

Exploring the concerns and needs of patients with terminal head and neck cancer and their caregivers

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Introduction: This study explored the concerns and needs of patients with terminal head and neck cancer (HNC) and their caregivers. **Methods:** Seven dyads (seven patients and six caregivers) were consecutively recruited from a head and neck cancer (HNC) service. Individual semi-structured interviews were conducted to explore the concerns and needs held. The data from the qualitative interviews were analysed using Framework analysis. **Results:** Five themes emerged: feeling lessened or limited by HNC; difficulties faced by the caregiver; concerns surrounding death; feelings of uncontrollability and uncertainty; and needs. Uncertainty regarding the future trajectory of the HNC was the concern for which participants needed most help. **Conclusions:** It is suggested that clinicians might provide most support by being responsive to dyads' wishes to know a terminal diagnosis and to communicate this in a clear and sensitive way. In addition, caregivers might benefit from further informational support to help them manage new responsibilities.

Key words: Head and neck neoplasms, terminally ill, caregivers, concerns, needs, communication, framework analysis, qualitative research

INTRODUCTION

Head and neck cancer (HNC) is the sixth most common cancer in the world (Parkin *et al.*, 1999) and includes cancers of the oral cavity, oropharynx, larynx, salivary gland, nose, sinuses, middle ear and nerves and bones of the head and neck (National Institute for Clinical Excellence, NICE, 2004a). In western populations, poor diet, high alcohol consumption and tobacco use are the most common aetiological factors, and there is an association between HNC and low socioeconomic status (Health and Social Care Information Centre, 2006).

Whilst recent reports document overall improvements in the patient experience (Department of Health, DH, 2004), patients with HNC face a unique combination of difficulties, leading to the assertion that it is the most emotionally distressing of all cancers (Koster and Bergsma, 1990). HNC and its treatment can result in impairment to functions including swallowing, breathing, talking (NICE, 2004a), eating, taste and smell (De Leeuw *et al.*, 2000). In addition, whilst Teunissen *et al.* (2007) found pain to be a ubiquitous experience of cancer, a meta-analysis of 52 studies across cancer types concluded that pain was most prevalent in those with HNC (Van den Beuken-van Everdingen, 2007). Patients can experience psychological distress (Mathieson and Stam, 1991) and an assault to self-concept (Moss and Carr, 2004) due to facial disfigurement resulting from the HNC or its treatment. Furthermore, research indicates that of all the difficulties

encountered, the most pervasive concerns held by patients with HNC were in relation to disruptions in communication with their partner, family functioning and interaction with the wider community (Rapoport *et al.*, 1993).

It is evident therefore that HNC exists within a social context and impacts others beyond the patient. Family members and friends who provide unpaid support for the patient (termed 'caregiver') hold "a dual role in the coping process, as primary provider of support to the ill partner, and as family member who needs support in coping with the illness-related stresses he or she is experiencing" (Revenson, 1994, p.122). Research by Hodges and Humphris (2009) found that in a sample of 101 patients with HNC and their caregivers it was the latter who held greatest fears regarding cancer recurrence, emphasising the importance of exploring and addressing concerns held by those who care for the patient. In addition, caregivers have been found to experience poorer psychological health as a result of caring for their loved ones (Jansma *et al.*, 2005). This may in part be due to prioritising the patients' needs above their own, meaning that their own needs are not voiced or met (Baghi *et al.*, 2007), and provides further evidence to suggest the importance of research that allows focus to be placed on the needs of the caregiver.

In terms of survival, HNC holds a 50% mortality rate five years post-diagnosis (Sciubba, 2009), a rate which has changed little in the last fifty years (Goldstein *et al.*, 2008). As such, a

large proportion of patients and their caregivers have to face the prospect of dying or of losing a loved one. Ledeboer *et al.* (2005) acknowledged in their review of the literature that the difficulties experienced by those in the terminal stage are not well known. To understand the difficulties it is useful to differentiate between 'concerns' which have been concluded to be aspects an individual experiences as problematic, and 'needs': those areas for which further professional help would be perceived to be of benefit by the individual (Osse *et al.*, 2005). A survey of general practitioners indicated that they believed patients with terminal HNC to have received sufficient psychosocial care (Ledeboer *et al.*, 2006). However, in a retrospective study, bereaved caregivers stated that more psychosocial support had been required both for the patient with terminal HNC and for themselves (Ledeboer *et al.*, 2008), highlighting that research which directly accesses patients' and caregivers' experiences is essential. Evidence from a recent study with patients diagnosed with an oral cancer recurrence (known to be associated with poor prognosis) does go some way in highlighting patients' responses to bad news (Griffiths *et al.*, 2008), however caregivers' views were not sought.

