

# Health-Related Quality of Life, Satisfaction with Care, and Cosmetic Results in Relation to Treatment among Patients with Keratinocyte Cancer in the Head and Neck Area: Results from the PROFILES Registry

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## Abstract

**Background:** Little is known about the impact of keratinocyte cancer (KC) and its treatment on health-related quality of life (HRQoL). **Objectives:** The objectives of the present study were (1) to evaluate HRQoL among patients with KC in a population-based setting and compare this with an age- and sex-matched normative population and (2) to compare HRQoL, satisfaction with care, and cosmetic results among patients who underwent conventional excision, Mohs' micrographic surgery, or radiotherapy. **Method:** A random sample of 347 patients diagnosed with cutaneous basal cell or squamous cell carcinoma in the head and neck area between January 1, 2010, and December 31, 2014, were selected from the Netherlands Cancer Registry (NCR) and were invited to complete a questionnaire on HRQoL, satisfaction with care, and cosmetic results. Data were collected within Patient-Reported Outcomes Following Initial Treatment and

Long-term Evaluation of Survivorship (PROFILES). Outcomes were compared to an age- and sex-matched normative population. **Results:** Two hundred fifteen patients with KC returned a completed questionnaire (62% response). Patients with KC reported better global quality of life (79.6 vs. 73.3,  $p < 0.01$ ) and less pain ( $p < 0.01$ ) compared to the normative population. No statistically significant differences in HRQoL, satisfaction with care, and cosmetic results were found between patients with KC who underwent conventional excision, Mohs' micrographic surgery, or radiotherapy. **Conclusions:** The impact of KC and its treatment seems relatively low and more positive than negative as patients reported better HRQoL compared to an age- and sex-matched normative population, probably due to adaptation. No statistically significant differences between treatment types were found concerning HRQoL, patient satisfaction, and cosmetic results. This information could be used by healthcare

professionals involved in KC care to improve patients' knowledge about different aspects of the disease as patient's preference is an important factor for treatment choice.

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## Introduction

Keratinocyte cancer (KC) is the most common cancer in the Western world [1, 2]. Basal cell carcinomas (BCCs) and squamous cell carcinomas (SCCs) account for, respectively, 80 and 20% of cases of KC [2–4]. These cancers are called KC because they share lineage with keratinocytes and histologically resemble epidermal keratinocytes [3]. Keratinocytes are vulnerable to damage from sun exposure and therefore KCs usually develop on sun-exposed areas, especially the head and neck [5–8]. BCCs are slow-growing cancers that are nearly always asymptomatic, while SCCs may grow faster and may induce tenderness or pain, but are also mostly asymptomatic [3]. However, SCCs are more aggressive cancers with a tendency to metastasis, especially the larger ones located on the lips and ears [9].

KC is typically treated with surgical excision. However, less invasive options exist, such as radiotherapy, cryotherapy, or topical therapy [3, 4, 10]. Choice of treatment depends on various factors, both clinical and personal. Important clinical factors are aggressiveness of the cancer, size and localization of the lesion, and especially for BCC, histological subtype [4, 11]. In addition, elderly patients and those with comorbid conditions are less suitable for surgical excision and are more likely to receive a less invasive treatment option. Furthermore, cosmetic aspects and patients' preferences may also have an impact on the choice of treatment, since treatment of KC can cause substantial facial cosmetic and functional disturbances [11]. Previous research showed that most prevalent concerns of patients with KC include worries about tumor recurrence, as well as the potential size and conspicuousness of the scar [12].

