

## REVIEW

# The psychosocial experiences of head and neck cancer caregivers following (chemo)radiotherapy: A systematic qualitative review and narrative synthesis

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## Abstract

**Objective:** Oropharyngeal cancer, a type of head and neck cancer (HNC), the incidence of which is increasing, often affects younger patients than traditional HNC, having distinct psychosocial consequences. Treatment side effects mean many rely on informal caregivers following (chemo)radiotherapy. The purpose of this review was to describe current understanding of the psychosocial experiences of these caregivers in the post-treatment phase.

**Methods:** A systematic search for relevant studies between January 2010 and October 2022 in three electronic databases (CINAHL, MEDLINE and PsycINFO) was followed by citation searching. Inclusion criteria were developed to ensure studies explored caregivers' experiences during the post-treatment phase following oropharyngeal cancer (chemo)radiotherapy. Thematic analysis informed by the 'Cancer Family Caregiving Experience Model', identified stressors, appraisals and responses. Themes evolved through the synthesis of recurrent concepts across the studies and a narrative of psychosocial experiences and their impact upon caregiver well-being was developed.

**Results:** Fifteen HNC papers which included exploration of the psychosocial experiences of oropharyngeal cancer caregivers following (chemo)radiotherapy were selected. Findings were synthesised to develop five themes: an emotional struggle, supporting nutrition, altered lifestyles, changes within relationships and support needs.

**Conclusions:** The completion of (chemo)radiotherapy signalled a transition for these caregivers as they undertook burdensome responsibilities. Experiences indicated that preparation for the role, assessment of needs, and targeted support is required. Additionally, caregivers' recognition by healthcare professionals as caring partners could help moderate this demanding experience.

## KEYWORDS

cancer, caregivers, head and neck cancer, oncology, oropharyngeal cancer, psycho-oncology, psychosocial, qualitative, radiotherapy, systematic review

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## 1 | BACKGROUND

The increased incidence of head and neck cancer (HNC), despite falling rates of tobacco use in the western world, has been attributed to a sharp rise over the last 30 years of oropharyngeal cancer.<sup>1,2</sup> This HNC sub-group, associated with the prevalent human papillomavirus (HPV), more commonly occurs in younger, working-age people<sup>3</sup> compared with traditional HNC. It is, however, more responsive to treatment resulting in a more favourable prognosis<sup>4</sup> and survivorship. The considerable impact of HNC diagnosis and radiotherapy, frequently given concurrently with chemotherapy (i.e., chemo-radiotherapy), means patients often require support from informal family caregivers, predominantly spouses or partners.<sup>5,6</sup> Although they may not have to manage the addictive smoking and alcohol behaviours associated with traditional HNC, oropharyngeal cancer caregivers may have to cope with other psychosocial issues.<sup>7</sup> These include having to handle a life-threatening illness during middle-age and potentially the impact of a sexually transmitted infection following their partner's HPV positive diagnosis.<sup>8,9</sup>

As cancer treatment has become increasingly out-patient based, research of the caregiving experience has developed. As a vital care resource, exploration has focused upon the physical, psychosocial, relationship and economic consequences of caregiving,<sup>10,11</sup> which affect the whole family. Support is required to sustain care, but HNC caregivers' unmet needs 6 months after diagnosis have been shown to be among the highest of all cancers.<sup>12</sup> High treatment toxicity sets HNC caregiving apart, necessitating emotional support as well as practical tasks (e.g., enteral feeding and dressings). Side effect severity peaks at the end of treatment just as care becomes home-based. Demands upon caregivers therefore increase in the post-treatment phase; a time of uncertainty about the illness trajectory, impacting upon their physical and psychological health.<sup>13–15</sup> Suboptimal psychological well-being has been identified along the HNC care pathway trajectory including in over 40% of caregiving dyads before treatment<sup>16</sup>; one third of these dyad members had significant levels of depressive symptoms. Throughout the 6-week radiotherapy course, caregivers' distress levels have been reported as higher than of those 'cared for',<sup>17</sup> including post-traumatic stress disorder.<sup>18</sup> A recent review of caregivers' needs found that whilst those related to information diminished over time, social and psychological support needs did not, peaking in the post-treatment phase.<sup>19</sup> Earlier research found greatest distress 6 months after diagnosis<sup>5</sup> and almost 40% of HNC caregivers reported symptoms suggestive of psychological anxiety, typically regarding fear of recurrence (FOR).<sup>20</sup>

Past reviews have observed that caregiving varies with treatment type and disease characteristics, requiring exploration of its psychosocial impact and consequent support needs to inform interventions within specific contexts.<sup>5,10,19</sup> Greater psychological distress in young, female spouses<sup>5,21–23</sup> has been found, characteristics likely to be those of oropharyngeal cancer caregivers. Although more recently reflecting some of the demographic change,<sup>24</sup> HNC reviews have included mixed populations and both short and long-

term perspectives of varied treatments. As yet the psychosocial experiences of oropharyngeal cancer caregivers during the post-treatment phase following (chemo)radiotherapy have not been reported. The post-treatment phase is considered here, as by past authors,<sup>13</sup> to extend up to 2 years post-diagnosis. The aim of this systematic review was to establish current understanding of oropharyngeal cancer caregivers' psychosocial experiences and support needs following (chemo)radiotherapy. It therefore explored existing qualitative research to describe both experiences of the caregiving role and its impact.