Further research specific to the terminal stage is necessary rather than extrapolating from the literature regarding earlier stages of HNC because the concerns of patients with HNC and their caregivers change along the illness trajectory (Mah and Johnston, 1993) and so too might their support needs. For example, concerns specific to the terminal stage might relate to hopes for what Steinhäuser and colleagues (Steinhäuser *et al.*, 2000) termed a 'good death,' found to consist of: pain and symptom management; clear decision making; preparation for death; a sense of completion; contributing to others; and being treated as an individual. Meta-analytic evidence suggests that the most consistent factor contributing to a good death is a sense of control over the process. In Ledeboer *et al.*'s (2008) study with caregivers of patients with terminal HNC, one tenth reported a lack of awareness that the HNC was incurable, which influenced preparations for dying and perceptions of support. Overall, the literature regarding terminal HNC is scant. The research that currently exists has not addressed the concerns and needs of both patients and caregivers, has focused mainly on physical symptoms and has used retrospective or indirect methodologies such as surveying healthcare professionals rather than patients themselves (Shedd *et al.*, 1980; Ethunandan *et al.*, 2005; Ledeboer *et al.*, 2006). Whilst the DH (2008a) end of life care strategy recommended that patients' needs within the terminal stage of the disease are assessed, and the potential need for support for friends and family has been acknowledged elsewhere (NICE, 2004b; DH, 2008b), the exact nature of the concerns and needs held by patients with terminal HNC and their caregivers is unknown and thus may continue to go unaddressed. This study therefore adopted a qualitative approach to investigate the concerns and needs of patients with terminal HNC and their caregivers.

METHODS

Design

This study used individual in-depth semi-structured interviews with patients and their caregivers. Qualitative methodologies are those using an interpretive approach to address questions which demand an understanding of social phenomena and the contexts in which they exist, from the perspective of those who are questioned (Snape and Spencer, 2003).

Participants

A consecutive sample of patients and their caregivers (referred to within this paper as 'dyads') attending a HNC service in the UK within a three month period (May to July 2008) were invited to participate in the study. Inclusion criteria were as follows: the patient had a diagnosis of HNC which had been deemed terminal by clinicians and for which curative treatment had ended; the patient was thought to be emotionally, mentally and physically well enough by clinicians involved in their care to be approached about the research study; the patient had a family member or friend who they identified as providing them with care and support; and both patient and caregiver were aged above 18 and were able to communicate in English verbally or in writing.

Procedure

Professionals from the HNC team identified patients who met the inclusion criteria. For those patients who attended the outpatient clinic, healthcare clinicians presented the research topic at their next scheduled appointment and introduced the researcher, who provided information sheets and an overview of the research. Potential participants without a scheduled appointment were sent information sheets by the specialist nurse with a cover letter from the HNC team. A reminder letter was sent four weeks later if no response had been received, after which no further contact was made. For both recruitment methods, patients and caregivers were asked to contact the researcher if they wished to participate, upon which a convenient appointment was organised.

Interviews were digitally-recorded and lasted 45-90 mins. and conducted in a room in the hospital building away from the HNC clinic (n=2) or at the patient's home (n=11). Patients and caregivers were interviewed separately other than for one dyad (dyad 6), where the caregiver was interviewed first and then acted as an interpreter during the patient's interview due to limited comprehensibility of his speech. A semi-structured interview schedule asked broad questions to enable those aspects most salient to the participant to emerge. Topics included current concerns and needs, coping and communication. The schedule was developed from discussion with HNC clinicians, members of a support group for patients recovered from HNC, and themes within the extant literature. Pilot interviews were conducted with two members of the HNC support group and changes to the schedule made based on their comments. The study protocol paid attention to issues including confidentiality, informed consent and debriefing, and was approved by the local NHS research ethics committee.