Patient-reported outcomes and health-related quality of life (HRQoL) are increasingly important outcomes in daily patient care [8, 13, 14]. HRQoL refers to an individual's physical, psychological, and social well-being, which may be affected by disease and treatment [15]. Since patients with KC are likely to develop multiple cancers during a lifetime, KC and its treatment may be associated with impaired HRQoL [16]. Despite the high incidence rates of KC and the importance of incorporating patient values into evidence-based medicine, little is

known about the impact of specific treatment options for KC on HRQoL [13, 17]. In addition, attention on the perspectives of patients with KC has been increasing over the past 2 decades, since previous research focused mainly on patients with melanoma [14, 18]. Satisfaction with care is also a part of the patient-reported outcomes and more applicable to diseases with multiple treatment options, such as KC [19]. As patients with KC have strongly expressed the need for a shared decision-making process [20, 21], in which they are actively engaged and value detailed information regarding their disease and treatment options, healthcare professionals who are working with patients with KC need to understand their psychosocial concerns and needs in order to offer appropriate care services [22].

The aims of the present study were (1) to evaluate HRQoL among patients with KC in a population-based setting and compare this with an age- and sex-matched normative population and (2) to compare HRQoL, satisfaction with care, and cosmetic results among patients who underwent conventional excision, Mohs' micrographic surgery, or radiotherapy.

## Materials and Methods

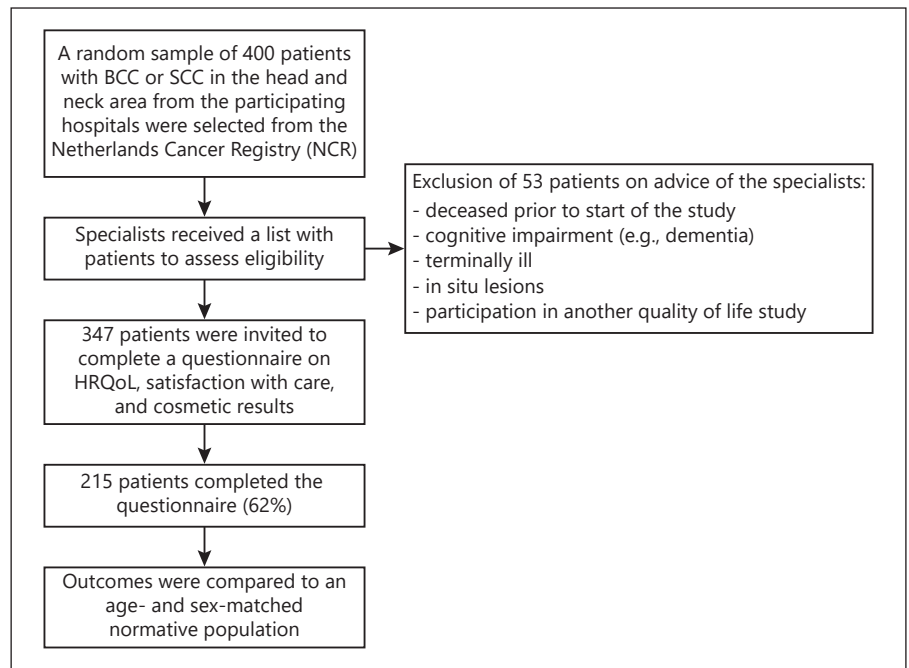
For further details, online supplementary Material (see [www.karger.com/doi/10.1159/000502033](http://www.karger.com/doi/10.1159/000502033)) [14, 23–29] (Fig. 1).

## Results

### *Patient Characteristics*

A total of 215 patients with KC returned a completed questionnaire (62% response). Respondents were younger compared to nonrespondents ( $p < 0.001$ ) and had a more recent diagnosis of KC ( $p = 0.004$ ; Table 1). No differences between responding and nonresponding patients were found according to type of cancer or localization.

