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Health literacy impacts self-management, quality of life and fear of recurrence in head and neck cancer survivors

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Abstract

Purpose Little is known about whether health literacy is associated with affects certain key outcomes in head and neck cancer (HNC) survivors. We investigated (i) the socio-demographic and clinical profile of health literacy and (ii) associations among between health literacy and self-management behaviours, health-related quality of life (HRQL) and fear of recurrence (FoR) in HNC survivors.

Methods A population-based survey was conducted in Ireland. Health literacy was assessed using a validated single-item question. Socio-demographic, clinical and psychosocial outcome variables (FoR, self-management behaviours, HRQL) were collected. Multivariable linear regression was performed to estimate associations between health literacy and each psychosocial outcome.

Results Three hundred ninety-five (50%) individuals responded to the survey. Inadequate health literacy was evident among 47% of the sample. In adjusted models, HNC survivors with inadequate health literacy had significantly lower levels of self-management behaviours in the domains of health-directed behaviour, positive and active engagement in life, self-monitoring and insight, constructive attitudes and approaches and skills and technique acquisition. Inadequate health literacy was independently associated with lower functional well-being and HNC disease-specific HRQL. FoR was also significantly higher among those with inadequate health literacy.

Conclusions HNC survivors with inadequate health literacy have lower levels of self-management behaviours, lower functional HRQL and increased FoR compared to those with adequate health literacy.

Implications for Cancer Survivors Clinicians, healthcare providers and those developing interventions should consider how inadequate health literacy among HNC survivors might affect post-treatment outcomes when developing services and providing support for this group.

Keywords Head and neck cancer · Health literacy · Health-related quality of life · Fear of recurrence · Psycho-oncology · Self-management

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Background

Head and neck cancer (HNC) is the sixth most common cancer worldwide with approximately 686,000 new cases diagnosed annually [1]. HNC survival has increased [2] with improvements in 5-year survival reported in Denmark (49 to 62%) [3], in Ireland (46 to 54%) [4], in the USA for nasopharyngeal cancer (36 to 55%) [5] and in the Netherlands for hypopharynx cancer (28 to 34%) [6]. A systematic review of human papillomavirus (HPV)–related HNCs demonstrated a 72% reduction in both head and neck squamous cell carcinoma (SCC) and tonsillar SCC specific mortality [7]. Improving survival is generally a result of treatment advances and increasing use of concurrent chemotherapy and radiation [2]; however, changes in the aetiology of HNC (associated with increasing human papillomavirus (HPV) positive HNC,

which usually have better prognosis than HPV-negative cases) are also likely to play a part [7, 8].

Treatment for HNC may result in considerable morbidity with potential consequential challenges such as facial disfigurement, speech and breathing impairments and problems eating and swallowing [9–12]. From a psychosocial perspective, anxiety, distress and fear of cancer recurrence (FoR) can affect survivors' health-related quality of life (HRQL), particularly after completion of treatment [13, 14].

Self-management is defined as "awareness and active participation by the person in their recovery, recuperation and rehabilitation, to minimise the consequences of treatment, and promote survival, health and well-being" [15]. Self-management is particularly important for cancer survivors in the post-treatment period when they are faced with managing routine oncology appointments, understanding the signs and symptoms of potential recurrence of their cancer and regaining a level of normality in their social roles and routines [16–18].

Improving self-management behaviours can positively affect survivors' HRQL [19]. Recently systematic reviews of self-management interventions for cancer patients [20] and survivors [21] stated that a majority of included studies report significant improvements in HRQL domains. Improving HRQL is a specific goal of cancer survivorship care [22] and is of particular importance in HNC, being identified as a priority outcome for HNC clinical trials [23]. FoR is also an important issue among cancer survivors and has been reported to be higher among HNC survivors compared to other cancer survivors [24] and has been shown to have negative associations with HRQL, psychosocial well-being [25], tobacco use [26], physical and emotional symptoms and alcohol use [27]. Different self-management behaviours in HNC survivors have also been associated with both lower FoR and higher FoR [19].