PATIENTS WITH TERMINAL HEAD AND NECK CANCER

Table 1. Participant details

Dyad	Name ^a	Sex	Age	Occupation	Type and length of relationship	Current diagnosis ^b date TNM staging ^c	Previous diagnosis date	Date curative treatment ended
1	P: Mary	F	78	Retired post	Married 56 years	ACC of parotid gland (2008)	Benign parotid tumour (1946) recurrence (1952)	2008
	C: John	M	82	Retired engineer				
2	P: Charlie	M	73	Retired market seller	Married 48 years	Recurrent SCC of pyriform fossa (2002) T3N2bM0	SCC of pyriform fossa (1995)	2002
	C: Alice	F	82	Retired market seller				
3	P: Tom	M	64	Semi-retired hair stylist	Intimate relationship 20 years	Metastatic SCC of oropharynx T3N3M1 (2008)	SCC of oropharynx (2007)	2008
	C: Sue	F	61	Team leader in Care Home	Married 1 week			
4	P: Harry	M	54	Publican retired retired due to ill health	Friends 20 years	Recurrent and metastatic SCC of retromolar trigone and oropharynx (2004) T4NOM1	SCC of tonsil (2003)	2004
	C: Mick	M	57	Previously a publican now a carer				
5	P: Agnes	F	89	Retired manageress of store	Mother and son 65 years	Recurrent SCC metastatic SCC of floor of mouth (2008) T2N1M0	SCC of tongue (2007)	2008
	C: Ian	M	65	Engineer				
6	P: Dave	M	53	Caretaker	Married 20 years	Recurrent SCC of tongue base and submandibular glands (2008) T4N2cM0	SCC of tongue base and submandibular glands (2007)	2008
	C: Linda	F	48	Housewife				
7	P: George	M	53	Retired car mechanic	Friends 5 years lived together 6 months	Recurrent SCC of oropharynx (2008)	SCC of oesophagus (2002) recurrent SCC of tonsil (2005)	2008
	C: not interviewed							

^aP= patient, C= caregiver

^bACC= Adenoid Cystic Carcinoma, SCC= Squamous Cell Carcinoma

^cT= tumour, N= node, M= metastasis. Higher numbers indicate greater extent of disease

Analysis

The interviews were transcribed verbatim and analysed using Framework analysis (Ritchie and Spencer, 1994), with the aid of NVivo 8. Framework analysis was chosen because it is a rigorous method which allows exploration of topics where little research has been conducted (Ritchie and Spencer, 2003). Furthermore, it remains grounded within the data and does not demand purposeful sampling (Ritchie and Spencer, 1994), important when the population from which the sample is recruited is small.

The analysis process consists of five stages: familiarisation; identifying a thematic framework; indexing; charting; and mapping and interpretation (Ritchie and Spencer, 1994). Once the transcripts had been read a number of times (familiarisation), recurrent themes within the data were noted and used to develop an initial thematic framework. All transcripts were then systematically annotated using this framework (indexing), a process which enabled the framework to be refined (Ritchie and Spencer, 2003). Each theme was then organised into two tables (charting) of patients' and caregivers' data to allow comparison within and between participants and dyads, and to view the data as a whole. The final stage, mapping and interpretation, involved synthesis of all the material gathered. This required studying the matrices to identify patterns and to provide an overall interpretation of the data (Ritchie and Spencer, 1994).

Quality assurance checks

The 'matrix based analytic method' of Framework analysis (Ritchie and Spencer, 2003) makes transparent the process of analysis. The principal researcher (KF) kept a diary to aid reflexivity and neutrality. Additionally, two of the thirteen transcripts were indexed by an independent analyst using the initial thematic framework. Discrepancies were discussed and minor changes made to the framework. Lastly, the other author (SS) read all the transcripts alongside the final write-up to check that the mapping and interpretation had remained grounded within participants' accounts.

