Cardiology in the Young

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Impact of a structured patient education programme on early diagnosis of prosthetic pulmonary valve endocarditis

Daniela Babic[1], Ramona Hämmerli[1], Bruno Santos Lopes[1], Christine Attenhofer Jost[1], Daniel Tobler[2], Markus Schwerzmann[3], Barbara Hasse[4], Francesca Bonassin Tempesta[1] and Matthias Greutmann[1]

[1]Department of Cardiology, University Heart Center, University of Zurich, Zurich, Switzerland; [2]Department of Cardiology, University Hospital Basel, University of Basel, Basel, Switzerland; [3]Center for congenital heart disease, University Hospital Inselspital, University of Bern, Bern, Switzerland and [4]Division of Infectious diseases and Hospital Epidemiology, University Hospital Zurich, University of Zurich, Zurich, Switzerland

Original Article

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Author for correspondence:
M. Greutmann, MD, Department of Cardiology, University Heart Center, University of Zurich, Raemistrasse 100, 8091 Zurich, Switzerland.
Tel: ++41 44 255 3883;
Fax: ++41 44 255 8701.
E-mail: Matthias. Greutmann@usz.ch

Social Media Synopsis: Patient education leads to earlier diagnosis and improves outcomes of prosthetic pulmonary valve endocarditis: Lessons learnt from a single centre experience.

Abstract

Background: Infective endocarditis is a major threat after prosthetic pulmonary valve replacement. Early diagnosis may improve outcomes. *Methods:* A structured patient education programme for prevention and early diagnosis of infective endocarditis was developed at our institution since 2016. Time delay between onset of symptoms of prosthetic pulmonary valve endocarditis and its diagnosis (defined as initiation of appropriate high-dose intravenous antibiotic treatment) was compared for patients presenting before (cohort 1) and after (cohort 2) initiation of the patient education programme. *Results:* Between 2008–2019, 26 patients (median age 24.9, range: 16.8–62.0 years, 73% male) were diagnosed with prosthetic pulmonary valve endocarditis, 13 patients (cohort 1) before (1.7 cases/year) and 13 patients (cohort 2) after June 2016 (3.7 cases/year). There were no differences in baseline characteristics or clinical presentation between the study cohorts. Overall, the median delay between onset of symptoms and diagnosis of infective endocarditis was 6 days (range: 0–133 days) with a significantly longer delay among patients in cohort 1, compared to cohort 2 (25 days, range: 5–133 days versus 3 days, range: 0–13 days, $p < 0.0001$). A delay of >7 days was documented in 11/13 patients (85%) in cohort 1 as compared to 1/13 (8%) in cohort 2 ($p < 0.001$). Need for urgent valve replacement or permanent deterioration of prosthetic valve function was higher in cohort 1, compared to cohort 2 (11/13, 85% versus 5/13, 39%; $p = 0.041$). *Conclusions:* Prosthetic pulmonary valve endocarditis is increasingly recognised. A structured patient education programme may improve early diagnosis and clinical outcomes.

Prosthetic valve conduits in pulmonary position are used for repair of a variety of congenital cardiac defects including patients with conotruncal defects, such as tetralogy of Fallot or pulmonary atresia and patients undergoing the Ross procedure for primary aortic valve disease. Particularly in patients with repaired tetralogy of Fallot and residual pulmonary regurgitation, prosthetic pulmonary valve replacement has become increasingly popular these days.[1] In recent years, several reports have raised concerns about high rates of infective endocarditis late after prosthetic pulmonary valve replacement, particularly in patients with bovine jugular vein grafts (Contegra™ or Melody™ valves, Medtronic, Minneapolis MN). Prosthetic pulmonary valve endocarditis is associated with high morbidity and substantial mortality.[2–5]

As native pulmonary valve endocarditis is extremely rare and patient cohorts with prosthetic pulmonary valves are just emerging, prosthetic pulmonary valve endocarditis is a rather novel entity and its diagnosis may pose unique challenges compared to left heart endocarditis. These challenges include atypical clinical presentation (e.g. septic pulmonary embolism) and often challenging echocardiographic visualisation of the prosthetic pulmonary valve. As delayed diagnosis of prosthetic pulmonary valve endocarditis may be associated with increased morbidity and mortality, careful assessment of factors associated with delayed diagnosis may be important. To address some of these challenges, we have initiated a dedicated patient education programme focusing on risks of infective endocarditis and measures to facilitate early diagnosis as part of routine clinical follow-up at our institution since the year 2016.