The mean age at completion of the questionnaire was 71.3 years, with a mean time since diagnosis of 3.3 years. Most patients were diagnosed with BCC (81%) and almost half of all patients reported they have had more than one skin cancer. Medium educational level was most common (60%). Comorbid conditions were reported by 75% of patients. In the normative population, mean age at questionnaire completion was 69.3 years, with a comorbidity percentage of 70%. In our sample, 49% of patients with KC underwent conventional excision, 26%



**Fig. 1.** Flowchart of Materials and Methods. Data collection process.

**Table 1.** Sociodemographic and clinical characteristics of responding and nonresponding patients with keratinocyte cancer, and an age- and sex-matched normative population

	Respondents ( <i>n</i> = 215)	Nonrespondents ( <i>n</i> = 130)	Normative population ( <i>n</i> = 255)
Gender			
Male	116 (54)	66 (51)	137 (54)
Female	99 (46)	64 (49)	118 (46)
Age at time of survey, years	71.3±11.9	76.6±14.1*	69.3±12.8
<50	14 (7)	6 (5)	16 (6)
50–59	24 (11)	13 (10)	27 (11)
60–69	38 (18)	13 (10)	45 (18)
70–79	89 (41)	31 (24)	105 (41)
80+	50 (23)	67 (52)	62 (24)
Years since diagnosis, years	3.3±1.4	3.7±1.5*	
Educational level <sup>1</sup>			
Low	34 (17)		95 (37)*
Medium	120 (60)		62 (24)*
High	47 (23)		98 (38)*
Partner			
Yes	66 (31)		83 (33)
No	149 (69)		172 (67)
Self-reported comorbidities, <i>n</i>	1.5±1.5		1.4±1.3
Most frequent comorbid condition			
Hypertension	64 (32)		92 (36)
Arthritis	65 (32)		81 (32)

Values are *n* (%) or mean ± SD. \* *p* < 0.05, significantly different from respondents.

<sup>1</sup> Educational level: low, none/primary school; medium, lower general secondary education/vocational training; high, pre-university education/high level vocational training/university.

**Table 2.** Sociodemographic and clinical characteristics of questionnaire respondents who were treated with radiotherapy, conventional excision, or Mohs' micrographic surgery

	Conventional excision (n = 106)	Mohs' micrographic surgery (n = 19)	Radiotherapy (n = 55)	p value
Sex				0.34
Male	54 (51)	8 (42)	33 (60)	
Female	52 (49)	11 (58)	22 (40)	
Age at time of survey, years	68.2±11.9	67.4±13.2	75.9±9.7	
<50	9 (8)	4 (21)	0 (0)	≤0.001
50–59	17 (16)	1 (5)	4 (7)	
60–69	24 (23)	4 (21)	6 (11)	
70–79	39 (37)	6 (32)	28 (51)	
80+	17 (16)	4 (21)	17 (31)	
Education level <sup>1</sup>				0.37
Low	14 (14)	1 (5)	10 (20)	
Medium	59 (60)	11 (58)	32 (63)	
High	26 (26)	7 (37)	9 (18)	
Partner (yes)	77 (73)	17 (89)	36 (65)	0.13
Type of cancer				0.30
BCC	86 (81)	18 (95)	48 (87)	
SCC	15 (14)	1 (5)	7 (12)	
Unknown	5 (5)	0 (0)	0 (0)	
Skin cancer				0.04
One skin cancer	44 (42)	9 (50)	33 (63)	
Multiple skin cancers	60 (58)	9 (50)	19 (37)	
Localization				≤0.001
Forehead	16 (15)	1 (5)	4 (7)	
Scalp	23 (22)	1 (5)	3 (5)	
Nose	26 (25)	6 (32)	33 (60)	
Ear	9 (8)	3 (16)	6 (11)	
Lip	3 (3)	3 (16)	2 (4)	
Other parts of head and neck	29 (28)	5 (26)	7 (13)	
Comorbidities, n	1.2±1.2	1.4±1.7	1.6±1.2	0.22
Most frequent comorbid condition				
Hypertension	21 (21)	8 (42)	20 (41)	0.02
Arthritis	26 (26)	6 (32)	16 (33)	0.67

Values are n (%) or mean ± SD.

