

Discussion

The aims of this thesis were to develop and validate a disease-specific health-related quality of life (HRQoL) questionnaire and assess HRQoL and patient perception on disease, treatment and provided information in keratinocyte carcinoma (KC) patients. This final chapter reflects on the main findings and limitations, and concludes with a discussion on future perspectives.

Health

In order to discuss HRQoL, it is important to discuss the definition of health. The definition used until 2011 was formulated by the World Health Organization (WHO) in 1948 and describes health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”[1] This definition has been criticized but was never adapted. In 2011, Hubert et al proposed a new definition; “health is the ability to adapt and self-manage”, which has been accepted since.[2]

(Health-Related) Quality of life

Since the introduction of ‘quality of life’ in medicine, it is being used increasingly as an outcome of care in studies. Unfortunately, there is no consensus on a definition for ‘quality of life’ and it may appear as health status, physical functioning, perceived health status, subjective health, health perceptions, symptoms, need satisfaction, individual cognition, functional disability, psychiatric disturbance, well-being and -quite often- several of these at the same time. In order to clarify these issues, the term ‘health-related quality of life’ was defined as the value of a life affected by illness and disease. It is a multidomain concept representing the general perception of the effect of illness and treatment on physical, psychological, and social aspects of life. [3]

It has been stated that in reality it is impossible to separate effects due to health and other effects which are a consequence of changing patterns such as finance, friendship, occupation and ageing.[4-6] It does however add value to the patient’s perspective and the clinicians perspective in the evaluation of treatment outcomes. And aiming for the best possible physical and emotional state compatible with the medical condition has the best chance of achieving a high quality of life.[7] The European Organization for Research and Treatment of Cancer (EORTC) Quality Of Life Group uses the following definition: HRQoL covers the subjective perceptions of the positive and negative aspects of cancer patients’ symptoms, including physical, emotional, social, and cognitive functions and, importantly, disease symptoms and side effects of treatment. [8] When incorporating HRQoL measurement into clinical practice, it is recommended to evaluate the usefulness of the questionnaires as experienced by the patient. [9] An example of HRQoL use in clinical practice is in patients with chronic idiopathic urticaria. The guideline of the Dutch Society of Dermatology recommends that measurement with a disease specific and a dermatol-

ogy specific HRQoL instrument, and a specific minimal score, is necessary before starting omalizumab treatment. [10]

In oncology, the aforementioned EORTC Quality Of Life Group started to develop the EORTC quality of life core questionnaire (QLQ-C30) in 1986. The main goal was to develop an instrument suitable for standardized HRQoL measurement in international clinical trials in oncology. [11] In the following decades, the majority of clinical trials in oncology reported HRQoL assessment, especially in systemic treatments for metastasized cancer with or without radiotherapy since there are substantial disease and treatment effects on the short and long term. The tendency to investigate HRQoL in cancer therefore was mainly in metastasized cancer. Non-metastasized cancer and KC were only studied sparsely during this period.

In dermato-oncology, specifically in KC patients, the first sparse attention for HRQoL was in the late 90's, suggesting little to no HRQoL impact in BCC patients, measured with generic and dermatology specific HRQoL questionnaires. [12] This is most likely due to the often straightforward surgical treatment and lack of severe and lasting side effects of treatments. Measuring HRQoL with both a generic and a specific HRQoL instrument is preferable over only using a generic HRQoL instrument to assess impact and responsiveness.[13] Unfortunately, existing HRQoL questionnaires for KC were not suitable for use, because of methodological flaws, such as the use of multiple issues and questions combined in one item. They also failed to capture one of the most reported issues in skin cancer patients; the often required behavioral changes (and related psychological issues) to reduce sun exposure.[14] A previous study by Holterhues et al. showed that Dutch melanoma survivors reported a better quality of life than the general population, but nevertheless, reported substantial impact on 'melanoma specific' items suggesting that their diagnosis did affect their quality of life.[15] In this thesis we identified the HRQoL issues in KC patients (chapter 3) and tested the impact of these issues in population based samples (chapter 5 and 6). The identified issues have some overlap with issues in existing HRQoL questionnaires used in skin cancer patients, such as concerns about appearance and scarring, sun behavior and fear of cancer recurrence or spreading.[16-18] The BaSQoL questionnaire however also captures treatment and diagnosis related issues and issues related to long-term behavioral changes.