The aims of our study were therefore to evaluate the delay between onset of symptoms of infective endocarditis to first medical contact and to the initiation of appropriate antibiotic therapy, to define predictors that may be associated with delayed diagnosis and to assess the impact of a structured patient education programme on diagnostic delays.

Methods

For the purpose of this study we identified all patients followed at our institution with a history of definitive prosthetic pulmonary valve endocarditis (according to the modified Duke criteria).[6] Patients were identified in our adult congenital heart disease registry (SACHER-registry, ClinicalTrials.gov Identifier NCT 2258724).[7] All patients enrolled in the registry gave written informed consent, and the local ethics committee approved the study.

Demographic data, the type of underlying congenital heart defect, the type of prosthetic valved conduit, the culprit micro-organism and features of clinical and echocardiographic presentation were identified from chart review and review of clinical imaging. Echocardiographic presentation such as worsening pulmonary regurgitation was defined as new or an increase of ≥1grade in prosthetic valve regurgitation compared to the last echocardiography prior to the acute illness. Echocardiographic presentation as worsening valvar obstruction was defined as an increase in peak systolic gradient of >20 mmHg compared to the last echocardiography before endocarditis. Prosthetic regurgitation was graded as none/trivial, mild, moderate or severe as previously reported.[8]

To assess the potential delay in the diagnosis of infective prosthetic pulmonary valve endocarditis, particular attention was paid to the time interval between onset of clinical symptoms of infective endocarditis (fever, malaise, weight loss, etc.) and diagnosis of infective endocarditis. The latter was defined as initiation of appropriate combined high-dose intravenous antibiotic therapy. To delineate potential predictors and causes of delayed diagnosis, the time interval between onset of symptoms and first medical contact (patient delay) and between first medical contact and initiation of high-dose intravenous antibiotic therapy (physician delay) were analysed. Diagnostic procedures (imaging and blood cultures) and therapeutic measures before initiation of appropriate antibiotic therapy were carefully reviewed.

After reviewing our institutional experience (analysed for our national cardiology conference at the end of 2015), a dedicated patient education programme concerning infective endocarditis has been developed as part of routine clinical follow-up since 2016. This programme includes individual patient counselling by a dedicated nurse who explains the risks and symptoms of infective endocarditis and emphasizes the importance of seeking rapid medical advice in case of symptoms. Patient education is enhanced with visual illustration and is completed by handing out a small booklet to each patient at the end of the clinic visit that summarises the most important facts and recommendations about infective endocarditis (Fig 1).

Overall, our structured patient education for infectious endocarditis takes about 5–10 minutes at baseline and 1–2 minutes during follow-up visits.

To determine the impact of the structured patient education on early diagnosis and clinical outcomes of prosthetic pulmonary valve endocarditis, the time delay between onset of symptoms and diagnosis of infective endocarditis was compared between patients presenting before July 2016 (cohort 1) and patients diagnosed after the initiation of the patient education programme (cohort 2).

Statistics

Continuous data are presented as mean ± standard deviation or median with range as appropriate. Categorical data are presented as number with percentage. For comparison between groups, chi-square tests, Fisher's exact test, Student's t-test or Mann–Whitney test were used, as appropriate. Two-sided p-values <0.05 were considered statistically significant. All statistical analyses were performed using a commercially available software package (IBM SPSS Statistics, Version 26).

Results

A total of 26 patients with definitive prosthetic pulmonary valve endocarditis, treated at our centre between 2008 and 2019, were identified in our database. Patient characteristics, clinical and echocardiographic findings are presented in Table 1. The most common underlying congenital cardiac defects were tetralogy of Fallot or pulmonary atresia with ventricular septal defect (20 patients, 77%) and patients after the Ross-operation (three patients, 12%). The most common types of implanted prosthetic valves were jugular bovine vein grafts (Contegra^{TM} conduits, Medtronic, Minneapolis MN) in 12 patients (46%), percutaneously implanted bovine jugular vein grafts (Melody^{TM} valves, Medtronic, Minneapolis MN) in seven patients (27%), followed by other xenografts in six patients (23%) and one patient (4%) with a homograft conduit. None of the patients had a history of intravenous drug abuse, HIV infection or diabetes mellitus. Only one patient (causative microorganism of endocarditis: *Streptococcus viridans*) had a documented history of dental procedure (with appropriate antibiotic endocarditis prophylaxis) 3 weeks prior to the diagnosis of infective endocarditis. None of the patients had previous implantation of endocardial pacemaker or defibrillator leads.

