

British Journal of Nursing

Head and Neck cancer peer-to-peer support and quality of life: systematic scoping review --Manuscript Draft--

Manuscript Number:	bjon.2021.0165R2
Full Title:	Head and Neck cancer peer-to-peer support and quality of life: systematic scoping review
Short Title:	
Article Type:	Literature review
Keywords:	Head and Neck Cancer; Peer support; Social support; Self-help; Scoping review; quality of life
Corresponding Author:	Rebecca Hatton University of Liverpool Liverpool, UNITED KINGDOM
Corresponding Author Secondary Information:	
Corresponding Author's Institution:	University of Liverpool
Corresponding Author's Secondary Institution:	
First Author:	Rebecca A Hatton
First Author Secondary Information:	
Order of Authors:	Rebecca A Hatton Ms Julie Crane Professor Simon N Rogers Professor Jo Patterson
Order of Authors Secondary Information:	
Abstract:	<p>Background/Aim: The aim of this scoping review is to summarise the current evidence for peer-to-peer support and its impact on Quality of Life (QOL) in Head and Neck Cancer (HNC).</p> <p>Methods: Five search engines were used: PubMed, CINAHL, APA PsycInfo, Web of Science and Handle on QOL for publications between 1981 and 2020. Adapted PICO (population, intervention, comparator and outcome) and Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) methodology was used.</p> <p>Results: Of the 1408 papers identified, 10 met the inclusion criteria: five qualitative, two cross-sectional, one case-control, one cohort and one quasi-experimental design. There were four common themes: patient experience of peer-to-peer support, delivery of peer-to-peer support, engagement with peer-to-peer support and impact on QOL.</p> <p>Conclusion: The review highlights the paucity of evidence in respect to QOL and peer-to-peer support in HNC. It provides a summary of the literature and identifies areas for clinical practice and future research.</p>
Suggested Reviewers:	
Response to Reviewers:	Many thanks for your helpful comments about theory. We agree that making explicit the limited reference to theory is helpful and have added the following paragraph: "Only one of the papers made reference to theoretical frameworks (Algtewi et al., 2015). Algetewi et al noted that the relationship between social relations and physical health was first identified by Durkheim, later taken forwards by Cobbs (1976) and Berkman and Syme (1979). It would appear that theory underpinning peer to peer

	<p>support is limited - this is an area worthy of further exploration."</p> <p>With regards to Maslow, whilst we appreciate that self-determination as a motivation theory might be applicable, the attraction of Maslow's theory is the requirement for people to be able to meet their basic physiological needs. For patients with H&N cancer, even this is a challenge. Neck-breathers have additional safety needs and there is evidence to suggest that people have difficulty with intimacy following H&N cancer. Thank you for giving us the opportunity to reflect upon this, it is genuinely an area for potential exploration, we hope you agree with our perspective.</p>
Additional Information:	
Question	Response
Please enter the word count of your manuscript excluding references and tables	3048

Head and Neck cancer peer-to-peer support and quality of life: systematic scoping review

Hatton RA, Crane J, Rogers SN, Patterson J

Miss Rebecca A Hatton, Medical Student, School of Health Sciences, Institute of Population Health/Liverpool Head and Neck Centre, University of Liverpool, 1.17 Thompson Yates Building, The Quadrangle, Brownlow Hill, Liverpool L69 3GB

R.Hatton@liverpool.ac.uk

Ms Julie Crane MA, PGCert, RGN, SFHEA, Centre Manager, NWCR Centre - University of Liverpool, Department of Molecular and Clinical Cancer Medicine

University of Liverpool, 200 London Road, Liverpool, L3 9GA

J.Crane@liverpool.ac.uk

Professor Simon N Rogers, Faculty of Health, Social Care and Medicine, Edge Hill University, Ormskirk, L39 4QP and Liverpool Head and Neck Centre, Liverpool University Hospital Aintree, Liverpool, UK

SIMONN.ROGERS@liverpoolft.nhs.uk ORCID: 0000-0002-5989-6142

Professor Jo Patterson BSc(Hons), MSc, PhD, FRCSLT, School of Health Sciences, Institute of Population Health / Liverpool Head and Neck Centre, University of Liverpool

1.17 Thompson Yates Building, The Quadrangle, Brownlow Hill, Liverpool L69 3GB

joanne.patterson@liverpool.ac.uk

Corresponding author

Professor Jo Patterson BSc (Hons), MSc, PhD, FRCSLT, School of Health Sciences, Institute of Population Health / Liverpool Head and Neck Centre, University of Liverpool

1.17 Thompson Yates Building, The Quadrangle, Brownlow Hill, Liverpool L69 3GB

T: +44 (0)151 795 1359 joanne.patterson@liverpool.ac.uk

Abstract

Background/Aim:

The aim of this scoping review is to summarise the current evidence for peer-to-peer support and its impact on Quality of Life (QOL) in Head and Neck Cancer (HNC).

Methods:

Five search engines were used: PubMed, CINAHL, APA PyscInfo, Web of Science and Handle on QOL for publications between 1981 and 2020. Adapted PICO (population, intervention, comparator and outcome) and Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) methodology was used.

Results:

Of the 1408 papers identified, 10 met the inclusion criteria: five qualitative, two cross-sectional, one case-control, one cohort and one quasi-experimental design. There were three common themes: patient experience of peer-to-peer support, delivery of peer-to-peer support and engagement with peer-to-peer support.

Conclusion:

The review highlights the paucity of evidence in respect to QOL and peer-to-peer support in HNC. It provides a summary of the literature and identifies areas for clinical practice and future research.

