Evaluation of Skin Cancer Care

Integrating different perspectives

Sven van Egmond

Lay-out and printing by Optima Grafische Communicatie

Evaluation of Skin Cancer Care

Integrating different perspectives

Evaluatie van huidkankerzorg

Verschillende perspectieven geïntegreerd

Proefschrift

ter verkrijging van de graad van doctor aan de
Erasmus Universiteit Rotterdam
op gezag van de rector magnificus
Prof. dr. F.A. van der Duijn Schouten
en volgens besluit van het College voor Promoties.

De openbare verdediging zal plaatsvinden op
dinsdag 23 maart 2021 om 10.30 uur.

door

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geboren te Leiderdorp

Erasmus University Rotterdam

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Chapter 1

General introduction

Parts of the introduction are based on:
M. Wakkee, S. van Egmond, M. Louwman et al. Opportunities for improving keratinocyte cancer care in primary and specialist care: a Dutch cohort study. *Eur. J. Cancer 117 (2019) 32-40*

EPIDEMIOLOGY OF SKIN CANCER

Skin cancer is the most common type of cancer worldwide among Caucasians and its incidence is still rising.[1-3] The two most common subtypes of skin cancer are basal cell carcinoma (BCC) and squamous cell carcinoma (SCC), both commonly referred to as keratinocyte carcinoma (KC).[2] KC is usually not deadly, however, they could cause considerable functional and cosmetic morbidity as KC is typically found on sun-exposed areas such as the face.[1,4] In 2017, over 48,000 Dutch inhabitants received the diagnosis BCC and over 12,000 were diagnosed with SCC.[5] Melanoma is the third most common subtype of skin cancer with an incidence of nearly 6,200 in that same year.[6] Additionally, these high incidence numbers only include the first diagnosed tumour per type of skin cancer. Considering that more than one-third of KC patients develops at least one subsequent KC,[7] it is no surprise that the economic burden of KC is substantial.[8-11]

IMPACT OF SKIN CANCER ON THE (DUTCH) HEALTHCARE SYSTEM

A national skin cancer expenditure analysis in the US showed that in 2013 $2.5 billion was spent on skin cancer-related diagnoses in Medicare patients alone (i.e. $7,60 per capita). Half of this spending was attributed to KC.[9] KC ranked as 5th most expensive cancer to treat among Medicare patients,[9] among the highest per head in Australia[8] and among the five most costly cancers in the Netherlands.[11] As KC puts pressure on healthcare systems, it is advocated to evaluate current KC care to identify opportunities to improve efficiency of care.

In 2013 the Dutch National Health Care Institute launched a project called 'appropriate care'.[12] The rationale of this project is that every citizen must be able to count on receiving good health care. No more and no less than necessary, while also avoiding unnecessary costs. Therefore, healthcare was assessed systematically to evaluate whether diagnostics and (therapeutic) interventions are being deployed in a patient-oriented, effective and cost-effective manner. Due to the before mentioned high economic burden, skin cancer care was also evaluated as part of this project.

In order to interpret the results of this evaluation, one should first understand the Dutch healthcare system. Since 2005, all hospital visits and admissions are categorised in diagnosis-related groups (DRGs).[13] Each DRG includes all hospital activities and services associated with a patient's care. Regarding the enlistment of medical specialists, currently about half are employed (i.e. on salary) and the other half are paid per DRG (i.e. fee-for-service).[14]

Dutch inhabitants however do not have direct access to a medical specialist. They need a referral from a general practitioner (GP). This so-called 'gatekeeper' function is also the case in other countries such as the UK and Australia.[15-17] The two main arguments for having a healthcare system with a gatekeeper are that it reduces costs and that care is being provided more efficiently.[18] However, the evidence regarding the effect of a gatekeeper system on healthcare and patients remains ambiguous and is complicated by the heterogeneity of systems and studies.[19]

EVALUATING KERATINOCYTE CANCER CARE IN PRIMARY CARE

To identify areas of improvement in KC care, daily practices of both GPs and dermatologists were invesigated.[20] The Integrated Primary Care Information database allowed us to study the GPs' policy with respect to care of patients with (suspected) KCs.[21] A random selection was made of 1597 patients suspicious for- or confirmed KC in primary care. All patients were diagnosed between 2009 and 2013 and followed up until 2016. Details on diagnosis, treatment and care during follow-up were described.

GPs' skin cancer policy

GPs reported a skin malignancy in their initial differential diagnosis in approximately half of all confirmed KC cases. The specific diagnosis was correctly predicted for half of all BCCs, but only in 15% of all SCCs. This may also explain the relatively high proportion of direct excisions by the GP without prior biopsy of SCCs (27%) compared to BCCs (10%). Furthermore, the relatively fast, often exophytic growth of SCCs may also urge a GP to take more immediate action compared to BCCs.

Ideally, the role of the GP as gatekeepers in the management of suspicious skin lesions is to control the referral rate and treat low-risk tumours, such as low-risk BCC. The newly introduced (June 2017) clinical guidelines for GPs regarding suspicious cutaneous lesions are based on this principle.[22] Thus, during the investigated period, GPs could not rely on guidelines. If the GP suspected KC, the majority of patients were referred to a dermatologist. However, one-third of suspected KC lesions were skin malignancies, leading to unnecessary referrals.

Overall, GPs treated almost a third of all suspected KC lesions, but one-third of those treatments were not primarily directed at KC (e.g. antibacterial and/or antimycotic ointments). This observation does not necessarily suggest 'mistreatment' but that GPs first pragmatically treated the most likely diagnosis and kept an open mind that the skin lesion might be malignant. The new Dutch primary care and the UK guidelines recommend to directly refer when having a strong suspicion of high-risk KC (including all SCCs) and to take a biopsy from other suspected KC.[15,16] If the guideline is implemented successfully, the increased use of histology will improve appropriate care. In addition, clear agreements on referral indications will decrease the surgical treatments in primary care.

Keratinocyte cancer follow-up in primary care

Variable patterns of follow-up visits in primary care for suspicious cutaneous (pre) malignancies suggest that patients initiate GP visits. A single visit to evaluate treatment and provide instructions for self-examination should be sufficient. UK guidelines on KC also recommend self-examination or follow-up in primary care for primary adequately treated BCCs.[16]

EVALUATING KERATINOCYTE CANCER CARE IN SECONDARY CARE

To identify areas of improvement in secondary KC care, the Netherlands Cancer Registry was used.[20,23] A random selection was made of 1,569 histologically confirmed KC patients in secondary care. All patients were diagnosed between 2009 and 2013 and followed up was included until 2016. Details on diagnosis, treatment and care during follow-up were described. For medical specialists, clinical guidelines for BCC and SCC were implemented in 2002 and 2012 respectively.[24,25]

Dermatologists' skin cancer policy

For BCC, a biopsy is recommended because histological growth patterns guide treatment decisions, unless it concerns low-risk or multiple BCCs. These guidelines seem to be followed (i.e. no excisions of high risk-BCCs without biopsy) because the biopsy rate among BCC (59-66%) was much higher than the proportion of high-risk BCC (17-36%).

The histological clearance rate of excisions was higher for BCC (97%) compared to SCC (95%) and similar to other studies.[26-28] The discrepancy between BCC and SCC might be explained by suboptimal clinical preoperative margins for SCC, less guidelines adherence concerning excision margins, more diagnostic excisions for SCC that are not followed by curative excisions and/or limited use of micrographic Mohs' micrographic surgery for SCC compared to BCC.

Keratinocyte cancer follow-up in secondary care

Comparable to a preliminary study, 83% of patients with BCC received more follow-up than recommended.[20,29] In surprising contrast to BCC, patients with SCC received less follow-up than recommended. Although more than 80% of patients with SCC have stage I tumours of which only a very small fraction will develop metastasis.[30] The Dutch and European guidelines recommend five years of follow-up for all patients with SCC.[31,32] The UK guidelines are less stringent and recommend to discharge low-risk patients with SCC after a single postoperative visit, where instructions for self-examination and prevention are provided.

Low-risk BCC follow-up visits in hospital care is considered to be of low-value, as the current Dutch BCC guideline states to only monitor high-risk patients (e.g. patients with long-term immunosuppressants) or patients with a high-risk BCC.[33] There is no evidence that earlier detection leads to improved health outcomes, while evidence exists that significant delay to treatment (up to 12 months) is not relevant to the outcome of the intended operation due to the slow growth rate.[34] This low-value follow-up care seems a feasible option to de-adopt (i.e. the process of reducing or removing low-value clinical practices).[35]

REDUCING THE BURDEN OF KERATINOCYTE CANCER ON THE HEALTHCARE SYSTEM

Substitution of care to primary care is often mentioned as a suggestion to reduce the burden of KC on the healthcare system. However, substitution is not only suggested for dermatology, but also for many other diseases like cardiovascular diseases, diabetes mellitus and psychological disorders, which will substantially affect the workload of a GP.[36] In addition to feasibility with respect to the workload for GPs, the question remains whether quality of care is preserved. Without proper training, clinical guidelines are insufficient to preserve patient care.[37] Although skin-related complaints and referrals to dermatologists are high in primary care,[38-40] it is worrisome that dermatology is not required at both the undergraduate and postgraduate training programs of GPs in the Netherlands and many other European countries.[39,41,42] While in Australia, GPs play a larger role in skin cancer management after receiving extra training and accreditation. In the UK, services for the management of low-risk BCCs can be commissioned from accredited GPs with specialist dermatology training who participate in a regular histological accuracy audit.[43] GPs can play a pivotal role in the early detection, diagnosis and management of many skin cancers considering they have had sufficient formal training, time and resources available.[44]

In 2016 the SKINCATCH (i.e. SKIN Cancer And Tumour Health Care) trial was initiated to assess whether low-risk BCC treatments could be substituted to primary care without loss of quality.[45] GPs participating in this trial received a 2-day training in skin cancer management including skin cancer surgery. Unfortunately, the inclusion and excision rate of participating GPs was low. Some of the barriers reported by participating GPs were trial related, such as administrative challenges and patient recruitment issues. However, they also indicated other barriers, such as high workload, low volume of low-risk BCC patients and patients requesting a referral. Important vectors that are also applicable outside this trial setting. The trial demonstrated that substitution of low-risk BCC treatments was still a bridge too far, which means that it is necessary to explore other solutions to keep our healthcare systems sustainable for skin cancer.

Other initiatives focussing on GPs have been attempted to reduce the skin cancer burden, such as dermatologists working in GP clinics to reduce referrals and to educate GPs. However, this did not make it into national practice, mostly due to problems with the current financial structure of the healthcare system.[46] This financial system is also a barrier for teledermatology to be successful.[47] Artificial intelligence in the form of mobile applications (mHealth) with skin cancer recognition software may be used as a tool for GPs to increase their diagnostic accuracy and reduce the number of improper referrals to secondary care.[48] However, currently, the technology is not advanced enough, and the current landscape is still too divided for successful implementation.[49]

De-adoption of low-value follow-up visits in secondary care

Initiatives focussing on primary care seem unfeasible at the moment, so opportunities to reduce the skin cancer burden in secondary care were reviewed. The evaluation of daily practice of dermatologists revealed that low-risk BCC patients received more follow-up than recommended in the current guidelines, which is considered a low-value service. The high volume of BCC makes this a suitable option for de-adoption.

De-adoption of low-value care is a fairly new concept, with little research conducted on this subject compared to implementation of care. Some may think that de-adoption is the reverse process of implementation. However, the processes of implementation and de-adoption are likely to be different and work in different ways. Traditional implementation methods based on increasing awareness and knowledge are unlikely to be effective for de-adoption.[50]

Multifaceted strategies are required to address the three levels of barriers, which are barriers related to patients, physicians and the system.[51] There are additional barriers on all three of these levels, which include (among others) anxiety of no longer receiving an intervention among patients, fear of medical malpractice among physicians and economic and political factors such as cost-benefit considerations among organisations.[52,53] Researchers often fail to include all relevant stakeholders as partners in the design, testing, and dissemination of interventions.[54]

Apart from the stakeholders' factors, other factors of de-adoption differ from implementation as well. Such as the types of action (i.e. remove, replace, reduce or restrict), types of strategies (e.g. more affective based interventions to reduce anxiety) and unintended negative consequences (e.g. decrease in patient trust, increase of other interventions).[53]

AIMS OF THIS THESIS

The main aim of this thesis was to stimulate the de-adoption of low-value BCC follow-up care. Although de-adoption of care differentiates from implementation of care concerning the aforementioned contextual factors, the 'Grol and Wensing Implementation of Change Model' can still be used to develop and evaluate a strategy for de-adoption of care.[55] The aims of this thesis align with this model of change (**Figure 1**).

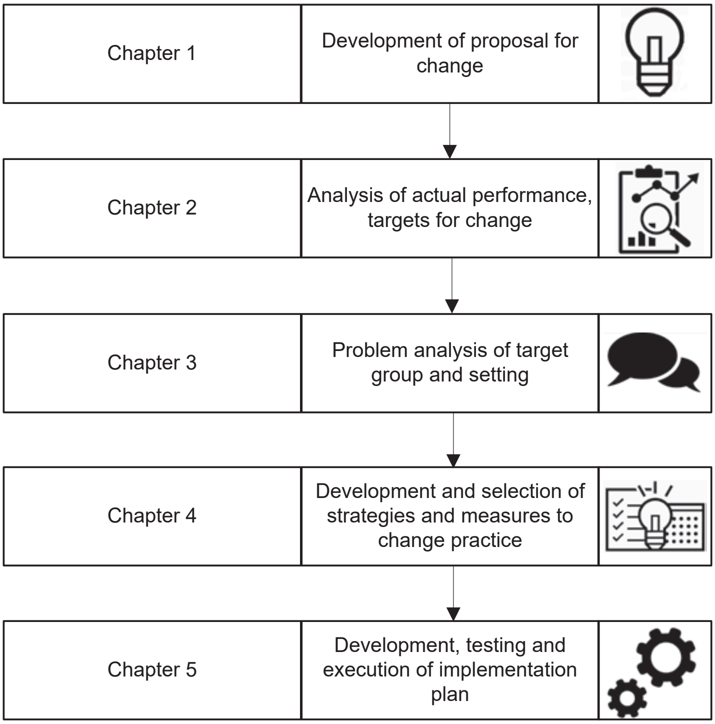

Figure 1. Implementation of change model by Grol and Wensing[55], which was used as guiding principle for the de-adoption of low-value basal cell carcinoma follow-up care.

The first step was to determine a concrete and feasible proposal for desired improvement in existing practice. This proposal for change was developed in **Chapter 1** by describing daily skin cancer practise of GPs and dermatologists. By comparing daily practice to guidelines, areas for improvement were found.

In order to assess actual performance, indicators to measure performance in a valid and reliable way are needed. This is preferably employed by a systematic method. In **Chapter 2** a nationwide claims database was used to define quality indicators of skin cancer care, benchmark performance and reveal practice variation.

Before a de-adoption strategy can be developed, the target groups (i.e. stakeholders) must be analysed. This includes determining the barriers and facilitators to changing practice from each target group's viewpoint. A qualitative approach was used in **Chapter 3** to determine the thoughts and believes of skin cancer patients and dermatologists.

The aim of **Chapter 4** was to select a de-adoption strategy. The relative importance of the needs and preferences expressed by patients and dermatologists were quantified. The most important factors were integrated in a discrete choice experiment, which learned us which trade-offs they are willing to make in order to accept fewer BCC follow-up visits.

Finally, in **Chapter 5**, a de-adoption strategy based on the previous work was tested and executed. Efficacy, cost-effectiveness, and budget impact analyses of the strategy were conducted.

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Chapter 2

Practice variation in skin cancer treatment and follow-up care: A Dutch claims database analysis

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Accepted for publication in Dermatology

ABSTRACT

Background: Quality indicators are used to benchmark and subsequently improve quality of healthcare. However, defining good quality indicators and applying them to high volume care such as skin cancer is not always feasible.

Objectives: To determine whether claims data could be used to benchmark high-volume skin cancer care and to assess clinical practice variation.

Methods: All skin cancer care related claims in dermatology in 2016 were extracted from a nationwide claims database (Vektis) in The Netherlands.

Results: For over 220.000 patients a skin cancer diagnosis-related group (DRG) was reimbursed in 124 healthcare centres. Conventional excision reflected 75% of treatments for skin cancer, but showed large variation between practices. Large practice variation was also found for 5-fluorouracil and imiquimod creams. The practice variation of Mohs micrographic surgery and photodynamic therapy was low under the 75th percentile, but outliers at the 100th percentile were detected, which indicates that few centres performed these therapies far more often than average. On average, patients received 1.8 follow-up visits in 2016.

Conclusions: Claims data demonstrated large practice variation in treatments and follow-up visits of skin cancer and may be a valid and feasible dataset to extract quality indicators. The next step is to investigate whether detected practice variation is unwarranted and if a reduction improves quality and efficiency of care.

INTRODUCTION

The high incidence of skin cancer, the low mortality rate, the long lag time to recurrence and/or low rate of severe treatment related complications make it difficult to monitor quality of skin cancer care.[1] Benchmarking is a monitoring method which originated within commercial industry and has found its way into healthcare. Originally, benchmarking was used to improve organizational issues (e.g., staffing ratios), but soon after to improve clinical outcomes by benchmarking clinical practice.[2] Benchmarking is a management approach which can be used to create a spirit of competition and to stimulate best practices at best cost.[3] A way to translate benchmarking into medical care is often by using quality-indicators. These quality-indicators are thought to reflect quality of delivered care and can include items related to volume, complications and mortality rates.[4]

Analyses of quality-indicators can be used to reveal clinical practice variation, reflecting differences in care policy or outcomes between healthcare providers.[5] In only 15 percent of medical interventions the choice of treatment is clear and the differences in provider judgment are negligible (e.g., hospital admission rates for hip fractures), making practice variation very common.[6] To a certain degree practice variation is acceptable, but too much variation can be unwarranted and may be the result of under- or overtreatment.[7,8] In the event of undertreatment, patients may not receive the care they actually need, which reduces their chance of receiving optimal care. When overtreatment occurs, patients may be exposed to unnecessary side effects and/or costs caused by intervening more than is medically justified.[9] For example, an identical skin cancer patient may be treated by Mohs micrographic surgery (MMS) in one healthcare centre and by conventional excision in another centre.

There are sets of quality-indicators which are mandatory to be registered for certain types of cancer in the Netherlands. Such as complications and survival rates after resection of pancreas carcinoma and the number of incomplete resections of ovarian carcinoma.[10] However, for high-volume cancer such as skin cancer it is not feasible for healthcare providers to register quality-indicators for each patient.[11] Therefore, quality-indicators for skin cancer are currently only registered for stage 3C or higher melanoma in specialised melanoma centres.[10] To obtain a complete overview of skin cancer care, routine data may be a promising data tool.[12]

The aim of the current study is to determine whether claims data can be used to benchmark high-volume care and to assess whether there is clinical practice variation in type of treatment and number of follow-up visits of skin cancer patients.

PATIENTS AND METHODS

Data source

Since 2005, all hospital visits and admissions in the Netherlands are categorised in diagnosis-related groups (DRGs). Each DRG includes all hospital activities and services associated with the patient care provided for a certain diagnosis. All activities related to diagnosis, treatment and follow-up are registered by the healthcare provider and included in a DRG, resulting in one reimbursement claim (Figure 1).[13] These claims are collected by healthcare insurers and subsequently sent to a national information centre (Vektis B.V., Zeist) in the Netherlands. This nationwide claims database was used for the current study. As all Dutch inhabitants are obliged to have a healthcare insurance, the coverage is over 99% and a recent study determined this database to be over 95% accurate when compared to local patient records.[14]

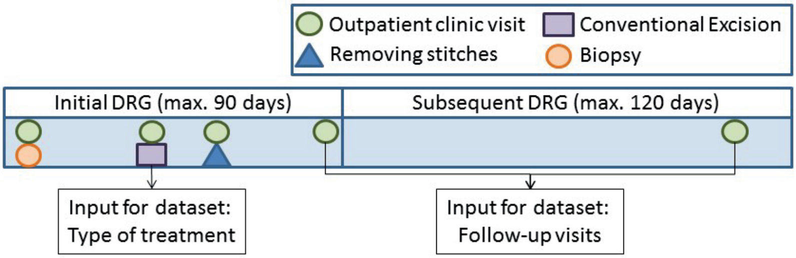

Figure 1. Example of a Diagnosis-Related Groups (DRGs) for a skin cancer patient. In this schematic example, a patient received a biopsy during the first visit, during the second visit the skin cancer was removed by conventional excision, then the sutures were removed and thereafter the patient received two follow-up visits. The conventional excision was included in the analyses of practice variation of treatments. The last two outpatient clinic visits, without any other registered activity on the same day, were considered follow-up visits and included in practice variation analysis of follow-up visits.

Data extraction and analysis

All patients with a DRG reimbursed for a cutaneous malignancy within dermatology care in the most recent available calendar year (2016) were included. This includes patients who were diagnosed before 2016, but only had a follow-up visit in 2016. The data sets only included cutaneous malignancies (i.e. basal cell carcinoma, squamous cell carcinoma, melanoma and rare types of skin cancer). Pre-malignancies, such as Bowen's disease and actinic keratosis were not included. It is not possible for patients to have diagnosis codes for both a cutaneous malignancy and a pre-malignancy (e.g. squamous cell carcinoma and actinic keratosis). Unfortunately, there were no specific diagnosis codes for each subtype of skin cancer. The ICD-10 codes were introduced from 2016 which differentiates between different subtypes of skin cancer (except for basal cell carcinoma and squamous cell carcinoma), but the saturation of this data was too poor to use for the current study. Two data sets were extracted from Vektis' nationwide claims database, based on health care activities (Figure 1):

- One dataset contained types of treatment indicated for skin cancer: conventional excision, MMS, photodynamic therapy (PDT), 5-fluorouracil and imiquimod cream. Destructive therapies, such as cryotherapy, were not included, because patients could be treated this way for their actinic keratosis during follow-up for their skin malignancy. If a patient received multiple treatments, for example topical treatment and excision, both treatments were registered. The number of treatments were stratified per healthcare centre.
- The second dataset contained the number of follow-up visits and was also stratified per healthcare centre. A follow-up visit was defined as a visit at the dermatology outpatient clinic after a skin cancer treatment, without any other activity registered on that day (e.g., removing sutures).

The maximum timeframe of an initial DRG is 90 days and 120 days for a subsequent DRG. When this time limit has passed and a new care activity is registered for this patient for the same diagnosis, a subsequent DRG will be opened. The eligible DRG codes are listed in Table S1. The number of referrals from other healthcare centres was determined by searching for a skin cancer DRG at another healthcare centre up to 90 days before prior to the DRG in the main analysis (i.e., tertiary care). The healthcare centres were categorised as university hospital, general hospital or independent sector treatment centre (ISTC) and anonymised for the researchers.

The analyses were performed by using SAS software (version 9.3; SAS Institute Inc, Cary, NC) and Microsoft Excel (Microsoft, Redmont, WA, USA). Charts were created of the distribution of treatment types and average number of follow-up visits per centre. Finally, after the healthcare centres were ranked on the proportion of type of treatment or follow-up visits, percentiles (p0, p25, p50, p75, p100) and the differences between percentiles (p25-p75 and p0-p100) were determined to reveal practice variation. To determine whether results are skewed by small healthcare centres, a sensitivity analysis was performed by excluding the centres with the lowest quartile in terms of number of patients.

RESULTS

In total, 124 healthcare centres in the Netherlands reimbursed at least one DRG for a skin malignancy within dermatology care in 2016 for over 220,000 unique patients (Table 1). The total number of patients is higher than the total number of treatments, as patients who solely received follow-up care in 2016 were included as well. Nearly 400,000 follow-up visits took place in dermatology care for skin cancer in one year.

Table 1. Total number and distribution of treatments and follow-up visits for a skin malignancy per type of treatment centre in 2016

Type of healthcare centre	Number of healthcare centres[a]	Number of patients[b]	Number of follow-up visits	Number of treatments[c]
ISTCs	46 (37.1%)	24,857 (11.2%)	55,462 (14.1%)	17,125 (12.6%)
General hospitals	74 (59.7%)	180,525 (81.4%)	304,980 (77.4%)	108,758 (80.2%)
University hospitals	8 (6.5%)	16,498 (7.4%)	33,530 (8.5%)	9,715 (7.2%)
Total	124	221,880	393,972	135,598

[a] Healthcare centres with at least one patient with a follow-up visit for a skin malignancy
[b] Patients with at least one follow-up visit for a skin malignancy in 2016
[c] Conventional excision, Mohs micrographic surgery, Photodynamic therapy, 5-fluorouracil and imiquimod cream
Abbreviation: ISTCs, Independent sector treatment centres.

Treatments

An overview of the type of treatment quality indicator scores per healthcare centre are displayed in Figure 2. In 2016, general hospitals were the most consistent in treating their skin cancer patients by conventional excision, of which the hospitals with the least conventional excisions were performing more MMS. The two independent sector treatment centres with the highest percentage of MMS (30% and 24%) had a substantial proportion of their patients referred from other healthcare centres (24% and 17%). The university hospital with 33% MMS had 35% of their patients referred from other healthcare centres, compared to 2% to 13% referred patients of the other university hospitals.