The diagnosis of infectious pulmonary valve endocarditis was made at a median of 9.3 years (range: 0.7–15.2 years) after prosthetic valve implantation. The most common identified microorganisms were methicillin-sensitive *Staphylococcus aureus* (nine patients, 35%) and *Streptococcus viridans* (nine patients, 35%), followed by microorganisms of the HACEK group (five patients, 19%) and *Coxiella burnetii* (Q-fever endocarditis in two patients, 8%). Both patients with Q-fever endocarditis were diagnosed before June 2016. The first patient had several sets of negative blood cultures at the local hospital and was treated for presumptive pneumonia. When he was referred to the tertiary care centre, typical vegetations were seen on transthoracic echocardiography and the diagnosis was confirmed by serology. Under treatment, prosthetic valve function remained normal. The second patient was treated with a 1-week course of oral antibiotics without prior blood cultures, 2 months before presentation to the tertiary care centre. On presentation, typical vegetations and severe prosthetic valve regurgitation were seen on transthoracic echocardiography. High-dose intravenous antibiotic treatment was initiated, and diagnosis was confirmed on serology, after three sets of blood cultures remained sterile. One patient had a culture-negative endocarditis (the patient was pre-treated with oral antibiotics prior to sampling of blood cultures for presumptive respiratory tract infection in the setting of septic pulmonary embolism).

The most common symptoms at presentation were fever (24 patients, 82%), chills (18 patients, 69%), night sweats (six patients, 23%), weight loss (four patients, 15%) and cough (three patients 12%). All patients received a 6-week course of intravenous antibiotic treatment, except for the two patients with Q-fever-endocarditis who were treated with a prolonged regimen of doxycycline and hydroxychloroquine. Twenty patients (77%) presented with

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Table 1. Baseline characteristics and clinical presentation, stratified for the two study cohorts

	All patients (n = 26)	Cohort 1 (n = 13, 2008–June 2016)	Cohort 2 (n = 13, July 2016–2019)	p-value*
Age (years)	24.9 (16.8–62.0)	22.3 (16.8–51.7)	27.3 (17.0–62.0)	0.115
Male gender (%)	19 (73)	9 (69)	10 (77)	1.0
Time since prosthetic pulmonary valve replacement (years)	9.3 (0.7–15.2)	6.8 (0.7–11.1)	12.4 (3.8–15.2)	0.115
Bovine jugular vein graft (%)	12 (46)	6 (46)	6 (46)	0.345
Previous percutaneous pulmonary valve (%)	7 (27)	4 (31)	3 (23)	0.345
Staphylococcus aureus endocarditis (%)	9 (35)	5 (39)	4 (31)	0.360
Delay of >7 days between onset and diagnosis (%)	12 (46)	11 (85)	1 (8)	<0.001
Septic pulmonary embolism (%)	8 (31)	6 (46)	2 (15)	0.101
Permanent prosthetic valve deterioration (%)	16 (62)	11 (85)	5 (39)	0.041

*For comparison between cohort 1 and cohort 2.

