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EDITORIAL

The congenital database and the Streif in Kitzbühel

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The Streif in Kitzbühel, Austria, is regarded as the most challenging ski downhill race. It starts with the 'Mausefalle' (the mousetrap), a stunning, almost vertical jump—the most dangerous in the whole championship circuit—that propels skiers within seconds to a rocket speed and a landing compression of over 1000 kg (Fig. 1). Every champion will tell you that you may have already lost the race with a timorous jump, but you still have not won it with an intrepid and successful one. Only about 150 of the 3312 m would have been accomplished, and the rest of the steep slope is a succession of fall away turns and leaps, many with limited visibility and on glaring ice.

This month, the Journal publishes two reports from the two largest congenital databases—the European and the The Society of Thoracic Surgeons (STS) National ones [1, 2]—and gives the opportunity to recall the main objectives and limitations of these registries. In one report, the various methods to enlarge the right ventricular outflow tract (RVOT) in Tetralogy of Fallot are evaluated, and in the other, an overview of a large spectrum of congenital procedures with its attendant mortality is given.

The primary goal of the database is to improve the quality of care and patients' safety [3]. The congenital database gathers and monitors the procedures performed in the field of congenital heart defects, and reports their early outcome. This analysis and the establishment of an average performance set a reliable reference for individual measurement and should positively impact on the quality of care. The 30-day mortality rate is the cornerstone of the outcome. This rate certainly provides important information regarding an operative risk but, like the Streif initial jump, remains incomplete in the assessment of the overall success or benefit of an operation. In many situations, an increased operative risk is bargained with a better long-term quality of life and survival. Take the arterial switch, the double switch or the Bex-Nikaidoh procedure as examples. None of them would compete favourably in a 30-day mortality with their technically easier counterparts such as the Senning procedure, a physiological correction or a Fontan pathway, respectively. Still, these demanding operations are rightly favoured by expert surgeons, because of their proven mid-term and their anticipated long-term benefits [4, 5]. The same shortcoming arises from Sarris *et al.*'s report [2]. Using only the early mortality—without any reoperation rate—to evaluate the various methods of RVOT opening can only lead to incomplete and dubious conclusions that many of us might draw in spite of the repeated warnings from the investigators. Congenital cardiac surgeons have learned since long back that the less the myocardium is cut into, the better the heart will function. The decision regarding the infundibulum is no longer taken blindly as a 'rule of school' but is actually dictated by local findings. With an infundibulum methodically left intact, many kids would come back for a second relief of an excessive obstruction [6, 7].

The second drawback of any such registry study is that it does not account for the temporospatial characteristic of the truth. The truth in London is already not the one prevailing in Madrid or in Paris (not to mention the one in less-developed countries) for many good reasons related to local expertise, facilities and beliefs and convictions. Likewise, the truth of today will only partly be valid in the next decade. Consider simply the fate of the chronic pulmonary insufficiency in longstanding Fallot patients. Not long ago, our reluctance to reoperate on these patients was great because of a significant mortality rate, which was mainly due to the fact that these procedures were performed too late, on already exhausted hearts [8]. With better criteria to implant a valve in the pulmonary position, the mortality rate of these redo procedures has dropped dramatically [9]. We are now all convinced that a first redo on a tired ventricle is more perilous than a second or third redo on a well functioning one. The booming of percutaneously implantable valves will also drastically reduce the need for reoperation [10]. When, on top of that, one considers that, as a rule, a ventricle tolerates a volume load better than a pressure load [11], it is difficult to advocate a preference for a residual significant stenosis over a calibrated transannular patch with some degree of regurgitation. Limiting the evaluation to the mortality rates of the various methods of the correction of Tetralogy of Fallot, the information given by the database, is like giving the ranking of the skiers after the initial jump of the Streif. Some may appear to be to be in a better position at that time, but the ultimate winners will be those able to negotiate the subsequent turns and leaps with the straightest line and least impairment. The divergence between the surgical and the ultimate outcome is certainly less pronounced in an adult database because the critical 'surgical jump' happens much later in the race, closer to the final strides of life.