Conflict of interest statement

No conflicts of interest

Key words: Head and Neck Cancer; Peer support; Social support; Self-help; Scoping review;

Quality of life

Key points:

- Head and Neck cancer (HNC) is associated with life changing effects on quality of life (QOL)
- Peer-to-peer support has a role in HNC patient care
- The number of published studies reporting on peer-to-peer support and impact on QOL in HNC individuals is very limited
- Further clinical evaluation and research is required in order to help better understand and optimise the role of peer-to-peer support for HNC individuals

Reflective questions:

- What is the published evidence relating to peer-to-peer support and QOL in HNC
- What cohorts and study designs have been used in previous publications
- What themes emerge when collating and summarising the literature on peer-to-peer support and QOL for HNC patients
- How does the current literature help inform future clinical practice and research

Abstract

Background/Aim:

The aim of this scoping review is to summarise the current evidence for peer-to-peer support and its impact on Quality of Life (QOL) in Head and Neck Cancer (HNC).

Methods:

Five search engines were used: PubMed, CINAHL, APA PyscInfo, Web of Science and Handle on QOL for publications between 1981 and 2020. Adapted PICO (population, intervention, comparator and outcome) and Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) methodology was used.

Results:

Of the 1408 papers identified, 10 met the inclusion criteria: five qualitative, two cross-sectional, one case-control, one cohort and one quasi-experimental design. There were four common themes: patient experience of peer-to-peer support, delivery of peer-to-peer support, engagement with peer-to-peer support and impact on QOL.

Conclusion:

The review highlights the paucity of evidence in respect to QOL and peer-to-peer support in HNC. It provides a summary of the literature and identifies areas for clinical practice and future research.

Introduction

Head and neck cancer (HNC) and its treatment is associated with life-changing challenges, with many patients experiencing substantial detrimental changes to appearance, eating, speech, and swallowing function (Fang and Heckman 2016). These impact on physical, emotional and social well-being. Such challenges can reduce a patient's willingness to interact socially and can be associated with increased anxiety and depression (Korsten et al. 2019) which can be associated with reduced Quality of Life (QOL) (Hammermüller et al. 2021). The prevalence for depression in HNC patients is higher than other cancers, ranging from 22% to 57% (Archer et al. 2008). Patients with HNC have unmet supportive care needs which need to be recognised and treatment individualised (van Sluis et al. 2020). QOL and these unmet needs may be improved through social support (Dahill et al. 2020). One way of achieving this is through peer-to-peer support, although this has received little attention in the literature (Rogers 2021).

Peer-to-peer support is when individuals who have experienced a similar event provide social, emotional, or practical support for each other to help them to better cope with their situation (Park et al. 2019). Peer-to-peer support can be delivered in a range of formats, including face-to-face or online support groups, one-to-one peer support and professionally-led peer support groups (Hoey et al. 2008). Peer-to-peer support can be beneficial, improving knowledge, awareness and provide reassurance, which may help an individual prepare for the future and reduce feelings of isolation (Baker 2020). However, there are some problems associated with peer-to-peer support including the sharing of incorrect information, the feeling of being let down by a peer and the ethical consideration of confidentiality when confiding in a fellow peer (Baker 2020). Much research focuses on peer-to-peer support and QOL in breast cancer and demonstrates a clear QOL benefit (Ashbury et al. 1998; Taleghani et al. 2012; Tehrani et al. 2011). Although peer-to-peer support is recognised as an important

component in cancer care, there seems to be relatively little evidence specific to QOL and HNC. The aim of this scoping review is to identify, collate and summarise the existing literature on peer-to-peer support and its impact on QOL in HNC patients. It provides a useful summary of the relevant literature and includes considerations for clinical practice and future research.

Methods

This review follows the methodology proposed by Levac *et al.* (2010) and further developed by the Joanna Briggs Institute (JBI) (Peters 2020). A scoping review was chosen over a systematic review as the aim was to assess the selected literature, summarise the findings and identify knowledge gaps. The quality of the papers was assessed by the JBI criteria checklist (Lockwood *et al.* 2015; Moola *et al.* 2020; Tufanaru *et al.* 2020). The main research question was identified using the PICO (population, intervention, comparator and outcome) format (Aslam and Emmanuel 2010). The main research question was ‘What evidence is there for peer-to-peer support in patients with HNC and QOL?’.

Search strategy

Five search engines were used PubMed, CINAHL, APA PyscInfo, Web of Science and Handle on QOL. The search terms were ‘Head and Neck neoplasms’ or ‘mouth cancer’ or ‘laryngeal cancer’ or ‘oral cancer’ or ‘oropharyngeal cancer’ or ‘head cancer’ or ‘neck cancer’ and ‘social support’ or ‘self-help group’ or ‘peer support’ and ‘quality of life’ or ‘health related quality of life’.

Selection criteria

Papers published from 1981 to October 2020 were retrieved. Papers were included if they related to HNC patients, full text available in English, including full paper publications and reviews, randomized controlled trials, cohort studies, case-control studies and qualitative

studies. The nature of peer-to-peer support included one-on-one peer-to-peer support, support group or self-help group and online or web-based support group. Papers were excluded if only published as a commentary, or abstract conference presentation or the nature of support was provided by a healthcare professional (e.g., nurse-led intervention).

The selection process was guided and constructed according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) checklist (Tricco et al. 2018). Rayyan was used as a data management tool to store titles, abstracts and delete duplicate papers found during the database search (Ouxxani et al. 2016). All authors met throughout the process to agree the search terms, inclusion and exclusion criteria. Papers were collated by the main author (RH). All identified papers were subject to an initial title and abstract review to decide if they met the inclusion criteria, 10% were checked by JP for agreement. The full papers were then screened with 20% being assessed at random by the research team, as a reliability check for the final selection, discussing any papers where there was uncertainty regarding eligibility. The final papers were then hand and citation searched for any papers that may fit the topic of the review.

