The effects of head and neck cancer on relationship intimacy in adults. A systematic review of the literature

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Abstract

Objectives
This systematic literature review aimed to explore the effects of head and neck cancer (HNC) on relationship intimacy in adults and identify the current support available to HNC patients and their partners in relation to relationship intimacy.

Methods
Seven databases, CINAHL, Pubmed, Scopus, Web of Science, SocINDEX, PsycARTICLES, Psychology and Behavioural Science Collection, were searched using grouped terms “head and neck cancer and intimacy” and “head and neck cancer and support”. Studies written in English, aiming to assess adult patients with HNC and its effects on relationship intimacy, and studies assessing the use of intimacy specific support tools/methods were included. The review protocol was registered June 2022 with PROSPERO ID: CRD42022329614.

Results
Thirty publications were included within the review. Six topics emerged: relationships; communication; sexual interest; barriers, couples-based communication intervention strategies and assessment tools. Whilst there were positive dyadic changes observed, many patients reported negative experiences relating to changes in relationship roles, sexual issues and poor communication with partners and health care professionals that affected intimacy. There were five interventions identified and of those, the results varied, with some improvements noted in psychological wellbeing, but not necessarily sexual interest and enjoyment.

Conclusions
HNC profoundly affects relationship intimacy. However, both patients and healthcare professionals find it challenging to discuss these issues often leaving it an unmet need.
Appropriate training and development for healthcare professionals that facilitates communication between clinician and patient is necessary to support conversations on intimacy needs.

Implications for healthcare practice

There exists a need for patients to receive support in relation to intimacy following diagnosis and treatment and the evidence suggests that this may be more effective post treatment and from healthcare professionals that are appropriately trained. Couples’ communication interventions may prove useful, but further research is required on the efficacy of combining both psychological and sexual support together.

Layperson Summary

Head and Neck Cancer refers to cancer of the mouth, tongue, throat, nose, salivary glands and middle ear. Traditionally this cancer has been more common in men over the age of 50 years, particularly those who have misused alcohol and tobacco. However, there has been an increase in oral cancer in younger healthier people attributed to the Human Papillomavirus, a common sexually transmitted infection.

Treatments can have long lasting effects emotionally and physically on individuals one of which is relationship intimacy. Many head and neck cancer patients and their partners struggle to be intimate following treatment, experiencing issues such as loss of closeness, emotional security, communication, sexual desire, sexual function, sexual satisfaction, embarrassment and fatigue.

Searching seven academic databases, this review aimed to explore the effects of head and neck cancer on relationship intimacy in adults and identify the current support available to patients and their partners in relation to relationship intimacy.

The review highlighted that many patients felt intimacy was an important part of their lives, but it had been negatively impacted since diagnosis. However, both patients and healthcare professionals feel uncomfortable to discuss it at clinic appointments leaving it an unmet need. Appropriate training and support for healthcare professionals is necessary to create a supportive environment to discuss this sensitive topic.

Key Words
Head and neck cancer; relationship intimacy; sexuality; couples; psychosexual, psychosocial

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What is already known about the topic

- HNC cancer has significant effects on quality of life leading to depression, anxiety, and social isolation.
- Treatment side effects cause changes in intimacy leading to loss of desire, function, satisfaction, embarrassment over body image and fear of rejection.
What this paper adds

- HNC patients are experiencing profound effects on their intimate relationships.
- Patients and healthcare professionals are not consistently discussing intimacy issues leaving this an unmet need.
- Healthcare professionals are best placed to offer support to couples at risk of relationship intimacy but are not equipped with the competence and confidence to do so.

1. Introduction

HNC is ranked the 6th most common cancer worldwide with over 12,000 newly diagnosed cases each year in the UK, and approximately 1,300 in Scotland. Recently, there has been a notable increase in the incidence of oropharyngeal cancer (OPC) associated with the human papillomavirus (HPV). However, HPV OPC affects a younger, healthier age group who have had little exposure to alcohol and tobacco. Evidence suggests that sexual practices contribute to the risk factors associated with this common sexually transmitted infection with over 6,000 newly diagnosed cancers of the tonsil and base of tongue commonly found in HPV OPC reported. It is predicted that by 2030 oral cancers will increase by 75%.