Health literacy, defined as having the appropriate skills, knowledge, understanding and confidence to access, understand, evaluate, use and navigate health and social care information and services [28], has been associated with poor health outcomes generally [29], particularly in chronic conditions [30–32]. Inadequate health literacy has also recently been identified as a barrier to adaptive self-management behaviours in those with long-term chronic conditions [33], although evidence for whether this holds for cancer appears to be scarce [34].

In cancer, inadequate health literacy is associated with lower uptake of cancer screening, a greater likelihood of postoperative complications, reduced uptake of prescribed chemotherapy, higher information needs and fewer information seeking behaviour [34]. Furthermore, a small number of studies have identified an association between poor health literacy and lower HRQL in cancer patients [35, 36].

To date, two single-site studies investigating health literacy in HNC patients have been published [37, 38]. Koay et al. report that in HNC patients currently receiving treatment, poor health literacy was associated with younger age, higher distress and low education levels [37]. Nielsen et al., investigating the prevalence of health literacy and its association with HRQL, report that inadequate health literacy was only associated with lower social/emotional HRQL [38]. For HNC survivors, the consequences of treatment may be more onerous than for (some) other forms of cancer, where many survivors may have suboptimal health literacy [37]. Indeed, Megwalu has observed that health literacy among HNC patients is grossly understudied and that there is a need to examine its effect on outcomes in this patient group [39].

This study aimed to investigate for the first time in a population-based sample of HNC survivors (i) the socio-demographic and clinical profile of health literacy and (ii) associations between health literacy and HRQL, self-management behaviours and FoR.

Methods

Setting

In May 2015, a national postal survey was conducted among HNC survivors in Ireland. In collaboration with the population-based National Cancer Registry Ireland (NCRI), 1208 potential eligible participants (1–5 years' post-diagnosis, completed primary treatment and not receiving treatment for a recurrence or secondary cancer) were identified. All survivors who were eligible were screened by their consultant (27 of 82 consultants did not take part reducing the sample by 125 HNC survivors). Screening confirmed that an individual (a) was alive, (b) was aware they had cancer, (c) was not receiving palliative care, (d) had not developed a second invasive cancer (apart from non-melanoma skin cancer), (e) had completed primary treatment for HNC, (f) was not receiving treatment for a recurrence or secondary cancer and (g) was considered disease free for the preceding 4 months, and (h) there was no medical or other reason why it would be inappropriate to contact them about the study. A final sample of 785 patients received an invitation to complete a questionnaire. Ethical approval was obtained from participating hospitals. Further details have been described elsewhere [19].

Measures

Socio-demographic and lifestyle data were collected via questionnaire and included highest level of education completed, relationship and employment status, residential status (living alone or with others), residential location (urban/rural), medical card status,[1] current smoking status, alcohol use (AUDIT

[1] Those below a certain income threshold are provided with a medical card which entitles them to access healthcare, including primary care, in the Irish public health system, free at the point of delivery

C) [40] and comorbidities. The NCRI provided data on sex, age at time of survey completion, cancer site (oral cavity, salivary glands, pharynx and larynx), treatments received within the first year from diagnosis (cancer-directed surgery, radiotherapy, chemotherapy or combinations thereof) and stage of disease at diagnosis. HPV status was not available from the NCRI database at time of data collection.

Health literacy was measured using the single-item Brief Health Literacy Screen [41], which is a validated measure shown to be effective at identifying inadequate health literacy [42, 43]. The measure asks "How confident are you filling out medical forms by yourself?" with five response options: "Extremely", "Quite a bit", "Somewhat", "A little bit" and "Not at all". As recommended [41], responses were collapsed into two groups with "Extremely" and "Quite a bit" combined to indicate adequate health literacy and the remaining three responses ("Somewhat", "A little bit" and "Not at all") combined to indicate inadequate health literacy.

