

Survey of Adult Patients with Vascular Anomalies Reveals Acute Need of Adult Hematologists to Enter the Field

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PURPOSE

The quality of life and prognosis of patients with vascular anomalies (VA) have improved significantly with advances in surgical and interventional techniques and medical therapies. Since most of the conditions present at birth or during childhood, pediatric specialists are coordinating the care for these patients, who have ongoing medical needs requiring multidisciplinary management. Most children's hospitals have established age cut-offs, after which patients can no longer be followed at pediatric institutions. While for surgical or endovascular interventions it may be easier, adult patients with VAs have great difficulties finding adequately trained physicians willing to take over their pharmacologic management.

METHODS

To ascertain the challenges adult VA patients face, we collected data from patients ≥ 18 years of age with vascular anomalies in collaboration with patient advocacy groups, who posted our anonymous survey on their websites and social media.

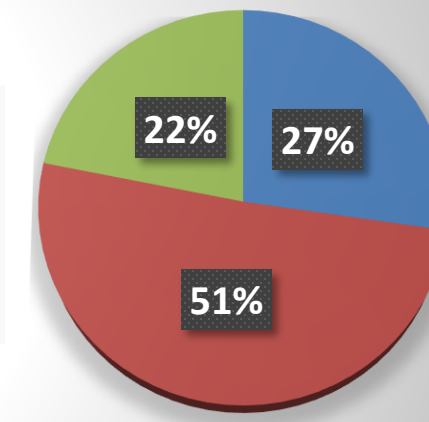
**Over a 6-month period (January – June 2019):
249 adult patients responded anonymously.**

CONCLUSIONS

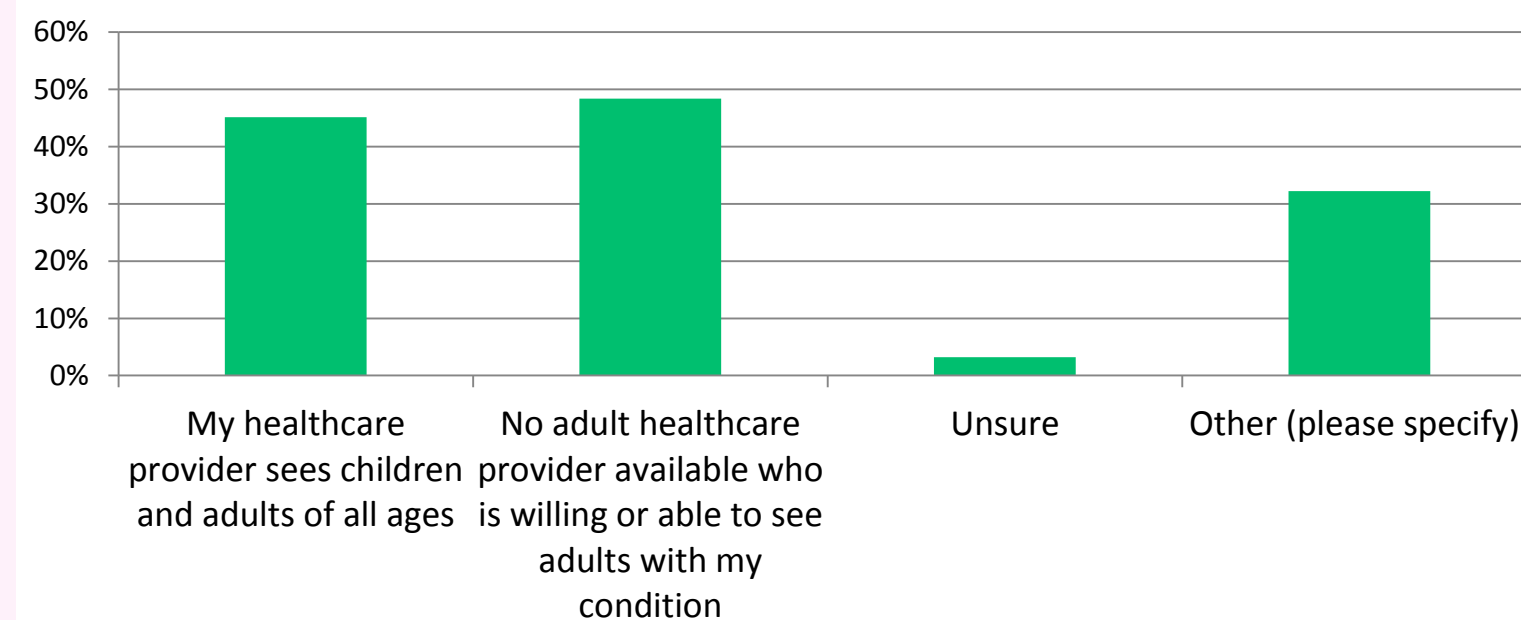
Adult-trained hematologists are essential for managing this cohort of patients who have hematologic complications and require medical therapies. Our data supports the need for a generation of specialists who can manage adult patients with complex vascular malformations. The results of the survey will be used to promote advocacy of vascular anomalies education.

