis or when it is needed. The patients input will be combined with clinical data such as echocardiography and lab results to formulate an individualized therapy recommendation. Currently, a prototype of this app is being evaluated in 4 academic centres: Maastricht University Medical Centre, Uniklinik RWTH Aachen, Queens University Belfast and University College Dublin.