

Title:

The Lived Experience of Head and Neck Cancer Patients Receiving Curative Radiotherapy: A Systematic Review and Meta-Ethnography.

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Abstract

This review aims to explore, appraise and synthesise the existing evidence of the meaning that head and neck cancer (HNC) patients assign to the experience of receiving curative radiotherapy. Qualitative evidence synthesis was undertaken using meta-ethnography. Published literature was identified using seven databases: AMED, ASSIA, CINAHL, EMBASE, MEDLINE, PubMed and PsycINFO. Databases were searched from January 2005 to April 2017. The strategy was supplemented by grey literature and citation searches.

Out of 1403 titles, 57 abstracts and 35 full texts were screened. Ultimately, 8 studies were eligible for inclusion. The evidence base was moderate to strong in quality. Most of the studies showed that HNC patients undergoing radiotherapy have unmet needs. Four related concepts were identified: the disruption to life that the disease and radiotherapy treatment cause; patients' feelings of isolation; the need for patients to make sense of their situation; and the waiting and uncertainty that radiotherapy creates.

The current literature suggests that both head and neck cancer and radiotherapy cause disruption in patients' lives. Radiotherapy causes many unpleasant side effects, and in this difficult treatment period, HNC patients feel isolated, uncertain and in need of coping strategies. Therapy radiographers are ideally placed to offer a supportive relationship. By having a deeper understanding of patients' lived experience, radiographers may form stronger relationships and more effectively help patients through their radiotherapy.

Background

Head and neck cancer (HNC) is an umbrella term that encompasses up to 31 heterogeneous cancers of the respiratory tract and upper digestive tract, including tumours of the larynx, oropharynx, nasopharynx and salivary glands. The aetiology of HNC is unknown, but its incidence is associated with social deprivation and heavy consumption of tobacco and/or alcohol¹. In the UK, there were 11,449 cases of HNC in 2014, which meant it constituted 5% of all cancer cases². Incidence in the UK has been rising steadily. There has been a 30% increase in HNC diagnoses since the 1990s¹, and oropharyngeal cancer has doubled in incidence in just over a decade³. Changes in the patterns in causation, including HPV-related cancer, together with a population that is aging and growing, means that compared to the year 2007, the UK oral cancer rate in 2030 has been predicted to rise by approximately 75%⁴.

Cancer of the head and neck is a traumatic disease. As Wood and Bisson⁵ discuss, from diagnosis, patients find adjusting to their condition a heavy psychological burden. According to Singer *et al.*⁶, HNC patients show more distress than any other. Treatment for HNC usually involves surgery, radiotherapy and chemotherapy. All three primary treatment options are, individually, associated with significant morbidity and threaten a patient's quality of life, social functioning, sense of self and well-being^{7,8}. All are associated with a high degree of anxiety and depression^{8,9}. When any of the treatments are delivered in combination, side effects are likely to be intensified¹⁰.

Radiotherapy has advanced considerably as a treatment over recent years because of technological developments and increased computing power. Intensity-modulated radiotherapy (IMRT) and volume modulated arc therapy (VMAT) utilise the latest technology to better target tumour volumes and avoid healthy tissue. However, radiotherapy is still associated with a range of severe side effects, including difficulties eating, loss of taste and smell, dry mouth and painful swallowing¹¹. The physical side effects of radiotherapy often lead to a range of psychosocial problems. Patients experience anxiety, depression and difficulties with coping. As the side effects increase towards the end of treatment, patients must draw upon an increasing number of coping strategies.

The physical and psychological effects of radiotherapy on HNC patients have been the subject of several systematic reviews¹²⁻¹⁶. Lang *et al*¹⁵, conducted a meta-synthesis of 29 studies concerning the psychological experience of living with head and neck cancer. Like many of the studies of HNC patient experience, this meta-synthesis did not distinguish between the different treatment options. It did not compare or contrast surgery versus radiotherapy or chemotherapy. Many patients will receive all three treatments during their trajectory of care, but since each is intrinsically different to the others, failure to consider them in isolation may have meant important concepts were missed. More research is needed on the experience of radiation treatment from the patient perspective. Radiotherapy is an often misunderstood treatment that can induce anxiety^{17,18}. Nervousness about side effects is common among HNC patients because radiotherapy affects key aspects of daily living¹⁹, but also, patients are often concerned about the nature of the treatment units²⁰, meeting fellow patients¹⁷, or simply frightened about dealing with the transition from a previous treatment to new one²¹. Exploring how patients make sense of their experience is vital in providing high-quality, person-centred care²². Therefore, the final research question was: “What is the lived experience of head and neck cancer patients receiving curative radiotherapy?”

Methods

A scoping search was conducted to refine the strategy and a review protocol was registered with PROSPERO (registration number: CRD42017067872).

Primary searches involved the electronic databases AMED, ASSIA, CINAHL, EMBASE, MEDLINE, PubMed and PsycINFO. Free-text, thesaurus terms and Medical Subject Heading (MeSH) terms were selected to represent the research question. An example of the final search strategy used for MEDLINE is shown in Supplementary Table S1. Amended search strategies were used for each electronic database.