The effects of treatment (usually combination of surgery, systemic anti-cancer therapy (SACT) and radiotherapy) are long lasting with some experiencing facial disfigurement and functional impairments for example, speech, eating, drinking, breathing, and swallowing difficulties. Patients must learn to cope with the impact of their new appearance on social activities and acceptance from family and friends. This can significantly impact quality of life (QoL) with HNC patients at further risk of experiencing loneliness causing profound psychological and psychosocial effects.

Relationship intimacy and sexuality are also affected with many struggling to reintegrate into their ‘new normal’, build their confidence and identity to be able resume intimate relationships without fear of rejection or embarrassment. Defining intimacy is multifaceted and goes beyond sexual relations to include closeness and connections with others and is often linked to what patients experienced prior to diagnosis. Resuming intimate relationships is particularly challenging for HNC patients due to treatment side effects such as appearance changes caused by surgery and radiation wounds/burns, erectile dysfunction, dry mouth, fatigue, trismus, restricted airways and oral secretions all of which impacts desire, satisfaction and sexual functioning.

Whilst relationship intimacy may not be a priority for patients during active treatment, it can commonly be ‘politely overlooked’ or not recognised as an issue. Due to the sensitivity of the topic, patients, their partners and health care professionals find it difficult to raise and can therefore go unreported and unmet. Sexual health is fundamental to one’s health and well-being and intimacy is an essential psychological need that can help reduce depression and mental ill health and improve happiness and general wellbeing. A more holistic, person centred approach that routinely assesses the intimacy needs of patients has been recommended.
Given the significant and profound effects of treatment, this review is crucial to understand the needs of this patient group and the effectiveness of interventions by combining the current knowledge to identify areas for future improvements in care.

This systematic review aimed to update the knowledge of the effects head and neck cancer has on the intimacy needs of patients and what support for intimacy needs currently exists for patients and partners. Our research questions (RQ) were:

1. What are the effects of HNC on relationship intimacy in adults?
2. What current support is available to HNC patients and their partners in relation to relationship intimacy?

2. Methods

To support transparency and accuracy, the review followed the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA). The review was registered with PROSPERO June 2022 (see supplementary File 1 for details).

2.1 Information sources and searches:

The systematic search included the following grouped terms “head and neck cancer and intimacy” and “head and neck cancer and support” using a combination of Boolean operators, truncation markers and MeSH headings. Soc Index, Pub Med, Psychology and Behavioural Sciences Collection, Scopus, Web of Science, PsycArticles and CINAHL databases were searched (see supplementary File 2 for an example). The search strategy was validated by a subject specialist librarian and subsequently amended for each database. Studies assessing adult patients with HNC and its effects on relationship intimacy and those assessing the use of any intimacy support tools/methods to address intimacy issues were included in the review. Studies that included HNC and intimacy and or sexuality as either their main objective or secondary objective were included in the review. All qualitative, quantitative, interventional, observational, and mixed methods studies were included in the review. Studies written in English were included with no set date parameters to capture all seminal work. Reference lists of articles were hand searched for any additional work. See supplementary File 3 for details.

2.2 Data management

Endnote 20 software was used as the reference management system. All titles and abstracts were transferred to Endnote and de-duplicated. Three members of the team (SL, CP, ES) independently screened each title and abstract retaining those that met the eligibility criteria of the research study. Of those retained, full text papers were reviewed by SL, CP, ES to determine inclusion or exclusion in the review and recorded on a specific data extraction MS Excel spreadsheet. There were no disagreements noted. A MS Excel data extraction spreadsheet was created to detail the data from all included studies. Quality was assessed using the Critical Appraisal Skills Programme (CASP) checklist.
2.3 Data synthesis

The review took the form of a narrative synthesis due to data variability, based on common topics to address both research questions. For the qualitative studies retrieved, the selected papers were thematically analysed for similarities and differences and grouped into topics using NVivo software. Findings from the quantitative papers were extracted and grouped into topics either already established from the thematic analysis of the qualitative papers or grouped into new topic headings as findings arose. Results were organised thematically based on the research questions and are presented in a narrative synthesis.

2.4 Methodological quality and risk of bias

The Critical Appraisal Skills Programme (CASP) checklist\(^1\) was used to assess methodological quality of included studies. This took place after data extraction to preclude reporting bias and also to ensure that no studies based on poor quality prioritised studies with more sophisticated findings.\(^2\)

Each study was evaluated and rated by answering “yes”, “no”, “can’t tell” to each quality criterion. A score of 1 (denoting ‘yes’) was given if the study met the criterion. A score of 0 (denoting ‘no’ or ‘can’t tell’) was given if the study did not meet the criterion or if there was uncertainty. Qualitative studies were scored from 0-10, cohort studies were scored from 0-12 and randomised controlled trials were scored from 0-11.

