

INVITED COMMENTARY

What Does the Patient Really Want to Know?

Anders Wanhainen *

Department of Surgical Sciences, Section of Vascular Surgery, Uppsala University, Uppsala, Sweden

With a 30 day mortality rate that is at least twice as high after open surgery for abdominal aortic aneurysm (AAA) compared with endovascular repair, many of us think the choice of surgical method is simple, as can be seen in recent statistics. But, are we certain that the patient agrees with this, or even understands what it means?

To help patients understand risks is of great importance in assisting informed decision making in different clinical situations. In the case of AAA repair, the issue can be very complex; should it be treated at all, and if so by which surgical technique? It is therefore important to communicate relevant information, to which the patients can relate and understand. Patients seem to favour clear definitions and absolute risk differences (rather than relative risks). However, to communicate relevant information, it must be possible to extract such information from the available literature.

In this issue, de Mik and co-workers present a systematic review on the quality of reported complications and mortality in relation to risk communication with patients prior to elective AAA repair.¹ Among 47 contemporary randomised clinical trials and comparative observational or registry studies included in the review, only two studies and one study, respectively, presented absolute risk differences in mortality and complications. Furthermore, lack of a clear definition of the outcomes was common, and often it was unclear whether the numbers given referred to events or patients. The authors call for better adherence to reporting standards, specifically stating absolute risk differences, to facilitate evidence based risk communication with patients.

The outcomes defined by the CONSORT statement² and SVS reporting standard,³ which formed the basis for the evaluation in the review, are not necessarily those that patients regard as the most important or relevant, however. Important outcomes for patients and their relatives may be very different from those usually considered important by vascular surgeons, such as 30 day mortality and major cardiovascular complications. For instance, independence, freedom from pain, disability, or amputation, and early return home may be more important than survival per se.³

This lack of agreement was acknowledged in the 2019 European Society for Vascular Surgery AAA Guidelines, which for the first time involved the patient's perspective developed together with patient representatives,⁴ and the need to develop a core outcome set (COS) intended for AAA studies was recently addressed in an editorial in this journal.⁵

COS is an agreed standardised collection of key outcomes that should be measured and reported, as a minimum, in all trials for a specific clinical area. Central to the development of COS is the involvement of patients, in addition to other stakeholders. Establishing COS for AAA repair that reflects patient priorities will ensure that these outcomes are monitored and assessed in future clinical practice and research, effectively putting the patient in the centre of care. It will aid decision making for health professionals, as well as supplying the information necessary to allow patients and their relatives to make well informed decisions.

The question "What does the patient want to know?" currently lacks a clear answer. Better adherence to already established guidelines and reporting standards is necessary when designing and reporting future studies, and a step in the right direction to improve risk communication with patients and relatives, as underlined by de Mik et al. In the effort for continued quality improvement, patient involvement should be given the highest priority.

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* Corresponding author.

E-mail address: anders.wanhainen@surgsci.uu.se (Anders Wanhainen).

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