

# Patient Reported Outcomes in Multidisciplinary Care for High-risk Head and Neck Cutaneous Squamous Cell Carcinoma

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**Multidisciplinary care pathways may improve quality of care, yet little is known about patients' perspectives regarding multidisciplinary treatment for high-risk head and neck cutaneous squamous cell carcinoma. This study examined health-related quality of life, decisional conflict, and satisfaction with care in 78 high-risk head and neck cutaneous squamous cell carcinoma patients undergoing multidisciplinary care. Pre-treatment, patients completed a baseline questionnaire, the EuroQoL-5D-5L, and the Decisional Conflict Scale. One month post-treatment, they completed the EuroQoL-5D-5L, Basal and Squamous Cell Carcinoma Quality of Life, and EORTC IN-PATSAT32 satisfaction questionnaires. Mean generic health-related quality of life scores were 0.76 pre-treatment and 0.81 post-treatment ( $p=0.077$ ), with minimal impact on disease-specific health-related quality of life (mean Basal and Squamous Cell Carcinoma Quality of Life scores ranging from 0.46 to 1.05). However, 73.7% of patients expressed worries about prognosis, and 12% of patients reported concerns regarding *diagnosis and treatment* substantially affecting health-related quality of life. The mean Decisional Conflict Scale total score was 26.61, with 19.2% of patients exceeding the clinically relevant threshold of 37.5, indicating decision delay or uncertainty regarding implementation. Approximately one-third of patients reported a need for better decision-making support. Overall, patients reported high satisfaction with care. In conclusion, while multidisciplinary care had minimal impact on health-related quality of life and resulted in high patient satisfaction, one-third of patients required more comprehensive information and value clarification.**

**Key words:** cutaneous squamous cell carcinoma; head and neck; high risk; multidisciplinary care; questionnaires; quality of life.

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Cutaneous squamous cell carcinoma (cSCC) accounts for 20% of keratinocyte carcinomas and has a continuously rising incidence (1, 2). In general, cSCC

## SIGNIFICANCE

Diagnosis and treatment of high-risk head and neck cutaneous squamous cell carcinoma often benefits from a multidisciplinary approach. As little is known about how patients experience this care, we investigated the health-related quality of life, decisional conflict, and satisfaction with care in 78 patients with high-risk head and neck cutaneous squamous cell carcinoma. On average, patients experienced limited impact on health-related quality of life, no serious decisional conflicts, and were satisfied with care. However, many patients were worried about their prognosis, diagnosis, and treatment. Results indicate room for improvement regarding information provision and clarification of personal values.

is known to have a good prognosis with overall 5-year disease-specific survival rates of 79.1–99.4% (3–5).

The American Joint Committee on Cancer (AJCC) classifies high-risk cSCC based on several factors, including invasion beyond the subcutaneous fat or >6 mm, perineural invasion (nerve deeper than the dermis or  $\geq 0.1$  mm in diameter), and minor bone erosion (6, 7). Additional high-risk features include tumour location (lip, ear, temple, and cheek), tumour diameter ( $\geq 2$  cm), poor differentiation, nodal metastasis, and immunosuppression (6).

Approximately 80% of all cSCCs occur in the sun-exposed head and neck area, which is associated with a 1.5 to 3.8 times higher risk of poor prognostic outcomes compared with cSCCs located on other areas of the skin (3, 8–12). Patients with high-risk cSCC located in the head and neck area (HR-HNcSCC) are often elderly, in a frail condition with a high prevalence of comorbidities and polypharmacy (13). Besides, the head and neck area is of aesthetic and functional importance (8, 9). Therefore, these patients often require complex care, provided by multiple specialists.

Multidisciplinary care pathways have been developed for patients with HR-HNcSCC to improve quality of the care provided (14). However, little is known about how patients experience these multidisciplinary pathways.

Understanding patient perspectives and values is crucial, as their preferences may differ from medical recommendations, which are often focused on curative intent.

In this study, we investigated health-related quality of life (HRQoL), decisional conflict, and satisfaction with care in HR-HNcSCC patients, to better tailor multidisciplinary care to individual patient situations, needs, and preferences.