The results are reported using the PRISMA four-phase flow diagram (Moher et al. 2009). All authors reviewed the full pdfs and agreed on the data extracted from the selected papers. Key data comprised author(s), year of publication, country of publication, aim of paper, study design, cohort of patients, number of patients, category of peer support, study methods and main findings (Table 1). All papers were quality assessed using JBI's checklists according to study design (Lockwood et al. 2015; Moola et al. 2020; Tufanaru et al. 2020). As all types of study were included in the search, a narrative synthesis was planned to extract and combine all relevant findings. This involved analysing the data for key themes and concepts.

Following this, four common themes were developed and agreed by all authors with the data and links between papers explored.

Results

The initial database search retrieved 1,406 papers and hand-searching retrieved two. Reference management software identified 385 duplicates, leaving 1,023 papers. Titles and abstracts screened out 911 papers, with reasons listed in Figure 1. There was disagreement between reviewers on just three papers, all were accepted into the next stage of review. The remaining 112 papers were then full-text screened. Overall a total of ten papers were taken for full review.

Study characteristics

The studies varied in design and included five qualitative, two cross-sectional, one case-control, one cohort and one quasi-experimental design. Four papers focused on individuals with laryngectomies. Papers were all published between 2001-2019 in six different countries: Norway, The Netherlands, Canada, United Kingdom, United States and Germany. Table 1 describes the characteristics and findings of the included papers.

Study quality

All papers were screened for quality against the appropriate JBI criteria checklist. All qualitative studies were of high-quality, but none fulfilled these criteria, 1) providing a statement about the authors influence on the study and 2) the potential of the researcher to have influenced the study and vice-versa. A common weakness in the quantitative papers was their use of unvalidated measures, negating the potential for data synthesis (Carroll-Alfano 2019; Mowry and Wang 2011; Oskam et al. 2013; Relic et al. 2001).

Data Synthesis

Four common themes were identified across the papers: patient experience of peer-to-peer support, delivery of peer-to-peer support, engagement with peer-to-peer support and impact on QOL.

Patient experience of peer-to-peer support

Patient experience of peer-to-peer support varied, and papers included advantages and disadvantages. All papers agreed that peer-to-peer support could be beneficial. The main benefit noted was sharing information, gaining an insight into the future, and connecting with others, helping to reduce the feeling of uncertainty and isolation. In an open question, 75% of patients reported family support as the most important way of helping them cope, whereas a third identified self-help groups (Relic et al. 2001). Patients reported that the residential program provided a safe and supportive environment to practice new skills whilst benefiting from interacting with peers who exchanged information and provided encouragement (Kristensen et al. 2019). Those who engaged in peer support as mentors reported feeling important and valuable as they were able to provide information and help a fellow peer (Egestad 2013).

Disadvantages of peer-to-peer support were explored in three qualitative studies (Egestad 2013; Kristensen et al. 2019; van Sluis et al. 2020). Some felt meeting a peer did not fully prepare them for life after surgery, with some peers neglecting to share long-term difficulties (van Sluis et al. 2020). Others feared meeting patients with more advanced cancer as this could be their future (Kristensen et al. 2019); meeting a peer had the potential to increase emotional distress (Egestad, 2013).

Delivery of peer-to-peer support

All papers gave details on how the peer-to-peer support intervention was delivered. The commonest form was in-person support groups with seven papers reporting other modes

including online support groups or one-on-one peer support. Patients who were female (80.3% of females vs 66.4% of males), and those living in urban areas were more likely to attend in-person support groups (58.7% urban vs 24.5% rural) (Carroll-Alfano 2019; Mowry and Wang 2011). People living in rural areas were more likely to participate in online support groups than those living in urban areas (59.2% vs 47.8%) (Carroll-Alfano 2019).

Mechanisms for access varied, with patients independently finding online support groups to communicate with each other (Dooks et al. 2012). People with a laryngectomy accessed both in person and online support groups in similar measures (52% vs 46%) (Carroll-Alfano 2019). Patients used these forums to access information (43% of online messages), emotional support and to improve their confidence (Algtewi et al. 2015).

Engagement with peer-to-peer support

Timing of peer-to-peer support introduction and the nature of the relationship affected participation and engagement. All papers reported on post-treatment peer support, except one, which introduced support while patients were under-going radiotherapy (Egestad 2013). Two papers looked at factors affecting access with both finding attendance decreased with time post-treatment (Carroll-Alfano 2019; Oskam et al. 2013). Carroll-Alfano (2019) reported high uptake in the first year following treatment (78% at 0-3 years) dropping to 63% beyond ten years.

Two papers explored issues relating to lack of engagement (Kristensen et al. 2019; van Sluis et al. 2020). For some this was due to physical symptoms such as fatigue, or fear of meeting someone else with more advanced HNC as they were afraid this would be their future (Kristensen et al. 2019). Having a peer with whom the patient could identify with regards to age and family circumstances was important (van Sluis et al. 2020).

A questionnaire looking at the need and use of peer support found 35% of patients expressed a need but only 20% accessed peer support, however this was taken from a small sample size (n=26) (Oskam et al. 2013).

Some patients may be limited to what peer support they can access. With some patients not being familiar with computers or technology online support is harder to access. Though one participant spoke of how proud they felt after learning to use a computer and being able to contact friends and family as a result (Dooks et al. 2012).

