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A qualitative exploration of physical and psychosocial well-being in the short and long term after treatments for cervical cancer

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Millet, Nessa, Esther L. Moss, Fehmidah Munir, Eva Rogers, and Hilary McDermott. 2022. "A Qualitative Exploration of Physical and Psychosocial Well-being in the Short and Long Term After Treatments for Cervical Cancer". Loughborough University. https://hdl.handle.net/2134/19722211.v1.

TITLE: A qualitative exploration of physical and psychosocial well-being in the short and long-term after treatments for cervical cancer. **ABSTRACT** Objective: Cervical cancer is predominantly a cancer of younger women and improvements in oncological outcomes have led to an increase in cervical cancer survivors living with the long-term effects of treatment. Understanding the recovery process after treatment is essential to increase awareness of the short and long-term needs of survivors. The aim of this study was to qualitatively explore the recovery process and return to daily activity of cervical cancers survivors from a biopsychosocial perspective. Methods: Participants were twenty-one women treated for cervical cancer between the ages of 18 and 60 years, living in the UK. Interviews were undertaken face to face and via the telephone using a semi-structured interview schedule. Results: Data analysis revealed themes which represented participants' experience and perceptions of treatment as a paradox; emotional needs after treatment; and a journey of adversarial growth. A key finding from this analysis were the nuanced experiences between treatment modalities, with physical changes perceived to be more disruptive following radical treatments, whilst psychological repercussions were significant regardless of treatment type. Conclusion: This study provides novel insight into the varied recovery experiences of those treated with surgery and/or chemoradiotherapy for cervical cancer, which can be used to improve the survivorship experience. Keywords: survivorship, Cervical cancer, Recovery, Quality of life **Word count**= **4**,237

Recovery after Treatment of Cervical Cancer European Journal for Cancer Care

Introduction

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Improvements in oncological outcomes and routine screening have resulted in increased cervical cancer 2 survivorship (Landy, Pesola, Castañón, & Sasieni, 2016; Pesola & Sasieni, 2019). The 5 year net 3 survival for England and Wales has increased from 51.5% in 1971-1972 to 67.4% in 2010-2011(Cancer 4 Research UK, 2021b) and therefore more women are living with the impacts of treatment. 5 6 Understanding the recovery process and the experience of cancer survivors is essential to increase awareness of survivors' needs. Several recovery frameworks have been put forward (e.g., Harvey, 7 8 2009), which are mainly informed by breast cancer survivorship research (Kaiser, 2008). In 9 gynaecological cancer, the survivorship experience is understudied, and is likely to vary considerably between cervical, uterine, ovarian and vulval cancer due to significant differences in patient 10 characteristics (e.g., age) and treatments. There has been a tendency to approach cervical cancer 11 12 recovery from a medical and acute symptom management model (Wu et al., 2021). Yet, how these 13 issues and symptoms are experienced, processed, and how women make sense of their recovery journey, 14 has not been fully explored, particularly among those who receive cervical excision for early-stage 15 disease. Understanding the recovery process of cervical cancer survivors is of particular importance as such an 16 17 experience may not fit the recovery frameworks developed from other cancers. Most cervical cancers are associated with the human papillomavirus (HPV), an infection that can be transmitted through 18 19 sexual contact. In the UK, cervical cancer is perceived by women and men to be associated with sexual 20 activity rather than HPV, leading to the development of stigma surrounding cervical cancer (Waller, McCaffery, & Wardle, 2004). Previous research has demonstrated that British women, particularly 21 22 those from ethnically diverse backgrounds perceive that attending cervical cancer screening could imply 23 sexual promiscuity (Ekechi et al., 2014; Patel, Moss, & Sherman, 2018; Patel, Sherman, Tincello, & Moss, 2019). The existence of screening and vaccination further develops the idea that cervical cancer 24 is a controllable and preventable disease. In turn, diseases and cancers deemed to be associated with 25 26 lifestyle tend to receive less sympathy from others and are associated with self- blame on the part of the 27 patient (Else-Quest, LoConte, Schiller, & Hyde, 2009; Shepherd & Gerend, 2014). Investigations have found that young women who receive an abnormal smear test, fear blame and exclusion from others 28 29 (Kahn et al., 2007). Thus, preconceptions which exist surrounding cervical cancer may add complexity 30 to the survivorship experience, particularly when considering that the highest incidence in the UK is 31 the 30-34 year age group (Cancer Research UK, 2021a) and that treatment effects can include loss of fertility and/or early menopause (Moss et al., 2016). 32 The biopsychosocial model suggests a dynamic relationship between interpersonal, biological, 33 psychological systems and contextual factors to shape health over the life span (Lehman, David, & 34 Gruber, 2017). The model has been previously used in cancer recovery (Jacobson, 2018) and is well 35 36 placed to explain the multi-dimensional experiences of cervical cancer survivors. An appreciation of

