Tackling Loss to Follow-Up in Type B Aortic Dissection

Factors contributing to gaps in surveillance after aortic dissection, lessons and limitations from the EVAR experience, and strategies to improve long-term follow-up.

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CASE EXAMPLE

A man in his 50s presented with an acute type B aortic dissection (TBAD) with no malperfusion or rupture. He was admitted and his blood pressure (BP) was treated, but because his pain persisted despite good BP control, he underwent thoracic endovascular aortic repair (TEVAR). He was discharged a week later with three new medications to control his BP, pain-free and feeling fine. He returned for his 1-month CT but then missed his later follow-up visits because he felt fine and couldn't take another day off work. The next time we saw him was 3 years later in the emergency department, with chest pain and a large false lumen aneurysm perfused through retrograde flow (Figure 1).

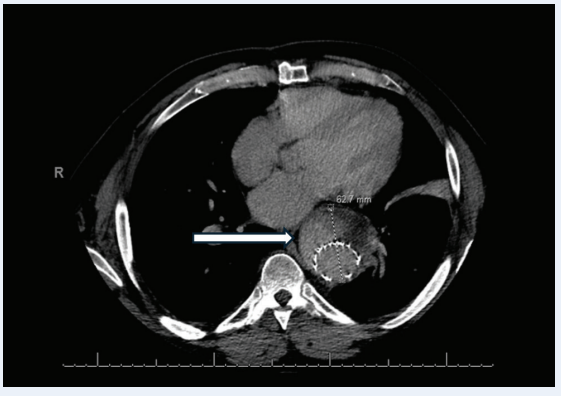


Figure 1. TBAD treated with a thoracic stent graft. The arrow indicates a large retrograde endoleak.

The sample case is not an unusual story. After aortic dissection (AD), dropping out of follow-up is closer to the rule than the exception. TBAD care has improved significantly over the past 20 years, with faster diagnosis, better imaging, and TEVAR for complicated and, increasingly, uncomplicated TBAD. However, long-term follow-up has lagged. We recently reviewed the socioeconomic, psychosocial, and system barriers behind loss to follow-up.[1] In this article, we take a more practical look at how common loss to follow-up is after TBAD, why these patients drop out, what we can borrow from the literature on endovascular aneurysm repair (EVAR), and what strategies may help (Sidebar).

HOW BIG IS THE PROBLEM?

In a recent study of 272 AD survivors, only 26.5% had surveillance imaging at 1 year and 27.6% had seen a cardiovascular specialist. Fewer than 1 in 10 (9.6%) completed the recommended scans at 1, 6, and 12 months.[2] In an earlier series, 51.5% were lost to follow-up, with 30% developing aneurysmal degeneration.[3]

When one urban academic center tried to reach 88 AD patients treated over a decade, it could contact only 60 patients to complete a phone survey. Of those, only 25 had seen their surgeon, and 34 had seen no one about their AD at all. Nearly half said they thought the problem had been fixed and they didn't need to come back.[4]

Getting lost to follow-up carries significant risk. Patients who did not keep up with guideline-recommended follow-up after AD had approximately twice the risk of aortic-related death.[5] Socioeconomic disadvantage adds to the problem. In our own experience, patients from poor neighborhoods had worse survival after AD.[6]

AD SURVEILLANCE: WHAT WE DO AND DON'T KNOW

What We Know

- Most dissection patients do not complete recommended surveillance, and only about 1 in 10 completes the first-year imaging schedule
- Believing they are cured is one of the most common reasons patients stop coming
- Anxiety, depression, and PTSD are common after dissection
- Organized programs with dedicated staff improve follow-up in aneurysm care

What We Don't Know

- Whether any specific intervention improves follow-up in dissection patients
- Whether better follow-up itself lowers aortic death or whether patients who stay in care are simply different from those who leave
- Whether risk-based imaging schedules, now used after EVAR, are safe in chronic dissection
- How to track patients reliably when they move or change health systems
- What navigator and NLP programs cost and whether they pay for themselves

LESSONS FROM EVAR AND WHERE DISSECTION IS DIFFERENT

Follow-up after EVAR has been studied much more thoroughly, and the pattern is alarming. Among nearly 9,700 Medicare patients, only 43% had complete surveillance, and Medicaid eligibility independently predicted incomplete follow-up.[7] A meta-analysis of more than 40,000 EVAR patients put average noncompliance at 42%.[8] Single-center rates range from 23% noncompliance to 41% of patients completely lost to follow-up.[9,10] The debate continues over how often EVAR patients need imaging because those who stayed in surveillance had more reinterventions but no better survival over the first 5 years.[8] That debate has pushed EVAR toward risk-based schedules, with less imaging for patients with unremarkable early CT results.

Patients with AD are different than patients with abdominal aortic aneurysms (AAAs); they are younger, less compliant with medical therapy, and have decades for a false lumen to grow and the damaged aorta to evolve. Even after TEVAR, the disease isn't excluded because the distal aorta often stays dissected, with a patent or partially thrombosed false lumen that can keep dilating. Additionally, the data we have for AD compared to AAA points the other way. In AD, missed follow-up is tied to higher mortality.[5]

WHY PATIENTS DROP OUT OF SURVEILLANCE

"I Feel Fine"

The most common barrier is patients' perception about their disease. They hear that the tear was treated and take it to mean they are cured. In a recent qualitative study of patients after EVAR, "no pain, no problems" and a quick return to normal life were among the main reasons people stopped coming back for monitoring.[11] Detailed explanations of endoleaks and aortic anatomy did little to change behavior. What stuck with the patients was plain talk about rupture, death, and complications that can grow without any symptoms.