HRQL was assessed using the Functional Assessment of Cancer Therapy (FACT-G) questionnaire and the HNC-specific (FACT-HN) questionnaire [44], which include 39 statements in five domains; physical, social/family, emotional, functional well-being and HNC specific. Higher domain scores indicate higher/better HRQL.

The Health Education Impact Questionnaire (HEIQ) [45] was used to measure participants' use of self-management behaviours. The measure includes 42 items across eight domains (positive and active engagement in life, health-directed behaviour, constructive attitudes and approaches, skill and technique acquisition, self-monitoring and insight, health service navigation, social integration and support and emotional well-being). Higher scores indicate better self-management behaviours on all domains, with the exception of the "Emotional well-being" domain, where higher scores indicate lower emotional well-being.

FoR was measured using the validated Fear of Relapse/Recurrence Scale (FRRS) comprising five statements on the ability to plan for the future, risk of relapse, cancer return and belief in cancer being cured [46, 47]. Higher scores indicate greater FoR.

Statistical analysis

Analysis was carried out in STATA 14 [48]. To investigate the profile of health literacy in HNC, we compared the characteristics of those with adequate and inadequate health literacy using chi-square and *t* tests as appropriate. Because inadequate health literacy was common, we used modified Poisson regression to estimate associations between socio-demographic and clinical variables and inadequate health literacy [49]. Variables statistically significant ($p < 0.05$) in univariable models were fitted together in a multivariable model.

To investigate associations between adequate and inadequate health literacy and the outcomes of interest, we compared each using *t* tests and mean scores for each outcome, HRQL domains, self-management behaviours (emotional well-being was excluded from the analyses) and FoR. We used multivariable linear regression to estimate associations between health literacy and each outcome, after adjusting for covariates; the candidate socio-demographic, lifestyle and clinical covariates are shown in Table 1. We developed a separate model for each outcome, to ensure adequate control of confounding. To develop these models, we initially investigated associations between (i) health literacy and each outcome and (ii) each potential covariate and each outcome. Then, for each outcome separately, those variables which were statistically significant ($p < 0.05$) in these univariable analysis were fitted together in a model in which health literacy was already included. We reduced each model, retaining health literacy and covariates for which the *p* value for the likelihood ratio test (LRT) was < 0.05. We took care to avoid multicollinearity throughout, and the variance inflation factors and tolerance of the final models were above 0.1 and less than 10.

Results

Study sample

Completed surveys were returned by 395 HNC survivors (response rate 50%). Of these, 47% had inadequate health literacy (Table 1). Sixty-nine percent of respondents were male, 33% were aged 50–59 and 29% were aged 60–69. Thirty percent of respondents had laryngeal cancer, 28% pharyngeal cancer, 36% cancer of the oral cavity and 6% cancer of the salivary glands (Table 1). The mean time since diagnosis was 2.9 years (data not shown).

The analysis of aggregated survey and NCRI data indicated no significant differences between respondents and non-respondents (age at diagnosis, sex, current smoking status, treatment received, cancer site, stage at diagnosis or time since diagnosis). In addition, we have also compared our results to available national head and neck cancer rates on sex and cancer site and no differences exist [4]. Therefore, we can report that the results are representative of the general head and neck cancer population.

Profile of health literacy in HNC survivors

In univariable analysis, there were significantly higher proportions of individuals with inadequate HL among 50–59-year-olds (55% vs 25% in ≤ 49-year-olds, 51% in 60–69 and 47% in 70 +; $P = 0.001$), those with only primary education (73% vs 44% in secondary and 19% in tertiary; $P < 0.001$), those

Table 1 Participant characteristics overall and univariable analysis by health literacy status (adequate or inadequate) with *P* values