## MATERIALS AND METHODS

### Study design and patients

In this observational descriptive study, we recruited patients with HR-HNcSCC from the multidisciplinary head and neck skin cancer outpatient clinics of Maastricht University Medical Centre (MUMC+) and Radboud University Medical Centre (Radboudumc) from March 2022 until July 2023.

Patients with HR-HNcSCC from the surrounding region are referred to both academic hospitals, where they receive care as part of an established multidisciplinary pathway. This pathway includes a multidisciplinary tumour board comprising a dermatologist, pathologist, radiologist, maxillofacial surgeon, and plastic surgeon. Additionally, patients can be seen by multiple specialists during integrated outpatient consultations. During diagnostic work-up, patients are supported by case managers who facilitate communication between specialties, and guide patients through each step of their care pathway.

Patients were eligible for inclusion if they were over 18 years old and had a histologically diagnosed primary or recurrent HR-HNcSCC, for which multidisciplinary evaluation and treatment took place in the MUMC+ or Radboudumc. Eligible patients willing to participate received relevant information concerning the study and signed informed consent. Patients were excluded if they had inadequate knowledge or understanding of the Dutch language, or were otherwise unable to complete the questionnaires. This study was reviewed by the local Medical Ethics Review Committee of Maastricht UMC+ (METC azM/UM, 2021-2918-A-3).

### Data collection

Data on baseline patient, tumour, and treatment characteristics were collected (**Table I**). These data were derived from patient records and a questionnaire developed by the research team. In addition, whether patients were offered a choice between multiple treatment options was recorded.

### Patient-reported outcomes

Patient-reported outcomes on generic HRQoL, disease-specific HRQoL, decisional conflict, and patient satisfaction with care were evaluated at 2 time points. Patients were asked to complete a baseline questionnaire, the EuroQoL 5 Dimension-5L (EQ-5D-5L), and the Decisional Conflict Scale (DCS) questionnaire (Appendix S1)

**Table I. Collected data on baseline patient, tumour, and treatment characteristics**

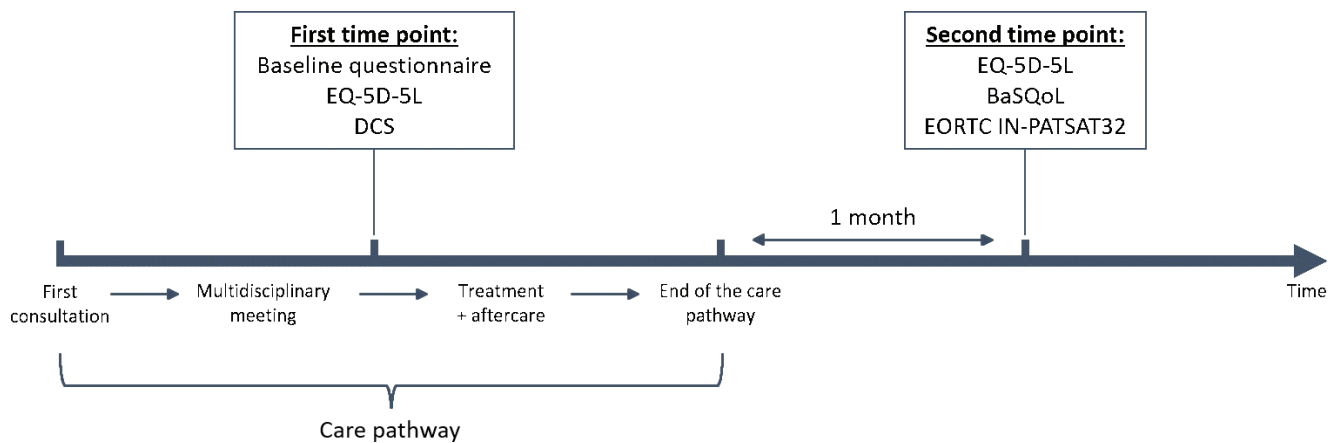
Item	Features
Patient-related data	Gender Age at inclusion World Health Organization (WHO) performance status Marital status Educational level Presence of comorbidities Presence of informal care Prior history of skin cancer
Tumour-related data	Primary, recurrent, or metastatic tumour TNM stage according to the 8th edition of the AJCC (Ref. 6) Largest diameter in millimetres Location Degree of differentiation The presence or absence of perineural and lymphovascular invasion Invasion depth in millimetres
Treatment-related data	Type of treatment Use of general anaesthesia Treatment centre (MUMC+ or Radboudumc)

