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Variation in Integrated Head and Neck Cancer Care: Impact of Patient and Hospital Characteristics

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Abstract

Background: Monitoring and effectively improving oncologic integrated care requires dashboard information based on quality registrations. The dashboard includes evidence-based quality indicators (QIs) that measure quality of care. This study aimed to assess the quality of current integrated head and neck cancer care with QIs, the variation between Dutch hospitals, and the influence of patient and hospital characteristics. **Methods:** Previously, 39 QIs were developed with input from medical specialists, allied health professionals, and patients' perspectives. QI scores were calculated with data from 1,667 curatively treated patients in 8 hospitals. QIs with a sample size of >400 patients were included to calculate reliable QI scores. We used multilevel analysis to explain the variation. **Results:** Current care varied from 29% for the QI about a case manager being present to discuss the treatment plan to 100% for the QI about the availability of a treatment plan. Variation between hospitals was small for the QI about patients discussed in multidisciplinary team meetings (adherence: 95%, range 88%–98%), but large for the QI about malnutrition screening (adherence: 50%, range 2%–100%). Higher QI scores were associated with lower performance status, advanced tumor stage, and tumor in the oral cavity or oropharynx at the patient level, and with more curatively treated patients (volume) at hospital level. **Conclusions:** Although the quality registration was only recently launched, it already visualizes hospital variation in current care. Four determinants were found to be influential: tumor stage, performance status, tumor site, and volume. More data are needed to assure stable results for use in quality improvement.

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In 2006, the WHO stated that even when health systems are well-developed and appropriately resourced, quality remains a serious concern.¹ Therefore, it is important to gain insight into the care that is provided in order to monitor and effectively improve high-quality care.^{2,3} Quality of care can be monitored and measured by using a dashboard of valid and reliable quality indicators (QIs).^{4,5} A QI is defined as “a measurable element of practice performance for which there is evidence or consensus that it can be used to assess the quality, and hence change in the quality, of care provided.”⁶ Many QIs have already been developed for oncologic diseases^{7,8} and nononcologic diseases.⁹

Head and neck cancer (HNC) is the sixth most common cause of cancer worldwide.¹⁰ HNC and its treatment have a significant impact on a patient’s well-being because HNCs grow relatively quickly in an anatomically and functionally complex location.^{11–14} Patients often experience problems with speech, swallowing, and physical disfigurement due to surgery, systemic therapy, radiation, or a combination of these treatments.^{15–19} For an optimal result, it is crucial that medical specialists and allied health professionals (AHPs) deliver integrated care throughout the care process.

In 2014, a dashboard in the form of a quality registration, with census- and evidence-based QIs, was developed for measuring the quality of integrated care for patients with HNC, (eg, the Dutch Head and Neck Audit [DHNA]).²⁰ The start-up of a quality registration takes several years before stable data can be obtained.²¹ In addition to stable data, insight into determinants that influence variation in care at the patient and hospital levels can provide tools for explaining the QI scores and improving current care through medical staff learning from each other.²²

This is the first article with results from the DHNA—a recently launched quality registration that collects data prospectively. We aimed to obtain insight into the quality of currently delivered HNC care in the Netherlands and some of the influencing characteristics to test the value of the QI set as an instrument for monitoring and improving clinical performance for this quality registration.²³

Methods

Study Design

This is a prospective, observational, multicenter study for measuring current quality of integrated HNC care

with a recently launched quality registration, including 39 census- and evidence-based QIs.²⁰ We determined hospital variation in QI scores and explored this variation to explore whether differences at the patient and hospital levels would explain these variations. The Medical Ethical Committee of the region Arnhem–Nijmegen declared that ethical approval was not necessary.

Setting

In the Netherlands, approximately 3,000 patients are diagnosed with HNC annually. HNC care is centralized to 14 hospitals: 8 head and neck oncology centers (HNOCs) and 6 affiliated centers.²⁴ The number of patients treated annually varies between 70 and 600 per center. Medical specialists and AHPs involved in HNC care are united in 2 national foundations: one for medical specialists and another for AHPs; there is also a Dutch HNC patient association.

