

REVIEW

Factors associated with psychological distress for couples facing head and neck cancer: A systematic literature review

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Abstract

Objectives: Cancer patients in supportive relationships display improved health and survival outcomes. Identifying factors that might respond to intervention for Head and Neck Cancer (HNC) dyads is important as HNC patients and their partners experience heightened distress. This article systematically reviewed and evaluated the research findings and methodological quality of studies which identified factors influencing psychological distress for couples facing HNC.

Methods: PsycINFO, Medline, and CINAHL were searched. Studies were included if they used validated psychological distress measures and quantitative data collection methods. Eleven studies satisfied inclusion criteria.

Results: Studies identified factors associated with the psychological distress experienced by couples facing HNC, with substantial effect size variation. These factors included clinical, sociodemographic, relational, and psychological variables. Factors associated with increased psychological distress included disease burden, reduced social contact, perception of reduced relationship quality, and less adaptive/assimilative coping although the effect sizes displayed considerable heterogeneity. Overall, studies possessed good methodological quality but generally could have been improved by minimising the risk of non-response bias and fully reporting relational characteristics.

Conclusions: The implications of these results for clinical practice and future research are discussed. Further research is recommended to report effect sizes more consistently for both dyad members to gain greater insight into couple-level distress and to perform moderator analyses to identify which variables influence the magnitude of psychological distress.

KEYWORDS

anxiety, cancer, couple, depression, dyad, head and neck cancer, partner, psychological distress, Psycho-Oncology, systematic review

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1 | INTRODUCTION

Head and Neck Cancer (HNC) refers to malignancies that occur in the paranasal sinuses, nasal cavity, oral cavity, larynx, and pharynx. There are 300,000 HNC-related deaths and approximately 880,000 incidences of HNC annually.^{1,2} HNC and its related treatments such as radiotherapy, chemotherapy and surgery pose significant physical and psychological challenges³ concerning visible disfigurements and impaired eating, speaking, swallowing, and breathing.^{4,5} Psychological distress occurs frequently in HNC patients and can endure post-treatment.⁶ Psychological distress is a particular concern in HNC,^{7,8} as HNC survivors have increased suicide risk even compared with other cancer patients.⁹ Several factors contribute towards this, such as a significant symptom burden, functional difficulties (breathing, swallowing, eating), heightened recurrence risk, stigma associated with alcohol use/smoking in the development of cancer, and poor prognosis outcomes.¹⁰

Partners of HNC survivors also experience heightened psychological distress;^{11,12} this is consistent with spouses of other cancer-type survivors but could be pronounced in HNC due to high care-giving responsibilities and the severe physical and psychosocial impact of the diagnosis and related treatment.^{13,14} An HNC survivor's partner may need to provide considerable support with symptom management, rehabilitation tasks, emotional distress, and communication needs.^{6,14} Research suggests that rates of psychological distress in partners of HNC survivors are higher than distress reported in individuals diagnosed with other cancers, including breast and prostate cancer.^{15,16} A study investigating psychosocial adjustment for HNC caregivers in the post-treatment period (6–24 months) found that 39% of caregivers reported moderate to high distress.¹⁷ This highlights the far-reaching impact upon HNC caregivers during and beyond treatment.

Furthermore, HNC presents difficulties for couple-level functioning relating to intimacy and sexuality; this includes treatment-related consequences that impact on physical connection such as the presence of a feeding tube, body image concerns, and oral difficulties such as a persistent dry mouth or excessive salivation.^{18–20} Additionally, the physical sequelae of HNC can impact upon couple-level communication; the structures commonly affected by treatment are important for both verbal and non-verbal communication, such as speaking and achieving facial expressions.²¹ These difficulties are reflected in research indicating a decline in marital functioning one year post-treatment.²² Another study reported that 83% of HNC spouses and 100% of patients stated that there was increased marital dispute during treatment.²³

It is important to support couples to maintain relationships while they experience the stressors of diagnosis and treatment, as supportive partner relationships are implicated in increasing quality of life, improved adaptation to the cancer, and better survival rates;⁶ Research found that being married reduced the chance of death for HNC patients by 33%²⁴ and substantially improved performance status during treatment in comparison to unmarried patients.²⁵ Research recommends that developing couple-based

interventions for dyads experiencing HNC could focus on communication and collaboration.²⁶ Understanding a wide range of influencing factors is important, as the development of couple-based interventions has been predominately aimed at patients and partners experiencing breast or prostate cancer.²⁷ However, a broader understanding of the psychological, clinical, relational, social, and demographic factors²⁸ that influence dyadic psychological distress, either as causes or exacerbating/buffering factors, is currently missing from the HNC literature. The development of this understanding would make it easier to both identify malleable factors which could be targeted in such couple-based interventions and screen for/assess couples who may be especially vulnerable to experiencing psychological distress.

Psychological distress is variously defined across literature. This review defines it as an aversive emotional state which is experienced by an individual when they are presented with a stressor or demand that causes either temporary or permanent harm.²⁹

1.1 | Rationale for current review

While other reviews have examined factors associated with depression and quality of life in HNC patients,^{7,8} no review has systematically investigated the factors influencing distress for both HNC patients and their partners. This review aims to systematically identify and synthesise the key findings of studies that identify these associated factors. Furthermore, the review aims to provide a detailed appraisal of the methodological quality of the identified papers. Due to evidence indicating that couples facing HNC experience heightened levels of distress,³⁰ a clearer understanding of factors influencing this experience could inform clinical practice and add to existing theories such as the relationship intimacy model of couples' psychosocial adaptation to cancer.³¹ This model suggests that couples affected by cancer adopt relationship behaviours which either increase or reduce dyadic closeness: this closeness is hypothesised to influence the couple's adaptation to cancer.³¹ A broader understanding of any influencing relational and psychological factors warrants particular attention, given the potential malleability of couple-level relational interactions and individual-level psychological responses/appraisals in reducing psychological distress, as compared to demographic and clinical factors. However, an awareness of the influencing demographic, social, and clinical factors is also important in supporting clinicians/researchers to screen for/assess couples who are vulnerable to experiencing greater distress.

