

Loneliness and quality of life following head and neck cancer

Anna Dahill BDS MJDF. DCT, Regional Maxillofacial Unit, Aintree University Hospital, Lower Lane, Liverpool, UK. anna.dahill1@nhs.net

Helen Al-Nakisbandi BDS MJDF. DCT, Regional Maxillofacial Unit, Aintree University Hospital, Lower Lane, Liverpool, UK. Helen.Al-Nakisbandi@aintree.nhs.uk

Kathryn B Cunningham CPsychol PhD MSc MA (Hons). Research Fellow in Primary Care, University of St Andrews, School of Medicine, St Andrews, UK. kb92@st-andrews.ac.uk

Gerald M Humphris PhD MClInPsychol CPsychol FRCP (Edin). Chair of Health Psychology, University of St Andrews, School of Medicine, St Andrews, UK. gmh4@st-andrews.ac.uk

Professor Derek Lowe MSc C.Stat. Medical Statistician, Director, Astraglobe Ltd, Congleton, Cheshire. astraglobeltd@btconnect.com

Professor Simon N Rogers FDS, RCS, FRCS, MD. Evidence-Based Practice Research Centre (EPRC), Faculty of Health and Social Care, Edge Hill University, St Helens Road, Ormskirk, and Consultant Regional Maxillofacial Unit, Aintree University Hospital, Lower Lane, Liverpool, UK. simonn.rogers@aintree.nhs.uk

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Address for correspondence: Professor Simon N Rogers MD FDS FRCS(OMFS), Liverpool Head and Neck Centre, Aintree University Hospital, Liverpool, L9 1AE, UK.
simonn.rogers@aintree.nhs.uk

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Abstract

Loneliness is associated with low quality of life, mental illness, poor physical health and premature mortality. Head and neck cancer (HNC) patients are at risk of loneliness due to the consequences of the cancer and its treatment on important social interactive functions such as appearance, speech, facial expression and eating. Patients treated for primary squamous cell HNC between January 2015 and December 2016 were surveyed in early 2019 using the University of Washington Quality of Life questionnaire v4, the Cancer-Related Loneliness Assessment Tool and four nationally recommended indicator questions. The survey comprised 140 patients, with mean (SD) age at diagnosis of 63 (11) years. Tumour sites were oropharyngeal (42%), oral (35%), laryngeal (14%) and elsewhere (9%). In response to the single direct question 'How often do you feel lonely?' three-quarters said 'hardly ever' and only 6% 'often'. Similar responses were obtained for the other three recommended indicator questions. It is encouraging that only a relatively small proportion appear to have significant issues with loneliness. Similarly, the response to the C-LAT would suggest about one-quarter having feelings of loneliness and a minority of patients having significant problems. Patients who were younger patients, living in more deprived circumstances, having advanced disease and having had chemo/radio therapy reported greater levels of loneliness. Loneliness was associated with worse overall quality of life, and physical and social-emotional functioning. Lonely patients need to be identified as early as possible so that support and intervention can be implemented and outcomes improved.

Introduction

Loneliness is increasingly recognised as a critical public health issue in Western society, and in 2018 the UK Government appointed the first-ever ‘Minister for Loneliness’ to tackle the problem.¹ Loneliness is linked with low quality of life (QOL),² mental illness,^{3,4} and poor physical health,^{4,5} including negative prognosis for a variety of medical conditions.⁶ It also has significant economic implications.⁴ Cancer and its treatment can impact greatly on social relationships, and people living with and beyond the disease are particularly vulnerable to loneliness.⁷ Head and Neck cancer (HNC) and its treatment can result in difficulties with appearance, poor social eating, speaking, swallowing, pain, role functioning and depression, as reported in the Patient Concerns Inventory.⁸ These difficulties can affect the way a person interacts and engages with those around him/her, and can thus generate feelings of loneliness.⁹

Despite recognition that loneliness should be addressed as part of comprehensive cancer care,^{7,10,11} it is challenging to identify and assess loneliness in people living with and beyond cancer for several reasons. These include patients’ reluctance to actively mention loneliness to clinicians, clinicians’ difficulties identifying loneliness in patient consultations and problems with existing direct and indirect measures of loneliness that could be used to systematically identify loneliness in patients.^{12,13,14} In response to this Cunningham et al. developed the Cancer-related Loneliness Assessment Tool (C-LAT)¹⁵ (Table 2) – a self-report questionnaire capturing the essential elements of cancer-related loneliness following treatment completion. This Tool is conceptually-sound, asking about the two essential aspects of loneliness – 1) the patient’s perceived relationship deficiencies since being diagnosed with cancer and the sources of these, 2) the patient’s psychological/emotional responses to such deficiencies. It is contextually-sensitive as the items were derived from qualitative research exploring loneliness in people living with and beyond cancer. The C-LAT has not been reported previously in HNC patients.