Recovery after Treatment of Cervical Cancer European Journal for Cancer Care how physical and psychosocial factors contribute to the recovery experience is needed to gain a holistic understanding of survivors' quality of life (QOL). For example, a reciprocal relationship has been found between the experience of pain and depression (Shacham, Reinhardt, Raubertas, & Cleeland, 1983), whilst the important role played by interactions with others is well established (e.g., Bahrami, 2011). QOL of cervical cancer survivors has been frequently reported via quantitative conceptualisations of physical, psycho-social and sexual health (Greimel et al., 2006). However, such benchmarks for QOL do not take into consideration how one's perception of self and health can change over time particularly after a major change in health status (Sandøe & Kappel, 1994). Additionally, other factors such as self-esteem, family income, education, social support and health promoting behaviours also influence QOL and should be considered alongside treatment modality and cancer stage (Ohno et al., 2010). Previous qualitative findings provide mixed conclusions regarding how women adapt to a survivorship identity in the long-term, highlighting the complexity of the survivorship experience (Clemmens, Knafl, Lev, & McCorkle, 2008; Lloyd, Briggs, Kane, Jeyarajah, & Shepherd, 2012). The aim of this current research was to explore the recovery experience in the short and long term and associated patterns of recovery among those treated with surgery and/or chemoradiotherapy from a biopsychosocial perspective.

Recovery after Treatment of Cervical Cancer European Journal for Cancer Care

Methods

Participants

 Participants were adult women treated for cervical cancer between the ages of 18 and 60 years, living in the UK. Those treated for pre-malignant lesions (cervical intra-epithelial neoplasia) only were excluded. Purposeful recruitment (Patton, 2002) took place between July 2019 and April 2020 via three main recruitment strategies. 1) Advertisement on social media platforms (Twitter, Facebook, Instagram); 2) relevant charities shared details of the research with their users; 3) a patient and public involvement group actively aided recruitment via word of mouth. A priori, a sample size of between 20-25 participants was deemed appropriate for the aims of this study, determined using information power guidance (Malterud, Siersma, & Guassora, 2016). The research team considered the high specificity of the target population and the study novelty to inform decision making regarding an effective sample size range.

- 17 Procedure
- Ethical approval was gained from a University Ethics Committee. Those interested were invited to contact the main researcher, who provided information about the study and research team via email.

 Following this, those who wished to participate were invited to complete an online consent form and
- demographic questionnaire. Eligibility was determined based on information obtained from the demographic questionnaire. A date and time for an interview was then arranged with all eligible
- participants.

Data collection

Interviews were undertaken by the main researcher who is a female PhD student with post-graduate level experience of conducting qualitative interviews in sensitive research contexts (e.g., mental health). The main researcher met with members of a patient and public involvement group (three cervical cancer survivors) prior to data collection to discuss relevant interview topics to aid preparation. Interviews were conducted between July 2019 and April 2020 either face to face on a university campus or via telephone, thereby enabling recruitment from a geographically diverse population within the UK. Telephone interviewing is acknowledged as a suitable method for exploring sensitive topics (Mealer & Jones, 2014), demonstrated within cancer (Rose, 1998) and mental health research (Marks et al., 1998) and produces comparable data in terms of quality, as the face-to-face method (Sturges & Hanrahan, 2004). Interviews were digitally voice recorded, with the knowledge and consent of participants.