	Total		Adequate health literacy		Inadequate health literacy		***P***
	N	%	N	%	*N*	%	
Demographic characteristics							
Sex							
Female	123	31.1	72	59.0	50	41.0	
Male	272	68.9	135	50.4	133	49.6	0.113
Total	395	100	207	53.1	183	46.9	
Age							
≤49	74	18.7	55	74.3	19	25.7	
50–59	129	32.7	57	44.9	70	55.1	
60–69	116	29.4	56	48.7	59	51.3	***0.001***
70+	76	19.2	39	52.7	35	47.3	
Total	395	100	207	53.1	183	46.9	
Education							
Primary	114	29.2	31	27.4	82	72.6	
Secondary	187	48.0	104	56.2	81	43.8	***< 0.001***
Tertiary	89	22.8	72	80.9	17	19.1	
Total	390	100	207	53.5	180	46.5	
Relationship status							
Not in relationship	132	34.7	61	46.2	71	53.8	
In relationship	248	65.3	137	55.7	109	44.3	0.079
Total	380	100	198	52.4	180	47.6	
Medical card							
No	110	28.1	79	71.8	31	28.2	
Yes	282	71.9	128	45.9	151	54.1	***< 0.001***
Total	392	100	207	53.2	182	46.8	
Urban/rural residence							
Urban	232	59.6	133	57.8	97	42.2	
Rural	157	40.4	73	46.8	83	53.2	***0.016***
Total	389	100	206	53.4	180	46.6	
Employment status							
Not working	284	73.0	146	51.8	136	48.2	
Working	105	27.0	60	57.1	45	42.9	0.347
Total	389	100	206	53.2	181	46.8	
Living alone							
No	272	74.1	151	55.7	120	44.3	
Yes	95	25.9	40	42.1	55	57.9	***0.022***
Total	367	100	191	52.2	175	47.8	
Clinical characteristics							
Cancer site							
Oral cavity	142	36.0	81	57.0	61	43.0	
Salivary glands	24	6.1	13	54.2	11	45.8	
Pharynx	110	27.9	63	58.3	45	41.7	0.081
Larynx	119	30.1	50	43.1	66	56.9	
Total	395	100	207	53.1	183	46.9	
Treatments							
Radiotherapy only	64	16.2	30	49.2	31	50.8	
Surgery only	109	27.6	59	54.6	49	45.4	
Radiotherapy/chemotherapy[a]	58	14.7	35	60.3	23	39.7	0.263

Table 1 (continued)

	Total		Adequate health literacy		Inadequate health literacy		*P*
	N	%	N	%	*N*	%	
Surgery/radiotherapy	64	16.2	36	56.3	28	43.8	
Surgery/radiotherapy/chemotherapy[b]	32	8.1	11	34.4	21	65.6	
Unknown	68	17.2	36	53.7	31	46.3	
Total	395	100	207	53.1	183	46.9	
Co-morbid condition							
No	196	50.0	102	52.6	92	47.4	
Yes	196	50.0	104	53.3	91	46.7	0.881
Total	392	100	206	53.0	183	47.0	
Stage at diagnosis							
I	120	30.4	62	52.1	57	47.9	
II	38	9.6	19	51.4	18	48.7	
III	44	11.1	26	59.1	18	40.9	0.741
IV	103	26.1	54	52.9	48	47.1	
Unknown	90	22.8	46	52.3	42	47.7	
Total	395	100	207	53.1	183	46.9	
Current smoker							
Not a current smoker	312	81.7	168	54.2	142	45.8	
Current smoker	70	18.3	35	50.0	35	50.0	0.525
Total	382	100	203	53.4	177	46.6	
AUDIT C							
Lower risk drinking	282	77.7	152	54.1	129	45.9	
Higher risk drinking	81	22.3	43	53.8	37	46.3	0.957
Total	363	100	195	54.0	166	46.0	

[a] 2 respondents had surgery and chemotherapy. [b] 4 respondents had chemotherapy only

with a medical card (54% vs 28% among those without a medical card; $P < 0.001$), those living in rural areas (53% vs 42% among those in urban areas; $P = 0.016$) and among those living alone (42% vs 58%; $P = 0.022$) (Table 1). In multivariable analysis, after adjustment for socio-demographic and lifestyle variables, only lower education levels (relative risk (RR) 0.56: 95% confidence interval (CI): 0.47 to 0.65; $P < 0.001$) and living alone (RR 0.56: 95% CI: 0.47 to 0.65; $P = 0.033$) were significantly associated with inadequate health literacy (supporting Table 1).