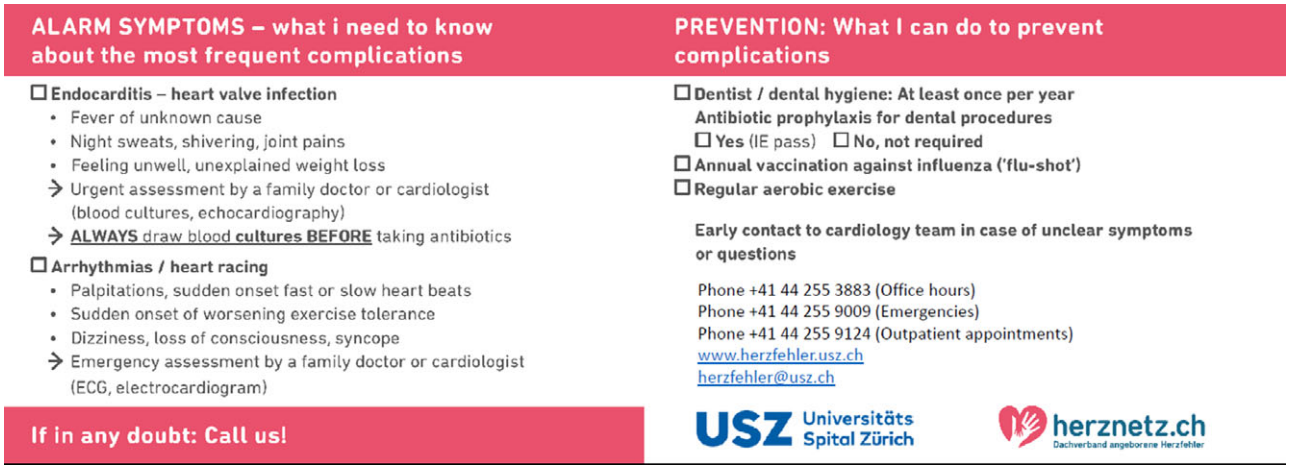

Figure 1. Handout for patients, given at the end of each clinic visit containing condensed information in lay terms about most common long-term complications in adults with congenital heart disease.

acute deterioration of prosthetic valve function, which was permanent in 16 patients (62%). In 21/26 patients (81%), vegetations were identified by transthoracic echocardiography. The most common hemodynamic presentation on echocardiography was new or worsening prosthetic valve stenosis (12 patients, 46%), followed by new or worsening valve regurgitation in six patients (23%) and a combination of novel obstruction and regurgitation in two patients (8%). In the other six patients (23%) prosthetic valve function was unchanged compared to last echocardiographic assessment prior to the diagnosis of endocarditis. Of all patients presenting with worsening prosthetic valve function, six patients (30%) required urgent pulmonary valve replacement at a median of 6 days (range: 3–19 days) after admission to our centre. The indication for urgent pulmonary valve replacement was critical or progressive right ventricular outflow tract obstruction in four patients and uncontrolled infection in two patients. Of the four patients with severe right ventricular outflow tract obstruction, two patients had endocarditis with *Staphylococcus aureus*, one patient with *Streptococcus mitis/oralis* and one patient with *Haemophilus influenzae*. Both patients, who were operated on for uncontrolled infection, had *Staphylococcus aureus* endocarditis. Three patients with permanent prosthetic valve dysfunction underwent elective pulmonary valve replacement at a median of 26 months (range: 19–61 months) after acute infective endocarditis, two of them by means of a percutaneous pulmonary valve replacement. One patient had already been scheduled for an elective pulmonary valve replacement due to severe prosthetic valve obstruction prior to the episode of infective endocarditis and underwent surgical pulmonary valve replacement 8 months later. There were no in-hospital or late deaths. One patient underwent implantation of an endocardial automated cardioverter-defibrillator due to recurrent sustained ventricular tachycardia 4 months after endocarditis.

Impact of structured patient education programme on presentation and outcome of infective endocarditis

Of the 26 patients with infective pulmonary valve endocarditis, 13 patients (50%) were diagnosed between 2008 and June 2016, before initiation of a structured patient education programme

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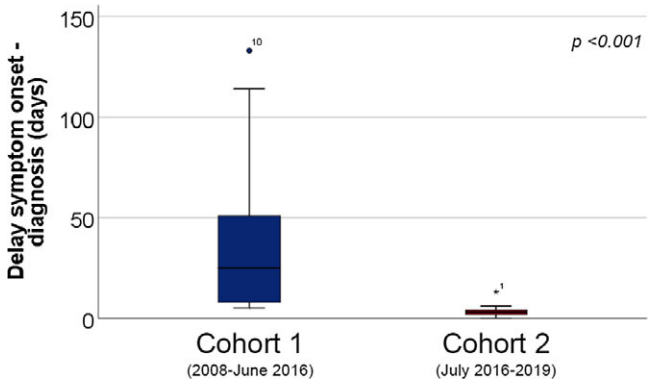

Figure 2. Total delay between onset of symptoms of infective endocarditis and initiation of high-dose intravenous antibiotic therapy, stratified for the two study cohorts.