Study Population

All patients with newly diagnosed HNC from December 2013 to January 2017 who were treated with curative intention in 1 of the 14 hospitals were eligible for registration in the DHNA.

QI Set

All 39 QIs of the DHNA had been systematically developed and based on national and international evidence-based guidelines. The Rand modified Delphi method was used for this purpose by the 2 national foundations for medical specialists and AHPs, and by the patient association.²⁰ This resulted in 5 outcome indicators (survival, recurrence, complication rate, and patient-reported outcomes and experiences), 13 process indicators from the perspective of medical specialists (performance in the diagnostic, treatment, and follow-up phases, as well as aspects regarding coordination and communication), 18 process indicators from the perspective of AHPs (malnutrition screening and involvement of speech therapist), and 3 structure indicators from the perspective of AHPs (number of available case managers and nurses for each hospital). In addition, 10 determinants at patient level and 1 at hospital level were selected (see following section).

Data Collection

The 14 hospitals were encouraged to have all patients treated for HNC self-register online in the

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DHNA. Health professionals working in the participating hospitals used this registration system to collect the necessary data for calculating QI scores and assessing determinants at the patient and hospital levels. Determinants were subdivided into the following categories: age (continuous), sex, smoking (never, former, or current smoker), alcohol consumption (never, former, or current drinker), WHO performance status (PS; 0 vs 1–4), tumor site (oral cavity and oropharynx; larynx and hypopharynx; or other); clinical TNM stage (early [stage I–II] vs advanced [stage III–IV]); and comorbidity (yes vs no) at patient level, and the volume of HNOCs and affiliated centers (<200 patients vs ≥200 patients) at hospital level. Volume was defined as the average curatively treated patients per year in the HNOCs and affiliated centers^{25,26} as registered by the Netherlands Comprehensive Cancer Organisation (IKNL).²⁷

Sample Size

Previous research shows that the precision of a QI score depends on the number of patients included (numerator).²⁸ Therefore, only QIs with a numerator of >400 patients were included for calculating a precise indicator score with a confidence limit of ±5 percentage points.

Data Analyses

Inclusion criteria for the analysis were: (1) patients who underwent curative treatment, (2) availability of sufficient data (at least patient age and date of first treatment initiation), and (3) at least 30 patients per hospital (Figure 1).²⁹ The last criterion assured that results were not skewed unfairly because of too few data points.

Descriptive Analyses: The following were assessed for each indicator:

- Denominator: total number of patients who should have received the care as recommended in the QI
- Indicator score: quotient of the number of patients who received care as recommended in the QI compared with the number of patients who needed to receive the care as recommended
- Missing data: percentage of missing values per indicator. Missing data for indicators may bias the results. A percentage >25% refers to poor data quality³⁰

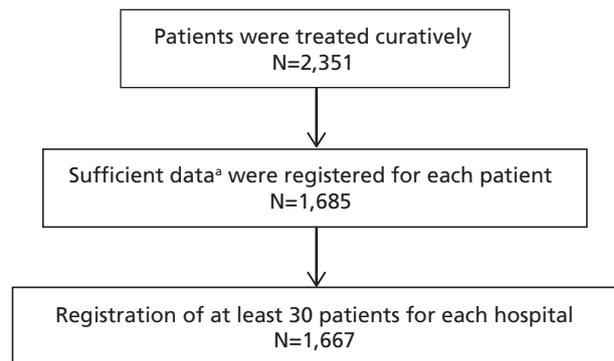


Figure 1. Inclusion of patients in this study.

^aAt least the age and date of the start of the first treatment are known.

Determinant Analyses: To assess determinants at the patient and hospital levels, we first studied the single relationship between indicators (eg, percentage of patients discussed in the multidisciplinary team meeting [MDT] before start of treatment) and determinants that could influence the indicator score (eg, tumor site) using a generalized linear mixed model. This model accounts for the nested structure of data, because individual patients (patient level = 1) are nested within hospitals (hospital level = 2). Determinants that had a univariate relationship of $P < .20$ were assumed to have a potential association with the indicator score and were selected as possible determinants for the multivariate model.

