

Quality of contemporary anticoagulation management in atrial fibrillation

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APPENDIX I

Impact paragraph

In this thesis, real-world concerns on issues potentially affecting the safe and effective use of oral anticoagulants (OAC) were explored, i.e. anticoagulation guideline adherence and off-label NOAC dosing in patients with newly diagnosed atrial fibrillation (AF). Investigating these concerns is of importance, as inadequate usage of OACs can potentially increase thrombosis or bleeding risk, both of which can have severe consequences for patients. The most important results of this thesis have been summarized and discussed in chapters 10 and 11. A further elaboration on the scientific and societal impact is discussed below.

Perhaps the most important achievement of this work was the creation and successful growth of a nationwide AF-registry, which combines efforts of the DUTCH-AF research team with the Netherlands Heart Registration (NHR). In this registry, data is gathered on patients with newly diagnosed AF with the aim to further explore concerns on the safe and effective use of OACs, such as medication persistence and adherence of NOACs. A major advantage of the combination of research with the quality registry program of the NHR is that the data is stored in a secure and futureproof environment and can continue to be supplemented with new data (i.e. from new patients, or more variables collected from these patients) even after the current study has finished. This opens research possibilities for future study groups, who can, with the approval of the AF Steering Committee and the Scientific Council of the NHR, use the collected data for their own analyses. This feature is very important, as this reduces time and costs involved with research, such as the process of gaining informed consent or collecting data. In this way, the data collected within the DUTCH-AF registry is not only accessible for the DUTCH-AF researchers, but is also accessible to anyone in the Netherlands with a decent research proposal. Moreover, this registry is unique in its design in that enrolled patients agree that they may be contacted when a future AF-related research proposal is formulated. This creates the possibility of collecting additional data, or to create a registry-based randomized controlled trial. As randomized controlled trials are often struggling with high costs and a slow enrolment process, the current AF registry was designed to make this process easier and cheaper. This is of great importance for the continuous improvement of the quality of AF care in the Netherlands, as well as internationally.

The collaboration with the NHR also provides the possibility to compare collected data from one participating centre with other participating centres. Even in a small country such as the Netherlands, treatment practices can vary significantly between hospitals, as different treatment approaches are often possible in the AF guidelines. The NHR platform creates the possibility for a participating centre to gain full insight into their own data, but can also compare their data with other (pseudonymized) centres for benchmarking. As atrial fibrillation is the most common sustained arrhythmia with over 45.000 newly diagnosed patients in the Netherlands every year,

any improvement in quality of AF care can potentially have a great impact.¹ The results of the DUTCH-AF registry will also be shared with individual, participating centres, where they can compare their centre specific results with the aggregated data of other participating centres.

The data from the DUTCH-AF registry is also shared with AF patients. Besides providing AF patients with current insights, data is also shared with the aim to gain their insights in how to improve the current nationwide registry program and to learn what patients instead of medical doctors want to know about atrial fibrillation. This is now primarily achieved via Harteraad, a Dutch federation for patients with cardiovascular disease. Moreover, the DUTCH-AF study group, the NHR and the Dutch Heart Foundation ("Hartstichting") have collaborated and published results of the AF registry, intended for medical doctors of non-participating centres as well as the general public.

Finally, the returned data is of increasing quality if an increasing number of caregivers collect data for the national AF-registry. Therefore, the DUTCH-AF study group and the NHR encourage all caregivers who treat patients with AF to join the registry, including anticoagulation clinics and primary practices. Besides sharing results and information on the national registry through scientific journals and congresses, physicians were also informed through newsletters, press release, social media and by word of mouth. Moreover, dozens of anticoagulation clinics, hospitals and primary care practices were actively approached to join the registry. Of course, enrolling patients and data-entry is time-consuming, so significant advances have been made to reduce efforts. Currently data entry through a case report form (CRF) is required, but the possibility has been created for participating centres to directly upload their data in a secure environment managed by the NHR. In this way, manual data entry could be reduced, and automatic data extraction is encouraged. Moreover, significant progress has been made to implement the dataset from the DUTCH-AF registry into commonly used Electronic Medical Records (EMR), with the aim to reduce double data-entry and to facilitate automatic data extraction.

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