Grey literature searches were conducted using the online system OpenGrey, the search engine Google Scholar, and ETHOS, the British Library e-theses online service. Backward and

forward citation searches were undertaken on all the studies included in the final synthesis. The Institute for Scientific Information (ISI) Web of Science indexing service and Google Scholar were used. Reference checking was undertaken on all the final studies.

Eligibility Criteria

Studies were included irrespective of origin, or quality as based on a critical appraisal. Exclusions were pragmatic: patients could not be children because their experiences were likely to be considerably different to adults; inpatients were excluded because their experience would be too heavily influenced by being on a ward; studies not written in English or without available abstracts were excluded because of the difficulty assessing their value; studies that only considered carers' or healthcare professionals' perspectives were excluded because the focus of the review was to develop themes specifically related to patient experience.

A timeline was set to only include articles published from 2005 to present day because patients' experiences of radiotherapy have altered significantly with the advent of IMRT. The year 2005 was chosen because it approximately dates the wide-scale introduction of IMRT.

Study Identification and Data Extraction

One researcher (RF) conducted the literature search. Search results were imported into the Mendeley (Elsevier) system where duplications were removed, and studies were screened by title and abstract against the inclusion/exclusion criteria. A second person (LF) independently verified the selections, and a third reviewer (EA) examined a random 10% of the results to improve validity. For data extraction, where available, full texts of articles were retrieved. If full text was unavailable or insufficient, an attempt was made to contact the corresponding author. Failure to retrieve full text precluded the study from data extraction.

A predefined extraction form was used to collect data about the study and its constructs. Themes reported in individual studies were extracted as second-order constructs, using the definition developed by Malpass *et al.*²³. Two reviewers independently extracted data (RF and LF). Studies were read and re-read so that reviewers were fully immersed in the themes. Concurrence was reached through discussion, and disagreements were arbitrated by the third reviewer (EA). A fourth reviewer (JC) provided advice when necessary.

Critical Analysis

All included studies were subjected to a quality assessment using the Critical Appraisal Skills Programme (CASP)²⁴. Gough's 'Weight of Evidence' framework²⁵ was adopted for this review because it evaluates three aspects of a study: quality of methodology, relevance of methodology and relevance of evidence to the review question. Each reviewer used the framework to gauge a study's overall relevance in answering the research question. Each study was appraised independently by two reviewers. One was the primary researcher (RF), a second had extensive experience of HNC patients from conducting on-treatment review clinics (LF). The third acted as arbiter and had meta-ethnography experience (JC).

No study was excluded based on quality assessment, but weight of evidence was considered when deciphering the key themes. Synthesis findings were examined to see if they remained the same when only key papers were included.

Meta-Ethnography

Meta-ethnography, as described by Noblit and Hare²⁶, was chosen for analysis and qualitative evidence synthesis. The process of meta-ethnography is underscored by Turner's theory of social explanation, which breaks the synthesis into three aspects: comparison, interrogation and translation. Translation involves researchers translating concepts from one study into another such that new interpretations and meanings arise. Epistemologically, meta-ethnography was suited to synthesising studies on HNC patients' experiences of radiotherapy because it allowed contextual, subjective experiences to be systematically synthesised.

Full copies of all selected studies were downloaded to NVivo (QSR International) along with the data extraction forms. Qualitative evidence synthesis was undertaken using the seven steps of meta-ethnography, as shown in Box 1.

Box 1. Seven stages of Meta-ethnography ²²	
1	Getting started
2	Deciding what is relevant to the initial interest
3	Reading the studies
4	Determining how the studies are related
5	Translating the studies
6	Synthesising the translations
7	Expressing the synthesis

Stages 1-4

Stage 1 was dealt with in forming the research question; stage 2 was encompassed by the search strategy; data extraction and critical appraisal formed stage 3. The synthesis began with each researcher reading and re-reading the studies so that they were fully immersed in the data. The studies were read in chronological order. Each reviewer then independently juxtaposed the second-order constructs in a grid and decided upon categories into which they could be grouped whilst maintaining their context and meaning. This enabled the researchers to complete stage 4 and establish there was enough similarity between second-order concepts for reciprocal translation to be feasible.

Through discussion, these key categories were refined and input as 'nodes' in NVivo 11. The key categories were then related back to the original studies using extractions from the

texts. During this process of coding, some key categories were upgraded to main categories and some became sub-categories. Each category and sub-category was defined using a representative statement.

Stages 5-7

Three phases, as suggested by Atkins *et al.*²⁷, were used to analyse how the categories related to each other:

Reciprocal Translation

Studies were arranged in a table in chronological order. The categories and sub-categories, created through discussion and refined with NVivo 11, were placed, as statements, in the columns of a table. Studies were placed in chronological order in rows. The chronology was important because it demonstrated if concepts were durable over time. This was useful because of the rapid evolution of radiotherapy technology over short periods of time. The statements were then translated across the studies so that the emerging third-order concepts were refined into their final versions.