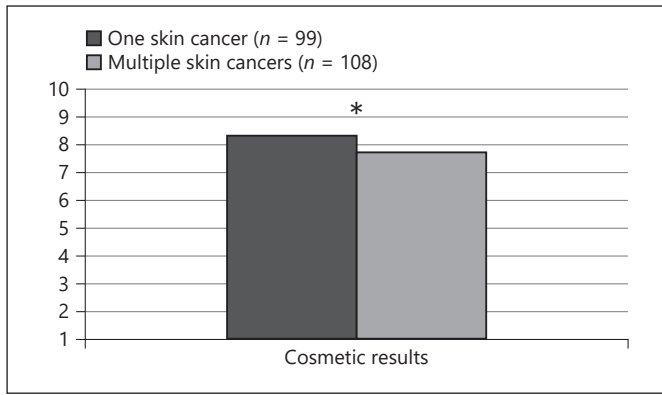
<sup>1</sup> Education level: low, none/primary school; medium, lower general secondary education/vocational training; high, pre-university education/high level vocational training/university.

had radiotherapy, and Mohs' micrographic surgery was received by 9% of patients with KC. The remaining patients received a variety of treatments, such as photodynamic therapy, cryotherapy, or topical chemotherapy. This group, however, was too small to be further outlined. Patients who received radiotherapy were significantly older (75.9 years) than patients with KC who underwent conventional excision or Mohs' micrographic surgery (68.2 and 67.4 years, respectively,  $p < 0.001$ ). In addition, patients who received radiotherapy had more often cancer located on the nose (60%) compared to pa-

tients treated with conventional excision or Mohs' micrographic surgery (25 and 32%, respectively,  $p < 0.001$ ; Table 2).

#### *Comparison between Patients with Multiple Skin Cancers and One Skin Cancer*

Patients with multiple skin cancers were less satisfied with the cosmetic results compared to patients with one skin cancer (8.3 vs. 7.7,  $p < 0.01$ ; Fig. 2) and were more concerned about their appearance (0.18 vs. 0.32,  $p = 0.04$ ). No significant differences were found on HRQoL, as



**Fig. 2.** Differences in cosmetic results between patients who have had one skin cancer ( $n = 99$ ) and patients who have had multiple skin cancers ( $n = 108$ ).  $* p < 0.001$ .

measured with the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) and the Basal and Squamous Cell Carcinoma Quality of Life Questionnaire (BaSQoL), between patients with one or multiple skin cancers (all  $p > 0.05$ ). No differences between patients with infiltrative and noninfiltrative BCC were found in HRQoL scores, general satisfaction with care, and cosmetic results (all  $p > 0.05$ ).

#### *Comparison between Patients with KC and an Age- and Sex-Matched Normative Population*

No statistically significant differences were observed between patients with KC and an age- and sex-matched normative population on physical, emotional, cognitive, social, and role functioning (EORTC QLQ-C30; all  $p > 0.05$ ). However, patients with KC reported statistically significant better scores on global quality of life (79.6 vs. 73.3,  $p < 0.01$ ) and they reported less pain ( $p < 0.01$ ) compared to a normative population (Fig. 3a, b). These represented small clinically important differences. Other symptoms were comparable ( $p > 0.05$ ).

#### *Comparison between Treatment Groups*

No differences in global quality of life, functioning scores (both EORTC QLQ-C30) or BaSQoL mean scores were found among patients treated with conventional excision, Mohs' micrographic surgery, and radiotherapy (all  $p > 0.05$ ; Fig. 4a, b; Table 3).