2 | OBJECTIVES

- (1) Systematically identify and synthesise key findings of studies that identify factors associated with psychological distress for both HNC patients and their partners
- (2) Offer a detailed appraisal of the methodological quality of the identified research papers

3 | METHODS

The review was pre-registered with the International Prospective Register of Systematic Reviews (PROSPERO: ID = CRD42020213101)

3.1 | Eligibility criteria

Studies were considered for inclusion if they satisfied the following criteria:

1. Consisted of a sample of couples where one member had experienced HNC. Adult patients at any stage of HNC were included. In line with medical literature^{32,33} and previous systematic literature reviews,³⁴ thyroid cancer patients were included. However, oesophageal cancer was not included³⁵
2. Available in English language for practicality
3. Published in a peer-reviewed journal to ensure a minimum standard for scientific rigour and quality
4. Included a validated measure of psychological distress which was reported as an outcome measure (either a primary or secondary outcome)
5. Reported separately extractable data for both members of the couple to gain a holistic picture of couple-level psychological distress and the factors influencing this
6. Used a quantitative method for data collection and analysis. The current review did not list a mixed-methods design as exclusion criteria but would only extract quantitative data
7. Reported a measure of association between psychological distress and the relevant influencing factor

3.2 | Studies were excluded if:

1. A heterogeneous cancer sample was described with no isolable HNC data
2. The dyads in the study were not specifically described as partner dyads (i.e., caregiver or family member dyads)

No limits existed regarding quantitative study designs or publication years, other than the limitations imposed due to the time periods covered by databases. Where two papers reported results relating to the same study and participants, they were included if each paper asked different questions of the data.

3.3 | Systematic search

Research articles were systematically searched for using the Ovid host (www.ovid.com); the CINAHL, PsycINFO, and MEDLINE databases were searched from the start of the database to the 20 October 2020. A research librarian was consulted to generate

individualised search terms for each database (Appendix S1). Search terms consisted of medical subject headings (MeSH) and free-text search terms (Appendix S1). The three key review search concepts were 'partners,' 'head and neck neoplasms,' and 'psychological distress'; however, several search terms were produced for each key term to ensure thorough searches. The search terms were exploded where appropriate to access articles using different terminology. Following the identification of relevant search terms, the list of terms for each key concept were linked using the Boolean operators of 'or/and' to produce the search results for the three databases. The search results were gathered and any duplicates between databases were removed using the Mendeley reference manager (www.mendeley.com). The reference lists of included articles were hand-searched to identify additional articles.

3.4 | Data extraction

Articles were initially screened by title and abstract by a single investigator (LM). All results from one database were additionally screened by a second author (NM) to generate an inter-rater reliability score: overall weighted kappa = 1.00 (perfect agreement). When it was not possible to assess eligibility through abstract and title screening, full-text copies of the articles were sourced and reviewed by one author (LM) to determine eligibility. Data were extracted using a pre-designed table. Extracted data included: first author, publication year, country, study aims, design, sample size (% male), mean age (age range/standard deviation), primary location of cancer, relationship status (%), mean length of relationship (standard deviation, relationship length range), psychological distress measure, and non-negligible findings. Primary data were converted where necessary to compute associations (transforming medians and ranges to means and SDs^{36,37} and converting standardised mean-differences to correlation coefficients [*r*];³⁸ ultimately all associations were converted to a single metric [*r*]).

3.5 | Quality assessment

The first author rated the methodological quality of the articles using a quality appraisal tool. There is no 'gold standard' quality appraisal tool³⁹ so an adapted version of the Mixed Methods Appraisal Tool was used (MMAT).⁴⁰ This was the preferred choice as it supplied criteria on both quantitative descriptive studies and quantitative non-randomised studies which was appropriate based on the heterogeneous study designs represented by the included papers. The criterion of 'Have relational sample characteristics been fully reported?' was included to enhance the methodological quality assessment regarding which studies had provided full details on the relational details of their sample. Each study was rated as follows against each criterion; 2 = 'Yes,' 1 = 'Cannot tell,' 0 = 'No.' The individual scores were summed, generating a score out of 18; a higher score reflects a study of higher quality. Hong et al.⁴⁰ recommend not making

TABLE 1 The conceptual grouping of influencing factors

Higher order factor	Lower order factor
• Clinical	Cancer (disease and treatment characteristics) disease burden
• Sociodemographic and social network	Social contact gender patient versus carer role age education
• Relational (within-couple)	Perception of relationship quality relationship behaviours communication intra-dyad coping styles and satisfaction dyadic relational factors
• Psychological	Illness perceptions/appraisals coping styles goal disturbance self-efficacy

inferences regarding study quality and risk of bias based on the overall score. It is suggested that the ratings of each criterion are supplemented by detailed explanations of how the score was chosen to clarify the quality of the studies.⁴⁰ The modified appraisal tool used can be found in Appendix S2; this tool also provides operational definitions for individual quality items. To assess the inter-rater reliability of quality appraisal, a subsample of studies (50%) was randomly selected for double coding by a second reviewer (a co-author), with any differences of opinion resolved through discussion. Prior to discussion, the overall weighted kappa = 0.965.

3.6 | Coding of influencing factors

A coding system was developed to allow conceptual grouping of factors, producing a common nomenclature for the current review. These factors were coded as follows. The factors were assigned to one of four higher-order (general) categories: Clinical, Sociodemographic and social network, Relational, and Psychological. Within each higher-order category, lower-order (specific) categories were found to identify the relevant factors more specifically. The higher-order and lower-order categories are displayed in Table 1.