Impact of peer-to-peer support on QOL

Two papers reported on QOL outcomes and peer-to-peer support groups using different questionnaires; the University of Michigan Head and Neck Quality of Life instrument and the Medical Outcomes Study Short Form-36 Item Health Survey version 2 and found conflicting results (Mowry and Wang 2011; Vakharia et al. 2007). Mowry et al. (2011) looked at eight domains related to global QOL and reported no significant improvement in QOL for those attending a support group. In contrast, Vakharia et al. (2007) found that patients who attended support groups had significantly higher scores in three domains of Head and Neck QOL: eating; emotion and pain. Patients in support groups also reported higher scores in treatment response and global bother ($p < 0.05$ and $P < 0.001$) respectively. Both reported on small samples (37 and 47 participants), each sample having a similar mean age (61 and 63.5 years). However, the gender ratio of participants varied, with the study reporting positive findings recruiting only male participants (Vakharia et al. 2007) and the other reporting on a group where 60% of participants were female (Mowry and Wang 2011).

Discussion

This systematic scoping review was performed to select and appraise the literature on peer-to-peer support in HNC and its impact on QOL, and identify the gaps in knowledge.

Peer-to-peer support can be beneficial and allows the sharing of information, however it also has its disadvantages and may not be suitable for everyone. There is limited literature and only four of the ten papers focused on QOL with two specifically studying the effect of peer-to-peer support on QOL. Neither Vakharia *et al.* (2007) nor Mowry *et al.* (2011) found that peer support groups adversely affected QOL, but they disagreed on how beneficial support groups were. Vakharia *et al.* (2007) measured improvement in a number of QOL domains. Mowry *et al.* (2011) did not reproduce these results finding no significant improvement in any of the five QOL domains.

There is unmet supportive care needs in HNC patients and an emphasis to recognise these needs and tailor treatment to the individual. van Sluis *et al.* (2020) states that peer-to-peer support could be one method of fulfilling these needs and matching peers may enhance an individual's experience with peer-to-peer support. However, the range of tumour types and treatments may affect how well individuals relate. Thus, highlighting the lack of homogeneity for HNC and the difficulties of matching meaning peer support may not address these unmet needs. The diversity of HNC sites covered by the papers reviewed means the patient groups may not be directly comparable as they will face different challenges, for example some may have profoundly different ways of breathing, altered appearance, others more bothered by substantial eating and drinking problems.

Patient's needs, expectations and fears regarding peer support are multifaceted. Individuals will have different support needs, and some may not find peer support beneficial. Relating to a peer is a complex issue as some will relate regarding treatment and side effects (Egestad 2013) whilst others will look for a deeper connection, wanting someone of a similar age and gender (van Sluis *et al.* 2020).

The majority of papers reviewed focused on in-person support groups, however the current pandemic means there has been a substantial change in meeting and communicating. There is a burgeoning number of online HNC support groups, which could be particularly beneficial for those in rural areas, allowing them to participate without needing to travel (Carroll-Alfano 2019). Online groups may mean a larger number of patients participate in peer support and therefore there is a greater chance of meeting someone with a similar disease, side effect or personal profile. However, online is not going to suit everyone, for example, laryngectomy patients who communicate through writing may struggle with virtual meetings. Another platform of support that has increased in recent years and may have provided support for HNC during the pandemic is social media, for example Instagram, where patients can document their journey, seek support and community allowing patients all over the country to connect and share information (Gao et al. 2021).

Knowledge gaps

This review has identified several gaps in the literature, notably 1. a lack of evidence around peer-to-peer support and impact on QOL 2. how might HNC peer-to-peer support be best delivered, including mechanisms (e.g., groups, remote access), timing and matching peers to patients appropriately. Given the paucity of evidence we recommend the gaps are explored using qualitative methodology, in particular in-depth interviewing to investigate patients experience and preferences regarding peer support.

Minimal reference was made to developing theory of how peer support might work and for whom it might suit. One paper alluded to Durkheim's theory i.e. a collective societal consciousness creates social integration (Algtewi et al., 2015). The application of theoretical frameworks is an area worthy of further exploration. It might also be useful to explore the extent to which a patient's motivation impacts on their experience of peer support. Maslow's

hierarchy of needs would be a useful theoretical framework to underpin such work (Maslow 1943).

Comparison to other literature

This scoping review found limited evidence to support that peer-to-peer support improves QOL in HNC. In other tumour groups, there are also conflicting results, with some papers reporting it improves QOL and others disagreeing (Taleghani et al. 2012; Tehrani et al. 2011; Toija et al. 2019). These results highlight the need for further research into peer support and QOL in all cancer areas, to unpick these different outcomes.

Barriers to accessing support in HNC are similar to those in breast cancer with some patients not wanting to access support groups due to fear of meeting someone with more advanced cancer and the lack of availability of support groups (Kemp et al. 2018).

Strengths and Limitations

To the authors' knowledge this is the first scoping review that looks at peer-to-peer support in HNC and its effect on QOL. The review was conducted systematically and robustly.

However, the search was limited to those published in English. Due to the small number of papers, the limited sample size and varied study designs no clear consensus could be reached.

Conclusion

Although it is widely accepted that peer-to-peer support is an important resource in the care of patients with cancer, there is paucity of evidence in how this might improve QOL in HNC patients. The review summarises the current literature and its limitations. The review highlights the challenges in providing peer-to-peer support and emphasises the need for support to be individualised. Further research is needed to better understand how peer-to-peer support can be optimised in clinical practice and its impact on patients' QOL.