One aim of this study was to assess the issue of loneliness as measured by the C-LAT, as well as by the national indicators of loneliness that the Office for National Statistics (ONS) recommends are included in all studies of loneliness.¹⁶ Another aim was to explore associations of these measures with case-mix and with health related quality of life (HRQOL) in a cohort of HNC survivors at 2-3 years post diagnosis.

Method

Eligible patients were those treated with curative intent for primary squamous cell head and neck carcinomas at the Head and Neck Centre, Aintree University Hospital between January 2015 and December 2016 and who were alive in January 2019. These patients were surveyed in early 2019 using the University of Washington Quality of Life questionnaire (UW-QOLv4),¹⁷ the Cancer-Related Loneliness Assessment Tool (C-LAT) and four national indicators of loneliness. Patients with cutaneous and salivary gland malignancy, those treated with palliative intent, those with cognitive impairment and those living overseas were excluded. Clinical and demographic data were collected from the clinical record, including tumour site, treatment, stage and Multiple Deprivation (IMD) 2015 data derived from patient postcodes. Patients were placed within quintiles based on the distribution of IMD ranks across the whole of England; a minority of patients could not be classified as such because they lived in either Wales or the Isle of Man.

The UW-QOL v4 questionnaire consists of 12 single question domains, these having between 3 and 5 response options scaled evenly from 0 (worst) to 100 (best) according to response hierarchy. UW-QOL domains are presented within two subscales, physical function and social-emotional function, as derived from earlier work.¹⁸ The physical function score is the mean of the appearance, swallowing, chewing, speech, taste and saliva domain scores, while the social-emotional function score is the mean of the pain, activity, recreation, shoulder, mood and anxiety domain scores. In regard to the single item overall QOL scale patients were asked to consider not only physical and mental health, but also other factors, such as family, friends, spirituality or personal leisure activities important to their enjoyment of life. Question domains regarding intimacy¹⁹ and fears of recurrence²⁰ were also developed using a similar system of possible responses as the UWQOL v4.

The C-LAT consists of ten two-part items. The first part of each of the items asks about the patient's perceived relationship deficiencies, and sources, since being diagnosed. The response options are "Strongly agree", "Somewhat agree", "Somewhat disagree" and "Strongly disagree". The worst two categories were regarded as indicating a perceived deficiency in social relationships. Patients scoring in these categories on a particular item are asked to complete the second part paired with this item. This measures how much they were 'bothered'/the degree of their distress/unhappiness regarding these deficiencies on a visual

analogue scale with the anchors “Not at all” (0) and “As much as possible” (6) at either end of the scale. The worst three categories (4,5,6) were regarded as indicating a feeling of loneliness for each item and from these an overall proportion expressing loneliness on one or more items was computed. Also, for each of the ten items, multiplying the proportion with perceived deficiency from Part 1 by the proportion indicating a feeling of loneliness from Part 2 estimated the proportion overall with a significant problem.

The ONS national indicators of loneliness are four questions asking about feelings of loneliness. Three do so indirectly (they do not mention the term ‘lonely’) and they are from the University of California, Los Angeles Loneliness Scale (three-item version). The final question asks directly about feelings of loneliness. The response options used in our survey for all four questions were: “Often”, “Some of the time” and “Hardly ever”. These items, although limited in scope provided reference to respondents in other fields.¹⁶

Fisher’s exact, Chi-squared, Mann-Whitney or Kruskal-Wallis tests were used as appropriate to compare loneliness assessments between patient subgroups. Missing data are reflected by differing denominators.

Aintree University Hospital Clinical Audit Department approved this study.

