Reflections on the Treatment Decisions and Patient Journey in a Case of May-Thurner Syndrome and Lymphoedema: Case Study.

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Lymphoedema is generally accepted as a possible side effect of cancer treatments, venous disease, trauma and injury and it is a long term condition. (Lymphoedema Support Network, “Skin Care” 2014). Despite ongoing advances in the diagnosis and management of lymphoedema, it is sometimes difficult to ascertain the true cause when there is a co-existing rare, venous disorder, such as May-Thurner Syndrome.

May-Thurner Syndrome (MTS) also known as iliolumbar compression syndrome (IVCS) occurs when there is compression of the left iliac vein by the overlying right iliac artery, due to an anatomical variant (Kibbe et al 2004, Hayer et al 2012). The symptoms include left leg swelling and pain and it occurs more frequently in women.

This case report aims to:

- Raise awareness of May-Thurner Syndrome as a differential diagnosis in leg pain and swelling.
- Report the patient journey from diagnosis to ongoing treatments of May-Thurner and lymphoedema.
- Reflect on the benefits and burdens to the patient in the role of main co-ordinator of her care.

Background

A 33 year old lady developed left leg swelling and pain in the third trimester of pregnancy. Deep vein thrombosis (DVT) was excluded. Following the birth of the baby, further investigations led to a diagnosis of May-Thurner Syndrome (MTS). Within a few months, iliac vein stenting was performed but there was no significant improvement in the leg swelling, although the pain did improve. Once again no DVT was identified. The patient also attended the Specialist Lymphoedema Clinic prior to stenting to assist with the management of the leg swelling. This was thought to be secondary to the venous disease. However, despite strict adherence to the advised treatments for managing the lymphoedema, the swelling remained more than 20% larger than the unaffected right leg.

Further explorations of available treatment for MTS by the patient, led to further stenting of the left iliac vein. Within a few weeks there was improvement in the circulatory symptoms and a slow steady reduction in the leg swelling. The left leg is now only 15% larger than the right one. The patient’s commitment to wearing compression stockings, caring for the skin and exercising which ensures the swelling is maintained. In between each course of lymphoedema treatment at the out-patient clinic.

Acknowledgement:
Thank you to the patient for sharing her experience, and staff at Strathcarron Hospice.

References:

Before and after treatment pictures

The patient has been the main co-ordinator of her care throughout the last 3 years. Her determination to seek an accurate cause for the venous problem and then the resultant leg oedema has involved the NHS and private sector including several different disciplines. To date, she has MTS and lymphoedema, but despite lymphangiography it is not clear if there was a problem in the left leg lymphatics prior to development of MTS.

Below outlines the lymphoedema treatments the patient has received in the last 2 years including self-management:
- Decongestive lymphoedema treatment on alternate days for 2 weeks, every 2/3 months.
- Class 4 compression garments including one-legged tights & Farrow wrap.
- Continuous exercise - walking, swimming, horse-riding.
- Motzchus skin care – no infections.
- Manual Lymphatic Drainage (MLD)privately, in between treatments at clinic.
- Pneumatic compression pump – home use.
- Hiramat – home use.

Discussion

Lymphoedema and MTS are long term conditions, although the latter is resolved currently due to the placement of stents. This patient demonstrates tenacity and her experience highlights the frustration in obtaining an accurate diagnosis and then appropriate management. The extra burden of exploring treatment options could have been too much for someone coming to terms with having a long term condition, having a new baby and coping with changes to family life and work. Instead it has led to her becoming proficient in managing her condition and this is the first case of MTS seen in our service and it has raised awareness of this as differential diagnosis in leg pain and swelling. It is more commonly seen in women and the incidence is likely under reported (Moussa & AbuRahma 2013).

Recommendations

Improved access to diagnostics such as intra vascular ultrasound may lead to more prompt diagnosis and then treatment of MTS. Encouraging more collaboration between services to ensure inter-disciplinary approach and management to improve patient outcomes and equity.