(representing cohort 1) and 13 (50%) thereafter (representing cohort 2). The annual number of cases with prosthetic pulmonary valve endocarditis amounted to 1.7 cases/year for cohort 1 and 3.7 cases/year in cohort 2. Of patients in cohort 2, 11/13 (85%) had documented patient education prior to diagnosis of infective endocarditis, one of the patients at the time of the transition visit to the adult clinic, the others during routine follow-up visits. The remaining two patients without documented patient education had not been followed at our centre prior to diagnosis of infective endocarditis.

There were no significant differences in baseline characteristic and clinical presentation between the two cohorts (Table 1). The median duration from onset of symptoms to diagnosis of infective endocarditis was 6 days (range: 0–133 days) for the entire population. In cohort 1, the first medical contact was the patient's general practitioner in seven cases (54%), the local cardiologist in one patient (8%), the local hospital in four patients (31%) and the tertiary care centre in one patient (8%). In cohort 2, the first medical contact was the patient's general practitioner in two patients (15%), the local hospital in seven patients (54%) and the tertiary care centre in four patients (31%). These differences were not statistically significant ($p > 0.05$).

In almost half of all patients (46%), it took more than a week until the diagnosis was established. As illustrated in Figure 2, there was a significant difference in time delay between symptom onset and diagnosis of infective endocarditis in the two study cohorts. The decrease of time delay from onset of symptoms to the diagnosis of prosthetic pulmonary valve endocarditis was caused by a significant decrease in the delay of both, the patient and the physician (Fig 3). A delay of >7 days between onset of symptoms and diagnosis of infective endocarditis was documented in 11/13 patients (85%) in cohort 1 as compared to 1/13 (8%) in cohort 2 ($p < 0.001$).

In cohort 1, five patients (38%) received at least one course of oral or intravenous antibiotics (dose not appropriate for infective endocarditis) without prior sampling of blood cultures, whereas in cohort 2 there was none. Although there was no systematic screening for septic pulmonary embolism, there was a trend towards less septic pulmonary embolism in cohort 2 as compared to cohort 1.

In cohort 1, nine patients (69%) had undergone echocardiography at their local hospital (five transthoracic studies and four studies with combined transthoracic and transesophageal echocardiography). Findings of infective endocarditis were missed in eight of these patients (89%), even though typical echocardiographic findings (independently mobile vegetations) could be demonstrated by transthoracic echocardiography in all of these patients, once echocardiography was repeated at the referral centre. In cohort 2, seven patients (54%) had undergone echocardiography at their local hospital (four transthoracic studies and three studies with combined transthoracic and transesophageal echocardiography). Findings of infective endocarditis were missed in two of these patients (29%). The most common erroneous diagnoses at the time of presentation were respiratory tract infections (three patients), cholecystitis and urinary tract infections.

There was a significantly lower rate of urgent pulmonary valve replacement or permanent deterioration of prosthetic valve function among patients diagnosed after July 2016 as compared to patients in cohort 1 (5/13, 39% versus 11/13, 85%, $p = 0.041$).

Predictors of delayed diagnosis

A number of potential factors delaying the diagnosis of infective endocarditis were evaluated. These included age, gender, type of underlying defects, time since pulmonary valve replacement and living conditions. For the overall patient cohort, no significant predictors for a delayed diagnosis of prosthetic valve endocarditis were found. As there was no significant delay in diagnosis within cohort 2, a separate analysis of predictors of delayed diagnosis was performed for patients within cohort 1. In cohort 1, patients with prosthetic valve endocarditis caused by *Staphylococcus aureus* were diagnosed earlier as opposed to those with non-staphylococcus aureus endocarditis (8 days, range: 5–11 days versus 40 days, range: 7–133 days, $p = 0.011$). In addition, patients living with their parents or spouses had a shorter patient delay compared to those living alone (4 days, range: 1–30 days versus 51 days, range: 38–63 days, $p = 0.026$).

Discussion

In this study of adults with prosthetic pulmonary valve endocarditis, we demonstrate the importance of a structured patient education programme in improving the diagnosis and treatment and potentially the outcome of patients with infective prosthetic pulmonary valve endocarditis despite the increasing number of affected patients.