Distribution of answers by diagnosis

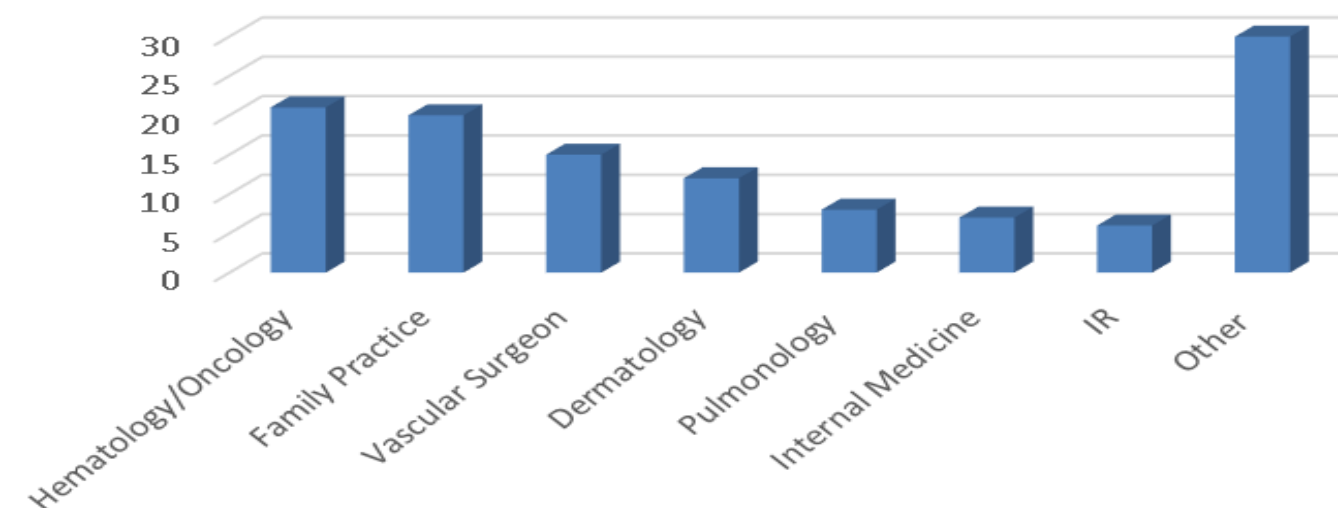
- Complex Lymphatic Anomalies (GLA, GSD, CCLA, KLA)
- Klippel-Trenaunay Syndrome
- Other



Why are you still being treated by a PEDIATRIC specialist for your VA?



