

THE EXPERIENCE OF LIVING WITH HIV AND ANAL CANCER: AN EXPLORATORY STUDY

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BACKGROUND

- The incidence of anal cancer in people living with HIV is up to 40 times higher compared with the general population [1] and it occurs at a much younger age [2-3].
- Incidence has risen with the widespread use of HAART [4-5]. This may relate to the longer survival of people living with HIV
- Prognosis is good, but chemoradiotherapy causes long-term toxicities to skin, bowel, bladder & sexual function all of which have a significant psycho-social impact.
- This combines with other intersecting challenges such as HIVrelated stigma & being part of the LGBTQ+ community.

This work explored the experiences of patients treated at our London centre to identify their specific challenges and inform future research to improve their care.

AIM

To understand experiences and identify specific challenges of people living with HIV & treated with chemoradiotherapy for anal cancer

METHODS

- Exploratory qualitative study consisting of a focus group and individual interviews
- Approval granted for a service evaluation by the Royal Marsden and Institute for Cancer Research Committee for Clinical Research
- Eligible patients: living with HIV, diagnosed with anal cancer, completed pelvic chemoradiotherapy and currently in follow-up at our centre
- Focus group had a researcher and a patient representative facilitator. Discussion & interviews digitally recorded & transcribed
- Data were analysed using a thematic analysis approach [6], aided by reflexive notes [7] & with patient representative input.

RESULTS

- A total of 8 men participated in this study.
- The participants had a median age of 60 years (range 50-68)
- One focus group and 4 individual interviews were conducted
- Participant demographics and timing of HIV & anal cancer diagnosis presented in Table 1

Adopting own

coping

strategies

Isolation &

impact on

sexual

relationships

"My diagnosis was in 1989.....initially at that point they

were telling me I was going to die of AIDS.....I think you

end up having a very weird relationship with death"

"the fatigue meant there was much

less that I could do, but I made a

"For me I made hash cakes. I had

some morning noon and night at my

"because I had a couple of little

making it. So after that it put me

incidents of not going and

walking home and not quite

off going anywhere basically"

"Emotionally as a gay man -

It's our part – so all of that

had to stop in a way...that

"a perfectly normal bodily function is going to

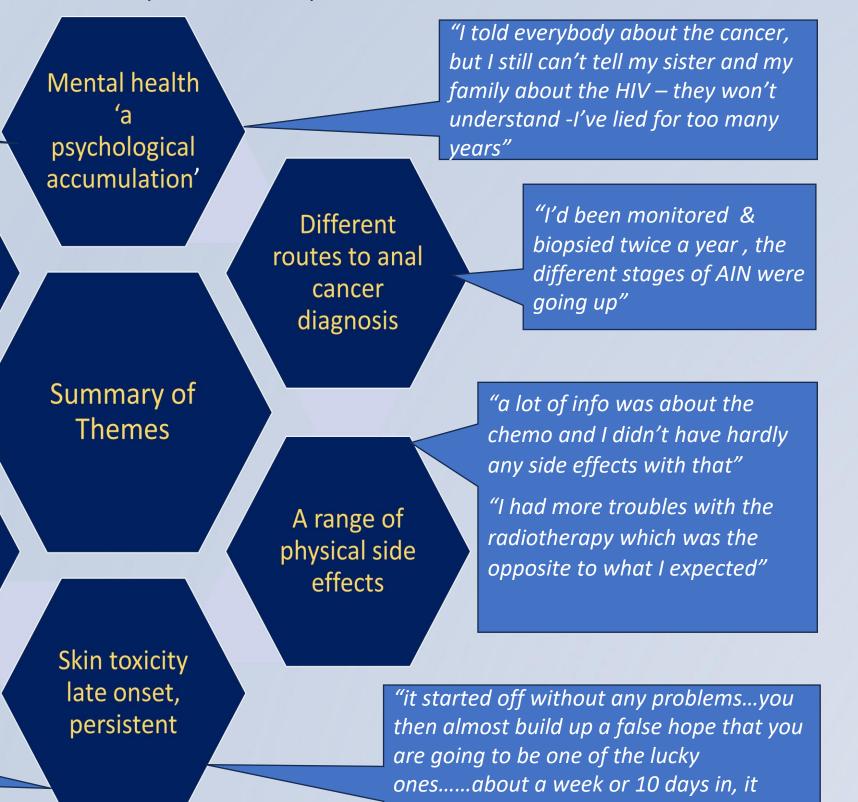
Figure 1 Summary of main themes developed

make you want to scream or die"

point of carrying on"

worst times"

- Six main themes were developed from the data, they are summarised with corresponding participant quotations in Figure 1
- Long term survival with HIV led to existing mental health challenges for some: a 'psychological accumulation'
- A range of physical side effects, skin toxicity had biggest impact
- Anal cancer treatment could exacerbate social isolation & impact on sexual relationships
- People adopted their own coping strategies & resilience from previous life experiences



really started hitting"

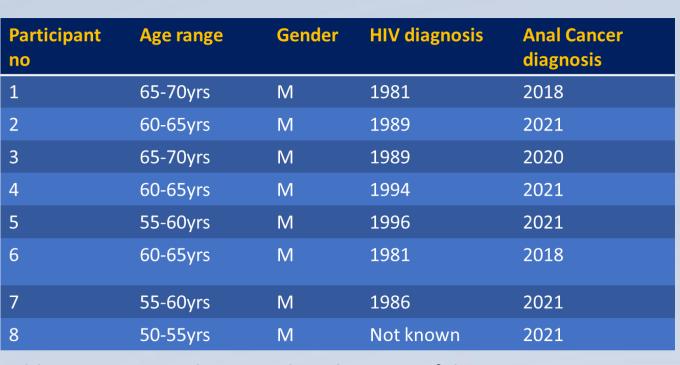


Table 1 Participant demographics & timing of diagnoses

CONCLUSIONS

- This single centre study provided rich and in-depth qualitative data about experiences & challenges of an under-served population
- It forms an important basis for future research, informing the identification of future interventions
- It led to the establishment of a first of its kind support group hosted by Maggie's Centre, West London
- This work will be taken forward in an NIHR funded research project starting later in 2024



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door is closed"

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