Treatment of aortic aneurysms registered in Swedvasc

Development reflected in a national vascular registry with an almost 100% coverage

**Background**

The population-based Vascular Registry in Southern Sweden (VRISS) was started in 1987, covering a population of 1.7 million inhabitants and with a 1-year follow-up, the first vascular registry with that aim [32]. Over time more units agreed to participate, and in 1994 the registry covered the whole country with 8.8 million inhabitants (today 10 million), the name being changed to Swedvasc [4].

The data collected in the registry have been relatively stable over time, but one obvious change has been to include the rapid development within the field of endovascular treatment, where, when the registry started, the only option was percutaneous transluminal angioplasty (PTA).

Within the international Vascunet collaboration, founded in 1997 [5] there has been an initiative to perform validation of registries [3, 29]. In 2014 Swedvasc was analyzed and validated by Maarit Venermo, Finland, and Tim Lees, UK, their conclusion being a “highly accurate” registry, where AAA data in the registry had a 96.2% agreement with official hospital statistics [30].

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The aim of this review paper is twofold: to point out the factors which have contributed to the high coverage of the Swedvasc registry and to use registry data to illustrate the development of treatment of abdominal aortic aneurysms (AAA).

**The Swedvasc registry**

When the registry started the purposes were as follows:
1. To evaluate results in routine care
2. To create a platform for optimal healthcare planning
3. To create an instrument for evaluation of quality of care
4. To follow the development of new technologies
5. To create a basis for research
6. To create a platform for education

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During the life of the registry it would not come as a surprise that the compliance has varied and sometimes been less than optimal with underreporting depending on various factors, such as colleagues in opposition to register, presumed small impact on patient care, lack of time for clinically busy vascular surgeons etc. The underreporting can be on patients and when patients actually are reported, the underreporting may be on various variables, most often preoperative risk factors. So for instance, data on smoking are often missing; however, as the purpose of this communication is to contemplate on a high coverage, factors contributing to this can be summarized as follows:
1. Sweden is a small country with relatively few vascular surgeons (<200) knowing each other with stimulation to cooperate and also inducing some intercollegial pressure to participate.
2. Starting in a small scale and allowing centers to join spontaneously, when they realized that the registry was functioning: voluntarily and not mandatory.
3. A simple data form which had to be a compromise between “covering all” and what was accepted by colleagues to contribute and still detailed enough to be meaningful to be used in analyses.
4. Becoming an organization within the Swedish Society for Vascular Surgery, where all Swedish vascular surgeons are members.
5. Organizing regular meetings for the responsible surgeons with discussions both on the registry and on scientific problems as well as social contacts.
6. Economic support from SKL (Sveriges Kommuner och Landsting, Swedish Association of Local Authorities and Regions). The SKL has ranked Swedvasc to belong to the group of registries in the country with highest quality, among approximately 100 health care registries.
7. Since 2002 Swedvasc is part of Uppsala Clinical Research Centre (UCR) a research organization for registries, particularly involved in cardiovascular diseases and their treatment.
8. The use of Swedvasc for research purposes has been very fruitful and Swedvasc data have until now been used in 15 PhD theses. Research projects can be suggested by all vas-
Table 1  Surgical treatment for abdominal aortic aneurysms (AAA) in Sweden 1994–2016

|                | 1994–1999 | 2000–2005 | 2006–2011 | 2012–2016 |
|----------------|-----------|-----------|-----------|-----------|
| Intact AAA repair |           |           |           |           |
| EVAR, %         | 6.1       | 19.5      | 47.0      | 62.7      |
| Rate per 100,000 | 8.0       | 9.1       | 11.3      | 10.2      |
| Ruptured AAA repair |         |           |           |           |
| EVAR, %         | 0.8       | 4.9       | 18.6      | 37.3      |
| Rate per 100,000 | 3.7       | 3.9       | 3.4       | 2.4       |