3.7 | Data analysis

The decision to not conduct a meta-analytic synthesis was informed by the marked heterogeneity across articles, particularly regarding timings of outcome assessments and measurement of psychological distress. A narrative synthesis of the quantitative data is provided and the effect sizes of the association between the influencing factors and psychological distress are reported in Table S2⁴¹ (available as supplementary information) and explored. Specifically, when synthesising across studies/estimates, we report effect-size ranges and medians to quantify associations of interest without making assumptions about underlying distributions.⁴² Where a study reports multiple coefficients for a given category of factors or range of (patient and partner distress) outcomes, we take the median estimate for that study; a central estimate across studies is then estimated as the median of study medians. These central estimates are reported alongside ranges (smallest to largest reported effect) to convey the

full span of associations observed across studies. Estimates (range and central tendency of effects) are reported in this way for all higher-order factors; within each higher-order factor, estimates are also reported for the lower-order factor(s) that were considered most robust (i.e., those that appear to have the *largest overall effect[s]*, based on estimates from *at least two primary studies*). For interpretation of the magnitude of associations (effect-size *r*) we follow Cohen's (1988) convention:⁴³ 0.10 = small, 0.30 = moderate, 0.50 = large.

4 | RESULTS¹

4.1 | Results of the search/study selection

Figure 1 displays the systematic search process in a PRISMA flowchart⁴⁴ and provides details regarding exclusion reasons. The systematic searches and hand-searching of reference lists produced 1330 results. Duplicates were removed, producing 1190 results. Abstract and title screening was conducted which led to 38 results. A final full-text screening led to the inclusion of 11 studies.

4.2 | Study and sample characteristics

Eleven studies were included (see study references list). Table S1, available as supporting information. Studies were assigned a reference number for identification within the review.

All studies were published during or after 2003. Studies were conducted in the USA [S1 - S3, S9], Switzerland [S4 - S6], the UK [S7, S11], and The Netherlands [S8, S10]. The average reported age of HNC patients ranged from 46.5 to 63 and the average reported age of partners ranged from 47.21 to 61. The average reported percentage of male patients ranged from 29% to 100% and the average reported percentage of male spouses ranged from 0% to 71%. Two papers used the same sample but asked different questions of the data [S2 and S3]. The total participant sample from the papers presents as 516 HNC patients and 478 partners but actually reflects 486 patients and 448 partners as Badr et al.^{6,45} were based on the same sample of 30 patients and 30 spouses. The studies used either cross-sectional, longitudinal, or randomised-control trial designs. The

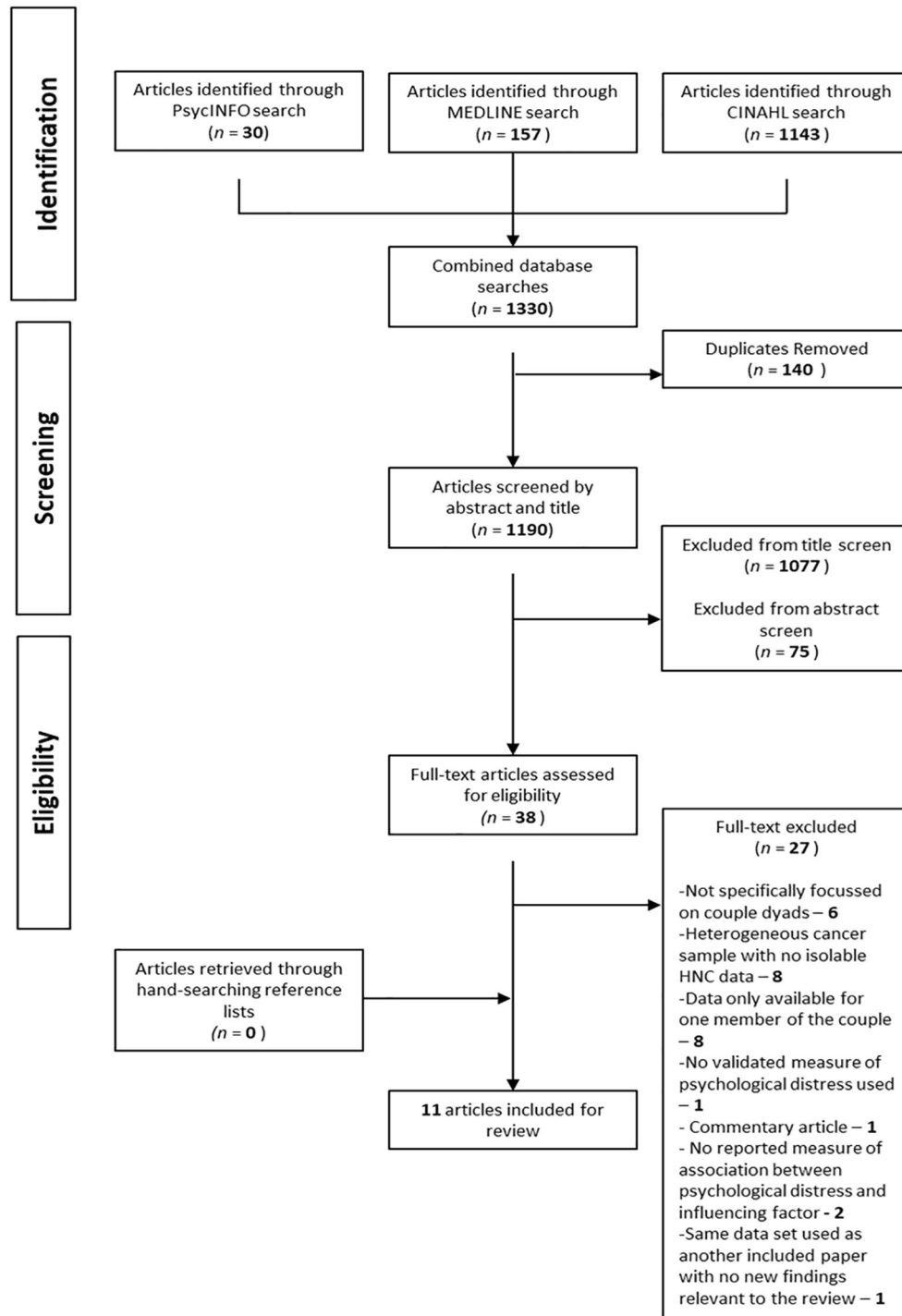


FIGURE 1 PRISMA flow chart depicts the process of selecting studies. Adapted from Moher et al.⁴³

primary HNC locations included oropharyngeal, oral cavity, nasal cavity, paranasal cavity, laryngeal, hypopharyngeal, thyroid, nasopharynx, salivary gland, and parotid cancer. The relationship length of couples ranged from 2 weeks to 58 years. However, not all studies provided relational information (S6–S8, S10–S11). All studies provided a measure of psychological distress, most commonly the Hospital Anxiety and Depression Scale [S6, S8–S11]