Refutational Analysis

The emergent third-order concepts were compared to the primary studies using refutational analysis, similar to Smith *et al.*²⁸. This process was distinct from 'refutational synthesis' as described by Noblit and Hare, and involved searching for contradictions between the concepts and the primary data. Studies were set against each other to highlight differences, encourage further discussion and refine the analysis. This was to demonstrate contextual differences between studies and bring to light heterogeneity in the populations.

Line of Argument

In stage 6, reviewers used the results from reciprocal translation and refutational analysis to weigh the commonalities and contradictions of the studies and develop new

interpretations. Each reviewer (RF, EA, LF) created a mind map to show their synthesis. The new interpretations were discussed with a fourth reviewer (JC) until a consensus was reached about a final overarching model. In stage 7, the final synthesis was expressed in a narrative form, written and agreed between the reviewers. A schematic form of the overarching model was created to clarify concepts in a clear, visual way.

Results

The literature search spanned the period of 1st January 2005 to 30th April 2017. The final records covered a range of settings and countries. A total of 1403 records were identified by the search strategy. After deduplication of the records and screening of the titles and abstracts, 35 records were potentially eligible. Full-text assessment reduced the final number of eligible studies to 8. The search results are summarised in the PRISMA flow diagram²⁹, Figure 1.

Study Characteristics

Eight studies formed the meta-ethnography^{21,30-36}. The characteristics of these studies are summarised in Table 1. The total number of HNC patients sampled was 120, of which 89 were male and 31 were female. Sample numbers ranged from 5 to 26. Half of the studies used purposive sampling (1)(3)(6)(8) and half used convenience (2)(4)(5)(7). The combined age range was 34 to 80 years, but only five studies reported on the age range of the participants. All studies sampled people with HNC receiving radiotherapy. Curative-intent is specified in four studies (1)(2)(3)(5) and implied in four (4)(6)(7)(8). Only three studies recorded if participants had undergone surgery (1)(3)(5). The most common mentioned in the remaining studies were oral, oropharyngeal, pharyngeal, and laryngeal. The nature of the interviews was divided between structured (4), semi-structured (1)(2)(3)(5)(7)(8), and unstructured (6).

Quality

Gough's Weight of Evidence overall evaluations demonstrated that five of the studies' findings would have a moderate relevance to answering the review question (2)(3)(4)(6)(7), and three would have strong relevance (1)(5)(8). The overall weight of evidence was moderate to strong, which was probably because the research question was so specific that non-relevant studies were excluded during the literature search. The similarity in weight of evidence evaluations was likely due to comparable methodologies across the studies.

Generally, the final studies scored well on the CASP ratings, with all eight papers scoring positive marks in five of the ten elements: aims, methodology, data collection, statement of findings and value. Reviewers were unanimous that all eight studies had clear aims and appropriate methodology to answer their research question. Lack of description and discussion about methodology accounted for most of the negative scores. This was most apparent in the 'reflexivity' element, where only two of the studies (1)(6) explicitly considered the relationship between researcher and participants.

Results of Synthesis

Stages 1-3 of were achieved through the literature search. For stage 4, each researcher recorded the broad categories that emerged from second-order constructs of the studies. Following discussion, it was decided that the studies were about similar enough concepts to justify reciprocal translation. Reciprocal translation of the final third-order constructs is shown in Supplementary Table S2. The final constructs were 'Feeling of Isolation', 'Making Sense of the Experience', 'Life Disrupted by Radiotherapy' and 'Waiting and Uncertainty'.

Concept 1: Feeling of Isolation

Withdrawal from social circles commonly occurred upon diagnosis, but was exacerbated by the side effects of radiotherapy. HNC patients chose to be alone because they were embarrassed by the consequences of their illness or the result of radiotherapy side effects (1)(6)(7). Eating problems, including dribbling, difficulty swallowing and choking, led to HNC patients wanting to eat alone (1)(7). Since eating is culturally a social event, withdrawal had a major effect on HNC patient's feelings of isolation. Similarly, patients perceived the

inability to speak fluently as a barrier to social interactions because of their fear of rejection by others (6). HNC patients benefitted from having friends or relatives for support, but more than half of patients reported changes in their social lives by the end of the treatment (7). Coping with treatment was much easier with support from family and friends (2)(5)(7), but sometimes those people did not have enough knowledge of the disease, treatment or side effect and this could increase patients' feelings of being alone (1).

Egestad (5) highlighted the importance of building a relationship with radiographers. Patients felt they were 'watched over' by radiographers, but did not always form satisfactory relationships with them. This was evident not only in their feelings of isolation, but in the lack of quality information patients believed they received.

The line of argument developed here was that HNC patients suffer disease-related and radiotherapy-related physical effects which lead to physical and psychological problems. Compounding this issue are patients' social withdrawal, feelings of shame, and perceived lack of quality information they receive. At the intersection of all these needs is the radiographer. Because radiographers deliver daily radiotherapy and are knowledgeable about side effects, they are ideally placed to, as Larsson *et al.* (1) suggest, 'hold the hand' of HNC patients and alleviate the feeling of being isolated. But, whilst HNC patients believe radiographers watch over them, they feel radiographers prioritise delivering treatment over patient contact.