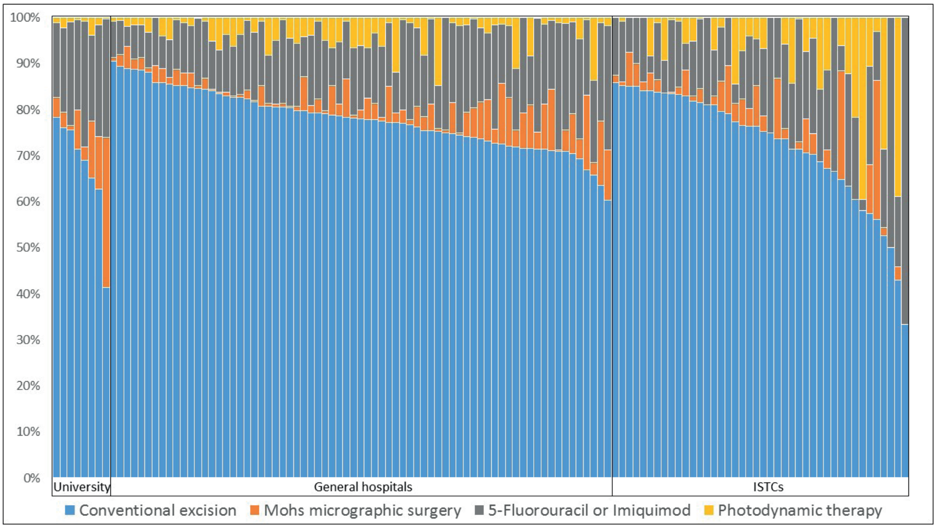

Figure 2. Distribution of Quality Indicator (QI) scores of the treatments indicated for skin cancer in 2016. Each bar represents one healthcare centre. Abbreviations: University, University hospitals; ISTCs, Independent sector treatment centres

Patients in university hospitals were treated with 5-fluorouracil or imiquimod cream in 22% of the cases, compared to 15% and 12% of patients in general hospitals and independent sector treatment centres respectively (online suppl. Fig. S1). In independent sector treatment centres, 6% of skin cancer patients were treated with PDT, while in university and general hospitals 1% and 3% of patients were treated with PDT.

On average (taking the 50th percentile), 77.0% of all malignancies were treated by conventional excision in 2016 (Table 2). This proportion was reasonably comparable with the application of conventional excision in the 25th (71.3%) and 75th percentile (82.4%). The outliers however also showed healthcare centres with only 33.3% (p0) or more than 90% (p100) use of conventional excision. Most practice variation is revealed for topical treatment for skin cancer (5-fluorouracil and imiquimod), as the p0-p100 ranges from 0% to 66.7%. The low percentages of MMS and PDT until the 75th percentile (<7%) and the high percentage at p100 (>32%) indicate that few healthcare centres provided that care more often in 2016.

Table 2. Percentiles of the distribution of Quality Indicator (QI) scores of different types of skin malignancy treatments and follow-up visits between healthcare centres in 2016.

	p0	p25	p50	p75	p100	Difference between	
						p25-p75	**p0-p100**
Conventional excision	33.3%	71.3%	77.0%	82.4%	90.6%	11.1%	57.2%
Mohs micrographic surgery	0%	0.9%	3.0%	6.7%	32.8%	5.8%	32.8%
5-fluorouracil or imiquimod	0%	10.5%	14.6%	18.5%	66.7%	7.9%	66.7%
Photodynamic therapy	0%	0.6%	1.8%	6.1%	39.5%	5.5%	39.5%
Average number of follow-up visits per patient	0.44	1.48	1.75	2.01	6.61	0.53	6.17

Follow-up visits

Figure 3 provides an overview of the number of follow-up visits per healthcare centre. The average number of follow-up visits per patient was 2.0 for university hospitals, 1.7 for general hospitals and 2.0 for independent sector treatment centres. The fourteen healthcare centres with the highest number of follow-up visits per patient were all independent sector treatment centres with an average of 2.4-6.6 follow-up visits per patient.

The difference in the average number of follow-up visits between healthcare centres from the 25th percentile and the 75th percentile was 0.53 follow-up visits per patient (Table 2). The number of follow-up visits per patient at these percentiles (1.48 – 2.01) did not differ much from the 50th percentile (1.75). However, the p100 showing an average number of follow-up visits of 6.61 per patient reveals that there were some healthcare centres on the higher end contributing to practice variation.

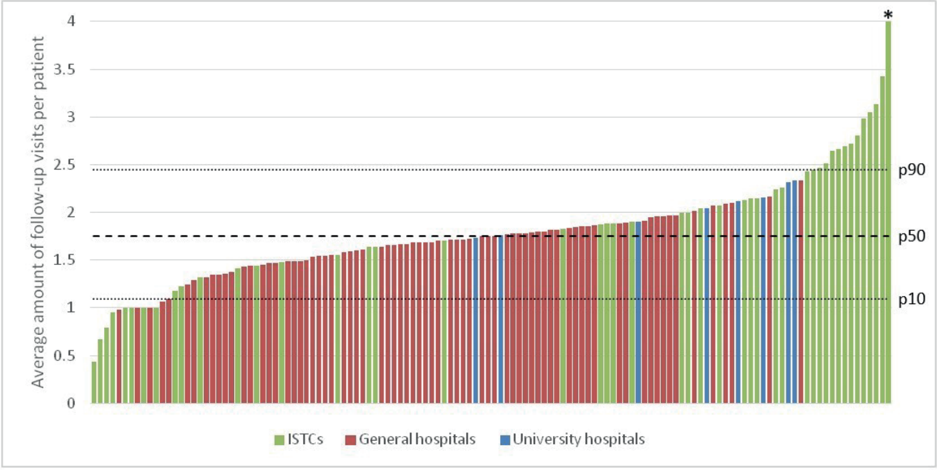

Figure 3. Average number of follow-up visits per patient per healthcare centre in 2016. Each bar represents one healthcare centre. Abbreviation: ISTCs, Independent sector treatment centres. *The Y-axis was cut off at 4.0 for clarity; this healthcare centre's value was 6.6.

The sensitivity analysis, which was used to detect if results were skewed by small healthcare centres, did not differ from the main analysis concerning the interquartile range (p25-p75). The results of the sensitivity analysis were different from the main analysis on the p0-p100 range of topical treatments (25.2%) and follow-up visits (2.1). This means that healthcare centres with a relative small amount of skin cancer patients, deviate more from the 50th percentile and caused more practice variation than larger healthcare centres regarding these quality indicators.

DISCUSSION

This study shows that claims data is able to detect relevant clinical practice variation in terms of skin cancer treatment and follow-up care. Proportion of specific treatments and follow-up could be valid quality indicators and routinely collected claims data may be a good data source for benchmarking.

The amount of clinical practice variation was highest for conventional excision, followed by topical creams. This variation could be explained by referral rate of dermatologists to plastic surgeons depending on his/her surgical experience and skills, or the available facilities of the healthcare centre to provide high numbers of excisions. The practice variation in MMS and PDT was low under the 75th percentile, but outliers at the 100th percentile were detected. MMS and PDT are treatments which were (and are) not provided in all healthcare centres, which means that there has to be practice variation. As shown by Arits et al., PDT is both more expensive and less effective than 5-fluorouracil and imiquimod cream, which led to guideline changes in 2014.[15,16] The high amount of PDT in some healthcare centres might be explained by lack of knowledge of the guideline change. The near 100% compliance rate of conventional PDT might be a rationale to prefer this treatment for a subset of patients of whom is to be expected that they will not comply with creams at home (e.g. stopping treatment too early due to side-effects). However, it may also have been stimulated by a financial incentive, as PDT was more profitable for healthcare centres than conventional excision and topical treatments.

The average amount of follow-up visits per skin cancer patient was 1.8 in 2016. Considering skin cancer patients comprises 24% of all dermatology patients, these follow-up visits account for a large part of dermatology care.[17] Comparing the 25th percentile to the 75th percentile indicates little practice variation between healthcare centres regarding the number of follow-up visits per skin cancer patient. However, it is remarkable that the fourteen healthcare centres with the highest number of follow-up visits per patient were all independent sector treatment centres.

Making use of claims data has some limitations. As the information was aggregated, it should be interpreted carefully. It does not allow analyses on absolute frequencies, but rather a comparison of relative frequencies between healthcare providers. No conclusions regarding under- or overtreatment can be drawn on the basis of practice variation found in the current study, because centres could treat different patient populations. For instance, due to lack of detailed information on the patient level (e.g. age, type of tumour), the case mix of each centre could not be determined. For this reason, it was not possible for the authors to determine whether the high percentage of MMS and high number of follow-up visits are due to specialisation in complex skin cancer care. Although the number of referrals provides an indication, no causality can be established. Strengths of claims databases are that it is routinely registered data, it is virtually complete due to obligatory registration and that the summaries of quality indicators of claims data match summaries of quality indicators of the actual medical records.[18]

The next step is to determine whether the practice variation found in our study is warranted. Institutions such as the Ministry of Health or health insurers (in collaboration with clinical experts) could request healthcare centres to retrieve their own quality indicator scores from Vektis and investigate why certain centres deviate from the average. This process of audit and feedback might already effectively reduce possible unwarranted practice variation.[19] There are several other options to reduce the variation, such as the development and implementation of guidelines (most common strategy), improving shared decision-making and introduction of financial incentives.[20-25] Multifaceted strategies have been proven to be more effective in reducing practice variation than single strategies.[26]

In conclusion, claims data can be used to benchmark high-volume care and to reveal clinical practice variation on routinely collected quality indicators. The current study revealed that there might be under- and/or overtreatment in the case of conventional excisions and topical creams. In addition, it showed that there is little practice variation regarding follow-up visits, but it was surprising to see that the fourteen healthcare centres with the highest number of follow-up visits per patient were all independent sector treatment centres. It should be explored if the variation found in the current study is warranted and if further actions should be undertaken to reduce the practice variation.

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Chapter 3.1

Needs and preferences of patients regarding basal cell carcinoma and cutaneous squamous cell carcinoma care: a qualitative focus group study

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British Journal of Dermatology 180.1 (2019): 122-129.

SUMMARY

Background: Despite the high and rising incidence rate of keratinocyte cancer (KC) and the importance of incorporating patient values into evidence-based care, few studies have focused on the perspectives of patients with KC.

Objectives: To identify the needs and preferences of patients with basal cell carcinoma (BCC) and squamous cell carcinoma (SCC) regarding care.

Methods: A qualitative study was conducted consisting of three focus groups with patients with BCC and three focus groups with patients with SCC. In total 42 patients participated. In each focus group, the patients' needs and preferences regarding treatment and follow-up were discussed, using a predefined topic list. All sessions were transcribed verbatim and analysed by two researchers.

Results: The following needs and preferences were identified: (i) the need to receive all relevant, tailored information; (ii) a physician who takes you seriously and communicates well; (iii) a short waiting period and the best treatment with direct results; (iv) to be seen by the same physician; a preference for a dermatologist during (v) treatment and (vi) follow-up; (vii) a general need for structured follow-up care and (viii) a full-body skin examination during follow-up. Patients with BCC additionally expressed the need for openness and transparency and wanting to participate in shared decision making.

Conclusions: It is advocated to organize skin cancer care that is better tailored to the needs of patients with KC, providing patient-centred care. This should include investing in the patient–physician relationship, and personalizing the type and form of information and the follow-up schedules. Adding the patient's perspective to current guidelines could facilitate this process.

INTRODUCTION

Basal cell carcinoma (BCC) and squamous cell carcinoma (SCC) are among the most common cancers with increasing incidences worldwide.[1,2] Due to their keratinocyte origin, they are nowadays commonly referred to as keratinocyte carcinoma (KC).[3] The estimated global prevalence of KC was 5.529.600 in 2013.[4] Although the costs per case are low, this high prevalence drives the costs of KC up to 600 million, 350 million, 150 million and 100 million in the U.S.A., Australia, Germany and the U.K. respectively.[5] KC therefore poses a considerable burden on health care systems.

To wisely manage finite sources, a strong initiative has spread over all medical societies over the past five years which aims to reduce low-value care,[6-10] i.e. healthcare that it is of little or no value to the patient and consequently should not be provided routinely, or not at all.[11] Providing follow-up care to low-risk BCC patients has been defined as an example of low-value care. Although the risk of a subsequent BCC is high (29% in five years)[1], evidence is lacking that regular follow-up visits translate into improved patient outcomes.[12] In addition, another trend aimed to reduce costs has been care substitution, which aims to shift skin cancer care from medical specialists towards general practitioners (GP) or nurse practitioners (NP) and physician assistants (PA) specialised in dermatology.[13-15] It is of paramount importance that these GPs, NPs and PAs have had sufficient dermatological training.

Evidence based medicine includes three components: research-based evidence, professional expertise, and patient values.[16] Given that patient values are a core component of evidence based medicine,[16] it is surprising that the experiences, needs and preferences of KC patients have received limited attention and were mainly focused on melanoma patients.[17-34] A recently conducted qualitative review[35] on the needs and experiences of skin cancer patients found that only three out of sixteen studies included KC patients.[29,36,37] These qualitative KC studies focused mainly on experiences, psychological impact of hearing the diagnosis and quality of life and all identified the need for information among patients. An in-depth evaluation of preferences and needs regarding treatment and follow-up care is however lacking for this large patient group.[35]

The aim of the current qualitative study is therefore to identify the needs and preferences of BCC and SCC patients regarding KC care. The results of this study can be used as input to organise skin cancer care that is better tailored to the needs of patients and incorporates patient values and preferences in addition to evidence and clinical expertise.

METHODS

Study design and methodological considerations

A qualitative study consisting of six focus groups was conducted. Qualitative research is ideally suited to provide an in-depth picture of patients' needs and preferences.[38,39] Furthermore, the interactive component of the focus groups enables people to ponder, reflect and listen to experiences and opinions of others. This interaction helps participants compare their own personal realities to those of others.[40]

This focus group study has been designed and is reported in accordance with the SRQR (Standards for Reporting Qualitative Research) recommendations.[41]

Study setting and selection of participants

We selected participants for the BCC and SCC focus groups from the three types of health centres providing dermatologic care: academic hospitals (Erasmus MC), peripheral hospitals (Elisabeth-TweeSteden hospital) and independent sector treatment centres (DermaPark and Mohs Klinieken). One focus group for each diagnosis was organised at each type of health centre, where electronic patient files were screened to select patients with a history of exclusively BCC or SCC. Additional information about the selection procedure can be found in Appendix A.

Data collection

Three focus group sessions were held with BCC patients and three with SCC patients. A total of 42 patients participated, varying from 4-8 per group. The patients had a semi-structured discussion about their needs and preferences regarding treatment and follow-up care. A topic guide was used to structure the discussion (see Appendix B). The topic guide originated from earlier experiences of the investigators and from theoretical grounds derived from the literature.[17,42-45]

The sessions were moderated by an experienced moderator of focus groups (M.L., M.D. or Y.M.) and co-chaired by an independent dermatology-trained physician or dermatologist. The moderator explicitly stated that no consensus had to be reached and made sure that everyone was able to share their opinion, to prevent less confident participants from being constrained. All sessions were audio-taped and transcribed verbatim.

Data analysis

Two researchers (S.v.E. and M.L.) independently openly-coded the first two transcripts using the qualitative software program ATLAS.ti 8.0. The codes were discussed and adjusted when needed, which resulted in a preliminary coding scheme. The remaining four transcripts were coded by one researcher, then checked by the other. Different interpretations of codes were discussed and refined until agreement was reached. Data saturation was reached when no new codes (groups) were created in the third focus group of each diagnosis.

The analysis proceeded by the iterative and interpretive process of constant comparison, in which different codes were compared and the relationship between codes was explored to detect emerging themes. Separate code lists were created for BCC and SCC patients to be able to identify differences and similarities between the groups. In case comparable themes emerged in the different focus groups, the same theme titles were used to enhance visibility of similarities and differences between the groups of patients. The overall analysis process resulted in the identification of core themes and sub-themes concerning BCC and SCC patients' needs and preferences regarding KC care.

Ethical considerations

The Medical Ethics Committee of the Erasmus University Medical Center declared that the Medical Research Involving Human Subjects Act was not applicable to this study and approved the study protocol (MEC-2016-204). Participation was on a voluntary basis and all patients participating in the study provided written informed consent.

RESULTS

Needs and preferences of BCC and SCC patients regarding treatment and follow-up

The characteristics of the 42 participants are described in Table 1. Eight sub-themes emerged from the data on the needs and preferences of both BCC and SCC patients, two additional sub-themes were only relevant for BCC patients. The findings and sub-themes are described in detail below. Additional quotations illustrating each sub-theme are presented in Appendix C.

Need for all relevant, tailored information and comprehensible explanation

Both BCC and SCC patients mentioned the importance of receiving all information relevant to their treatment and follow-up, including a clear and comprehensible explanation. In this way they know what to expect and prepare for. BCC patients indicated an additional need for information on the disease background, preventative measures and all available treatments. SCC patients did not express this need. With respect to follow-up care, both patient groups mentioned that clear information on self-inspection would reduce the need for follow-up visits. They wish to receive information that is specifically tailored to their diagnosis and needs, preferably on paper.

Table 1. Participants' characteristics

	Participants **n**	**Male** **n (%)**	**Age** **Median, years (IQR)**	**Setting**
BCC total	**20**	**13 (65)**	**68.0 (60-78)**	
- Group 1	8	4 (50)	67.5 (54-74)	Academic hospital
- Group 2	4	3 (75)	71.5 (60-82)	Peripheral hospital
- Group 3	8	6 (75)	68.5 (67-77)	ISTC
SCC total	**22**	**12 (55)**	**76.5 (70-82)**	
- Group 1	7	5 (71)	73.0 (70-82)	Academic hospital
- Group 2	8	4 (50)	80.5 (76-85)	Peripheral hospital
- Group 3	7	3 (43)	75.0 (69-80)	ISTC

IQR, interquartile range; BCC, basal cell carcinoma; SCC, squamous cell carcinoma; ISTC, Independent sector treatment centre.

> *"But I want to know what the background of that story is and I still don't know that. The only thing he keeps saying at the end of a discussion is it won't kill you. Yeah, okay."*
> (Patient BCC group 1)

Need for openness and transparency

BCC patients want openness and transparency from their physicians with respect to their prognosis, treatment options and follow-up policy. Not hearing about their prospects from their physician makes them feel insecure. They do not want their physician to withhold views or ideas about their situation and want their physician to express when he/she is uncertain. SCC patients did not report this need.

> *"I would like to have more openness, that he tells what the possibilities are that we have further, and now that's still an open question, in two months we'll see again, think yes, don't you yourself have a vision that it's gone, or that something must happen again, the uncertainty remains."*
> (Patient BCC group 2)

Need for shared decision making

BCC patients want to contribute in the decisions regarding the management of their disease, for example in treatment decisions or in being treated by the type of physician of their preference. In contrast, some SCC patients indicated explicitly, they do not want to be involved in shared decision making and rather have their physician to decide for them.

> *"The same as if at a given moment a physician says what do you think yourself, damn, and I answered, sir, you studied for that and maybe even at my expense, so should you ask me what it is, huh?"*
> (Patient SCC group 2)

Need for a physician that listens, takes you seriously and communicates well

Patients from both groups reported the need for a physician that listens, takes you seriously and communicates well. Patients find it important to be able to tell their story to a new physician, even though it is well documented in their medical file. They prefer a personal approach from the physician as this creates trust.

> *"Yes, a doctor can be very skilled but not get along with people, that's a real shame, actually, because you have to trust, uh, that doctor."*
> (Patient BCC group 3)

Need for short waiting period and to receive best treatment with direct results

BCC and SCC patients mentioned the importance of being treated fast and to receive the best treatment with direct results. Patients want to have a short waiting period because they do not want to be in uncertainty for too long. They rather have more skin removed than necessary in order to be tumour free in one session. SCC patients specifically preferred to be treated by Mohs' micrographic surgery, as this has the highest likelihood of being tumour free by the end of the day.

> *"If the biopsy was taken and they have confirmed it is SCC, okay, treatment within 14 days. That is what I think."*
> (Patient SCC group 3)

Need for continuity of care, to be seen by same physician

Both patient groups expressed a need for continuity of care, i.e. to be treated by the same physician every time, so he or she will make the patient's problem his or her problem instead of passing the problem to another physician. Another reason is that they do not need to tell the same story every time. In addition, they want a physician they can trust based on prior experiences. With respect to follow-up, some BCC patients indicated that the physician who treated them should also be the one who performs the follow-up visits, because they gained trust in this physician. SCC patients did not express this need.

> *"Yes sure, I also return to the same dentist every time, to name a thing".*
> (Patient SCC group 3)

Preference for dermatologist as a treating physician compared to GP, NP or PA

Overall, both BCC and SCC patients prefer to be treated by dermatologists, as they are the experts specialised in skin care, as opposed to GPs who are generalists. Furthermore, dermatologists have better equipment than GPs and have the option to ask support from nurses or colleagues when needed.

> *"I indeed have more trust in specialised people, certainly if we're thinking in the direction that it is perhaps cancer, then I want to be where the specialist is."*
> (Patient BCC group 2)

Some BCC and SCC patients, however, indicated that GPs might be involved in their treatment under certain conditions. According to some BCC patients, GPs may perform certain tasks such as excising small tumours, especially because of the short waiting period for GPs, but only when they have received proper training. Some SCC patients would let the GP perform the excision if it is superficial and the GP reassures them he or she is confident enough to do it. In addition, some BCC patients would allow being treated by an NP or PA, but only under the conditions of sufficient training and experience and under supervision of a dermatologist. SCC patients reported not to allow having their tumour excised by an NP or PA. They think their tasks should be limited to superficial treatments such as changing stitches or cleaning wounds.

> *"Basically, they are now being trained by the dermatologists, with a supervisor. So yes I would not have any problems with that I think, no."*
> (Patient BCC group 1)

Need for structured follow-up care

In general, both BCC and SCC patients prefer periodic follow-up visits, with a possibility to come in-between visits when they discover new suspicious lesions. They believe it is too hard for them to distinguish age-related skin lesions from cancer and cannot complete full-body self-inspection themselves. Periodic follow-up visits create a feeling of being taken seriously and provides certainty. Some BCC patients, however, believe periodic follow-up visits are not necessary, as long as they have easy and quick access to a dermatologist whenever they detect new suspicious lesions.

> *"I find another problem, that is that I can't see half my body, and the dermatologist nice lamp, under a good lamp, with good eyes, an assistant next to him, and there free and worked out back and forth, what do you think in a manner of speaking and then I say the frequency if you in my case then once every half year then I'd like to see him even if I have no problems myself.*

> (Patient SCC group 3)

Preference for dermatologist for follow-up visits as compared to GP, NP or PA.

With regard to follow-up visits, both groups prefer to be seen by dermatologists, rather than by GPs, NPs or PAs, especially for the first visit after treatment. They believe dermatologists are the experts, whereas they have insufficient confidence in the knowledge and expertise of GPs.

> *"No, not by the general practitioner, he is still not the specialist, even if he acknowledged it, still a pat on the back for him but he is still not a specialist in that area."*
> (Patient SCC group 3)

However, some BCC patients indicated that they would accept follow-up visits being performed by NPs or PAs, under the conditions that he or she is qualified and that the dermatologist feels confident enough to refer the patient to them. SCC patients reported that they do not to want the GP being involved in follow-up care. Some SCC patients indicated that they see a possibility for going to the GP when they have a suspicious lesion in between the periodic follow-up visits at the dermatologist.

> *"I mean that I come back to the dermatologist every half year myself but in the interim I might dare to leave it to my general practitioner, something like that."*
> (Patient SCC group 3)

Need for full body skin examination during follow-up visits

Both BCC and SCC patients expressed the need for a full body skin examination. They want to have their whole skin checked during follow-up visits, as they cannot check their whole body themselves. SCC patients emphasised the importance of full body skin examination because of their fear that the tumour can metastasize.

> *"...She (dermatologist) only looked at my face, and I thought that was very strange because you can get metastases in your whole body, and she really only really looked at my face and really no further, but did feel the glands because... she says because as soon as there was something there we can also feel it in the thickened glands."*
> (Patient SCC group 3)

DISCUSSION

This first in-depth exploration on the needs and preferences of KC patients identified a range of themes, which could be used to organise skin cancer care that is more tailored to the needs and preferences of this large patient group.

The need for information has already been identified in previous qualitative KC studies.[29,36,37] However, we found that both BCC and SCC patients emphasised the importance of receiving this information tailored to their specific situation and explained comprehensibly. Additionally, BCC patients indicated a need for more extensive information with respect to their diagnosis, treatment and prognosis in order to actively participate in the decision making process, whereas SCC patients explicitly stated not to want to be involved. This difference may be explained by the fact that BCC patients are generally younger and probably in an overall better condition than SCC patients,[1,46,47] which is consistent with previous studies stating that older patients and patients with a lower level of perceived health are less likely to participate in shared decision making.[48-51]

Both patient groups also expressed the need for a physician that listens, takes you seriously and communicates well. This makes patients feel valued, increase their self-worth and gives them a sense of control.[52] Related to this was the need of patients to be seen by the same physician, at least for the treatment and first follow-up visit, because this increases patients' trust in their physician.[53] The need of patients to receive tailored information, in some cases participate in decision making and to have a physician they can trust, suggests that care should be more patient-centred and more time should be invested in the patient-physician relationship.[53] Research has shown that patient-centred care leads to improved health outcomes.[54,55]

It should be stressed that there were far more similarities than differences in preferences and needs between the BCC and SCC patient groups. In addition, qualitative studies with melanoma patients and even other types of cancers patients have demonstrated many similar themes (e.g. the need for more information and lack of trust in the GP).[35,56,57] Whereas some needs and preferences may be relevant to all types of patients (e.g. a general need for information), others may be more disease-specific (e.g. the need for full-body skin examination) or related to personal characteristics of patients rather than the diseases themselves. Several studies have indeed shown that patient characteristics such as demographic variables, comorbidities, perceived health status and patients' attitude towards involvement of care are associated with patient preferences.[58-60] Future (skin) cancer related qualitative research could take this into account by including subgroups like older patients or patients with certain comorbidities.