4.3 | Factors influencing psychological distress for couples

Several factors influenced psychological distress. These factors were grouped into higher-order (general) categories of Clinical, Socio-demographic and social relational, Relational, and Psychological factors, and then sub-divided into lower-order (specific) categories, as

represented in Table 1. The accompanying narrative provides a synthesis of the results of the studies and characterises the range and median of effect sizes for the higher-order factors to allow for clearer cross-comparative statements to be made regarding the relative strength and directionality of classes of variables. Lower-order factors with the strongest associations are highlighted narratively when they are based on estimates from at least two primary studies.

4.4 | Clinical variables

Five studies identified clinical factors associated with psychological distress (S3, S6, S9–S11). Observed effects varied (absolute r values [r_s] from 0.01 to 0.66) but were typically of small magnitude (median of medians = 0.27). These clinical variables were sub-divided into two lower-order categories: (1) Cancer (disease and treatment characteristics) and (2) Disease Burden. Regarding cancer (disease and treatment characteristics), absolute r_s (observed across two studies) ranged from 0.01 to 0.28 (median of medians = 0.09, negligible effect) with the strongest relationship indicating that current provision of treatment to patients was associated with lower traumatic stress for partners. Regarding disease burden, absolute r_s (observed across four studies) ranged from 0.09 to 0.66 (median of medians = 0.31, moderate effect) with the strongest relationship indicating that eating difficulties were associated with greater depression in patients.

4.5 | Sociodemographic and social network variables

Six studies identified sociodemographic and social network factors associated with psychological distress for couples (2, 5, 6, 7, 9, 10). Again, observed effects varied (absolute r_s from 0.05 to 0.68) but were typically small (median of medians = 0.29). Sociodemographic and social network factors were sub-divided into five separate categories: (1) Social contact; (2) Gender; (3) Patient versus carer role; (4) Age; and (5) Education. Of these, social contact showed the most robust associations with outcome (across three separate studies): absolute r_s ranged from 0.17 to 0.64 (median of medians = 0.45, moderate effect) with the strongest relationship (in study [10]) indicating that decreased social contact was associated with increased patient distress. Regarding age, absolute r_s (reported across two studies) ranged from 0.05 to 0.68. The strongest sociodemographic effect, observed in study (2), related to age and indicated that older age was associated with lower anxiety in patients. However, the average effect for age (based on estimates across two studies) was small (median of medians = 0.22, absolute r_s ranging from 0.05 to 0.68).

4.6 | Relational variables

Seven studies (S1–S4, S6–S7, S10) identified relational factors associated with psychological distress for couples experiencing HNC.

Observed effects were again wide-ranging (r_s from 0.01 to 0.59) though typically small (median of medians = 0.12). The relational factors were categorised into five lower-order factors: (1) Perception of relationship quality, (2) Relationship behaviours, (3) Communication, (4) Intra-dyad coping styles, and (5) Dyadic relational factors. Of these, dyadic relational factors (pertaining to the inter-relationship between patient and partner distress levels) showed the most robust associations with outcome: demonstrating the strongest average effect (median of medians = 0.28) based on estimates from four separate studies (with observed r_s ranging from 0.12 to 0.49). These associations essentially evidence interdependence of patient-partner distress. The strongest relational effect observed in primary studies (0.59) pertained to perception of relationship quality (4)—specifically indicating that negative or mixed-valence changes in relationship quality were associated with increased patient anxiety—although the average effect for this factor was small (median of medians = 0.17, r_s ranging from 0.02 to 0.59) across the four studies reporting relevant estimates.

4.7 | Psychological variables

Three studies [S8–S10] identified psychological variables associated with psychological distress for couples facing HNC. Absolute effect sizes ranged from 0.06 to 0.73 and were typically large (median of medians = 0.60), with the strongest relationships indicating that health-related self-efficacy is inversely associated with depression in patients (–0.71) and partners (–0.73). Psychological variables were sub-categorised into four lower-order categories: (1) Illness perceptions/appraisals; (2) Coping styles; (3) Goal disturbance; and (4) Self-efficacy. Of these factors, estimates for coping styles were arguably most robust as they were based on data from two studies (whereas effect estimates for other factors were based on data from a single study). Regarding coping styles, absolute r_s ranged from 0.29 to 0.66 (median of medians = 0.48, moderate); the strongest observed relationship (0.66) was between passive coping and greater patient distress—paralleled by the similarly large association between passive coping and greater partner distress (0.62) in the same study (S10). Findings in study (S10) were mirrored in study (S8), which found a strong negative relationship between active re-engagement coping and patient depression (–0.60) alongside smaller negative associations between active coping and patient and partner anxiety (–0.29 and –0.33 respectively).

4.8 | Quality appraisal and risk of bias within studies

Table 2 presents the quality appraisal results. The adapted MMAT⁴⁰ (Appendix S1) was primarily used to ensure that relevant design characteristics were present and inform critical analysis. However, the chief function of the quality appraisal was to identify areas of weakness in the studies to date and inform recommendations for future work. Level of agreement between reviewers was assessed

TABLE 2 Methodological quality of the included studies

Quality appraisal criteria	Study Number										
	1	2	3	4	5	6	7	8	9	10	11
1. Are there clear research questions?	2	2	2	2	2	2	2	2	2	2	2
2. Do the collected data allow to address the research questions?	2	2	2	2	2	2	2	2	2	2	2
3. Is the sampling strategy relevant to address the research question?	2	2	2	2	2	2	2	2	2	2	2
4. Is the sample representative of the target population?	2	1	1	1	1	2	1	1	2	1	1
5. Are the measurements appropriate?	2	2	2	2	2	2	2	2	2	2	2
6. Is the risk of non-response bias low?	0	2	2	1	1	1	1	1	2	1	1
7. Is the statistical analysis appropriate to answer the research question?	2	2	2	2	2	2	2	2	2	2	2
8. Are there complete outcome data?	2	2	2	2	2	2	2	2	2	2	2
9. Have relational sample characteristics been fully reported?	2	2	2	2	2	0	0	0	2	2	0
Quality appraisal total score	16	17	17	16	16	15	14	14	18	16	14

Note: This appraisal tool is an adaptation of the Mixed Methods Appraisal Tool (MMAT)⁴⁰ which can be found in Appendix S1. The scoring refers to whether the criterion is present within the study: 2—'Yes,' 1—'Cannot Tell,' 0—'No.' It was possible to achieve a maximum score of 18.