Interview Schedule

Recovery after Treatment of Cervical Cancer European Journal for Cancer Care

A semi-structured interview guide was used, which explored women's experience of physical and psychological recovery following treatment for cervical cancer (Table 1). Due to the subjective nature of cancer recovery, the schedule focused on asking broad questions about recovery and allowed the participants to guide in areas of perceived importance to them. As women in this study were at varying stages after treatment, they were invited to reflect on their cancer diagnosis and feelings associated with this, alongside the experience of treatment. This 'warm up question' (Lloyd et al., 2012, p365) allowed women to firmly place themselves in the context of their treatment phase and to reflect chronologically.

9 [Table 1 here]

Data analysis

Interview data were analysed inductively, whereby the researchers did not intend to apply predetermined theories or frameworks to the analysis. In doing so, theories related to cancer recovery (e.g., the biopsychosocial model) were not consulted before the analysis, however, knowledge of previous literature was gained during the construction of the interview schedule. Thematic analysis was used to derive a thematic framework from the data, adhering to the flexible six- step approach outlined by Clarke & Braun (Clarke & Braun, 2017). Firstly, data was transcribed verbatim. Then, the lead author read all transcripts twice, before coding the data. A second researcher (ER), independent of the research team then read through and coded four transcripts for rigour and trustworthiness. The two researchers met to discuss similarities and resolve differences in the codes attributed to the data sets. Initial codes were drafted and organised into themes using a thematic tree. The final analysis generated three main themes each accompanied by sub-themes which were evidenced with participant quotations. These were named in a final thematic tree.

1 Results

- 2 Twenty-one women with a mean age of 37 years (28 to 55 years) participated with a mean interview
- 3 length of 58 minutes. Four women withdrew from the study before taking part in an interview. One
- 4 participant withdrew due to cancer recurrence, whilst reasons for withdrawal of the other participants
- 5 could not be obtained. Participant characteristics and treatment details are illustrated in table 2.
- 6 Inductive thematic analysis of the data revealed three main themes: Treatment as a paradox, emotional
- 7 fluctuations, and adversarial growth.

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9 [Table 2 here]

Theme 1: Treatment as a paradox

- 11 Reflections on Treatment
- Whilst participants reflected on their treatment with gratitude, there was also a sense that it had caused
- them harm which was long lasting and, in some cases, irreversible. Treatment was perceived as an all-
- 14 consuming experience which followed the shock of diagnosis, a time when participants felt as though
- they had lost control over their health. Navigating the treatment period was perceived to be particularly
- difficult for those who endured a longer treatment phase, receiving chemoradiotherapy. "Oh it's just
- 17 pure poison". (2-5 years post-chemoradiotherapy). The debilitating symptoms experienced during
- 18 treatment, such as fatigue, severe sickness and hair loss challenge the idea that treatment is a cure.
- 19 Instead, treatment is paradoxically viewed as both a cure and an illness.
- 20 Family members were perceived to be supportive during the treatment phase, for example, at
- 21 appointments, women would rely on family members to absorb information on their behalf: 'It kind of
- 22 all just went over my head but my daughter came with me and she was taking notes' (2-5 years post-
- chemoradiotherapy). Conversely, women spoke about the perceived burden that they were placing on
- 24 those close to them which hindered their ability to emotionally process the experience. One woman
- 25 reflected, "I wasn't properly processing and dealing with it because people around me were really
- 26 upset and I remember feeling guilty and really worried about them, but not being upset about what was
- 27 happening to me. (<2 years post-surgery).
- 28 Treatment after-effects
- 29 Participants commonly referred to the negative physical and psychosocial impacts of treatment. Sexual
- 30 issues, such as a loss of sensitivity and pain during intercourse, related to the removal of the cervix or
- 31 scar tissue were common for women who had undergone surgery. Three women also referred to a fear
- and a loss of enjoyment associated with penetrative sex, for example "I'm frightened of it being painful"
- and "it impacts you psychologically as well, because you lose the mood", along with concerns for their
- partner, "no one wants to hear that they're causing the other person pain". Maintaining open lines of