A limitation of our study is that we only included patients who were treated by dermatologists. This may have led to a selection bias in patients' preference for a dermatologist as a healthcare provider. Since the role of GPs in BCC care is currently expanding,[13-15] future focus groups may also be organised in a primary care setting. By organising six focus groups in different medical specialist settings, we were able to create arepresentative sample of KC patients treated by dermatologists. However, the qualitative design does not allow us to draw conclusions on differences in the needs and preferences between patients from different medical settings.

Obviously, it is not possible in most health care systems to accommodate all the wishes of the patients, for example the preference to always be seen by a dermatologist. A recent discrete choice experiment among low- and high risk BCC patients found that patients accept fewer follow-up visits and have them performed by a GP, if the first treatment evaluation is performed by the initial health care professional and if they receive a personalised information hand-out.[61] An intervention study among melanoma patients also showed that providing personalised information is more effective in increasing adherence to advice compared to generic information.[62] Melanoma patients were also found to accept fewer follow-up visits from a non-specialist under certain conditions, such as increased continuity of care and rapid clinical review of anything causing concern.[31,32] These trade-offs should be taken into account when developing future policies.

In conclusion, KC patients expressed a set of specific needs and preferences regarding KC care. The new insights from our focus group study could be used to tailor skin cancer care according to the needs and preferences of these patients. This could be achieved by enhancing patient-centred care, e.g. by investing in the patient-physician relationship and by personalising the type and form of information, the way of explanation, and the follow-up schedules. In continuation of this study, an initiative has already started to investigate the effects of providing BCC patients with a personalised hand-out on paper.[63] With this hand-out we hope to reduce the pressure on the current health care system by reducing the need for low-value BCC follow-up visits, while increasing patient satisfaction. Adding the patient's perspective to current guidelines on BCC and SCC could further improve the quality of skin cancer care.

ACKNOWLEDGEMENTS

The authors would like to thank the patients who participated in the focus groups. We also thank Yesim Misirli and Esther de Bekker for organising and moderating a part of the focus groups.

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Chapter 3.2

Factors influencing current low-value follow-up care after basal cell carcinoma and suggested strategies for de-adoption: a qualitative study

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British Journal of Dermatology 180.6 (2019): 1420-1429.

SUMMARY

Background: Providing follow-up to patients with low-risk basal cell carcinoma (BCC) can be considered as low-value care. However, dermatologists still provide substantial follow-up care to this patient group, for reasons not well understood.

Objectives: To identify factors influencing current BCC follow-up practices among dermatologists and suggested strategies to de-adopt this low-value care. In addition, views of patients regarding follow-up care were explored.

Methods: A qualitative study was conducted consisting of 18 semi-structured interviews with dermatologists and three focus groups with a total of 17 patients with low-risk BCC who had received dermatological care. The interviews focused on current follow-up practices, influencing factors and suggested strategies to de-adopt the follow-up care. The focus groups discussed preferred follow-up schedules and providers, as well as the content of follow-up. All (group) interviews were transcribed verbatim and analysed by two researchers using ATLAS.ti software.

Results: Factors influencing current follow-up care practices among dermatologists included complying with patients' preferences, lack of trust in general practitioners (GPs), financial incentives and force of habit. Patients reported varying needs regarding periodic follow-up visits, preferred to be seen by a dermatologist and indicated a need for improved information provision. Suggested strategies by dermatologists to de-adopt the low-value care encompassed educating patients with improved information, educating GPs to increase trust of dermatologists, realizing appropriate financial reimbursement and informing dermatologists about the low value of care.

Conclusions: A mixture of factors appear to contribute to current follow-up practices after low-risk BCC. In order to de-adopt this low-value care, strategies should be aimed at dermatologists and GPs, and also patients.

INTRODUCTION

Basal cell carcinoma (BCC) is the most common cancer in Caucasian people, and incidence rates are increasing worldwide.[1] It is a slow growing tumour which seldom metastasises and is mostly treated by a conventional excision.[2,3,4] Although BCC patients have an increased risk of getting a subsequent BCC,[1] several European BCC guidelines try to identify high-risk patients for follow-up depending on patient and tumour characteristics.[5-7] As evidence that providing follow-up care to (low-risk) BCC patients leads to improved patient outcomes is lacking, BCC guidelines increasingly advise against annual follow-up after treatment of a single 'low-risk' BCC (i.e. primary BCC, smaller than 2 cm, located outside the H-zone and has a nodular or superficial subtype).[5-7]

Due to rising healthcare costs and finite recourses, policymakers focus more on de-adopting low-value care, which concerns healthcare that is of little or no value to the patient and consequently should not be provided routinely.[8-11] Several initiatives on de-adoption of care have been initiated resulting in lists of low-value services, such as the 'Choosing Wisely' lists, identifying potential candidates for de-adoption. [8,12-14] Since follow-up for low-risk BCC patients can be considered as low-value care, it was included in the Dutch list of low-value services (*Manuscript in preparation*).

Despite several European guidelines not recommending it, dermatologists seem to provide follow-up care to this large patient group. The number of newly diagnosed BCCs in the Netherlands is estimated to exceed 50.000 in 2020,[1] and almost 50 percent of these can be considered low-risk.[4] A Dutch study showed that low-risk BCC patients receive, on average, a total of 3.8 follow-up visits in three years.[4] A study from the UK showed that after complete excision of a BCC outside the central 'T' area of the face, a quarter of the dermatologists reviewed it more than once.[15] The underlying reasons of dermatologists for providing follow-up care to this patient group are thus far poorly understood.

We conducted present qualitative study as important first step of an intervention study, which aims to reduce the number of low-value follow-up visits of low-risk BCC patients by Dutch dermatologists. The aim of this study is to identify factors influencing current low-value BCC follow-up practices among dermatologists and suggested strategies for de-adoption. In addition, views and preferences of patients regarding follow-up care were explored as they are important stakeholders in the de-adoption process.

METHODS

Study setting

In the Netherlands, medical specialists can work either in a partnership within a hospital paid under fee-per-service (54% of specialists in 2015) or on salary (46% in 2015, mostly in academic hospitals). A small minority of physicians also work in an independent sector treatment centre (ISTC).[16] These different payment systems could lead to different financial incentives for physicians.[17] The average price of a follow-up visit at the dermatologist in the Netherlands in 2018 was 100 Euro.[18]

Study design and methodological considerations

A qualitative study was conducted consisting of 18 individual semi-structured interviews with dermatologists and three focus groups with a total of 17 low-risk BCC patients (varying from five to six per session). This qualitative design was chosen because it enabled us to obtain information about behaviour, underlying motivation, and needs and preferences of all stakeholders.[19]

Selection of participants

Interviews

To select participants, a purposeful sampling method was used,[20] in which information-rich dermatologists known by the authors were invited to participate in an interview. Using this method, we strived for maximum variation in terms of the following relevant characteristics of the target group: types of medical centres in which dermatologic care is provided in the Netherlands (ISTCs, peripheral hospitals and academic hospitals), gender, knowledge of skin cancer and years of working experience. Initially, five dermatologists were interviewed as part of a pilot. This was ultimately extended to 18 dermatologists in total. Potential participants received an invitation by email, containing an information leaflet about the study. Potential participants could register for an individual interview by contacting the researchers.

Focus groups

One focus group was organised at each of the three types of medical service centres. To select participants, electronic patient records from an ISTC (Mohs Klinieken), a peripheral hospital (Elisabeth-TweeSteden hospital) and an academic hospital (Erasmus MC) were screened. Patients were selected if being treated for a low-risk BCC (i.e. non-aggressive subtype, outside the 'H-zone', smaller than 2cm and primary tumor[21]) in the past year. Patients with previous skin malignancies and non-Dutch speakers were not invited, as were patients who did not seem fit enough to join a focus group based on their age and comorbidities. Invitation letters were sent to their home address, containing an invitation and information leaflet. They were offered a gift voucher of 40 Euro to compensate for participating, as stated in the information leaflet. Patients could sign up for the focus group by contacting the researchers.

Data collection

Interviews

All interviews were conducted by an experienced qualitative researcher (ML): eleven were held face to face at the healthcare provider's working place and seven were conducted by phone.

A predefined topic list was used to structure the interview, consisting of the following main themes: current practices regarding BCC follow-up care, factors influencing providing follow-up care, and suggested strategies to de-adopt low-risk BCC follow-up care (See Appendix A). The original topic list also included management of actinic keratosis and squamous cell carcinoma, however, this part falls outside the scope of the current study.

Focus groups

The three focus groups were held at the centres where the patients were treated (Erasmus MC, Elisabeth-TweeSteden hospital and Mohs Klinieken). The sessions were moderated by experienced moderators of focus groups (ML and SD) and co-chaired by a physician independent of the hospitals (SvE).

In each focus group session, patients had a semi-structured discussion about needs and preferences regarding BCC treatment and needs and preferences regarding BCC follow-up care. In this study, we only focused on BCC follow-up care. A predefined topic list was used (See Appendix A) to structure the discussion, which included the following main themes: general needs and preferences regarding follow-up care, preferred follow-up schedules, preferred types of healthcare providers and areas for improvement of care. To prevent the less confident participants from withholding their opinion, the moderator made sure that everyone was able to say something and explicitly stated that opinions are never right or wrong.

Both the dermatologists and patients provided written informed consent and gave permission to audio-tape the session. In addition, they filled out a small questionnaire to collect socio-demographic information (e.g. age, gender).

Data processing and analysis

All interviews (n=18) and focus groups (n=3) were transcribed verbatim. Next, all identifying characteristics were removed from the transcripts and they were imported into AtlasTi 8.0, a professional tool designed for qualitative data analysis.

Two researchers (ML and SD or SvE) independently studied and coded the first three transcripts (two dermatologist interviews and one patient focus group). Different interpretations of codes were discussed and redefined until agreement was reached, which resulted in a preliminary coding scheme. The remaining 18 transcripts were coded by ML or SvE and checked by either SD, SvE or ML. Disagreements were discussed until consensus was reached. After 18 interviews with dermatologists and three focus groups with patients, thematic saturation, defined as when little or no changes to the codes were made, was reached for all covered research areas.

After the initial coding process the analyses proceeded by the iterative and interpretive process of constant comparison. The final codes were discussed and emerging themes were grouped. The information in each category of factors was reflected on and interpreted jointly. Inter-observer reliability was tested by group discussions (on meaning) of codes and relationships between codes. This resulted in the identification of core categories of factors influencing current low-risk BCC care and strategies to de-adopt it. In addition, core themes of patients regarding their needs and preferences on follow-up care emerged.

Ethical considerations

Ethical approval for this study was obtained from the Medical Ethical committee of the Erasmus MC (MEC-2016-204).

The current study has been designed and reported in accordance with SRQR (Standards for Reporting Qualitative Research) recommendations.[22]

RESULTS

Description of participants

The characteristics of the participating dermatologists and low-risk BCC patients are displayed in Table 1.

Factors influencing current low-value BCC follow-up practices among dermatologists

Five types of factors emerged as influencing current low-value follow-up care among dermatologists.

Table 1. Characteristics of participating dermatologists and BCC patients

	Dermatologists (n=18)	Focus group 1 (n=5)	Focus group 2 (n=6)	Focus group 3 (n=6)
Male n (%)	10 (56)	1 (20)	2 (33)	3 (50)
Age Median, years (IQR)	45 (38-54)	56 (47-63)	67 (56-68)	72 (62-78)
Setting		Academic	Peripheral	ISTC
- Academic	2 (11)			
- Peripheral	9 (50)			
- ISTC	3 (17)			
- Combination of the above	4 (22)			
Professional experience Median, years (IQR)	12 (6-20)			

IQR, interquartile range; ISTC, Independent sector treatment centre

Complying with patient preferences and needs

According to the dermatologists, patients visiting their practices often prefer follow-up visits as this is reassuring to them after their skin cancer diagnosis. Another reason, according to dermatologists, is the lack of trust by patients in their GP, as he or she will be the first person of contact for the patient after being discharged from follow-up. Dermatologist indicated to comply with these preferences, for example by seeing patients once a year, or to provide follow-up visits to the patients until they are confident enough to do it on their own. In addition, dermatologists indicated that their predecessor often provided annual follow-up visits to the patients creating an unnecessary habit. This makes it hard for them to explain to patients that they do not need follow-up visits anymore and they rather avoid these discussions (Box 1).

Box 1. Illustrative quotes on complying with patient preferences and needs

"There are also people who just think the idea of skin cancer is frightening, and even if you explain it they keep thinking so anyway, and if they then get the choice or propose so themselves, may I come back again, then I say well I would like to see you once a year, and they are completely relieved, I think that's a good thing."

- **Dermatologist 12**

"Yes. And certainly when your predecessors have all said that you have to come back annually. It would be strange if I'd then go and say all right, no, you are now discharged. So I do that with some, but some of them don't accept that yet either."

- **Dermatologist 9**

Lack of trust in GPs to recognise suspicious lesions

Another factor contributing to providing low-value follow-up practices to patients is the lack of trust among dermatologists in GPs to adequately recognise suspicious skin lesions. They believe that GPs lack knowledge of skin cancer and do not see enough skin cancer to establish sufficient experience. The dermatologists indicated that they often receive referrals suggesting poor diagnostic skills of the GPs. As a result, dermatologists indicated to sometimes prefer continuing providing follow-up to low-risk BCC patients themselves, rather than making the GP the first person of contact for the patient. However, some dermatologists reported that discharging the patient depends on the expertise of the particular GP of the patient (Box 2).

Box 2. Illustrative quotes on the lack of trust in GPs to recognise suspicious lesions

"Yes, we just know the neighbourhood and we know who's a good general practitioner is and who isn't, and those who have a good general practitioner [we discharge] and others we keep ourselves for follow-ups." - **Dermatologist 5**

Believes in the usefulness of follow-up visits

As patients have a high chance of a subsequent BCC, follow-up visits are useful, according to some dermatologists. In addition, the usefulness of providing follow-up care to patients was reported for patients who, they believe, are not capable enough to self-examine their skin. Follow-up visits are sometimes provided by dermatologists as a means to educate patients, until they are believed to be capable of performing checks themselves (Box 3).

Box 3. Illustrative quotes on the believes in the usefulness of follow-up visits

"The reason for me is of course that they have a higher chance of a second basal cell carcinoma in the first two years, that's one reason." - **Dermatologist 2**
"Yes, it's someone who won't notice it himself as easily, those you'll see sooner than someone that you can instruct well." - **Dermatologist 12**

Financial incentives to perform follow-up visits

Generally, dermatologists reported not to be influenced by the financial incentives themselves, but indicated to know other dermatologists that are. Reasons reported were the need to reach certain targets within hospital partnerships and personal gain. Particularly, dermatologists indicated that their predecessors were influenced by financial incentives, but these incentives were thought to be still present today (Box 4).

Box 4. Illustrative quotes on the financial incentives to perform follow-up visits

"Because look, in a lot of hospitals with partnerships and things like that, certain targets have to be met, and if those targets all get dropped, then, ehm, it can all lead to financial problems of a club." - **Dermatologist 9**
"Those are the perverse financial incentives (laughs) that, eh, that are not beneficial for a lot of colleagues, it seems to me (...) I don't want to knock on my colleagues though, because most are trying their best to keep to the guidelines of course." - **Dermatologist 10**

Force of habit

Providing follow-up care to low-risk BCC patients used to be standard care, and dermatologists reported that when a guideline changes it is hard to subsequently change common daily practice. They believe this is particularly true for older dermatologists, whereas younger dermatologists generally adhere better to current guidelines (Box 5).

Box 5. Illustrative quote on the force of habit

"And that's not unwillingness, but it's just that it's the same when you have been eating broccoli on your birthday for years and then if you suddenly can't eat broccoli you are deeply sad. That's just in your system." - **Dermatologist 13**

Patient views and preferences regarding BCC follow-up care

Three main themes emerged from the focus groups with low-risk BCC patients concerning follow-up care.

Varying needs with regard to regularity of follow-up care and skin examination

Some low-risk BCC patients, who were all treated by a dermatologist in secondary care, reported a preference for yearly follow-up visits. They indicated that – after being shocked to hear their diagnosis – a yearly check-up would reduce their anxiety. They prefer appointments to be pre-scheduled, to reduce the threshold to contact their dermatologist. In addition, initiating an appointment makes some patients feel like a nag. In terms of content of the follow-up visits, these patients indicated they would like to receive a full body skin examination (FBSE) during the follow-up visit. They find it hard to self-examine their skin and FBSEs performed by dermatologists gives them more confidence about their skin.

However, some patients indicated they find follow-up care not necessary. As a result of the very low chance of a BCC to metastasize, they believe self-examination of their skin is sufficient. They stated that regular follow-up visits should not be imposed to patients and are not worth the associated costs (box 6).

Box 6. Illustrative quotes on varying needs with regard to regularity of follow-up care and skin examination

"They have indeed said that whenever there's something please come back, but yes, when is there something? I feel like there is always something, so then what's... then you could say once a year, yes, well, then rather once every six months, but maybe even once a month actually. You know, for me it's never often enough." - **Patient focus group 1**
"That eh skin cancer really is something that doesn't proliferate so much, so then I think, I think yeah (...) then [follow-up] is not really necessary I think. Then I'll keep a bit of a close eye on it myself." - **Patient focus group 2**

Overall preference for a dermatologist to perform the follow-up visits

Patients in a secondary care setting overall prefer a dermatologist to perform follow-up visits because of their specialisation, whereas they consider the GP to be a generalist. As a result, patients have more confidence in dermatologists and also believe that dermatologists take them more seriously than GPs.

However, some patients stated that follow-up visits may also be performed by GPs as long as they have received appropriate skin cancer education, know their limits and refer to dermatologists when needed. In addition, some patients reported to prefer the GP to perform the follow-up visits. They mentioned that GPs are closer to home and more accessible than dermatologists (Box 7).

Box 7. Illustrative quotes on the overall preference for the dermatologist to perform the follow-up visits

"I really don't question the qualities of my general practitioner, but I think it's a bit safer here, more professional as well of course. With a general practitioner, yes, if he'd had a refresher course it would be different." - **Patient focus group 3**
"What I just said, that they see me coming at dermatology every time like there she is again with her spots, but then the general practitioner is a bit more accessible" - **Patient focus group 1**

Need for improved written information provision

In general, patients reported to be satisfied with the information on skin cancer and self-examination as received - mostly orally - from the dermatologist. However, patients indicated a need to receive more written hand-outs information about skin cancer and self-examination, as they find it hard to remember everything the dermatologist has said during consultation. They also indicated that it may be useful to provide pictures of skin cancer on hand-outs to improve the instructions on self-examination. They prefer to receive specific information from dermatologists rather than having to search the internet themselves for more information, as this often scares them (box 8).

Box 8. Illustrative quotes on the improvements for information provision

"That there are also pictures included, that there are several of them. Looking at what it looks like when it's calm and when it eh, yeah, gets malicious, what, what, what are the differences? The skin around it, does it get red, does it get white, does it contract, how does that that birthmark develop, that, that, that kind of stuff. You read it sometimes but then you think oh, you know, I don't have it so, eh, don't look at it any more. But if you do have it that you can check back and then you think God, have to be alert eh…" - **Patient focus group 2**
"You're also going to Google for yourself like is it, eh, yeah, and whether you run a risk that it can spread for example. Well that has been confirmed hasn't it, that it's rare in any case, but even that has lingered somewhat with me; is it never or is it rarely? It has been a bit of a thing." - **Patient focus group 1**

Suggested strategies to de-adopt low-value follow-up care by dermatologists

Four types of strategies suggested by dermatologists emerged from the data to de-adopt low-value follow-up care.

Educating patients with improved information

According to dermatologists, explaining to patients that follow-up care is not needed and explaining how to self-examine their skin, will reduce their anxiety and need for follow-up care. Dermatologists suggested that this could be achieved by expanding information and explanation to patients during consultation. Improved hand-outs for patients with more information about skin cancer and self-examination was reported to make it easier for them to discharge patients from follow-up (Box 9).

Box 9. Illustrative quotes on educating patients with improved information

"Well, here also I think make more, eh, patients aware of eh, ehm, of what a basal cell carcinoma can look like, so that they can recognise it faster, say. Then you have, so that you don't need to check too often out of fear." - **Dermatologist 14**
"I think a nice hand-out would be handy because I think that many people, if you just have a good hand-out with which people can be discharged, then it is also much easier to discharge people." - **Dermatologist 9**

Educating GPs to increase trust of dermatologists and patients

Educating GPs in skin cancer care was also suggested as a strategy by dermatologists to facilitate the de-adoption of low-value follow-up care. Increasing the trust of both dermatologists and patients in GPs will ease discharging patients from follow-up. Dermatologists reported that, in particular, the diagnostic accuracy of the GPs should be improved. For example, by taking more biopsies in order to learn from the histology report. They also mentioned that GPs should work more like a dermatologist, by always performing a FBSE and by using dermoscopy (Box 10).

Box 10. Illustrative quotes on educating GPs to increase trust of dermatologists

"I think that GPs should have a lower threshold to perform biopsies, because when you perform a biopsy you also learn from that, right, you have a suspicion of a spot and you get a result so then you know am I okay or not, so I think that, I think that that's one of the most important, maybe even more than skills." - **Dermatologist 4**
"Well there's a lot of discussion about dermatoscopy in primary healthcare, eh, I think that, say, dermatoscopy, say, not so much for melanoma, but for skin cancers is helping the GP. I also think that the GP, eh, well, ehm, eh, that, I think it also comes from research, right, that they can especially better recognise benign skin abnormalities with it." - **Dermatologist 11**

Realising appropriate financial compensation and consult times

Realising appropriate financial compensation and consult times was also suggested as a strategy to de-adopt follow-up care. One way to realise this, as indicated by dermatologists, is to increase the time of the consult for high-risk oncology patients in dermatology. Currently, dermatologists generally have ten minutes per patient, without discriminating between low-risk and complex oncology patients. As a result, they currently use the leftover time of low-risk oncology patients for more complex patents. By increasing planned consultation time for complex oncology patients, the quality of care for complex patients can be maintained, making it more attractive to de-adopt the low-risk low-value care.

Dermatologists also mentioned to tackle financial incentives by penalising dermatologists who provide low-value care, for example by only reimbursing high-value care and not covering for the low-value follow-up visits. In addition, using a macro budget (i.e. budget restriction on national healthcare expenditure[23]) was suggested as an option to overcome this problem (Box 11).

Box 11. Illustrative quotes on realising appropriate financial compensation and consult times

"If for example patients go to the GP more often, perhaps the time for the complex dermato-oncological patient should, perhaps they should also get more time, so that they are better looked at, and that it in any case doesn't lead to losses..." - **Dermatologist 9**
"It is like if you run a red light and you don't get a ticket you keep running red lights, and if you are not punished for it, you just keep doing your own thing." - **Dermatologist 13**

Informing dermatologists on the low-value of follow-up care

Providing dermatologists with adequate information and convincing them about the low-value of follow-up visits, was also suggested as a strategy to de-adopt this care. This way unfounded fears regarding the risks of discharging patients from follow-up could be eliminated. According to dermatologists, this could be achieved by increasing awareness among dermatologists about the current BCC guidelines, which restricts follow-up care to high-risk patients. It was also proposed to visualise the (low) risks of de-adopting this care for patients on a piece of paper. In addition, the costs associated with providing this care on a yearly basis could be added (Box 12).

A complete overview of all illustrative quotations for each theme, including additional quotations, can be found in Appendix B.

Box 12. Illustrative quotes on informing dermatologists on the low-value of follow-up care

"Yes, then they just have to follow the guideline better, more familiarity with the guidelines, so they follow the guideline, in principle yes." - **Dermatologist 14**
"Yes, they should actually know that, of course. Look, every dermatologist always wrestles with yes, thirty, forty percent chance that a second one develops, but yes, also a sixty, seventy percent chance of it not. And baso is not generally a serious tumour, and usually very easy to see." - **Dermatologist 18**
"Do you know what also really works, very simple, give them a paper and show them what it means for the costs of the healthcare if you see someone every three months and make it visual with a little pie chart or with a, you know, just very simple, and these are the healthcare costs if you see someone once a year." - **Dermatologist 13**

DISCUSSION

The current study has identified factors contributing to low-value follow-up care by dermatologists after low-risk BCC and suggested strategies for de-adoption. In addition, the views of patients regarding follow-up care were explored.