(across six studies, i.e., a sampling frame of 50%) and, prior to resolving any differences, overall weighted kappa = 0.965 ('almost perfect' agreement).

All 11 studies satisfied the initial screening questions regarding clear research questions and the collected data addressing the research questions. If a study failed these initial questions, then further appraisal may have been unfeasible or inappropriate.⁴⁰ All studies reported sampling strategies; non-probability sampling was used by all studies which was appropriate due to the specific study population in question. However, regarding the requirement for sample populations to be representative of the target population, only three of the studies had samples judged to be representative of the population (S1, S6, S9). Two studies drawing from the same data set (S2–S3) did not have representative samples as the majority of the sample population were comprised of advanced-stage HNC patients which limits the generalisability of findings to early-stage HNC patients. It was not possible to ascertain whether the sample populations for six studies (S4–S5, S7–S8, S10–S11) were representative of the target populations as the reasons for eligible individuals not participating were not supplied. Additionally, in one study (S10), it was difficult to establish how many of the approached dyads had actually agreed to participate. Most of the papers satisfied the requirement to have appropriate measures for their specific research questions. However, one paper (4) employed a self-designed, non-validated questionnaire to measure intimacy changes. Only three studies were considered to satisfy the criterion requiring the risk of non-response bias to be low (S2–S3, S9). Study 1 displayed a potential non-response bias, as differences were found between respondents and non-respondents: non-respondents were found to have worse performance status in relation to their cancer treatment and were found to have higher levels of spousal distress at the recruitment stage. In seven of the included studies (S4–S8, S10–S11), it was difficult to judge non-response bias, as these studies did not

provide enough information to assess whether those who participated were different from those who did not in terms of the variables of interest.

All studies were judged to have used appropriate statistical analyses. Additionally, all studies provided complete outcome data; although there is no widely agreed cut-off value for what is considered an acceptable level of outcome data completion, this review adopted the conservative figure of 95% to categorise a study as providing complete outcome data.⁴⁶ Seven of the studies satisfied the requirement to have fully reported relational sample characteristics: this was an additional quality criterion due to the relational focus of the current review. Four studies did not meet the requirements for this criterion due to studies either only partially reporting characteristics or providing no information (S6–S8, S11).

5 | DISCUSSION

5.1 | Key findings

The current review identified factors associated with psychological distress for couples facing HNC relating to four variables: clinical, sociodemographic and social network, relational, and psychological. The findings will be discussed in relation to each variable. Overall, the strongest magnitude of association was found for psychological variables (individual differences in coping, illness perceptions, self-efficacy, and goal disturbance).

Regarding clinical factors, several studies identified that the HNC disease burden predicted increased psychological distress for patients and partners. These findings are consistent with research identifying HNC as an especially traumatic cancer due to both the illness and the aggressive treatment options it necessitates.^{10,23} There was considerable variation in the reported effect sizes which

ranged from small to large and the overall median r was small. However, two studies did not find an association between these variables for patients (S3, S6). Notably, some studies only reported an effect size in relation to the experienced disease burden for the patient rather than both dyad members. In terms of cancer (disease characteristics), the median r was negligible, indicating that disease characteristics of the cancer did not predict distress for couples as compellingly as disease burden. This aligns with literature from breast cancer populations, which found no effect of either the type of surgery or the type of adjuvant therapy on subsequent distress levels.²⁸ However, fewer studies in the review investigated the role of disease characteristics in influencing distress, as opposed to disease burden, so it is possible that with larger sample sizes, a stronger relationship may have been found.

Regarding sociodemographic and social network factors, several factors were identified. Two studies (S7, S10) identified large, significant relationships between supportive social contact and lower levels of psychological distress for couple members. These results are consistent with literature suggesting that social support produces less psychological distress for those experiencing HNC.^{47,48} The quality of research on this topic would be further enhanced if future research consistently reported effect sizes for both patients and partners. In relation to gender, a negligible median r was found: this aligns with research from another systematic review which found that gender was a significant predictor of distress in only two out of 13 papers.²⁸ In terms of age, a small, negative r was found, indicating that a younger age was associated with greater distress: this finding reflects research which found that younger age was related to increased anxiety 18 months after an HNC diagnosis.⁴⁹

Regarding relational factors, there was a relationship between the perception of relationship quality and psychological distress for both patients and partners as identified by four studies (S1, S2, S4, S6). The reported effect sizes for this relationship displayed considerable variation, ranging from small to large. These findings are important for clinicians and researchers to consider, as research shows that the quality of partnered relationships is linked to psychological adaptation and cancer-related health outcomes.⁵⁰ These results might inform future research and clinical practice: when considering potential interventions for HNC dyads experiencing distress, there is potentially greater scope for intervening with more malleable relational factors as opposed to more static clinical and sociodemographic factors. In terms of communication and intra-dyad coping styles, small median r s were found: this was inconsistent with evidence highlighting the importance of intra-dyad coping styles in improving distress outcomes in couples with HNC.⁴⁵

Three studies identified psychological factors (S8–S10) which appeared to have the strongest relationships with distress (large median of study medians)—perhaps partially reflecting the interdependence of mood and cognition (individual appraisal and response-style), and common method variance (for factors assessed via subjective self-report measures). Findings from two independent studies (S8, S10) converged in suggesting that greater distress (for both patients and partners) is associated with passive (vs. engaged)

ways of coping. In terms of illness perceptions/appraisals, a small median r was found: previous research has found limited support for the role of appraisal of illness and subsequent distress.²⁸ However, the previous evidence was based on a small number of studies and was based on the patient's perception of the illness: there is a paucity of research investigating the relationship between partner perceptions of the illness and distress outcomes.