RESULTS

Sample characteristics

In total, 20 patients were approached. Seven patients and their caregivers (14 people) agreed to take part: four spouse dyads, one mother-son dyad and two friend dyads. However the caregiver of one patient was not interviewed, due to severity of mental health difficulties which precluded informed consent and participation. The patient's data were still used in the research. All participants were of white British origin, and for all patients, reason to end curative treatment was stated to be unlikely success of further intervention. *Table 1* shows participants' details but the names provided are fictitious for reasons of confidentiality.

Qualitative analysis

The analysis indicated five themes identified as concerns or needs by patients and caregivers. These were named: feel-

ing lessened or limited by HNC; difficulties faced by the caregiver; concerns surrounding death; feelings of uncontrollability and uncertainty; and needs. These are discussed alongside quotations from participants. Following each quotation, the pseudonym, role (p=patient, c=caregiver), number relating to the dyad order within this paper, age and type of relationship, are given in parentheses. Detailed analysis of how patients coped with their concerns and needs will be reported in a separate paper (Foxwell and Scott, in press).

Feeling lessened or limited by HNC

Participants expressed a wide range of physical, functional, practical, cosmetic, psychological, spiritual and social concerns which indicated the negative (lessening or limiting) impact which the HNC experience was perceived to have on patients' lives.

"I seem to be getting a bit more pain now, and uh, I don't have much energy." (George, p7, 65yrs, friend dyad)

"Since her operations she has aged terribly. She used to be so young and she was so independent, she was very independent. And now things seem to get on top of her." (Ian, c5, 65yrs, mother-son dyad)

"I don't like eating in front of [Alice]. I, I try and then it comes down my nose, or I have to go 'aaarrgg' to get it out. [...] I can't go in a cafe, oh I could, but people wouldn't like that..." (Charlie, p2, 73yrs, spouse dyad)

Feeling that the HNC had diminished them was evident in patients' descriptions of limitations experienced. For male patients, not being able to fulfil previously held roles and having to rely on others appeared problematic.

"If I'm left on my own I can't do nothing." (Dave, p6, 53yrs, spouse dyad)

"He keeps having to ask anybody to do anything. He thinks ... 'Why should I have to ask? Why can't I do it myself?'" (Mick, c4, 57yrs, friend dyad)

The psychological impact of HNC on patients was most explicitly voiced by their caregivers.

"Um..... to be quite honest with you, at the moment, I feel that.. he can't suffer anymore. Does that make sense? [crying]." (Alice, c2, 69yrs, spouse dyad)

Difficulties of the caregiver

Caregivers consistently expressed worries about their lack of knowledge in responsibilities such as preparing food and interpreting symptoms. Regardless of amount of experience as a caregiver, all spousal partners expressed anxiety regarding aspects not previously encountered.

"When somebody all of a sudden they seem a lot better and then slowly start getting worse again you don't know whether you are right in presuming that it is tiredness[...] Where as if it's just something normal you had you would just take your chance and get on with it." (Linda, c6, 48yrs, spouse dyad)

"You couldn't plan in the morning what you were going to have in the evening, because he didn't know what he thought he might be able to eat...so there were a few stressful times there...you know, for God's sake! Give me a clue..." (Sue, c3, 61yrs, spouse dyad).

Concerns about, or acknowledgement of, the physical burden and emotional impact of HNC on the caregiver were also described, more often by patients.

"Oh aye, its breaking his heart, I know." (Agnes, p5, 89yrs, mother-son dyad)

"Everything's got to be... in order...which is fine, you know, but quite wearing" (Sue, c3, 61yrs, spouse dyad)

The impact of the HNC on the caregiver was discussed with reference to the state of the caregiver's physical health in older dyads.

[Mary] *"He's 82 ...and we take the car to [local town] and then get the train...He's not getting any younger and to have to run about like that..."*

[Interviewer] *"So is that a worry?"*

[Mary]: *"I watch him all the time. Well he's had four bypasses, he's had three stents, two that failed..."* (Mary, p1, 78yrs, spouse dyad)

Concerns about death

Separation of the dyad was one concern evident predominantly in caregivers' discussions of death and dying. This was expressed through anxieties about managing tasks previously undertaken by their partner or of being lonely.