Consistent with previous studies, complying with patient preferences was reported as a main reason to provide low-value follow-up care.[24-26] In an US study, 51% of physicians reported to order unnecessary tests to keep the patient happy or because the patient insists on getting it.[27] As for patients in our study, we found that part of them indeed preferred receiving periodic follow-up care, mainly to reduce their anxiety. Some patients, however, indicated to find periodic follow-up care unnecessary. Educating patients has been proven to be useful,[28] as it may reduce patients' anxiety, and, as a consequence, their need for periodic follow-up.[29,30] A recent review on BCC care emphasises the importance of counselling patients about self-screening.[31] Providing more, and preferably written, information to patients therefore seems a useful and feasible strategy to de-adopt low-value follow-up care. Since this strategy was suggested by both dermatologists and BCC patients, the likelihood of success of such an intervention increases.[32,33]

A lack of trust in GPs to adequately identify suspicious lesions was also identified by dermatologists as a reason to provide low-value follow-up care to BCC patients. Even though follow-up care is to be de-adopted and not to be substituted by GPs, a lack of trust in GPs of both dermatologists and patients plays an important role, as the GP will be the first healthcare provider of contact for the patient after being discharged. Trust has been found to be an important factor not only between patients and physicians, but also between GPs and specialists, as higher trustworthiness improves the communication between physicians.[34-36] Improving GPs' education in skin cancer may increase the level of trust between physicians, and that of patients, and may therefore reduce the perceived need to keep patients under dermatological follow-up.[37] A first step to improve skin cancer knowledge of GPs is to improve the exposure to dermatology in the medical curriculum, as this is currently underexposed in the Netherlands, but also internationally.[38-41] However, it is also important to note that specialists and patients in secondary care are more likely to be negatively biased towards GPs due to selection bias. In addition, it could be argued that dermatologists should support the position of GPs towards patients to increase the level of trust between patients and their GPs.

The Dutch BCC guideline changed its recommendation in 2007; from providing follow-up care to all BCC patients for at least five years, to restricting follow-up to high-risk BCC patients.[42,43] Although over ten years have passed since this adjustment, dermatologists still indicated providing follow-up care to be a force of habit, particularly for older dermatologists. In line with this, physicians who have been in practise longer are found to be at risk for decreased guideline adherence and providing lower-quality care.[44,45] Also, it is known that implementation of changes in practise can take many years, and de-adoption processes take even longer.[46-49] Merely giving the care time to change may therefore by itself be effective in diminishing this low-value care, particularly as new dermatology residents are adopting current guidelines. To accelerate this process, interventions such as new funding models which promote behavioural change could be useful.[50,51]

Finally, in accordance with previous studies, dermatologists also stated to be influenced by reimbursements.[52-54] In order to reduce ineffective care, macro-level financial strategies enacted by the government or national institutes may be appropriate.[55] A particular effective option could be to increase compensation for the first consult after treatment while lowering compensation for additional follow-up visits. The benefits of this differential compensation are: (1) dermatologists have more time in the initial consult after treatment to provide patients with adequate information; (2) financial incentives to provide low-value follow-up care are removed and; (3) do not negatively influence the financial state of the partnership or department. This financial intervention is worth considering because changes to policy and/or funding models are among the most successful interventions in de-adoption.[32,52,56]

A strength of this study is that we explored factors influencing current low-value BCC follow-up care as well as strategies to de-adopt this care from the perspectives of the stakeholders. Interventions are commonly created on the basis of theory and evidence, and in practise often depend on the experiences and preferences of researchers.[57,58] As acceptance of the target group is an essential step for initiating change,[32,33] integrating the preferences of the stakeholders in an intervention is likely to improve the success of an intervention.[58] In addition, by conducting a comprehensive qualitative study which also includes the perspective of patients, we were able to gain a more complete overview of both contributing factors and strategies which have the highest potential to be effective in the de-adoption process. The used methodology can be used as an example for studies aimed at reducing low-value care concerning other medical conditions. Moreover, the results of this study may be used in other countries dealing with a high incidence of BCCs and pressure on their healthcare system. This may particularly apply to countries with a GP gatekeeper system or fee-for-service reimbursement systems, such as most western countries.[59,60]

A limitation of this study is that we only invited patients treated by dermatologists to participate in our focus groups. Although the focus of our study was on the key stakeholders in the de-adoption process (i.e. the dermatologists and the patients treated by dermatologists), future studies could also include the views of GPs and of patients solely treated by GPs. In contrast to a previous study with high-risk BCC patients,[61] some low-risk BCC patients in the current study actually preferred the GP as opposed to the dermatologist as the GP is closer to home and easier accessible. Gaining insight in this subgroup of patients who trusts the GP could provide valuable information to further facilitate the de-adoption process.

In conclusion, this study provides insight into current practices regarding low-risk BCC follow-up regimens through the eyes of dermatologists and patients, and offers suggestions to de-adopt this low-value care. It shows that the needs of patients and complying with them, a lack of trust in GPs and financial incentives are mainly responsible and that educating patients and GPs as well as realising appropriate financial compensation are suggested to be particularly effective in de-adopting the low value follow-up care. The effect of one strategy, educating low-risk BCC patients with improved patient information containing personalised information, is currently being tested.[62] This and the other proposed strategies may be implemented at a larger scale in the future to stimulate the de-adoption of low-value follow-up care after low-risk BCC.

ACKNOWLEDGMENTS

The authors would like to thank S.M. Droger for her contribution to moderating the focus groups and analysing part of the data.

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Chapter 3.3

Complex skin cancer treatment requiring reconstructive plastic surgery: An interview study on the experiences and needs of patients

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Accepted for publication in Archives of Dermatological Research

ABSTRACT

Introduction To provide patient-centered care, it is essential to explore what patients consider important and to adjust care accordingly. This may specifically be relevant for patients with complex skin cancer, for whom the care process is often more complicated and psychological and social problems may play a larger role.

Objectives to explore the experiences and needs of patients who had undergone surgical treatment by a dermatologist for a complex skin cancer with a subsequent reconstruction by a plastic surgeon.

Methods An interview study was conducted among 16 patients who had undergone surgical treatment by a dermatologist and reconstruction by a plastic surgeon for basal cell carcinoma, cutaneous squamous cell carcinoma, or lentigo maligna. The interviews focused on patients' experiences and needs regarding care using a predefined topic list. All interviews were audio-taped, transcribed verbatim and inductively analyzed using Atlas.ti.

Results Patients reported a need for a skilled and friendly physician who tailors information and communication to their individual situation. A need for continuity of care and improved collaboration between healthcare providers was also emphasized. Furthermore, patients experienced complications and unmet expectations and expressed a need for shared decision-making at various steps throughout the treatment process (depending on age). Patients also considered completeness of tumor removal, follow-up visits with multiple specialists to be planned the same day and recognition of the psychological impact of the disease on the partner important.

Conclusions To improve patient-centered care for complex skin cancer patients, more efforts should be directed towards improving continuity of care and collaboration. Furthermore, it is advocated for physicians to be sensitive to the individual needs of patients and their partner and adjust information, communication and (supportive) care accordingly.

INTRODUCTION

Basal cell carcinoma (BCC), cutaneous squamous cell carcinoma (cSCC) and lentigo maligna (LM) are among the most frequent (pre)malignancies of the skin, with increasing incidence worldwide.[1-3] BCC and cSCC are subtypes of non-melanoma skin cancer and LM is considered a precursor of LM melanoma.[3,4] The main treatment modality of loco(regional) skin cancer is surgery, which in most cases is performed by dermatologists.[5-8]

In patients with complex skin cancer, the lesion is usually located at the scalp or face, making it challenging to remove and reconstruct due to size, location and/or depth.[9,10] This group predominantly consists of elderly patients with large tumors, but also includes younger patients with smaller tumors, located at areas where cosmetic outcome is an important factor, such as the nose. Irregularities or disfigurements after skin cancer treatment may therefore lead to social and psychologic problems.[11,12]

Aside from being more prone to social and psychologic problems, complex skin cancer patients are usually treated by a multidisciplinary team of dermatologists, plastic surgeons, and radiation oncologists as part of a step-by-step process. The patient (preferences) and the lesion must first be assessed to assure that surgery is the best treatment.[13] If surgery is the preferred option, the specific method is chosen depending on the type and size of the lesion.[13] Usually, dermatologists remove the tumor with Mohs micrographic surgery (MMS) in case of BCC or cSSC or by means of a staged micrographic surgery technique (Breuninger) in case of LM.[13-17] Subsequent reconstructions may be more challenging, requiring the expertise of a plastic surgeon.[13] In addition, some patients require adjuvant radiotherapy. This step-by-step process, involving multiple healthcare providers, may complicate the care process for this patient group.

High-quality care should ideally be tailored to the needs of individual patients (i.e. patient-centered care).[18,19] A qualitative systematic review focusing on the needs and experiences of skin cancer patients revealed the scarcity of qualitative studies regarding this subject.[20] Existing literature on patients with complex skin cancer has predominantly focused on surgical techniques.[21,22] Knowledge about complex skin cancer patients' experiences and needs regarding their care is currently lacking.

The aim of the current study was to explore the experiences and needs of patients who had undergone surgical treatment by a dermatologist for BCC, cSCC or LM with a subsequent reconstruction by a plastic surgeon. The results of this study can be used as input to facilitate patient-centered care for complex skin cancer patients by tailoring care to their needs.

PATIENTS AND METHODS

Study design

A qualitative interview study among complex skin cancer patients was conducted. Qualitative research is most suitable for gaining an in-depth understanding of patients' experiences and needs.[23,24] Individual interviews rather than focus groups were used because the average age of complex skin cancer patients is high and some of them were affected by disabling hearing impairment. In addition, for some patients skin cancer is a sensitive subject, which might prevent them from speaking freely about their disease in focus groups.[25]

Study setting

The study took place at Erasmus MC in Rotterdam, the Netherlands. This is an academic tertiary referral center for skin cancer patients and among the largest MMS centers in Europe with approximately 1,700 MMS procedures annually. Approximately 10% of patients treated with MMS require reconstruction by a plastic surgeon, usually under general anesthesia. Therefore, a special outpatient clinic is present at this center for patients who need to be evaluated by both a dermatologist and plastic surgeon.

Study sample

Electronic patient files were screened to select patients older than 18 years who had been to the special outpatient clinic mentioned above. We consecutively included patients who underwent surgical treatment within the preceding year by a dermatologist, followed by a reconstruction by a plastic surgeon for a BCC, cSCC or LM. Patients were excluded if they had other types of skin malignancies or if they were not able to speak Dutch. Data regarding gender, age, skin cancer type and location, type of treatment and method of reconstruction were collected from the electronic patient files.

Eligible patients were sent a letter containing study information and an invitation to participate in a 30-minute interview directly before or after their already planned follow-up consultation. If there was no more consultation planned, patients were asked to be interviewed by phone. After two weeks, a reminder was sent. If another person was present during the consultation (e.g. caretaker or partner), this person was also invited to join the interview to include their perspective.

We used purposive sampling, i.e. we explicitly selected information-rich cases to answer our research question by including a variable sample of patients in terms of sex, age and diagnosis.[26] Participant recruitment ended after data saturation was reached, which was the case when there were no new code (groups) created.

Data collection

Sixteen interviews were held; 13 were conducted face-to-face and three by telephone. A topic guide, based on previous research of the authors, expert opinion and information derived from the literature, was used to structure the interviews (see appendix A).[27-30]

The first three interviews were conducted by two researchers (M.H. and S.v.E), the remaining interviews were held by one (M.H.). The interviewers were not involved in the medical care of the interviewed patients. Interviews started with the explanation that everything would be analyzed anonymously and stimulated free expression of opinions. All sessions were audiotaped, transcribed verbatim and anonymized.

Data analysis

An inductive approach to data analysis was used allowing meaning to emerge from the data, rather than from pre-determined categories.[31] Two researchers (S.v.E. and M.H.) independently openly coded the first four transcripts, by using the qualitative data analysis software ATLAS.ti (Version 8).[32] These codes were discussed with a third researcher (M.L.) and adjusted if necessary, which resulted in a preliminary coding scheme. Next, all transcripts were coded using this coding scheme by one researcher (M.H. or S.v.E), then checked by the other.

Interpretive and iterative constant comparison followed the initial coding phase, in which different codes were compared and the relationship between codes was explored to detect emerging themes. The overall analytical process resulted in the identification of main themes and sub-themes regarding the experiences and needs of patients with complex skin cancer.

Ethical considerations

The medical ethics committee of Erasmus MC declared that the Medical Research Involving Human Subjects Act did not apply to the present study (MEC-2018-1677). All participants provided written informed consent and participation was voluntarily. This study has been designed and is reported in accordance with the SRQR (Standards for Reporting Qualitative Research) recommendations. [33]

RESULTS

Patient characteristics

The median age of the participants (7 women and 9 men) was 71.5 years (range 47-87). Six patients were diagnosed with BCC, five with cSCC and five with LM. Further tumor and treatment details are described in Table 1.

Table 1. Characteristics of participating patients

Patient	Age	Sex	Diagnosis	Location	Treatment	Method of reconstruction	Interview
1	87	Male	LM	Cheek	Staged excision	FTSG from supraclavicular	Individual
2	71	Male	cSCC	Forehead	Re-excision and ART	Free skin grafted muscle flap	With partner
3	87	Male	cSCC	Scalp	Re-excision and ART	Free skin grafted muscle flap	With partner
4	65	Female	BCC	Nose	MMS	FTSG from preauricular	Individual
5	78	Male	cSCC	Scalp	MMS and ART	Free skin grafted muscle flap	Individual
6	73	Female	cSCC	Lower leg	Staged excision	SSG from upper leg	Individual
7	47	Female	cSCC	Lower leg	Staged excision	SSG from upper leg	Individual
8	67	Male	LM	Fifth digit of hand	Staged excision	FTSG from groin	With partner
9	51	Female	LM	Nose	Staged excision	Local bilobed flap	Individual
10	80	Male	LM	Vertex	Staged excision	Secondary intention*	Individual
11	52	Male	BCC	Nose	MMS	FTSG from preauricular	Individual
12	72	Male	BCC	Nose	MMS	Local hatchet flap	With partner
13	64	Female	BCC	Nose	MMS	Paramedian Forehead Flap	Individual
14	78	Female	BCC	Nose	MMS	FTSG from groin	Individual
15	55	Female	LM	Nose	Staged excision	FTSG from preauricular	Individual
16	72	Male	BCC	Cheek	MMS	Local advancement flap	With partner

ART, adjuvant radiotherapy; MMS, Mohs micrographic surgery; LM, lentigo maligna; cSCC, cutaneous squamous cell carcinoma; BCC, basal cell carcinoma; FTSG, Full-thickness skin graft; SSG, Split-thickness Skin Graft

*Was initially planned for SSG and tissue expander, but reconstruction was postponed.

Complex skin cancer patients' experiences and needs

Based on the patient interviews, twelve sub-themes were identified on the experiences and needs of complex skin cancer patients (Figure 1).

1. Patients' experiences and needs regarding healthcare providers

1.1 Need for a skilled and friendly physician who provides clear and honest information

Patients emphasized the importance of a physician who communicates clearly and provides honest information throughout the entire process of care (Table 2). In this way, they fully know where they stand and what to expect. They need to trust their physician and the provided information. In addition, they reported the importance of physicians to be skilled, but also to show compassion and to be friendly.

1.2 Need for a physician who tailors information and communication to individual patients

Patients expressed the importance of information and communication to be tailored to individual patients' needs (Table 3). They suggested that physicians should ask each patient whether he/she needs more information and adjust the information provision accordingly. Furthermore, patients indicated that physicians should adjust their explanation to the particular patient to make sure every patient understands.

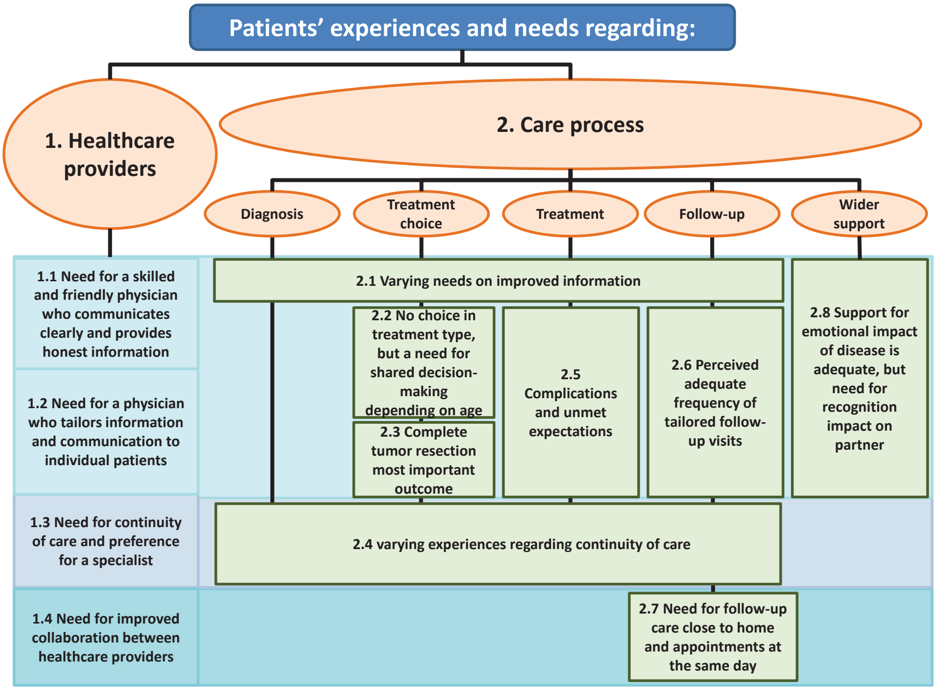

Figure 1. Overview of identified themes and sub-themes on the experiences and needs of complex skin cancer patient

Table 2. Illustrative quotes on need for a skilled and friendly physician who provides clear and honest information

"And be honest, don't make it worse, don't make it less serious. Just say it as it is." **– Patient 11 (52-year-old male)**
"The kindness of the people, of the physicians [is most important]. And their expertise" **– Patient 14 (78-year-old female)**

Table 3: Illustrative quotes on need for a physician who tailors information and communication to individual patients

"But I wasn't asked whether I needed more information. (...) It's never a bad thing to hear that" **– Patient 15 (55-year-old female)**
"That they explain things in a clear, understandable way to the patient. Sometimes they are talking to clinicians and other occasions, with all due respect, they are talking to pavers. They must explain things clearly to both of them and that is a matter of choosing the right words." **– Patient 11 (52-year-old male)**

1.3 Need for continuity of care and preference for a specialist

Patients generally expressed the need to be seen by the same physician during diagnosis, treatment and follow-up visits (Table 4). This ensures them that their physician has all relevant information and also strengthens the bond with their physician. In addition, patients reported to prefer to be treated by a specialist instead of a physician assistant (PA), because they feel he/she is the expert. Patients particularly wished to be treated by a skilled expert, as their skin cancer is often located in the face and they wanted it to be done neatly. Nevertheless, patients generally stated it to be acceptable if PAs would provide information and explain things about the treatment process.

Table 4. Illustrative quotes on need for continuity of care and preference for a specialist

"You know what also disappointed me, it suddenly comes to mind, I think we drove to Rotterdam about seven times and every time I was seen by another person. Instead of one physician who would treat me. At a certain point you have a bond with someone and then suddenly you are seen by someone else." **– Patient 8 (67-year-old male)**
"I really wanted the specialist to do that. (...) That it really had to be done by the specialist himself because after all it is my face." **– Patient 15 (55-year-old female)**

1.4 Need for improved collaboration between healthcare providers

Patients expressed the need for improved collaboration between healthcare providers and between hospitals (Table 5). They noticed that healthcare providers sometimes communicate past each other and are not aware of important information. They indicated to sometimes receive wrong information due to miscommunication, such as a wrong dismissal date. A national electronic patient file for all hospitals was suggested to improve communication.

Table 5. Illustrative quotes on need for improved collaboration between healthcare providers

"That things get mixed up now and then (...) Yes, this is not necessarily just about me... I notice this in general. They [dermatologist and plastic surgeon] also say that about each other. That things do not go smoothly." **– Patient 7 (47-year-old female)**
"Well there was some confusion because the plastic surgeon said that I could go home after I had been treated, but the nurse on the ward said that I had to stay overnight." **– Partner of patient 8 (Partner of 67-year-old male)**

2. Patients' experiences and needs regarding the care process

2.1 Varying needs on improved information provision

Whereas many patients indicated to be satisfied with the information they received, a need for improved information was also often reported (Table 6). This applied to all phases of the care process. Some patients indicated that they received hand-outs in addition to oral information and some patients were also shown pictures of other complex skin cancer patients. These pictures were regarded as informative by some patients, whereas others preferred not to see them and reported that physicians should at least warn patients beforehand. Patients often searched the internet for additional information themselves, but as this was sometimes experienced as shocking, they generally preferred to receive clear information on hand-outs from physicians. Overall, patients emphasized the importance of written information besides oral information, because they were not able to remember all information provided during consultation. This was specifically the case for follow-up care.

Table 6. Illustrative quotes on varying needs on improved information provision

"Yes, that they ask if you want to see pictures and that they can be shocking. That they would warn you in advance. But I had already seen them and that was not a disaster in itself but if I were given the choice I would rather not have seen them" **– Patient 4 (65-year-old female)**
"I still Googled a bit at home but not too much because it doesn't make you feel well." **– Patient 4 (65-year-old female)**
"Yes, you leave and that's it. Yes, the medical world knows more than a layman. Then you could put a resume on a piece of paper and pass it on. So you have something tangible." **– Patient 1 (87-year-old male)**
"You know, I have had so many things, at a certain point I just let it happen." **– Patient 6 (73-year-old female)**

2.2 No choice in treatment type, but a need for shared decision-making, depending on age

Overall, patients mentioned that they were not given a choice in treatment (Table 7). They did not consider this as a problem, because they fully trusted the physician in choosing the best treatment. Some patients stated that they were told what would happen if their tumor would not be treated, but receiving no treatment was never a real option for patients: they came all the way from a general hospital to have their skin cancer removed. Some patients appreciated that they were able to decide on type of reconstruction and between local or general anesthesia.

Table 7. Illustrative quotes on no choice in treatment type, but a need for shared decision-making, depending on age

"With me it was actually the case that there was never any choice. It had to be removed and that was it" **– Patient 7 (47-year-old female)**
"That physicians mention a few options. I can imagine that old people don't really like this, but I do like to hear them. So they can include me in their thoughts and decision-making. There might also be people who will just go along with things, but I am not like that." **– Patient 11 (52-year-old male)**
"Yes, they are specialists, I am no expert so I don't know. They told me that this would be the best solution. I just trust them, because of their experience." **– Patient 10 (80-year-old male)**

Specifically younger patients expressed the need to be involved in the decision-making process and preferred to discuss treatment choices if available. They stressed the importance of being informed about all treatment options including the benefits and disadvantages. As such, they are able to make an informed decision together with their physician. On the contrary, older patients generally stated to fully trust their physician in making the decision, as he or she is the expert.

2.3 Complete tumor resection most important outcome

Patients indicated that they considered the complete removal of the tumor to be more important than the cosmetic outcome (Table 8). They reported to be scared of recurrence and therefore found it most important that it was completely removed, regardless of the scar size. Still, they preferred the scars to be as small as possible. They preferred surgery opposed to radiotherapy, because surgery confirms complete clearance of the tumor. Furthermore, patients expressed a preference for the skin cancer to be removed as quickly as possible to prevent it from growing further. Improvement of quality of life was also mentioned as an important outcome.

Table 8. Illustrative quotes on complete tumor resection most important outcome

"Even though it won't be perfectly beautiful, and it will never be. There is not much more to improve. I don't really mind that spot and that scar, as long as I look a little presentable." **– Patient 12 (72-year-old male)**
"Although the cancer might not be completely gone (...) my quality of life has indeed improved and that is important to me." **– Patient 13 (64-year-old female)**

2.4 Varying experiences regarding continuity of care and type of healthcare provider

Patients reported various experiences regarding continuity of care during the entire care process (Table 9). Some patients were seen by the same healthcare provider every time, whereas others reported to have seen a different physician on each occasion. Seeing multiple physicians made them feel that the physicians were not really involved in their care, even if they prepared the consultation well. Overall, patients reported to be satisfied with the received care by medical specialists. In general, patients did not like to be treated by PAs or residents instead of specialists, particularly if they had not given permission for this.

2.5 Complications and unmet expectations

Some patients mentioned that they had experienced complications such as bleeding, infections and pain (Table 10). They stated that their treatment went better than expected, but the time until full recovery was disappointing. After having been shown pictures

Table 9. Illustrative quotes on varying experiences regarding continuity of care and type of healthcare provider

"I had two people at my bedside who were both physicians, but who didn't have a clue what kind of patient they had in front of them" **– Patient 2 (71-year-old male)**
"Then you get a different one every week. Even a PA once, I had not given permission for her to do the procedure on me. And then I immediately said that I did not want that. (…) At one point, I had the same surgery assistants three times in a row. That's really great." **– Patient 15 (55-year-old female)**

of the expected result and receiving explanation of the expected scar size, patients still reported that their scar turned out larger than expected. It also bothered patients that their scar sometimes frightened other people. According to patients, improved information and explanation beforehand could facilitate being properly prepared for potential complications.

Table 10. Illustrative quotes on complications and unmet expectations

"Yes, at first I thought it wouldn't be too bad, but it takes a long time and I hope that this will only get better. Applying drops and ointment every day, that is quite challenging" **– Patient 15 (55-year-old female)**
Partner of patient: "*Yes, it shocks people.*" Patient: *"Recently we were visiting some people and the first thing they said is what is that and what have you done? That is of course not very pleasant."* **– Patient 3 (87-year-old male)**

2.6 Perceived adequate frequency of tailored follow-up visits

Patients generally reported to be satisfied with the frequency of the follow-up checks by their dermatologist and plastic surgeon (Table 11). Some patients expressed the need for an increase or decrease of the interval time between visits. Most patients, however, stated they could adjust the frequency according to their needs. Patients experienced the hospital to be easily accessible; if they noticed new lesions in between follow-up visits, they could come by right away. During follow-up visits they preferred a physician to perform a full body skin examination as they lack the expertise to self-examine their skin adequately.