Another unique feature of the BaSQoL questionnaire is the use of different time-frames within the questionnaire. This was created since patients mentioned a distinct difference in behavior before and after the initial skin cancer diagnosis. The first part of the BaSQoL captures the impact of these changes. The second part of the questionnaire assesses the usually short period between diagnosis and treatment. This is a known stressful period for

patients with cancer with a high impact on the HRQoL and measurement helps to assess the patient's experience of this period. Patients with high HRQoL impact may benefit from additional care, especially in case of first tumours. The final part of the BaSQoL is more classic in the way that it concerns the HRQoL impact of the skin cancer in the past week. By using this three time periods concept, the questionnaire addresses the several issues in the right context. The downside to this is that it requires more thought and therefore may be more difficult to complete.

The validation of the English version of the BaSQoL and the simultaneous assessment of the construct validity by comparison with the Skin Cancer Index, test-retest stability and responsiveness to change completed the validation of the newly created questionnaire (chapter 4).

The measurement of the HRQoL impact in KC patients in chapter 5 and 6 showed a higher impact in younger patients and patients who were dissatisfied with provided information about the disease. Female patients had higher impact in some of the subscales, but surprisingly not on the appearance subscale. In comparison to an age- and sex-matched normative population, patients with KC reported statistically significant better scores on global quality of life as measured by the EORTC QLQ-C30 questionnaire. This is also seen in melanoma and may be explained by the so-called response shift; adaptation to the new situation of having a skin cancer diagnosis and better assessment of their QoL than before diagnosis.[19, 20] Patients with BCC even have a lower all-cause mortality in comparison to the general population. [21]

When comparing BaSQoL scores of patients who have had different treatments for their KC (conventional excision, Mohs' micrographic surgery or radiotherapy), no differences were found. In general, the impact of KC and its treatment seems relatively low in different treatment groups. These findings are similar to the findings of Chren et al. in 2007, comparing conventional excision, Mohs' micrographic surgery and electrodesiccation and curettage. [22]

The use of the BaSQoL in KC still needs further investigation. Especially to determine the optimal timing of questionnaire administration and clinical implications of scores. The BaSQoL seems to be a useful tool to assess the impact of KC diagnosis in order to identify these patients at risk for major HRQoL impact.

A problem in the current way of measuring HRQoL in oncology is the extensive and lengthy course of the development of a questionnaire. The development of the BaSQoL, from phase 1 to the final acceptance of the manuscript took 5 years (Figure 1), similar to many

other HRQoL questionnaire developments in oncology. Especially in questionnaires for cancer addressing symptoms due to systemic therapy, by the time the questionnaire is ready for use, it is already outdated due to the rapid development and implementation of new cancer therapies. [23, 24] Another approach in this field, to monitor symptoms during systemic cancer treatment, is the Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE). It is a questionnaire which is customizable for use in cancer trials, measuring symptomatic adverse events. The specific items which are needed for a study can be selected from the item bank (which is a database of previously studied and validated items).[25] In this way, a new questionnaire can be assembled rather quickly, fitted for the new therapy, without the time consuming process of developing a completely new questionnaire. Fortunately, symptoms are not much of an issue in KC or KC treatment options and are thus not included in the BaSQoL.

Patient Reported Outcomes

Patient Reported Outcomes (PROs) are outcomes about a disease, health or treatment directly from patients without interpretation. It includes HRQoL, but also other outcomes such as severity and frequency of symptoms, treatment satisfaction, functional status and well-being but in general, it reflects how patients feel.[26] It includes for example symptom checklists such as pain and itch, which are also being used in chronic idiopathic urticaria [10]. By collecting PRO's, the caregivers are able to understand the impact of disease and treatment better and therefore able to intervene and thus optimize how patients feel. [27] In cancer, PRO monitoring has shown improvements in patient-care-provider communication. [28] It also helps to identify issues patients might not have raised and that clinicians would therefore assume were not of concern, on which tailored care can be provided. In oncology, the web-based self-management application "Oncokompas" is being integrated in routine cancer-care, monitoring health-related quality of life and support cancer survivors in finding and obtaining optimal supportive care. [29] It assesses a wide range of outcomes, covering the following domains: physical, psychological, social, healthy lifestyle and existential issues. Completing PROs might also make patients feel cared for, and therefore improving emotional functioning.[30] It was shown, that improved physician-patient communication resulted in better HRQoL and emotional functioning for a proportion of patients. [31] In research it can be used to identify the benefits and harms of treatments and interventions.[32] This all will improve outcomes and also patient-centeredness, as is demonstrated in a study using the PRO-CTCAE, even improving survival when using web-based symptom monitoring versus routine surveillance following treatment for lung cancer. [33]