The overall confidence in this finding was moderate because, although isolation was recurring through five of the studies, the depth, and therefore adequacy, of the data supporting it was questionable.

Concept 2: Making Sense of the Experience

The concept of 'Making Sense of the Experience' (1)(2)(4)(7)(8) related to the experience of radiotherapy primarily, but like all the final concepts, it was shadowed by the experience of the disease. The concept manifested as existential questions about the future (1)(7), reflections on past choices (2)(8), and strategies for enduring treatment (4).

The diagnosis of cancer promoted reflection on 'understanding what happened' and the patients' personal responsibility for their situation (8, p327). This was often related to diet, alcohol, smoking and lifestyle. Patients contemplated the strengths of their relationships and '*reappraised their place in the world in terms of role and identity*' (2, p27). Inevitably, a cancer diagnosis led to thoughts of death and dying (7)(8), but reflection and reappraisal did not necessarily cause regret, and could lead to personal growth (2).

Going through a course of radiotherapy led patients to develop mental coping strategies (2)(4). Reflecting on their life meant patients re-evaluated their daily routine. This could result in planning to work less, appreciating family and extending their social network. Patients described an ability to change their perspective to help them get through radiotherapy, but having previous experience of dealing with stressful situations facilitated this. Some patients resigned themselves to their situation, some developed a '*fighting spirit*' and some adopted a positive attitude (1). Mental outlook was a prevalent theme in helping patients cope and became more important as treatment progressed (4).

The line of argument for this concept is that making sense of the radiotherapy experience is shadowed by making sense of a cancer diagnosis. HNC patients reappraised their lives and choices, even if they subsequently adopt an attitude of resignation. Coping strategies vary among patients, but a positive mental outlook is generally considered important by those undergoing radiotherapy. For optimum care, radiographers may need to consider a patient's whole cancer journey and reflect on the importance of encouragement and positivity.

Confidence in this finding was low, mainly because, whilst the theme of making sense was a thread through five papers, it was difficult to establish whether it related specifically to radiotherapy or more generally to HNC cancer.

Concept 3: Life Disrupted by Radiotherapy

Daily life was altered by having to attend daily treatment for up to seven weeks. The radiotherapy environment was highly technical and frightening for patients (1). Being fixed

to the treatment couch by a mask was specifically mentioned as an unpleasant experience (1)(2)(4)(5). Patients dealt with the distress of radiotherapy by imagining they were somewhere else, a process called escape-avoidance (2). As HNC patients continued their treatment, many managed to adapt to their 'new normality' (1), and their focus was switched away from their cancer and its associations with dying. Conversely, others were reminded of their illness when receiving radiotherapy (5).

Tiredness and lack of energy were common side effects, alongside dry mouth, soreness, difficulty swallowing and taste changes (1)(3)(4)(6)(7). Physical effects led to a reduced desire and ability to eat, which worsened as treatment progressed. Side effects often appeared in clusters, with patients having to cope with 'up to seventeen symptoms at a time' (4). Patients stated the physical side effects affected them psychologically and created feelings of 'hopelessness, anxiety and depression' (6). Physical symptoms left patients emotionally drained (7).

The line of argument drawn from this concept is that physical side effects from radiotherapy are severe and inevitable. The distress they lead to may be alleviated by maintaining as normal a way of life as possible, but on a day-to-day basis imaginative exercises help to distract from the radiotherapy process. Once patients are more accustomed to the radiotherapy environment, it can offer a temporary reprieve from thoughts about an uncertain future.

The confidence in this finding was high. Physical symptoms and distress were the most common themes in all eight studies, and it was clear that radiotherapy disrupted patients' lives. There was a large degree of coherence as disruption was considered from the point of view of eating problems, experience of pain, coping strategies, experiencing radiotherapy and relationships with radiographers.

Concept 4: Waiting and Uncertainty

Waiting was a theme across the whole trajectory of cancer care, from diagnosis through every stage of treatment (1). Patients waited anxiously for radiotherapy to begin because

they did not want delays in their treatment, but then, as side effects occurred, waited for the treatment to end (1). Waiting continued after treatment as patients were anxious to find out if radiotherapy had been successful. Many patients emphasised the importance of believing in their future (7). They were often anxious about radiotherapy and its side effects (4). When patients had no knowledge of what would happen to them or did not receive adequate information, they suffered more anxiety (5).

When patients took responsibility for their choices, even the choice to undergo radiotherapy, it reduced uncertainty and improved their ability to cope (2). Coping strategies varied, but educating patients about the strategies used by other patients helped them get through radiotherapy (4). Having confidence that radiographers were giving the correct treatment increased patients' sense of being safe (5). Although HNC patients were always given information about treatment and side effects, it was often misinterpreted or lacking in detail (8). When clear information flowed between radiographers and patients it built relationships, provided knowledge and reduced uncertainty, but poor information increased feelings of insecurity and loneliness (5).