5.2 | Study limitations

Systematic literature reviews can be associated with limitations such as heterogeneity, issues concerning study selection, and incomplete or inaccurate analyses and outcomes.⁵¹ It is therefore crucial to consider the limitations of the papers and current review. A limitation of the studies concerned the heteronormative sample populations; while no studies reported that they had specified heterosexuality as an inclusion criterion, the vast majority of participating couples were heterosexual. However, little published research has explored the impact of cancer upon non-heterosexual individuals, and such patients have reported negative experiences during healthcare treatment.⁵² This is particularly problematic in this review, as literature suggests that non-heterosexual patients may experience greater psychological distress than heterosexual patients: a study examining women experiencing breast cancer found that lesbian women disclosed greater stress levels during diagnosis and treatment.⁵³ There is also an under-representation of racial and ethnic minorities, and individuals of a lower socioeconomic status in cancer research more generally;⁵⁴ these details were not reported for the included studies so it is difficult to ascertain if this was an issue for the current review but it may have affected the representativeness of the studies. Furthermore, almost all included studies used cross-sectional study designs; this is limiting as it means that causality cannot be determined from the provided correlational information.⁵⁵ This is problematic as examining the bi-directional relationships between influencing factors and the psychological distress experienced by couples was not possible.

Regarding the current review's limitations, only peer-reviewed papers were included to ensure a minimum standard for scientific quality. However, excluding grey literature could introduce publication bias which increases the likelihood of finding papers with a 'positive' result.⁵¹ Another potential limitation concerns the inclusion criterion specifying that papers must explicitly identify that participants were in a relationship: the findings cannot, therefore, be assumed to apply to other caring dyads. The current review excluded papers unavailable in English meaning that eligible papers written in another language may have been excluded, therefore introducing language bias.⁵⁶ A further consideration is the decision to include thyroid cancer patients within the definition of Head and Neck Cancer. This is contested, with more recent literature not including it.⁷ However, previous systematic literature reviews on HNC have included thyroid cancer patients³⁴ and in this study, the results from the studies including thyroid cancer patients were relatively

consistent with other types of HNC. Finally, the key findings of the current review are based on a relatively small number of papers, reducing their generalisability. However, there is still a paucity of information available on this topic, so the small number of included papers is reflective of the available evidence.

5.3 | Clinical implications

The reviewed studies indicate factors that could influence clinical practice, and potentially reduce psychological distress levels for couples experiencing HNC. These areas include:

1. Considering ways to increase the helpful received social support available to couples (directing couples to HNC support groups where they can meet others, signposting couples to supportive organisations/HNC charities)
2. Including partners in psychological work where appropriate/providing individual support for partners (support couples/individuals with marital difficulties which could accompany the significant disease and psychological burden associated with HNC)¹⁸
3. Providing partners with preparatory information regarding the impact of HNC and how to access support when the patient receives their diagnosis/initial treatment⁵⁷
4. Establishing the nature of couple's disease burden, regarding the physical and functional sequelae of diagnosis and treatment, alongside factors such as disrupted schedules/working patterns—this could identify areas where couples may benefit from further support.
5. Assessing coping styles and providing psychological intervention to promote coping⁶ for both patients and partners (this could include individual intervention around adaptive self-regulation which could be achieved through re-engaging in more realistic goals/identifying and modifying beliefs around locus of control or self-efficacy)

5.4 | Research implications

This review identifies that various research projects have a broadly similar interest in investigating factors influencing psychological distress in couples experiencing HNC; however, most studies have measured different factors. Future research would benefit from a more systematic approach which reflected the different layers of factors influencing distress: these range from the psychological and patient-clinical, through to the relational, and then beyond to broader contextual factors including social support and demographics. When studies in this area focus on just one of these categories, crucial data may be missed. Furthermore, future studies might benefit from reporting on the relationship between factors predominately experienced physically by the patient, such as disease burden, and spousal

distress to provide a fuller picture of the distress experienced by the dyad as evidence suggests that partners are affected by the patient's disease-related symptoms. This would help to achieve a broader picture of the distress experienced by couples. Research on this topic suggests that the effectiveness of social support as a buffer against psychological distress could be related to the number of physical health issues a patient experiences; future research could usefully investigate whether the benefit which dyad members derive from social support is moderated by the extent of the patient's physical sequelae.⁴⁸ This would support a more nuanced understanding of how particular factors may interact to influence distress. Regarding the influence of relational factors, future studies could usefully employ moderator analyses to find variables which influence the relationship magnitude between the perception of relationship quality and psychological distress.

6 | CONCLUSIONS

This review identifies several factors associated with psychological distress for couples experiencing HNC. Based on available evidence, among the strongest correlates of distress are malleable psychological factors—such as coping responses—and this finding holds promise for developing psychologically-informed interventions that might thereby promote better outcomes for patients and partners. However, across studies, there is considerable heterogeneity in terms of effect sizes, and methodological limitations in terms of inconsistent reporting of associations for both patients and partners alongside small, under-powered samples. This review highlights the importance of future research addressing the paucity of literature in this area while also using large, representative samples and reporting for both dyad members to improve the quality of the studies. This review has also offered clinical and research recommendations to better understand and support couples experiencing HNC.

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REFERENCES

1. Fitzmaurice C, Allen C, Barber RM, et al. Global, regional, and national cancer incidence, mortality, years of life lost, years lived with disability, and disability-adjusted life-years for 32 cancer groups, 1990 to 2015: a Systematic Analysis for the Global Burden of Disease Study Global Burden. *JAMA Oncol* 2017;3(4):524-548.
2. Bray F, Ferlay J, Soerjomataram I, Siegel RL, Torre LA, Jemal A. Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA A Cancer J Clin*. 2018;68(6):394-424.
3. Lang H, France E, Williams B, Humphris G, Wells M. The psychological experience of living with head and neck cancer: a systematic review and meta-synthesis. *Psycho Oncol*. 2013;22(12):2648-2663.