- 1 communication and discussing alternative ways to be intimate were management strategies: "I think
- 2 we've always been able to tell each other anything. We try to make sure that we're still intimate with
- 3 *each other, even though we're not doing that"* (< 2 years post-surgery).
- 4 Neuropathy in the hands, legs and feet as a result of chemotherapy impacted balance and the ability to
- 5 carry out daily activities like climbing the stairs or riding a bike. This was described by one woman as
- 6 "numbness in my feet and legs and I lose my balance, and I've lost power" (< 2 years post-surgery and
- 7 Chemoradiotherapy). Lymphadenectomy complications were also common. These varied from
- 8 numbness in the groin region and lymphatic fluid collections to the development of lower and upper
- 9 leg lymphoedema. Severe lymphoedema was viewed as highly disruptive due to the uncomfortable
- management strategies available and its contribution to body image concerns.
- You've already had your hysterectomy and that's bad enough, but then you've got a big leg
- and you've got to wear a stocking, otherwise your leg swells up. In the summer, you can't wear
- shorts, so it just impacts everything because your appearance is completely different. (5-10
- years post-surgery)
- Women perceived radiotherapy to be particularly toxic due to the unpredictable nature of its long-term
- impact. Those who received radiotherapy reported short-term bowel side effects and long-term bladder
- symptoms. Ultimately, participants were grateful that their cancer had responded to the treatment.
- However, there was a shared sense that the psychological repercussions of managing the physical
- 19 treatment after-effects were significant and was an aspect of survivorship that they were ill-prepared to
- deal with.

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Theme 2: Emotional fluctuations

- 22 Challenges to Identity
- 23 The transition from being a patient to a survivor was a time that challenged participants' identity,
- 24 particularly those treated with chemoradiotherapy. Being consumed in a routine of appointments, under
- 25 the care of medical professionals to being discharged led to feelings of isolation and a questioning of
- 26 identity and purpose. Participants also felt that their identity was threatened due to changes in how they
- 27 were treated by those close to them. "People lose the ability to treat you like who you are and that's the
- 28 hardest thing. You almost lose your identity and you become someone with cancer" (5-10 years post-
- 29 chemoradiotherapy).
- 30 For women who were diagnosed prior to the onset of menopause, losing the ability to achieve a
- 31 pregnancy or, if this was possible, to have a vaginal delivery, significantly interfered with future plans.
- 32 This was a main source of disparity between how women viewed their ideal self as a mother and how
- 33 they viewed themselves after treatment. "I think when it comes to having a child, emotionally I think

- 1 I'm more affected because I can't give birth and that's something I've always wanted to do" (2-5 yrs
- 2 post-radical trachelectomy). Additionally, women spoke about feelings of guilt for wanting to fall
- 3 pregnant, as they may be putting their child at risk, particularly after trachelectomy or for fear that the
- 4 cancer returned, and their child would be left without a mother, demonstrated by a participant many
- 5 years after her treatment, "There's the whole side of things, should I be starting a family in case this
- 6 *comes back?*" (5-10 years post-surgery and chemoradiotherapy).
- 7 Long-term worries
- 8 Whilst for some, the physical after-effects of treatment improved in the short term, psychological
- 9 repercussions seemed to stay with women regardless of treatment modality. A prominent talking point
- were anxieties and worries associated with the potential for cancer recurrence and the disruption that
- this caused in daily life. Heightened anxiety was associated with pain or discomfort similar to cancer
- symptoms and in the time before and after a check-up.
- After I got the all-clear, I was like, well what if it comes back? Now over a year later, I'm worse
- than I was. I question it if I have any different symptoms or if it's coming up to that appointment
- and afterwards because sometimes, they can make you wait quite a while (2-5 years post-
- surgery).
- Many women struggled to cope with these worries long after treatment, due to a myriad of complex
- emotions. Emotional processing seemed to be hindered by self-blame and guilt stemming from missed
- 19 smear tests, for example "There was a lot of guilt, because if I had that smear test, I wouldn't have
- 20 needed these treatments" (< 2 years post-surgery) or for early-stage cancer survivors, an expectation to
- 21 recover quicker than those who they perceived to be worse off than them.
- I don't feel like I have dealt with it. People say 'Oh you've fought a battle', but I never had
- symptoms, I don't feel like I've got the right to be upset or hurt about it, like, snap yourself out
- of it, there's women who have gone through a lot more (<2 years post-surgery).
- 25 Feelings of guilt are also associated with societal misconceptions and stigma surrounding HPV, as
- 26 illustrated by one woman: "Obviously, HPV is an STI and I think everyone that I met who had gone
- 27 through cervical cancer grappled with the idea that it was their fault because there is stigma attached
- 28 to this" (<2 yrs post-surgery and chemoradiotherapy). Thus, misconceptions related to cervical cancer
- 29 aetiology provided a complex recovery path for women, as not only were women dealing with the
- 30 impacts of treatment but also the potential that this burden was their doing.