We tested all of the selected determinants together in a multilevel logistic regression model or multivariate model. Patients were automatically excluded (list-wise deletion) from the analysis if indicator or determinant data were missing. Missing was defined as the state in which data were randomly missing, and was tested by comparing the population included for the analysis with the original population of the study. We needed a minimum of 10 patients for each degree of freedom in the model to develop a reliable multilevel model. Odds ratios with 95% CIs described the association between indicator scores and determinants.

Indicator scores were recalculated for each indicator and for each part of the associated determinant. For example, an indicator could be recalculated for all patients with an early tumor stage and for all patients with an advanced tumor stage. If multiple determinants were associated with a single indicator, for example tumor stage and PS, we combined

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the different determinants and calculated stratified scores for the different categories.

Results

Study Population

In total, 1,667 patients satisfied the inclusion criteria for this analysis. Patients originated from 5 HNOCs and 3 affiliated centers. Median patient age was 65 years (range, 64–68 years) and most were male (68.5%; range, 60%–72%) (Table 1). Missing data for most patient characteristics varied between 0% and 32%; however, 75% of the comorbidity data were missing. Regarding volume, 3 of 8 HNOCs and affiliated centers were classified as low-volume centers (<200 curatively treated patients) (results not

shown). However, not all hospitals were able to register all treated patients (Table 2).

Current HNC Care and Variation

A total of 9 process indicators had a numerator of >400 patients: 7 from the medical specialist perspective and 2 from the AHP perspective (Table 3). The indicator for a case manager or nurse practitioner being present at the consultation to discuss the treatment plan had the lowest score and a high variation (adherence to QI-9: 28.9%; range, 0%–90%), and the indicator for the availability of a treatment plan had the highest score (adherence to QI-2: 100%; no range). The scores of 3 process indicators for an MDT and a treatment plan had an adherence of >90%, and the variation between hospitals was small, particularly for an MDT before treatment (QI-1: 95.4%; range, 88%–98%), availability of a treatment plan (QI-2: 100%; no range), and registration of whether the patient was treated according to protocols (QI-3: 97.2%; range, 86%–99%). The scores of 3 lead-time indicators varied between 48.4% and 82.6% adherence, with the lowest score for starting the first treatment within 30 calendar days from first consultation (QI-7: 48.4%; range, 24%–78%) and the highest score for finishing diagnostics within 21 calendar days (QI-6: 82.6%; range, 63%–100%). Variation between hospitals was greatest for malnutrition screening (QI-8: 49.9%; range, 2%–100%). Three indicators had >25% of missing data: involvement of a dental team before radiotherapy, start of first treatment within 30 days of first consult, and malnutrition screening before treatment.

Determinants

Comorbidity, nationality, and marital status had ≥75% missing data and were therefore excluded from

	Results		Missing Data ^a
	n	% (Range)	
Median age at start of treatment	1,667	65 y (64–68 y)	0%
Sex			0.1%
Male	1,142	68.5% (60%–72%)	
Female	524	31.5% (29%–40%)	
Tobacco smoking			28.7%
Never-smoker	220	18.9% (15%–34%)	
Former smoker	462	39.7% (18%–43%)	
Current smoker	483	41.5% (33%–65%)	
Alcohol consumption			27.5%
Never drinker	272	23.4% (11%–41%)	
Former drinker	88	7.6% (5%–18%)	
Current drinker	801	69.0% (41%–76%)	
WHO performance status			32.0%
None	80	8.5% (1%–97%)	
1–4	862	91.5% (3%–100%)	
Score			0.8%
0 (perfect health)	570	66.7% (10%–92%)	
>0	285	33.3% (8%–90%)	
Tumor site			0.1%
Oral cavity and oropharynx	666	47.7% (43%–61%)	
Larynx and hypopharynx	437	31.3% (15%–42%)	
Other	293	21.0% (16%–32%)	
Clinical TNM stage			21.1%
Early (stage ≤II)	582	47.1% (39%–59%)	
Advanced (stage >II)	654	52.9% (39%–66%)	
Comorbidity			75.0%
Yes	415	0% ^b	
No	0		

^aLow percentages registered in the category “unknown” are not presented.