3. Results

3.1 Study characteristics

Overall, the database searches yielded 5,502 articles. A total of 30 studies (5 qualitative, 3 quantitative, 19 cohort and 3 RCTs) were included in the review reporting evidence from a total of 3,744 participants (samples ranging from 6 to 354). The majority of participants were male, over 50 years and married. Studies were carried out in USA (n=13), Turkey (n=3), Australia (n=1), Italy (n=1), Canada (n=3), Netherlands (N=3), Germany (n=1), Sweden (n=1) and the UK (n=4) (see supplementary File 4 for details).

3.2 Quality appraisal and risk of bias

Overall, the quality of studies was assessed to be moderate to high. The qualitative articles ranged from 7 to 10 (out of a possible 10); the cohort studies ranged from 7 to 12 (out of a possible 12) and the RCTs ranged from 6 to 8 (out of a possible 11). The three RCTs outlined that participants were either randomised using number generators or randomly allocated by an independent person. The randomisation was deemed sufficient to eliminate bias and the outcomes of each study were important for this population.

3.3 Synthesis of results
The results for RQ1 will be presented first followed by the results for RQ2. With regards to RQ1, the review of the literature revealed 4 main topics: relationships; communication; sexual interest; barriers. For RQ2 the literature revealed 2 main topics; couples-based communication intervention strategies and assessment tools. An overview of the topics addressed in each study are included in supplementary file 4.

The term ‘partner’ will be used throughout to refer to couples who are in an intimate relationship with each other (irrespective of marital status).

3.3.1 RQ1 What are the effects of HNC on relationship intimacy in adults?

**Relationships**

Twelve papers explored the impact of HNC on relationships yielding mixed results.

a. *Roles*. Role changes were commonly observed. Role changes often involved the shift from partner to carer which creates the context into which intimacy can be affected. Supporting the patient to adhere to their daily self-care routines, health monitoring, communicating with medical teams and taking extra domestic responsibilities were described. However, these extra responsibilities were reported to negatively impact carer health, causing increased fatigue and ill-health. Whilst partners reported the difficulties and sometimes frustrations in continually supporting adherence to treatment plans, patients at times resented too much help when they wanted to be more independent. Thus making it challenging for the patient to re-establish equitable roles to retain levels of intimacy and adapt to a new relationship following completion of treatment. The role change saw individuals feeling more like a patient instead of a partner in an intimate relationship.

b. *Positive relationship effects*. Positive changes were almost always associated with feelings of greater togetherness and closeness. There was sense of accomplishment at being part of their partner’s recovery, with many studies reporting that couples going through the treatment together had strengthened their relationship and brought them closer together.

c. *Negative relationship effects*. Eight studies discussed how HNC had negatively impacted on their relationships. Often there was a period of grief for the relationship that once was with a notable decline in intimacy. Surgery left those with major facial disfigurement with feelings that their partners were ashamed of how they looked. Despite significant marital distress identified in some couples, very few felt able to discuss this given an opportunity. Feelings of blame and guilt about exposing partners to HPV caused detrimental effects on relationships and in some cases relationships broke down, ended in divorce or separation. Reasons for conflict included lack of adherence, regular reminding of patients to self-care routines, poor communication, role changes and old grudges. However, it was noted that in circumstances where one’s mortality is at risk, conflicts seem less trivial and tends to resolve.
Twelve papers explored communication with three main aspects arising (a) couples’ communication; (b) information seeking; (C) communication with health care professionals.

a. Couples’ communication. Communication was felt to be an influencing factor within relationships. However, results varied across the studies with some positive outcomes noted when couples communicated with one another about the diagnosis to some preferring to hold back information from their partners. Two papers reported that the majority of patients had disclosed their HPV diagnosis to their partners with no negative effects on the relationship, but changes in intimate behaviours were observed. However, for others poor communication had led to a weakened relationship due to not always wanting to discuss their diagnosis, not knowing how to initiate conversation, or shielding the partners from cancer concerns. Communication can be adversely impacted, with reports ranging from 17% of patients to 22% of partners after surgery. Reasons cited were attributed to side effects of the disease and treatment, with patients reporting ill health, poor tongue movement, xerostomia and swelling from tracheostomy devices making it difficult to be heard and often feeling literally and metaphorically voiceless. These feelings can progress into fear, vulnerability, sadness, and anger for some.

