From Pelvic Radiation to Social Isolation

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Introduction:

Pelvic radiation can cause chronic bowel symptoms including urgency, frequency, bleeding and incontinence. Symptoms can arise months or years after radiotherapy, persist long-term and decrease quality of life (Andreyev et al 2011). This qualitative study explored the impact of bowel symptoms on the lives of cancer survivors following pelvic radiation.

Methods:

• Semi-structured interviews with 28 survivors of prostate and gynaecological cancers, experiencing chronic bowel symptoms, recruited through UK cancer charities and hospitals (50% female; age range 34-82 years.).

Analysis:

Reflexive thematic analysis led to 4 themes describing a process (Fig 1):

- 1. Losing Control of bowels.
- 2. Embarrassment and Fear of losing control in public.
- 3. Managing and Reacting to prevent or contain leakage.
- 4. Restriction of place/time/activity and Withdrawal from social situations.

We applied these themes to experiences in the workplace (Fig 2).

Figure 1: Four themes describing a process leading to social isolation



- I've got no control over it, it just happens and it's within, literally I get this feeling I need to go to the toilet, and I've got to go, I really have to go. And it's not just minutes, it can be literally seconds. (124, male)
- I'd just like to be a little bit more in control of my bowel, rather than my bowel being in control of me. (110, female)



- I'm terrified of going to events with people and ending up with my bowel evacuating. I'm terrified of that, I'm
- The fear is always there that there will be an embarrassing situation. (115, male)

Reacting &

Managing

- If I'm going to be somewhere...I'll take an Imodium before I go, even if I haven't had an upset stomach...it's just planning ahead, because it's not nice...having that extra worry. (108, female)
- ...everywhere I go ... I think ... where's the toilet, where can I go, what can I do, where have I got to go, how can I get back to the car? And that's what I do. And that's really my life now. (124, male)

- ... it's changed my life in respect of what I used to be like. I have no inclination to really go anywhere. That's the way it's affected me. (126, male)
- I'm virtually a recluse, and I don't want to be like that. (124, male)

Withdrawal

Restriction &

Figure 2: Applying the themes to describe experiences in the workplace

Loss of control can be an ever-present possibility in the workplace

• ...it was that fear of going into work ...will I poop myself today?... will I need to spend hours on the toilet? (104, female)

Toilets may be accessible but their use may cause embarrassment

• If I go to the toilet...I am worried that I have to walk all the way through the office. I've called it the walk of shame... if I had a problem everyone would know. (109, female)

Bowel symptoms can be embarrassing to discuss with managers

• We have met up a few times before I went back to work...I said oh I've got some bowel issues and I rolled my eyes...I didn't say any more than that...it's quite a hard thing to talk to your boss about. (113, female)

Inflexible timing of work makes symptoms harder to manage

• The phone's constantly, constantly going, you end one call you start another. So, to go to the loo you have to kind of log out...I feel I always have to explain I may be longer... (110, female)

Withdrawal has psychological and financial consequences

• ...to suddenly not be working and you're just sat at home thinking what, what do I do? What am I going to do? You've got money issues then as well... (104, female).

Conclusions:

- Chronic bowel symptoms have a major impact on survivors' lives. Symptoms can prevent a return to pre-treatment roles and bring psychological and financial consequences.
- Symptoms can lead to restrictions and social withdrawal.
- The complex needs of survivors in the workplace may not be sufficiently recognised.

References:

Andreyev HJ, Wotherspoon A, Denham JW, Hauer-Jensen M. "Pelvic radiation disease": new understanding and new solutions for a new disease in the era of cancer survivorship. Scand J Gastroenterol. 20101229th ed. 2011;46(4):389–97.

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