4. Ledebner QCP, Velden L-A, Boer MF, Feenstra L, Pruyn JFA. Physical and psychosocial correlates of head and neck cancer: an update of the literature and challenges for the future (1996-2003). *Clin Otolaryngol*. 2005;30(4):303-319.
5. Millsopp L, Brandom L, Humphris G, Lowe D, Stat C, Rogers S. Facial appearance after operations for oral and oropharyngeal cancer: a comparison of casenotes and patient-completed questionnaire. *Br J Oral Maxillofac Surg*. 2006;44(5):358-363.
6. Badr H, Herbert K, Chhabria K, Sandulache VC, Chiao EY, Wagner T. Self-management intervention for head and neck cancer couples: results of a randomized pilot trial. *Cancer*. 2019;125(7):1176-1184.
7. Dunne S, Mooney O, Coffey L, et al. Psychological variables associated with quality of life following primary treatment for head and neck cancer: a systematic review of the literature from 2004 to 2015. *Psycho Oncol*. 2017;26(2):149-160.
8. Korsten LHA, Jansen F, Haan BJB, et al. Factors associated with depression over time in head and neck cancer patients: a systematic review. *Psycho Oncol*. 2019;28(6):1159-1183.
9. Frampton M. Psychological distress in patients with head and neck cancer: Review. *Br J Oral Maxillofac Surg*. 2001;39(1):1-4.
10. Milette K, El-Baalbaki G, Thombs BD. Intimacy processes and psychological distress among couples coping with head and neck or lung cancers. *Psycho Oncol*. 2010;19(11):1235-1236. Available from: <https://proxy.library.lincoln.ac.uk/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2010-23833-014&site=ehost-live>
11. Nightingale CL, Lagorio L, Carnaby G. A prospective pilot study of psychosocial functioning in head and neck cancer patient-caregiver dyads. *J Psychosoc Oncol*. 2014;32(5):477-492. Available from: <https://proxy.library.lincoln.ac.uk/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2014-38565-001&site=ehost-live>
12. Posluszny DM, Dougall AL, Johnson JT, et al. Posttraumatic stress disorder symptoms in newly diagnosed patients with head and neck cancer and their partners. *Head Neck*. 2015;37(9):1282-1289. Available from: <https://proxy.library.lincoln.ac.uk/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=cmedm&AN=24817018&site=ehost-live>
13. Kam D, Salib A, Gorgy G, et al. Incidence of suicide in patients with head and neck cancer. *JAMA Otolaryngol Head Neck Surg*. 2015;141(12):1075-1081.
14. MPJ Offerman, Schroevens MJ, van der Velden LA, de Boer MF, Pruyn JFA. Goal processes & self-efficacy related to psychological distress in head & neck cancer patients and their partners. *Eur J Oncol Nurs [Internet]*. 2010;14(3):231-237. Available from: <https://proxy.library.lincoln.ac.uk/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=ccm&AN=105039110&site=ehost-live>
15. Vickery LE, Latchford G, Hewison J, Bellew M, Feber T. The impact of head and neck cancer and facial disfigurement on the quality of life of patients and their partners. *Head Neck*. 2003;25(4):289-296. Available from: <https://proxy.library.lincoln.ac.uk/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=cmedm&AN=12658733&site=ehost-live>
16. Zabora J, BrintzenhofeSzoc K, Curbow B, Hooker C, Piantadosi S. The prevalence of psychological distress by cancer site. *Psycho Oncol*. 2001;10(1):19-28.
17. Ross S, Hall A, Lake N, Drive S, Mosher CE, Ronis-tobin V. Psychosocial adjustment of family caregivers of head and neck cancer survivors. *Support Care Cancer*. 2013;18(2):171-178.
18. Badr H, Herbert K, Reckson B, Rainey H, Sallam A, Gupta V. Unmet needs and relationship challenges of head and neck cancer patients and their spouses. *J Psychosoc Oncol*. 2016;34(4):336-346. Available from: <https://proxy.library.lincoln.ac.uk/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=cmedm&AN=27269579&site=ehost-live>
19. Rhoten BA. Head and neck cancer and sexuality. *Cancer Nurs* 2016;39(4):313-320.
20. Badr H, Milbury K, Majeed N, Carmack CL, Ahmad Z, Gritz ER. Natural language use and couples' adjustment to head and neck cancer. *Health Psychol*. 2016;35(10):1069-1080.
21. Rhoten BA, Murphy B, Ridner SH. Body image in patients with head and neck cancer: a review of the literature. *Oral Oncol*. 2013;49(8):753-760. Available from: <https://doi.org/10.1016/j.oraloncology.2013.04.005>
22. Gritz ER, Carmack CL, de Moor C, et al. First year after head and neck cancer: quality of life. *J Clin Oncol*. 1999;17(1):352. Available from: <https://doi.org/10.1200/JCO.1999.17.1.352>
23. Badr H, Herbert K, Reckson B, Rainey H, Sallam A, Gupta V. Unmet needs and relationship challenges of head and neck cancer patients and their spouses. *J Psychosoc Oncol*. 2016;34(4):336-346.
24. Aizer AA, Chen M-H, McCarthy EP, et al. Marital status and survival in patients with cancer. *J Clin Oncol*. 2013;31(31):3869-3876. Available from: <http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=104108941&site=ehost-live>
25. Kanski AA, Pajak TF, Movsas B, et al. Disadvantage of men living alone participating in radiation therapy oncology group head and neck trials. *J Clin Oncol*. 2006;24(25):4177-4183.
26. Manne S, Badr H. Intimacy processes and psychological distress among couples coping with head and neck or lung cancers. *Psycho Oncol*. 2010;19(9):941-954.
27. Badr H, Krebs P. A systematic review and meta-analysis of psychosocial interventions for couples coping with cancer. *Psycho Oncol*. 2013;22(8):1688-1704.
28. Cook SA, Salmon P, Hayes G, Byrne A, Fisher PL. Predictors of emotional distress a year or more after diagnosis of cancer: a systematic review of the literature. *Psycho Oncol*. 2018;27(3):791-801.
29. Ridner SH. Psychological distress: concept analysis. *J Adv Nurs*. 2004;45(5):536-545.
30. Bakhshaei J, Bonnen M, Asper J, Sandulache V, Badr H. Emotional disclosure and cognitive processing in couples coping with head and neck cancer. *J Behav Med*. 2020;43(3):411-425. Available from: <https://proxy.library.lincoln.ac.uk/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=cmedm&AN=31414332&site=ehost-live>
31. Manne S, Badr H. Intimacy and relationship processes in couples' psychosocial adaptation to cancer. *Cancer*. 2008;112(11 suppl):2541-2555.
32. Heroiu Cataloiu A-D, Danciu CE, Popescu CR. Multiple cancers of the head and neck. *Maedica (Buchar)*. 2013;8(1):80-85. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/24023604%0Ahttp://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC3749768>
33. Shah JP, Lydiatt W. Treatment of cancer of the head and neck. *CA A Cancer J Clin*. 1995;45:352-368.
34. Morris N, Moghaddam N, Tickle A, Biswas S. The relationship between coping style and psychological distress in people with head and neck cancer: a systematic review. *Psycho Oncol*. 2018;27(3):734-747.
35. Berry MF. Esophageal cancer: staging system and guidelines for staging and treatment. *J Thorac Dis*. 2014;6(suppl.3):289-297.
36. Luo D, Wan X, Liu J, Tong T. Optimally estimating the sample mean from the sample size, median, mid-range, and/or mid-quartile range. *Stat Methods Med Res*. 2018;27(6):1785-1805.
37. Wan X, Wang W, Liu J, Tong T. Estimating the sample mean and standard deviation from the sample size, median, range and/or interquartile range. *BMC Med Res Methodol*. 2014;14(1):1-13.
38. Hedges L, Olkin I. *Statistical Methods for Meta-Analysis*. London, UK: Academic Press; 1985.