Table 2  The 30-day mortality (%) after AAA repair in Sweden 1994–2016

|                | 1994–1999 | 2000–2005 | 2006–2011 | 2012–2016 |
|----------------|-----------|-----------|-----------|-----------|
| Intact AAA repair |           |           |           |           |
| Open repair     | 6.2       | 7.7       | 3.1       | 2.5       |
| EVAR            | 3.4       | 3.9       | 1.2       | 1.1       |
| Ruptured AAA repair |         |           |           |           |
| Open repair     | 45.6      | 47.3      | 30.4      | 28.1      |
| EVAR            | 68.8      | 31.1      | 20.6      | 21.2      |

The use of Swedvasc data can be exemplified by analyzing treatment of AAA in the whole of Sweden (from 1994 onwards). It must be emphasized that the information is based only on those patients receiving invasive treatment (open or endovascular surgery). The registry has no data on those dying from ruptures without undergoing treatment (most dying outside hospital) and no data on those with a known AAA, where invasive treatment has not been considered to be indicated.

An AAA repair was performed in >20,000 patients in the period 1994–2014 [17]. There was an increase in surgery for intact AAA, although there were indications of a stoppage in AAA repair in recent years [17]. There was a simultaneous decrease in repair for ruptured cases.

The 30-day mortality is shown in Table 2 and this has been significantly influenced to the better over the years (Swedvasc report).

The increased use of endovascular repair (EVAR) was obvious for both manifestations of AAA.

The increased use of endovascular repair (EVAR) was obvious for both manifestations of AAA (Table 1). During the period there has been an increase in the age of the patients treated for intact AAA from 71.2 years in 1994–1999 to 72.5 years in 2010–2014 (p < 0.001).

The 30-day mortality is shown in Table 2 and this has been significantly influenced to the better over the years (Swedvasc report).
The understanding of abdominal compartment syndrome (ACS) has increased over time and thereby how it influences the outcome. In 2008 ACS and decompression laparotomy were introduced as variables in Swedvasc. Thereafter 6612 operations have been analyzed, 20.3% for rupture and in total 52% operated on with EVAR [10]. After repair of ruptures 6.8% developed ACS after open surgery and 6.9% after EVAR. An additional 10.7% were treated with abdomen left open prophylactically after open repair of the aneurysm. After repair of intact AAAs the corresponding figures were 1.6% versus 0.5% (p < 0.001). Decompression laparotomy was performed in 77.3% after open repair for ruptured AAAs and in 84.6% after EVAR (NS). In patients treated for ruptured AAA with ACS the 30-day mortality was 42.4% versus 23.5% in those without ACS (p < 0.001) and after 1 year the corresponding figures were 50.7% versus 31.8% (p < 0.001). The fewer cases with ACS after repair of intact AAA had a significantly higher mortality both at 30 days and at 1 year compared with...
with high validity has been verified by external and with a very good compliance. The survival data of the population registry data and with linkage to the unlimited vascular registry with 1-year follow-up Swedvasc is the first population-based Discussion

those without ACS (11.5% vs. 1.8% and 27.5% vs. 6.3%, respectively [both \( p < 0.001 \)]. When ACS developed, renal failure, multiorgan failure and intestinal ischemia were more frequent than in those without ACS (\( p < 0.001 \)). These complications resulted in a significantly longer stay in intensive care units.

During the Swedvasc period, screening for AAA has been successfully introduced since 2006 and from 2015, 65-year-old males in the whole country are invited to attend an ultrasonographic investigation [28]. In this group of patients open repair is significantly more frequent than EVAR as compared to those with AAAs not detected by screening[18]. In patients treated with open repair there was no difference in 30-day, 90-day or 1-year mortality in AAA detected by screening compared to AAA not detected by screening in controls (1.0% vs. 3.2%, 2.1 vs. 4.5% and 4.1 vs. 5.8%, respectively, all not significant). None of the patients treated with EVAR in either group died within 30 days.