^bDue to problems with the registration system, we were unable to perform any further calculations.

Hospital	N
1	47
2	111
3	252
4	480
5	234
6	55
7	64
8	424

^aDuring this period, data were registered in the audit for each hospital.

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further analysis. Multilevel analyses showed that 3 determinants at patient level (tumor stage, tumor site, and PS) and 1 determinant at hospital level (hospital volume) influenced the scores of 6 indicators significantly (Table 3). Patients with advanced tumor stage or with tumors in the oral cavity and oropharynx compared with the larynx and hypopharynx showed greater adherence to indicator scores for involvement of the dental team (QI-4; exclusion of T1 larynx carcinoma), completing diagnostics within 21 calendar days (QI-6), malnutrition screening (QI-8), and a case manager or nurse practitioner being present at the consultation to discuss the treatment plan (QI-9). Imperfect health (high PS) was associated with low indicator scores for malnutrition screening. High-volume centers were associated with better adherence to indicator scores for registration of whether the patient had been treated according to the protocol (QI-3), for referral to the hospital within 7 calendar days (QI-5), and for completing diagnostics within 21 calendar days (QI-6). Stratified QI scores varied from the original QI scores (Tables 3 and 4). The lowest increase of adherence, from 28.9% to 30.4%, was seen for QI-9 (presence of a case manager or nurse practitioner at the consultation). The greatest increase of adherence,

from 49.9% to 81.9%, was seen for the QI-8 (malnutrition screening).

Discussion

This study aimed to assess the variation of current HNC care between Dutch hospitals and the influence of patient and hospital characteristics. Quality of current care was low for the QI regarding the presence of a case manager at the consultation to discuss the treatment: the case manager was present in nearly one-third of all hospitals. Hardly any variation was seen between hospitals regarding the QI for the percentage of patients discussed in the MDT. However, almost all hospitals scored differently, varying from 2% to 100%, for the malnutrition screening QI. Four characteristics at patient and hospital levels had a large influence on indicator scores: tumor stage, PS, tumor site, and hospital volume.

Previous research shows that care, despite national guidelines, is not always delivered the same way in different hospitals.^{31,32} We also found large variation in care delivery from the perspectives of medical specialists and AHPs. The largest variation was for QIs from the perspective of AHPs, perhaps because of the lack of evidence-based guidelines. Regarding patient charac-

Table 3. Results of Indicators From Medical Specialist and AHP Perspectives

QI	Topic – Indicators (Perspective)	Denominator (n)	Indicator Score (%)	Range Between Hospitals (%)	Missing Data (%)	Influencing Patient and Hospital Characteristics
1	MDT meeting occurs before treatment (MS)	877	95.4	88–98	14.1 ^a	None
2	Treatment plan available (if patient discussed in MDT meeting before start of treatment) (MS)	836	100	0	18.1 ^b	NA
3	Registration of whether patient was treated according to protocols (MS)	835	97.2	86–99	17.7	Hospital volume
4	Involvement of dental team before start of radiotherapy (MS) ^c	713	83.7	67–100	25.1 ^d	Tumor stage
5	Referral to hospital (within 7 calendar days) (MS)	975	79.6	53–100	4.5	Hospital volume
6	Finishing diagnostics (within 21 calendar days) (MS)	1,010	82.6	63–100	1.1	Tumor site and hospital volume
7	Start of first treatment (within 30 calendar days) from first consult (MS)	978	48.4	24–78	26.3	None
8	Malnutrition screening at intake or before start of treatment (AHP)	619	49.9	2–100	39.4 ^a	Tumor stage and performance status
9	Presence of case manager/nurse practitioner at consultation to discuss treatment plan (AHP)	1,013	28.9	0–90	0.8 ^a	Tumor site

Abbreviations: AHP, allied health professional; MDT, multidisciplinary team; MS, medical specialist; NA, not applicable; QI, quality indicator.