b. Information seeking. How and when patients and their partners access information relating to their relationship needs was also explored. The need to receive information was rated highly in one study, with over 80% of participants reporting that it was at least “somewhat important” to receive information about sexual issues. The timing of receiving information varied across each study with some participants preferring information at the time of diagnosis or early in the process, whilst others felt that the need for information about changes in sexual practices were higher during the longer-term survivorship period. Seeking information from appropriate sources was also discussed, with HPV patients mainly using the internet to find out more about the condition. The credibility of the information found through digital searches was questioned as was the amount of available information to patients. A further article reported the preferred method of receiving information was from a health professional followed by printed leaflets. Yet there is still evidence that patients may not have enough information to be able to communicate with their partner about their condition.

c. Communication with health care professionals. Conversations regarding sexual issues with a health professional were scarce ranging from 6% to 31%. There was recognition that education was important, particularly for OPC HPV patients, but was not provided at time of diagnosis often leading to increased stress. Lack of information was potentially attributed to clinician knowledge. Patients with sexual issues would prefer to talk to their health care professional in the first instance and
at clinic appointments respectively which can improve outcomes,\textsuperscript{13,36} although men may find it more difficult.\textsuperscript{12} In some cases, it was not raised at all by health care professionals as they felt uncomfortable.\textsuperscript{23} Despite the sensitivity of the topic, it is recommended that health care professionals should be the ones to raise it to encourage patients to openly share their issues, recognising however that they will require training and support to do this\textsuperscript{13,23} or risk it being left as an unmet need.\textsuperscript{13} Conversely, one article noted that very few patients (20\%) wished to receive support from professional services.\textsuperscript{16} Unfortunately, up to 46\% of patients feel that current tools do not adequately capture issues related to sexuality specifically for HNC patients.\textsuperscript{13} There therefore exists a need for further health professional supportive measures in addressing intimacy needs of patients.\textsuperscript{12}

\textit{Sexual interest}

\textbf{Four concepts emerged from this topic: (a) sexual relationships; (b) sexual functioning; (c) desire; (d) satisfaction.}

\textbf{a. Sexual relationships.} Studies reported that HNC had negatively affected patients and partners intimate and sexual relationships. Reasons cited were fear of transmission, lack of desire, physical changes, having a tracheostomy, respiratory sounds, erectile dysfunction, resentment, and treatment side effects.\textsuperscript{16,25,34,37} One article refers to changes in sexual relationships as an ‘unmet need’, with 17.2\% reporting a change immediately post treatment increasing to 26.7\% in the survivorship period.\textsuperscript{35} HPV patients and partners reported experiencing changes in their sexual behaviours six months from diagnosis.\textsuperscript{25} Patients reported that their sex lives were worse since diagnosis,\textsuperscript{37} had experienced a decline in their sexual relationships\textsuperscript{26} or had stopped sexual relations all together since diagnosis.\textsuperscript{34} Those with both minor and extensive facial disfigurement\textsuperscript{19} and those with partial and total laryngectomy\textsuperscript{38} also reported worsened sexual relations. Whilst a high number of patients reported changes in intimacy,\textsuperscript{34} a small number felt the change was positive.\textsuperscript{16,37} Despite participants feeling that sexuality and being sexually active is important to them,\textsuperscript{16,37,39} only two studies reported a decline in sexual contact\textsuperscript{26,37} with women potentially more affected than men.\textsuperscript{26} Couples being intimate through kissing was reported as a form of close affection even for those with altered mouth function.\textsuperscript{24} However, in some cases, patients required physiotherapy to relearn how to kiss due to the physical side effects of treatment.\textsuperscript{23,28} The relationship between age and sexuality was unclear. Two papers noted no significant relationship between the two\textsuperscript{12,15} whilst other reports have contradicting results.\textsuperscript{13,40} Another suggested that intimacy problems can vary greatly among age groups (ranging from 36\% to 16\% across different age groups).\textsuperscript{10} Such variability in the data could be attributed to the number of participants in each study and their age, the treatment they received and stage of disease.
b. **Sexual functioning.** Sexual problems were reported as the second most common issue experienced by HNC patients. Those experiencing sexual dysfunction reported issues relating to arousal during intercourse, oral sex and obtaining and sustaining an erection during intercourse. Male patients commonly reported erectile dysfunction, regardless of age or disease/treatment related. Conversely in another study 58% of men and all women experienced no sexual dysfunction. A further study reported that men were more likely to report intimacy issues and in another, both men and women experienced sexual difficulties equally. Partial and total laryngectomy patients also reported experiencing sexual dysfunction with one study reporting that older adult laryngectomy patients experienced less sexual function issues compared with younger laryngectomy patients. Only one study reported that total and partial laryngectomy patients did not experience sexual dysfunction. Patients with advanced stages and those who received surgery, chemotherapy and radiotherapy reportedly experienced higher levels of sexual dysfunction.

