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The SA Heart Association Registry: time to SHARE your data

The South African Heart Association Registry is aptly named the SHARE registry. Yet one of the factors contributing to low rates of participation appears to be a reluctance to share information from our practices and our departments. This reluctance is difficult to fathom as the standard of cardiology and cardiac surgery practiced in South Africa is considered to be high and perhaps more to the point, South African cardiologists and cardiac surgeons are not shy to sing the praises of our profession and the standard of cardiac services locally. We like to reminisce about people and events such as Chris Barnard and the first heart transplant performed in Cape Town and John Barlow's description of mitral valve prolapse and rightly so. However, our proud past does not guarantee that our current practice puts us at the forefront of our profession.

National registries such as SHARE, our cardiac catheterisation laboratory (cathlab) registry, play an important role in ensuring that we follow best practice strategies and that we remain on par with the rest of the world. In the words of Winston Churchill: "No matter how beautiful the strategy, you should occasionally look at the results." We cannot claim that we offer high quality care or effective care centred around our cathlabs if we do not measure and assess what we do.

The reasons for incomplete participation in the national registry are of course not limited to an apparent unwillingness of some individuals and centres to share their data. Lack of infrastructure such as computer and internet access is probably the least of these. A shortage of staff dedicated to the task of data capturing on the other hand is however a major factor and the playing field in this regard is not equal across the various centres. Generally government hospitals are not in a position to pay data capture specifically for the task of data capture, whereas some private hospitals do. The participation by private hospitals on the other hand depends heavily on the hospital group involved.

We can analyse the reasons for non-participation from all angles and come up with a multitude of reasons preventing us from participating, but in the final analysis it boils down to the simple fact that if we regard it as an important initiative and want to participate we will easily overcome any apparent

obstacles. The question should not be “What is preventing me from participating?” but rather “What do I need to do to ensure that I am participating?” If a well known sportswear manufacturer were the sponsor you all know what they would be telling you... Just do it.

It is true that the information gained from registries have a number of limitations such as selection bias and reporting bias. The main drawback remains incomplete data capture, both through incomplete data capture within a specific centre and through incomplete participation by centres across the country as already referred to. Be that as it may, any data about our cathlabs will be an improvement over no data. Once we have wide participation from most centres, strategies to improve the quality and completeness of data from individual centres will soon follow.

Our government’s intentions to implement a National Health Insurance (NHI) system in the near future and the publication of the NHI green paper last year was followed by the implementation of a pilot phase of the project in ten districts last month. Opinions about the NHI plan amongst cardiac practitioners cover a wide spectrum of viewpoints. Most are of the opinion that we should engage with government on the process so that the benefit of our expertise can improve the product. Government’s main requirement in this regard will be quality data. If we are to advise government, will our advice be based on anecdotes and “personal experience” supplementing international data, or will our advice be based on factual information of the South African situation which we have collected through initiatives such as the SHARE registry?

Even at this early stage in its existence the SHARE registry has generated data that is of significant interest and as the data becomes more comprehensive and robust the registry will become an invaluable tool to guide our own individual practices and departments as well as providing the data that policy makers will require for implementing successful strategies and programmes.

Data extracted from the SHARE registry indicate that the percentage of patients undergoing angiography and PCI following a prior MI is much less than the international trend (Table 1). Does this fact and the

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TABLE I: Patient demographics – SHARE[®] vs BCISR[#]

	BCISR 2009	SHARE 2010
Age (mean)	65.0 yrs	61.1 yrs
Sex (male)	73.9 %	65.4 %
Diabetic	18.2 %	23.3 %
Prior MI	28.8 %	11.9 %
Prior PCI	22.3 %	21.0 %
Prior CABG	8.6 %	17.4 %

Data from the SA Heart Congress, 2011, East London.

*SHARE (South African Heart Association Registry). #BCISR (British Cardiovascular Intervention Society Registry).

fact that a higher percentage of patients undergoing angiography in South African cathlabs have normal coronary arteries (29%) suggest that we have a lower threshold for diagnostic angiography than for example cardiologists in the United Kingdom? We should note that the proposed NHI plan will exclude funding for “Diagnostic procedures outside the approved guidelines and protocols as advised by expert groups”.

Is it important for you to take note of the fact that only 19.5% of arterial access in the SHARE database is via the radial route and that the trend appears to be downward? In contrast the data from the British Cardiovascular Intervention Society Registry (BCISR) shows an increasing trend and use of the radial access route is approaching 50% (Figure 1).