Results

There was a 36% (140/389) response to the survey. There was no notable response bias observed in respect of gender, age group, IMD, tumour site, tumour stage and treatment (results not shown). The mean (SD) age at diagnosis of responders was 63 (11) years and 66% (93/140) were male. Almost half (42%, 55/130) of sample patients living in England lived in the most deprived '20%' of small areas in England. Primary tumour site was oropharyngeal for 42% (59), oral for 35% (49), laryngeal for 14% (19) and elsewhere for 9% (13). Tumour stage was 'Early (T1N0 or T2N0)' for 39% (55) and 'Late' for 61% (85). Primary treatment was surgery alone for 36% (51), chemotherapy and/or radiotherapy without surgery for 28% (39) and surgery with adjuvant therapy for 36% (50).

In response to the ONS national indicators of loneliness that ask about a lack of companionship, feeling left out, feeling isolated from others and feeling lonely, around one quarter of patients had issues 'some of the time' or 'often' with each of these in turn (Table 1). Just over half (55%, 77/140) responded 'hardly ever' to all four questions, while 11% (16/140) stated 'often' at least once.

Referring to the first part of the C-LAT items (about the patient's perceived relationship deficiencies, and sources, since being diagnosed), 56% (70/125) reported that others expected them to move on and get on with their lives (Table 2), 44% (55/126) that they spent more time on their own than they used to and 32% (41/127) that they had too much time to think and worry about things. Only around one in five patients (17%-21%) reported that they do not participate in the social activities that they used to, do not share feelings, problems and worries with friends and/or family, feel other people do not understand what they had been through/are going through and do not play the same role in life as they used to. Fewer patients (6%-10%) reported being treated differently by other people, and not feeling as close to their family and friends as they used to. Overall, 38% (47/123) scored in the worst two categories for one or two of the ten items, 22% (27/123) for three or four, 15% (19/123) for five to nine, while 24% (30/123) did not score in the worst two categories for any of the items.

Referring to the second part of the C-LAT items (about the patient's psychological/emotional responses), the relationship deficiencies bothering patients the most, or causing them the most distress/unhappiness (i.e. those generating the most loneliness) were about not feeling as

close to family as they used to (71%, 5/7), not playing the same role in life as they used to (62%, 13/21), other people not treating them the same as they used to (62%, 8/13), not participating in the social activities they used to (59%, 16/27) and not feeling as close to friends as they used to (55%, 6/11). One-quarter (24%, 34/140) expressed a feeling of loneliness on one or more of the 10 items, with 15 patients expressing this for just one item, 12 patients for 2-4 items and 7 patients for 5 or more items. Multiplying the proportion with perceived deficiency from Part 1 by the proportion indicating a feeling of loneliness from Part 2 for each item provides an assessment of the proportion with a significant problem, and across the 10 items these ranged between 4% and 13% (Table 2).

In this responder sample greater levels of loneliness (measured by patients responding 'often' to one or more of the 4 national indicators), were observed in younger patients, those living in more deprived circumstances, those with more advanced disease and those having had chemo/radio therapy (Table 3). Greater loneliness was associated with worse overall quality of life and with both physical and social-emotional aspects of quality of life, as well as with lower intimacy and increased fear of recurrence. Greater loneliness was also observed across all high-scoring UW-QOL domains apart from taste and shoulder (results not shown).

Discussion

As a consequence of HNC, patients and their carers are at risk of loneliness.^{7,9,21} Loneliness involves all HNC sites, stage, and treatments, and is not confined to those with major post treatment difficulties such as laryngectomy or gastrostomy tube dependency. This study is the first in the UK to ask patients about loneliness following HNC using the Cancer-Related Loneliness Assessment Tool and the four recommended national indicators of loneliness, and to relate this to HRQOL using a commonly reported HNC specific questionnaire (UW-QOLv4). The Cancer-Related Loneliness Assessment Tool is a novel questionnaire with some initial evidence of validity. It assessed relational deficiencies experienced by patients and the sources of these as well as the psychological/emotional responses to those relationship deficiencies (i.e. the degree of loneliness experienced).

Although novel there are several limitations. The main limitation is the relatively low response rate, acknowledging that there seemed to be no obvious response bias by clinical characteristics. Unfortunately there was insufficient data from the case notes on other

attributes such as marital status, living alone/with others, living at home/residential/nursing. A possible reason for low response was the large number of questions in the survey, as this study was combined with additional questions related to timing of treatment and possible recurrence.