c. **Desire.** HNC can affect sexual interest with lack of mood feeling less interested and treatment effects cited as most common causes. Post treatment, studies showed that patients were still experiencing a lack of desire and with sexuality needs extending into survivorship. When there was lack of sexual desire, the nature of relationships was noted to be affected. Patients reported not feeling satisfied with their level of sexual desire or the frequency of sexual activity. Whilst sexual activity was considered important, studies reported participants never being sexually active, not wanting to engage in sexual activity, stopping sexual relations since treatment and having less sexual contact after treatment. Post radiotherapy, less than half of patients may engage in sexual intercourse or oral sex, while HPV survivors reported participating in less sexual activity (particularly women), having no sexual activity or a significant decline in frequency of sexual intercourse and a decline in oral sex. Not surprisingly, only one study reported a libido improvement during recovery.

d. **Satisfaction.** Patients reported that HNC had negatively affected their ability to enjoy sexual relations. Patients experienced low levels of satisfaction with orgasms and in some instances low satisfaction with their current partner were directly linked to levels of enjoyment with sex and sexual function. Those who were less satisfied with their sexual relations experienced negative changes in their sexual relationships, however there was no significant difference in satisfaction scores a year after treatment. With regards to gender, results varied from no correlation to reports that men had higher levels of sexual satisfaction than women but in the longer term these differences tended to fade. Whilst being married was not related to higher levels of satisfaction, other factors appeared to be more important: being close with a partner and feeling secure in a relationship. Whether age plays a role in sexual satisfaction is still unclear, as evidence is inconclusive.

**Barriers**
Four types of barriers were identified relating to: Physical; Psychological and social aspects as well as body image.

a. Physical Barriers. Treatment related fatigue was most frequently reported to affect sexual activity both during and after active treatment. Other barriers were attributed to pain; medication side effects; feeding tubes; oral problems relating to dry mouth, mobility, bad breath, mucus and saliva; fear of respiration; neck wounds and neck mobility; constipation and weight loss.

b. Body image. Facial disfigurement impacts on how confident patients are in their own self-image and how others view them. Patients commonly reported feeling less attractive and troubled by their appearance post treatment, by wanting to hide scars and uneven smiles before accepting their new self. Yet, the link between body image and sexual satisfaction remains unclear as it is minimally explored.

c. Psychological Barriers. Those couples who reported more positive communication and greater cancer specific intimacy within their relationship were more likely to experience less distress. Partners were more stressed than patients, owing to fear and guilt that they may have been responsible for transferring the HPV to the patient. One study reported a strong correlation between distress and sexual difficulties. However, another study reported no effect on sexual functioning in relation to psychological distress. Similarly, another article also concluded that sexual functioning was not related to depression or self-esteem. Intimacy is the key mediator between communication and distress in a relationship, however, it remains unclear from the evidence if there exists a correlation between distress and sexual functioning.

d. Social Barriers. Patients can experience social withdrawal and isolation due to treatment side effects, often bound up in body image anxieties and concerns functioning in public such as eating and drinking. Evidence suggests that for patients who had difficulty in social functioning prior to HNC also experienced less sexual intimacy which persisted up to six months post treatment. Similarly, in another article, those patients reporting issues with intimacy often have significant issues relating to physical and social-emotional functioning. A patient’s physical appearance often means that they find it too difficult to go out and socialise together as a couple, however, having support from existing relationships was important to be able to achieve this. For those not in a relationship, appearance changes were just as important, with patients reporting low confidence as a barrier to meeting new people. This is especially true for those who felt people were avoiding them and looking away. Finally, many patients find it challenging to socialise in large groups and loud places, because of the difficulty to be heard.