Patients with KC who underwent radiotherapy were more satisfied with the cosmetic results than patients who underwent conventional excision or Mohs' micrographic surgery (8.5 vs. 7.8 and 7.9, respectively), but this differ-

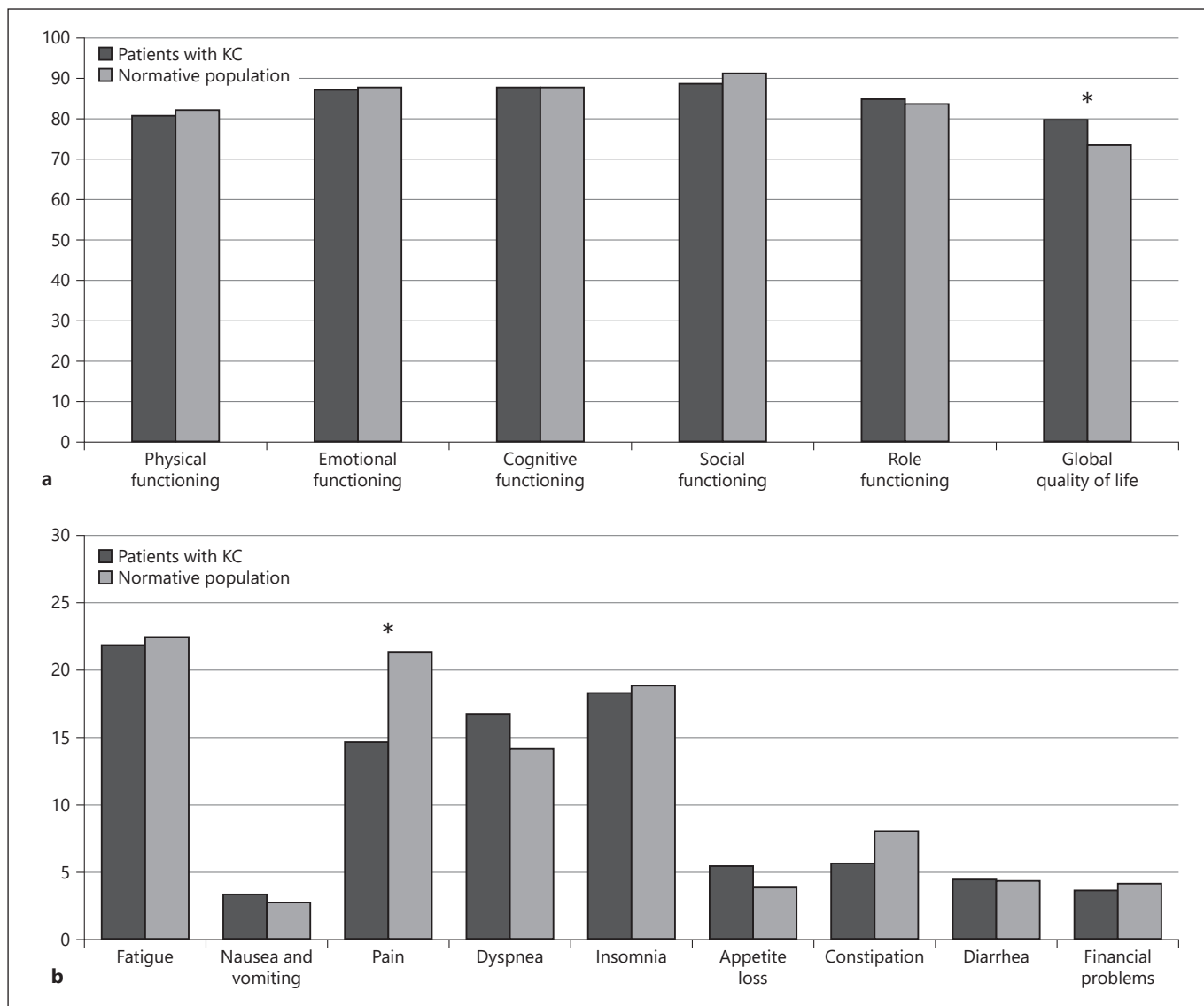
ence was neither statistically significant ( $p = 0.06$ ) nor clinically relevant. Patients who underwent radiotherapy reported better scores for hospital comfort/cleanliness (72.1 vs. 62.9,  $p = 0.03$ ) compared to patients treated with conventional excision. No other statistically significant differences were found between treatment groups. In all treatment groups, approximately half of the patients rated their general satisfaction with care as "very good" or "excellent".