Discussion

Swedvasc is the first population-based vascular registry with 1-year follow-up data and with linkage to the unlimited survival data of the population registry and with a very good compliance. The high validity has been verified by external analysis [30]. As most treatment for AAA is performed in patients with concomitant arteriosclerotic disease, a follow-up of at least 1 year seems highly recommendable.

The registry was started by and is still maintained by the vascular surgical profession

Except for the reasons already discussed, one important factor for the almost 100% coverage is probably that the registry was started by and is still maintained by the vascular surgical profession and not being forced from above by authorities, who sometimes are far from the real clinical life. The dedication and idealistic work of all responsible colleagues is a great advantage, which is hereby acknowledged. The high compliance is of utmost importance for reliable data, as patients not reported to the registry tend to have a worse outcome [9]. To keep validity high, both internal and external regular validation should be undertaken with a continuous feedback to the participating centers and surgeons [15, 27].

Sometimes there is a vivid discussion between proponents for registries as opposed to randomized trials. It is our firm view that both types are needed. When interpreting data it is important to be aware that both strategies have their strengths and weaknesses, and the two research strategies are in fact complementary. The generalizability of results from randomized trials must always be surveyed when being used in the whole population at risk, and that is made in validated registries, reflecting the real-world situation.

One valuable step in recent years has been the cooperation with registries in other countries in the Vascunet network with the possibility of direct comparisons and where observations of differences can stimulate improvements in care and to design scientific projects [8, 19]. At present the network includes 12 registries from Europe, New Zealand and Australia.

Several changes have been observed over time within the registry both in treatment and outcome, and we have chosen AAA to exemplify the temporal development from 1994, a period when Swedvasc has covered the whole Swedish population. A finding, which is important to emphasize, is the decrease in postoperative mortality, another is the increasing use of EVAR. Similar trends have been reported in a German registry [25, 26] as well as in the Vascunet collaboration [6].

If and how the use of a registry influences the outcome is a question not easily answered. The situation is complex with several potential components, such as changes in patient selection, techni-
cal developments, better anesthesia and intensive care, more optimized risk factor management, especially the introduction of pathological and other treatment and there may even be factors that we presently are not aware of. Observations within the registry may lead also to changes, one example being the AAA treatment in the UK. In an early Vascunet comparison the postoperative mortality after elective AAA repair was significantly higher in the UK than in the other participating countries [22]. This lead to an in-depth analysis of the situation, the development of a Vascular Services Quality Improvement Program (VSQIP) and stimulated the formation of comprehensive vascular networks. One conclusion was too many operations in small units, and after correcting this situation by centralization the UK mortality does not differ from that in the other Vascunet countries [21]. Another observation within Swedvasc is the increasing number of treated patients, and this is seen in spite of the decreasing AAA prevalence in Sweden [16, 24]. The explanation can be at least two-fold, the introduction of screening, diagnosing more small and asymptomatic aneurysms, and the introduction of EVAR with more liberal indications, for instance treating more older and more patients with comorbidities, where open surgery was not an option before the endovascular era.

An important change over the years is the decrease in treatment for ruptures with the much higher risks than when treating electively. This can be explained by a combination of a falling prevalence of the disease, the introduction of screening, and on the increasing number of elective operations. If the development of AAA treatment will influence the total mortality in the disease is unknown and will be difficult to investigate with the extremely low autopsy rate we have today (<10%). Most patients with ruptures die outside hospital or in non-surgical wards [2, 14], and moreover the registry has no information on the turndown rate for surgery.

Conclusion

Many factors have contributed to the high coverage of the Swedvasc registry, and that has made it possible to study the development of treatment and outcome including complications, which in this article is exemplified with abdominal aortic aneurysms.

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Compliance with ethical guidelines

Conflict of interest. D. Bergqvist, K. Mani, T. Troeng and A. Wanhamien declare that they have no competing interests.