In response to the single direct question ‘How often do you feel lonely?’ three-quarters said ‘hardly ever’ and only 6% ‘often’. Similar responses were obtained for the other three ONS recommended indicator questions. It is encouraging from these responses that only a relatively small proportion appear to have significant issues with loneliness. Similarly, the response to the C-LAT would suggest about one-quarter having feelings of loneliness and a minority of patients having significant problems. However our study could underestimate the extent of loneliness because of the low response to our survey per se and also to a lesser extent from within the C-LAT because of the lower Part 2 responses for items 8 to 10. In our cohort more loneliness was noted in patients who were younger, lived in more deprived areas, had more advanced disease and were treated with chemo and radiotherapy as an adjunct to surgery. It is possible that younger patients feel more socially isolated but under report this. The relationship to isolation and lower socio-economic status is confirmed by others.⁴ Of note is the association of loneliness with fear of cancer recurrence (FCR). Thirty percent of those with the highest rating of FCR reported one or more aspects of loneliness relative to those respondents stating nil FCR and no elements of loneliness. We speculate that patients experiencing loneliness may ruminate and dwell on possible indicators of recurrence and its consequences. Distress in the form of anxiety resulting in longer term symptoms of depression are sequential psychological states that would accompany the ‘setting condition’ of loneliness. It is interesting in the Lee-Jones et al model of FCR²² that there is a lack of description of possible setting conditions. The development of FCR into a state that becomes aversive may be triggered in some patients through the experience of loneliness.

Loneliness has been shown in this study to be consistently associated with virtually every area of HRQOL. Such associations reflect the interaction of physical and social-emotional function with feelings of loneliness. Meal times are often a time when friends and family come together, and the loss of this can reduce the opportunity for social interaction. Impairment to communication is a significant predictor for loneliness²³ and lack of confidence in appearance has social implications²⁴. The results from our survey are consistent with the functional and emotional impact of HNC leading to social dysfunction.

Although it might be difficult to introduce loneliness questionnaires into routine clinical practice, existing tools such as the Patient Concerns Inventory²⁵ and Holistic Needs Assessment.¹¹ might serve as a way to help identify those who are lonely through the conversation that takes place in the clinical setting. A detailed questionnaire such as the C-LAT might then be more appropriate.

Due to the multi-factorial aspects of loneliness it is a challenging issue for intervention. Raising awareness might in itself be helpful. GPs may be in a better position than the tertiary care team. A government initiative launched in 2018 to help tackle loneliness²⁶ includes funding to enable GPs to refer patients experiencing loneliness to a range of community activities and to community workers who can then offer tailored support. Third sector groups, for example Maggie's Cancer Caring Centres²⁷ and Macmillan Cancer Support²⁸ might be able to direct patients and carers to appropriate support. Formal interventions for loneliness in other contexts have also shown potential benefit. A review from Gardiner et al²⁹ evaluating the effectiveness of various interventions to alleviate loneliness in older adults found that although the evidence was not clear cut, all of the interventions they reviewed had some success in reducing loneliness. They identified 6 categories of intervention: social facilitation, psychological therapies, health and social care provision, animal, befriending and leisure/skill development thereby indicating a considerable range of mechanisms for development and trialling.

In conclusion, loneliness can be a hidden consequence of HNC. There is significant association with HRQOL. It is possible that interventions can reduce the level of loneliness and this should have a positive impact on mental health and HRQOL³⁰. Further research is needed to develop and test the feasibility and effectiveness of interventions to alleviate loneliness in this population.

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Table 1. The four ONS recommended National Indicator questions about loneliness.