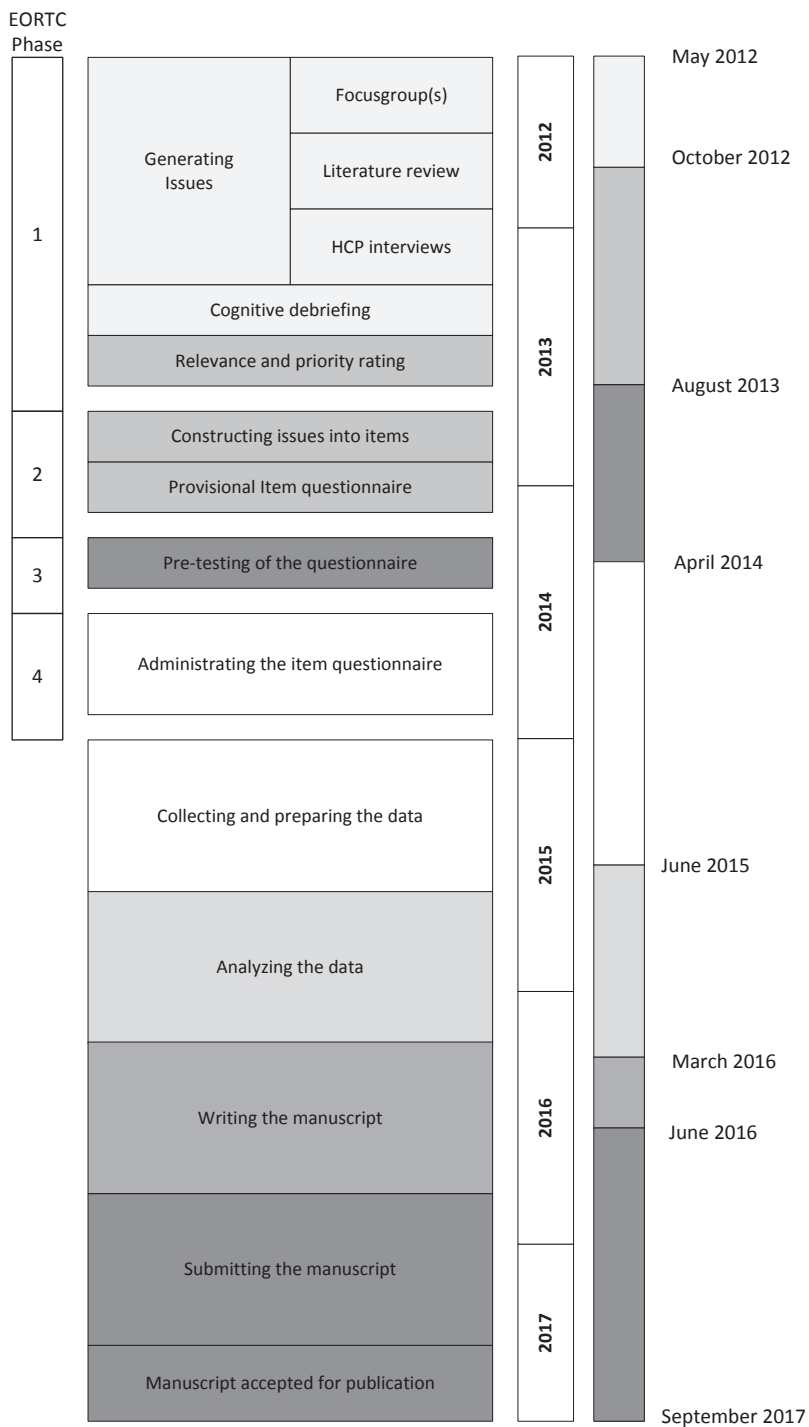


Figure 1. Timeline of the development of the BaSQoL questionnaire.