This article does not contain any studies with human participants or animals performed by any of the authors.

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Fachnachrichten

Bertelsmann Stiftung: Patienten wollen mehr Infos über Ärzte

Im Vergleich zu anderen Ländern erfahren Patienten in Deutschland bei der Suche nach einem Arzt relativ wenig über dessen Kompetenz und Hygiene in seiner Praxis. Das ließe sich ändern, sagt die Bertelsmann Stiftung.

Viele Patienten haben das Bedürfnis, vor dem ersten Besuch bei einem Arzt mehr Informationen zu bekommen. Dabei nehmen sie durchaus Qualitätsunterschiede zwischen den Praxen wahr. Das zeigt eine Befragung von TNS Emnid unter 1007 Bürgern im Auftrag der Bertelsmann Stiftung und der Weissen Liste, die ein Arztbewertungsportal betreibt. Demnach nehmen 38% der Befragten sehr starke oder eher starke Qualitätsunterschiede beim Besuch von Arztpraxen wahr. 53% wünschen sich vor dem Arztbesuch mehr Informationen, und immerhin 27% fürchten, aufgrund fehlender Informationen nicht den richtigen Arzt zu finden.

Vor einem Arztbesuch werden als wichtige Informationsquellen immer noch Verwandte, Bekannte und Freunde (75%) sowie der Arzt, „bei dem ich bereits in Behandlung bin“ (73%), als Erstes genannt. Mit 66% folgt dann bereits das Internet, hat die Umfrage weiter ergeben. Über Netz suchen Patienten gezielt nach einem Arzt in der Nähe (55%), auf der Homepage der Praxis (40%) oder gezielt in Arzt suchportalen (29%).

Neutralität ist den Patienten wichtig

Von den Arzt suchportalen wünschen sich die Patienten laut Umfrage, dass sie neutral und werbefrei sind (86% stimmen dieser Aussage sehr oder eher zu). Sie sollten zudem Patientenberatung regelmäßig erheben (70%), Daten zur Qualität von Arztpraxen enthalten (65%), und Ärzte verpflichten, Infos zu veröffentlichen (63%). Dabei richtet sich das Informationsbedürfnis vor allem auf die Fachkenntnisse und Erfahrungen des Arztes mit der Behandlung der eigenen Erkrankung. 94% der Umfrageteilnehmer ist genau das „sehr wichtig“ oder „eher wichtig“. Immer noch 90% sind Informationen über Maßnahmen zur Hygiene in der Praxi wichtig. 80% priorisieren auch Informationen über die Behandlungsergebnisse des Arztes bei bestimmten Erkrankungen, 74% wollen zudem Informationen über die Ausstattung der Praxis mit Geräten.

Wunsch und Wirklichkeit klaffen dabei auch im Bewusstsein der Patienten teils weit aus einander. So fühlen sich nur 52% der Befragten über Hygienemaßnahmen gut informiert und 58% über Behandlungsergebnisse. Etwas besser sieht es bei Informationen über Fachkenntnisse und Erfahrung des Arztes bei der eigenen Erkrankung aus: 74% fühlen sich in diesem Punkt gut informiert.

Datenschutz sei kein Hindernis

Der Datenschutz sei kein stichhaltiges Argument gegen mehr Offenheit zur Qualität und Erfahrung in Arztpraxen. Das habe ein Rechts gutachten im Auftrag der Stiftung ergeben. Die Privatsphäre der Patienten wäre keineswegs gefährdet, wenn Daten anonymisiert genutzt würden. Mit Blick auf die Ärzte müsse das Informationsinteresse der Öffentlichkeit jedoch gleichrangig mit deren Schutzbedürfnissen gewürdigt werden. Kommen zusätzliche Belange wie der Gesundheitsschutz und das Patientenwohl hinzu, könne die Offenlegung der Daten sogar geboten sein, heißt es.

Quelle: Ärzte Zeitung www.aerztezeitung.de