before treatment (pre-treatment). One month after finishing the entire multidisciplinary pathway, including aftercare such as wound assessments, patients were asked to complete the "post-treatment" EQ-5D-5L, Basal and Squamous Cell Carcinoma Quality of Life (BaSQoL), and European Organisation for Research and Treatment of Cancer Patient Satisfaction (EORTC IN-PATSAT32) questionnaires (**Fig. 1**). Questionnaires were administered by postal mail, or, if not feasible, by phone. The scores on the questionnaires were calculated using the corresponding standardized manuals (15–21).

The selected questionnaires were chosen because they provide insight into different aspects of the patients' experiences regarding care. The DCS measures decisional conflict regarding health-related decisions, reflecting the patients' experience of the decision-making process. The BaSQoL is a disease-specific questionnaire evaluating the influence of skin cancer and its treatment on the HRQoL. The generic HRQoL was evaluated using the EQ-5D-5L and was measured at both time points, in order to evaluate change in HRQoL over time. The EORTC IN-PATSAT32 assesses patients' experiences regarding different aspects of care. More information regarding the different subscales and interpretation of (sub)scores of all questionnaires is provided in Appendix S1.

### Statistical analysis

Categorical data were presented as absolute numbers and percentages. Normally distributed continuous data were presented as mean with standard deviation ( $\pm$ SD), and skewed data as median with inter-quartile range (IQR). A paired-samples t-test or non-parametric Wilcoxon test was used to compare the EQ-5D-5L scores pre- and post-treatment. Proportions of patients with scores exceeding clinically relevant cut-off values, as specified in manuals, were computed to signal specific problems among the study population. Differences in baseline characteristics between groups with and without scores exceeding cut-off values were tested for significance. For



**Fig. 1. Schematic presentation of administration of the questionnaires at 2 specific time points.** Abbreviations: EQ-5D-5L, EuroQol 5 Dimension-5L; DCS, Decisional Conflict Scale; BaSQoL, Basal and Squamous Cell Carcinoma Quality of Life; EORTC IN-PATSAT32, European Organisation for Research and Treatment of Cancer Patient Satisfaction.

this purpose, the  $\chi^2$  or t-test for independent samples or the Mann–Whitney  $U$  test was used. All analyses were performed using IBM SPSS Statistics (version 28; IBM Corp, Armonk, NY, USA). A two-sided  $p$ -value of  $<0.05$  was considered statistically significant.

#### Power calculation

The purpose of this study was to describe experiences of patients receiving multidisciplinary care using questionnaires on patient-reported outcomes. One of the goals was to evaluate to what extent the HRQoL is affected by care, measured by means of the EQ-5D-5L. To detect an effect size (Cohen's  $d$ ) of 0.5 with a power of 80% and an alpha (two-sided) of 5%, 64 patients were required. When accounting for a potential 20% loss-to-follow-up, 80 patients had to be included.

## RESULTS

#### Patient and tumour characteristics

Between March 2022 and July 2023, 105 participants were eligible to participate in the study. Twenty-five patients refused participation and 2 patients were subsequently excluded as these patients refused treatment for their cSCC. For 20 of the 27 non-responders for whom a limited set of baseline characteristics was available, these characteristics were comparable to those of the study participants. In total, 78 patients completed the pre-treatment questionnaires and 76 patients filled in the post-treatment questionnaires. The median time interval between administering both questionnaires was 15.0 (IQR, 10.0–18.8) weeks.