Table 11. Illustrative quotes on perceived adequate frequency of tailored follow-up visits

"If I want to come more often, I'm able to do so (…) when I call I can come by immediately" **– Patient 7 (47-year-old female)**
"She said, and I agree with her, 'I expect an active attitude from the patient, when you see spots yourself, you keep an eye on them'." **– Patient 11 (52-year-old male)**
"Obviously, as a layman you can't see whether there are any more bad spots that have not been removed." **– Patient 1 (87-year-old male)**

2.7 Need for follow-up care close to home and appointments at the same day

Patients who live far away from the hospital stated that they preferred to have follow-up visits in a hospital closer to their home to minimize their traveling time (Table 12). Specifically elderly patients reported the need for hospital visits to be scheduled at the same day to decrease the number of hospital visits. They also mentioned to be bothered with the high parking costs which were accompanied by the follow-up visits.

Table 12. Illustrative quotes on need for follow-up care close to home and appointments at the same day

"I was actually referred back to [name hospital], but that was also my own choice because I thought they could check me there just as well." **– Patient 9 (51-year-old female)**
"I don't know, when she says you have to come then or then, I just come again. But yesterday we also visited two [specialists] and now I am here again. So preferably as many consecutive visits as possible." (...) "Yesterday 6.5 euros [parking costs], last week again 6.5 euros. We are only old age pensioners." **– Patient 2 (71-year-old male)**

2.8 Support for emotional impact of disease is adequate, but need for recognition impact on partner

Patients indicated the whole process to be intense (Table 13). Some patients reported they became more emotional and more ashamed because of the impact of the treatment and disappointing recovery and scars. Despite the emotional impact of the disease, patients indicated not to require psychological care, although this was offered to them. Instead, they preferred to talk to friends or their primary care physician about it.

Patients also expressed the need for recognition and attention of the impact of the disease on partners, as it may be difficult for them to cope with. For example, it might be easier for patients to accept the risks of high-risk surgery than for their partner. Providing more attention to partners of patients in the entire care process was therefore suggested.

Table 13. Illustrative quotes on support for emotional impact of disease is adequate, but need for recognition impact on partner

"I became much more emotional after the operation. I've never had that before. My kids also said, 'I don't really recognize my father like that'." **– Patient 2 (71-year-old male)**
"No. I have my own network, both friends and colleagues and privately. So no, I didn't feel the need to talk to someone else about it." **– Patient 11 (52-year-old male)**
"It's really difficult for the partners. People often forget about this. If you want another area for improvement: more attention for the partner" **– patient 5 (78-year-old male)**

DISCUSSION

This study focused on the experiences and needs of complex skin cancer patients, who had undergone surgical treatment by a dermatologist and subsequent reconstruction by a plastic surgeon, and revealed a range of themes which could be used as input to organize patient-centered care for this unique patient group.

Several needs regarding healthcare providers emerged which are reflected in patients' experiences and needs regarding the entire care process. Consistent with various previous studies, both in- and outside the field of (skin)cancer, patients emphasized the importance of a friendly physician who provides clear and honest information.[34-39] Particularly the need for clear information seems a profound need among patients. Although patients in our study were generally satisfied with the provided information, the need for improved information (provision) reflects through all phases of the care process. They suggested to provide more comprehensive written information, which is currently being implemented in our department. Aside from receiving clear and honest information, the need for physicians to tailor information and communication to individual patients was identified. To enhance patient-centered care, it is therefore advocated to improve information provision and to adapt it to individual patients. This could be achieved by improving communication skills (e.g., increased focus on shared decision-making) in the medical curriculum and by using tools such as question prompt lists or patient-reported outcome measures.[40-42]

Complex skin cancer patients also expressed the need for continuity of care and improved collaboration between healthcare providers. A need for continuity of care, defined as a continuous caring relationship with a healthcare provider, was also identified in qualitative studies focusing on (non-complex) skin cancer patients.[27,43] According to patients, this strengthens the bond with their physician. Continuity of care is associated with various positive outcomes including decreased chance of hospitalization, costs reduction and improved compliance with medical regimes.[44-47] The need for optimal collaboration between healthcare providers, may not be surprising as their care process is a complex step-by-step process, involving multiple healthcare providers. According to patients this process could be improved, as they experienced that healthcare providers sometimes communicate past each other. Related to this, patients indicated to prefer multiple follow-up visits of different medical specialties to be planned on the same day, which also demands effective collaboration between medical departments.

With respect to experiences and needs regarding the care process, complex skin cancer patients had different needs regarding shared decision-making. Especially younger patients preferred to be involved in treatment decisions. On the contrary, elderly patients preferred the physician to make the decision for them, as they believed the physician is the expert. This is consistent with previous studies indicating older patients are less likely to participate in shared decision-making.[48,49] Being able to adjust the frequency of follow-up visits to a patient's own needs was also experienced positively by patients and probably contributes to their satisfaction with the frequency of follow-up visits. Furthermore, patients recognized the high emotional impact of the disease. Whereas they considered their own received support as adequate, they emphasized the need for recognition of the impact of the disease for their partner. It is therefore advocated for physicians to be sensitive to the needs for psychological support of both patients and their partners, as partners are known to be an essential source of social support for patients.[50] Improved collaboration between healthcare providers of different disciplines, such as medical specialists, social workers and psychologists, has demonstrated to facilitate the identification of unmet physical and psychosocial needs.[11,12,51]

Although cosmetic outcome is also important, the most important aspect for complex skin cancer patients is that the tumor is completely removed. However, patients also reported complications and unmet expectations. Even after seeing pictures before the surgery, patients did not expect the size of the facial scars to be that large. Previous research already has revealed a gap in the communication between surgeons and patients about the expectations of scarring due to surgery.[52] Discrepancies in expectations could be addressed in guidelines to educate surgeons on the impact of (even minor) facial scars to patients.[52] It also, once more, emphasizes the importance of improved information and communication.

Results of this study imply that in order to improve patient-centered care for complex skin cancer patients, information, communication, as well as wider care aspects should be tailored to individual patients and their partner. This is in line with recent trends of individualizing care based on the individual needs of patients. Besides improving information and communication skills of physicians, shared decision-making tools (decision aids) can be used in the care process.[53,54] In addition, healthcare applications (apps) may be used to stimulate personalized information provision for patients. As far as these apps are integrated within the care pathways, they may also facilitate personalized (follow-up) care and improve coordination between healthcare providers.[55,56] Several studies have shown that patient centered or personalized care improves patient experiences and outcomes.[57,58]

A limitation of this study was that we only interviewed patients of one academic hospital. Although qualitative research is always context specific,[59] the generalizability of our findings increases as we reached maximum variation in our sample of patients in terms of relevant characteristics (e.g. age, sex and diagnosis). A strength of our study is that our qualitative study, using a thorough methodology, to our knowledge is the first study providing an in-depth understanding of the experiences and needs of patients with complex skin cancer.

In conclusion, the current study provides insight into the experiences and needs of complex skin cancer patients and provides suggestions to improve patient-centered care. Continuity of care and improved collaboration between heath care providers is essential for this group of patients. Furthermore, given the differences in experiences and needs within these patients, it is advocated for physicians to be sensitive to the individual needs of patients and adapt their information, communication and care accordingly. This should not be limited to the walls of the hospital, but also include the wider context, for instance by also focusing on interdisciplinary collaborations and by offering psychological support to partners of patients.

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Chapter 4.1

What are the most important factors in basal cell carcinoma follow-up care? The perspective of patients

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Accepted for publication in Skin Health and Disease

Dear editor,

Basal cell carcinoma (BCC) is the most common type of (skin)cancer worldwide in Caucasians and its incidence is still rising.[1] The high incidence of basal cell carcinoma (BCC) causes substantial burden on healthcare systems. This demands resources to be used efficiently, depending on the healthcare system, for example by de-adopting low-value care or substituting low-risk skin cancer care to primary care[2,3] Aside from being efficient, care should be tailored to the needs and values of patients (i.e. patient-centred care).[4] Insight into the patient perspective is therefore crucial.

Previous qualitative studies among patients with BCC revealed that they prefer a physician who takes them seriously and communicates well, to receive all relevant information including a proper explanation, and to be seen by the same physician each time.[2,5] In addition, they value several disease-specific factors such as a short waiting period for the best available treatment and regular follow-up care including a full body skin examination in order to reduce their fear and to detect new tumours early.[2,5]

Although an overview of the needs of patients with BCC is informative, qualitative research does not allow us to draw conclusions on the relative importance of each of these factors to patients. For dermatologists to be able to effectively tailor their follow-up care to the needs and preferences of patients, it is useful to assess which factors are considered most important to them. The aim of this study was therefore to determine the relative importance of factors regarding follow-up care to patients with BCC.

A ranking list questionnaire was developed (see eSupplement), based on the needs of patients elicited from previous qualitative studies.[2,5] The list consisted of five items regarding the patient-physician relationship, five disease-specific items and two external items (Table 1). One hundred and one consecutive BCC patients from the department of Dermatology Erasmus Medical Center (Rotterdam, The Netherlands) were asked to participate following their outpatient clinic visit with a physician for their BCC (diagnostic or follow-up visit). After providing written informed consent, participants ranked the items from 1 (most important) to 12 (least important). The items were subsequently aggregated to include patient-physician relationship factors (items 1,2,4,5,7), disease-specific factors (items 3,6,8,9,10) and external factors (items 11,12). To test the differences between groups of factors, the Wilcoxon signed-rank test was used in SPSS v24. The highest ranked group of factors was compared to the second highest group and the second highest group was tested for statistically significant difference to the third group. A p-value <0.05 was considered statistically significant.

All of the 101 approached BCC patients completed the questionnaire (100% response rate). About one-third of patients were diagnosed with BCC for the first time, the median age was 66 years and 56% were female. They scored patient-physician related factors as most important, with 'explanation of the seriousness of the skin cancer' as the most important factor regarding BCC care (Table 1). The second most important factor

Table 1. BCC follow-up care needs, ranked by 101 BCC patients (lower median equals more important)

	Ranking **Median (IQR)**	
Age (years)	68 (58-75)	
Male	45%	
Items*		
1. Explanation of the seriousness of skin cancer	3	(2-5)
2. Feeling that the physician listens well to the patient	4	(1-6)
3. Full skin examination during follow-up appointment	4	(2-7)
4. Being seen by the same physician	5	(2-9)
5. Explanation of the follow-up procedure and self-examination of the skin	5	(3-8)
6. Early detection of skin cancer	6	(3-10)
7. Type of care provider (DE, GP, NP)	7	(5-8)
8. Side effects of skin cancer treatment	7	(5-9)
9. Frequency of follow-up screening interval	7	(5-9)
10. Duration of the follow-up appointment (5-20 minutes)	9	(6-10)
11. Costs of follow-up care	11	(9-12)
12. Travel costs and/or travel time	11	(10-12)
Aggregated Items		
Items regarding patient-physician relationship (1, 2, 4, 5, 7)	5	(3-6)
- **Reference**	-	
Items regarding disease-specific factors (3, 6, 8, 9, 10)	7	(5-7)
- Z-score compared to patient-physician relationship	4.5 ($p<0.001$)	
Items regarding external factors (11, 12)	11	(9.5-11.5)
- **Z-score compared to disease-specific factors**	7.9 ($p<0.001$)	

BCC, basal cell carcinoma; IQR, interquartile range; DE, dermatologists; GP, general practitioner; NP, nurse practitioners
*Items are ordered based on ranking score

to patients is the 'feeling that the physician listens well to the patient'. Patients ranked patient-physician related factors higher than disease-specific factors ($p<0.001$). Of the disease-specific factors they ranked 'full skin examination during follow-up appointment' and secondly 'early detection of skin cancer' as most important. The external factors (costs and travel time) were considered least important (compared to disease-specific factors; $p<0.001$).

Whereas physicians traditionally tend to focus on disease-oriented aspects and outcomes,[6] this study highlights the importance of patient-centred aspects of care to BCC patients. Particularly explanation of the seriousness of the skin cancer and the feeling that the physician listens well were considered important to patients. This is consistent with previous studies showing that physicians' interpersonal skills largely determine patient satisfaction.[7] To facilitate physician-patient communication, training programmes for physicians which include active, practice-oriented strategies have been proven to be effective.[8] Of the disease-specific factors, patients ranked a full body skin examination as most important followed by early detection of skin cancer. Although dermatologists perform routinely full body skin examinations more often than GPs and internists (81% versus 60% and 56% respectively), there is still room for improvement.[9]

A limitation of the current study is that only patients from a single university medical centre were included. However, the patients characteristics of our sample correspond well to those of the average BCC patients, which Increases the generalisability of our results.

In conclusion, findings from this study emphasize the importance of integrating patient-physician relationship factors with traditional medically orientated aspects of BCC care. This is especially relevant because increased patient satisfaction results in increased compliance and subsequently improved health outcomes.[10] Results of this study are currently used in a discrete choice experiment to determine which trade-offs stakeholders are willing to make to integrate these aspects in skin cancer care.

ACKNOWLEDGEMENTS

This study was funded by VGZ (Health insurance company). The funder had no involvement in study design, data collection, data analysis, manuscript preparation and/or publication decisions.

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Chapter 4.2

What do patients and dermatologists prefer regarding low-risk basal cell carcinoma follow-up care? A discrete choice experiment

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ABSTRACT

Background: Follow-up after low-risk basal cell carcinoma (BCC) is being provided more frequently than recommended by guidelines. To design an acceptable strategy to successfully reduce this 'low-value' care, it is important to obtain insights into the preferences of patients and dermatologists.

Objectives: To determine the preferences and needs of patients and dermatologists to reduce low-risk BCC follow-up care, and the trade-offs they are willing to make.

Methods: Eighty-four dermatologists and 266 BCC patients (21% and 72% response rates respectively) completed a discrete choice experiment. A panel latent class model was used for analysis.

Results: If the post-treatment visit was performed by the same person as treatment provider and a hand-out was provided to patients containing personalised information, the acceptance of having no additional follow-up visits (i.e. following the guidelines) would increase from 55% to 77% by patients. Female patients and older dermatologists, however, are less willing to accept the guidelines and prefer additional follow-up visits.

Limitations: The low response rate of dermatologists.

Conclusion: This discrete choice experiment revealed a feasible strategy to substantially reduce costs, while maintaining quality of care, based on the preferences and needs of BCC patients, which is supported by dermatologists.

INTRODUCTION

Basal cell carcinoma (BCC) is a subtype of keratinocyte cancer and the most common type of cancer among Caucasians.[1] The probability that a BCC metastasizes or causes death is low, but BCCs can cause significant morbidity by local spread. Most BCCs are treated relatively simple by excision or even topical treatment for certain low-risk BCCs.[2,3]

The high and rising incidence of BCC puts healthcare systems under pressure.[4] To manage finite resources, low-value care (i.e. care which provides no or little clinical benefit to patients) should be reduced.[5] Current guidelines recommend to provide follow-up care to high-risk BCC patients, which implies that providing follow-up to low-risk BCC patients (i.e. primary BCC, < 2 cm, located outside the H-zone, with a nodular or superficial subtype) is considered low-value care. Evidence is lacking that increased follow-up care leads to improved health outcomes.[6,7] However, a recent study shows that Dutch dermatologists still provide low-value follow-up care to 83% of low-risk BCC patients.[8]

Qualitative interviews with dermatologists and focus groups with BCC patients revealed the factors influencing this low-value care, such as the wishes of patients to remain in dermatological follow-up and dermatologists complying with patients wishes.[9,10] In order to design a successful strategy to de-adopt low-value BCC follow-up care, it is important to learn how important each of these factors are to the patients and dermatologists. Therefore, this study aimed to quantify the preferences of BCC patients and dermatologists, and to determine which trade-offs they are willing to make to accept a reduction of low-risk BCC follow-up.

METHODS

Study sample

BCC patients

Dutch speaking patients, 18 years or older, presenting at the dermatologists with a lesion that was clinically suspicious of BCC or recent biopsy confirmed BCC were approached by their treating dermatologist to participate. These were patients from one university hospital (Erasmus MC), three general hospitals (Elisabeth-TweeSteden Hospital, Amphia Hospital, Bravis Hospital) and two independent sector treatment centres (DermaPark, Mohs Klinieken) in the Netherlands. Patients received an envelope containing information about the study, an informed consent form, a questionnaire which included a Discrete Choice Experiment (DCE) and a pre-paid return envelope. All patients who agreed to participate returned a signed informed consent form to participate in the current study, which was approved by the Medical Ethical Committee of the Erasmus MC (MEC-2014-374). Patients were excluded afterwards if the pathologist concluded that the lesion was not a BCC.

Dermatologists

All dermatologists and dermatology residents in the Netherlands (from here onward both mentioned as dermatologists) received an email with a digital link to the questionnaire containing the same DCE as the patients. Additionally, dermatologists were encouraged to complete the questionnaire during a national conference.

DCE: Attributes and levels

The DCE concept originates from mathematical psychology, but has increasingly found its way into healthcare.[11] A DCE repeatedly presents varying alternative situations to respondents and asks them to choose their most preferred alternative.[12] The DCE method assumes that each alternative can be described by their characteristics ("attributes"), that the respondent's valuation of the alternative depends on the levels of these attributes, and that the choices are based on a latent utility function.[13] In a DCE, preferences for health outcomes and non-health outcomes can be taken into account simultaneously.[14] This makes the DCE an ideal method to measure preferences for aspects of low-risk BCC follow-up visits, and to determine how to reduce this care without trial-and-error-implementation.

In addition to a literature review,[15-21] we constructed our DCE based on focus groups with BCC patients and interviews with dermatologists to carefully detect and select relevant attributes.[9,10,13] This ultimately led to the final determination of six attributes (Table 1).

Study design and questionnaire

Based on the six attributes and their levels, many different choice alternatives and choice tasks can be generated. It is not feasible to present all possible combinations to a respondent without creating an unreasonably long questionnaire. In order to achieve maximum efficiency from the minimum amount of 'choice tasks' needed (i.e. to counterbalance statistical needs and the burden for the respondent), a D-efficient design was created using Ngene software (http://www.choice-metrics.com).[22] We took two-way interactions between the attributes 'The additional follow-up visit(s) will be planned' and 'The additional follow-up visit(s) will be conducted by' into account, based on the outcomes of the qualitative study. We created a set of 24 choice tasks, which was blocked[14] in two sets of twelve for BCC patients and a full set was presented to dermatologists, as we expected the sample size as well as the response rate of dermatologists to be smaller. Each choice task contained three alternatives: two alternatives containing

Table 1. Attributes and levels of the discrete choice experiment on low-risk BCC follow-up care.

Attributes	**Attribute Levels**
Standard post-treatment visit performed:	Not by same person as treatment provider (Ref) By the same person as treatment provider
In addition to oral information, extra information[1] will be provided by:	E-health (Ref) Personalised Letter General hand-out General website
The additional follow-up visit(s) will be planned:	1 year after treatment (Ref) 6 and 12 months after treatment[2] 1 and 2 years after treatment
The additional follow-up visit(s) will be conducted by:	Nurse practitioner (Ref) General practitioner Dermatologist
The duration of the additional follow-up visit(s) will be:	5 minutes (Ref) 10 minutes 15 minutes
Part of skin to be checked during the additional follow-up visits	Face, upper body and treated area (Ref) Full body

Abbreviations: Ref, Attribute of reference

[1] Extra information about severity of disease, prognosis, further treatment and/or follow-up and self-examination instructions. Which could be general information, or personalised via E-health or personalised letter.

[2] Both visits within the time frame of one diagnosis-related group (DRG).

BCC follow-up schemes and one alternative to choose 'no additional BCC follow-up' (i.e. following the guideline)

In addition, to simulate real life choices as close as possible, the corresponding real-life costs of each follow-up scenario were shown. Each attribute was explained in the survey before the choice tasks were presented. To test choice consistency, an extra choice task 13 was included, which was identical to choice task 4. Demographic questions were added to the questionnaire. The questionnaire including the DCE was pilot tested using think-aloud technique on a random group of 22 BCC patients and ten dermatologists, where they could ask for clarification when needed and to test if the length was acceptable. The DCE was clear to these patients and dermatologists and did not lead to any changes.

Sample size

The results of the pilot were used to determine that 250 BCC patients were required to complete the DCE.[23] By taking an expected response rate of 70% into account,[24-26] we invited 371 patients. As the response rate of physicians is notoriously low,[27-29] we invited all dermatologists and dermatology residents (n=620) in the Netherlands.

Statistical analyses

The analyses were conducted by using Stata 4.2 (http://www.stata.com) and NLOGIT 5.0 (Econometric Software Inc.[30]). Each choice task was considered as one observation. To take the sample size, the fact that one respondent completed 12-24 choice tasks, the model fit and our interest in preference heterogeneity into account, a panel latent class analysis (LCA) was conducted for the final analyses. An LCA determines whether patterns in preferences (i.e. latent classes of preferences) exist and provides a modelled probability for each respondent to belong in a certain class.[31] Demographic covariates retrieved from the questionnaire were linked to the probability that respondents belonged to a specific class, in order to determine the composition of the classes. Taking the smaller sample size of dermatologists into account, without demographic covariates that could be linked to specific classes, a more simplistic model (Multinomial logit with interaction terms of the demographic covariates with the attribute-levels) was conducted. We performed a sensitivity test by excluding respondents who failed the consistency test (i.e. choosing different alternatives on the identical choice tasks) from the analyses. After testing for two-way interactions and attribute linearity, the optimal latent class utility function was:

Scenario with additional follow-up visits:

$$\begin{aligned}
V(alt1)_{nsj|c} = {} & \beta_{1|\mathrm{c}} \text{ same healthcare professional}_{\mathrm{nsj|c}} \\
& + \beta_{2|c} \text{ additional information by personalised letter}_{\mathrm{nsj|c}} \\
& + \beta_{3|c} \text{ additional information by general handout}_{\mathrm{nsj|c}} \\
& + \beta_{4|c} \text{ additional information by general website}_{\mathrm{nsj|c}} \\
& + \beta_{5|c} \text{ additional followup at 6 and 12 months after treatment}_{\mathrm{nsj|c}} \\
& + \beta_{6|c} \text{ additional followup at 1 and 2 years after treatment}_{\mathrm{nsj|c}} \\
& + \beta_{7|c} \text{ additional followup conducted by general practitioner }_{\mathrm{nsj|c}} \\
& + \beta_{8|c} \text{ additional followup conducted by dermatologist}_{\mathrm{nsj|c}} \\
& + \beta_{9|c} \text{ duration of additional followup visit 10 minutes}_{\mathrm{nsj|c}} \\
& + \beta_{10|c} \text{ duration of additional followup visit 15 minutes }_{\mathrm{nsj|c}} \\
& + \beta_{11|c} \text{ inspected skin part full body }_{\mathrm{nsj|c}}
\end{aligned}$$

$$\begin{aligned}
V(alt2)_{nsj|c} = {} & \beta_{1|\mathrm{c}} \text{ same healthcare professional}_{\mathrm{nsj|c}} \\
& + \beta_{2|c} \text{ additional information by personalised letter}_{\mathrm{nsj|c}} \\
& + \beta_{3|c} \text{ additional information by general handout}_{\mathrm{nsj|c}} \\
& + \beta_{4|c} \text{ additional information by general website}_{\mathrm{nsj|c}} \\
& + \beta_{5|c} \text{ additional followup at 6 and 12 months after treatment}_{\mathrm{nsj|c}} \\
& + \beta_{6|c} \text{ additional followup at 1 and 2 years after treatment}_{\mathrm{nsj|c}} \\
& + \beta_{7|c} \text{ additional followup conducted by general practitioner }_{\mathrm{nsj|c}} \\
& + \beta_{8|c} \text{ additional followup conducted by dermatologist}_{\mathrm{nsj|c}} \\
& + \beta_{9|c} \text{ duration of additional followup visit 10 minutes}_{\mathrm{nsj|c}} \\
& + \beta_{10|c} \text{ duration of additional followup visit 15 minutes }_{\mathrm{nsj|c}} \\
& + \beta_{11|c} \text{ inspected skin part full body }_{\mathrm{nsj|c}}
\end{aligned}$$

Scenario without additional follow-up visits:

$$V(alt3)_{nsj|c} = \beta_{12|c} + \beta_{13|c}\text{same healthcare professional}_{nsj|c} + \beta_{14|c}\text{ additional information by personalised letter}_{nsj|c} + \beta_{15|c}\text{ additional information by general handout}_{nsj|c} + \beta_{16|c}\text{additional information by general website}_{nsj|c}$$

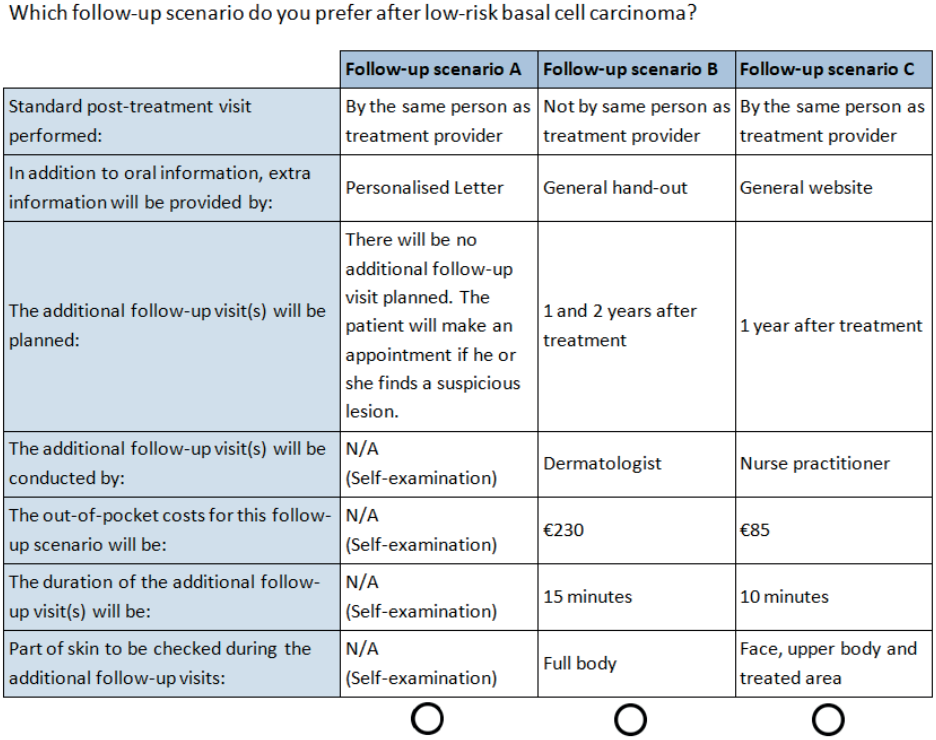
Where

Vnsj|c	represents the observable utility that respondent 'n' belonging to class segment 'c' has for alternative 'j' in choice set 's';
alt	represent the three alternatives in the choice set;
β 12|c	represent an alternative-specific constant for the 'no additional BCC follow-up scenario' compared to the 'additional BCC follow scenario' for a certain class;
β 1-11|c	are class-specific parameter weights (coefficients) associated with the attributes of the DCE to provide additional follow-up;
β 13-16|c	are class-specific parameter weights (coefficients) associated with the attributes of the DCE to not provide additional follow-up.