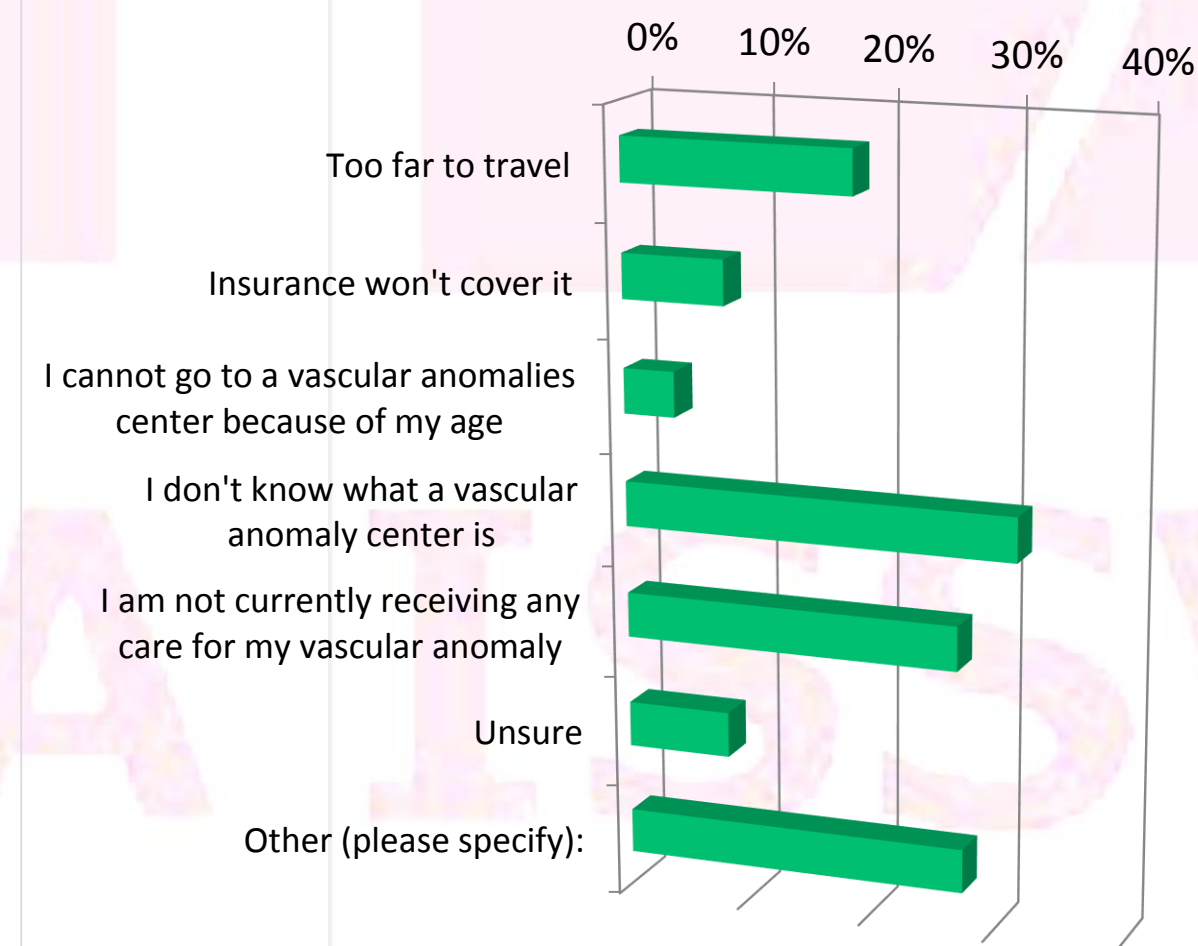
What specialty is your coordinating doctor that writes prescriptions, orders labs, etc?



RESULTS:

- from the participants receiving care from a pediatric provider, 97% have NO PLAN for when their pediatric specialist can no longer provide care for their vascular anomaly
- 34% patients have given up trying to find a physician willing to provide care
- 45% patients have no consistent care provider for the vascular anomaly
- 60% are seeing providers who have no special interest or training in VAs.
- 35% patients were evaluated in the emergency room due to VA complications at least once over the last 1 year (8% more than 3 times)
- 28% patients have been admitted to the hospital at least once in the last 1 year due to the vascular anomaly (3% more than 3 times)
- 83% patients never had a discussion about vascular anomaly management during adulthood

If you do not CURRENTLY receive care at a vascular anomalies center, why not?



How far do you travel to see your doctor?