The cohort of adults with congenital heart disease after surgical or percutaneous bioprosthethic pulmonary valve replacement is rapidly growing with increasing evidence of high risk of infective endocarditis in this cohort.[1,4,9–11]

Prosthetic pulmonary valve endocarditis is associated with high morbidity and substantial mortality.[2] As in all cases of infective endocarditis, early diagnosis with prompt initiation of high-dose intravenous antibiotic treatment may preserve valve function and prevent complications, such as septic embolism or uncontrolled infection. Our early experience, before initiation of a structured patient education programme, demonstrates an unacceptable time delay between onset of symptoms until the correct diagnosis was made and appropriate treatment was initiated. There may be several potential explanations for this delay: First, although presenting symptoms of infective endocarditis in our patient cohort were fairly common (fever, chills, night sweats and malaise), the perception of increased risk for infective endocarditis may have been lacking among patients themselves and among treating non-specialist physicians, given the young patient age. Thus, symptoms were often attributed to common infectious diseases, such as respiratory tract infections. Septic pulmonary embolism was misdiagnosed as pneumonia. This led to a high rate of inappropriate empiric antibiotic treatment without prior sampling of blood cultures, which contributed to a delayed diagnosis.

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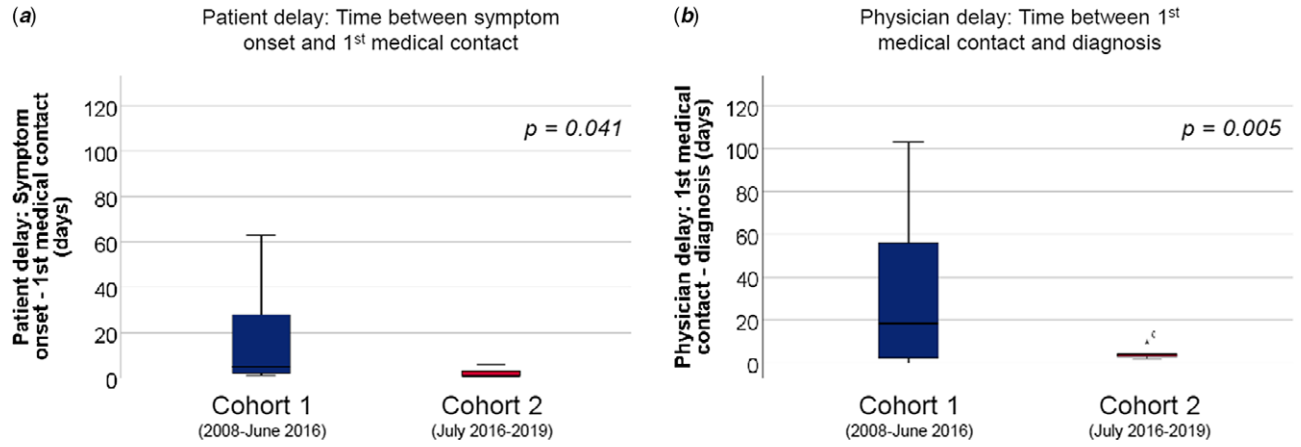

Figure 3. Panel A: Delay between onset of symptoms and first medical contact (patient delay) stratified for the two study cohorts. Panel B: Delay between first medical contact and diagnosis of infective endocarditis stratified for the two study cohorts.

Second, while native pulmonary valve endocarditis is an exceedingly rare entity, prosthetic pulmonary valve endocarditis is increasingly observed at referral centres – but not so at non-specialist local hospitals. Echocardiographic assessment of prosthetic pulmonary valves may be difficult for non-specialist cardiologists. Indeed, in our early experience, typical signs of endocarditis were often missed on echocardiography at non-specialised centres, which contributed to delayed diagnosis and inadequate treatment. A recent study from Australia has demonstrated a high rate of management errors in adults with congenital heart disease, when not treated at specialised centres.[12] This underscores the need for a dedicated and integrated care model for this vulnerable patient cohort. There is a strong need to establish well-functioning care networks between specialist centres and local caregivers (general practitioners and local hospitals) that allow for a trusting collaboration and early transfer in case of a suspected endocarditis.