39. Katrak P, Bialocerkowski AE, Massy-Westropp N, Kumar VSS, Grimmer KA. A systematic review of the content of critical appraisal tools. *BMC Med Res Methodol*. 2004;4(1):1-11.
40. Hong QN, Fàbregues S, Bartlett G, et al. The Mixed Methods Appraisal Tool (MMAT) version 2018 for information professionals and researchers. *Efi*. 2018;34(4):285-291. Available from: http://mixedmethodsappraisaltoolpublic.pbworks.com/w/file/fetch/127916259/MMAT_2018_criteria-manual_2018-08-01_ENG.pdf%0Ahttp://mixedmethodsappraisaltoolpublic.pbworks.com/
41. Nathans LL, Oswald FL, Nimon K. Interpreting multiple linear regression: a guidebook of variable importance. *Pract Assessment, Res Eval*. 2012;17(9):1-19.
42. Grimshaw J, Thomas R, MacLennan G, et al. Effectiveness and efficiency of guideline dissemination and implementation strategies. *Heal Technol Assess*. 2004;8(6):iii-iv.
43. Cohen J. *Statistical Power Analysis for the Behavioral Sciences*. 2nd ed. Hillsdale, NJ: Erlbaum; 1988.
44. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med*. 2009;6(7):e1000097.
45. Badr H, Herbert K, Bonnen MD, Asper JA, Wagner T. Dyadic coping in patients undergoing radiotherapy for head and neck cancer and their spouses. *Front Psychol*. 2018;9(1780):1-14.
46. Higgins JP, Sterne JA, Savovic J, et al. A revised tool for assessing risk of bias in randomized trials. *Cochrane Database Syst Rev*. 2016;10(Suppl 1):29-31.
47. De Leeuw JRJ, De Graeff A, Ros WJG, Hordijk GJ, Blijham GH, Winnubst JAM. Negative and positive influences of social support on depression in patients with head and neck cancer: a prospective study. *Psycho Oncol*. 2000;9(1):20-28.
48. Katz MR, Irish JC, Devins GM, Rodin GM, Gullane PJ. Psychosocial adjustment in head and neck cancer: the impact of disfigurement, gender and social support. *Head Neck*. 2003;25(2):103-112.
49. Neilson K, Pollard A, Boonzaier A, et al. A longitudinal study of distress (depression and anxiety) up to 18 months after radiotherapy for head and neck cancer. *Psycho Oncol*. 2013;22(8):1843-1848.
50. Burman B, Margolin G. Analysis of the association between marital relationships and health problems: an interactional perspective. *Psychol Bull*. 1992;112(1):39-63.
51. Gopalakrishnan S, Ganeshkumar P. Systematic reviews and meta-analysis: understanding the best evidence in primary healthcare. *J Fam Med Prim Care*. 2013;2(1):9-14.
52. Katz A. Gay and lesbian patients with cancer. *Oncol Nurs Forum*. 2009;36(2):203-207.
53. Matthews AK, Peterman AH, Delaney P, Menard L, Brandenburg D. A qualitative exploration of the experiences of lesbian and heterosexual patients with breast cancer. *Oncol Nurs Forum*. 2002;29(10):1455-1462.
54. Ford JG, Howerton MW, Lai GY, et al. Barriers to recruiting underrepresented populations to cancer clinical trials: a systematic review. *Cancer*. 2008;112(2):228-242.
55. Spector PE. Do not cross me: optimizing the use of cross-sectional designs. *J Bus Psychol*. 2019;34(2):125-137.
56. Tricco AC, Tetzlaff J, Sampson M, et al. Few systematic reviews exist documenting the extent of bias: a systematic review. *J Clin Epidemiol*. 2008;61(5):422-434.
57. D'Souza V, Blouin E, Zeitouni A, Muller K, Allison PJ. Multimedia information intervention and its benefits in partners of the head and neck cancer patients. *Eur J Cancer Care (Engl)*. 2017;26(4). Available from: <https://proxy.library.lincoln.ac.uk/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=cmedm&AN=26777257&site=ehost-live>

SUPPORTING INFORMATION

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