Theme 3: Adversarial Growth

32 *Re-establishing normality*

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Participants disclosed their personal experiences of re-establishing normality after treatment, such as 1 returning to work. Co-operation and understanding from the employer was a vital aspect to ensure 2 participants could work safely, e.g., "Work have a menopause initiative, so they do consider that 3 sometimes, if I've had a particularly bad week sleeping wise, they let me work my hours over four days 4 5 instead of five, so that I can have an extra day of sleep" (5-10 yrs post-chemoradiotherapy). Family and motherhood were also significant considerations when resuming normal activities for most 6 7 participants. "I didn't have a choice after the first couple of weeks. People couldn't keep helping with 8 the kids, I just had to get on with doing sort of jobs like hoovering" (2-5 yrs post-surgery), suggesting 9 that in some cases, participants were obliged to resume their role as care giver. 10 Acceptance 11 Several participants disclosed that having cancer had changed their perspective on life and in some cases changed them as people, generally reflecting on the experience as a period of learning and 12 13 adversarial growth through acceptance. There was a whole grieving process which at the time hit me like a tonne of bricks, but it was 14 a very empowering thing to go through and I've used it for many things since. You do need to 15 16 be thankful for what you've learnt from it and the person you've become (5-10 yrs post-surgery 17 and chemoradiotherapy). 18 Often, helping others and raising awareness of the importance of smear testing was a strategy for participants to see the positives from their cancer experience. Physically, behaviour changes for 19 improved health such as weight loss through physical activity or diet changes and accepting one's own 20 21 physical limitations caused by treatment were ways that participants created a new normal, as seen by 22 the following participant who suffered with neuropathy: "I just have to get over the embarrassment 23 factor! I've just come to terms with the fact that when I do exercise, and if I push myself, I'm going to 24 fall over!" (2-5 yrs post chemoradiotherapy). 25 However, this sub-theme was less common in those diagnosed more recently, who tended to focus 26 predominantly on what they had lost from cancer, suggesting that acceptance of a new identity and 27 outlook is a long-term process. 28 29 30 31

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Discussion

This is the first study to qualitatively explore the recovery experience of cervical cancer survivors regardless of treatment modality and time since treatment, thus allowing a holistic view of the survivorship experience to be interpreted. A key finding were the nuanced recovery experiences after surgery and chemoradiotherapy. Physical changes were perceived to be far more disruptive and pronounced in those who received more radical treatments, in particular radiotherapy, which is a common finding (e.g., Mirabeau-Beale & Viswanathan, 2014). In comparison, psychological repercussions were significant irrespective of the treatment received and seemed to be most disruptive in the first two years after treatment. This distinction provides insight into unmet psychosocial needs of this population, which were perceived by participants in this study and by women in a recent charity report to be overlooked in comparison to physical needs [33]. Previous research suggests that those treated for gynaecological cancers report more unmet needs than those treated for breast cancer, particularly regarding psychological support (Faller et al., 2017), whilst psychological distress is often the most commonly reported after-effect of treatment (Le Borgne et al., 2013). However, it is generally found that those who receive chemoradiotherapy are subject to more severe psychological sequalae and worse QOL than those treated for early-stage malignancies (Xie et al., 2013) which contradicts our findings. This suggests that the psychological burden after early-stage malignancies may be more pronounced after treatment for cervical cancer compared to other, more commonly studied gynaecological cancers, such as endometrial cancer. Emotional support was an important unmet need identified during the recovery period. Peer support was found to be lacking in this population, despite its enormous potential, particularly amongst those treated with surgery who reported not feeling worthy to share their struggles when comparing themselves to those who had endured more advanced cancer. Additionally, participants did not want to burden their family members, whilst some women experienced self- blame by attributing their cancer to a missed smear test or sexual activity which further inhibited their ability to share and process their worries. Negative coping styles which may arise from this such as disengagement and cognitive avoidance have been linked to poorer well-being after gynaecological cancers (Costanzo, Lutgendorf, Rothrock, & Anderson, 2006). Social support between stage matched malignancies could be an effective way to bridge this gap as a mechanism for survivors to create realistic expectations of recovery, whilst support from women further on in the recovery process may also be helpful (Phillips, Montague, & Archer, 2017). A study which trialled a telephone support group reported positive outcomes such as creating emotional bonds and talking openly about similar and shared experiences (Pistrang, Jay, Gessler, & Barker, 2013) which are all areas that participants in this study felt were lacking in their recovery period. Therefore, service providers should consider the emotional needs of