HNC patients addressed uncertainty by attempting to maintain a feeling of control over their situation. Cognitive and physical control was a goal for all patients (2). Coping strategies such as listening to music during treatment, imagining they were somewhere else, or adopting a positive mental outlook helped patients navigate radiotherapy (2). Strategies to cope with physical side effects included liquidising food, sucking on toffees, and gargling with artificial saliva (3).

The line of argument that was developed for concept 4: HNC patients spend much of their cancer treatment journey waiting in suspense. They feel in the dark about the nature of radiotherapy and its side effects and believe the information they receive does not meet their needs. When patients exert cognitive and physical control by adopting coping strategies to alleviate side effects, anxiety and uncertainty are reduced. Radiographers can influence this by providing high quality information and educating patients about successful coping strategies used by others.

Confidence in this finding was high because the theme was clear in seven studies. It was discussed with respect to eating problems, relationships with radiographers, coping strategies and symptom experience.

Based on the generated concepts, an overall line of argument was developed and is presented as a conceptual model in Figure 2. The conceptual model contrasts the unmet needs of HNC patients against examples of met needs. The examples of met needs were 'safe environment', 'expertise' and 'correct treatment', and were chosen because they reflect non-controversial aspects of the role a therapy radiographer would be expected to provide as part of their professional duty and which would be regularly audited as part of a clinical governance programme.

Discussion

Findings of Synthesis

The findings of this study indicate that head and neck cancer patients' experiences of curative radiotherapy are influenced by four key concepts: (1) their feeling of isolation; (2) their ability to make sense of the experience of their illness and its treatment; (3) the disruption that the disease and radiotherapy cause in their lives; (4) and the waiting and uncertainty that accompanies their cancer treatment journey.

It was clear from this review that patients' experiences of radiotherapy are strongly linked to their experiences of head and neck cancer in general. Receiving a diagnosis of cancer is stressful, and the nature of head and neck cancer means it has a big impact on daily living. As expected, side effects were the most discussed theme. Side effects distinguish radiotherapy from other treatments, although the daily schedule of outpatient appointments and the highly technological environment were also significant themes in the patients' experiences.

All four key concepts were influenced by many factors and overlapped each other to some extent. For example, feeling isolated was affected by the strength of individuals' relationships with friends and family, and their social situation before their diagnosis. If patients had strong relationships beforehand, they were less likely to be distressed. But, even then, there was evidence that patients sometimes felt isolated because their family and friends did not fully understand their situation and did not have enough knowledge to offer the appropriate support. Physical side effects caused psychological distress that made patients likely to withdraw from their social networks at a time when they most needed to seek help. Coping with both the illness and treatment was easier when patients took control of the situation by having a positive attitude, using distraction techniques, and reappraising their lives.

Radiotherapy was paradoxical because on one hand patients' lives were disrupted, but on the other, they found the experience 'safe and secure' and one that distracted them from existential thoughts about death and dying. To facilitate the best experience for HNC patients, radiographers need to build relationships where they can offer them individually-tailored information, expertise, encouragement and advice.

Rose-Ped *et al.*³⁷ showed that healthcare professionals, such as radiographers, provide support in the form of physical symptom management, but psychological support may be lacking, and this has been echoed by Larsson *et al.*³⁸. Similarly, the National Institute for Clinical Excellence³⁹ highlighted that the need for psychological and emotional support was often not recognised by healthcare professionals. Radiographers appear to accept HNC patients' brave faces whilst on treatment, and do not tend to delve deeper⁴⁰.

The findings demonstrate a mismatch in the psychological needs of the HNC patient and the style of care provided by therapy radiographers. Saegrov and Halding⁴¹ emphasised the importance of healthcare professionals taking responsibility for providing support to patients, so perhaps radiographers need to re-evaluate the emotional and psychological aspect of the care they offer.

One theme that consistently arose in the studies was information. Information can play a large role in alleviating anxiety in radiotherapy patients⁴², but the clear issue in this review was the lack of satisfaction HNC patients had regarding the information they received. There appeared to be a problem in the information flow between patient and radiographer, possibly due to the difference in their priorities. Information provided by radiographers tends to focus on the management of physical side effects, but the findings highlighted that patients can benefit from learning about the kind of coping strategies others have adopted. Information also needs to be framed so that it offers encouragement and helps patients to form a positive mental outlook.

The systematic review and meta-ethnography was executed using a rigorous methodology that was clearly defined. Peer-reviewed tools were adopted, such as PRISMA and CASP. A wide-ranging search strategy was used to ensure no relevant studies were missed. All three researchers were therapy radiographers by background, so it is possible there was a narrower interpretation of the findings, and possibly bias, than if researchers with no knowledge of radiotherapy had been involved. However, it is also possible that this experience gave some useful insights.

A major strength of this review was the development of a new theoretical model to describe the meaning of radiotherapy for HNC patients. Qualitative evidence synthesis means individual studies can be integrated into an overarching theory, whilst keeping the original context of their findings. Meta-ethnography enables the development of conceptual theories beyond those of single studies, which can have a real-life impact on healthcare services and provide deeper understanding of the patient experience.