## **Discussion/Conclusion**

In this study, patients with KC reported better global quality of life and less pain compared to an age- and sex-matched normative population. Similar results have previously been observed among patients with other types of cancer [30, 31] and among patients with melanoma [32]. A possible explanation is that patients score better because they adapt to the new situation of having a skin cancer diagnosis, assessing their quality of life better than before the diagnosis, the so-called response shift [33].

Although different treatment options may lead to different HRQoL scores, we found similar scores on functioning and global quality of life among patients with KC who underwent conventional excision, Mohs' micrographic surgery, or radiotherapy. This is in line with research among patients with KC that showed similar HRQoL after excision and Mohs' micrographic surgery [13]. It was expected that patients who underwent radiotherapy might experience their treatment as more severe, as they need to visit the hospital several days in a row for therapy. Irradiation can also result in complaints about "burning" of the skin [34, 35]. We found that patients who underwent radiotherapy were more satisfied with the cosmetic results; however, this was not statistically relevant. The mean time since diagnosis was  $>3$  years, so it might be that complaints about burning of the skin are not relevant anymore after a few years, while scars as a result of conventional excision or Mohs' micrographic surgery might remain more visible, especially when patients have had multiple skin cancers. It is likely that adverse aspects of different treatment options have a greater impact on HRQoL when patients are closer to diagnosis [13]. In this study, we included only patients with KC who were diagnosed at least 1 year before questionnaire completion. More complaints might be expected when patients are closer to treatment.

Patients who had multiple skin cancers reported lower cosmetic results and more concerns about their appear-



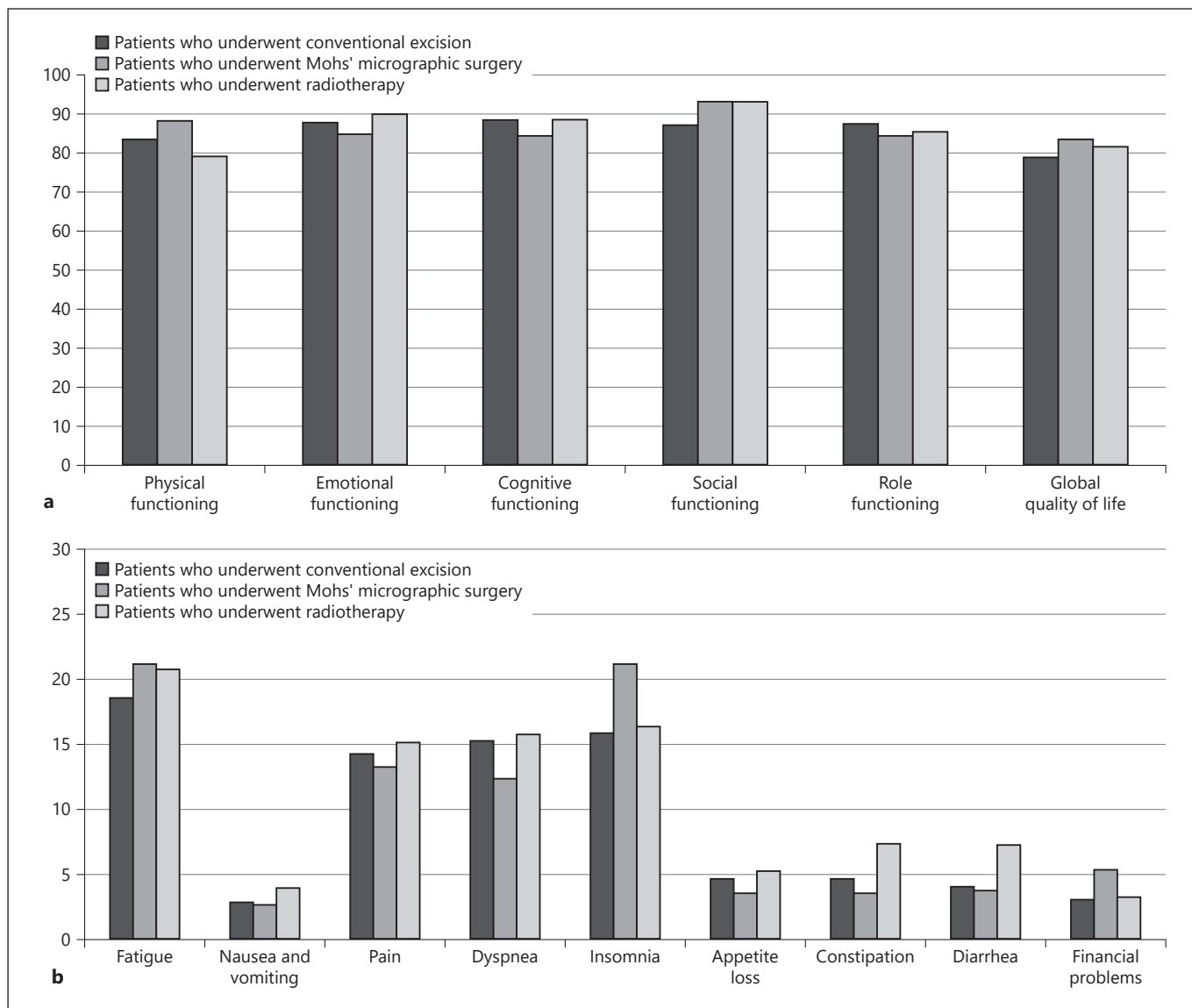
**Fig. 3.** Differences on EORTC QLQ-C30 mean functioning and global quality of life (a) and symptom scores (b) between patients with KC ( $n = 215$ ) and an age- and sex-matched normative population ( $n = 255$ ). \*  $p < 0.05$  and small clinically important difference. Note: a higher score on functioning scores implies a better