## 2 | METHOD

Narrative synthesis was the review method chosen for its suitability in summarising heterogeneous fields of research.<sup>25</sup> The use of more interpretative methods, such as meta-ethnography, was inappropriate as findings would not be translatable across diverse studies.

### 2.1 | Search strategy

Preliminary searches retrieved studies and reviews to identify keywords and common alternatives for the terms 'caregivers' and 'psychosocial'. Few studies solely exploring the experiences of oropharyngeal caregivers were found and so the research question, developed using 'Population, Exposure and Outcome',<sup>26</sup> became:

What are the psychosocial experiences and needs of caregivers of HNC patients following (chemo) radiotherapy?

Searching using terms related to time point (i.e., 'after' or 'following') and treatment modality retrieved few studies, so were subsequently omitted. Search strategies adapted for CINAHL, MEDLINE, and PsycINFO databases used free text, Medical Subject Headings and Thesaurus terms (Supplementary information S1). Citation searching was undertaken.

### 2.2 | Eligibility criteria

Criteria were developed in discussion with co-authors to ensure selected studies included oropharyngeal cancer caregivers and explored the post-treatment phase following (chemo)radiotherapy, thereby creating a distinct population to previous reviews (Table 1). Studies were included if they reflected the typical HNC population<sup>27</sup> that is, at least 25% were oropharyngeal cancer caregivers. Where HNC sub-site was not given, studies were included if at least 25% participants were aged 40–65, typical of oropharyngeal cancer patients.<sup>3</sup> Studies were excluded where more than half of participants

TABLE 1 Eligibility criteria.

| Inclusion criteria  | Exclusion criteria  |
|---|---|
| Qualitative HNC studies or qualitative findings in mixed methods HNC studies, with analysis of psychosocial experience or support needs of most caregivers in post-treatment phase following (chemo)radiotherapy (50% < 2 years)                      | Quantitative studies<br>Explorations of experiences only of diagnosis, (chemo)radiotherapy, or of long-term survivorship (i.e., two or more years after treatment)  |
| HNC studies with at least 25% oropharyngeal cancer patients. If site not given, at least 25% participants aged 40–65, typical of oropharyngeal patients and caregivers. (If ages not given, assumed similar to patient unless child/parent caregiver) | HNC studies with fewer than 25% oropharyngeal patients or if site not given, fewer than 25% aged 40–65<br>Mixed cancer site studies without separate analysis of HNC caregiving or only surgical or palliative HNC caregivers |
| Research published Jan 2010–Oct 2022 reflecting increasing incidence of HPV+ve oropharyngeal cancer   | Development or evaluations of rehabilitation or self-management interventions or assessment tools   |
| Primary studies, peer reviewed.<br>English language<br>Study populations 18 years and above.  | Expert opinion papers or conference abstracts.  |

were 2 years or more beyond treatment, considered to be beyond the post-treatment phase. Qualitative findings from mixed methods studies were included where separate methods and analyses were discernible. Quantitative studies were excluded as they do not convey the subjective experience of caregivers as defined by them.

### 2.3 | Selection of studies

Titles and abstracts were screened for eligibility by SM. Co-authors checked a random 5% sample of excluded studies.

### 2.4 | Quality appraisal

Eligible studies were appraised using the validated Critical Appraisal Skills Programme Qualitative checklist,<sup>28</sup> enabling structured examination of reliability for inclusion to be assessed using 10 quality criteria. The Mixed-Method Appraisal Tool (MMAT)<sup>29</sup> was used to assess how well selected studies using this approach were designed and executed, for example, if there was clear rationale and description of the integration of the components.<sup>30</sup>

### 2.5 | Data extraction and narrative synthesis

Study characteristics were tabulated, organised chronologically and by design, to illustrate context. Following repeated reading of the papers, findings were extracted, and thematic analysis used to identify preliminary themes illustrating psychosocial experiences. The Cancer Family Caregiving Experience Model<sup>31</sup> was used as a guide to identify the stress process described, as previously in surgical HNC.<sup>21</sup> Based upon the Transactional Model of Stress and Coping<sup>32</sup> the model enables caregiving transitions to be conceptualised.<sup>33</sup> It builds upon a patient-centred approach, emphasising

the significance of family in the care and well-being of the cancer patient.<sup>34</sup> Deductive analysis involved the identification of primary stressors from the patient's illness and caregiving demands which initiated the stress process. Subsequent secondary stressors from strain, or 'spill over' effects and challenges followed transition into the caregiver role. Appraisals of these stressors and caregivers' cognitive and behavioural responses were also identified. A Synthesis table was used to map the themes to the elements of the stress process. Recurrent concepts across the studies<sup>25</sup> illustrated how the experience of HNC caregiving manifested. The model also helped identify relationships between the elements of the stress process and health and well-being outcomes reported across the studies. The significance of contextual factors related to oropharyngeal cancer caregivers, such as younger age, was considered. A narrative was developed under each theme describing psychosocial experiences of HNC caregiving.