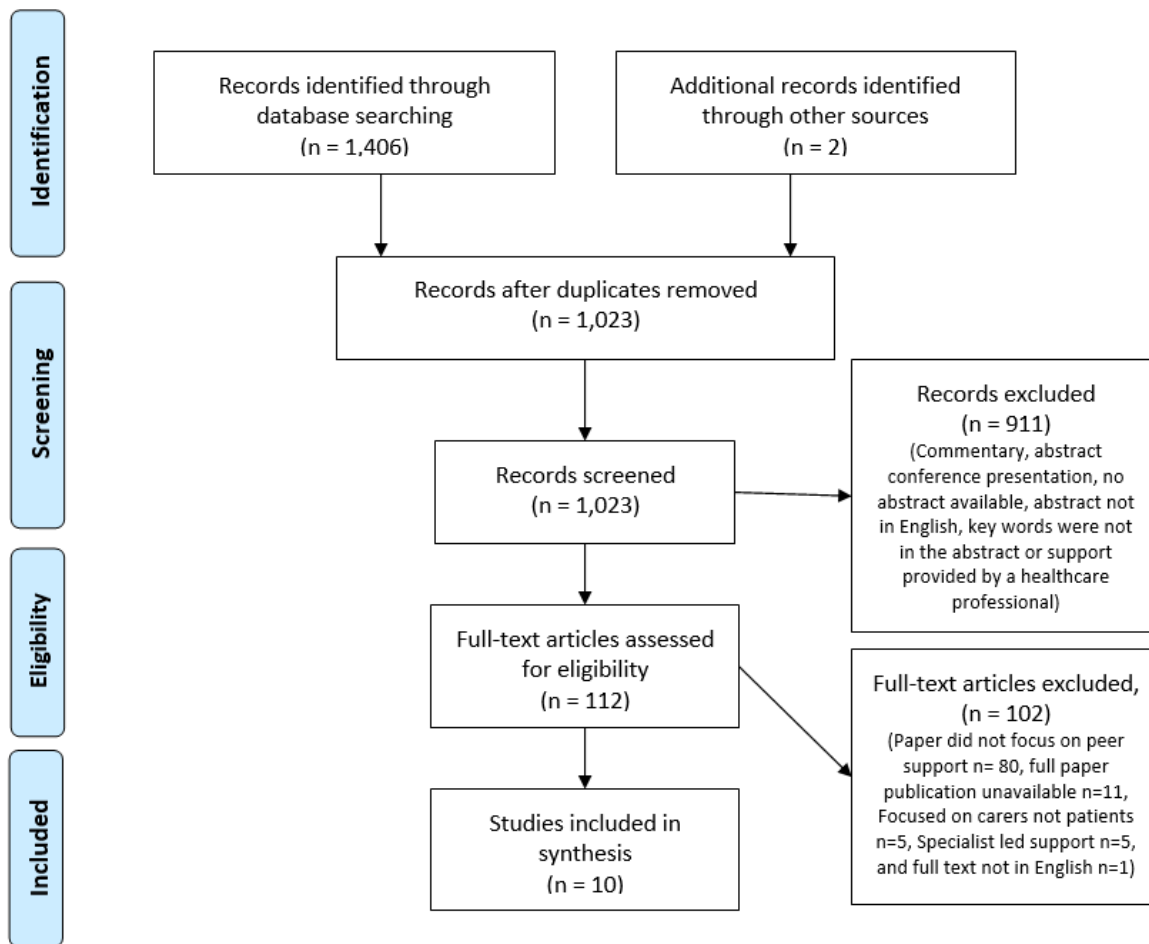


Figure 1. Flow chart on database search based on inclusion criteria for scoping review (Moher et al. 2009)

Table 1. Data extraction sheet

Author (s), Year of publication and Country of publication	Aim of paper	Study design	Cohort of patients	Number of patients	Category of peer support	Methods	Main findings
Egestad 2013 Norway	Explore peer support during radiotherapy	Qualitative	HNC patients during radiotherapy treatment	11	One-to-one support and group support	In depth interviews	Participants thought it was important to meet fellow peers as it can reduce uncertainty, loneliness and allow the sharing of information.
Van Sluis et al. 2020 The Netherlands	Explore recovery needs	Qualitative	Women with Laryngectomies	8	One-to-one support and support groups	Semi-structured interviews	Women specific challenges included altered appearance, altered voice and not being able to perform care activities. It was also found that meeting a laryngectomised individual prior to surgery had mixed responses
Dooks et al. 2012 Canada	Identify what support is available following laryngectomy post hospital discharge	Qualitative	Patients with laryngectomies	9	Web-based support groups	In depth interviews	Many types of support including peer support are crucial for a positive transition. One of these may be web based support groups, which may help improve communication.
Algtewi et al. 2015 United Kingdom	Identify support provided by online HNC groups	Qualitative	Mixed cohort of HNC patients	203	Online support group	Content analysis of online messages	Online support groups are used by individuals with HNC to seek many different types of support, the most common being informational and emotional.

Kristensen et al. 2019 The Netherlands	Explore outcomes of a residential rehabilitation program	Qualitative	HNC patients	40	Support group and One-on-one support	Semi-structured focus group interviews	The program was beneficial as it allowed peers to meet and share information and encouragement in a positive environment. This helped participants gain better coping mechanisms
Carroll-Alfano 2019 United States of America	Explore education, counselling, support groups for laryngectomy patients	Cross-sectional	Patients with laryngectomies	236	Support groups (online and in-person)	Anonymous survey	Only 40.5% and 49% of participants felt they received adequate education before and after surgery respectively. 71.0% of participants reported participating in any type of support group
Relic et al. 2001 Germany	Investigate QOL outcomes of HNC self-group	Cross-sectional	Patients with laryngectomies	29	Support group	HRQOL questionnaire (EORTC QLQ-C30 and EORTC H&N35) with open questions	31% of patients reported self-helps helped them to cope with their condition and HNC specific symptoms e.g., talking to others were related with a lower QOL
Mowry and Wang 2011 United States of America	Compare QOL between HNC patients attending support groups to those who do not	Case-control	HNC patients	37	Support group	Medical Outcomes Study Short Form-36 Item Health Survey version 2 and a non-validated supplementary questionnaire	No statistical significance between the support group and non-support group identified for any QOL domain (role physical, physical function, social function, role emotion and general health), however it was a small sample size.

