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Women treated for gynaecological cancer during young adulthood – A mixed-methods study of perceived psychological distress and experiences of support from health care following end-of-treatment

Elisabet Mattsson^{a,*}, Kim Einhorn^b, Lisa Ljungman^c, Inger Sundström-Poromaa^b, Karin Stålberg^b, Anna Wikman^b

^a Department of Health Care Sciences, Ersta Sköndal Bräcke University College, Stockholm, Sweden

^b Department of Women's and Children's Health, Uppsala University, Uppsala, Sweden

^c Division of Nursing, Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Stockholm, Sweden

HIGHLIGHTS

- Gynaecological cancer poses great stress on young women even after end of treatment.
- Health care needs adequate resources for long-term psychosocial follow-up.
- Multi-professional teams are warranted in gynaecologic oncology care.
- Young survivors' family life and work participation need further attention.

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ABSTRACT

Objective. To investigate the prevalence and predictors of cancer-related distress in younger women treated for gynaecological cancer, and to explore women's needs and experiences of psychosocial support following end-of-treatment.

Methods. Data were collected from 337 gynaecological cancer survivors, 19–39 years at diagnosis, using a study-specific questionnaire and the Swedish Quality Register of Gynaecologic Cancer. Predictors of distress were investigated with multivariable logistic regression analysis. Open-ended questions were analysed with content analysis.

Results. The prevalence of cancer-related distress was 85% ($n = 286$) including fear of cancer-recurrence ($n = 175, 61\%$), anxiety ($n = 152, 53\%$), depression ($n = 145, 51\%$), fear of death ($n = 91, 32\%$), concerns regarding sexuality ($n = 87, 34\%$) and fertility ($n = 78, 27\%$), and changed body image ($n = 78, 27\%$). Multi-modal treatment (OR 2.25, 95% CI 1.13–4.49) and a history of psychological distress (OR 3.44, 95% CI 1.41–8.39) predicted cancer-related distress. The majority of women experiencing distress also reported a need for support after end-of-treatment ($n = 205, 71\%$). One-third of those receiving support reported the received support as inadequate ($n = 55, 34\%$). Eight categories described reasons for not seeking support, e.g., lacked strength to seek professional support and too busy managing every-day life and, wanted help but did not know who to turn to. Four categories described reasons for not receiving sought support e.g., found it difficult to openly express feelings, psychosocial care was under-dimensioned, insufficient and unprofessional.

Conclusion. Results identify the importance of support and longer-term follow-up for young survivors of gynaecological cancer. The support needs to be organised to meet this group's specific needs.

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1. Introduction

Cancer is a leading cause of disease-related death among women aged 20 to 39 years [1]. Young women diagnosed with cancer face numerous challenges from the onset of the disease through treatment and beyond including delays in diagnosis, treatment side effects,

* Corresponding author at: Department of Health Care Sciences, Ersta Sköndal Bräcke University College, Stigbergsgatan 30, Box 11189, SE-100 61 Stockholm, Sweden.
E-mail address: elisabet.mattsson@esh.se (E. Mattsson).

financial concerns, and social and emotional issues [2,3]. Women diagnosed with gynaecological cancer, i.e., ovarian, uterine, cervical, vulvar, and vaginal cancer, are likely to face additional consequences beyond those common to all cancer patients as the body parts involved are emotionally charged, associated with childbearing and sexuality. Not surprisingly, previous research shows that women affected by gynaecological cancer are likely to suffer significant physical and psychological morbidity [4–7]. However, studies specifically addressing psychological distress in young women treated for gynaecological cancer are lacking.

The risk for gynaecological cancer increases with age, and represents one of the most prevalent forms of cancer in the female population. In Sweden, young women (20–39 at diagnosis) account for approximately 8% of all women diagnosed with gynaecologic cancers yearly [8]. Studies including women of all ages with gynaecological cancers indicate higher levels of psychological distress including clinical levels of anxiety, depression and posttraumatic stress disorder (PTSD), as well as greater decrements in body image and more sexual problems than in other types of cancer, with high levels of distress reported up to four years following the diagnosis [4–7]. Further, a gap between the gynaecologic cancer survivors' experience of supportive care service and the actual service required, i.e., unmet health care needs, has been identified [7,9,10], where symptoms of anxiety, depression and PTSD were associated with greater unmet needs [7]. However, whether conclusions drawn from studies of women of all ages can be generalised to a younger age group, who may be facing specific challenges, remains an open question. The only available information on young women with gynaecologic cancer is derived from two studies with mixed patient populations. In one study, more than half of women (55.6%) reported experiencing at least one unmet need and this perceived lack of support was more commonly found among younger women previously treated for gynaecological cancer [7]. Further, one study on survivors of breast and gynaecological cancer, diagnosed during adolescence and young adulthood (ages 15–29) found that young cancer survivors consistently reported poorer mental health and were four times more likely to suffer from significant psychological distress in comparison with non-cancer matched controls [11].