## 3 | RESULTS

### 3.1 | Search results

Following retrieval of 1670 papers, 348 duplicates were removed leaving 1324, with two added from citation searching (Figure 1). SM used the eligibility criteria to screen titles and abstracts, selecting 55 papers for full-text review. A further 40 were ineligible, with any ambiguities such as data collection timepoint discussed with co-authors. 15 papers were eligible for inclusion, including two based upon the same study population, but with different foci.<sup>35,36</sup> 40% of these were agreed by co-authors following full-text review. Quality appraisal (Supplementary information S2) found minimal limitations in the 12 qualitative papers, with methods well described, although assessment of reflexivity was brief. The application of the MMAT resulted in near total positive scores for the three mixed methods studies.

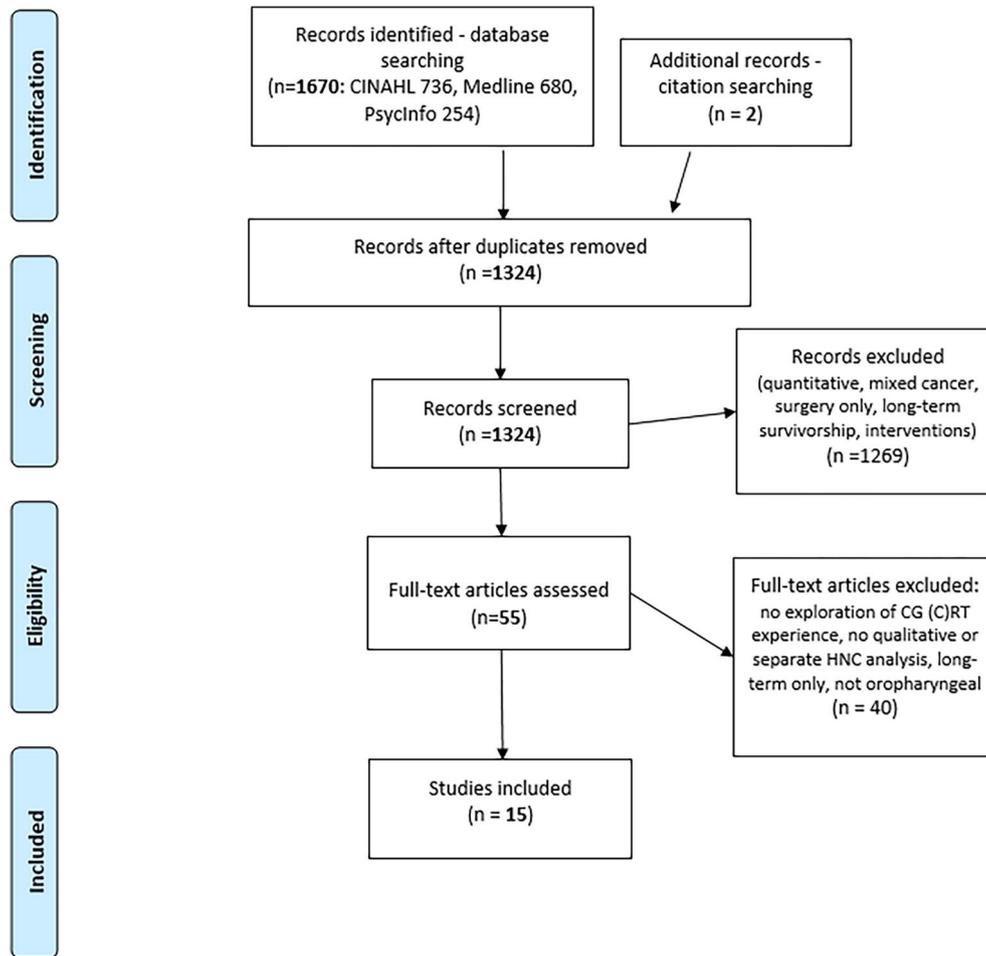


FIGURE 1 Prisma flow diagram.

### 3.2 | Study characteristics

Where HNC sub-group was stated, over half of participants cared for oropharyngeal cancer patients. Caregiving was mostly provided by spouses or partners (M 87%), 86% of whom were female. Considerable heterogeneity existed in research approaches and foci, with eight caregiver-only papers and seven including both caregivers and patients. Of these caregiver and patient studies one compared experiences of tube feeding,<sup>37</sup> two focused on spouses' shared experiences,<sup>38,39</sup> and four explored separate experiences or needs.<sup>40-43</sup> See Supplementary information S3.