Oskam et al. 2013 The Netherlands	Looks at QOL and the perceived need and use of healthcare services	Cohort	Advanced oral or oropharyngeal cancer patients treated with surgery and adjuvant radiotherapy	80	One-on-one support	2 HRQOL questionnaires (EORTC QLQ-C30 and EORTC H&N35) and a non-validated supplementary questionnaire	The deterioration in HRQOL at baseline versus long-term was statistically significant in eight of the twenty eight domains presented Uptake of peer support during treatment was 20% versus 35% at long-term follow-up
Vakharia et al. 2007 United States of America	Compare QOL of HNC patients who do and do not participate in a support group	Non-randomised Quasi-experimental	HNC patients	47	Support group	Validated University of Michigan Head and Neck QOL instrument	Those who attended the support group had higher scores in three Head and Neck QOL domains ($p < 0.01$). Speech was the only domain that was not significant (70.3% versus 57%) for the support group and non-support group respectively.

References

- Algtewi EE, Owens J, Baker SR. 2015. Analysing people with head and neck cancers' use of online support groups. *Cyberpsychology*. 9(4):1-20.
- Archer J, Hutchison I, Korszun A. 2008. Mood and malignancy: Head and neck cancer and depression. *Journal of oral pathology & medicine : official publication of the International Association of Oral Pathologists and the American Academy of Oral Pathology*. 37(5):255-270.
- Ashbury FD, Cameron C, Mercer SL, Fitch M, Nielsen E. 1998. One-on-one peer support and quality of life for breast cancer patients. *Patient Education and Counseling*. 35(2):89-100.
- Aslam S, Emmanuel P. 2010. Formulating a researchable question: A critical step for facilitating good clinical research. *Indian journal of sexually transmitted diseases*. 31:47-50.
- Baker P. 2020. Talking through it: The role of peer support for people with throat cancer. Throat Cancer Foundation, Fallkirk.
- Berkman LF, Syme SL. 1979. Social networks, host resistance and mortality: A nine-year follow-up study of Alameda County residents. *American Journal of Epidemiology*. 109:186-204.
- Carroll-Alfano MA. 2019. Education, counseling, support groups, and provider knowledge of total laryngectomy: The patient's perspective. *Journal of Communication Disorders*. 82:105938.
- Cobb S. 1976. Social support as a moderator of life stress. *Psychosomatic medicine*. 38:300-314.
- Dahill A, Al-Nakishbandi H, Cunningham KB, Humphris GM, Lowe D, Rogers SN. 2020. Loneliness and quality of life after head and neck cancer. *British Journal of Oral and Maxillofacial Surgery*. 58(8):959-965.
- Dooks P, McQuestion M, Goldstein D, Molassiotis A. 2012. Experiences of patients with laryngectomies as they reintegrate into their community. *Supportive Care in Cancer*. 20(3):489-498.
- Egestad H. 2013. The significance of fellow patients for head and neck cancer patients in the radiation treatment period. *European Journal of Oncology Nursing*. 17(5):618-624.
- Fang CY, Heckman CJ. 2016. Informational and support needs of patients with head and neck cancer: Current status and emerging issues. *Cancers of the head & neck*. 1.
- Gao RW, Smith JD, Malloy KM. 2021. Head and neck cancer and social media: The patient experience and cancer survivorship. *The Laryngoscope*. 131(4):E1214-E1219.
- Hammermüller C, Hinz A, Dietz A, Wichmann G, Pirlich M, Berger T, Zimmermann K, Neumuth T, Mehnert-Theuerkauf A, Wiegand S et al. 2021. Depression, anxiety, fatigue, and quality of life in a large sample of patients suffering from head and neck cancer in comparison with the general population. *BMC Cancer*. 21(1):94-94.
- Hoey LM, Ieropoli SC, White VM, Jefford M. 2008. Systematic review of peer-support programs for people with cancer. *Patient Education and Counseling*. 70(3):315-337.
- Kemp E, Koczwara B, Butow P, Turner J, Girgis A, Schofield P, Hulbert-Williams N, Levesque J, Spence D, Vatandoust S et al. 2018. Online information and support needs of women with advanced breast cancer: A qualitative analysis. *Supportive Care in Cancer*. 26(10):3489-3496.