^aPatients for whom at least the intention of the treatment was clear and for whom diagnostics were carried out.

^bPatients for whom at least the intention of the treatment was clear, diagnostics were carried out, and there was a treatment plan.

^cExclusion of patients diagnosed with T1 glottic carcinoma.

^dPatients for whom at least the intention of the treatment was clear, and they were treated with radiotherapy.

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Table 4. Influenced Scores of Indicators in the Multilevel Analyses and Corresponding Stratified Indicator Score

QI	Topic – Indicators	Patient and Hospital Characteristic	n	OR (95% CI) ^a	Indicator Score (%) ^a
3	Registered whether patient was treated according to protocol	Hospital volume	138	Low volume: Ref	Low volume: 93.2
			674	High volume: 2.255 (1.073–4.740)	High volume: 99.0
4	Involvement of dental team before start of radiotherapy ^a	Tumor stage	204	Early-stage: Ref	Early-stage: 72.5
			411	Advanced-stage: 3.066 (1.901–4.946)	Advanced-stage: 90.3
5	Referral to hospital (within 7 calendar days)	Hospital volume	1,096	Low volume: Ref	Low volume: 57.1
			67	High volume: 3.521 (1.722–7.196)	High volume: 85.1
6	Completing diagnostics (MDT; within 21 calendar days)	Tumor site	220	Other: Ref	Other & low volume: 55.8
			485	O/O: 1.710 (1.102–2.652)	O/O & low volume: 70.3
			304	L/H: 0.889 (0.564–1.399)	L/H & low volume: 62.3
		Hospital volume	135	Low volume: Ref	Other & high volume: 86.4
			699	High volume: 3.692 (1.342–10.162)	O/O & high volume: 90.6 L/H & high volume: 82.1
8	Malnutrition screening at intake or before start of treatment	Tumor stage	220	Early: Ref	Early-stage & PS 0: 56.6
			309	Advanced: 4.110 (2.466–6.849)	Early-stage & PS >0: 23.6
		PS	270	PS 0: Ref	Advanced-stage & PS 0: 81.9
			199	PS >0: 0.595 (0.356–0.995)	Advanced-stage & PS >0: 38.1
9	Presence of case manager or nurse practitioner at consultation to discuss the treatment plan	Tumor site ^a	204	Other: Ref	Other: 37.7
			426	O/O: 0.627 (0.403–0.974)	O/O: 30.8
			280	L/H: 0.487 (0.303–0.781)	L/H: 30.4

Abbreviations: L/H, larynx and hypopharynx; MDT, multidisciplinary team; O/O, oral cavity and oropharynx; OR, odds ratio; PS, performance status; QI, quality indicator.

^aExclusion of patients diagnosed with T1 glottic carcinoma.

teristics, a small increase was seen in the stratified QI scores for the single determinants of tumor stage and site compared with the raw QI scores. However, if the QIs were calculated for both different tumor stage and PS, the stratified QI score was much greater than the raw QI score. Both determinants are often used for case mix correction.³³ If indicators are to be used to compare quality of care between hospitals, adjustment of the indicator scores might be needed. When more data are available, the prognostic value of patient characteristics for survival could be investigated. Regarding hospital characteristics, previous studies show an association between varying hospital volume and survival.^{25,34} We determined the influence of hospital volumes on our QI set and found it had a positive influence on lead time and registration if a patient was treated according to the protocols. In the future, the association between volume and patient outcomes, such as survival and recurrence percentage, can also be assessed for patients with HNC to investigate whether further concentration of HNC care in the Netherlands is beneficial. In addition, more research must be conducted regarding the characteristics of low-volume and high-volume hospitals and the association with indicators in order to obtain points of interest to improve care.