One study's mealtime observations of caregiving dyads informed interviews examining caring for someone with dysphagia (swallowing difficulties).<sup>44</sup> Four phenomenological papers explored caregivers' lived experiences,<sup>35,45-47</sup> two studied nutritional experiences<sup>42,43</sup> and another determined couples' experiences of communication changes.<sup>41</sup> Grounded theory guided one study in conceptualising how dyadic experiences were shaped.<sup>38</sup> Most were cross-sectional (n.12) collecting data via semi-structured interviews (n.9), mostly within 6 months of treatment. Only 5.7% of caregivers were 18 months or beyond from diagnosis or treatment, thereby meeting this review's aim of understanding experiences during the post-treatment phase.

Studies of both patients and caregivers analysed transcriptions as one data set, recognising shared themes but, if appropriate, those derived from only one group.<sup>37,41</sup> A deductive approach guided by quantitative data led analysis in one mixed method study,<sup>48</sup> whilst another used pre-determined codes of social control.<sup>39</sup>

### 3.3 | Narrative synthesis

The psychosocial experiences of these caregivers were shaped by their appraisal of and responses to stressors described in the studies, affecting their health and well-being, and resulting in support needs. Primary stressors from immediate caring responsibilities, such as managing patients' symptoms and emotions resulted in secondary stressors. The Synthesis table (Supplementary information S4), represents how the stress process manifested across the five identified themes. These were: an emotional struggle; supporting nutrition; altered lifestyles; changes within relationships; and support needs. Table 2 presents theme distribution across the papers. A narrative was developed, providing an account of psychosocial experiences of HNC caregivers including those caring for oropharyngeal cancer patients following (chemo)radiotherapy.

TABLE 2 Themes.

|  | Emotional struggle | Supporting nutrition | Altered lifestyle | Changes in relationships | Support needs |
|--|--------------------|----------------------|-------------------|--------------------------|---------------|
| Caregiver only papers:                 |                    |                      |                   |                          |               |
| Penner et al, '12 <sup>46</sup>        |                    | x                    | x                 | x                        |               |
| Patterson et al, '13 <sup>44</sup>     | x                  | x                    | x                 | x                        |               |
| Nund et al, '14 <sup>45</sup>          | x                  | x                    | x                 | x                        | x             |
| Bond et al, '14 <sup>48</sup>          | x                  |                      | x                 | x                        |               |
| Schaller et al, '14 <sup>49</sup>      | x                  |                      | x                 |                          | x             |
| Fronczek, '15 <sup>47</sup>            | x                  |                      | x                 | x                        | x             |
| Halkett et al, '20 <sup>35</sup>       | x                  | x                    | x                 | x                        | x             |
| Weaver et al, '22 <sup>36</sup>        | x                  | x                    | x                 | x                        |               |
| Caregiver and patient papers:          |                    |                      |                   |                          |               |
| Mayre-Chilton et al, '11 <sup>37</sup> |                    | x                    | x                 | x                        | x             |
| Nund et al, '15 <sup>41</sup>          |                    |                      | x                 | x                        | x             |
| Richardson et al, '15 <sup>40</sup>    |                    |                      | x                 |                          | x             |
| Badr et al, '15 <sup>39</sup>          |                    | x                    |                   | x                        | x             |
| Badr et al, '16 <sup>38</sup>          | x                  |                      | x                 | x                        | x             |
| Findlay et al, '20 <sup>42</sup>       | x                  | x                    |                   |                          | x             |
| Hiatt et al, '21 <sup>43</sup>         | x                  | x                    |                   |                          | x             |

### 3.3.1 | An emotional struggle

Appraisal of the primary stressors of a cancer diagnosis and severe side effects led to a range of emotions whilst suffering in silence, avoiding adding to the patient's, or other family members' distress.<sup>35</sup> Caregivers feared what was to come and could be overwhelmed by information. Others were uncertain whether any amount of information could have helped prepare them for the duration and escalating severity of treatment consequences, expressing shock and disbelief.<sup>42,43</sup> Both insufficient information and information overload could result in hypervigilance, triggering distress, including FOR.<sup>47</sup> Efforts by spouses to shield partners from negative thoughts and keep each other positive<sup>44</sup> added to burden:

I was stressed all the time because I felt like I had to be strong for him. I couldn't break down, I just couldn't.<sup>38</sup>

They avoided conflict whilst constantly needing to remind patients about self-care, feeling unappreciated and neglected when unsuccessful. Coping whilst helplessly watching suffering meant their distress was greater than that of patients.<sup>38</sup> Another study found caregivers' distress was related to patients' lability, irritation, agitation, and aggression,<sup>48</sup> as well as their depression and mood swings:

...when he became depressed. It was like we had lost a child...he cried every day<sup>48</sup>

Clustering of symptoms affecting eating and appetite and night-time behaviours including hypersomnia, exacerbated distress. An emotional struggle included caregivers experiencing pain,<sup>49</sup> as patients' fear, anger and worry were overwhelming and difficult to separate from physical pain, for example, due to oral mucositis. They felt unable to understand the patients' suffering and powerless to help, whilst experiencing anxiety, loneliness and disturbed sleep.<sup>49</sup> They were fearful of undertaking complex care tasks associated with inflicting further pain, when ill-prepared for the role's responsibilities. Describing gaps in analgesia knowledge, they wanted a key healthcare professional (HCP) to use a holistic approach to meet their needs. Caregivers sought to navigate complex healthcare systems despite confusion about the role of multiple HCPs and who to contact.<sup>47</sup> Despite absorbing huge amounts of information about the disease and treatment, facilitating decision-making, after treatment the absence of HCPs led to feelings of diminished self-efficacy. Lack of support heightened emotions:

Once treatment is over you are cast off to sail alone. It is a very lonely, fearful and frustrating time...much worse than during treatment when there is wonderful support.<sup>45</sup>

These caregivers had anticipated a fast recovery, but instead a prolonged state of stress and feeling overwhelmed led to some considering abandoning their caregiving role,<sup>36</sup> with burnout

heightened by a lack of HCP support.<sup>43</sup> Coping included being organised, focusing on tasks<sup>35</sup> and if caregivers prioritised their own needs, accessing help from others. Adult offspring coped by taking time away from caregiving.<sup>35</sup> Positive appraisal of ability in the role included recognition of previously unknown inner strength whilst sharing their loved one's suffering,<sup>42</sup> and satisfaction of playing a part in their recovery, boosting wellbeing:

I learned I had more patience and am a lot stronger than I thought.<sup>38</sup>

### 3.3.2 | Supporting nutrition

Responsibility for patients' recovery through nutrition underpinned caregivers' expectations of their role<sup>36</sup>; to 'fix it'.<sup>35</sup> However, eating difficulties challenged such seemingly tangible aspirations, leading to 'utter despair'<sup>36</sup> and they had to battle to maintain control:

I felt helpless, I couldn't seem to be able to do anything to assist him.<sup>43</sup>

In response to patients' reduced eating ability caregivers changed or restricted their own diet, feeling guilty and isolated, eating separately,<sup>42</sup> even secretly.<sup>44</sup> Those with families tried to meet everyone's needs, taking time to make different meals, whilst striving to ensure patients had the necessary nutrition. Although their burden could be reduced by co-ordinated multi-disciplinary HCP care, they frequently became advocates:

I was very protective of (spouse) ... I didn't care whether they agreed with me or not, I was on a mission<sup>42</sup>

The severity of dysphagia determined patients' dependency, affecting caregiver well-being.<sup>46</sup> Observations<sup>39</sup> and interviews with dyads found motivating patients to eat was a key caregiver role, one that could cause friction if they did not engage.<sup>44</sup> Monitoring for signs of improvement, such as food intake and swallowing, triggered frustration and worry about choking, illustrating significant responsibility and emotional burden.<sup>45</sup> Shocking 'overnight' weight loss heightened FOR, challenging efforts to retain positivity<sup>44,45</sup> and confronting caregivers' power to help.<sup>43</sup> Providing nutritional care in the 6 months following treatment in response to severe dysphagia resulted in exhaustion.<sup>42</sup> Caregivers felt ill-prepared and wanted opportunities to build practical skills,<sup>43,45</sup> not understanding the significance of information received until the reality was witnessed:

But until it happens...as the symptoms progress—nothing prepares you for that...<sup>42</sup>

Gastrostomy feeding removed frustration and worries about calorie intake,<sup>43</sup> but new concerns arose related to the technical

aspects of care, including pain and leakage.<sup>46</sup> Caregivers described 'stamping out fires all the time'.<sup>46</sup> Fluctuations in symptom severity necessitated shifts within their role, the dyad, their social network, and the healthcare system, requiring information, communication, and support. Caregiver focus group participants reported<sup>37</sup> feeling unprepared for 'the tube', incomprehension of its purpose and negative views of its social impact. However, continued access to HCPs by gastrostomy patients helped them cope. They disliked supplements which caregivers found helpful to aid calorie fortification in food preparation. Differing perspectives could reduce support given by caregivers, heightened when patients acted as gatekeepers to HCPs, particularly after treatment when such contact was reduced.<sup>43</sup> Early notions of patient weight loss as a healthy outcome (if over-weight at diagnosis) were replaced by distress as it became uncontrolled, as reported in interviews 2 weeks after treatment. In recovery, concerns moved to rebuilding lost strength and muscle mass but maintaining a lower healthier weight, with a focus on healthy living to prevent cancer recurrence.<sup>43</sup>

### 3.3.3 | Altered lifestyles

Supervision of anxious patients<sup>48</sup> and management of their pain and fatigue were among secondary stressors for caregivers, disrupting lifestyles. They had to balance competing responsibilities<sup>38,49</sup> in order to fulfil multiple roles, for which they were unprepared.<sup>45,46</sup> Time was consumed by household chores, providing meals or enteral feeding, making them feel 'tied down',<sup>47</sup> observing that '...my life is not my own'.<sup>36</sup> They reprioritised their lives to help actively manage side effects, attend appointments<sup>35</sup> and 'be there'.<sup>40</sup> Frustration at restrictions and loss of control was kept from those they cared for. They described feeling depleted and emotionally drained but were reluctant to relinquish their role and leave patients at home alone.<sup>40</sup> They declined social invitations, limiting opportunities for valued practical and emotional support from family and friends<sup>37,44–46,49</sup>:

...life was on hold, we didn't go out, we didn't visit people and he preferred they didn't visit us.<sup>41</sup>

Appraisal of stressors facilitated decisions about working outside of the home and leaving patients alone or stopping work when caregiving became too onerous.<sup>36</sup> Some took time off to assist with time-consuming gastrostomy feeding schedules<sup>46</sup> or returned home throughout the working day to provide care; flexibility from employers was appreciated:

I just had to take another month off because he just wasn't ready to be left alone.<sup>35</sup>

Although strenuous, alongside all the domestic chores, returning to work did provide opportunities for distraction, facilitating self-care for some,<sup>49</sup> which was otherwise commonly neglected.<sup>35,38</sup> Strategies

to cope included being highly organised mitigating feelings of helplessness, expressive writing,<sup>35</sup> and accepting change.<sup>45</sup>

### 3.3.4 | Changes within relationships

Family members had little choice in becoming caregivers, challenging them to balance other roles.<sup>46</sup> They became more *'like a mother'* than spouse, requiring navigation of tensions in relationships<sup>36</sup> as patients handed over self-care<sup>48</sup> and acted out of character. Fundamental relationship support previously enjoyed, was lost:

I thought I've got someone to take care of me and all of a sudden 'my loved one' was like a little child. So that kind of bothered me because I wanted someone to take care of me...but I was doing all that..<sup>47</sup>

Daily activities as a couple, and as a family changed, including sharing meals<sup>44</sup>; normally an opportunity to solidify relationships.<sup>45</sup> Their maintenance added stressors beyond those experienced by individuals alone.<sup>38</sup> Spouses described living separate lives, including social and leisure activities. They mourned lost intimacy after treatment resulting from body image worries related to dry mouth, bad breath, mucus, or feeding tube.<sup>37</sup> Relationships could also be affected by undiscussed intense reactions following an HPV+ve diagnosis and concerns about fidelity:

I said, "Could you have done that?" and he said, "No, definitely not" and he just shut the door. So, I said alright; I didn't want to go down that lane. I wanted to talk to him about it, but he shut me down.<sup>35</sup>

Changes to communication were also stressors within relationships,<sup>38</sup> requiring adaptations.<sup>41</sup> Xerostomia (reduced saliva affecting vocal fold lubrication and the speed, sequencing and accuracy of sound articulation), dental extraction and chemotherapy-induced hearing loss significantly affected speech, requiring extra effort to speak. Acceptance by family and friends, HNC survivors and their caregivers assisted emotional and practical adjustment. Consequently, social avoidance by patients saddened and frustrated caregivers:

I felt that he had removed himself from family life and he didn't communicate, maybe because he couldn't.<sup>41</sup>

Conflict resulted from apathetic and sleep deprived patients with no interest in daily life or complying with rehabilitation regimens,<sup>38</sup> potentially impacting upon long-term recovery.<sup>48</sup> Motivating partners through the use of social control was explored during conversations about side effect management.<sup>39</sup> Strategies to encourage self-care included making oral care preparations readily available, alongside positive and negative tactical communication. Couples (reporting high marital satisfaction) were able to view *'well intended naggin'* (i.e. negative social control) beneficently, but if not perceived as founded upon

love and concern, could lead to tension. Positive social control, which included seeking opinions and offering options using empathy and humour, was also motivated by a need to regain control and reassurance:

I just kinda watch you. Has he done his exercises? I don't watch specifically to make sure everything's done –it just helps me to know you're doing your part.<sup>39</sup>

Despite the challenges faced, some positively appraised their shared experience, becoming closer as a couple<sup>38,45</sup>:

It...can either make you stronger or it can destroy a family. And if we could go through this, it is almost like there is nothing else that we cannot handle.<sup>38</sup>

### 3.3.5 | Support needs

The unique role of HNC caregivers in actively managing treatment side effects alongside providing emotional support, time to talk, empathy and understanding, resulted in their own support needs, including for relationships.<sup>38</sup> Psychological support, equally desired by caregivers and patients,<sup>49</sup> could facilitate understanding and articulation of fears and emotions *'I cannot express to him'*.<sup>40</sup> For some this was available but not accessible.<sup>35</sup> Family and friendship networks provided support,<sup>45,47</sup> as did sharing experiences with peers who *'had been where they were'*.<sup>40</sup> However, preoccupation with role prevented support group membership,<sup>38</sup> whilst patients' lack of engagement could restrict access.<sup>43</sup>

Caregivers struggled with balancing responsibilities including childcare and work, maintaining self-care and coping with any guilt associated with taking time off from caring.<sup>38,46</sup> They spoke of not knowing what to do or feeling unable to help.<sup>42</sup>

It's tough stuff after the treatment finishes...after that it's up to the home carer and they haven't been there before, they've got no expertise and to a great extent no technical information either.<sup>37</sup>

