patient's bleeding risk.[821] Patients may be anticoagulated with low-molecular-weight heparin, vitamin K antagonists, or unfractionated heparin. There are no data to support the use of direct oral anticoagulants in NBTE. In a randomized open-label multicentre study comparing rivaroxaban and warfarin in patients with thrombotic APLs, the use of rivaroxaban was associated with an increased rate of thrombo-embolic events and major bleeding.[825] The role of surgery is controversial and remains to be clarified. However, surgery should be considered in patients with severe valve dysfunction or with large vegetations.[823]

12.13. Infective endocarditis and malignancy

There are limited data on the prevalence, clinical presentation, management, and outcome of IE in patients with malignancy. In a retrospective Japanese cohort study including 170 patients, 17.6% had active malignancy.[826] Compared with patients without malignancy, patients with malignancies were older, nosocomial IE was more frequent, and procedures before IE (non-dental, i.v. catheter insertion, invasive endoscopic, or genitourinary procedures) were more frequent.[826] Another recent study from the EURO-ENDO registry of 3085 patients with IE found a history of malignancy in 11.6% of patients.[827] Patients with a history of malignancy had a similar rate of theoretical indications for surgery, but surgery was performed less often in this group. Mortality was higher in the malignancy group with independent predictors for mortality being elevated creatinine >2 mg/dL, congestive HF, and unperformed cardiac surgery when indicated.[827] In IE patients with concomitant cancer, indications for valve surgery should be discussed within the Endocarditis Team, including a cardio-oncologist and the oncologist in charge of the patient, in order to take into account the risks and benefits of surgery and cancer prognosis.

13. Patient-centred care and shared decision-making in infective endocarditis

13.1. What is patient-centred care and shared decision-making and why is it important?

Patient-centred care encourages involvement and collaboration between patients, families, and healthcare providers during all stages of diagnosis, treatment, and recovery.[828–831] Core elements of patient-centred care include: involvement of family and caregivers, respect for patients' preferences and values, care co-ordination and continuity, information and education, as well as physical comfort and emotional support (*Figure 14*).[828–830]

Shared decision-making involves a bidirectional process where patients, family, and healthcare providers share information and discuss care options in the context of the patients' preferences, beliefs and values, and the best available evidence ensuring that the patient understands the risks,[832,833] benefits, and possible consequences of the different options.[834–836] The majority of patients prefer sharing decisions about their own health, if they are sufficiently informed and prepared.[837,838] Patient-centred care and shared decision-making have been shown to contribute to improved concordance between care providers and patients on treatment plans, as well as increased patient satisfaction, quality of life, and health outcomes.[830,839–843]

13.2. Patient-centred care and shared decision-making in infective endocarditis

The severity of IE, the complex and comprehensive diagnostics and treatment, as well as the long illness trajectory, put special emphasis on patient-centred care and shared decision-making in IE (*Figure 14*). Quality of life appears to be impaired in IE survivors, with a significant number of patients developing symptoms of anxiety, depression, or even post-traumatic stress disorder following IE treatment.[604,844]

The time of diagnosis is often emotionally distressing to the patient and family, as they face a life-threatening condition and lengthy treatment.[845]

During the diagnostic and active treatment phase, healthcare providers should make every effort to minimize patient discomfort (e.g. related to symptoms and diagnostic procedures), and alleviate distress in both patient and family by providing support and comprehensive and timely information about the patient's condition, therapeutic options, and prognosis. Independent of the therapeutic strategy (i.e. surgical vs. conservative), patient-centred care is key to ensure a good physical and mental outcome during a lengthy treatment and hospitalization associated with IE. Maintaining continuity of care, when possible, by minimizing the number of providers the patient encounters and minimizing transfers between and within units, is all part of a patient-centred care approach. Allowing family visits at any time and providing the opportunity to uphold personal integrity and autonomy are important issues for patients. National patient organizations and associations may be an option for offering information and support to patients and their families.

The role of outpatient antimicrobial treatment options in IE should be discussed using a shared decision-making approach, involving the patient's partner or family if possible. The outpatient treatment should be in concordance with the patient's and family's preferences, also considering transportation and self-care abilities. To monitor possible complications, it is important to inform and educate patients and caregivers about the signs and symptoms of disease progression or recurrence.

The early period after discharge can be challenging for patients and their families, and patients report slow physical and mental recovery after IE, often extending longer than anticipated.[603,604,846,847] Patient-centred care should therefore extend further than the clinical treatment at the hospital to ensure a good outcome after discharge. Though little research has explored patients' and families' needs for recovery and rehabilitation following IE, patients with heart disease report experiencing new and continuous challenges and a lack of knowledge and understanding after discharge, which should be addressed to optimize recovery.[848]

It is recommended that a recovery plan is developed in collaboration with the patient and their caregivers and that the plan is reviewed and potentially adjusted following a short period after discharge.[849]

Physical exercise should be recommended based on an individual assessment of functional capacity (guided by physicians and physiotherapists), and patient education and psychosocial support should address the main problems and concerns patients and families have. Importantly, patient education should also include information about the risk of recurrence and preventive measures described in *Sections 3* and *11*. Special consideration should be taken for patients with no close relatives. Self-support groups or mentors may be introduced to patients without support networks. Also, follow-up by telephone from the ward staff, until full recovery has been reached, may be an option.

A palliative approach aims to improve the quality of life of patients and their families who are facing problems associated with life-threatening illness, which is relevant for many patients with IE. This approach includes a holistic, needs-based perspective with the aims of