To inform the development of psychological interventions addressing the specific needs of young gynaecologic cancer survivors, psychological distress and the needs for support among these women warrants further attention. Therefore, the aim of this study was to investigate the prevalence and predictors of self-reported cancer-related distress in younger women treated for gynaecological cancer, and to explore women's needs and experiences of psychosocial support following end-of-treatment.

2. Methods

2.1. Participants and procedure

Participants were identified via the Swedish Quality Register of Gynaecologic Cancer [12]. The register consists of four sub-registries: i) ovarian cancer (ICD-10: C56.9, C57.0, C48.1, C48.2, C76.2, C76.3), including fallopian tube, peritoneal, and abdominal or pelvic cancers, since 2008; ii) uterine cancer (ICD-10: C54), since 2010; iii) cervical and vaginal cancer (ICD-10: C52, C53), since 2011; iv) vulvar cancer (ICD-10: C51), since 2012. Women diagnosed with gynaecological cancer between 2008 and 2016, aged 19–39 at time of diagnosis, and who had completed primary treatment were identified via the registry. Women with borderline tumours of the ovary, or carcinoma in situ of the cervix, vulva, or vagina were excluded. Information on contact details was obtained via the SPAR-registry ('Statens personadressregister', by Swedish acronym).

Potential participants were sent information about the study together with a brief study-specific questionnaire to complete and return by post. The information letter contained a study code, which enabled

participants to complete the survey online if they preferred. By responding to the survey, participants consented to their responses being used for research purposes. Up to two reminder letters were sent. Ethical approval was granted by the Regional Ethical Review Board in Uppsala, Sweden (Dnr: 2016/221).

2.2. Measures

2.2.1. Clinical and sociodemographic variables

Clinical data were obtained from the Swedish Quality Register of Gynaecologic Cancer [12] and included date of birth, diagnosis, date of diagnosis, treatment, and date of treatment completion. As information on recurrence is not yet reliable in the register, data were not obtained. Socio-demographic information was gathered via the study-specific questionnaire and included marital status, number of children, and education.

2.2.2. Cancer-related distress and perceived needs for support

A study-specific questionnaire was used to explore self-reported cancer-related distress and needs for support following end-of-treatment. The questionnaire included questions addressing:

- 1) cancer-related distress ("Following end-of-treatment, have you experienced psychological distress related to your cancer disease?" [Yes/No], "If yes, please describe" [open response]);
- 2) needs for support ("Have you experienced a need for support?" [Yes/No]);
- 3) support-seeking ("Have you sought support for cancer-related distress?" [Yes/No]);
- 4) forms of support ("From whom did you seek support?" [Counsellor/Psychologist or Psychotherapist/Other, please define]);
- 5) reasons for not seeking support ("If you did not seek support for cancer-related distress, please describe the reasons why" [open response]);
- 6) support received ("Did you receive the support you needed?" [Yes/No], "If you did not receive the support you sought, please describe the reasons why" [open response]);
- 7) previous adverse events ("Have you previously experienced difficult life events (prior to your cancer disease)?" [Yes/No]);
- 8) previous psychological distress ("Have you previously experienced psychological distress (prior to your cancer disease)?" [Yes/No]; "If yes, please describe" [open response]); and,
- 9) previous psychological support ("Have your previously sought support for psychological distress (prior to your cancer disease)?" [Yes/No].

2.3. Data analysis

2.3.1. Statistical analysis

Standard descriptive statistics were used to describe participant characteristics in terms of clinical, socio-demographic and cancer-related distress and need for psychological support variables. Responses describing cancer-related psychological distress were categorised into non-mutually exclusive categories (i.e., symptoms of anxiety, depression, posttraumatic stress, fear of recurrence, fear of death, sexuality and sexual function, fertility concerns, body image concerns, loneliness, anger/irritation, guilt, grief, stress/stress intolerance, fatigue). One additional variable was generated, describing whether support received was judged to be adequate or not, by combining responses to the items addressing support received. On this variable, support was defined as inadequate if support had been received but described as lacking in some way.

Differences in clinical characteristics of women who participated in the study compared with women who declined participation were analysed using chi-square tests for categorical variables and independent samples *t*-test for continuous variables. Results are presented as

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