Attention was focused upon swallowing rehabilitation and nutrition<sup>43</sup> but the connected needs of dental and oral care, and pain management, were neglected, indicating gaps in knowledge.<sup>39</sup> Deficiencies were exacerbated by a lack of lay language and confusion about the role of specialists until side effects manifested, such as the speech therapist when speech was not affected.<sup>45</sup> Specific information and emotional support needs of caregivers such as adult offspring were unrecognised by HCPs.<sup>35</sup> Honest, full and direct information was wanted, alongside empathic, holistic,<sup>49</sup> personalised support.<sup>40</sup> Although there was awareness of HCP availability,<sup>47</sup> more post-treatment contacts were needed,<sup>40,45</sup> for example, to discuss the impact of treatment consequences upon their own lives<sup>41</sup> and nutritional advice to prevent cancer recurrence.<sup>43</sup>

## 4 | DISCUSSION

This review described the psychosocial experiences of HNC caregivers following (chemo)radiotherapy and considered the significance of contextual factors related to oropharyngeal cancer. Five themes informed by the Cancer Family Caregiving Experience Model<sup>31</sup> were generated reflecting multiple perspectives related to HNC caregiving<sup>19</sup>: an emotional struggle, supporting nutrition, altered lifestyles, changes within relationships and resultant support needs.

The completion of treatment emphasised transition into the caregiving role<sup>33</sup> when side effects peaked, requiring adaptations to changing demands.<sup>23</sup> Emotional responses to the unexpected severity and duration of side effects indicated HNC caregiving burden, setting it apart from other cancers. However, as for other cancer caregivers,<sup>50</sup> unmet information, communication and psychological support needs exacerbated burden. Although clear instructions for HNC side effect management were helpful,<sup>39</sup> information was often overwhelming. Consequences for these caregivers included self-perpetuating FOR-induced hypervigilance<sup>51</sup> and a heightened sense of responsibility for recovery through nutrition. They expressed despair when not able to prevent continued weight loss and were anxious about its meaning. As for patients<sup>52</sup> therefore, the meaning of food changed following treatment for HNC caregivers who, if unable to fulfil responsibilities, may experience long-lasting psychosocial consequences.<sup>53</sup> However, in contrast to traditional HNC<sup>24</sup> and other cancers with reduced eating ability,<sup>53</sup> this review found weight loss at diagnosis could be perceived as beneficial. Following treatment, some caregivers were not concerned about supporting patients to regain weight but their sense of responsibility for healthy nutrition persisted.

These caregivers often had families to care for and paid work to manage, likely to be more typical of younger oropharyngeal cancer caregivers than of those caring for traditional HNC patients. Termed a 'sandwich generation' with competing responsibilities for younger and older dependents, the additional role was assumed, even if not ready.<sup>54</sup> Most caregivers were spouses or partners whose relationships shaped and were shaped by experiences. Being more like a mother than a spouse, when potentially already fulfilling motherly roles, illustrated the burden faced. Sources of tension and conflict were common and the reciprocal influence within the dyad of one partner's negative experience upon that of the other, reduced mutuality. Furthermore, within cancer research, more conflict has previously been found in couples with school age children,<sup>55</sup> typical of oropharyngeal cancer caregivers. Relationship tension could also result from causal attribution of HPV-related disease and associated fidelity worry. Silenced HPV concerns, such as a sense of stigma or transmissibility, concurred with avoidant communication seen in past studies.<sup>8,9</sup> Relationships were also liable to be affected by gaps in HPV knowledge<sup>56,57</sup> and reduced intimacy,<sup>58</sup> which may persist into long-term survivorship.

However, this review found some positive appraisal of impact upon relationships including increased closeness; the dyad moderating, or buffering, stressors.<sup>59</sup> Additionally, personal resources such

as optimism and development of mastery may reduce stressor impact, help find meaning in the role and psychological adjustment, or 'discovery of growth'.<sup>31,55,60</sup> Although caregivers were reluctant to set aside responsibilities for self-care this indicated re-prioritisation and goal engagement,<sup>61</sup> which as a feature of self-regulation<sup>62</sup> and mastery, could moderate distress. Social support is also known to buffer burden<sup>63</sup> and mediate distress, as previously seen in HNC, in couples<sup>64</sup> and during survivorship.<sup>5</sup> Those able to access support from others included sharing roles with secondary caregivers, enabling a return to work, and some respite.<sup>14,65</sup> Support from peers allowed experiences to be compared and understood. Cancer caregivers are unlikely to obtain such 'experiential homophily' from existing social networks, who may be unable to provide the help needed (e.g., inappropriately positively reframing HNC and caregiving challenges<sup>66</sup>).