"I think that's the main worry – the financial aspect of it. Because I've tried to grasp what she does, when she goes through the bank statements, checks that we are spending wisely or not...but um... I just can't get to grips with it." (John, c1, 82yrs, spouse dyad)

"I hope we won't be too long without one another..." (John, c1, 82yrs, spouse dyad)

It was more exceptional for patients to discuss issues around separation from their partner. However, in one dyad the caregiver alluded to this being the aspect her husband most feared, not discussed in the patient's own interview.

"He don't mind, he's not frightened to die, but um... he don't want to leave me on me own [crying]. Sorry [crying]." (Alice, c2, 69yrs, spouse dyad)

For another dyad, the patient was able to perceive possible benefit to result from the separation.

"If I wasn't here he would nay come up here and he'd be at home all the time." (Agnes, p5, 89yrs, mother-son dyad)

Hopes that the patient would die well, free from suffering, were expressed by almost all participants. For caregivers, enabling their partner to have the death they hoped for, by holding knowledge of what the patient wanted and agreeing to support and carry out their wishes, also appeared integral to perceptions of a good death.

"Um.. I'm just hoping [Charlie] might go to sleep.. I don't know. I don't really know." (Alice, c2, 69yrs, spouse dyad)

"I just hope that it won't be a painful end for her... hope that it will be more or less pain-less dying process.....[...] ... and I pray that I will be able to ... look after her as much as possible." (John, c1, 82yrs, spouse dyad)

"When he does go, he wants to go from MY house. He doesn't want, he says 'I'm going from here.' He says. [...] and I went 'nah, that's alright, he can stay here in the bed.'" (Mick, c4, 57, friend dyad)

A minority of caregivers reflected on the journey thus far, considering decisions made to have contributed to or detracted from what they perceived to be a good end to life.

"And uh..... they had to cut her up pretty bad..... I mean, if I had known... then what I know now then I would have said to her 'don't get the operations at all' because uh, I'd rather she'd just died in dignity, then go through what she's been through." (Ian, c5, 65yrs, mother-son dyad)

For patients, enjoying life, putting things in order and spending time with family were important to contributing to the end of life that they hoped for.

"I want to go to Orlando. Uh... a cruise. Oh I can afford it, and make time for the family." (Harry, p4, 54, friend dyad)

"I'm trying to make notes to arrange my own funeral. Oh I don't want that, and I won't have that..." (Mary, p1, 78, spouse dyad)

In addition, some patients expressed hopes of a good death, one which was quick and of which they were unaware. There appeared to be some acknowledgement that this might also ease the process for their partner.

"I hope I wake up one day and say 'Oh my God, I don't feel very well' bang and it's over.[...] It's a shock for everybody around, but it, it's job and done." (Tom, p3, 64yrs, spouse dyad)

"With cancer you don't want to know the dates beforehand, you just want to let it [death] happen." (Dave, p6, 53, spouse dyad)

Feelings of uncontrollability and uncertainty

Cancer was often perceived to be an uncontrollable force, with both patients and caregivers discussing their feelings

of helplessness over the future trajectory of the HNC.

"I can go to a fork, I can go to the left or to the right, but it's not going to make any difference 'cos it's still going to join up the road up a bit." (Tom, p3, 64yrs, spouse dyad)

"That is living with cancer, because it...it, you don't know what's quite going to happen." (Alice, c2, 69yrs, spouse dyad)

Dyads appeared to differ in the extent to which they felt that they had control over their knowledge of the terminal status of the HNC. Although all participants showed some understanding that the patient might die from HNC, there was variation in whether they felt they had been explicitly informed of a terminal diagnosis.

"[Tom]...he likes to know all the ins and outs...and they [clinicians] will answer any question... and I admire them for iteven though they hurt..." (Sue, c3, 61yrs, spouse dyad)

"I had the impression they didn't want to do a lot anymore...and plus the very fact that they got me a Macmillan nurse, it's not a good sign is it?" (George, p7, 65yrs, friend dyad)

For some, the perceived lack of clarity from clinicians around the terminal status led to experiences of confusion and anger.

