Stigma: The invisible side of bladder cancer

To understand the impact of stigma on people affected by bladder cancer, 312 patients or caregivers of which 69 from the United Kingdom have shared their experiences in a survey and qualitative interviews.

Bladder cancer patients are primarily worried about disease disadvantage, followed by self stigma and external stigma.

1. What is disease disadvantage?

Delayed or misdiagnosis

The diagnosis failures are Systemic Disadvantage

The system seems to be set up to let people down, with multiple delays, misdiagnosis and refusal to take symptoms seriously.

“Keep going to your GP. You have to shout loud.”

Lack of bladder cancer knowledge

A natural reluctance to talk about private bodily functions in public. Bladders, urination, incontinence, sex organs are all intensely private.

Men and older patients in particular, want to keep this to themselves – it’s not common to talk about such private things.

The choice to hide

Some patients want to regain ownership of their lives and their bodies. They have a desire to portray normality to the world – to protect yourself and also save yourself from the awkwardness of others.

“Why do you have to collapse in the ER before people take you seriously?”

Hamster wheel of treatments

Life is effectively on hold as seemingly endless rounds of treatment, scans and retreatments become a reality. It is often impossible to commit to any plans or live a normal due to repeated, painful and uncomfortable hospital trips.

Scanxiety

A big part of the trauma of this rollercoaster is the inevitable fear of recurrence – as the time for another scan comes round, patients are fearful and anxious – it’s another attack on their mental health, already vulnerable through self stigma.

“Scanxiety, you know what’s coming, you get a bit more snappy, more anxious as the date gets closer.”

Making a difference for patients in the UK

56% of patients want a change in support and advice for carers

46% of patients want a change in the type of information

60% of patients want a change in emotional/psychological support

43% of international patients say their mental state has negatively impacted the relationship with their partner.

57% of international patients felt the opportunity to talk to other bladder cancer patients was important.
2. Experience of internal stigma

A fear of being judged

Self-stigma is a significant issue for patients as they often anticipate and believe that others will judge them.

Patients in the UK resonated with the following statements:

- **16%** I don’t think many people even know what bladder cancer is
- **16%** I sometimes blame myself for my illness
- **14%** Society treats people with bladder cancer worse than people with other cancers
- **20%** Sometimes I feel ashamed
- **18%** I feel judged sometimes

Experience of stigma and disease disadvantage have less impact on older patients across the surveyed countries:

- **Aged 18-39**: 75%
- **Aged 40-59**: 71%
- **Aged 60+**: 44%

Of the patients reported that bladder cancer had a severe or moderate impact on their lives.

3. Experience of external stigma

- **45%** of young patients felt blame from their family
- **43%** of young patients felt blamed by the doctor
- **31%** of patients feel that they have embarrassed their family, friends or colleagues by their illness

Making a difference for caregivers

Improving the lives of caregivers from the surveyed countries:

- Advice on how to help them manage their pain: 44%, 44% Agree, 88%
- Tips on how to talk to the doctors and nurses and what questions to ask: 55%, 31% Agree, 86%
- Training and advice in how to look after a cancer patient in general: 33%, 52% Agree, 85%
- Advice on how to keep them feeling positive and avoiding depression: 40%, 45% Agree, 85%
- More time to look after my partner / child / parent / friend / relative: 40%, 43% Agree, 83%

23% of caregivers have been diagnosed with depression or anxiety.