The Psychological Aftermath

AD is a near-death experience, and the physical and psychological effects can persist after patients return home. In a review of 649 patients with AD, 49.3% had a mental health diagnosis, most often anxiety or depression.[12] Among 295 survivors of type A dissection, 23% screened positive for posttraumatic stress disorder (PTSD), and 44% said they had felt on guard or watchful in the past month.[13] For some patients, the CT scanner or the hospital where they nearly died is a trigger. Avoidance is a core feature of PTSD, and some missed appointments could be exactly that. In addition, ongoing substance use makes BP control and follow-up more difficult.

Costs, Distance, and Other Barriers

Surveillance costs patients more than we tend to think. Out-of-pocket spending on CT imaging rose 61% over 2 decades, even as the average cost of the scan decreased.[14] Parking, gas, a lost shift, and childcare also add cost. Distance is a consideration, but this doesn't only apply to rural patients. In a city like Detroit, 10 miles without a car can be harder than 100 miles with one. In a study of EVAR patients at a Sydney hospital, patients who dropped out lived closer to the hospital than those who stayed.[9] Language is another barrier. Non-English speakers were less likely to complete imaging after AD as well as after EVAR.[2,9]

The System Itself

AD care usually runs through several teams, and each hand off is a chance to lose the patient. A cardiac surgeon repairs the type A dissection, but the residual distal

dissection may not clearly "belong" to anyone. A patient with uncomplicated TBAD may leave on the medicine or cardiology service with no aortic surgeon involved. BP control depends on primary care, and imaging depends on radiology scheduling. If the patient has kidney disease, this opens another gap. With increasing renal insufficiency, repeated contrast CTA is hard to justify, and an MRI or a noncontrast study is not obtained: The scan simply doesn't happen.

WHAT WORKS

The evidence on solutions is thinner than the evidence on the problem, and most of it comes from AAA programs. Still, a few approaches stand out.

Establish Clear Responsibility for Follow-Up

The strongest signal in the literature favors organized programs with dedicated staff.[1] A regional multidisciplinary dissection program increased follow-up from 75% to 85% with standardized order sets and a defined clinic protocol.[15] Veterans Affairs, which combines one health system with travel vouchers, nurse phone calls, and reminders, reported 90% imaging adherence in the first year after EVAR.[16] What these programs share is a person whose job is to follow these patients and help coordinate care.

Use Data to Identity Gaps in Surveillance

Natural language processing (NLP) can read radiology reports and clinical notes to flag patients with aortic disease who are overdue for imaging. One center used an NLP-supported nurse navigator to track more than 3,000 aneurysm patients in accordance with Society for Vascular Surgery guidelines.[17] Dissection should be an easy target for the use of artificial intelligence as the diagnosis is usually stated clearly in the chart.

Communicate the Importance of Surveillance Before Discharge

The discharge conversation should focus on consequences, not anatomy. Something like: "Your aorta is still torn. It can grow without any pain. This scan is how we catch it before it bursts." Put it in writing, in the patient's language, with family in the room. Schedule the first CT and clinic visit before the patient leaves the hospital. If the follow-up appointment is missed, a member of the staff should be tasked with calling the patient to arrange for another appointment.

Screen for Distress

A short screen for anxiety, depression, and PTSD at the first clinic visit takes a few minutes. Patients who screen positive should be referred for care, and the aortic team should treat them as high risk for dropping out. Patients with psychiatric issues and diagnoses are less likely to be compliant and follow up. There should be an emphasis on diagnosis and treatment of these disorders.

Make It Easier to Show Up

Book imaging and the clinic visit on the same day. Use telehealth for BP and medication checks between scans. Have a plan for MRI or noncontrast imaging in patients with kidney disease. Bring in social work early for transportation and insurance problems. In the Ann Arbor EVAR series, patients who needed a social work consult were less likely to stay in follow-up, so that need is itself a useful red flag.[10]

Partner With Primary Care to Coordinate Ongoing Surveillance

Many patients would rather see their own doctor, who is closer to home and someone they already trust.[11] Send the primary care physician a clear surveillance schedule with BP and heart rate targets, and make it simple to order the next scan locally and send the images back to the aortic team.

CONCLUSION

Survival after acute AD has improved significantly, but many patients drift out of care once they go home. The chronic phase is when the false lumen grows and when reinterventions need to happen, and too many patients aren't in the system and are lost to follow-up before then. A reminder letter won't fix this. It takes an aortic program that owns the patient from day 1, gives a clear message about why follow-up matters, screens for distress, lowers the cost of showing up, and uses data to find the patients who have slipped away.

This matters for research too. Trials such as IMPROVE-AD, which randomizes patients with uncomplicated TBAD to TEVAR or medical therapy, depend on keeping patients in follow-up for years. The answers we need about AD will only be as good as our ability to keep patients coming back. ■

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