The second report, which presents the results in congenital cardiac surgery on both sides of the Atlantic, is perplexing [1]. Courteously, no formal comparison is made, but everyone is prone to make it (we have not acquired a scientific mind to not

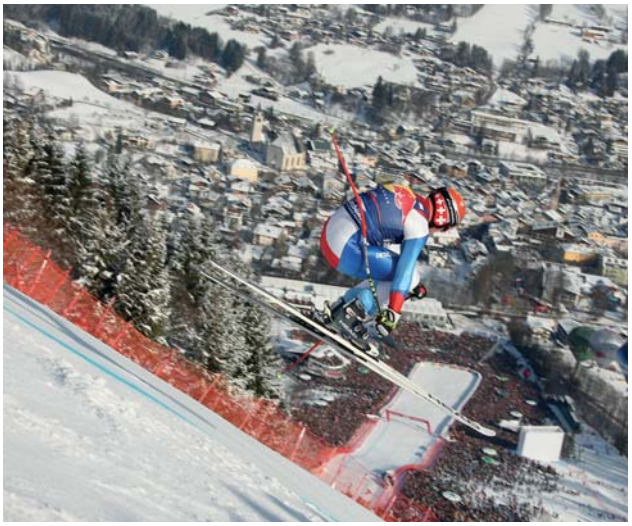

Figure 1: Didier Cuche in the Streif heading for his fourth victory in the mythic race. The Swiss champion won it one more time in 2012 and beat the famous record set by the legendary Franz Klammer. Note the finish line far below (Courtesy of Didier Cuche).

use it), and will then be confronted with intriguing facts. The first one will be the difference in the caseload distribution within categories. In continents where the same incidence of diseases is expected—and in the absence of an asymmetric distribution of acquired disease, like rheumatic valve disease could produce—this difference is difficult to understand. Even more puzzling will be the analysis of the mortality rates, which are higher (at times almost doubled) in all categories of procedures in the European database compared with the STS one. This difference, probably reaching statistical significance, results in a worrisome excess of deaths in the European cohort. This embarrassing surplus will surely torment any surgeon on this side of the Atlantic with the unrelenting question: is the quality of our work, of my work, so much behind? Some reports from individual European units are in accordance with the STS predictions and will comfort us somehow [12, 13]. Certainly, the states in the USA and Canada have a more homogenous distribution of high-quality surgical expertise and facilities in congenital heart disease than the various countries in Europe. Disparities between the eastern and western blocks probably still exist, but they have been considerably attenuated over the past years and cannot account for the magnitude of the reported differences in mortality. In a laconic sentence of the article, it is stipulated that no less than 30% of the so-called European data stems from other continents. If this turns out to be true, then the relevance of the adjective European should eventually be questioned. However, this is only the slightest problem. For us, the database sets the standards against which we monitor our results. It helps us identify the areas of suboptimal performance needing prompt action to remain within, or regain, accepted limits. By setting the average standard at an inferior level, borderline units will not timely undertake these actions, and more children may suffer from unsatisfactory management. We still have in mind the so-called Bristol affair. The implicated unit had the surgical results many had 10–15 years earlier, but, in 1998, it was already prohibitively high and led to an unprecedented press scandal [14]. Developing countries are progressing fast, but many units have still not reached the standards we were working with a decade ago [15]. In an ideal world, the distribution of performances would be concentrated around a median line with a limited dispersion (a narrow bell-shaped curve for statisticians). The STS distribution looks like the ranking of the first group (the downhill specialists) of the Streif competitors, while the European one resembles the final ranking, the one that also includes the slalom specialists and the amateur skiers.

It is not our intention to contest the usefulness of the database in congenital cardiac surgery. We need it. Simply, its objectives should not be overplayed. The database is an instrument for everyone to measure his/her own performance and compare it with colleagues or institutions working under similar conditions. It is not an instrument to denounce the poor performance of one team or one surgeon, and likewise, it is also not an instrument for praise or advertisement (all too often, we have seen in congresses surgeons proudly showing their own circle radiating in the pole position). Finally, it should be used extremely cautiously as an instrument for the evaluation of therapies and recommendations, because it reflects no more than the ranking after the first Streif jump in an often long, tortuous and eventful 'congenital cardiac life'. If, however—through the process of comparison and appropriate reaction—the database was able to prevent, even if only once, another 'Bristol affair', then its justification and objectives would have been more than fully accomplished.

Conflict of interest: none declared.

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