Associations between health literacy and HRQL, self-management and FoR

Self-management

In unadjusted models, significantly lower mean scores were observed (indicating lower levels of self-management behaviours) among those with inadequate health literacy for the self-management domains "Health-Directed Behaviour" (adequate mean (M) 3.01: 95% CI 2.92 to 3.11; inadequate M: 2.86: 95% CI 2.77 to 2.96; $P = 0.029$), "Positive and Active Engagement in Life" (adequate M: 3.02: 95% CI 2.94 to 3.09; inadequate M: 2.88: 95% CI 2.80 to 2.96; $P = 0.013$), "Self-monitoring and insight" (adequate M: 3.09: 95% CI 3.03 to 3.15; inadequate M: 2.99: 95% CI 2.93 to 3.05; $P = 0.018$), "Constructive Attitudes and Approaches" (adequate M: 3.25: 95% CI 3.17 to 3.33; inadequate M: 3.07: 95% CI 2.99 to 3.15; $P = 0.001$) and "Skills and Technique acquisition" (adequate M: 2.98: 95% CI 2.91 to 3.06; inadequate M: 2.86: 95% CI 2.79 to 2.92; $P = 0.016$) (Supporting Table 2). In adjusted regression models (adjusted for socio-demographic, lifestyle and clinical variables: see Table 2 footnotes for significant variables remaining in the adjusted models), self-management behaviours were significantly lower among those with inadequate health literacy for "Health-Directed Behaviour" (Coef: −0.15; 95% CI 0.28 to −0.01: $P = 0.029$), "Positive & Active Engagement in Life" (Coef: −0.15; 95% CI −0.25 to −0.04: $P = 0.007$), "Self-monitoring and Insight" (Coef: −0.09; 95% CI −0.17 to −0.01: $P = 0.022$), "Constructive Attitudes and Approaches" (Coef: −0.14; 95% CI −0.26 to −0.03: $P = 0.012$) and "Skills and

Technique Acquisition" (Coef: −0.12; 95% CI −0.22 to −0.02: $P = 0.019$) (Table 2). There were no significant differences among those with adequate and inadequate health literacy in the adjusted models for the "Social integration and support" or "Health service navigation" scales (Table 2).

HRQL

In unadjusted models, significantly lower mean scores (corresponding to worse HRQL) were observed among those with inadequate health literacy for the "Functional Well-being" scale (adequate M: 20.37: 95% CI 19.51 to 21.24; inadequate M: 18.71: 95% CI 17.67 to 19.75; $P = 0.015$) only. In adjusted models (see Table 3 footnotes for significant variables remaining in the adjusted models), those with inadequate health literacy had significantly lower "Functional Well-being" (Coef: −1.49; 95% CI −2.76 to −0.22: $P = 0.0220$) scores and HN-specific subscale scores (Coef −4.95; 95% CI −9.87 to −0.02: $P = 0.046$). There were no significant differences among those with adequate and inadequate health literacy in the adjusted models for the "Physical well-being", "Social/Family well-being" or "Emotional well-being" scales (Table 3).

FoR

FoR did not differ between those with adequate and inadequate health literacy (adequate M: 13.33: 95% CI 12.70 to 13.97; inadequate M: 14.20: 95% CI 13.50 to 14.90; $P = 0.071$) in the unadjusted model (Supporting Table 2). In the adjusted model (see Table 3 footnotes for significant variables remaining in the adjusted models), FoR was significantly higher (indicating greater fear of recurrence) among those with inadequate health literacy (Coef 0.98; 95% CI 0.04 to 1.92: $P = 0.040$) (Table 3).