Baseline patient and tumour characteristics are presented in **Table II**. The mean age at the time of inclusion was 77.3 ( $\pm 8.6$ ) years and 67.9% of patients were male. The proportion of patients with a low education level was 57.9% and 83.3% had a WHO performance status of 0

or 1. The majority of patients (74.4%) received surgical excision, 11.5% were treated with primary radiotherapy, and 12.8% received surgery with adjuvant radiotherapy. One patient (1.3%) received immunotherapy. Among those who underwent surgical excision with or without adjuvant radiotherapy ( $n=68$ ), 26.5% had a skin graft, 23.5% underwent primary closure, 17.6% received a local flap, 14.7% were treated with a purse-string suture, and 11.8% experienced secondary granulation. For 4 patients (5.9%), no data was available on the closure technique.

#### Health-related quality of life

All 78 patients completed the pre-treatment EQ-5D-5L and 76 patients the post-treatment EQ-5D-5L (97.4%). The mean EQ-5D-5L index value pre-treatment was 0.76 ( $\pm 0.23$ ) and slightly increased to 0.81 ( $\pm 0.21$ ) post-treatment ( $p=0.077$ ) (**Table III**). The mean EQ-VAS score was comparable pre- and post-treatment at 72.25 ( $\pm 16.22$ ) vs 73.42 ( $\pm 18.47$ ), respectively ( $p=0.625$ ). Pre-treatment, no patient had a mean EQ-VAS score of 100, defined as “best imaginable health” status, whereas post-treatment, 4 patients (5.3%) reported a mean EQ-VAS of 100.

Seventy-four patients (94.9%) completed all questions on the BaSQoL questionnaire. The mean scores on the subscales ranged between 0.46 and 1.05, reflecting “no” to “little impact” on disease-specific HRQoL. The highest mean scores were observed for subscales *diagnosis and treatment* and *worries*. Nine patients (12%) reported substantial concerns relating to the *diagnosis and treatment*. Fifty-six patients (73.7%) expressed *worries* about metastasis and the future, with these *worries* being substantial in 7.9% of patients. Fifty-seven patients (76%) reported that the word “cancer” frightened them at the time of diagnosis. In contrast, the subscale *appearance* had the lowest mean score, indicating minimal impact of appearance-related concerns on quality of life (**Table III**).

**Table II. Patient- and tumour-related characteristics of the total patient population (n = 78)**

Feature	Total (n = 78)
Gender, n (%)	
Male	53 (67.9)
Female	25 (32.1)
Age at inclusion, years, mean ± SD	77.3 ± 8.6
WHO performance status, n (%)	
0–1	65 (83.3)
2–4	13 (16.7)
Education level, n (%)*	
Low	44 (57.9)
Middle	20 (26.3)
High	12 (15.8)
Unknown	2
Marital status	
Single	12 (15.4)
Married	47 (60.3)
Widowed	14 (17.9)
Domestic partnership	5 (6.4)
Informal care, n (%)	
No	52 (67.5)
Yes	25 (32.5)
Unknown	1
Comorbidities, n (%)	
No	11 (14.1)
Yes, 1	13 (16.7)
Yes, more than 1	54 (69.2)
History of skin cancer, n (%)	
No	35 (44.9)
Yes	43 (55.1)
Included tumour	
Primary	62 (79.5)
Recurrent or metastatic	16 (20.5)
Location, n (%)**	
Low-risk location	37 (47.4)
High-risk location	41 (52.6)
TNM stage, n (%)***	
I	21 (26.9)
II	15 (19.2)
III	37 (47.4)
IV	5 (6.4)
Tumour diameter, mm, median (IQR)	20.0 (11.3–26.0)
General anaesthesia, n (%)	
No	64 (82.1)
Yes	14 (17.9)
Type of treatment, n (%)	
Surgery	58 (74.4)
Primary radiotherapy	9 (11.5)
Surgery and adjuvant radiotherapy	10 (12.8)
Immunotherapy	1 (1.3)
Closure technique, n (%)	
Secondary granulation	8 (11.8)
Primary closure	16 (23.5)
Purse-string suture	10 (14.7)
Skin graft	18 (26.5)
Local flap	12 (17.6)
Missing	4 (5.9)
Not applicable (no surgery)	10
Treatment centre, n (%)	
MUMC+	46 (59.0)
Radboudumc	32 (41.0)
Multiple treatment options offered, n (%)	
No, only 1	36 (46.2)
Yes, but a strong preference by doctors	17 (21.8)
Yes, patient decided	25 (32.1)

SD: standard deviation; IQR: interquartile range; DCS: Decision Conflict Scale; WHO: World Health Organization.