- all survivors irrespective of treatment modality, whilst further trialling of peer support systems is
- 2 needed to determine what is viable and effective during the recovery period.
- 3 From a biopsychosocial perspective, QOL can be evaluated by combining the impacts of treatment
- 4 through functional and psycho-social well-being (Jacobson, 2018). In terms of functional impacts,
- 5 pain was a common experience in the short term, whilst physical morbidities such as
- 6 lymphadenectomy complications (e.g., lymphoedema), neuropathy and bladder issues negatively
- 7 impacted QOL in the long-term. A lack of information about management strategies for physical
- 8 morbidities contributes to distress and anxiety after cervical cancer (Ohno et al., 2010). There is a
- 9 large body of evidence to suggest that high levels of anxiety and depression exacerbate pain
- 10 (Honerlaw, Rumble, Rose, Coe, & Costanzo, 2016). This reciprocal relationship between physical and
- 11 psychosocial well-being can be demonstrated within our findings, for example, when participants
- 12 referred to pain as symptoms for potential cancer recurrence, which was a large source of worry or
- when lymphoedema led to body image concerns. Thus, this further supports the prioritisation of
- 14 psychosocial support after treatment in conjunction with adequate information provision to target
- 15 overall QOL.
- Positive outcomes of the treatment experience were also identified; however, these were not
- synonymous with the perception of 'moving on' from cancer but rather seemed to result from
- accepting the cancer into one's life. Outcomes after cancer such as a renewed appreciation for
- 19 life/family and health behaviour change are well documented (Clemmens et al., 2008; Lloyd et al.,
- 20 2012). It has been suggested that one's recovery 'goal posts' tend to move during recovery, with the
- 21 period shortly after treatment being associated with a desire to regain pre- illness normality whilst the
- long term is associated with creating a new normal (Sandsund, Pattison, Doyle, & Shaw, 2013).
- Participants in our study identified with this pattern through a process of post-traumatic growth. Such
- 24 growth took the form of developing management strategies, for example altering lifestyle behaviours
- 25 to take back control of their health, being open with others about issues and developing an awareness
- of their physical limitations. Participants perceived their cancer experience to have allowed them to
- 27 create a new sense of self that made them mentally stronger, more rational and health-conscious
- 28 individuals. In other populations, the cancer experience has been found to be transformative (Pelusi,
- 29 1997). However previously, cervical cancer survivors have tended to downplay their cancer
- 30 experience to normalise adversity (Clemmens et al., 2008). This may be due to differences in cultural
- 31 values when faced with illness, for example representing self-belief and will power as these studies
- were conducted in America (Marilyn & Lewis, 2002). Additionally, the growth mindset visible in this
- 33 study was predominantly in those who were between two- and ten-years post treatment, suggesting
- that the development and acceptance of a new identity is a long-term journey.
- 35 Study limitations