The studies selected for the final synthesis were assessed as moderate to strong in quality. No study would have been excluded, but the strength of the studies improved the confidence of the researchers during discussions. The confidence in the assessment of findings was mostly moderate, with one low rating. The concepts appeared robust across the papers and echoed those found in other studies of HNC patient experience, but it was often unclear if the themes related directly to radiotherapy or how influential other factors had been, such as surgery or chemotherapy. This was not discussed in any of the papers

and, when describing the participants' baseline characteristics, only three studies stated if they had undergone surgery.

Study Limitations

The studies came from seven different countries, but there was no discussion about the individual healthcare systems. Socioeconomic status was also poorly described. The transferability of the review across cultures is questionable because the demographic data suggested predominantly Caucasian participants, and all settings were high-income economies. Conversely, the homogeneity of the samples in the final papers suggests the synthesis findings are transferable across western, high-income economy populations.

The review intended to assess patient experiences within the context of technologically advanced radiotherapy. Intensity-modulated radiotherapy (IMRT) is the standard treatment for head and neck cancer in the UK, but it was unclear if it was being used in any of the studies. There was no mention of IMRT in any of the eight papers, but it was still assumed by the researchers. It was likely to be a fair assumption considering seven of the studies were published in 2012 or later, but the lack of certainty is a limitation of the review.

Clinical Implications

Central to the key concepts in this synthesis is the role of the therapy radiographer. HNC patients begin radiotherapy already feeling distressed about their illness, so they require support right from the beginning of treatment. They have often been waiting for the radiotherapy to begin and are uncertain about its nature. The highly technological environment is alien and adds to their anxiety, but radiographers can make the treatment journey more tolerable by building relationships and providing suitable information.

Conclusions

The findings highlight that patients feel isolated and often withdraw from their social networks, but need guidance, information and expertise to help them through the treatment. Radiotherapy disrupts their daily lives, both through physical side effects, and through the damage to their psychological wellbeing that these side effects cause. Disruption comes from both radiotherapy and the cancer itself, and it is often difficult to separate one from the other. It is important to recognise that HNC patients face a complicated journey through various treatments which all impact on one another. Making sense of their experience helps patients to navigate their treatment, especially if they can develop coping strategies that involve a positive mental outlook.

Policy-makers, managers and healthcare professionals can use the results of this study to consider improvements that could be made. HNC patients undergoing radiotherapy have many unmet needs which, this review would suggest, require further study. Research needs to focus on the anxiety and uncertainty patients feel and whether interventions, especially regarding different kinds of information provision, are possible. Therapy radiographers need to reflect on the focus of their day-to-day role and consider if there should be more emphasis on the patient-radiographer relationship.

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Statement Regarding Ethics and Any Potential Conflicts of Interest

Ethical approval was not necessary for this study because it was a review article. The authors have no conflicts of interest to declare.

References

1. Cancer Research UK. Oral cancer incidence statistics | Cancer Research UK [Internet]. 2017 [cited 2017 Mar 13]. Available from: <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/oral-cancer/incidence>
2. Macmillan UK. The Rich Picture: People With Head And Neck Cancer [Internet]. 2017 [cited 2017 Mar 13]. Available from: https://www.macmillan.org.uk/_images/head-neck-cancer_tcm9-282784.pdf
3. Mehanna H, Paleri V, West CML, Nutting C. Head and neck cancer—Part 1: Epidemiology, presentation, and prevention. *BMJ*. 2010;341.
4. Mistry M, Parkin DM, Ahmad AS, Sasieni P. Cancer incidence in the United Kingdom: projections to the year 2030. *Br J Cancer*. 2011 Nov 22;105(11):1795–803.
5. Wood S, Bisson JI. Experience of incorporating a mental health service into patient care after operations for cancers of the head and neck. *Br J Oral Maxillofac Surg*. 2004 Apr;42(2):149–54.
6. Singer S, Krauß O, Keszte J, Siegl G, Papsdorf K, Severi E, et al. Predictors of emotional distress in patients with head and neck cancer. *Head Neck*. 2012 Feb;34(2):180–7.
7. Kugaya A, Akechi T, Okuyama T, Nakano T, Mikami I, Okamura H, et al. Prevalence, predictive factors, and screening for psychologic distress in patients with newly diagnosed head and neck cancer. *Cancer*. 2000 Jun 15;88(12):2817–23.
8. 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 Feb;25(2):103–12.
9. McCaffrey JC, Weitzner M, Kamboukas D, Haselhuhn G, LaMonde L, Booth-Jones M. Alcoholism, depression, and abnormal cognition in head and neck cancer: A pilot study. *Otolaryngol Neck Surg*. 2007 Jan 17;136(1):92–7.
10. Llewellyn C, McGurk M, Weinman J. Are Head and Neck Cancer Patients' Expectations Regarding Treatment and Recovery Influenced by Information: A Qualitative Pilot Study. *Heal Psychol Updat*. 2004;13(4):8–10.
11. Howren MB, Christensen AJ, Karnell LH, Funk GF. Psychological factors associated with head and neck cancer treatment and survivorship: evidence and opportunities for behavioral medicine. *J Consult Clin Psychol*. 2013 Apr;81(2):299–317.