A statistically significant coefficient of an attribute(level) shows that the attribute is important for the respondents in their decision to accept a certain BCC follow-up. The sign of the coefficient shows whether they prefer (positive sign) or disfavour (negative sign) the particular level of the attribute. The size of the coefficients indicates the relative importance (bigger equals more important).

Expected choice probability of BCC follow-up scenarios

To make DCE results more practical for policy makers, we calculated choice probabilities for several scenarios. To simulate current practice, the alternative 'current intensive (and expensive) BCC follow-up practice' was fixed at the following attribute levels: standard post-treatment visits performed by a different person treatment provider, extra information provided by a general handout, two additional follow-up visits in a year conducted by a dermatologist and a ten minute consultation during which the face, upper body and treated area is checked. The choice probabilities were calculated with different scenarios of 'no BCC follow-up according to guideline', to determine the optimal choice probability. The scenarios are based on previous qualitative studies.[9,10]



Which follow-up scenario do you prefer after low-risk basal cell carcinoma?

	Follow-up scenario A	Follow-up scenario B	Follow-up scenario C
Standard post-treatment visit performed:	By the same person as treatment provider	Not by same person as treatment provider	By the same person as treatment provider
In addition to oral information, extra information will be provided by:	Personalised Letter	General hand-out	General website
The additional follow-up visit(s) will be planned:	There will be no additional follow-up visit planned. The patient will make an appointment if he or she finds a suspicious lesion.	1 and 2 years after treatment	1 year after treatment
The additional follow-up visit(s) will be conducted by:	N/A (Self-examination)	Dermatologist	Nurse practitioner
The out-of-pocket costs for this follow-up scenario will be:	N/A (Self-examination)	€230	€85
The duration of the additional follow-up visit(s) will be:	N/A (Self-examination)	15 minutes	10 minutes
Part of skin to be checked during the additional follow-up visits:	N/A (Self-examination)	Full body	Face, upper body and treated area
	○	○	○

Figure 1. Choice task example of the discrete choice experiment

The expected choice probability scenarios are calculated on LCM results, by which the exponent of the total utility for a certain alternative was taken and divided by the exponent of utility of all alternatives in that scenario taking the class probabilities into account. The 'current intensive BCC follow-up practice' and 'no BCC follow-up according guideline' were chosen to resemble real life situations to determine which scenario without low-value follow-up visits is the most acceptable scenario by patients.

RESULTS

Respondents' characteristics

A total of 266 patients (72% response rate) and 131 dermatologists (21% response rate) completed and returned the questionnaire. Twelve dermatologists (9.1%) and 49 BCC patients (18%) failed the consistency test), however excluding these respondents only affected the significance due to lower sample size, therefore all respondents were included in the final analysis. The characteristics of the BCC patients and dermatologists are displayed in Table 2.

Table 2. BCC Patients' and dermatologists' characteristics

	Patients (n=266)	**Dermatologists (n=131)**
Age, *mean years (SD)*	67.2 (12.3)	42.9 (10.9)
Male	49.6%	36.6%
Type of healthcare centre		
- **University hospital**	32.7%	21.4%
- **General hospital**	35.7%	24.4%
- **ISTC**	31.6%	13.7%
- **Multiple types**	N/A	9.9%
- **Missing**	0	30.5%
Educational level		
- **Low**	29.3%	0%
- **Medium**	39.1%	0%
- **High**	28.2%	100%
- **Missing**	3.4%	0%
Income[1]		
- **Low**	17.3%	N/A
- **Medium**	27.8%	N/A
- **High**	46.2%	N/A
- **Missing**	8.6%	N/A
History of skin cancer		
- **BCC**	34.2%	N/A
- **Other type**	9.8%	N/A
- **None**	54.9%	N/A
- **Missing**	1.1%	N/A
EQ-VAS score, *Mean (SD)*	80.9 (13.5)	N/A
Occupation		
- **Dermatologist**	N/A	76.3%
- **Dermatology resident**	N/A	22.9%
- **Missing**	N/A	0.8%
Working experience (including residency) *Mean years (SD)*	N/A	13.8 (10.7)
Subspecialisation in dermato-oncology		
- **Yes**	N/A	26.9%
- **No**	N/A	32.7%
- **Missing**	N/A	40.4%

SD, standard deviation; ISTC, Independent sector treatment centre; BCC, Basal cell carcinoma; EQ-VAS, EuroQol visual analogue*scale; N/A, not applicable*

[1] Low, medium and high income represents <€1.500, €1.500-€2.500 and >€2.500 net monthly personal income respectively

Latent class analysis of patients and dermatologists

BCC patients

Three latent classes of preference patterns were identified for the BCC patients, with class probabilities for class 1, 2 and 3 being 13%, 46% and 41% respectively (Table 3). The patients belonging to class 1 did not have a significant preference regarding receiving additional follow-up care. However, if they would receive additional follow-up care, they would strongly prefer this to be conducted by their general practitioner (GP). These were predominantly patients older than 65 years without a BCC in their medical history. The BCC patients belonging to class 2 had a strong preference to receive additional follow-up care. They preferred two additional follow-up visits at 6 and 12 months after treatment, conducted by a dermatologist and to have the standard post-treatment visit performed by the same person as the treatment provider. In addition, they would prefer to receive a personalised letter and preferred the follow up visits to include a total-body skin examination. The respondents with high probability to belong to this class were mainly women. The patients belonging to the third class strongly preferred no additional follow-up visits and if there would be additional follow-up, they would prefer the standard post-treatment visit performed by the same person as the treatment provider and the follow-up visit to last 15 minutes and to be conducted by their GP.

Table 3. Latent class analysis of BCC patients' (n=266) preferences regarding BCC follow-up care

	Class 1			**Class 2**			**Class 3**		
	Co-efficient	s.e.	p-value	Co-efficient	s.e.	p-value	Co-efficient	s.e.	p-value
With additional follow-up visit(s)									
Standard post-treatment visit performed:									
Not by same person as treatment provider (Ref)	0.16			-0.27			-0.48		
By the same person as treatment provider (β1)	-0.16	1.655	0.92	0.27	0.043	<0.01	0.48	0.139	<0.01
In addition to oral information, extra information will be provided by:									
E-health (Ref)	-0.75			0.03			-0.09		
Personalised Letter (β2)	1.45	4.298	0.74	0.14	0.097	0.15	-0.13	0.343	0.71
General hand-out (β3)	0.00	1.384	>0.99	0.04	0.102	0.72	0.10	0.269	0.71
General website (β4)	-0.70	3.540	0.84	-0.21	0.108	0.05	0.12	0.318	0.69
The additional follow-up visit(s) will be planned:									
1 year after treatment (Ref)	1.50			-0.06			0.28		
6 and 12 months after treatment (β5)	-0.40	2.676	0.88	0.15	0.053	<0.01	0.08	0.201	0.70
1 and 2 years after treatment (β6)	-1.10	1.650	0.50	-0.09	0.068	0.18	-0.36	0.190	0.06

Table 3. Latent class analysis of BCC patients' (n=266) preferences regarding BCC follow-up care (*continued*)

	Class 1			Class 2			Class 3		
	Co-efficient	s.e.	p-value	Co-efficient	s.e.	p-value	Co-efficient	s.e.	p-value
The additional follow-up visit(s) will be conducted by:									
Nurse practitioner (Ref)	-1.31			0.06			-0.58		
General practitioner (β7)	4.23	1.540	<0.01	-0.18	0.467	<0.01	1.31	0.154	<0.01
Dermatologist (β8)	-2.92	1.355	0.03	0.12	0.052	0.02	-0.73	0.240	<0.01
The duration of the additional follow-up visit(s) will be:									
5 minutes (Ref)	-1.16			-0.16			-0.26		
10 minutes (β9)	2.28	1.243	0.07	0.05	0.079	0.56	-0.17	0.208	0.41
15 minutes (β10)	-1.12	1.191	0.35	0.11	0.070	0.12	0.43	0.173	0.01
Part of skin to be checked during the additional follow-up visits:									
Face, upper body and treated area (Ref)	0.55			-0.11			-0.01		
Full body (β11)	-0.55	0.472	0.24	0.11	0.029	<0.01	0.01	0.152	0.94
Without additional follow-up visit									
Constant (no follow-up) (β12)	0.50	1.352	0.71	-2.15	0.115	<0.01	2.87	0.178	<0.01
Standard post-treatment visit performed:									
Not by same person as treatment provider (Ref)	-0.88			-0.59			0.13		
By the same person as treatment provider (β13)	0.88	0.770	0.25	0.59	0.148	<0.01	-0.13	0.235	0.59
In addition to oral information, extra information will be provided by:									
E-health (Ref)	-1.21			0.00			0.26		
Personalised Letter (β14)	1.20	3.045	0.69	0.00	0.241	>0.99	-0.13	0.235	0.59
General hand-out (β15)	-0.51	1.787	0.78	-0.23	0.286	0.43	-0.25	0.266	0.34
General website (β16)	0.52	3.487	0.88	0.23	0.247	0.36	0.12	0.329	0.72
Class probability model									
Constant	-2.23	1.405	0.11	0.77	0.340	0.02	-		
Gender (male)	0.09	0.786	0.91	-1.45	0.377	<0.01	-		
Older age (≥65 years)	1.82	1.074	0.09	0.04	0.372	0.91	-		
Medical history of BCC (yes)	-0.58	0.016	<0.01	0.00	0.000	0.79	-		
Class probabilities (%)									
Average	13			46			41		
Log Likelihood: -1675.151									

Effects coding was used to determine the effects of all attribute levels.[32]

BCC, Basal cell carcinoma; s.e., standard error; Ref, Reference

Choice probabilities of BCC follow-up alternatives

The choice probability of 'No BCC follow-up according to guideline' was 55% if the standard post-treatment visit would not be performed by the same person as the treatment provider and if patients would receive a general hand-out compared to 'Current intensive BCC follow-up'. This choice probability of 'No BCC follow-up according to guideline' increased from 55% up to 77%, if the standard post-treatment visit would be performed by the same person as treatment provider and if patients were offered a personalised handout as additional information. (Fig 2).

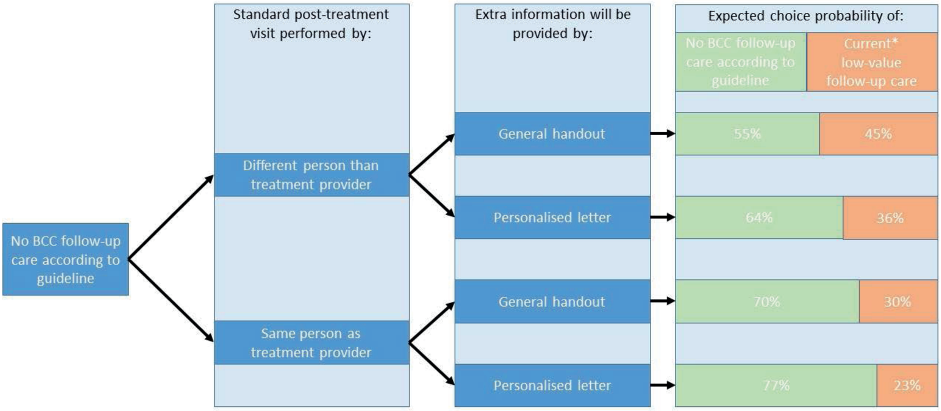


Figure 2. Expected patient choice probabilities of different BCC follow-up scenarios based on latent class model
*standard post-treatment visits performed by a different person than treatment provider, extra information provided by a general handout, two additional follow-up visits in a year conducted by a dermatologist and a ten minute consultation in which the face, upper body and treated area are checked.

Dermatologists

Two classes could be identified in the LCA regarding dermatologists (Table 4). The dermatologists belonging to class 1 strongly preferred no additional follow-up visits (i.e. according to the guideline). This contrasts with the dermatologists belonging to class 2, who strongly preferred additional follow-up visits, which they would prefer to be conducted by a dermatologist and include a total-body skin examination. The average class probabilities were 71% for class 1 and 29% for class 2. No covariates could significantly explain the latent class probabilities for dermatologists.

Multinomial logit with interaction terms of dermatologists

To test for interaction, the covariates age over 40 years, male gender and subspecialisation in oncology were multiplied with the strongest identifier of the classes: 'no

Table 4. Latent class analysis of dermatologists' (n=131) preferences regarding BCC follow-up care

	Class 1			**Class 2**		
	Co-efficient	s.e.	p-value	Co-efficient	s.e.	p-value
With additional follow-up visit(s)						
Standard post-treatment visit performed:						
Not by same person as treatment provider (Ref)	-0.94			-0.11		
By the same person as treatment provider (β1)	0.94	0.210	<0.01	0.11	0.125	0.38
In addition to oral information, extra information will be provided by:						
E-health (Ref)	0.30			0.19		
Personalised Letter (β2)	-0.32	0.337	0.34	-0.16	0.232	0.49
General hand-out (β3)	0.17	0.263	0.52	0.23	0.212	0.28
General website (β4)	-0.15	0.269	0.57	-0.26	0.211	0.21
The additional follow-up visit(s) will be planned:						
1 year after treatment (Ref)	0.75			0.48		
6 and 12 months after treatment (β5)	-0.59	0.292	0.04	-0.04	0.153	0.82
1 and 2 years after treatment (β6)	-0.16	0.264	0.55	-0.44	0.168	<0.01
The additional follow-up visit(s) will be conducted by:						
Nurse practitioner (Ref)	-0.31			0.13		
General practitioner (β7)	0.13	0.233	0.58	-0.91	0.184	<0.01
Dermatologist (β8)	0.18	0.253	0.47	0.78	0.184	<0.01
The duration of the additional follow-up visit(s) will be:						
5 minutes (Ref)	-0.12			0.18		
10 minutes (β9)	-0.18	0.268	0.51	-0.06	0.20	0.76
15 minutes (β10)	0.30	0.252	0.23	-0.12	0.16	0.44
Part of skin to be checked during the additional follow-up visits:						
Face, upper body and treated area (Ref)	0.06			-0.37		
Full body (β11)	-0.06	0.167	0.70	0.37	0.106	<0.01
Without additional follow-up visit						
Constant (no follow-up) (β12)	3.29	0.267	<0.01	-1.81	0.370	<0.01
Standard post-treatment visit performed:						
Not by same person as treatment provider (Ref)	-0.92			-0.58		
By the same person as treatment provider (β13)	0.92	0.201	<0.01	0.58	0.317	0.07
In addition to oral information, extra information will be provided by:						
E-health (Ref)	-0.36			0.72		
Personalised Letter (β14)	0.09	0.306	0.76	0.00	0.567	>0.99
General hand-out (β15)	0.22	0.294	0.46	-0.87	0.809	0.28
General website (β16)	0.05	0.328	0.88	0.15	0.519	0.78
Class probabilities (%)						
Average	71%			29%		
Log likelihood: -306.016						

Effects coding was used to determine the effects of all attribute levels.[32]
BCC, Basal cell carcinoma; s.e., standard error; Ref, Reference.

additional follow up'. This model demonstrated that predominantly young and male dermatologists preferred no additional follow-up for BCC patients ($p=<0.01$). Having a subspecialisation in oncology did not affect the preference for this attribute.

DISCUSSION

The current study quantified the preferences and needs of patients and dermatologists to accept a reduction of low-risk BCC follow-up care. We found that a reduction would be more acceptable if the post-treatment visit were to be performed by the same person as the treatment provider and additional information would be provided by a personalised letter for patients.

The observation of a preference for personalised letter as a feasible option to reduce low-value follow-up visits is supported by the preference for personalised information which was previously expressed in focus groups with BCC patients.[9] Other studies have also shown that personalised information satisfies cancer patients more than general information, as this tells them something new and is more often relevant to them.[33] A preference for continuity of care (e.g. same healthcare provider for treatment as post-treatment visit) has also been well documented to have positive effects on indicators of quality of care, such as increased patient satisfaction, decreased hospitalisations, decreased emergency department visits and improved receipt of preventive services.[34]

Mainly female patients preferred additional low-value BCC follow-up visits, conducted by a dermatologist. In contrast, predominantly male patients preferred to not receive additional follow-up, and should they get follow-up, they preferred the GP to conduct this. In contrast to studies where patients with other types of cancer preferred their follow-up care to be conducted by a medical specialist,[15,20] overall, the patients in our study preferred their GP for their follow-up care. This could be explained by the inclusion of the out-of-pocket costs in our DCE to make our scenarios as realistic as possible, which was linked to 'type of healthcare professional' and 'frequency of follow-up'. In addition, recent focus groups with low-risk BCC patients showed that they perceived their BCC as a not severe type of cancer and some patients actually preferred their GP to conduct follow-up care as he or she is closer to home and easier approachable.[10]

A limitation in this study is the low response rate of dermatologists. Although response rates are generally low among medical specialists (27%-68%),[26-29] the 21% in the current study was even lower. This could be explained by the facts that the DCE invitation was sent through a non-personal newsletter and that it encompassed a lengthy questionnaire. Additionally, we could not offer the physicians compensation and reminders could not be sent as they responded anonymously. This low participation may have led to a selection bias, as reflected in the mean age of the respondents being 43 years, which is lower than the nationwide mean age of dermatologists and residents.[35] The current study revealed that young male dermatologists preferred no additional follow-up care, which is in accordance with influencing factors explored in interviews with dermatologists.[10] Inclusion of older dermatologists would probably shift the results to more dermatologists preferring additional follow-up care, which would emphasize the need for a de-adoption strategy.

In conclusion, these results form a solid foundation for a feasible strategy to reduce the low-value BCC follow-up care, while maintaining quality of care. This follow-up would consist of having one healthcare provider for the initial treatment as well as the standard post-treatment evaluation combined with a personalised letter for the patient with information about their diagnosis, received treatment and personalised follow-up schedule. Further research is needed to determine whether implementation of this intervention will decrease the amount of low-value follow-up visits in practice, while maintaining patient satisfaction.

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Chapter 5

Efficacy, cost-effectiveness and budget impact of a personalized discharge letter for basal cell carcinoma patients to reduce low-value follow-up care

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ABSTRACT

Importance The incidence of keratinocyte carcinomas is high, rapidly growing and shows no signs of stabilizing, making it the fifth most expensive type of cancer in the Netherlands. Approximately 80% of keratinocyte carcinomas consist of basal cell carcinomas (BCC) with 50% being considered as low-risk tumors. Nevertheless, 83% of the low-risk BCC patients were found to receive more follow-up care than the Dutch BCC guideline recommends, which is limited to one visit post-treatment. More efficient management could reduce unnecessary follow-up care and related costs.

Objective To study the efficacy, cost-effectiveness and budget impact of a personalized discharge letter for low-risk BCC patients compared with usual care (no letter).

Design Model-based cost-effectiveness and budget impact analysis using individual patient data gathered via surveys.

Setting Multicenter; one academic hospital, three general hospitals, and two independent sector skin treatment centers.

Participants The study included 473 first-time BCC patients.

Intervention and control The intervention consisted of a personalized discharge letter in addition to usual care as defined in the Dutch BCC guideline, which consists of one follow-up visit post-treatment.

Main outcome measures The outcome measures were number of follow-up visits, costs and quality adjusted life years (QALY) per patient, incremental cost-effectiveness ratio and the budget impact.

Results A personalized discharge letter decreased the number of follow-up visits by 13% in the first year. The incremental costs after five years were -€26.38 per patient. The QALYs were 4.12 after five years and nearly equal in both groups. Using a five-year time horizon, the incremental cost-effectiveness ratio was expected to be -€9,446. The budget impact was -€2,9 million after five years.

Conclusion and relevance The distribution of a personalized discharge letter decreases the number of unnecessary follow-up visits and implementing the intervention in a large eligible population would results in substantial cost savings, contributing to restraining the growing BCC costs.

INTRODUCTION

Keratinocyte carcinoma (KC) is the most common malignancy worldwide with still rising incidence rates.[1-5] Of these carcinomas, basal cell carcinoma (BCC) is by far the most common type with a prevalence of 80% in Caucasian populations. The remaining 20% consists of cutaneous squamous cell carcinoma (cSCC).[2,6]In 2017, over 48,000 individuals were newly diagnosed with a BCC in the Netherlands and this increases by 8% annually.[7] This alarming growth of new cases results in a strain on dermatological care and budget.[8,9] Total KC costs are now 1,8 times higher compared to melanoma.[1,3,10] In addition to focusing on skin cancer prevention, interventions aimed at improving efficiency of care, especially in the case of high volume tumors such as the BCC, are equally essential to safeguard current care.

De-adoption of low-value care is a strategy that can be used to restrain costs. Low-value care is defined as "care that is unlikely to benefit a patient given the harms, costs, alternatives or preferences".[11] After a low-risk BCC, follow-up visits after the initial check-up can be labeled as low-value, because there is no evidence that extra follow-up provides a health benefit.[12,13] According to the Dutch BCC guideline, annual follow-up for BCC should therefore be limited to high-risk patients only. Dermatologists are recommended to check the scar of low-risk patients just once within 6-12 months after treatment and are advised to instruct patients in self-examination and provide additional information via brochures.[14] About 50% of the BCC patients are considered low-risk, but research has shown that 83% of these low-risk patients receive more follow-up than the guidelines recommend during the first five years after treatment.[3,15] There is currently no evidence that extra follow-up provides a health benefit. Therefore, care for low-risk BCC patients requires more efficient management and guideline adherence.

To avoid trial and error on de-adoption strategies, we conducted research on the needs and preferences of patients and dermatologists regarding current BCC management integrated within a choosing wisely project. BCC patients expressed the need for more information, tailored to their situation and indicated that this information would lower their need for frequent follow-up visits.[16] A discrete-choice experiment revealed that patients preferred a personalized printed discharge letter over other alternatives (e-health, general brochure or website).[17] These letters can contain relevant information on a patient's diagnosis, treatment, complications, follow-up and lifestyle recommendations. These letters improve the amount of received information and the self-management of patients by combining educational with personalized information.[18] Providing such a letter could reduce unnecessary follow-up visits among BCC patients and lower the costs of BCC management compared to current practice. The aim of this study was to explore the efficacy, cost-effectiveness and budget impact of a personalized discharge letter to first-time BCC patients in comparison with usual care.

METHODS

The efficacy, cost-effectiveness and budget impact were determined for the intervention consisting of the distribution of a personalized discharge letter in addition to usual care to first-time BCC patients, compared to usual care only. The principal outcome of effectiveness was the difference in the number of BCC related follow-up visits between both strategies. These results were used to conduct a cost-effectiveness analysis (CEA) and a budget impact analysis (BIA). A CEA compares the health outcomes with the costs of the intervention and control strategy per patient.[19] However, the decision to implement the intervention on a large scale also depends on the total budgetary impact. A CEA, followed by a BIA, allows decision-makers to foresee the entire expected impact of adopting the innovation in their local setting.[20,21] The analyses were performed according to the (inter)national guidelines of CEAs and BIAs as well as the CHEERS checklist for reporting.[22-26]

Study population and design

The study population consisted of patients with a first BCC who were included after treatment but prior to follow-up. Patients needed to be at least 18 years old and had to be able to speak Dutch. Patients with skin cancer prior to their first BCC were excluded. Patients were included in six healthcare centers in the Netherlands; one academic hospital, three general hospitals, and two independent skin sector treatment centers. All participants were asked to complete a survey at baseline and after three, six, and twelve months. Each survey consisted of general questions regarding demographics, their quality of life (based on the EQ-5D-3L questionnaire), the number of BCC related visits to the general practitioner (GP) and medical specialist, whether they received any subsequent skin cancer diagnosis and the SF-HLQ questionnaire to monitor the effects of a BCC on labor activities.[25,27]

First, the control patients were included in 2014 and their data were collected via surveys. These patients received usual care and could be offered general dermatological brochures, whichever the dermatologists considered appropriate. A discrete choice experiment was conducted in the control group, which showed that a printed personalized discharge letter could be a potential helpful intervention to reduce the need for unnecessary follow-up.[28,29] This personalized discharge letter contained information on the patient's diagnosis, treatment, chance of having a subsequent BCC, lifestyle recommendations, information on self-examination and advice for actions when new suspicious lesions would appear. An example of this letter can be found in appendix 1.