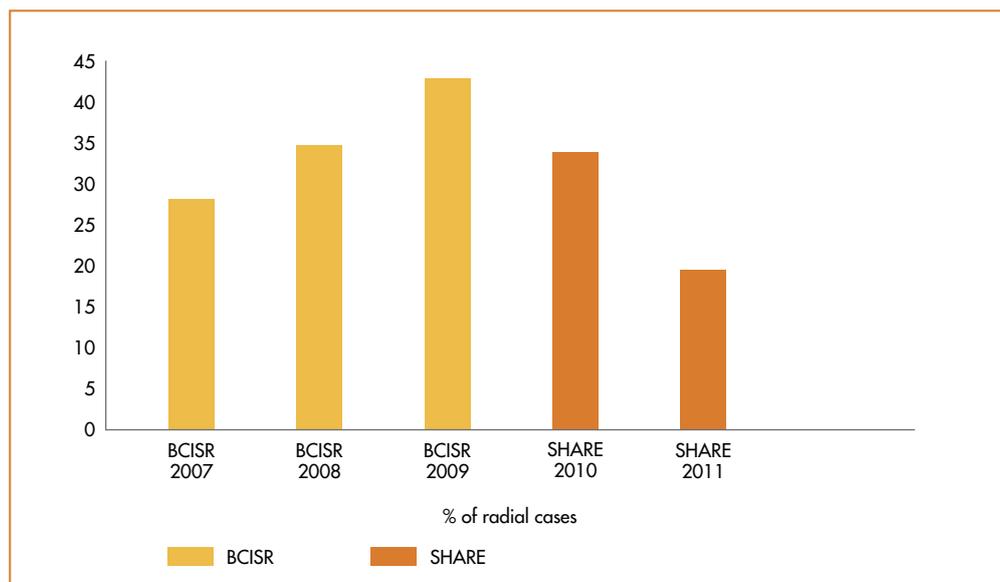


FIGURE 1: A comparison radial artery access (% of total) for coronary angiography – SHARE[®] vs BCISR[#]

*SHARE (South African Heart Association Registry). #BCISR (British Cardiovascular Intervention Society Registry).

Data from the SHARE registry indicates that up to 40% of patients undergoing PCI in our cathlabs have 3 or more lesions treated (compared to 8% for patients treated by our British counterparts) (Figure 2). Are we in line with international guidelines in this regard? Of course these observations may be based on an inadequate sample and incomplete data entry. Wide participation in the SHARE registry will ensure that we have the facts at hand. Non-participation will lead to rumours based on inaccurate data and decisions based on poor information.

In the interest of your patients, in the interest of your practice and in the interest of health care delivery in South Africa you simply need to SHARE your cathlab data.

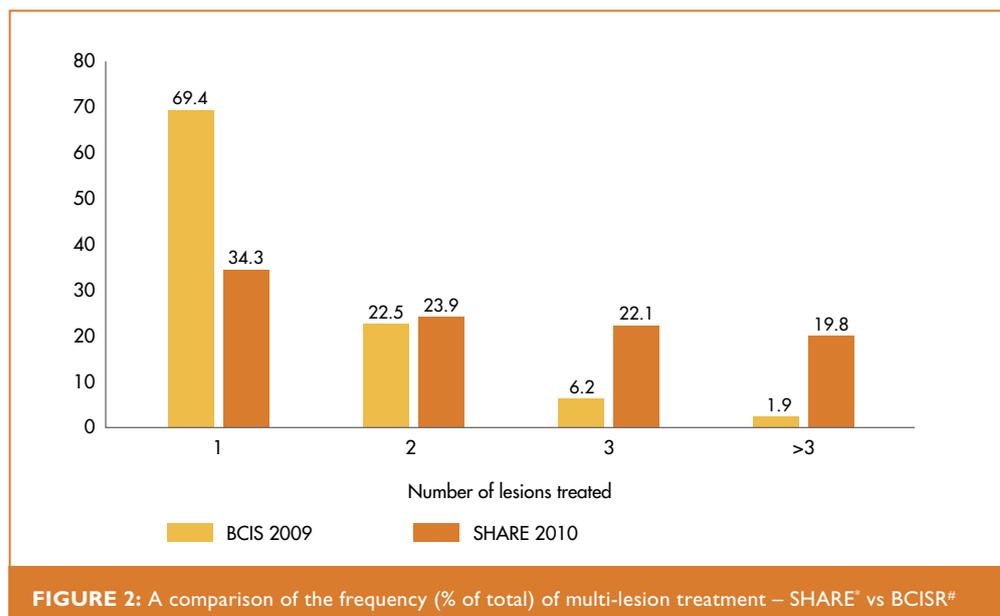


FIGURE 2: A comparison of the frequency (% of total) of multi-lesion treatment – SHARE* vs BCISR#
 Data from the SA Heart Congress, 2011, East London.
 *SHARE (South African Heart Association Registry). #BCISR (British Cardiovascular Intervention Society Registry).