health-related quality of life, whereas higher symptom scores refer to more symptoms. EORTC QLQ-C30, European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 30.

ance compared to patients who had only one skin cancer. Previous research showed that potential disfigurement and scarring is a concern for many patients [11, 12, 36], especially multiple scars from multiple skin cancers.

Approximately half of the patients with KC rated their general satisfaction with care as “very good” or “excellent”. High cure rates of both excision and radiotherapy (>90%) might therefore be an explanation for high satisfaction scores [37].

The current study has some limitations, such as the small sample size, which may limit the statistical significance of our findings. The sample size is especially small for patients treated with Mohs’ micrographic surgery. At the time the patients included in this study were treated, the benefits of Mohs’ micrographic surgery in the treatment of BCC and SCC had not yet been sufficiently demonstrated [38, 39]. Therefore, Mohs’ micrographic surgery was not yet a standard of treatment for KC and as a



**Fig. 4.** Differences on EORTC QLQ-C30 mean functioning and global quality of life (a) and symptom scores (b) among patients with KC who underwent conventional excision ( $n = 106$ ), Mohs' micrographic surgery ( $n = 19$ ), or radiotherapy ( $n = 55$ ). Note: a

higher score on functioning scores implies a better health-related quality of life, whereas higher symptom scores refer to more symptoms. EORTC QLQ-C30, European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 30.

result was used less frequently. The availability of Mohs' micrographic surgery in the NCR Eindhoven area has increased since 2014. The study should be replicated with a larger sample of KC patients to get more conclusive results. In addition, we did not have detailed information on radiotherapy schedules of KC. Therefore, we are not aware whether the frequency of radiotherapy appointments has an impact on HRQoL and satisfaction with care. Furthermore, we did not have detailed information on nonresponding patients. Previous research reported

that patients not participating in observational patient-reported outcome research may systematically have lower HRQoL scores compared to participants [40]. Therefore, observed outcomes might represent the healthier patient with better outcomes.