- Korsten LHA, Jansen F, de Haan BJF, Sent D, Cuijpers P, Leemans CR, Verdonck-de Leeuw IM. 2019. Factors associated with depression over time in head and neck cancer patients: A systematic review. *Psychooncology*. 28(6):1159-1183.
- Kristensen MB, Mikkelsen TB, Beck AM, Zwisler A-D, Wessel I, Dieperink KB. 2019. To eat is to practice—managing eating problems after head and neck cancer. *Journal of Cancer Survivorship*. 13(5):792-803.
- Levac D, Colquhoun H, O'Brien KK. 2010. Scoping studies: Advancing the methodology. *Implementation Science*. 5(1):69.
- Lockwood C, Munn Z, Porritt K. 2015. Qualitative research synthesis: Methodological guidance for systematic reviewers utilizing meta-aggregation. *International journal of evidence-based healthcare*. 13(3):179-187.
- Maslow, A.H. 1943. A theory of human motivation. *Psychological review*. 50(4) 370-396.
- Moher D, Liberati A, Tetzlaff J, Altman DG. 2009. Preferred reporting items for systematic reviews and meta-analyses: The prisma statement. *PLoS medicine*. 6(7):e1000097.
- Moola S, Munn Z, Tufanaru C, Aromataris E, Sears K, Sfetcu R, Currie M, Lisy K, Qureshi R, Mattis P et al. 2020. Chapter 7: Systematic reviews of etiology and risk. In: Aromataris E, Munn Z, editors. *JBIManual for Evidence Synthesis*. JBI.
- Mowry SE, Wang MB. 2011. The influence of support groups on quality of life in head and neck cancer patients. *ISRN otolaryngology*. 2011:250142.
- Oskam IM, Verdonck-de Leeuw IM, Aaronson NK, Witte BI, de Bree R, Doornaert P, Langendijk JA, René Leemans C. 2013. Prospective evaluation of health-related quality of life in long-term oral and oropharyngeal cancer survivors and the perceived need for supportive care. *Oral Oncology*. 49(5):443-448.
- Ouzzani M, Hammady H, Fedorowicz Z, Elmagarmid A. 2016. Rayyan—a web and mobile app for systematic reviews. *Systematic Reviews*. 5(1):210.
- Park HY, Kim MJ, Kim JY, Kim S, Choi JY, Kim JH, Jeong HY. 2019. Could peer support programs be a good resource for managing the unmet needs of cancer patients? *Journal of Cancer Education*. 34(5):950-957.
- Peters M, Godfrey, C., McInerney, P., Munn, Z., Tricco, AC. and Khalil, H. . 2020. Chapter 11: Scoping reviews In: Aromataris EaM, Z., editor. *JBIManual for Evidence Synthesis*. JBI.
- Relic A, Mazemda P, Arens C, Koller M, Glanz H. 2001. Investigating quality of life and coping resources after laryngectomy. *European Archives of Oto-Rhino-Laryngology*. 258(10):514-517.
- Rogers SN. 2021. Head and neck database listing evidence on qol [Internet]. Edge hill University; [accessed 2021 05 May]. Available from <http://www.handle-on-qol.com/Search+the+database.aspx>.
- Taleghani F, Babazadeh S, Mosavi S, Tavazohi H. 2012. The effects of peer support group on promoting quality of life in patients with breast cancer. *Iranian journal of nursing and midwifery research*. 17(2 Suppl 1):S125-130.

- Tehrani AM, Farajzadegan Z, Rajabi FM, Zamani AR. 2011. Belonging to a peer support group enhance the quality of life and adherence rate in patients affected by breast cancer: A non-randomized controlled clinical trial. *J Res Med Sci.* 16(5):658-665.
- Toija AS, Kettunen TH, Leidenius MHK, Vainiola THK, Roine RPA. 2019. Effectiveness of peer support on health-related quality of life in recently diagnosed breast cancer patients: A randomized controlled trial. *Supportive Care in Cancer.* 27(1):123-130.
- Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, Moher D, Peters MDJ, Horsley T, Weeks L et al. 2018. Prisma extension for scoping reviews (prisma-scr): Checklist and explanation. *Annals of Internal Medicine.* 169(7):467-473.
- Tufanaru C, Munn Z, Aromataris E, Campbell J, Hopp L. 2020. Chapter 3: Systematic reviews of effectiveness. In: Aromataris E, Munn Z, editors. *JB I Manual for Evidence Synthesis.* JBI.
- Vakharia KT, Ali MJ, Wang SJ. 2007. Quality-of-life impact of participation in a head and neck cancer support group. *Otolaryngology–Head and Neck Surgery.* 136(3):405-410.
- van Sluis KE, Kornman AF, van der Molen L, van den Brekel MWM, Yaron G. 2020. Women's perspective on life after total laryngectomy: A qualitative study. *International Journal of Language & Communication Disorders.* 55(2):188-199.