3.3.2 RQ2 What current support is available to HNC patients and their partners in relation to relationship intimacy?
Seven studies explored patient and partner support with two themes arising; (a) couples-based communication intervention strategies; (b) assessment tools.

a. Couples-based communication intervention strategies

Three randomised control trials (RCT)\textsuperscript{32,45-46} and two cohort studies\textsuperscript{30-31} tested and reported outcomes for couples-based communication intervention strategies with varying results. Interventions such as telephone-based teaching methods\textsuperscript{4} reported improvements in depression for both patients and partners whilst couples based supportive communication\textsuperscript{32} decreased partner distress. On the other hand, combined interventions still merit further investigation on how beneficial they are on improving sexual interest and enjoyment.\textsuperscript{46}

Interventions focussing solely on couples’ communication\textsuperscript{30-31} analysed in a laboratory setting revealed couples wished to talk more frequently about side effects (55%) and less about relationship issues (8%) during sessions\textsuperscript{30-31}. Whilst significant positive effects on psychological and martial adjustment were observed when patients and partners used pronouns during discussions, having a partner to share the coping process may be more important than couples emotionally disclosing feelings to one another.\textsuperscript{31} During the treatment phase patients experiencing fatigue and managing side effects are the immediate concerns and benefit most from problem solving than openly discussing their emotions\textsuperscript{30} during this stage.

A positive association between dyadic coping and psychological adjustment in patients was observed,\textsuperscript{45} providing a supportive space for both patient and partner to discuss feelings that can otherwise manifest negatively in a relationship enables trust and confidence in each other and has positive effects on relationships.\textsuperscript{32} However, partners may need more support when it comes to how they express their emotions\textsuperscript{30} and process negative feelings.\textsuperscript{3} The timing of interventions varied. Some evidence suggests that it may be more beneficial for HNC patients and their partners to receive problem solving support in the acute phase of treatment.\textsuperscript{30} The timing for emotional support seemed controversial, with some data supporting the acute phase being ideal\textsuperscript{32} and others pointing to more benefits post-treatment.\textsuperscript{45} Perhaps it is the type of interventions that may reap more benefits for patients\textsuperscript{46} by targeting both psychological and sexual problems simultaneously.

b. Assessment tools

Two cohort studies analysed and reported outcomes on questionnaire development and screening tools to assess the intimacy needs of HNC patients.\textsuperscript{13,27} Underreporting of intimacy issues remains a concern whether this be through patients or health care professionals feeling uncomfortable to raise and discuss the
issue or the lack of a specific tool to aid discussion during clinical appointments. The Mitchell-Hoole-Kanatas (MHK) questionnaire\textsuperscript{27} has been designed by HNC health care professionals and patients to explicitly identify the needs of this group of individuals. Issued alongside other routine validated tools at clinical appointments accessibility is relatively straightforward. With specific questions on relationships, sexual desire and sex life, it provides the patient with the opportunity to engage in further conversations that they might not otherwise have felt able to with their clinical teams. Whilst still in its developmental stage, early results using the tool identified that over half of the participants ability to enjoy a sex life had been affected. The tool was also able to identify the areas of most concern in relation to this, for example, bad breath, fatigue, loss of confidence.\textsuperscript{27} Further, a retrospective evaluation\textsuperscript{13} analysing the use of an intimacy screening question and Patient Concerns Inventory (PCI) prior to clinical appointments was able to identify those experiencing intimacy issues and or at risk of intimacy issues and those that wished to discuss this with their health care professional.\textsuperscript{13} Findings suggested that those who wished to discuss intimacy issues went on to score better at subsequent clinic visits as opposed to those who, despite disclosing they were experiencing significant intimacy issues, wished not to discuss this were more likely to continue to experience such problems. Both tools place emphasis on early screening and identification of those at risk. Using touch screen technology\textsuperscript{13} appears an efficient and reliable method of data collection that allows for patient monitoring and evaluation of outcomes which, as a method, the MHK tool may benefit from. Combining technology with a specific HNC tool has the potential to achieve early identification to improve people’s QoL. Whilst both tools do not provide solutions to the issues raised, they do however afford the patient the platform needed to discuss their concerns that will allow for appropriate support and care. It is suggested that nurses and the HNC team may be best placed to discuss intimacy issues with patients,\textsuperscript{13,27} however, appropriate training and support for clinical staff is required to fulfil this role.\textsuperscript{13}

4. Discussion

The aim of this review was to explore the effects HNC had on relationship intimacy and what current support exists for patients and their partners. The review highlights the ongoing challenges HNC patients and their partners face from diagnosis to survivorship and how intimacy remains an under-addressed area of holistic care.