\*Education level was defined as: low (elementary education, pre-vocational education), middle (middle-level applied education), or high (higher professional or scientific education). \*\*High-risk location was defined as tumours located on the ear, lip, cheek, and temple, according to the AJCC 8th edition (6). \*\*\*TNM stage according to the AJCC 8th edition (6).

### Decisional conflict

The DCS was completed by 73 patients (93.6%). The mean DCS total score was 26.61 ( $\pm 15.47$ ), which is below the threshold of 37.5 associated with clinically significant doubt about the decision (see Table III) (21). In 19.2% of patients ( $n = 14$ ), the DCS score was higher than 37.5. The highest mean scores were observed in the subscales *informed decision* at 32.44 ( $\pm 22.58$ ) and *values clarity* at 34.98 ( $\pm 24.91$ ). In respectively 32.0% and 34.2% of patients, the scores on these subscales exceeded 37.5, reflecting uncertainty or delay in the decision-making process.

To contextualize the degree of decisional conflict, patients were asked if they were offered a choice between multiple treatment options. According to 36 patients (46.2%), 1 treatment option was offered. Seventeen patients (21.8%) recalled that they were given multiple treatment options, but with a recommendation for 1 preferred treatment, and 25 patients (32.1%) reported they had a choice between multiple treatment options without a strong preference stated by the multidisciplinary team. The mean DCS total score was quite similar between these 3 groups: 24.77 ( $\pm 13.30$ ), 28.71 ( $\pm 11.94$ ), and 27.85 ( $\pm 20.27$ ) ( $p = 0.618$ ), respectively.

### Satisfaction with care

Forty-two patients (53.8%) fully completed the EORTC IN-PATSAT32 questionnaire. The mean score on the subscale *general satisfaction* was 79.85 ( $\pm 17.54$ ). There was no significant difference in mean general satisfaction between treatment centres (78.13  $\pm$  17.16 vs 82.41  $\pm$  18.10,  $p = 0.299$ ). The mean scores on all the other subscales of the EORTC IN-PATSAT32, specific for different aspects of the care pathway, ranged between 64.62  $\pm$  21.15 (*exchange of information between caregivers* subscale) and 77.82  $\pm$  21.25 (*doctors' technical skills* subscale) (see Table III). There is a high number of missing values for several subscales of the EORTC IN-PATSAT32 questionnaire, as some questions might not have been applicable to patients with short hospital visits.

### Factors associated with patient-reported outcomes

Differences in relevant baseline characteristics between groups with and without scores exceeding cut-off values were explored. Patients for whom concerns over diagnosis and treatment substantially affected HRQoL were more often female (66.7% vs 27.3%,  $p = 0.026$ ). Patients with a score exceeding 37.5 on the DCS *informed decision* subscale were more likely to have a tumour  $\geq 2$  cm in diameter (71.4% vs 44.0%,  $p = 0.041$ ). Patients with a score of  $\leq 75$  on the general satisfaction with care subscale more often had comorbidities (95.3% vs 70.8%,  $p = 0.018$ ) compared with patients with scores exceeding 75. No other clinically relevant differences

**Table III. Results of patient-reported outcomes on the EQ-5D-5L, DCS, BaSQoL, and EORTC IN-PATSAT32 questionnaires (n = 78)**