In conclusion, despite the cross-sectional design of this study, this population-based study gives an overview of the HRQoL that patients with KC experience after their disease and treatment. The impact of KC and its treatment seems relatively low and more positive than nega-

**Table 3.** Differences among patients treated with radiotherapy, conventional excision, and Mohs' micrographic surgery on mean BaSQoL and EORTC IN-PATSAT32 scores and cosmetic results, adjusted for age

	Conventional excision (n = 106)	Mohs' micrographic surgery, (n = 19)	Radiotherapy (n = 55)	p value
BaSQoL (0–3) <sup>1</sup>				
Behavior	0.7±0.7	0.5±0.5	0.6±0.7	0.27
Diagnosis and treatment	0.9±0.7	1.0±1.0	1.1±0.7	0.39
Worries	0.7±0.6	0.7±0.7	0.9±0.7	0.44
Appearance	0.3±0.5	0.2±0.5	0.3±0.4	0.19
Other people	0.7±0.7	0.5±0.6	0.6±0.7	0.28
EORTC IN-PATSAT32 (0–100) <sup>2</sup>				
Doctors' technical skills	65.4±19.4	68.9±14.4	66.6±22.0	0.77
Doctors' interpersonal skills	58.2±22.2	67.1±20.1	63.0±22.9	0.19
Doctors' information provision	64.5±21.4	71.9±22.1	69.3±22.0	0.24
Doctors' availability	55.5±24.3	65.3±19.0	59.7±25.2	0.23
Other hospital staff interpersonal skills and information provision	66.9±20.0	64.5±20.9	73.6±22.9	0.12
Exchange of information between caregivers	56.1±21.2	53.9±28.0	58.8±21.7	0.66
Waiting time	61.4±18.2	54.6±25.4	64.9±22.6	0.17
Hospital access	60.5±18.3	64.5±21.4	66.6±23.2	0.20
Hospital comfort/cleanness	62.9±19.2	68.4±18.3	72.1±23.6	<b>0.03</b>
General satisfaction	64.4±19.6	68.1±18.8	68.8±21.6	0.43
Cosmetic results (0–10) <sup>3</sup>	7.9±1.5	7.8±1.5	8.5±1.1	0.06

Values are mean ± SD. Results in bold are statistically significantly different.

<sup>1</sup> A higher score implies more impact of the disease. <sup>2</sup> A higher score implies more satisfaction. <sup>3</sup> A higher score represents more satisfaction with the cosmetic result.

tive as patients reported better HRQoL compared to an age- and sex-matched normative population, probably due to adaptation. No statistically significant differences between treatment types were found concerning HRQoL, patient satisfaction, and cosmetic results. This information could be used by healthcare professionals involved in KC care to improve patients' knowledge about different aspects of the disease as patient's preference is an important factor for treatment choice.

### Key Message

Patients with KC reported better HRQoL than an age- and sex-matched normative population.

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Catharina Hospital, Eindhoven; Elisabeth-TweeSteden Hospital, Tilburg; DermaPark, Uden; and Dr. Bernard Verbeeten Institute, Tilburg.

### Statement of Ethics

Patients gave their written informed consent. The study protocol was approved by a Medical Ethical Research Committee on human research.

### Disclosure Statement

The authors have no conflicts of interest to declare.

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## Author Contributions

L.P.J.A. was responsible for patient recruitment, data collection, data analysis, and drafting the manuscript. R.W.-S. was a major contributor in writing the manuscript and was also responsible for data collection. M.L.M.L. was a major contributor in writing the manuscript, was responsible for data collection, and was involved in the development of the idea. K.-P.R.,

M.R.T.M.T., and L.J.S. were responsible for data collection and revised the manuscript critically for important intellectual content. M.J.A. was involved in the development of the idea and revised the manuscript critically for important intellectual content. S.O. revised the manuscript critically for important intellectual content. M.W.J.L. was a major contributor in writing the manuscript and supervised this study. All authors read and approved the final manuscript.

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