HNC affects relationships both positively and negatively. Gruelling treatment often means that couples adapt to a new patient-carer dyad, which proves helpful in the early stages of treatment supporting patients to adhere to daily self-care routines, but also hinders the usual intimate side of relationships from occurring.\textsuperscript{12,28} Some couples come closer during the cancer journey\textsuperscript{14,16,23-25,28} especially those who are married and feel a sense of security within their relationship.\textsuperscript{24} However, many couples experience a decline in intimacy\textsuperscript{26} and increased distress owing to treatment effects such as disfigurement\textsuperscript{29} where feelings of
resentment and conflict can arise over self-care routines\textsuperscript{12,24,28} putting increased strain on an already fragile situation.

Communication was central with some couples finding talking helpful and, others finding it more challenging. Being open and honest within the relationship saw positive effects such as less distress and more intimacy,\textsuperscript{33} whilst for others resulted in notable changes in intimate behaviours.\textsuperscript{34} Treatment side effects also impeded communication between couples with patients finding it difficult to talk or to be heard through thick saliva and tracheostomy tubes leading to fear, anger and a sense of vulnerability.\textsuperscript{23} The literature acknowledges the importance of patients receiving credible information relating to their diagnosis, treatment and side effects. However, patients did not always feel they received enough information from their clinical teams and would seek further information from the internet to fill the gaps.\textsuperscript{23,34} There was no consensus on the timing of information at diagnosis\textsuperscript{23,36} versus post-treatment.\textsuperscript{35} This is comparable with the research in prostate cancer where men reported a lack of adequate information to manage sexual concerns.\textsuperscript{47}

There were also instances where sexual health was never broached at clinical appointments\textsuperscript{16} either due to patients feeling uncomfortable, especially males,\textsuperscript{12} or the health care professionals feeling uncomfortable.\textsuperscript{23} This is similar to other cancer studies who reported patients had very little communication with their health care professional about sexual health\textsuperscript{48} or it was avoided.\textsuperscript{49} This review has highlighted HNC patients want to have information on the changes they may experience during their treatment, and they would prefer it in the first instance to be from a health care professional.\textsuperscript{13,36}

All articles reported that HNC had negatively affected intimate and sexual relationships owing largely to treatment side effects.\textsuperscript{16,25,34,37} Whilst there was conflicting evidence regarding the ages of those most affected, the evidence did highlight that both younger and older adults experience intimacy problems. Many patients reported that sexuality plays an important part of their lives\textsuperscript{16,37,39} and they want to be intimate with a partner, but barriers such as fatigue,\textsuperscript{16,23} body image concerns,\textsuperscript{15,26} distress\textsuperscript{37} and functioning in public prevent patients participating in sexual activities and socialising.\textsuperscript{13} This is especially true for those patients who are single and want to seek a partner, but experience significantly low confidence to socialise and meet new people. Similar barriers to engaging in sexual relationships have also been reported in other cancers such as vaginal, vulva\textsuperscript{50} and prostate.\textsuperscript{47}

Couples-based communication interventions strategies although seem to improve psychological wellbeing, no gains were reported for sexual interest and enjoyment.\textsuperscript{32,45-46} Having a partner to cope with and share the experience with may be more beneficial than emotional disclosure during the immediate treatment phase,\textsuperscript{31} suggesting that communication interventions may be more meaningful for couples in the survival phase. Interventions that tackle both psychological and sexual problems simultaneously may prove more beneficial for couples.\textsuperscript{46}

\textbf{While there are commonly used communication tools to address intimacy and sexuality in cancer such as the PLISSIT (Permission, Limited Information, Specific Suggestions, Intensive Therapy) model; Extended PLISSIT model, BETTER (Bring up the topic, Explain, Telling,
Timing, Education, Recording and Signposting) model and EASSi (Engagement, Assessment, Support and Signposting) model.\textsuperscript{51} They are not specifically designed for HNC patients. The MHK tool requires further testing and validation, but it may prove useful as a platform for more holistic conversations between patients and their healthcare teams that explicitly address the needs of HNC patients.\textsuperscript{27} Similar positive results have been observed using the EASSi tool specifically designed for prostate cancer survivors that facilitates conversations and promotes routine sexual health care.\textsuperscript{47}