By routinely monitoring PROs, care can be tailored to match the patients' needs. [26, 28, 34] By providing feedback about the PRO, patients have their own responsibility to discuss issues with their treating physician or their general practitioner.

Another use for PRO is to monitor the patient post-treatment. The time between the (surgical) treatment and the first follow-up visit may be used to proactively address and manage symptoms and following problems (e.g. complications, urgent care evaluations). [35]

Patient centered care

The National Academy of Medicine (formerly known as Institute of Medicine) formulated six dimensions of patient-centered care, which stated that care must be: 1) respectful to patients' values, preferences, and expressed needs; 2) coordinated and integrated; 3) provide information, communication, and education; 4) ensure physical comfort; 5) provide emotional support – relieving fear and anxiety; and 6) involve family and friends.[36, 37] To measure these dimensions the use of PROs is needed. HRQoL measurement can help to identify needs and preferences, assess satisfaction on information and help to optimize physical and emotional needs. A recent qualitative study in BCC and SCC patients showed the wish for investing in the patient–physician relationship and personalizing the type and form of information and the follow-up schedules.[38] The BaSQoL can help to identify if there are any issues bothering the individual patient. The behavior subscale for example helps to evaluate if the patient can fit the often required behavioral changes after the first skin cancer diagnosis into his/her daily life whilst not interfering with patients' values and preferences. The worries and also the diagnosis & treatment subscales address fear and anxiety. On the other hand is the BaSQoL useful for assessment on group level and these results may be used to compare individual scores to group scores.

Specifically in cancer care, a more holistic approach to the patient is desirable, also assessing supportive care, encompassing clinical, ethical/existential and spiritual dimensions. [39] To measure the needs of supportive care, questionnaires exist. [40, 41] Existing HRQoL questionnaires may even be used to identify a change in patients' supportive care needs.[42] The BaSQoL may also be used for this purpose since it is specific enough to identify the patients with high impact of the diagnosis and treatment. In daily practice, we notice that additional (supportive) care is helpful in managing anxiety in patients. Detailed and personalized information provided by the doctor or the nurse helps to cope with the disease and manage it in daily life. Further research should assess how to use and interpret the BaSQoL for this purpose.

Another way to center the patient in the care process is to empower them to own their PRO results. A current study in lymphoma patients evaluates the impact of providing patients PRO with feedback. [43] Results of a pilot study suggest that a high number of patients wished to receive PRO feedback and that they would find the comparison of their scores versus a disease specific reference cohort most valuable. [44] This current ongoing study will provide information about the usefulness of providing feedback to the patient on PRO. Whatever the outcomes of this study will be, providing individual PRO results to the patient can help to address the deviant outcomes or subscales with their treating physician. But with empowerment also comes responsibility for the patient creating a bilateral perspective on the concept of 'shared decision making'.

Strengths and limitations of the studies in this thesis

The impact of KC on HRQoL seems to be limited in most patients, but the smaller proportion of patients on which KC has a larger impact on HRQoL need to be identified in order to provide additional care. Since the total number of KC patients is high, even a small proportion of patients with high HRQoL impact means that a high absolute number of patients might suffer.

The development of the BaSQoL questionnaire has been thorough in all aspects of the development in comparison to other skin cancer specific HRQoL questionnaires. The development phase was designed and executed mostly following EORTC questionnaire development guidelines. The patient sample was population-based with a generous sample size and the analyses were not only the state of the art Item Response Theory analyses, but also included conventional classical test theory principles. The population based approach which we used in chapter 3, 5 and 6 helps to study a large group of patients over several hospitals and clinics. However, information about treatment was also based on patients' self-report and therefore may be less accurate.

Interpretation of the BaSQoL subscale scores may be time-consuming in daily clinical practice since it concerns several subscales and a minimal clinically important difference or any other cut-off scores to help interpret the scores do not yet exist.

Development was done in one country and cross cultural difference may exist, but in the validation study of the English version of the BaSQoL in chapter 4 no indications for this were found.

