Penile Cancer Patient Journey

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Risk factors can be misinterpreted to implicate an individual's lifestyle thus creating a stigma attached to penile cancer

Self-image; perceived loss of masculinity; sexuality

Psychological trauma associated with radical treatment and adjustment thereafter

1. First Symptom

Any abnormal rash or lesion most commonly found on the penis. Early symptoms of penile cancer can be similar to non-cancerous conditions such as STIs, candida or common skin conditions.

2. Diagnosis

Usually following biopsy or circumcision performed by a urologist.

Note: Due to its rarity, early penile cancer can often be mistaken for a non-cancerous condition. Many HCPs and GPs will never have seen penile cancer.

The average length of delay before seeking medical attention may be 3 months.

If penile cancer is misdiagnosed or referred inappropriately then this delay can be much greater and therefore more invasive treatment may be needed.

3. Treatment

All curative treatment will involve some form of surgery to the penis itself. Minimally invasive diagnostic investigations, including sentinel lymph, node biopsy may be requested.

Note: Patients diagnosed will be referred to a regional supra-network or specialist centre where dedicated urological teams will perform organ-sparing surgery where possible.

Ideally: Patients receive the contact details and support of a specialist nurse who can act as a keyworker as part of the Multi-Disciplinary Team, as well as provide additional information on long-term effects/care and other means of support.

4. Surgery

This can be minimal but may be extensive. It will inevitably result in altered body image and have an impact on masculinity. Radical or partial inguinal/ abdominal lymphadenectomy may also be required. In some instances, reconstruction of the penis may be possible. However, this will depend on the extent of the disease.

Note: Patients may undergo glansectomy and refashioning of their penis using grafts.
More invasive forms of surgery such as partial or complete amputation may be performed for more advanced disease. All will involve a change in self-confidence and body image.

Patients who have had lymphadenectomy may also develop lymphoedema which will need to be managed on a long-term basis.

Penile reconstruction will involve several major operations over the course of the year. Counselling to cope with the initial results of the individual surgeries, and the support of the health care team is essential.

5. Chemo/Radiotherapy

Metastatic penile cancer may be treated with chemo or radiotherapy notably to lymph nodes. Common side effects: nausea, hair loss and reduced immunity. Lymphoedema may also manifest following radiotherapy.

Note: Metastatic penile cancer has a low response rate to chemo/ radiotherapy and patients are likely to have had more invasive surgery prior to this treatment being initiated.

The combined impact of these treatments can severely reduce the quality of life for patients in this situation.

6. Quality of Life

Patients with localised disease managed by glansectomy will usually experience a return to normal urinary and sexual function. Patients who've had invasive surgery will need to adapt to new urinary habits and may not be physically or psychologically able to have normal sexual intercourse.

Note: Patients who have undergone glansectomy/ partial amputation may need to use urinary funnels to direct urinary flow. Men who have had total amputation will have a perineal urethrostomy and will only be able to urinate by sitting down.

Ideally: Patients who have received treatment for penile cancer should be offered counselling, particularly psycho-sexual counselling. Peer support should be encouraged, although this is limited due to the rarity of penile cancer.