Other countries already have databases with the aim of improving quality of care and patient outcomes, such as the National Head and Neck Cancer Audit in the United Kingdom and the Danish Head and Neck Cancer database.^{35,36} A difference with our database is that the DHNA relies on census- and evidence-based QIs from the 3 different perspectives of medical specialists, AHPs, and patients, whereas the other databases are mostly set up from an epidemiologic perspective and form a base for clinical trials. An epidemiologic database is not primarily intended for quality registration. In addition to our initiative with quality-of-care data, de Ridder et al³¹ published a retrospective cohort evaluation study about the variation in HNC care in the Netherlands, showing hospital variation in volume and treatment of oropharyngeal and oral cavity cancer. However, conclusions were drawn from retrospective data that were collected for a purpose other than quality registration. The set up and prospective character of the DHNA makes it far more suitable for measuring and monitoring the quality of HNC care.

Low indicator scores do not necessarily mean that the quality of care is poor; rather, it is a signal to evaluate further. Dentler et al³⁷ define good-quality

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ity data as being available, complete, and correct. Further, they show that data quality can influence indicator results. Our quality registration is in the start-up phase. The quality of our data does not seem optimal. Regarding completeness, it is crucial to include all patients with HNC to conclude anything about general healthcare.³⁸ At the moment, registration is not complete, although all 14 hospitals were encouraged to register all patients with HNC treated in their hospital. Centers with low inclusion must be encouraged to include all patients. Completeness will be increased when feedback on indicator scores is actually used in hospitals and when these scores begin improving. Regarding availability, we excluded 666 patients (2,351 minus 1,685) due to insufficient data in the first step (Figure 1). This can be explained by the start-up phase of the registration in which hospitals are still figuring out how to collect data efficiently, resulting in incomplete records and incomplete patient inclusion. We assume that these patients' data are missing at random. Hereafter, the indicator with the highest number of included patients had a denominator of 1,013 patients. We assume that the difference between 1,685 and 1,013 patients is also random, due to a high registration burden and health professionals stopping halfway in the registration system. However, the percentage of missing data for the indicator scores, varying from 1.1% to 39.4%, might be due to high registration burden or to the fact that data were missing in the electronic record, such as the percentage of patients who received a malnutrition screening at predefined moments. It might be possible that health professionals skipped the section on malnutrition screening in the registration system. This type of missing data may also be random, because it would not depend on the type of patients. Regarding the missing data for the determinants, we take into consideration that most of the missing data will also be random due to the start-up phase and high registration burden. Regarding correctness, data from the DHNA will be compared with data from the Netherlands Cancer Registry, which is managed by the Netherlands Comprehensive Cancer Organisation. However, in the past years, the online self-registration system has improved due to the optimizing of registration guidelines, the learning curve of health professionals, and the exploring of links between electronic

patient record systems and the DHNA database. Therefore, better data quality is expected in the future. Hereafter, all indicators could be evaluated, rather than only the best-performing indicators.

Strengths and Limitations

A strength of this study is that it enabled census- and evidence-based QI scores to be assessed for nearly 1,700 patients. Because only indicators with a numerator of >400 were taken into account for calculating a precise indicator score, insight into the total quality of care for patients with HNC was impossible. In addition, data quality criteria, such as availability, completeness, and correctness, need further improvement. We will achieve this by giving feedback about missing data and indicator scores, advising on improvement processes, and validating the registered data. Furthermore, more data are necessary to perform a reliable case mix correction. However, we assume that the case mix will be comparable between the different participating hospitals for the following reasons: (1) distribution across the 14 hospitals is largely geographic and not based on specific expertise, and (2) Dutch health insurance is based on a social system with basic assurance for each citizen, and therefore it is unlikely that there is an association between socioeconomic status and quality of care. Lastly, based on the opinions of the caregivers involved in the registration, collection of data seems to be difficult and time-consuming. Focus on less labor-intensive registration systems and more automatic data collection is needed, particularly registration at the source. Initiatives in the United States and the Netherlands have already started.^{39,40}

Conclusions

Initiating a multidisciplinary quality registration system based on census- and evidence-based QIs is challenging; the main requirements are guidelines for developing QIs and sufficient data to evaluate the QIs, determine case mix, and assess the effects of variation on outcomes. However, our recently launched audit already visualizes the variation in current care among hospitals that deliver HNC care. One of the next steps for the DHNA will be to conduct more research to explore the association between variation in quality of care and differences in patient outcomes and to identify targets for quality improvement.

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