Discussion

This is the first population-based study to investigate associations between health literacy, self-management, HRQL and FoR in HNC survivors. The results indicate that HNC survivors with inadequate health literacy have lower levels of key self-management behaviours, worse functional and HNC-specific HRQL and higher FoR than those with adequate health literacy.

In our population-based sample, 47% of respondents had inadequate health literacy. A study of health literacy in Europe reported that 47.6% of the total sample ($n = 7795$) had inadequate or problematic health literacy (40% in Ireland) [50]. Other studies report 12–18% of HNC cancer patients with low or inadequate health literacy (both of which were single-site non-population-based studies) [37, 38]. While we cannot discount a possible overestimation of inadequate health literacy using a single-item measure, it is likely that our figure is accurate, taking into account the European study [50], and given HNC incidence is associated with deprivation (based on indices of unemployment, social class, type of housing tenure, car ownership, overcrowding, households below national median income and households reliant on means tested benefits [4, 51]), where the prevalence of limited health literacy is higher [50]. We would therefore expect to see a higher prevalence of inadequate health literacy in the HNC survivor population (47%) compared to the population in general (40%).

In terms of the socio-demographic variables associated with health literacy in this study, education has been observed to be related to health literacy in other settings [50, 52], while

Table 2 Multivariable linear regression—associations between adequate and inadequate health literacy and self-management domains (heiQ): coefficients (Coef) with 95% confidence intervals

	Health-directed behaviour[a]	Positive and active engagement in life[a]	Self-monitoring and insight[a]	Constructive attitudes and approaches[a]	Skills and technique acquisition[a]	Social integration and support[a]	Health service navigation[a]
	Coef (95% CI)	Coef (95% CI)	Coef (95% CI)	Coef (95% CI)	Coef (95% CI)	Coef (95% CI)	Coef (95% CI)
Health literacy							
Adequate	Reference	Reference	Reference	Reference	Reference	Reference	Reference
Inadequate	***− 0.15 (− 0.28 to − 0.01)[b]***	***− 0.15 (− 0.25 to − 0.04)[b, c]***	***− 0.09 (− 0.17 to − 0.01)[b,d]***	***− 0.14 (− 0.26 to − 0.03)[b,e]***	***− 0.12 (− 0.22 to − 0.02)[b, f]***	− 0.1 (− 0.21 to 0.01)[g]	− 0.09 (− 0.19 to 0.01)

[a] A negative coefficient indicates lower levels of self-management behaviour

[b] ***P < 0.05***

[c] Adjusted for current smoking status and comorbidity

[d] Adjusted for employment status

[e] Adjusted for medical card status

[f] Adjusted for current smoking status

[g] Adjusted for Age

Table 3 Multivariable linear regression—associations between adequate and inadequate health literacy and HRQoL domains (FACT-G and HNC specific) and Fear of recurrence (FoR): coefficients (Coef) with 95% confidence intervals (95% CI)

	FACT G				FACT H&N	Fear of Recurrence/ relapse
	Physical well-being[a] Coef (95% CI)	Social/ family well-being[a] Coef (95% CI)	Emotional well-being[a] Coef (95% CI)	Functional well-being[a] Coef (95% CI)	HNC specific[a] Coef (95% CI)	FoR Coef (95% CI)
Health literacy						
Adequate	Reference	Reference	Reference	Reference	Reference	Reference
Inadequate	− 0.70 (− 1.72 to 0.31)[c]	− 0.84 (− 2.15 to 0.48)[d]	− 0.73 (− 1.65 to 0.20)[c, e]	***− 1.49 (− 2.76 to − 0.22)*** [f, g]	***− 4.95 (− 9.87 to − 0.02)*** [f, h]	***0.98 (0.04 to 1.92)*** [f, i]

[a] A negative coefficient indicates poorer HRQL

[b] A positive coefficient indicates higher fear of recurrence/relapse

[c] Adjusted for age, sex, medical card ownership, current smoking status, comorbidity, stage at diagnosis

