



Satisfaction with Information Provision and Health-related Quality of Life in Basal and Squamous Cell Carcinoma Patients: A Cross-sectional Population-based Study

Rick WAALBOER-SPUIJ¹, Loes M. HOLLESTEIN^{1,2}, Tamar E. C. NIJSTEN¹ and Lonneke V. VAN DE POLL-FRANSE²⁻⁴; on behalf of the BaSQoL Group

¹Department of Dermatology, Erasmus MC University Medical Centre, Postbus 2040, NL-3000 CA, Rotterdam, ²Department of Research, Netherlands Comprehensive Cancer Organization (IKNL), Utrecht, ³CoRPS - Centre of Research on Psychology in Somatic diseases, Department of Medical and Clinical Psychology, Tilburg University, Tilburg, and ⁴Division of Psychosocial Research and Epidemiology, Netherlands Cancer Institute, Amsterdam, the Netherlands. E-mail: r.waalboer@erasmusmc.nl

Accepted May 22, 2019; E-published May 23, 2019

The incidence of keratinocytic carcinomas (KC) (basal cell carcinoma (BCC) and squamous cell carcinoma (SCC)) is high and further increasing. It is important to identify patients with high disease burden (1, 2). The Basal and Squamous Cell Carcinoma Quality of Life (BaSQoL) questionnaire was developed to measure disease specific Health-Related Quality of Life (HRQoL) (3). In other cancer patients it was shown that better information provision is associated with better HRQoL (4). Information provision is an important aspect of supportive care: increasing knowledge about disease and treatment leads to better illness perception, which could lead to a better HRQoL (5). This relation has not been described in KC patients, and may differ from other cancers, due to low mortality and low impact treatment. This study aims to assess the satisfaction with received information and the association with HRQoL in population-based sample of KC patients in the Netherlands. We hypothesized that, patients satisfied with received information report a better HRQoL.

METHODS

A cross-sectional study was performed among 1,173 patients, selected from the Southern region of the population-based Netherlands Cancer Registry (NCR). Data were collected during the validation of the BaSQoL (3, 6). Socio-demographic data were collected and disease specific data were gathered from the NCR. Unfortunately, there were no data on the provided information available.

Satisfaction with the information provision was measured with the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire INFO25 (EORTC QLQ-INFO25) (7). For this study, the 4-point Likert scale of the item 'satisfaction with information provision' was dichotomized into satisfied ('quite a bit' – 'very much') and dissatisfied ('not at all' – 'a little'). Cancer-

specific quality of life was measured by the EORTC QLQ-Core 30 (EORTC QLQ-C30) (8). The disease-specific BaSQoL has 5 subscales (3). Higher scores implicate a higher HRQoL impact. The self-reported comorbidity questionnaire measured comorbidity (9).

Statistical analyses

Mean values were compared with independent sample *t*-tests between patients who were satisfied and dissatisfied with information. Bar charts display the BaSQoL and EORTC QLQ-C30 subscales, stratified by satisfaction with information provision. The association between HRQoL (outcome) and satisfaction with information (covariate) was assessed with multivariable linear regression analysis. Other *a priori* selected covariates included: age, time since diagnosis, sex, education, occupation, partnership, comorbidity, and type of tumour. Multiple imputations ($n=25$) were used to account for the missing data (all covariates and outcomes included). Multiple linear regression assumptions were met.

p-values <0.05 (two-sided) from regression models were considered statistically significant. All other *p*-values were corrected (Benjamini-Hochberg procedure) and considered statistically significant if $p < 0.033$ (two-sided) (10). Analyses were performed in SPSS, Version 21.0 (Armonk, New York: IBM Corporation).