12. Zackrisson B, Mercke C, Strander H, Wennerberg J, Cavallin-Ståhl E. A systematic overview of radiation therapy effects in head and neck cancer. *Acta Oncol.* 2003;42(5–6):443–61.
13. Epstein JB, Hong C, Logan RM, Barasch A, Gordon SM, Oberlee-Edwards L, et al. A systematic review of orofacial pain in patients receiving cancer therapy. *Support Care Cancer.* 2010 Aug 11;18(8):1023–31.
14. Hovan AJ, Williams PM, Stevenson-Moore P, Wahlin YB, Ohrn KEO, Elting LS, et al. A systematic review of dysgeusia induced by cancer therapies. *Support Care Cancer.* 2010 Aug 22;18(8):1081–7.
15. 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. *Psychooncology.* 2013 Dec;22(12):2648–63.
16. Álvarez-Camacho M, Gonella S, Campbell S, Scrimger RA, Wismer WV. A systematic review of smell alterations after radiotherapy for head and neck cancer. *Cancer Treat Rev.* 2017;54:110–21.
17. Sehlen S, Hollenhorst H, Schymura B, Herschbach P, Aydemir U, Firsching M, et al. Psychosocial Stress in Cancer Patients during and after Radiotherapy. *Strahlentherapie und Onkol.* 2003 Mar;179(3):175–80.
18. Geinitz H, Marten-Mittag B, Schäfer C, Henrich G, Bittner I, Herschbach P, et al. Patient satisfaction during radiation therapy. *Strahlentherapie und Onkol.* 2012 Jun 16;188(6):492–8.
19. Ziegler L, Newell R, Stafford N, Lewin R. A literature review of head and neck cancer patients information needs, experiences and views regarding decision-making. *Eur J Cancer Care (Engl).* 2004 May;13(2):119–26.
20. Halkett GKB, Kristjanson LJ. Patients' perspectives on the role of radiation therapists. *Patient Educ Couns.* 2007 Dec;69(1–3):76–83.
21. McQuestion M, Fitch MI. Patients' experience of receiving radiation treatment for head and neck cancer: Before, during and after treatment. *Can Oncol Nurs J / Rev Can soins Infirm en Oncol.* 2016;26(4):325–35.
22. Benner P. *Interpretive Phenomenology: Embodiment, Caring and Ethics in Health and Illness.* Thousand Oaks, California, USA.: SAGE Publications; 1994. 372 p.
23. Malpass A, Shaw A, Sharp D, Walter F, Feder G, Ridd M, et al. "Medication career" or

- “Moral career”? The two sides of managing antidepressants: A meta-ethnography of patients’ experience of antidepressants. *Soc Sci Med*. 2009 Jan;68(1):154–68.
24. CASP. Critical Appraisal Skills Programme [Internet]. 2017 [cited 2017 Apr 12]. Available from: <http://www.casp-uk.net/casp-tools-checklists>
 25. Gough D. Weight of Evidence: a framework for the appraisal of the quality and relevance of evidence. *Res Pap Educ*. 2007 Jun;22(2):213–28.
 26. Noblit GW, Hare RD. *Meta-ethnography : synthesizing qualitative studies*. Sage Publications; 1988. 88 p.
 27. Atkins S, Lewin S, Smith H, Engel M, Fretheim A, Volmink J. Conducting a meta-ethnography of qualitative literature: Lessons learnt. *BMC Med Res Methodol*. 2008 Dec 16;8(1):21.
 28. Smith T, Purdy R, Lister S, Salter C, Fleetcroft R, Conaghan P. Living with osteoarthritis: a systematic review and meta-ethnography. *Scand J Rheumatol*. 2014 Nov 2;43(6):441–52.
 29. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *BMJ*. 2009;339.
 30. Larsson M, Hedelin B, Athlin E. Needing a Hand to Hold. *Cancer Nurs*. 2007 Jul;30(4):324–34.
 31. Andersen KS, Jarden M. Coping with radiotherapy for head and neck squamous cell carcinoma: a qualitative exploration. *Nord J Nurs Res Clin Stud*. 2012;32(1):25–9.
 32. Molassiotis A, Rogers M. Symptom experience and regaining normality in the first year following a diagnosis of head and neck cancer: A qualitative longitudinal study. *Palliat Support Care*. 2012 Sep 22;10(3):197–204.
 33. Haisfield-Wolfe ME, McGuire DB, Krumm S. Perspectives on Coping Among Patients With Head and Neck Cancer Receiving Radiation. *Oncol Nurs Forum*. 2012 May 1;39(3):E249–57.
 34. Egestad H. How does the radiation therapist affect the cancer patients’ experience of the radiation treatment? *Eur J Cancer Care (Engl)*. 2013 Sep;22(5):580–8.
 35. Charalambous A. Hermeneutic phenomenological interpretations of patients with head and neck neoplasm experiences living with radiation-induced xerostomia: The price to pay? *Eur J Oncol Nurs*. 2014;18(5):512–20.
 36. Schaller A, Larsson B, Lindblad M, Liedberg GM. Experiences of Pain: A Longitudinal,