Findings related to younger caregivers and HPV, pertinent to oropharyngeal cancer caregivers, distinguished this review from that of Aung et al.<sup>24</sup> The inclusion of more recent studies found greater responsibility for healthy nutrition post-treatment but also some positive growth. Similarities were apparent beyond those arising from the joint inclusion of seven studies, building upon implications for HCP caregiver support regarding expectations of the role and how it could be constructed, delivered, managed, or negotiated.<sup>67</sup> Caregivers were an important part of the caring team<sup>24</sup>; developing an understanding of complex self-management regimens, often poorly complied with by patients.<sup>68</sup> However, they were reluctant to seek help, placing patients' needs before their own, including, as previously observed, non-spouses.<sup>69</sup> Interventions facilitating HCP access, the preferred information source,<sup>70</sup> may enable preparation for both process and outcomes of role transition.<sup>33</sup> These could include baseline depression monitoring, predictive of caregiver burden 1 week after (chemo) radiotherapy,<sup>71</sup> and needs assessment, perceived by caregivers as extended post-treatment support.<sup>72</sup> Caregiver navigators with specialist training within the HCP team could identify and coordinate resources.<sup>73</sup> Sharing emotional responses to illness through such support may lessen burden and help develop coping strategies, facilitating adjustment.<sup>74</sup> Opportunities to discuss and assess competence may promote self-efficacy by reducing perception of task complexity<sup>14</sup> alongside HNC specific education. Confidence could be enhanced further through communication skills development, for example, positive social control, known to be more supportive to male patients (the majority in HNC), than negative female behaviour.<sup>55</sup> Such interventions could prove to be an efficient use of healthcare resources<sup>6</sup> and providing information jointly to patients and caregivers may reduce incongruent perspectives, increasing mutuality.<sup>75</sup> They could also make caregivers' value explicit as 'caring partners',<sup>24</sup> diminishing appraisals of being unprepared and powerless. Acknowledgement may in turn validate their own psychological support needs. Without such targeted support the cumulative outcomes of the stress process upon caregivers' own health and wellbeing could result in them becoming 'second order' patients.<sup>54</sup>

Further research is required to explore experiences specifically within oropharyngeal cancer caregiving in order to describe and

conceptualise the role and tailor supportive interventions. Gaps in knowledge include the experiences and needs of different caregiver types, including what it means to be an oropharyngeal cancer caregiver, the impact of an HPV+ve diagnosis and the desired relationship between caregivers and HCPs.

#### 4.1 | Study limitations

Although the majority of caregivers in this review cared for oropharyngeal cancer patients, current research has not selected participants on this basis, limiting exploration of distinct experiences. Five papers included retrospective accounts<sup>35,36,41,45,47</sup> which may reflect a response shift or current emotional states. The variety of approaches and foci of papers meant not all reflected every theme. Ensuring transparency of synthesis was challenged by its complexity for example, when studies incorporated both caregivers' and patients' experiences findings reflected those shared, but also those related to both the dyad itself and to the individual.

More female spouses (or partners) in these studies than other cancer caregiving populations<sup>74</sup> suggested distinct characteristics, having support implications, but may limit transferability of findings to other populations. Little distinction was made between caregiver types,<sup>35,49</sup> such as offspring accounting for a quarter of one study's population,<sup>40</sup> likely to have specific support needs including HCP relationships.<sup>70,76</sup> Additionally, caregiver status (i.e., primary or secondary) was unspecified.<sup>35</sup> Psychosocial experiences are likely to be impacted by caregiver type, affecting emotional closeness, making differentiation significant for support development. Underrepresentation of those most negatively impacted is possible. Reduced participation was evident along the care pathway trajectory in longitudinal studies,<sup>40,44</sup> distress resulting in early withdrawal.<sup>39</sup> Limitations to transferability included small populations (two had fewer than five) and all being within advanced healthcare systems; two thirds in Australia (n.6) and USA (n.4).

#### 4.2 | Clinical implications

Caregiver preparation and support could moderate stressors and enhance self-efficacy, validate needs intrinsic to the role, mediating health and well-being consequences. Tailored support could include:

- HNC knowledge and skills education.
- Role needs assessment to target information, distress monitoring and psychological support.
- Psychoeducation to guide cognitive responses and address modifiable behaviours.
- Interventions addressing specialist topics (e.g., healthy eating for recovery, relationship support<sup>38,39</sup> such as couple-based counselling to boost mutuality and if appropriate, encourage full disclosure,<sup>77</sup> adaptive communication<sup>59</sup> and emotional response training<sup>6,34</sup>).

- Access to HCPs (e.g., via navigators) and involvement as caring partners.
- Access to peer support (e.g., internet-based interventions<sup>78</sup>).

## 5 | CONCLUSION

The completion of (chemo)radiotherapy signalled a transition for HNC caregivers as they undertook burdensome responsibilities and experienced an emotional struggle, whilst supporting nutrition, coping with altered lifestyles and changes within relationships, resulting in their own support needs. The Cancer Family Caregiving Experience Model<sup>31</sup> provided a framework to describe these dynamic experiences and consider the significance of contextual factors related to oropharyngeal cancer. Supportive interventions from wider research were proposed. Role preparation and assessment of caregivers' needs alongside their recognition by HCPs as caring partners, is required to provide tailored support and help moderate this demanding experience, ultimately optimising patient care.

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### CONFLICT OF INTEREST STATEMENT

The authors have no conflict of interest to declare.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this review are available from the corresponding author upon reasonable request.

### ETHICAL STATEMENT

Ethical approval was not required as this was a review.

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#### SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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