	Hardly ever		Some of the time		Often		Not stated
How often do you feel that you lack companionship?	77%	106	16%	22	7%	9	3
How often do you feel left out?	72%	97	24%	32	4%	6	5
How often do you feel isolated from others?	70%	95	24%	32	6%	8	5
How often do you feel lonely?	72%	97	22%	30	6%	8	5

Table 2. The Cancer-related Loneliness Assessment Tool (C-LAT)

		C-LAT Part 1						C-LAT Part 2	
		Patients	1 Strongly agree	2 Somewhat agree	3 Somewhat disagree	4 Strongly disagree	% Worst two categories (A)	(If worst two categories in Part 1) then percentage rating 4-6* as to how much this bothered patients or caused them distress or unhappiness (B)	Estimate of Percentage of whole sample having significant problem (A) times (B)
1	I still participate in the social activities that I used to	126	50	49	17	10	21%	59% (16/27)	13%
2	I share my feelings, problems and worries with friends and/or family	128	59	44	17	8	20%	40% (10/25)	8%
3	Other people understand what I have been through/I am going through	127	57	47	14	9	18%	35% (8/23)	6%
4	Other people treat me the same as they used to	127	84	30	10	3	10%	62% (8/13)	6%
5	I still play the same role in life that I used to	127	61	44	15	7	17%	62% (13/21)	11%
6	I still feel as close to my family as I used to	126	104	15	2	5	6%	71% (5/7)	4%
7	I still feel as close to my friends as I used to	127	85	31	7	4	9%	55% (6/11)	5%
8	I spend more time on my own than I used to	126	19	36	23	48	44%	23% (7/31)	10%
9	I have too much time to think and worry about things	127	10	31	43	43	32%	25% (6/24)	8%
10	Other people expect me to move on and get on with my life	125	24	46	23	32	56%	15% (7/46)	9%

*In a 0-6 rating scale with 0=Not at all, 6=As much as possible

Table 3 Association of patient characteristics with the ONS National Indicator questions about loneliness and with the percentage indicating loneliness as derived from Part 2 of the C-LAT

		One or more 'often' for the 4 ONS indicators		P value (Fishers Exact test)	One or more C-LAT Part 2 responses of 4-6 on the 0-6 scale		P value (Fishers Exact test)
	ALL	11%	16/140		24%	34/140	
Gender	Female	15%	7/47	0.40	23%	11/47	>0.99
	Male	10%	9/93		25%	23/93	
Age	<55	37%	10/27	0.001	48%	13/27	0.02
	55-64	8%	4/49		22%	11/49	
	65-74	4%	2/45		16%	7/45	
	75+	-	0/19		16%	3/17	
IMD 2015 quintiles (England)	Q1 Most deprived	20%	11/55	0.03	36%	20/55	0.06
	Q2	20%	4/20		30%	6/20	
	Q3	-	0/17		18%	3/17	
	Q4	-	0/18		6%	1/18	
	Q5 Least deprived	5%	1/20		15%	3/20	
	Not available (Wales/IOM)	-	0/10		10%	1/10	
Site of cancer	Oral	10%	5/49	0.76	18%	9/49	0.32
	Laryngeal	5%	1/19		16%	3/19	
	Oropharyngeal	15%	9/59		32%	19/59	
	Other	8%	1/13		23%	3/13	
Clinical stage	Early (stage 1-2)	7%	4/55	0.28	15%	8/55	0.04
	Advanced (Stage 3-4)	14%	12/85		31%	26/85	
Primary Treatment	Surgery only	4%	2/51	0.06	12%	6/51	0.02
	RT/CT only	13%	5/39		28%	11/39	
	Surgery + adjuvant therapy	18%	9/50		34%	17/50	
Overall UW-QOL	Very good or Outstanding	3%	2/64	<0.001	11%	7/64	<0.001
	Good	9%	4/43		19%	8/43	
	Fair	11%	2/19		47%	9/19	
	Poor or very poor	73%	8/11		82%	9/11	
UWQOL physical function score	<60	43%	9/21	<0.001	67%	14/21	<0.001
	60-79	12%	5/41		27%	11/41	
	80-100	3%	2/72		11%	8/72	
UWQOL social-emotional score	<60	59%	10/17	<0.001	82%	14/17	<0.001
	60-79	5%	2/39		36%	14/39	
	80-100	5%	4/78		6%	5/78	
Intimacy	Dysfunction	36%	9/25	<0.001	60%	15/25	<0.001
	In-between	10%	2/21		33%	7/21	
	Best response	4%	3/84		8%	7/84	
Fear of recurrence	Dysfunction	30%	12/40	<0.001	48%	19/40	<0.001
	In-between	5%	4/76		17%	13/76	
	Best response	0%	0/21		5%	1/21	