Understanding the recovery process and return to daily activity in women treated for cervical cancer.

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WHY?

Improvements in treatment outcomes have resulted in an increase in the number of cervical cancer survivors (CCS; 60%; 1)

Understanding the psychological and physical recovery after CC is essential to appreciate the long term needs of survivors (2). The majority of survivorship research has been conducted in breast cancer survivors (3,4).

However, the CC survivorship experience may be unique due to the younger demographic compared to other gynaecological cancers. Additionally, guilt, stigma and self blame may impact recovery due to missed smear tests and CC being caused by a sexually transmitted disease (HPV)

AIM= To understand the recovery experience after treatment for cervical cancer in the short and long term among those treated with surgery and chemoradiotherapy

HOW?

Purposeful recruitment of CCS aged 18-60 years old via social media and posters

Telephone and face to face interviews with 21 CCS who were between 1 month and 10 years post treatment using a semi-structured interview guide which posed questions about participants' reflections on treatment (5); experience of recovery in short and long term. Interviews were digitally recorded using a dictaphone.

Data was transcribed into verbatim and analysed inductively using thematic analysis (Clarke & Braun (6)). Data was coded by 2 researchers separately to ensure trustworthiness. Codes were then complied into themes within a thematic tree.

FINDINGS

1. TREATMENT AS A PARADOX

Treatment was perceived as an all consuming experience, described as ***"pure poison"***, resulting in symptoms such as fatigue, severe sickness and hair loss which challenge the idea that treatment is a cure.

Family played a supportive role during treatment. Conversely, women spoke about the perceived burden that they were placing on family members: "***I wasn't properly processing and dealing with it because people around me were really upset and I remember feeling guilty and really worried about them"***

Participants referred to negative physical, psychological and social impacts of treatment in the long term. Sexual issues were common, e.g. ***I'm frightened of it being painful'.*** Neuropathy, lymphoedema and bladder and bowel issues were also frequently experienced physical issues after treatment.

2. EMOTIONAL FLUCTUATIONS

Participants often noticed a change in how others treated them after treatment **"People lose the ability to treat you like who you are and that's the hardest thing. You almost lose your identity and you become someone with cancer".**

Identity as a mother was challenged as a result of not being able to achieve pregnancy (hysterectomy) or vaginal delivery (trachelectomy), which interfered with future plans and how women viewed themselves after treatment.

The psychological repercussions of CC were significant regardless of treatment modality. Anxieties regarding reoccurrence, self-blame and guilt stemming from missed smear tests ***"There was a lot of guilt, because if I had that smear test I wouldn't have needed these treatments"*** or from societal misconceptions about HPV: ***HPV is an STI and everyone I met who had gone through cervical cancer grappled with the idea that it was their fault because there is stigma attached to this"*** were prominent issues.

3. A NEW NORMAL

Returning to work was a common way that women managed to regain a sense of familiarity, whilst childcare and motherhood were significant considerations when resuming normal activities for most participants, ***"I didn't have a choice after the first couple of weeks. People couldn't keep helping with the kids, I just had to get on with doing sort of jobs like hoovering"***

A number of women reflected on the experience as a period of learning and adversarial growth. ***"There was a whole grieving process which at the time hit me like a tonne of bricks, but it was a very empowering kind of thing to go through and I've used it for many things since"***

Helping others through raising awareness of the importance of smear testing was a way that women used their experience positively. Accepting one's own physical limitations was an important step in moving forward.

DISCUSSION AND LIMITATIONS

In line with previous research, physical changes were perceived to be more disruptive amongst those who received more radical treatments (7). However, psychological repercussions tended to be significant irrespective of the treatment modality.

Emotional distress was common. Triggers for this among early stage CCS were unrealistic expectations of recovery which was reinforced by a lack of peer support (5). Anxiety about recurrence was a source of worry amongst all CCSs, a common finding after gynae cancer (8)

Most participants in the long term described a journey of post traumatic growth, whereby their experience had made them mentally stronger, more rational and health-conscious individuals. This is a common narrative found in cancer survivorship literature (9)

The study population was White British. Therefore, results can only be applied to this portion of CCS. As high rates of CC have been identified in other ethnic groups (e.g. Eastern European; 10), future research should explore the recovery experience in other ethnicities.

Whilst the study benefitted from understanding the experience of CCS at varying time points since their treatment, this relies on the memory of those who are between 5-10 years post which may introduce inaccuracies in recall.

References

1. UK CR. Cervical cancer statistics and outlook [Internet]. 2017. Available from: http://www.cancerresearchuk.org/about-cancer/type/cervical-cancer/treatment/cervical-cancer-statistics-and-outlook
2. Elmir R, Jackson D, Beale B, Schmied V. Against all odds: Australian women's experiences of recovery from breast cancer. J Clin Nurs. 2010;
3. Kaiser K. The meaning of the survivor identity for women with breast cancer. Soc Sci Med. 2008;
4. Dirksen RN, Ruff S. Predicting well-being among breast cancer survivors. 2000;32:937–43.
5. Lloyd P, Briggs E, Kane N, Jeyarajah A., Shepherd J. Women's experiences after a radical vaginal trachelectomy for early stage cervical cancer. Int J Gynecol Cancer. 2012;18:362–71.
6. Clarke V, Braun V. Thematic analysis. J Posit Psychol. Routledge; 2017;12:297–8. Available from: http://dx.doi.org/10.1080/17439760.2016.1262613
7. Krikeli M, Ekonomopoulou MT, Tzitzikas I, Goutzioulis A, Mystakidou K, Pistevou-Gombaki K. Comparison of the impact of radiotherapy and radiochemotherapy on the quality of life of 1-year survivors with cervical cancer. Cancer Manag Res. 2011;3:247–51.
8. Sekse RJT, Raaheim M, Blaaka G, Gjengedal E. Life beyond cancer: Women's experiences 5-years after treatment for gynaecological cancer. Scand J Caring Sci. 2010
9. Clemmens DA, Knafl K, Lev EL, McCorkle R. Cervical cancer: Patterns of long-term survival. Oncol Nurs Forum. 2008;
10. Altobelli E, Lattanzi A. Cervical carcinoma in the European Union: An update on disease burden, screening program state of activation, and coverage as of March 2014. Int. J. Gynecol. Cancer. 2015.