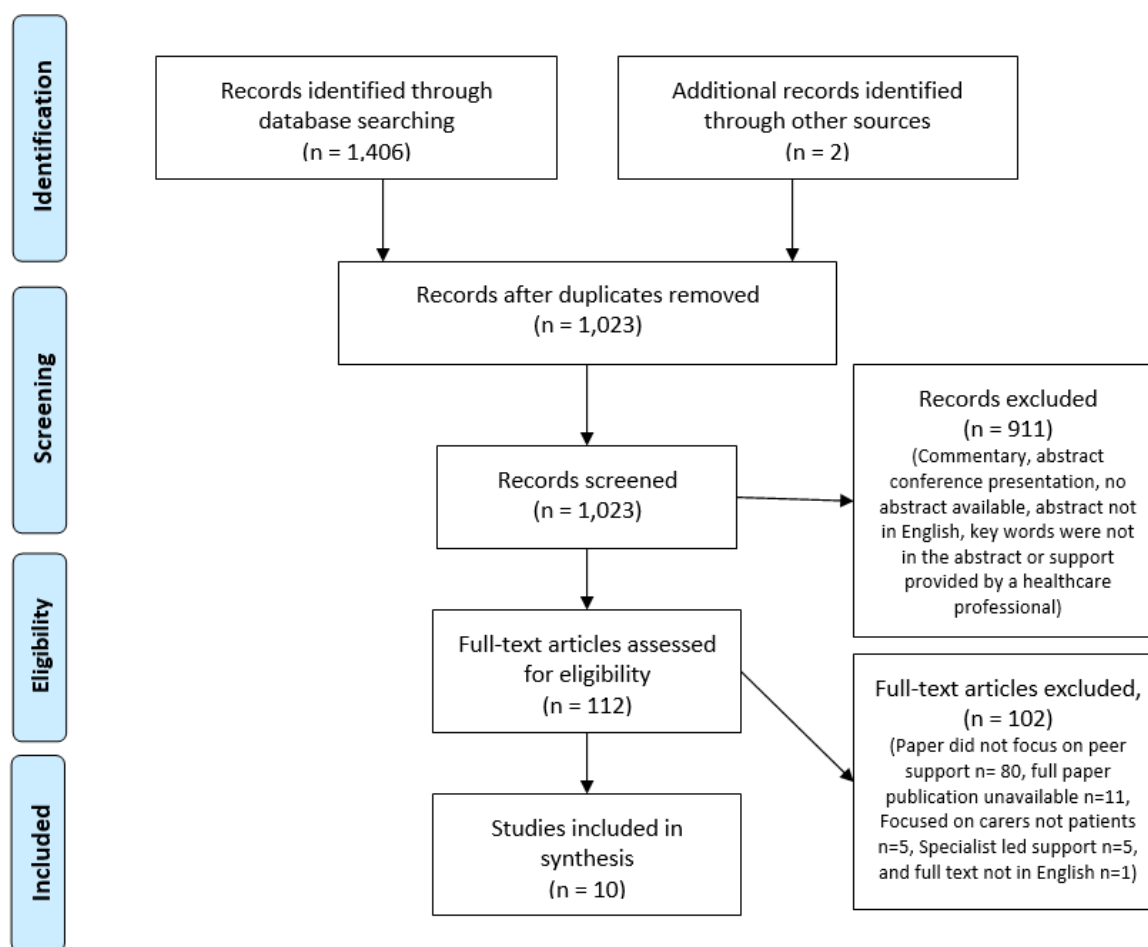


Figure 1. Flow chart on database search based on inclusion criteria for scoping review (Moher et al. 2009)

Table 1. Data extraction sheet

Author (s), Year of publication and Country of publication	Aim of paper	Study design	Cohort of patients	Number of patients	Category of peer support	Methods	Main findings
Egestad 2013 Norway	Explore peer support during radiotherapy	Qualitative	HNC patients during radiotherapy treatment	11	One-to-one support and group support	In depth interviews	Participants thought it was important to meet fellow peers as it can reduce uncertainty, loneliness and allow the sharing of information.
Van Sluis et al. 2020 The Netherlands	Explore recovery needs	Qualitative	Women with Laryngectomies	8	One-to-one support and support groups	Semi-structured interviews	Women specific challenges included altered appearance, altered voice and not being able to perform care activities. It was also found that meeting a laryngectomised individual prior to surgery had mixed responses
Dooks et al. 2012 Canada	Identify what support is available following laryngectomy post hospital discharge	Qualitative	Patients with laryngectomies	9	Web-based support groups	In depth interviews	Many types of support including peer support are crucial for a positive transition. One of these may be web based support groups, which may help improve communication.
Algtewi et al. 2015 United Kingdom	Identify support provided by online HNC groups	Qualitative	Mixed cohort of HNC patients	203	Online support group	Content analysis of online messages	Online support groups are used by individuals with HNC to seek many different types of support, the most common being informational and emotional.

Kristensen et al. 2019 The Netherlands	Explore outcomes of a residential rehabilitation program	Qualitative	HNC patients	40	Support group and One-on-one support	Semi-structured focus group interviews	The program was beneficial as it allowed peers to meet and share information and encouragement in a positive environment. This helped participants gain better coping mechanisms
Carroll-Alfano 2019 United States of America	Explore education, counselling, support groups for laryngectomy patients	Cross-sectional	Patients with laryngectomies	236	Support groups (online and in-person)	Anonymous survey	Only 40.5% and 49% of participants felt they received adequate education before and after surgery respectively. 71.0% of participants reported participating in any type of support group
Relic et al. 2001 Germany	Investigate QOL outcomes of HNC self-group	Cross-sectional	Patients with laryngectomies	29	Support group	HRQOL questionnaire (EORTC QLQ-C30 and EORTC H&N35) with open questions	31% of patients reported self-helps helped them to cope with their condition and HNC specific symptoms e.g., talking to others were related with a lower QOL
Mowry and Wang 2011 United States of America	Compare QOL between HNC patients attending support groups to those who do not	Case-control	HNC patients	37	Support group	Medical Outcomes Study Short Form-36 Item Health Survey version 2 and a non-validated supplementary questionnaire	No statistical significance between the support group and non-support group identified for any QOL domain (role physical, physical function, social function, role emotion and general health), however it was a small sample size.

Oskam et al. 2013 The Netherlands	Looks at QOL and the perceived need and use of healthcare services	Cohort	Advanced oral or oropharyngeal cancer patients treated with surgery and adjuvant radiotherapy	80	One-on-one support	2 HRQOL questionnaires (EORTC QLQ-C30 and EORTC H&N35) and a non-validated supplementary questionnaire	The deterioration in HRQOL at baseline versus long-term was statistically significant in eight of the twenty eight domains presented Uptake of peer support during treatment was 20% versus 35% at long-term follow-up
Vakharia et al. 2007 United States of America	Compare QOL of HNC patients who do and do not participate in a support group	Non-randomised Quasi-experimental	HNC patients	47	Support group	Validated University of Michigan Head and Neck QOL instrument	Those who attended the support group had higher scores in three Head and Neck QOL domains ($p < 0.01$). Speech was the only domain that was not significant (70.3% versus 57%) for the support group and non-support group respectively.