RESULTS

Of the 1,173 patients, 721 (61%) completed the questionnaire. Patient and tumour characteristics are shown in Table S1¹. There was no difference in satisfaction with information in tumour type (BCC vs SCC) or BCC subtype, facial tumour, not having a partner and having more comorbidities (Table S1¹). Thirty-seven percent (84/225) dissatisfied and 7% (28/416) satisfied patients indicated that they had wanted more information about skin cancer in general, causes, treatment, follow-up and how to recognize new lesions. Three percent ($n=24$) wanted less information. The information received was considered helpful in 68% ($n=417$). HRQoL was statistically significantly lower among patients who were dissatisfied with information provision (Fig. 1).

Satisfaction with information provision was associated with behaviour, diagnosis and treatment, worries and appearance BaSQoL subscales with negative beta values (–0.3 to –0.1), indica-

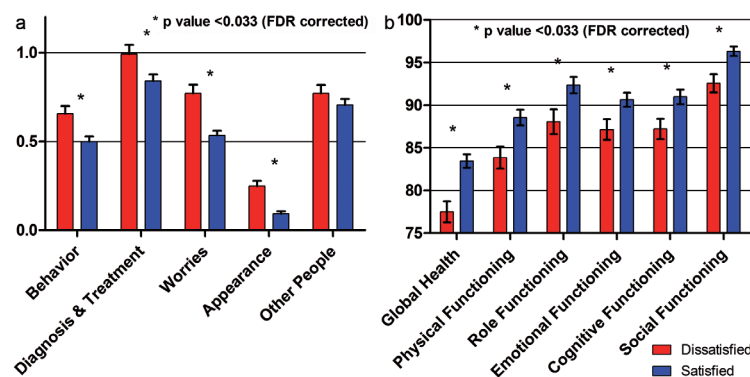


Fig. 1. Mean with standard error. Basal and squamous cell carcinoma quality of life (a) and European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire-C30 subscale scores and satisfaction with information provision (b).

ting satisfied patients had lower BaSQoL subscale scores, thus lower HRQoL impact (Table SIII¹).

Other factors associated with worse HRQoL were younger age (all BaSQoL subscales), less time since diagnosis (diagnosis and treatment, worries and appearance, indicating higher HRQoL impact with more recent diagnosis) and being female (diagnosis & treatment, worries and other people). Facial tumour location was associated with higher HRQoL impact in behaviour, diagnosis and treatment and appearance subscales. SCC led to higher scores than BCC in worries and other people subscales.

DISCUSSION

Patients dissatisfied with information provision had statistically significantly higher impact on 4 of 5 BaSQoL subscales and all EORTC QLQ-C30 subscales. There are two possible explanations. First, patients dissatisfied with provided information may not have sufficient knowledge about disease and treatment and therefore have inadequate illness perception causing more HRQoL impact. Second, patients reporting negative impact of their disease on HRQoL are generally more dissatisfied with care, thus also with information provision. Satisfaction with information and HRQoL were assessed at a single time point, so differentiation is not possible. Worse HRQoL (BaSQoL) was found in younger patients, similar to the findings in another study in cancer patients (11).

In contrast to our hypothesis, impact on appearance subscale was not different between sexes, whilst females experienced larger impact on diagnosis and treatment, worries and other people subscales. To improve HRQoL impact in KC patients, the BaSQoL could be used to identify patients with higher impact and provide supportive care accordingly.

This study also showed that 1/3 of Dutch KC patients was dissatisfied with the received information. Dissatisfied patients showed lower scores on all subscales of the provided information (EORTC INFO-25) compared to the satisfied patients. Comparable results were found in other cancers (5).

Patients dissatisfied with provided information, would like more information. This is desirable, because information provision helps understanding and coping with the disease and treatment choice (4). Factors associated with dissatisfaction with provided information were younger age, facial tumour, not having a partner and more comorbidity. Similar to our study, unmarried status was associated with patients' perception of inadequate information provision. In contrast to our study, lower income and education, female sex, and type of cancer with good prognosis were associated with dissatisfaction with information (12).

Strengths include the use of validated questionnaires and the generalizability. A limitation was the cross-sectional design and therefore inability to determine if dis-

satisfaction with information provision leads to decreased HRQoL or vice versa.

