Long term complications in grown-ups with congenital heart disease

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Background
Grown-ups with congenital heart disease (GUCH) is a growing patient group thanks to improvements in treatment, that require highly specialized health care. Due to increased risk of complications, this group has a lower life expectancy. One subgroup are patients with systemic right ventricle and increased risk of complications, why ventricular function is important to follow. Oral anticoagulation therapy is another area, which is critical to keep a high quality of in order to prevent thrombosis and bleedings.

Aim
The overall aim is to investigate and identify potential areas of improvement in diagnostics and therapy for the GUCH patient group in order to improve life expectancy and lower the complication rate. The first project aims to investigate if other diagnostic instruments than gold standard cardiac magnetic resonance imaging such as echocardiography, could be used to evaluate the systemic ventricular function.
For the second project, we aim to investigate the incidence of thromboembolism, bleeding and mortality in GUCH-patients with vitamin K antagonists (VKA) therapy.
For the third project, the aim consequently is to investigate the quality of the oral anticoagulation therapy with VKA by studying the time in therapeutic range (TTR) of prothrombin complex (International normalized ratio (PT/INR)).
SWEDCON is a national quality registry for congenital heart disease including GUCH-patients, aiming to monitor patients from birth through their entire lives. Patients were identified through the registry and required data was collected from the patient journals.

Preliminary results
The first paper published a correlation between systemic right ventricular function and global longitudinal strain on echocardiography.
For the second and third project, an internationally relatively high TTR was seen with a lower TTR in the group with complications. The TTR in GUCH-patients was lower than the national average. However, the incidence of thromboembolism and bleeds was lower.

Impact
The first paper together with previous studies supports use of echocardiography in this patient group.
TTR and incidence rates show that anticoagulation therapy with VKA is of high, but improvable quality.

Published work