An evaluation of using an intimacy screening question and Patient Concerns Inventory (PCI) in one study highlighted its potential benefits for identifying those at risk of intimacy issues. However, the assumption that all patients will want to discuss the issue and if so, who with, requires further investigation.\textsuperscript{13} The evidence suggests some patients may feel uncomfortable to discuss with their surgical team but feel more comfortable with their HNC nurse team. This was also found to be true for other cancer survivors transitioning care from their medical team to their primary care practitioners.\textsuperscript{48} The wider literature acknowledges that patients prefer their health care professional to initiate intimacy conversations,\textsuperscript{50} however, it is reported that many feel underprepared and lack knowledge to lead these discussions.\textsuperscript{49,52} This further highlights the need for training and support for clinical teams to undertake these assessments particularly with a rise in HPV OPC where there will be a need for ongoing care with this younger demographic.

5. Implications

During treatment patients’ priorities are focussed on surviving and getting through the treatment side effects. Beyond this period patients, whilst adjusting to their new normal, are recognising the changes in their intimate relationships and often need support to identify what those changes mean and the impact it is having. The importance of intimacy being discussed as part of patient care is a necessary part of holistic care planning, but barriers seem to exist for both patients raising it with their health care teams and health care professionals raising it with patients. This partly could be explained by having no specific HNC tool available that explicitly identifies the needs of this patient population and those couples at risk of intimacy issues. It could also be explained by the sensitive and private nature of the topic, which gives rise to the question of who should raise it, when should it be raised and who is the most appropriate health care professional to discuss these issues with? However, health care professionals are not always comfortable to do this in part due to confidence and competence. With HPV OPC predicted to overtake the traditional HNC, there will also be a much younger demographic of patients and partners at risk of intimacy issues that will require psychological and psychosocial support in the longer term. It is therefore essential that staff be provided with support and training to be equipped with the necessary skills of identifying, supporting and referring those couples at risk. For example, the use of the International Sexual Health Care Competency model\textsuperscript{53} offers CPD opportunities in communication and assessment from novice to advanced levels. Further, the Maximising Sexual Wellbeing: Cancer Care eLearning resource has shown
potential as a useful CPD resource in preparing health care professionals to support routine sexual health care.\textsuperscript{49}

As higher numbers of younger people with HPV OPC are being diagnosed and are seeking information on intimacy, they will require support from their health care teams to provide this sensitively. Whilst a few interventions have been trialled, there is evidence to support the advantages of couple’s communication interventions. The timing of interventions would suggest implementation in the survivorship period would be more beneficial as would combining psychological and sexual health together.

6. Limitations
This was a large systematic review with thirty articles included. The experiences and results of the participants in most studies were over the age of fifty years and in a long-term relationship which may not now be representative of the younger demographic being diagnosed with HPV OPC. Thus, further research into the experiences and intimacy needs of younger age groups may be valuable. Interpretation of results was problematic where intimacy was not defined as was the case in the majority of studies. Further consideration is the inclusion of studies with differences in tumour sites, stages and treatments that may challenge the generalisability of the findings of this review. Despite the limitations, this review provides evidence of the effects of HNC on relationship intimacy and the current support available to patients and partners. However, further research is needed to explore how healthcare professionals are identifying and supporting HNC patients with intimacy needs and how confident and competent they feel to do this. Further, an exploration of the perceived barriers for HNC patients in discussing intimacy concerns with their health care teams would benefit from future research.

7. Conclusion
The current literature highlights that for some couples their relationship can become closer and stronger during the cancer journey, but the majority experience profound effects such as loneliness, worsening sex lives, sexual dysfunction, social anxiety, lack of desire and satisfaction. However, both patients and their health care professionals are not consistently discussing these issues leaving it often an unmet need for the patient and partner. It is imperative that health care professionals be supported with training and development in areas that require sensitive person-centred care. To assist health care professionals to identify those couples at risk of intimacy issues a validated HNC tool that explicitly identifies the needs of this population would support a more holistic approach to patient care.

8. Conflict of interest
There are no financial or personal conflicts to report.
9. References


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