[e] Adjusted for age, sex, medical card ownership, current smoking status and comorbidity

[f] $P < 0.05$

[g] Adjusted for age, relationship status, medical card ownership, employment status, comorbidity, stage at diagnosis

[h] Adjusted for age, sex, relationship status, medical card ownership, current smoking status, comorbidity, stage at diagnosis

[i] Adjusted for age, sex, medical card ownership and current smoking status

living alone has been associated with lower health literacy [53, 54]. Sorensen et al. observed that the associations between low health literacy and financial deprivation, lower social status and lower educational attainment represent a challenge for public health [50]. We concur adding that HNC survivors with inadequate health literacy, lower educational attainment and who live alone are likely to be a very vulnerable group among the (growing) cancer survivor population. Moreover, given the associations we have observed between health literacy and maladaptive self-management, worse HRQL and higher FoR, these survivors should be offered interventions to support their recovery and rehabilitation.

Our results indicate that HNC survivors with inadequate health literacy have lower HRQL related to their functional well-being and HNC-specific symptoms. Consistent with our observations, Halverson et al. have reported positive correlations between better health literacy and better HRQL in patients with other cancers, but in particular for the functional well-being domain [35].

Halverson et al. suggest that cancer patients with low health literacy may have difficulty navigating complex and fragmented healthcare systems and may have difficulty managing treatment plans, potentially resulting in delays in treatment of side effects and suboptimal symptom management, all of which may exacerbate treatment-related symptoms resulting in poorer HRQL [35]. Given the particularly challenging post-treatment symptoms HNC survivors face (including eating, speech and breathing difficulties, elevated distress, anxiety and fear of recurrence and facial disfigurement [9–14]), this might explain why we found an association with inadequate health literacy and the HNC subscale and functional well-being subscale, and not other HRQL domains.

HNC incidence is strongly associated with deprivation (as defined above) and studies have reported poorer HRQL in HNC patients from more deprived backgrounds [55–57]. While we did not have information on deprivation, we have shown an association between inadequate health literacy and lower educational attainment and living alone; we might speculate that inadequate health literacy is one consideration in what might underlie poorer HRQL among those who live in more deprived areas of society. Further research to unpick relationships between deprivation, education, health literacy and HNC outcomes is warranted.

Self-management is a key component of recovery for cancer survivors [18]. Mackey et al. report a "deleterious association between health literacy and self-management" in chronic disease management and the need to understand the behavioural processes to ensure patients adopt good self-management behaviours [33]. Our study extends these conclusions into the realm of cancer survivorship. Our previous research suggests that developing effective ways of supporting self-management behaviours could improve HRQL and reduce FoR in HNC survivors [19]. This study complements those findings and points to the need to identify survivors with inadequate health literacy who may struggle to adopt good self-management practices, the consequence of which may be detrimental to their recovery and HRQL. Mean scores in particular domains within the heiQ were significantly different (albeit small); however, Elsworth and Osborne [58] report similar small effect sizes in the baseline data of their study examining benchmark estimates of change on the measure. Our findings imply that HNC survivors with inadequate health literacy may require additional support for self-management behaviours following treatment (specifically

related to having an active and healthy engagement in life, monitoring their own health and condition, having constructive approaches to their health and improving their skills to deal with health problems). This also implies a need for further investigation into how health literacy might influence self-management support and intervention research.

We have also shown that HNC survivors with inadequate health literacy have significantly higher FoR. FoR is a substantial issue among HNC patients and survivors [24]. Prevalence of FoR in HNC remains stable over time, in contrast with other cancers where decreases are often seen [24]. Our previous work has pointed to the need to understand if a threshold exists where adaptive self-monitoring becomes maladaptive hypervigilance in HNC survivors [19]. We concur with Savard et al. [24] that screening and treating HNC survivors as a matter of routine practice is of importance but add that screening for health literacy may also help identify those at increased risk of FoR after treatment.