Questionnaire	Score Mean ± SD	Score Median (IQR 25–75)	Missing values, n
Measurements before start of treatment (range of scale) <sup>a</sup>			
EQ-5D-5L			
EQ-Index (0–1)	0.76 ± 0.23	0.82 (0.67–0.90)	0
EQ-VAS (0–100)	72.25 ± 16.22	80.00 (65.00–80.00)	1
DCS (0–100)			
Total score	26.61 ± 15.47	25.00 (16.41–34.38)	5
Uncertainty	25.88 ± 18.64	25.00 (16.67–33.33)	2
Informed decision	32.44 ± 22.58	25.00 (16.67–41.67)	3
Values clarity	34.98 ± 24.91	25.00 (25.00–50.00)	2
Support	21.43 ± 18.31	25.00 (0.00–33.33)	1
Effective decision	21.22 ± 14.83	25.00 (12.50–25.00)	2
Measurements after treatment (range of scale) <sup>b</sup>			
EQ-5D-5L			
EQ-Index (0–1)	0.81 ± 0.21	0.85 (0.74–1.00)	2
EQ-VAS (0–100)	73.42 ± 18.47	75.00 (60.00–89.50)	2
BaSQoL (0–3)			
Behaviour	0.67 ± 0.62	0.50 (0.25–1.25)	3
Diagnosis and treatment	1.05 ± 0.80	1.00 (0.33–1.33)	3
Worries	1.00 ± 0.78	1.00 (0.50–1.50)	2
Appearance	0.46 ± 0.71	0.00 (0.00–0.67)	2
Other people	0.91 ± 0.78	1.00 (0.00–1.50)	2
EORTC IN-PATSAT32 (0–100)			
Doctors' technical skills	77.82 ± 21.25	75.00 (58.33–100.00)	4
Doctors' interpersonal skills	76.30 ± 20.82	75.00 (58.33–100.00)	4
Doctors' information provision	75.68 ± 20.64	75.00 (54.17–100.00)	5
Doctors' availability	69.79 ± 24.17	75.00 (50.0–100.00)	6
Nurses' technical skills	75.30 ± 19.34	75.00 (58.3–100.00)	9
Nurses' interpersonal skills	75.30 ± 18.69	75.00 (60.42–91.67)	9
Nurses' information provision	72.71 ± 19.43	75.00 (50.00–91.67)	9
Nurses' availability	71.97 ± 21.27	75.00 (50.00–90.63)	12
Interaction with professional	67.97 ± 17.04	66.67 (50.00–75.00)	30
Waiting time	66.30 ± 20.93	62.50 (50.00–81.25)	9
Access	69.64 ± 19.10	75.00 (50.00–75.00)	8
Exchange of information between caregivers	64.62 ± 21.15	75.00 (50.00–75.00)	13
Comfort/Cleanliness	72.14 ± 20.21	75.00 (50.00–100.00)	8
General satisfaction	79.85 ± 17.54	75.00 (75.00–100.00)	11

EQ-Index and EQ-VAS: score 1 and 100, respectively represent highest possible HRQoL; DCS: score 100 represents the highest possible degree of decisional conflict; BaSQoL: score 3 represents the highest possible impact on HRQoL; EORTC IN-PATSAT32: score 100 represents the highest possible level of satisfaction with care.

<sup>a</sup>Pre-treatment; <sup>b</sup>Post-treatment; SD: standard deviation.

between patient, tumour, and treatment characteristics within these groups were found.

## DISCUSSION

This observational descriptive study evaluating patient-reported outcomes during multidisciplinary care in patients with HR-HNcSCC shows that generic HRQoL was already high pre-treatment and increased slightly post-treatment. Although cSCC had limited impact on the disease-specific HRQoL, a subset of patients reported concerns related to their *diagnosis and treatment* and *worries* about prognosis to be of substantial impact on their HRQoL. Generally, *satisfaction* with care was high.

Arts et al. (22) investigated the disease-specific HRQoL and satisfaction with care in patients with keratinocyte carcinoma and found mean scores on the subscales of the BaSQoL ranging from 0.3 to 0.9. Waalboer-Spuij et al. (20) found mean BaSQoL subscale scores ranging from 0.3 to 1 in patients with cSCCs. In line with our findings, both studies report the highest scores on the *diagnosis and treatment* and *worries* subscales, and the lowest score on the *appearance* subscale (20, 22). The high score on the *diagnosis and treatment* subscale may be associated

with the shock of being diagnosed with cancer, as the word “cancer” at the time of diagnosis frightened 76% of patients. Aymonier et al., who used a self-designed questionnaire, found that 36.1% of patients with BCC and 66.8% of patients with localized melanoma were shocked by this diagnosis (23). In patients with HR-HNcSCC often large and mutilating invasive treatments are required, which may also contribute to patients' concerns regarding diagnosis and treatment. The high score on the subscale *worries* regarding prognosis might be associated with the risk of recurrence and/or metastasis in cSCC, despite the still rather high probability of progression-free survival (3–5). Providing patients with verbal and written information concerning the diagnosis, treatment, and corresponding survival rates might help to reduce their concerns on these topics.