"When the nurse from the hospice came, I said 'I don't know why they've sent a nurse from the hospice. You usually go to a hospice when you die, but as far as we know, you're not dying Mum.'" (Ian, c5, 65yrs, mother-son dyad)

Unmet concerns: needs

Whilst numerous concerns were highlighted by patients and caregivers, only a minority were suggested to be problems for which further help was required. The most prevalent need was for improved communication, particularly with professionals regarding treatment options and the future trajectory of the disease. Uncertainty therefore appeared to be the concern which participants felt least able to manage.

"They're covering things up. [...] You can't plan things properly unless you have the truth. The not knowing is hard." (Harry, p4, 54yrs, friend dyad)

One caregiver expressed a wish for professionals to offer opportunities for discussions around the impact of HNC and emotional support needs.

"If they sort of put the medical sort of thing to one side and just talked to people in general, how they are coping with things you know..." (Ian, c5, 65yrs, mother-son dyad)

A desire for improved communication within the dyad and wider support networks was also voiced. Some suggested a need to discuss the HNC and fears around dying further, but felt that this was not fulfilled by those around

them.

"I want to talk to her and she's not there." (Dave, p6, 53yrs, spouse dyad)

"I cannot believe that there is an afterlife. I just think I'll just go to sleep. But I need to talk about it. My daughter gets 'Mum, how can you be a Christian' she won't discuss it, she just thinks I'm an awful person as far as that's concerned. And my son just says 'well you're happy to believe in that, that's alright. He doesn't discuss it either.'" (Mary, p1, 78, spouse dyad)

However some caregivers suggested that they did not wish to acknowledge their own needs in certain contexts, as doing so would prevent them from supporting others.

"You really can't afford for them [the children] to get bogged down with everyone else looking as if they're worried or can't cope, you've.. you've got to sort of, in a way it does you good, cos its making you carry on." (Linda, c6, 48yrs, spouse dyad)

DISCUSSION

The aim of this exploratory study was to investigate the concerns and needs held by patients with terminal HNC and their caregivers. The analysis indicated five themes; feeling lessened or limited by HNC; difficulties faced by the caregiver; concerns surrounding death; feelings of uncontrollability and uncertainty; and needs.

The results suggest that patients with terminal HNC hold a number of physical, psychological and social concerns which diminish their sense of self, a recurrent finding within the curative HNC literature (e.g., Turpin *et al.*, 2009). HNC was also found to have an impact beyond the patient, with concerns expressed about caregivers' physical and psychological health. For caregivers themselves, worries about managing new and unfamiliar tasks in their role as carer were described.

Concerns around death and dying were evident in two ways. Caregivers in particular described a fear of the dyad being separated, manifest in references to future loss and loneliness, and anxieties about managing tasks previously undertaken by their partner. In addition, both patients and caregivers described hopes that the patient would experience a good end to life, bearing resemblance to concepts such as pain and symptom management, preparation, completion and contributing to others, as described within the 'good death' literature (Steinhauser *et al.*, 2000). Exploring ideas around dying well was not a specific aim of this study however, and further research to fully investigate the meaning of a good death in terminal HNC is necessary.

The most prevalent concern was around uncertainty regarding the future trajectory of the HNC. Patients and caregivers described experiences of lacking control, both over the disease and information received from professionals. A desire for improved communication within the dyad, informal support network and with professionals was expressed, seemingly meeting the criteria of a 'need' (Osse *et al.*, 2005).

The findings from the study suggest that for patients and caregivers to hold a sense of control over the HNC process, clearer and more open communication with professionals is required. Glaser and Strauss (1965) suggested five awareness contexts in which dying patients, their families and professionals engage. These are: 'closed awareness' where the patient does not know his or her prognosis, 'suspicion awareness' where the patient suspects what others know, 'mutual pretence' where all know the prognosis but pretend they do not, 'open awareness' where the prognosis is openly acknowledged and 'discounting awareness' where the patient's awareness is overlooked by clinicians. Whilst it is not clear from the current study what factors varied such that dyads appeared to differ in their level of awareness, it seemed to be the experience for some that information was withheld from them.