In terms of study limitations, the concept of health literacy has expanded in recent years to include a range of factors including numeracy, oral literacy and media literacy [59]. The single item health literacy measure was used as it is self-administered, reduces respondent burden and has been shown to be effective in capturing inadequate health literacy [41, 43]; however, it may be limited in its ability to capture broader facets of health literacy [59]. Research which examines wider concepts of health literacy and which facets (accessing, understanding, evaluating or informed decision-making) [60] of health literacy HNC survivors may struggle with would be valuable. In addition, while there are important differences between HPV-positive and HPV-negative HNC survivors [61], we were unable to explore this as NCRI data on HPV status was not available. Finally, while the cross-sectional design is a potential limitation, in that it is not possible to determine directions of associations, it is unlikely that worse HRQL or self-management leads to inadequate health literacy, rather than vice versa.

In terms of implications, identifying HNC survivors with inadequate health literacy, before, during or after treatment, could help to identify those at greater risk of a range of problems post-treatment. The findings are also relevant for those developing survivorship interventions and point to the importance of identifying survivors with inadequate health literacy in terms of intervention content and design. Health literacy is an under-investigated concept in the cancer survivorship literature. Our findings suggest there is a clear need for further exploration of health literacy in different patient groups and across the entire cancer journey, as well as the examination of its relationship with other important outcomes in this population. Self-management interventions for cancer survivors may well be best targeted at individuals with inadequate health literacy, but intervention design must take cognisance of this issue.

In terms of intervention development and implementation, recent evidence suggests that health literacy interventions can be effective, particularly for behavioural outcomes [62] and have been shown to increase levels of empowerment, decision-making skills and active roles in treatment [63]. The novel findings reported in our study imply that health literacy interventions for HNC survivors are required. While specific to the HNC population, our work has important and wider implications for cancer patients and survivors in general, and for the management of cancer, in particular in the post-treatment period.

While in the early stages of implementation, health literacy policies often focus on deficiencies in the quality of patient communication and patient engagement in healthcare systems; however, there is also recognition that the health literacy responsiveness of health systems needs to be improved [64]. Tackling this can promise improved clinical quality and safety and better health outcomes for patients [64]; however, where health literacy is identified as impacting on patient outcomes (as in this study among HNC survivors), policy should be developed to address those outcomes.

Conclusions

Overall this study shows that HNC survivors with inadequate health literacy have poorer self-management behaviours, poorer functional HRQL and increased FoR compared to those with adequate health literacy levels. While health literacy poses a challenge to improving outcomes in HNC survivors, clinicians and other healthcare service providers need to be cognisant of the role health literacy plays in recovery. Identifying inadequate health literacy in HNC survivors directly after treatment may prove useful for targeting additional supports to patients who may be at greater risk of poorer outcomes.

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Authors' contributions Nicholas Clarke: Conceptualization, data analysis and interpretation, original manuscript preparation, writing, review and editing

Simon Dunne and Clare Cullen: Data curation and design, interpretation, manuscript review and editing

Jean O'Connor: Data curation, manuscript review and editing

Linda Sharp, Deirdre Desmond and Laura Coffey: Funding acquisition, data design, interpretation, manuscript review and editing

Pamela Gallagher: Funding acquisition, conceptualization, supervision, data design, manuscript review and editing

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Compliance with ethical standards

Conflict of interest There is no conflict of interest to report.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. We received formal ethical approval for the study from the following institutions in Ireland: Galway University Hospitals (Merlin Park University Hospital Clinical REC_C.A.1100); South/South West Hospital Group (UCC Clinical REC_ECM_4_(bbb)_03/06/14); St. James's Hospital, Dublin (SJH/ J Cancer Surviv (2019) 13:43–55 53 AMNCH REC Reference: 2014/05/Chairman's_Action); Royal Victoria Eye and Ear Hospital, Dublin (RVEEH REC_25/06/14).

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