Although the mean DCS total score of 26.61 (± 15.47) was well below the threshold of 37.5 for clinically significant decisional conflict, 20% of patients had a mean DCS total score exceeding 37.5. Additionally, around one-third of patients reported a score >37.5 on the subscales *informed decision* and *values clarity*. Other studies in patients with head and neck cSCC and BCC reported that patients feel insufficiently informed about

the available treatment options, and the benefits, risks, and side effects of the treatment options (24, 25). In the current study, approximately half the patients (46.3%) recalled being offered only 1 treatment option, which may have contributed to feeling less involved in decision-making, or feeling uninformed or unable to express their personal values and needs. Improvement of care can be expected when focusing on patients' understanding of diagnosis, treatment, and prognosis. Besides, it is essential to consider which treatment fits a patient's personal situation and to clarify their values, priorities, and needs, as patient preferences might differ from the doctor's recommendations. This is particularly important in this group of frail patients, who require complex care and may experience a substantial impact on QoL as a result of treatment decisions. Patients may, for example, prioritize outcomes such as independence, symptom relief, and minimizing treatment burden over curative intent, which may conflict with the medical treatment preference. Therefore, value clarification is crucial to ensure that treatment decisions are truly reflecting the patient's wishes and priorities. These goals might be achieved by patient-centred counselling, better involvement of patients and caregivers in decision-making, and explicitly eliciting patient preferences, which allows patients to make a well-informed decision based on personal values. This is supported by van Winden et al., who recommend adopting a holistic approach and using screening tools (for example Geriatric 8) to identify patients who require additional counselling regarding their treatment decision (26).

The mean score on the EORTC IN-PATSAT32 *general satisfaction* subscale was 79.85 ( $\pm 17.54$ ), reflecting high general satisfaction. This score was remarkably higher than found in patients with low-risk head and neck keratinocyte carcinoma in a population with similar baseline characteristics (22). The higher satisfaction in our study population might be explained by the multidisciplinary approach.

### *Strengths and limitations*

Due to prospective data collection, data were consistent and relatively complete. A limitation of this study is that patients were asked to participate in the study by their treating physician, which may have inclined them to answer questions in a socially desirable way, also called social desirability bias. Furthermore, the fact that 25.8% of the eligible patients refused to participate could impact the generalizability of our results, especially as participants in patient-reported outcome studies often report more favourable outcomes compared with non-respondents (27). Although our study was powered for the primary outcome, we also explored between-group differences in relevant baseline characteristics. These analyses had no predefined hypotheses and the study

may not have been sufficiently powered to detect such differences. Nonetheless, these results offered valuable insights into patient and tumour characteristics that may influence patient-reported outcomes.

### *Conclusion*

While most patients reported high satisfaction and limited impact of the disease on their HRQoL, significant challenges remain in informed decision-making and clarity regarding personal values. To optimize care, healthcare providers should focus on enhancing communication and decision support for patients. This includes providing more detailed information on the diagnosis, treatment options, and prognosis, and ensuring that patients have a clear understanding of their personal preferences and values in the decision-making process. Addressing these areas could improve both patient satisfaction and the overall quality of care in HR-HNcSCC management.

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*Data availability statement:* The data underlying this article will be shared on reasonable request to the corresponding author.

*Ethics statement:* The patients in this manuscript have given written informed consent to publication of their case details. Approved by Medical Ethical Committee azM/UM, Maastricht University Medical Centre. Approval number: 2021-2918-A-3.

Trial registration: NCT05482880 (ClinicalTrials.gov).

*The authors have no conflicts of interest to declare.*

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