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Review Article

Assessment of sexual difficulties associated with multi-modal treatment for cervical or endometrial cancer: A systematic review of measurement instruments

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HIGHLIGHTS

- No single self-report measure in clinical trials included the physical, emotional and relational impacts on women's sexual well-being after cancer
- Development of an instrument that measures sexual dysfunction in women not sexually active due to treatment consequences is still required
- The Female Sexual Function Index (FSFI) remains the most suitable PROM for measuring sexual morbidity in gynae-oncology research and practice

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ABSTRACT

Background. Practitioners and researchers require an outcome measure that accurately identifies the range of common treatment-induced changes in sexual function and well-being experienced by women after cervical or endometrial cancer. This systematic review critically appraised the measurement properties and clinical utility of instruments validated for the measurement of female sexual dysfunction (FSD) in this clinical population.

Methods. A bibliographic database search for questionnaire development or validation papers was completed and methodological quality and measurement properties of selected studies rated using the **Co**nsensus-based **S**tandards for the selection of health **M**easurement **In**strument (COSMIN) checklist.

Results. 738 articles were screened, 13 articles retrieved for full text assessment and 7 studies excluded, resulting in evaluation of 6 papers; 2 QoL and 4 female sexual morbidity measures. Five of the six instruments omitted one or more dimension of female sexual function and only one instrument explicitly measured distress associated with sexual changes as per DSM V (APA 2013) diagnostic criteria.

None of the papers reported measurement error, responsiveness data was available for only two instruments, three papers failed to report on criterion validity, and test-retest reliability reporting was inconsistent. Heterosexual penile-vaginal intercourse remains the dominant sexual activity focus for sexual morbidity PROMS terminology and instruments lack explicit reference to solo or non-coital sexual expression or validation in a non-heterosexual sample. Four out of six instruments included mediating treatment or illness items such as vaginal changes, menopause or altered body image.

Conclusions. Findings suggest that the Female Sexual Function Index (FSFI) remains the most robust sexual morbidity outcome measure, for research or clinical use, in sexually active women treated for cervical or endometrial cancer.

Development of an instrument that measures sexual dysfunction in women who are infrequently/not sexually active due to treatment consequences is still required to identify women in need of sexual rehabilitation.

Contents

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1. Introduction

Worldwide approximately half a million women are diagnosed annually with invasive cervical cancer [1] with 5 year survival rates ranging from >80–90% after treatment for stage 1A/1B disease in developed countries, and a 62% all stage 5 year relative survival across Europe [2]. While rates of cervical cancer in developed countries are in decline, it is estimated that 0.5 million cases of endometrial cancer will be diagnosed worldwide by 2035, with a 5-year survival rate of >80% for stage 1 and a 76% 5 year relative survival for all stages [2,3,4].

Despite treatment advances and improved survival rates, late treatment consequences remain under-recognised and under-reported by health professionals and patients alike [5,6,7,8]. Although reporting of urinary and bowel effects associated with pelvic radiotherapy has become more common, details of treatment-induced female sexual morbidity remain limited [9,10,11]. Published studies suggest that 30–63% of women with cervical cancer experience sexual difficulties after pelvic radiotherapy [12,13]. Furthermore, the type and radicality of pelvic surgery may also influence the extent of sexual recovery achievable [14,15,16]. While fewer studies have focused on sexual function after endometrial cancer treatment [17,18] evidence suggests that this patient population, previously thought to be at low risk, also experience significant sexual dysfunction [19,20].

Treatment-induced physical effects after cervical or endometrial cancer include vaginal dryness, fibrosis, stenosis, shortening, vaginal bleeding, menopausal symptoms, skin reactions, urinary difficulties, disruption to bowel function and infertility [9,13,18,21]. Furthermore, psychological impacts include anxiety, depression, fear of sexual pain and altered femininity [11,22]. Hence, changes in sexual function and well-being associated with treatment remain important research and clinical outcomes in their own right [11,23,24].

The clinical assessment and management of sexual difficulties after gynaecological cancer remains a frequently overlooked aspect of recovery and rehabilitation, with health professionals and women themselves having difficulty in raising this topic [11,22]. Clearly, the first step towards being able to offer systematic management for the sexual consequences of cancer is timely and accurate clinical assessment [25,26].

The number of health status questionnaires available for measuring patient reported outcomes (PROMS) has increased dramatically over recent decades [26,27]. There is now a range of patient self-report questionnaires developed to assess female sexual dysfunction (FSD) specifically [23,28] or as one dimension of a broader quality of life (QOL) assessment [29,30]. However, many existing questionnaires do not include the full range of organic and psychogenic sexual disruptions encountered after gynaecological cancer treatment.

In general, disease-, treatment-, or symptom-specific questionnaires are better at identifying between-group differences (sensitivity) and changes over time (responsiveness) than generic cancer or sexual dysfunction questionnaires [31]. Nevertheless, the challenge facing clinicians and researchers is to select the most appropriate instrument that demonstrates psychometric rigour [27], reflects the full range of contemporary (DSM V) female sexual dysfunction diagnostic categories commonly encountered in gynae-oncology [32] and has clinical utility in identifying women most likely to benefit from specialist assessment and management [33].

A number of previous reviews have explored the development and use of QOL, symptom assessment and sexual function measures in gynaecological [34,35] or cervical cancer [29,30] survivors, with some discussion of psychometric rigour and/or clinical utility. However, there is a paucity of in-depth systematic reviews conducted to date that specifically evaluate the measurement properties and clinical utility of female sexual dysfunction questionnaires in women treated by pelvic surgery/radiotherapy for cervical and endometrial cancer.

This systematic review evaluates English language instruments for female sexual dysfunction (FSD) in women after pelvic surgery and/or radiotherapy for cervical or endometrial cancer. The COSMIN (**CO**nsensus-based **S**tandards for the selection of health **M**easurement **IN**struments) checklist [36] critically appraised published evidence of the measurement properties of these patient self-report instruments and a summary of the clinical utility of instruments is included. This paper also adheres to PRISMA (preferred reporting items for systematic reviews and meta-analyses) guidelines [37].

2. Methods

2.1. Search strategy

The following databases were searched for papers reporting the development or validation of questionnaires measuring sexual (dys)function in women with cervical or endometrial cancer: Embase (1990–2015), MEDLINE (1990–2015), PsycINFO (1990–2015), CINAHL (1990–2015), BNI (1990–2015), AMED (1990–2015) using Ovid.

As there have been significant developments in treatment for endometrial and cervical cancer, and in the conceptualisation of female sexual [dys]function over recent years, this review focused on full text articles published in the English language from 1990 to 2015.

We used the protocol by Terwee [38] to devise a search strategy with multiple search terms addressing the following instrument dimensions:

1. **The construct of interest**: Sexual [dys]function.
2. **Target population**: Female.

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