Interestingly, the initiation of a dedicated patient education programme decreased not only the delay between onset of symptoms and first medical contact (patient delay) but also the delay between first medical contact and initiation of appropriate high-dose intravenous antibiotic treatment (physician delay). This could be explained by the empowerment of patients with a better knowledge of their risks, which allows them to insist on appropriate diagnostic tests (sampling of blood cultures) and early contact with their specialist centre either directly or via their regional centre.

Despite our small number of patients, this study provides evidence that an earlier diagnosis of prosthetic pulmonary valve endocarditis leads to a lower rate of urgent prosthetic valve replacements and decreases permanent deterioration of prosthetic valve function.

Although the risk of infective endocarditis seems to be particularly high for patients after prosthetic pulmonary valve replacement, the risk may be elevated in a large number of patients with congenital and acquired heart disease. Based on data from our national registry for adults with congenital heart disease (SACHER-registry, ClinicalTrials.gov Identifier NCT 2258724), about 20% of all adult congenital heart disease patients are at highest risk for infective endocarditis. These are patients with prosthetic heart valves, previous infective endocarditis and unrepaired cyanotic defects. A much larger proportion of patients is not at highest but clearly at increased risk of infective endocarditis. This includes patients with native heart valve disease, such as bicuspid aortic valves or mitral valve prolapse and patients with trans-venous pacemaker or defibrillator leads. Although compared to patients with prosthetic heart valves, the absolute annual risk for infective endocarditis is clearly lower in patients with native valve disease, given by their sheer number; their overall impact on the burden of infective endocarditis on our medical systems is substantial. In our experience, these patients may be even less aware of their risk for infective endocarditis and delayed diagnosis is very common. Hence, while we used a subgroup of patients with a very high risk of infective endocarditis to demonstrate the impact of our patient education programme, it is our clinical experience that our findings are more generic and apply to all patients at increased risk of infective endocarditis.

The experience made by our team thus had an impact on our overarching strategy when national recommendations for the prevention of infective endocarditis were revised in 2020. Apart from defining high-risk patients, requiring antibiotic prophylaxis for dental procedures, patient information and education for all patients at risk for infective endocarditis was given a much higher weight in our current prevention strategy. As part of this revised national strategy, flyers were created for promotion of better patient education. These flyers (available in German, French, Italian and English) are available on the website of the Swiss Heart foundation (***links provided below***).

Links to flyers for patient education provided by the Swiss Heart Foundation

English version: www.swissheart.ch/fileadmin/user_upload/Swissheart/Shop/PDF_Broschueren/Flyer_Endokarditis_Erwachsene_EN_WEB.pdf

French version: www.swissheart.ch/fileadmin/user_upload/Swissheart/Shop/PDF_Broschueren/Flyer_Endokarditis_Erwachsene_FR_WEB.pdf

As a simple educational programme like ours could be useful for a larger audience, we encourage others to use the educational material developed by our programme (https://www.herznetz.ch/service/mini-kg.html) and to share their own experience and educational material with the medical community for a better outcome of our patients.

Limitations

Although patient charts and previous history were studied in great detail, this analysis suffers from the common limitations related to

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the retrospective nature of the study. The single centre setting and the small number of patients within this selected cohort of patients at high risk of infectious endocarditis may limit the generalisability of our findings to other patient populations with congenital or acquired heart disease and to other care settings. Given the setting of the study, it is difficult to discern, whether earlier diagnosis of infective endocarditis in patients diagnosed after June 2016 is a true effect of our patient education programme or in fact a consequence of a generally higher awareness of the problem among the medical community. The fact that patient delay was completely abolished in patients diagnosed after June 2016 is, however, a strong indicator of efficacy in our efforts of patient education.

Conclusions

Given the rapidly increasing number of patients with prosthetic pulmonary valve replacement, cases of prosthetic pulmonary valve endocarditis are increasing. Our study demonstrates that a structured patient education programme improves the early diagnosis of infectious endocarditis and may improve clinical outcomes. Further studies are required to investigate whether our findings can be transferred to other patient populations and to other settings of patient care. We offer and encourage others to use the patient educational material developed by our group, if deemed to be appropriate and helpful for their own programmes.

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Conflicts for interest. None.

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