Providing satisfactory information to KC patients should be improved, especially in younger patients, patients with a facial tumour, those without partner and with more comorbidity. Dissatisfaction with provided information is associated with HRQoL impact. Females and younger patients experienced a higher BaSQoL impact. These subgroups require more supportive care, but further research is necessary to identify these patients based on BaSQoL scores.

ACKNOWLEDGEMENTS

Members of the BaSQoL Group: M.J. Aarts, M.T. Bastiaens, O. Husson, B.A. Jagtman, F.H.J. Koedijk, D.I.M. Kuijpers, H.C.J. Liberton, J.M. Mommers, S. Oerlemans, K.P. de Roos, M.W.H. Timmermans, E. de Vries, L.J.M.T. Weppner-Parren.

This study was approved by the ethics committee of the Erasmus MC (Reference MEC-2013-420). This study was financially supported by Roche, Leo Pharma and Galderma.

The authors have no conflict of interest to declare.

REFERENCES

1. Flohil SC, de Vries E, Neumann HA, Coebergh JW, Nijsten T. Incidence, prevalence and future trends of primary basal cell carcinoma in the Netherlands. *Acta Derm Venereol* 2011; 91: 24–30.
2. Hollestein LM, de Vries E, Nijsten T. Trends of cutaneous squamous cell carcinoma in the Netherlands: increased incidence rates, but stable relative survival and mortality 1989–2008. *Eur J Cancer* 2012; 48: 2046–2053.
3. Waalboer-Spuij R, Hollestein LM, Timman R, van de Poll-Franse LV, Nijsten TE. Development and validation of the Basal and Squamous Cell Carcinoma Quality of Life (BaSQoL) Questionnaire. *Acta Derm Venereol* 2018; 98: 234–239.
4. Husson O, Mols F, van de Poll-Franse LV. The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: a systematic review. *Ann Oncol* 2011; 22: 761–772.
5. Husson O, Thong MS, Mols F, Oerlemans S, Kaptein AA, van de Poll-Franse LV. Illness perceptions in cancer survivors: what is the role of information provision? *Psychooncol* 2013; 22: 490–498.
6. van de Poll-Franse LV, Horevoorts N, van Eenbergen M, Denollet J, Roukema JA, Aaronson NK, et al. The Patient Reported Outcomes Following Initial treatment and Long term Evaluation of Survivorship registry: scope, rationale and design of an infrastructure for the study of physical and psychosocial outcomes in cancer survivorship cohorts. *Eur J Cancer* 2011; 47: 2188–2194.
7. Arraras JJ, Greimel E, Sezer O, Chie WC, Bergenmar M, Costantini A, et al. An international validation study of the EORTC QLQ-INFO25 questionnaire: an instrument to assess the information given to cancer patients. *Eur J Cancer* 2010; 46: 2726–2738.
8. Aaronson NK, Ahmedzai S, Bergman B, et al. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *J Natl Cancer Inst* 1993; 85: 365–376.
9. Sangha O, Stucki G, Liang MH, Fossel AH, Katz JN. The Self-Administered Comorbidity Questionnaire: a new method to assess comorbidity for clinical and health services research. *Arthritis Rheum* 2003; 49: 156–163.
10. Glickman ME, Rao SR, Schultz MR. False discovery rate control is a recommended alternative to Bonferroni-type adjustments in health studies. *J Clin Epidemiol* 2014; 67: 850–857.
11. Quinten C, Coens C, Ghislain I, et al. The effects of age on health-related quality of life in cancer populations: A pooled analysis of randomized controlled trials using the European Organisation for Research and Treatment of Cancer (EORTC) QLQ-C30 involving 6024 cancer patients. *Eur J Cancer* 2015; 51: 2808–2819.
12. Sim JA, Shin JS, Park SM, Chang YJ, Shin A, Noh DY, et al. Association between information provision and decisional conflict in cancer patients. *Ann Oncol* 2015; 26: 1974–1980.

¹<https://www.medicaljournals.se/acta/content/abstract/10.2340/00015555-3226>