The questionnaire is developed as an instrument to assess the impact of KC on patients' lives and not so much to evaluate the effect of (different) treatments.

A major limitation in the study described in chapter 3, the development and validation of the BaSQoL questionnaire, was that we did not compare the newly developed questionnaire to an existing one. In order to overcome this issue, we compared the BaSQoL to the Skin Cancer Index in the additional validation study of the English version of the BaSQoL in chapter 4.

Future perspective

The BaSQoL may be used in two different contexts. First it may be used on a group level, in a population based setting or a larger group of patients, for example in a hospital or clinic, to evaluate the impact of disease and care in general. It helps to assess which problems arise in KC patients, to help the physician address these items in outpatient consultations or to provide care and more extensive explanation by dermatology nurses. Furthermore, it can be used to measure before and after changes in care plans to assess the impact on group level (e.g. before and after reducing follow-up regimens for low risk KC patients or before and after implementation of new treatments). Variation between hospitals can also be assessed to identify and evaluate differences in order to improve care and learn from each other.

Second, the BaSQoL may be used on an individual patient level to assess the impact of the disease, diagnosis and the treatment. Although it was not developed for this purpose, it makes sense to use it as such. This has happened in the past with the EORTC QLQ-C30 questionnaire and which has been commented on frequently. Determination of minimal clinically important differences or cut-off scores would help to guide the clinician in which patient is at risk for high impact and therefore requires additional attention and care. Also the way the scores are presented back to the patient or the physician may lead to easier interpretation; further research is necessary to optimize this aspect. Using the BaSQoL as an instrument to assess the level of distress in patients, identifying distressed patients and providing supportive care may also help to reduce healthcare costs overall, as it has been shown that distressed patients use more healthcare services in comparison to non-distressed patients or a normative population. [45] Additional studies are needed to identify patients who may need psychological care and to assess if psychosocial interventions could reduce the frequency of medical contacts.

The data generated with studies from the first group (group-level data) can help to monitor the patient's PROs (individual-level data) and to compare individual-level data with mean group level outcomes. Knowledge about the patients individual PRO may even help in decision making in choosing the best suitable treatment. For example, a patient with a superficial BCC with high impact on the worries subscale might be better off treated with surgical excision with histopathological examination of the specimen instead of topical

treatment with 5-fluorouracil cream or imiquimod cream without the histopathological confirmation of the excision.

One of the greatest challenges is how to integrate routinely measurement of HRQoL instruments such as the BaSQoL in daily practice. The BaSQoL is short and therefore quick and easy to complete for patients, but calculation and interpretation of the scores is still time consuming. Creation of a web-based form can help to display the scores immediate. How this data is displayed to optimize interpretability is also an important aspect to consider. Mean scores for example can be presented next to the individual score. It can be displayed as a number, but also in a graph such as a bar chart, pie chart or a line chart. Deviant scores can be displayed in a different color to simplify interpretation. One study demonstrated that the best way to display individual PRO scores is to use a line chart with high scores meaning better HRQoL and a threshold line within the chart to identify the scores below which are possibly concerning. [46]

It also has to be assessed what the optimal moment in time is for questionnaire administration (e.g. 1 month after treatment, 3 months after treatment). The clinical meaning or interpretation of the subscale scores is another area of attention for future research. It can be assessed on an individual patient level using anchor-based methodology, which examines the relationship between scores on an HRQoL instrument and an independent measure (anchor), or on a population level by statistical analysis appointing a score of 1 or 2 SD above the mean as deviant. [47]

The use of modern technology such as questionnaire administration through apps and automated feedback to the patient and his/her electronic medical file about the PRO outcomes with practical advice when to act, what to do and whom to discuss the results with may help to empower patients and to use the questionnaire in daily practice. This is also stated in the directives agreement ('hoofdlijnen akkoord') on speciality care 2019-2022 as stated by the current Dutch government. [48]

Conclusion

The perception of KC patients on their disease and treatment and the related HRQoL impact is captured in the newly developed BaSQoL questionnaire. This thesis presents studies on the development and validation of this questionnaire and factors influencing the HRQoL in KC patients. More research is needed to optimize the use and interpretation of the BaSQoL questionnaire in order to confirm and sustain the KC patient empowerment.

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