

## Review

# Validated questionnaires on intimacy in patients who have had cancer

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## Abstract

Problems with intimacy in patients with cancer of the head and neck may not be recognised. Our aim was to review published papers on patient-reported outcomes that record concerns about intimacy, sex, and function, to help develop a tool for use in head and neck cancer. We specifically looked for instruments with evidence of validation in patients with cancer, which could be used to identify problems with intimacy and sexuality. After evaluating 2563 papers, we identified 20 that satisfied our inclusion criteria, and these have been presented in a tabulated form. This review has shown the need to develop a questionnaire on intimacy that is specific to patients with cancer of the head and neck. It is an important issue that must be addressed by clinical and research teams, and will be done most effectively if it is linked to specific interventions.

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**Keywords:** Quality of life; health related quality of life; oral cancer; intimacy; head and neck cancer; psychosexual therapy

## Introduction

Cancer is now considered to have many of the features of a chronic disease, and improved survival has led to a long-term focus on palliation.<sup>1,2</sup> There is now a new and growing demand on cancer clinicians to identify and monitor the complex, adverse effects of treatment, and to include them when

decisions are made. However, although the functional, psychological, and social impacts of cancer of the head and neck and its treatment have been well documented,<sup>3,4</sup> aspects such as intimacy and sex are often overlooked.<sup>5</sup> Any cancer can result in dramatic changes to sexual function, intimacy, relationships, and sense of self, and its impact can last for many years after treatment and result in serious physical and emotional side-effects.<sup>6–9</sup>

Problems with intimacy in patients with a history of gynaecological,<sup>10</sup> breast,<sup>11</sup> and prostate<sup>12</sup> cancer are often identified during consultations because of their obvious effects on sexual function, but this is not the case in patients with cancer of the head and neck. Other problems need to be resolved in a limited consultation time,<sup>13–16</sup> and, perhaps, clinicians fail to recognise the mouth as a “sexual organ”.

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We have reviewed published articles on patient-reported outcomes concerning intimacy and sexual function, to help develop a tool for use in patients with cancer of the head and neck.

**Material and methods**

We explored “sexual dysfunction following treatment for cancer” and devised a search strategy (Fig. 1) using the key terms: sexual function assessment and cancer; oncology and intimacy; intimacy and surgery and cancer; intimacy and radiotherapy and cancer; intimacy and chemotherapy and cancer; patient-reported outcomes; qualitative studies and intimacy; questionnaires; quality of life and sexual function; validated sexual function instruments; and patient satisfaction. The following databases were examined independently by the primary investigator and verified by another member of the research team: Medline, Embase (Excerpta Medica), HaPI (Health and Psychosocial Instruments), Science Citation Index / Social Sciences Citation Index® (Thomson Reuters), Ovid Evidence Based Medicine, and PsychINFO® (American Psychological Association).

All the instruments described in the papers selected were patient-reported outcome measures (PROM) that assessed sexual function in people with cancer. Rather than setting a standard value for inclusion, we examined the developmental processes to find evidence of validity, and looked for evidence of reliability rather than setting a cut-off value for the reliability coefficient, which was not always reported. The primary

investigator obtained all the data from the papers, which were independently assessed by an experienced member of the research team using the modified proforma described by Smith et al.<sup>17</sup> The final shortlist was based on these assessments and on discussion between the reviewers.

*Inclusion criteria*

Instruments had to be completed by the patient (patient-reported), and specifically developed for patients with cancer. They had to be in the English language and have published evidence of reliability and validity.

**Results**

In total, we identified 2563 papers related to sexual function after treatment for cancer. All articles were retrieved in full. After exclusion of the non-English manuscripts, and of editorials and papers that did not include instruments for the assessment of sexual dysfunction in their methodology, 587 indicated in the abstract and methods that they used quality of life measures. After close examination, a further 122 were excluded as there was no evidence to support the validity and reliability of the tools they described. Of the remaining 465 papers, 445 stated that the instrument used was validated and reliable, but it was not possible to obtain specific details (such as groups and their characteristics) that would satisfy the inclusion criteria. We found only 20 that involved tools that had evidence of validation in patients with cancer (Table 1). All questionnaires included intimacy-specific and generic outcome tools that included questions about intimacy.

*The UCLA Prostate Cancer Index*<sup>18</sup> is a disease-specific quality of life questionnaire that includes an assessment of sexual function in men with prostate cancer. The opinions collected from focus groups and surveys of patients helped to identify areas of importance. It is rather long and may be more suitable for research than for use in a busy clinic.

*The 35-item QLQ-H&N35*<sup>19</sup> comprises 7 multi-item scales that assess pain and problems with swallowing, senses of taste and smell, speech, social eating, social contact, and sexuality, in addition to 11 single items that assess symptoms. All items (except 5 single items that have a yes/no response) are rated on a 4-point Likert-type scale (not at all, a little, quite a bit, and very much).

*The PCI-H&N*<sup>20</sup> is used in head and neck oncology outpatient clinics as part of a holistic needs assessment that is specific to cancer of the head and neck. Items are grouped into 5 domains: physical and functional well-being (29 items), treatment-related (3 items), social care and social well-being (9 items), psychological, emotional, and spiritual well-being (14 items), and other (1 free-text item). It has face and content validity, and seems to be practical and appropriate for use in a busy clinic. It can help to focus the consultation and enables patients to discuss their concerns without taking up too much

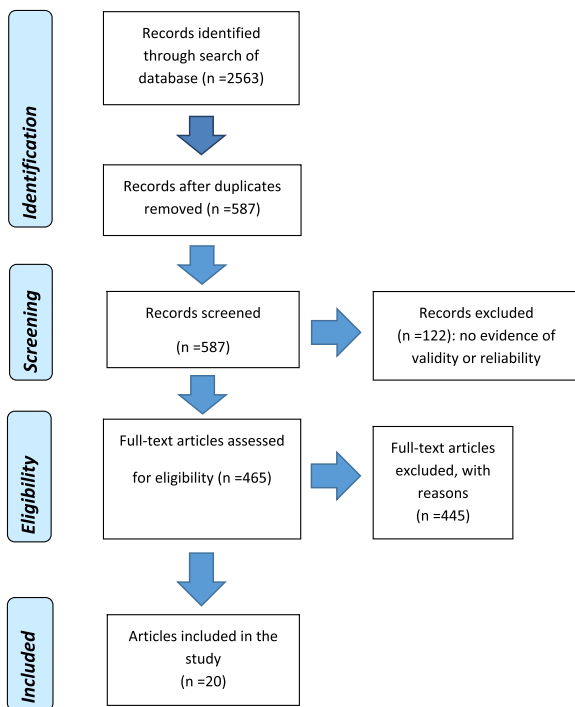


Fig. 1. Identification of papers included in the review.

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