- Qualitative Study of Patients with Head and Neck Cancer Recently Treated with Radiotherapy. *Pain Manag Nurs*. 2015 Jun;16(3):336–45.
37. Rose-Ped AM, Bellm LA, Epstein JB, Trotti A, Gwede C, Fuchs HJ. Complications of Radiation Therapy for Head and Neck Cancers. *Cancer Nurs*. 2002 Dec;25(6):461–7.
 38. Larsson M, Hedelin B, Athlin E. Lived experiences of eating problems for patients with head and neck cancer during radiotherapy. *J Clin Nurs*. 2003 Jul;12(4):562–70.
 39. NICE. Improving outcomes in head and neck cancers - The Manual; Improving outcomes in head and neck cancers - The Manual. 2004.
 40. Donovan M, Glackin M. The lived experience of patients receiving radiotherapy for head and neck cancer: a literature review. *Int J Palliat Nurs*. 2012 Sep;18(9):448–55.
 41. Saegrov S, Halding A-G. What is it like living with the diagnosis of cancer? *Eur J Cancer Care (Engl)*. 2004 May;13(2):145–53.
 42. McPherson CJ, Higginson IJ, Hearn J. Effective methods of giving information in cancer: a systematic literature review of randomized controlled trials. *J Public Health Med*. 2001 Sep;23(3):227–34.

Table 1. Summary of study characteristics.

Study (n=8)	Sample size (tumour site)	Gender (M/F); mean age (range) in years	Design; sampling	Method of data collection	Focus	Aim
(1) Larsson <i>et al.</i> (2007): Sweden	9 (5 oral, 4 pharyngeal)	7/2; median 70 (52-86)	Interpretive phenomenology, inspired by Colaizzi; purposive, maximum variation	Open dialogue interviews, 6-12 weeks after treatment	Eating problems**	Acquire a deeper understanding of head and neck cancer patients' lived experiences of daily life during the trajectory of care with a focus on eating problems
(2) Andersen and Jarden (2012): Denmark	5 (oral cavity, pharynx, larynx)	4/1; (50-65)	Hermeneutic method, related to Lazarus' coping theory; convenience	Semi-structured interviews, one month after treatment	Coping	Explore how patients with HNC cope with radiotherapy and side effects
(3) Molassiotis & Rogers (2012): England	16 (majority oral or oropharyngeal, 1 laryngeal)	14/2; 61 (34-80)	Qualitative, using Leventhal's self-regulation theory; purposive, maximum variation	Semi-structured interviews, at four time points	Symptom experience	Explore and understand the experience of receiving treatment for HNC with focus on symptom experience
(4) Haisfield-Wolfe <i>et al.</i> (2012): USA	21 (16 oropharyngeal, 5 laryngeal)	18/3; 59.2	qualitative content analysis; convenience	Structured interviews, at four time points	Coping	Describe coping among patients with laryngeal and oropharyngeal cancer during definitive radiation with or without chemotherapy
(5) Egestad (2013): Norway	11 (tonsil, larynx, nasopharynx, tongue, FOM, lymphoma)	7/4; median 57 (37-76)	Phenomenological hermeneutic approach; convenience	Semi-structured interviews, 1 month after treatment	Relationship with radiation therapist	Illuminate how HNC patients' encounters with radiation therapists influence patients; experiences going through radiotherapy

Table 1. (Continued.)

Study (n=8)	Sample size (tumour site)	Gender (M/F); mean age (range) in years	Design; sampling	Method of data collection	Focus	Aim
(6) Charalambous (2014): Cyprus	15 (not specified)	8/7; (39-66)	Hermeneutic phenomenology, inspired by Riceour; purposive -theoretical	In-depth interviews, 1-3 months' post-treatment.	Xerostomia ^{***}	Explore the in-depth experiences of patients living with radiation-induced xerostomia.
(7) Schaller <i>et al.</i> (2015): Sweden	26 (9 oral cavity, 9 pharynx, 4 larynx, 4 other)	19/7; 64	Qualitative content analysis; convenience	Qualitative semi-structured interviews, 1 and 6 months after treatment	Experience of pain	Describe how HNC patients experience pain and how pain influences those treated with radiotherapy
(8) McQuestion & Fitch (2016): Canada	17 (not specified)	12/5; NS [*]	Thorne's interpretive description and Giorgi's analytical technique; purposive, maximum variation	In-depth interviews, 3-4 months' post-treatment semi	Radiation treatment	Explore the experience of individuals receiving radiation treatment for cancer of the head and neck.

Key

*Age range not specified

**Participants with enteral feeding were excluded

***Participants had at least grade 2 xerostomia, based on RTOG scale