In 2016, new BCC patients were included in the study in the same health care centers after implementing the intervention, forming the intervention group. They received usual care with the personalized discharge letter post-treatment.

Efficacy

The efficacy of the intervention was expressed as the percentage reduction in BCC-related visits to a specialist during a period of one year between the control and intervention group.

Due to logistic errors in the distribution of the surveys in the intervention group, up to 47% and 45% of the participants did not respond at t=3 and t=6 months, respectively. This mainly resulted in missing data on the number of GP and specialist visits. The missing data were only correlated with age and therefore considered to be missing at random (MAR). The missing data were imputed with multiple imputation (MI) and pooled using SPSS® 26. With MAR data, MI increases the precision and reduces the level of bias compared to a complete case analysis.[30-32] The missing data were imputed and used for further modelling.

Cost-effectiveness analysis

The cost-effectiveness was estimated through decision modeling using a patient level health state transition model with a societal perspective. This decision model simulates potential effects on health outcomes and the costs that patients would have made over time to estimate the effect of the intervention.[19,22] The model consisted of several health states between which patients can transition once per cycle. The following health states were included: full recovery from first BCC, new BCC, new cSCC, new melanoma, death due to skin cancer and death due to other causes. Each cycle represented one year and allowed one transition from one state to another, except for death.

A schematic overview of the model structure can be found in Figure 1.

The patient characteristics of the survey were used to simulate a cohort of 10,000 hypothetical patients in the model. BCC is a condition with very low mortality rates; therefore, the incremental effects and costs were expected to stabilize after five years. To assess the stability of these incremental outcomes the model-based analysis was performed for a five- and ten-year time horizon. Each health state comes with certain costs and health utilities. Using a societal perspective, costs were accrued in different categories; medical costs, costs for patients and the costs of productivity losses. All costs were presented in euros (€) and converted to price level 2019 using the Dutch derived consumer price indices.[33] Costs were discounted by 4% and health outcomes by 1.5% according to the Dutch guideline for economic evaluations in healthcare.[25,34] Disaggregated total deterministic costs were used to express the impact on each cost category. The measured health outcomes were expressed in QALYs and calculated via the scores resulting from the EQ-5D-3L questionnaire. Full descriptions of the included costs, probabilities, utilities and their sources are provided in appendices 2 and 3. The efficacy results were used to model the number of appointments that were made. For the remaining four years, previous trial data were used.[35] The primary outcomes of

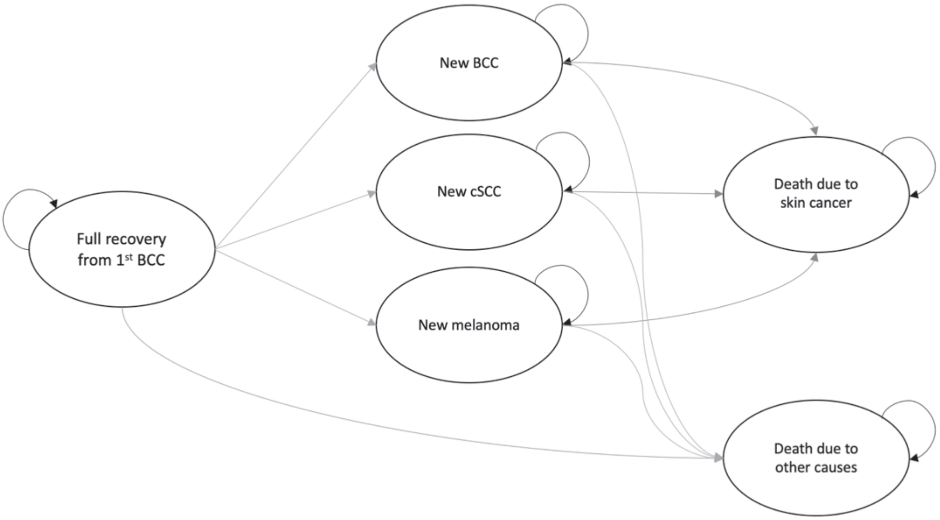

Figure 1. Schematic overview of the model
This model focuses on the effects of a personalized discharge letter on first-time BCC patients. Once patients receive a new diagnosis, they no longer meet the criteria of the first group. Expert consensus was reached over the fact that any new diagnosis might influence the effect of the letter, both positively and negatively. To solely model the effect of the letter, patients within the model cannot return to the first state once they have left it.

the model were the total and incremental costs and effects and the incremental cost-effectiveness ratio (ICER), which indicates the cost per QALY gained.[19]

To investigate the impact of the joint parameter uncertainty on the results, a probabilistic analysis (PA) was carried out. The PA shows how variation in the input of parameter values affected the outcomes of the model.[36] The PA was performed with 5,000 Monte Carlo simulations. The Monte Carlo simulation calculated the outcomes of the model by simultaneously drawing random parameter values from previously determined probability distributions. The health utilities were defined using a beta distribution, whereas the costs were defined using a gamma distribution. Variation in the number of appointments made was simulated using a Dirichlet distribution.[37] Prices were obtained from the Dutch Costing Manual or aggregated from national data and were therefore free of uncertainty.[38] As a result they were fixed (i.e., without distribution). The software related costs to facilitate the generation of the personalized discharge letter were estimated at €5,000 for the first hospital by an IT-specialist. Any additional hospital would have to pay an estimated €1,000 for implementation of the software. To address the uncertainty surrounding this estimate, a scenario analysis was conducted which considered implementation in a single hospital and national implementation. The model was re-run to monitor its effect on the outcomes. The parameter inputs are listed in Table 1.

Table 1. Parameter inputs

Parameter	Value	Standard error	Distribution	Source
General practitioner appointments				
Intervention				
0	0.986	-	Beta	Trial
1	0.014	-	Beta	Trial
Control				
0	0.978	-	Beta	Trial
1	0.021	-	Beta	Trial
Specialist appointments				
Intervention year 1				
0	0.209	-	Dirichlet	Trial
1	0.380	-	Dirichlet	Trial
2	0.266	-	Dirichlet	Trial
3	0.114	-	Dirichlet	Trial
4	0.023	-	Dirichlet	Trial
5	0.006	-	Dirichlet	Trial
6	0.002	-	Dirichlet	Trial
7-10	0.000	-	Dirichlet	Trial
>10	0.000	-	Dirichlet	Trial
Control year 1				
0	0.138	-	Dirichlet	Trial
1	0.325	-	Dirichlet	Trial
2	0.375	-	Dirichlet	Trial
3	0.136	-	Dirichlet	Trial
4	0.018	-	Dirichlet	Trial
5	0.006	-	Dirichlet	Trial
6	0.002	-	Dirichlet	Trial
7-10	0.000	-	Dirichlet	Trial
>10	0.000	-		Trial
Control year 2			Dirichlet	
0	0.700	-	Dirichlet	[39]
1	0.210	-	Dirichlet	[39]
2	0.040	-	Dirichlet	[39]
3-5	0.040	-	Dirichlet	[39]
6-10	0.010	-	Dirichlet	[39]
>10	0.000	-		[39]
Control year 3			Dirichlet	
0	0.820	-	Dirichlet	[39]
1	0.120	-	Dirichlet	[39]
2	0.050	-	Dirichlet	[39]
3-5	0.010	-	Dirichlet	[39]
6-10	0.000	-	Dirichlet	[39]
>10	0.000	-		[39]

Table 1. Parameter inputs (*continued*)

Parameter	Value	Standard error	Distribution	Source
Control year 4			Dirichlet	
0	0.780	-	Dirichlet	[39]
1	0.160	-	Dirichlet	[39]
2	0.050	-	Dirichlet	[39]
3-5	0.000	-	Dirichlet	[39]
6-10	0.000	-	Dirichlet	[39]
>10	0.000	-		[39]
Control year 5			Dirichlet	
0	0.940	-	Dirichlet	[39]
1	0.030	-	Dirichlet	[39]
2	0.030	-	Dirichlet	[39]
3-5	0.000	-	Dirichlet	[39]
6-10	0.000	-	Dirichlet	[39]
>10	0.000	-		[39]
Recurrence quality of life				
No recurrence	0.910	0.010	Beta	Trial
BCC after BCC	0.910	0.025	Beta	Trial
cSCC after BCC	0.910	0.025	Beta	Trial
Melanoma after BCC	0.719	0.011	Beta	[40]
Recurrence after first BCC				
BCC	0.258	0.052[a]	Beta	[41]
cSCC	0.045	0.009[a]	Beta	[41]
Melanoma	0.004	0.001[a]	Beta	[41]
Mortality				
BCC	0.001	0.000[a]	Beta	[42]
cSCC	0.021	0.004[a]	Beta	[43]
Melanoma	0.071	0.014[a]	Beta	[44]
General	Appendix 3	-	Fixed	[45]
Average productivity loss in hours				
Intervention	0.795	0.159[a]	Gamma	Trial
Control	1.606	0.321[a]	Gamma	Trial
Costs				
Follow-up at SP	€117.92	-	Fixed	[38]
Follow-up at GP	€34.95	-	Fixed	[46]
Intervention	€1.61	0.322[a]	Gamma	[47]
Software	€5,000.00	-	Fixed	Expert estimate
Travel expenses	€2.78	-	Fixed	[38]
Productivity loss male	€39.56	-	Fixed	[38]
Productivity loss female	€32.98	-	Fixed	[38]

Abbreviations: BCC, basal cell carcinoma; cSCC, cutaneous squamous cell carcinoma; SP, medical specialist; GP, general practitioner.

[a] ±20% of the deterministic value

The results of the PA were visualized in the incremental cost-effectiveness plane. Both the model and the PA were performed using Microsoft® Excel 2019 for Mac.

Budget impact analysis

A BIA was performed to calculate the budgetary impact of implementing the intervention in the Netherlands for a time horizon of five years. The BIA has a societal perspective equal to the CEA and shows the impact for the involved parties.[26] The eligible population for this BIA were low-risk BCC patients diagnosed with skin cancer for the first time. About 48,000 individuals were diagnosed with a BCC in the Netherlands in 2017.[7] Half of them were considered to be low-risk.[15] With an annual growth of 8% in new cases, the eligible population was calculated for five years.[4] The intervention uptake was defined as 40% in 2021, 50% in 2022, 60% in 2023, 75% in 2024, and 75% in 2025, based on estimates made by dermatologists, an implementation expert, and the results of focus group sessions held with dermatologists.[12] To address the uncertainty surrounding this estimate, scenario analyses with a lower and higher uptake were conducted. The lower uptake was defined as 20%-30%-40%-50%-50% and the higher uptake was 50%-60%-80%-80%-80%. These scenarios were also run for local (single hospital) and national implementation.

RESULTS

Efficacy

The results of 473 first-time BCC patients were used for this analysis; 278 patients were included as controls and thereafter 195 patients received the intervention. Their characteristics are listed in Table 2.

The number of visits to a specialist in the first year was 1.38 and 1.59 per patient in the intervention group and control group respectively. The distribution of a personalized discharge letter reduced the number of visits by 13% (0.21 visits; 95% CI 0.129 – 0.289; $P<0.001$) after imputation.

Cost-effectiveness

The costs per patient after the first five years were €328.24 for the intervention and €354.63 for the control group. This resulted in a cost saving of €26.38 per patient. A time horizon of ten years resulted in total costs of €367.76 for the intervention group and €394.13 for the control group. After ten years the expected cost saving would be €26.37 per patient, confirming that effects stabilized after five years. After a period of five years and ten years, the QALYs were 4.123 and 7.250 respectively. The QALYs in both groups were very similar with differences between the groups being smaller

Table 2. Patient characteristics

	Intervention (n = 195)	Control (n = 278)	P-value
Sex [n (%)]			
Male	94 (48.2)	145 (52.2)	0.75
Age (in years)			
Mean (SD)	64.8 (12.7)	66.4 (11.8)	0.15
Range	31-94	31-100	
Education [n (%)]			
Low	53 (27.1)	90 (32.4)	
Medium	84 (43.1)	104 (37.4)	0.38
High	62 (26.7)	74 (26.7)	
Self-reported previous actinic keratosis [n (%)]			
Actinic Keratosis	7 (3.6)	4 (1.4)	0.16
None	169 (86.7)	250 (89.9)	
VAS score at t = 0			
Mean (SD)	81.45 (11.8)	79.65 (14.5)	0.56
Range	30-100	19-100	

Abbreviations: SD, standard deviation; VAS, visual analogue scale.

than 0.003 for five years and 0.009 for ten years in favor of the intervention group. The ICER was -€9,446 per QALY gained after five years and -€3,138 after ten years. The deterministic results of the intervention showed that the cost category medical costs accounted to 80.7% of the total costs. The costs for patients made up 2.4% and the remaining 16.9% was made up of productivity losses.

The outcomes of the PA showed that 97% of the simulations were in the southern quadrants (Figure 2). This means that the intervention is very likely to be cost saving. Of all the simulations, 37% indicated health loss (left side of the y-axis) and 63% indicated health benefits (right side of y-axis), meaning that improvement of the health outcomes was more likely than deterioration.

A scenario analysis was conducted to measure the effect of uncertainty surrounding the costs of the software during implementation. When the software costs were divided over a local setting (one hospital) of 1,000 patients, the cost savings were €26.69 per patient, as mentioned before. If the software costs were divided over the national eligible population of about 31,000 patients, the cost saving was €26.38 per patient (a decrease of 1.2%). An overview of the analysis can be found in appendix 4.

Budget impact analysis

The budget impact of implementing the intervention in the Netherlands would be -€2,876,844 over a five-year period. Implementing the intervention in a single hospital

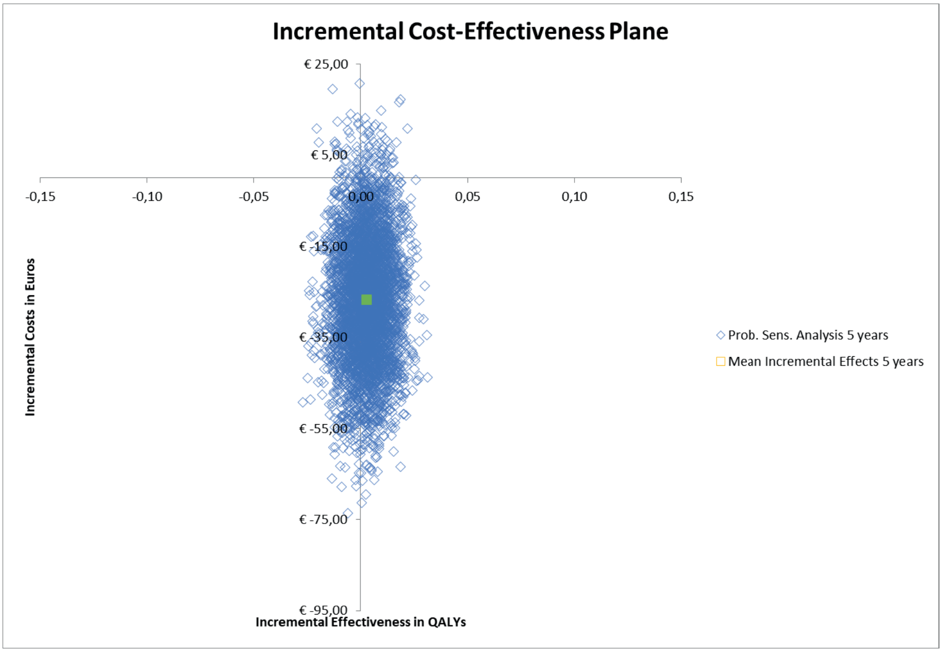

Figure 2. Incremental cost-effectiveness plane
Most simulations were in the southern quadrant, right side of the y-axis, indicating that intervention is most likely to be cost saving and that improvement of the health outcomes is more likely than deterioration.

resulted in a budget impact of -€121,230. The cost savings for each year and scenario are specified in Table 3.

After five years the intervention would result in cost savings on a national scale in the medical category of €2,101,780. The costs for all patients would drop by €60,763. The productivity loss would lower by €714,300. In the local setting the cost savings for the medical category would be €97,832, for the patients €2,909 and for productivity loss €20,488.

A scenario analysis was conducted to determine the impact of a lower and higher uptake. The total national savings on a lower estimate were €1,835,966. The total savings on a high estimate were €3,333,541. Locally, the lower estimate was -€77,367 and the high estimate was -€140,475. The full analysis can be found in appendix 5.

Table 3. Budget Impact Analysis of the implementation of the personalized discharge letter

Year	2021	2022	2023	2024	2025	Total
Local implementation (Erasmus MC, Academic Hospital)						
Eligible population	1,260	1,361	1,470	1,587	1,714	7,392
Expected uptake	40%	50%	60%	75%	75%	75%
Patients receiving the intervention	504	680	882	1,190	1286	4,542
Budget impact	-€13,451	-€18,159	-€23,534	-€31,772	-€34,313	-€121,230
Lower estimate	-€6,726	-€10,896	-€15,690	-€21,181	-€22,875	-€77,367
Higher estimate	-€16,814	-€21,791	-€31,379	-€33,890	-€36,601	-€140,475
National implementation						
Eligible population	30,247	32,667	35,280	38,103	41,151	177,448
Expected uptake	40%	50%	60%	75%	75%	75%
Patients receiving the intervention	12,099	16,333	21,168	28,577	30,863	109,040
Budget impact	-€319,207	-€430,929	-€558,484	-€753,954	-€814,270	-€2,876,844
Lower estimate	-€159,603	-€258,558	-€372,323	-€502,636	-€542,847	-€1,835,966
Higher estimate	-€399,009	-€517,115	-€744,646	-€804,217	-€868,555	-€3,333,541

DISCUSSION

To our knowledge, this is the first study evaluating both the efficacy, cost-effectiveness and budget impact of a personalized discharge letter in dermatology. The introduction of a personalized discharge letter resulted in 13% less follow-up in one year compared to usual care. This would save €26.38 per patient in five years, while the national budget impact would be saving almost €3 million in the same period with an annual saving of approximately €575,000. The expected QALYs remained nearly equal in both groups.

The cost category that experienced the highest cost saving were the medical costs, followed by productivity losses and finally the costs for patients. Insurance companies who pay for the medical costs will therefore experience the most (financial) benefits from implementation. The employers of patients, who will have lower productivity losses, are the second largest party who will benefit. Finally, the patients themselves will experience lowered costs.

To implement this intervention, an investment has to be made to develop the required software. After its development, other hospitals could participate as well. When more hospitals join, the number of patients who participate will be higher, resulting in lower intervention costs and an even greater benefit for all involved parties.

There were no data available on the uptake of such an intervention among dermatologists, although the dermatologists who participated in the current trial are eager to implement the letter into their routine care. To improve the chances of success, a well-defined implementation plan could increase the uptake.[48] Making the letter available in multiple languages or adding more graphical features can help to include harder to reach populations.[49,50] It is also important that the letter is easy to create. The less hassle it is to create the letter, the more likely that it will be used in practice. This could be achieved through software that automatically creates the letters and does not require manual adaptations.[51] Prior research has emphasized this; personalized information is rated positively by both patients and professionals and the uptake of the innovation improves when the letter is added to the electronic patient files.[18] Apart from this, personalized information in general has proven to be cost-effective in the long run.[52]

During the COVID-19 pandemic, there is an increased need for efficient capacity management. Personalized discharge letters provide a solution to decrease the number of follow-up visits. In addition, personalized discharge letters could also be created for other (skin) conditions to reduce low-value follow-up, such as melanoma. The Dutch melanoma guideline states that patients with stage 1A melanoma should receive a single follow-up visit one month after treatment to answer remaining questions, identify potential psychosocial problems and to provide instructions for self-examination.[53] As this is very similar to low-risk BCC follow-up, a personalized discharge letter could provide a solution in this situation as well.

A barrier in the implementation of this intervention is the effect on dermatologists, as follow-up visits provide revenue. A financial incentive was already identified as barrier for de-adoption in previous research.[12] On the other hand, the reduction of visits lowers the strain on dermatological care and the available time creates space for other, more pressing, consults. Barriers such as these should be considered and taken into the implementation plan, such as increased compensation for complex skin cancer patients.

Limitations and strengths

One of the limitations of this study was that patients in the control and intervention group were included in different time periods. During the study period, a new skin cancer guideline was published for GPs which might have altered the clinical practice and therefore the outcome of the intervention.[54] The guideline was published in 2017 and the inclusion period of the intervention group started shortly after its publication. Adoption of guidelines among clinicians is often slow making it unlikely that it had an effect on the outcomes.[55] In addition, the patient characteristics were very similar in both groups, suggesting that the effect of time on the outcomes caused by characteristics would be limited. Another limitation was that the effect of the letter has only been monitored for one year. Since patients usually make about one or two follow-up appointments, it is possible that the effect of the letter continued beyond the twelve months of monitoring, which would cause an underestimation of the efficacy. A strength of the design was that the trial was conducted at different types of dermatological departments (i.e., university medical center, general hospital, independent sector treatment center), which each have their specific target population creating a representative study population, making the results more generalizable to all Dutch BCC patients.

Conclusions

In conclusion, the personalized discharge letter decreases the amount of low-value follow-up visits among first-time BCC patients. It is a cost-effective strategy and has a positive impact on the healthcare budget in the Netherlands. The letter also provides a solution for the patients' need for more and tailored information, which is valuable in itself. Incorporating this intervention in routine BCC care can improve patients' satisfaction with care, helps to decrease the number of unnecessary follow-up visits, and subsequently lowers the costs.

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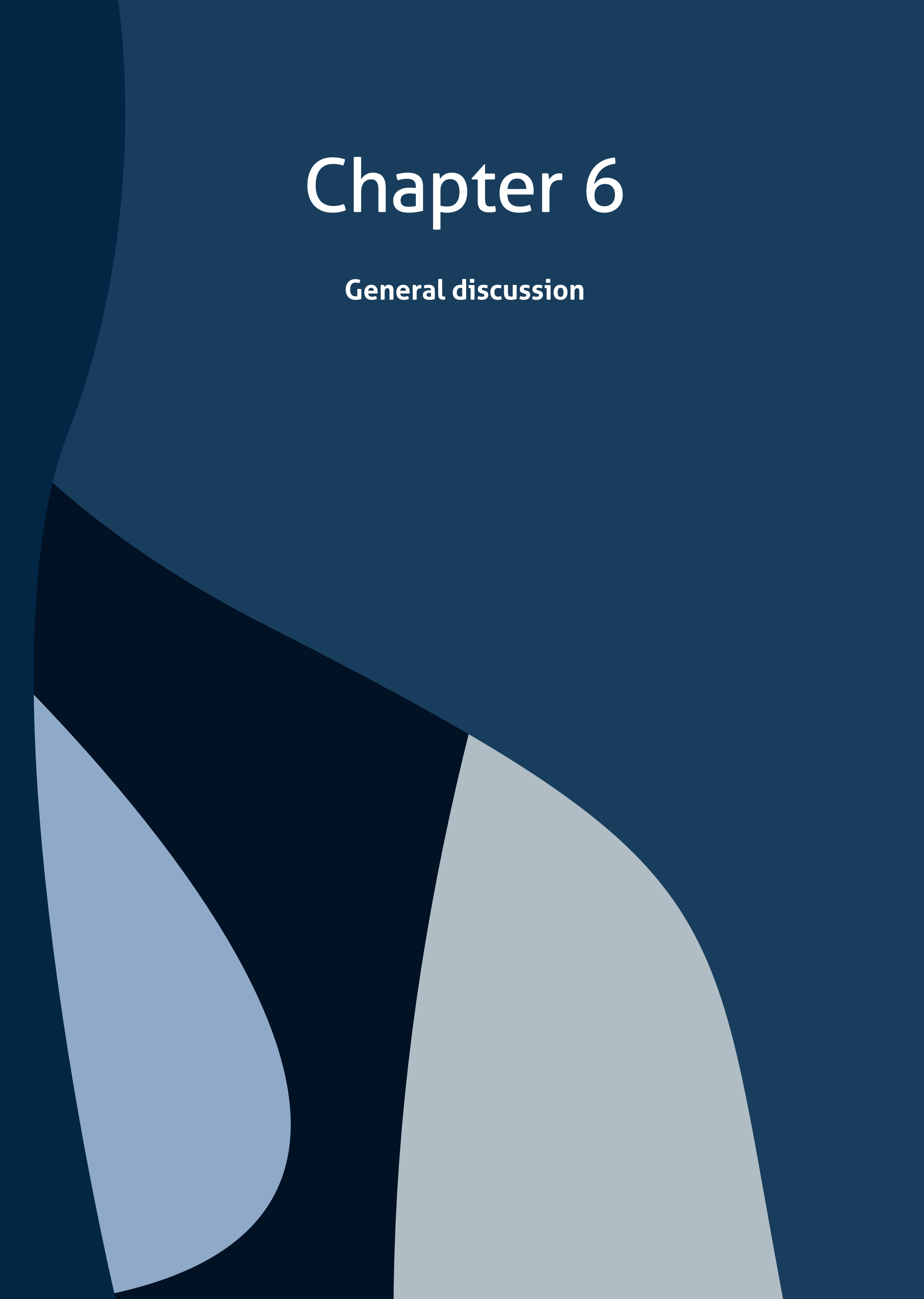
Chapter 6

General discussion



Basal cell carcinoma (BCC) is the most common type of (skin) cancer in the Netherlands and its incidence is still rising.[1] According to Dutch BCC guidelines, periodical follow-up care should be restricted to high-risk BCC patients. This implies that providing follow-up to low-risk BCC patients is considered low-value care. Low-value care is defined as care which has no or little benefit to the patient, wastes limited resources and may even cause harm to patients.[2] Nevertheless observational studies and analyses of clinical routine data demonstrate that low-risk BCC patients do often have follow up visits despite the recommendation in the national guideline.[3,4]

The main aim of this thesis was to develop and test a strategy to de-adopt low-value BCC follow-up care. This was done by following the steps of the implementation of change model by Grol and Wensing.[5] We started with a proposal for change (Chapter 1). Thereafter, performance was determined made by analysing claims data (Chapter 2). Qualitative research was conducted, including both patients and physicians, to uncover the factors influencing low-value follow-up care (Chapter 3). These factors were quantified to find which trade-offs BCC patients and dermatologists were willing to make to accept fewer follow-up visits (Chapter 4). This resulted in the development of the actual de-adoption strategy: a personalised letter for BCC patients. The personalised letter was tested in multiple healthcare centres resulting in a decrease in follow-up visits and it was evaluated that implementation in the eligible population would result in considerable cost savings (Chapter 5).