Despite variation in participant characteristics such as geographical location, age and time since 1 treatment (Table 2), participants were predominantly of White British ethnicity. It is plausible that the 2 recovery experience differs by ethnicity, with previous research finding ethnic variations in how 3 women attribute meaning to predominant societal cancer narratives, which are determined by cultural 4 models of illness (Coreil, Corvin, Nupp, Dyer, & Noble, 2012). Additionally, pain appraisal, the need 5 for information and ability to understand written information about recovery and contact with other 6 survivors have all been areas of variation between ethnic groups (Janz et al., 2008; Kim, Shaffer, 7 8 Rocha-Lima, Milton, & Carver, 2016). There are high rates of cervical cancer in other ethnic groups 9 within the UK, for example, women who have migrated from Eastern Europe (Altobelli & Lattanzi, 2015). The lack of ethnic variation within this study suggests a need for recruitment strategies which 10 specifically target ethnic minorities or those who are socially isolated. Additionally, it is possible that 11 12 participant self-selection led to the recruitment of those who were severely affected by their treatment as they may be more likely to come forward to be interviewed, and so these results may only be 13 representative a certain portion of survivors. 14 15 **Conclusions** This study provides unique insight into the recovery experience after treatment for cervical cancer in 16 17 the UK. Findings suggest that the psychological burden of a cervical cancer diagnosis and of coping with treatment related issues is significant regardless of treatment modality and highlights the unmet 18 psycho-social needs of this population in the initial years after treatment. Frequent experiences of 19 20 neuropathy after chemotherapy and lymphadenectomy complications were also found, which negatively impacted physical recovery. Future research should aim to trial stage matched malignancy 21 22 peer support after treatment and to understand the recovery experience in ethnic minorities groups 23 within the UK and in those who are socially isolated. 24 25 26 27 28 29 30 31 32 33 34

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Recovery after Treatment for Cervical Cancer	•
Psycho-Oncology	

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4 Table 1. A list of the main questions included in the interview schedule.
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	Age (years	Treatment)	Years since treatment	Ethnicity	Geographical location
1.	32	LLETZ	2-5	WB	East-Midlands
2.	1. 31	Could you tell me about how you were diagnosed? LLETZ; Lymphadenectomy	<2	WO	South-West
3.	2. 28 3.	What was treatment like for you? LLETZ; Cone Biopsy; Lymphadenectomy Can you tell me how your recovery was in the months sh	<2	WB	North-West
4.	32	LLETZ; Cone Biopsy - Physically	<2 <2	WB	South-East
5.	37	LLETZ; Cone Biopsy - Psychologically	5-10	WB	South-East
6.	30	Trachelectomy; Lymphadenectomy - Socially	2-5	WB	South-East
7.	38 4.	Hysterectomy How has recovery been in the long term?	<2	WB	North-West
8.	36	Hysterectomy; Lymphadenectomy - Can you tell me what you were able to do before	<2 • treatment?	WB	Scotland
9.	44	Hysterectomy; Lymphadenectomy - Is there anything that you cannot do since treatm	5-10	WB	East
10.	34 5.	Hysterectomy What aided your recovery?	2-5	WB	North-West
11.	49	Hysterectomy; Lymphadenectomy	2-5	WB	London
12.	6. 37	Was there anything that you found particularly challengi challenging aspect?	ng? what cont 2-5	WB	North-East
13.	368	Hally sterentones is Ghympradies her aburself since treatmen	$nt, \frac{2}{m}$ the long t	erWB	East-Midlands
14.	360.	Hally store none will Ghymnandies har your physical well-bein	ng since treatm	ne WB	Scotland
15.	301	What started would be morally of the start one who was going Lymphadenectomy	-	-	
16.	12. 55	Given what we have discussed, is there anything that you think smound is the address?	think we have 2-5	e missed or tha WI	t you Northern Ireland
17.	39	Chemoradiotherapy	5-10	WB	North-West
18.	37	Chemoradiotherapy	2-5	WB	South-West
19.	33	Chemoradiotherapy	2-5	WB	East-Midlands
20.	50	Chemoradiotherapy	2-5	WB	Scotland
21.	46	Chemoradiotherapy	2-5	WB	East-Midlands

² Table 2. Participant characteristics.

KEY: LLETZ= Large loop excision of the transformation zone; WB= White British; WO= White Other;

⁶ WI= White Irish: Participants 1-6 received fertility sparring treatments.