Although the current research was a small-scale exploratory study, the results point toward a number of clinical implications. The NICE (2004c: p.109) guidelines for HNC state that "patients should always be given full information about the expected effects of palliative interventions... to ensure that patients and carers understand that palliative treatment does not offer the prospect of cure". Kehl (2006) suggested that greater perceived responsiveness by professionals to patients' and caregivers' wishes to know a prognosis might enable them to feel more in control of the dying process, integral to attainment of a good death. Previous research such as that by Fallowfield and Jenkins (2004) has identified numerous processes within doctor-patient-caregiver interactions which can lead to less than optimal communication around a terminal diagnosis. The findings of the current study support conclusions previously made that further communication training and support which enables clinicians to be continually responsive to patients and caregivers might enable their needs to be more consistently met (Eggly *et al.*, 2006).

Recommendations have been made for professionals to support caregivers in aspects of their role in which they are unfamiliar (DH, 2008b). Previous research by Carr (2003) indicates that caregivers who feel supported during the terminal phase adjust better psychologically after the death of the patient. Healthcare professionals need to be aware that new symptoms or treatments not encountered before can be difficult for caregivers to manage alone. It might be that clinicians need to hold the responsibility for initiating such discussions, given that caregivers have been found to prioritise the patient's needs over their own (Baghi *et al.*, 2007).

From analysis of the data it is evident that patients with terminal HNC face physical limitations which can impact their sense of self and psychological well being, in which the caregiver might also share. As such, the HNC team might have an important role in helping prepare the dyad for possible changes and support them to maintain independence and emotional health. For a small number of individuals, psychological support and intervention might be helpful where communication difficulties within the support network or dyad prevail. However for most patients and caregivers,

being asked how they are managing and being given some time to talk might be the extent of their need, this is manageable without specialist intervention as suggested within the NICE (2004b) guidelines for improving supportive and palliative care for adults with cancer.

There are a number of limitations of the current research that should be considered. The sample was identified by HNC clinicians which might have introduced bias. In addition, six of the seven dyads were recruited from outpatient clinics, therefore it is possible that the recruited sample might not be representative of the wider population, for example in relation to degree of ill health. It must also be acknowledged that the number of dyads recruited and interviewed within this study was relatively small and as such the themes obtained may not be exhaustive. Future research with greater sample sizes which represent a range of dyadic relationships would be valuable.

Constraints due to the interview process were also present. Whilst efforts were made to ensure that participants understood that the data would be anonymised and remain confidential, a small number believed the interviewer to be employed by the HNC service, which might have impacted disclosure. In addition, adjustment to the interview procedure was necessary for two dyads. For dyad 7 only the patient was interviewed, which thus prevented comparison of accounts for this pair. For another dyad, the caregiver was present during the interview to act as interpreter. This may have altered the content and exact wording of the patient's interview. Finally, a wider issue relevant to most patients' interviews was a lack of clarity of some aspects of speech. Suggestions such as those by Philpin *et al.* (2005) regarding use of video recording and descriptive field notes, as well as the presence of another researcher, might aid future research with populations in which the understanding of the interviewer needs to be supported.

Finally, the process of conducting the research deserves some attention. The study raised numerous emotions for the interviewer. Most complex was the recognition that she might own more knowledge about a participant's terminal status than they themselves appeared to. The distress caused by uncertainty was highlighted in participants' accounts. This led to greater conviction on the interviewer's part of the importance of clinicians supporting their patients' and caregivers' understanding. Also central to the experience of conducting the research was the interviewer's awareness of her responses to the smell and noise of secretions of some of the patients during interviewing and when re-listening to transcripts. The interviewer's own responses, might offer insight into some of the consequences of HNC most difficult for dyads themselves to voice.

CONCLUSIONS

This study provides an additional contribution to the terminal HNC literature by developing an initial understanding of the concerns and needs of patients with terminal HNC and their caregivers. This patient and caregiver group has been neglected in previous research. Findings from this research

suggest that patients and caregivers hold numerous concerns, the most problematic of which being uncertainty regarding the future, for which further professional help was needed. It is recommended that professionals clearly communicate a terminal diagnosis of HNC, and are aware of the possible need for further informational, psychological and relational support for patients and caregivers.

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Conflict of interest

None declared.

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