This final chapter reflects on the main conclusions of this thesis by defining its place in current BCC care, among other suggestions for improvement. In addition, light is shed on the involvement of patients in different sections of research. It closes with final conclusions and prospects.

IMPROVING BASAL CELL CARCINOMA CARE

A care pathway for any disease mainly consists of prevention, diagnosis, treatment and follow-up. Some parts of the pathway may be more prominent for one disease than another. In the case of BCC, prevention could play a larger role than it currently is in the Netherlands. Regarding diagnosis, the gold standard is the clinical inspection by a dermatologist and/or by means of a skin biopsy to confirm the diagnosis and to identify the histological subtype. A sheer amount of research has been conducted on treatment of BCCs. The type of treatment is based on location, size and subtype of the BCC, but also patient characteristics and preferences. On the contrary, research regarding the added value of BCC follow-up and its different regimens is lacking. Chapter 1 provides an overview of current practice in primary and secondary care. **Figure 1** provides an overview of the BCC care pathway and suggested instruments to adjust components of

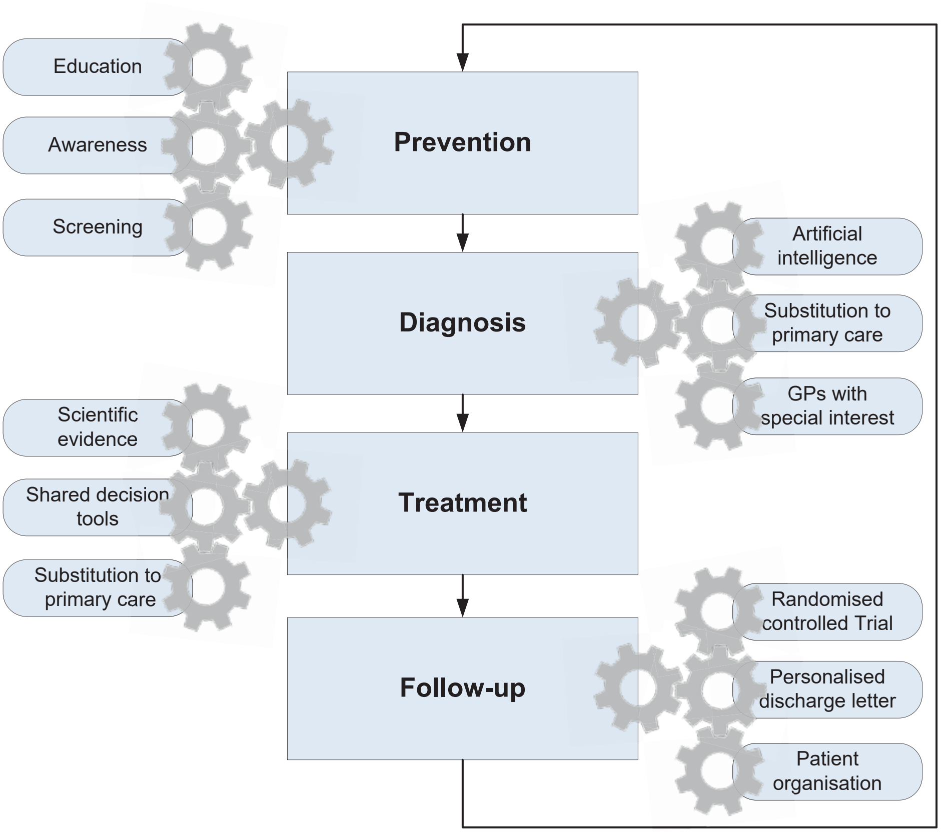


Figure 1. Overview of basal cell carcinoma care pathway and suggestions for improvement

care with. In the following sections, suggestions for improvement of each step of the pathway are discussed.

Prevention

Prevention is usually categorised into primary (i.e. preventing the onset of disease), secondary (i.e. detecting disease as soon as possible) and tertiary (i.e. reducing symptoms of a disease) prevention. Tertiary prevention is relevant for incurable and chronic diseases, which is not typically the case for BCC. Primary and secondary prevention are more relevant for BCC, as elaborated hereafter.

The most significant preventable risk factor for skin cancer is ultraviolet (UV) exposure from the sun and sunbeds.[6-8] For BCC, intermittent (recreational) UV exposure seems more important than chronic exposure, in particular UV exposure at a young age.[9,10] Last year the Dutch Cancer Society launched a campaign at primary schools to educate young children about sun protection with the aid of lesson packages and dermatologists as guest speakers,[11] but there is no active sun prevention programme aimed at adolescents in the Netherlands. A Canadian study revealed that 8.4 percent of the population aged 18-34 use tanning equipment, opposed to 1.7 percent aged 12-17.[12] The use of sunbeds at a younger age is correlated with earlier onset of BCC.[13]

This calls for prevention programmes aimed at this teenage population. Even though it is generally known that UV-radiation is the most important factor in developing skin cancer,[14] a tanned skin is currently still associated with beauty and positive health.[15] It seems difficult to change this behaviour in this important, but hard to reach age group. An opportunity to reach this teenage population is by means of Entertainment-Education (EE). EE is a communication strategy that uses popular media formats to engage with audiences on prosocial topics such as health, sustainability and social tolerance. A recent meta-analysis has found that EE has a significant effect on the persuasion of people, which consists of change in people's knowledge, attitude, behavioural intention and behaviour.[16] By using this method, the issue of skin cancer prevention could be dealt with properly and not too preachy, as the teenagers can be turned off by preachy messages.[17] EE can overcome this by the creation of a compelling storyline with positive and negative role models, with realistic consequences, which allows the audience to draw their own conclusions.[17] This might be an opportunity to change tanning behaviour early in life in order to prevent skin cancer later on.

Another form of primary prevention has already been initiated. The UV-index action plan ("Zonkrachtactieplan") was set up in 2019 by the Dutch Ministry of Health.[18] This is a group consisting of National Institute for Health and the Environment ("RIVM") together with other parties involved in efforts to prevent skin cancer. Their aim is to agree with all involved parties on clear and consistent communications regarding UV exposure in order to contribute to the awareness of people concerning UV-radiation. They will also increase knowledge of UV radiation by drafting a joint knowledge agenda in order to identify gaps and prioritise topics for research purposes.

Regarding secondary prevention, skin cancer screening of the general population has been a point of discussion for several years.[19] The main issue is that the evidence is currently inadequate to determine whether screening in asymptomatic individuals leads to a reduction in mortality, while evidence exists that screening may have adverse consequences.[20] The US Preventive Services Taskforce therefore concluded in 2016 that the current evidence is insufficient to assess the balance of benefits and harms of skin cancer screening.[21] One of their statements was that visual skin examination by a clinician has modest sensitivity and specificity for detecting melanoma, which in turn may lead to cosmetic and (more rarely) functional adverse effects resulting from biopsy and overtreatment.

In the near future, skin cancer screening might be possible with smartphone apps based on algorithms to detect skin cancer. A recent review stated that the current algorithm based smartphone apps cannot be relied on yet.[21] They found that the SkinVision app produced the highest estimates of accuracy, but in a hypothetical population of 1,000 adults in which 3% has a melanoma, four out of 30 melanomas would not be picked up as high risk, and more than 200 people would be given false positive results.[21,22] However, the technology is constantly improving and it might soon be accurate enough to be used as screening tool in the general population. Skin cancer screening might be implemented in the near future in the Netherlands, as the Dutch government recently analysed the costs and benefits of multiple screening scenarios, which implies their interest of actually executing it.[23] In addition, screening also implies a form of primary prevention, as participants are implicitly educated about skin cancer risk factors.[24]

Diagnosis

The Dutch BCC guideline for dermatologists states that, in principle, all lesions suspicious for BCC should be histologically confirmed by a skin biopsy before treatment.[25] However, exceptions are made for BCCs with a strong clinical suspicion on a low-risk location or for patients with many BCCs. The positive predictive value (PPV) of dermatologists regarding a clinical BCC diagnosis varies from 79% to 86%.[26-28] By using dermatoscopy, the PPV increases up to 96%.[29] However, dermatoscopy does not replace the gold standard, which is histological confirmation by a skin biopsy. This is not just needed to confirm the diagnosis, but also to determine the histological subtype, which affects therapeutic options. The disadvantages of histopathology are the processing time, chance of sampling error in case of biopsies and the related costs.

To improve the accuracy and efficiency of diagnosing skin cancer, the use of artificial intelligence (AI) might be a promising solution. At the moment, there is a lot of discussion regarding the use of mobile apps integrated with AI to diagnose skin cancer.[30] This is mostly due to missing of regulation, suboptimal diagnostic accuracy (especially false positives) and absence of evidence of the positive impact on health care (costs) of automated smartphone medical apps.[30,31] These obstacles do not seem insurmountable. The authors of a recent systematic review plead for a shift from a human-computer competition to human–computer collaboration.[31] They concluded that AI-based support improves diagnostic accuracy over either AI or physicians alone. Given the potential, it seems inevitable that AI will make its way into skin cancer diagnostics in one way or another.

Not all skin cancer patients have to be diagnosed and treated by a dermatologist. GPs might have a bigger role to play in the management of skin cancer (i.e. shift of care). However, the current dermatological expertise of GPs still has great room for improvement. It is astonishing that, although one out of every six primary care consultations concerns skin problems, it is possible to become a GP without any clinical dermatological experience.[32] As a consequence, there is still great variation between

GPs regarding skin cancer expertise. In 2017, the GP guideline 'suspicious skin lesions' was published.[33] It is known that merely publishing a guideline does not change care.[34] Barriers to adhere to guidelines by GPs are, among others, lack of agreement with the recommendations, organisational constraints and lack of knowledge regarding the guideline recommendations.[35] A recent study found that a tailored 2-day educational program regarding skin cancer management, including hands-on training, improved the GPs' diagnostic accuracy for skin tumours.[36] In addition, their approach and awareness towards suspicious skin tumours improved. Although long-term effects are still to be determined, it shows promising results.

Only after the basic dermatological expertise of GPs has been increased, GPs with special interests (GPSIs) could be introduced in the Netherlands to further increase efficiency of care. This concept entails that GPs refer patients with lesions suspicious for skin cancer to GPSIs instead of a dermatologist, in order to reduce excessive waiting lists, to improve the accessibility and convenience of care.[37] GPSIs are currently well integrated in the healthcare systems of UK and Australia.[38] This model has shown to be successful as GPSI care shows superior patient satisfaction and comparable outcomes to medical specialists.[38] In addition, waiting times are reduced and it is cost-effective.[39] The major disadvantage of GPSIs is that GPs are expected to be knowledgeable and skilled in a broad range of aspects of medicine and be able to integrate their knowledge and expertise to provide holistic, comprehensive care to their patients.[40] When GPs become too specialised, they might lose their generalist skills.

Treatment

A lot of research has been conducted regarding treatment of BCCs, including many randomised controlled trials.[41-43] Conventional excision is the golden standard for most BCC, except the superficial BCC subtypes that should be treated by topical therapies such as 5-fluorouracil cream.[44] Mohs' micrographic surgery is increasingly being performed, but also further developed by using digital imaging.[45,46] For patients with inoperable (locally advanced) or metastatic BCCs sonic hedgehog inhibitors are the first choice and the first clinical studies of immunotherapy show a positive response in these tumours.[47]

The question remains, what is the best treatment? Ideally, treatment choices are made in agreement after information exchange between physician and patient and on the involvement of both parties (i.e. shared decision making).[48] Type of treatment is partly physician dependent, which is confirmed by the practice variation displayed in Chapter 2. However, progress has been made over the past decade to also include patients' preferences. Although recurrence chance is usually considered the most important aspect of treatment by patients, this is not the case for all BCC patients. Patients also value the cosmetic result as an important factor in choosing a treatment (Chapter 3).[49] In order to find the best treatment for each patient, decision aids could provide a solution. Decision aids can also improve patients' knowledge of the options and help them to feel better informed and more clear about what matters most to them.[50] By helping patients decide which treatment aligns best with their preferences, patient-centred care will be improved.

Currently, BCC guidelines are very focused on curative rates. In contrast, palliative care (with less focus on complete excision) such as curettage and electrodesiccation or even watchful-waiting receives much less attention. A significant portion of BCC patients consists of elderly patients with a short life expectancy. For them, the side-effects of treatment may outweigh the burden of leaving their BCC untreated as they might not have lived long enough to develop symptoms such as itch or bleeding.[51,52] BCCs causing symptoms or located close to vital structures such as eyelids or ears should certainly be treated. Many BCCs, however, are detected during yearly screening by a dermatologist and may have remained undetected by patients and might never have been a problem for these patients. During a prospective population-based cohort study of people aged ≥ 45 years, about one in 25 participants was diagnosed with at least one cutaneous malignancy. Currently, life expectancy is not routinely taken into consideration in the selection of the most appropriate treatment.[53,54] The rationale to treat BCCs in fragile patients is that they may cause symptoms later, and then may require more extensive treatment. Although BCCs are slow-growing tumours, it is not yet clear how fast they actually grow and when they will cause symptoms. More research should be conducted concerning the natural course of BCCs in order to integrate watchful waiting into BCC guidelines, especially in case of frail elderly, and avoid unnecessary harm.[52]

Another suggestion for improvement is substitution of low-risk BCC treatments from secondary to primary care. The previously mentioned GP guideline recommends GPs to treat low-risk BCCs.[33] A recent randomised clinical trial aimed to assess whether low-risk BCCs can be surgically treated by GPs without loss of quality of care.[36] GPs included in the study received extensive training, but the study failed due to low inclusion and excision rates of these GPs. A process evaluation was conducted alongside the trial, which revealed administrative challenges, lack of time, high workload and low volume of BCC patients as barriers to success. Qualitative interviews showed that GPs and, to a lesser extent, dermatologists are positive regarding the substitution of low-risk BCC care. Aside from essential strategies such as improving GPs' skin cancer education, rearrangement of (financial) organisational structures in primary and secondary care are needed in order to successfully substitute treatments of low-risk BCCs to primary care.[55]

Follow-up care

Although it seems logical that more intensive follow-up schedules after any type of cancer will result in earlier detection of recurrence or new primary tumours, which would in turn allow earlier treatment and improved health outcomes, there is little evidence supporting this assumption.[56] On the contrary, evidence exists that less intensive follow-up schedules for certain types of cancer do not differ in effectiveness, are accepted by patients and do not have adverse effects on survival outcomes, while saving healthcare costs and reduce patients anxiety before follow up visits.[56] Recently, 3-year results of the Dutch MELFO study were reported.[57] This is a prospective randomised controlled trial on the effects of a reduced stage-adjusted follow-up schedule on cutaneous melanoma IB–IIC. Patients in the reduced follow-up group did not differ from the conventional follow-up group regarding quality of life, recurrence or survival. However, costs were 39% lower in the reduced follow-up group, while patients in this group reported lower stress symptoms than patients in the conventional follow-up group.

Unfortunately, the research conducted regarding BCC follow-up is scarce. The health benefit in BCC follow up is not mortality or disease progression because the rate of advanced disease is extremely rare. There is no evidence that earlier detection of BCC leads to improved health outcomes (i.e. cosmetic and functional morbidity or improved quality of life), while evidence exists that significant delay to treatment (up to 12 months) is not relevant to the outcome of the intended operation.[58] This led to the Dutch BCC guidelines stating to consider providing regular follow-up only to high-risk BCC patients.[25] Regarding the frequency and length of follow-up, the Dutch guideline states that in most cases annual monitoring will be sufficient, or more often if necessary, depending on the patient and if the attending physician deems this necessary. Chapter 2 reveals large practice variation in terms of skin cancer follow-up care, of which BCC constitutes a large part. This variation in routine care emphasises the need for a randomised controlled trial on different BCC follow-up schedules, in order to provide an evidence-based guideline which finds the best balance between health outcomes, patient preferences and healthcare costs. The current thesis provides a solution to reduce the number of follow-up visits for BCC patients: In Chapter 5 it was demonstrated that a personalised discharge letter for BCC patients, as was suggested in the focus groups with patients, is a relatively simple strategy to decrease low-value BCC follow-up visits.

After patients are discharged from follow-up or in-between follow-up visits, patients may require more medical information and reassurance (Chapter 3). In addition, some BCC (and other types of skin cancer) patients may want to connect with other skin cancer patients to share information and experiences. In response to these needs, a skin cancer patient organisation was founded in November 2019 called ‘De Huidkanker Stichting’.[59] This organisation’s goal is to represent the interests of all Dutch non-melanoma skin cancer patients. Patient organisations have a responsibility to connect peers and provide understandable and high-quality information, as this may drive patients to carry out treatment and motivate them to make lifestyle changes (e.g. use sunscreen) in everyday life.[60] This is important as the chance of being diagnosed with a subsequent skin cancer is high.[61]

INTEGRATING THE PATIENT PERSPECTIVE IN THE RESEARCH PROCESS

The position of patients is shifting in healthcare. Where the physician used to be in the lead, the voice of the patient is becoming increasingly important. Formerly, physicians informed patients about risks, benefits and alternative treatments based on what the physicians deemed important, but today physicians are obliged to inform patients based on what a reasonable patient deems important.[62] Shared decision making, a collaborative communication process between physicians and patients that integrates the best evidence available with the patients' values and preferences, is becoming the new standard in healthcare in most countries.[62,63] In order to facilitate shared decision-making, patients' needs and preferences must be known. This led to increased qualitative research to understand patients' values and believes and, in extent, incorporation of shared decision making in daily practice.[64]

However, the position of patients could be taken a step further: into the research process. In 1995 it was already argued in the BMJ that "*patients should help to decide which research is conducted, help to plan the research and interpret the data, and hear the results before anybody else*".[65] However, patient participation in research has not yet made the same progress as in clinical healthcare.[66] In order to increase patient involvement in research, it requires researchers to respect and recognize patients' unique, diverse and complementary experiential expertise.[67]

Commonly, patients are involved after research has failed (e.g. in a process evaluation to understand why sample size was not reached). However, failure this late in the process may be prevented if patients are involved sooner. **Figure 2** provides an overview of the research process from research prioritisation to implementation into daily practice. Patients could be more involved in any step of the process.

Including the patient perspective in the conduction of research

For most studies, patients are usually the 'subject' and their thoughts and believes are not relevant for the outcomes. This is, for example, the case when testing which type of treatment for skin cancer has the lowest recurrence chance. However, if the treatment with the lowest recurrence chance has too many side effects or is too time consuming for patients to receive, it will fail to be successfully implemented. This illustrates that the perspective of patients should be taken into account in trials.

The perspective of patients already have a central place in the field of implementation science, as the main goal is usually to identify factors that affect the uptake of implementation strategies.[68] Therefore barriers and facilitators across multiple levels of context, including the patient perspective, have to be identified. In the current thesis, patients were also involved as stakeholders in the development of the de-adoption strategy. Focus groups were held to understand their thoughts and believes to guide us

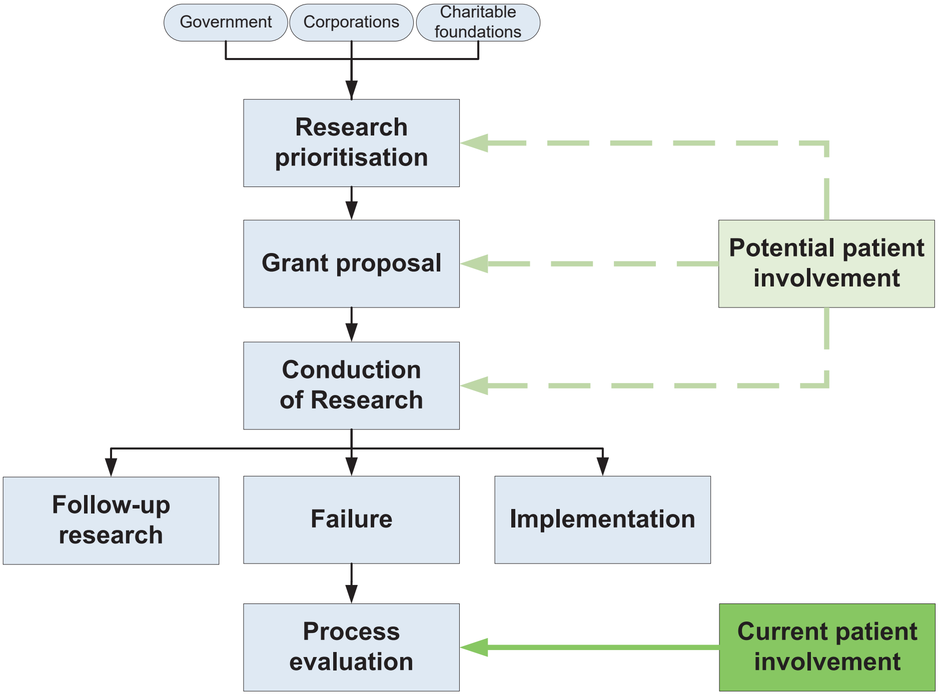


Figure 2. Overview of the research process

in the development of a strategy to reduce low-value BCC follow-up visits (Chapter 3). Thereafter, a discrete choice analysis was conducted in order to learn which trade-offs they are willing to make in order to increase the chance of success of the developed strategy (Chapter 4).

Including the patient perspective in the grant proposal

Even though the patients involved in the qualitative studies in Chapter 3 had a voice, they were still 'subjects', as the study protocol was already written before they participated. It should be advocated to involve patients in identifying clinically relevant research questions and drafting the study design including defining outcomes in the grant proposal. Patients could assist in the review of consent procedures and patient information sheets, refine research questions, suggestion of additional outcome measurements, review of trial data collection procedures and recommendations on the timing and location of trial follow-up data collection.[69] Fortunately, it is increasingly more common to involve patients in the design of clinical trials, as this increases the participation rate of patients in trials and makes results of studies more patient-centred.[70,71]

Involving patients in research prioritization

The last step up the ladder would be for patients to be involved in the prioritisation of research. There seems to be a mismatch between the research that gets done and the research that patients would like to see done, which is caused by the fact that what is scientifically relevant does not necessarily mean that it is relevant from the patient's perspective.[66,72] For example, a review of interventions for the treatment of osteoarthritis of the knee joint revealed that 59% of the studies were based on pharmaceutical- and 26% on surgical interventions, while 36% of surveyed patients ranked knee replacement as highest priority for research and 21% chose education as first choice and only 8% of patients ranked pharmaceutical interventions highest.[73] It was suggested that this mismatched was caused by commercial funding bias, vested researcher interests, professional dominance of research (i.e. medical and surgical professions directing research funding), publication and a lack of patient involvement in research. Several methods have been described to involve patients in research prioritisation, such as online crowd-voting, focus groups and modified Delphi method.[74] Organisations such as the James Lind Alliance facilitate patients, carers and clinicians to come together in 'Priority Setting Partnerships' to identify and prioritise the top 10 unanswered questions or evidence uncertainties that they agree are the most important.[75] Fortunately, patient organisations were involved in the establishment of the most recent prioritisation of research in dermatology in the Netherlands.[76]

Concerns of involving patients in research

Aside from the extra time and costs to include the patient perspective in research, another major concern is how to select representatives of the general population. The problem is that representatives of marginalised patient groups (e.g. with a lower level of education) may be the ones who are not able to bear the required work, which leads to excluding patients who are deemed "not able" to contribute.[77] This may lead to healthcare interventions that are tailored to those with the strongest voice, instead of the marginalised.[78] It is not uncommon for patients to receive training before contribution to research, however, this may result in the creation of 'professionalised' lay experts who do not longer represent the general population anymore.[79]

CONCLUSIONS AND PROSPECTS

This thesis provides the foundation for a strategy to reduce low-value BCC follow-up visits. By following the steps of the implementation of change model by Grol and Wensing, the chance of developing a successful strategy that would be accepted by all stakeholders was increased.[5] The testing phase showed promising results (Chapter 5).

However, the implementation model presented in Chapter 1 was not yet complete. As displayed in **Figure 3**, the next step is to integrate the personalised letter in routine care. The letter is currently in the process of being professionalised (i.e. print it directly from electronic patient files with as few clicks as possible) in order to increase the uptake of the strategy by dermatologists in the Netherlands. After it is integrated in routine care, (continuous) evaluation will take place and processed will be adapted where neces-

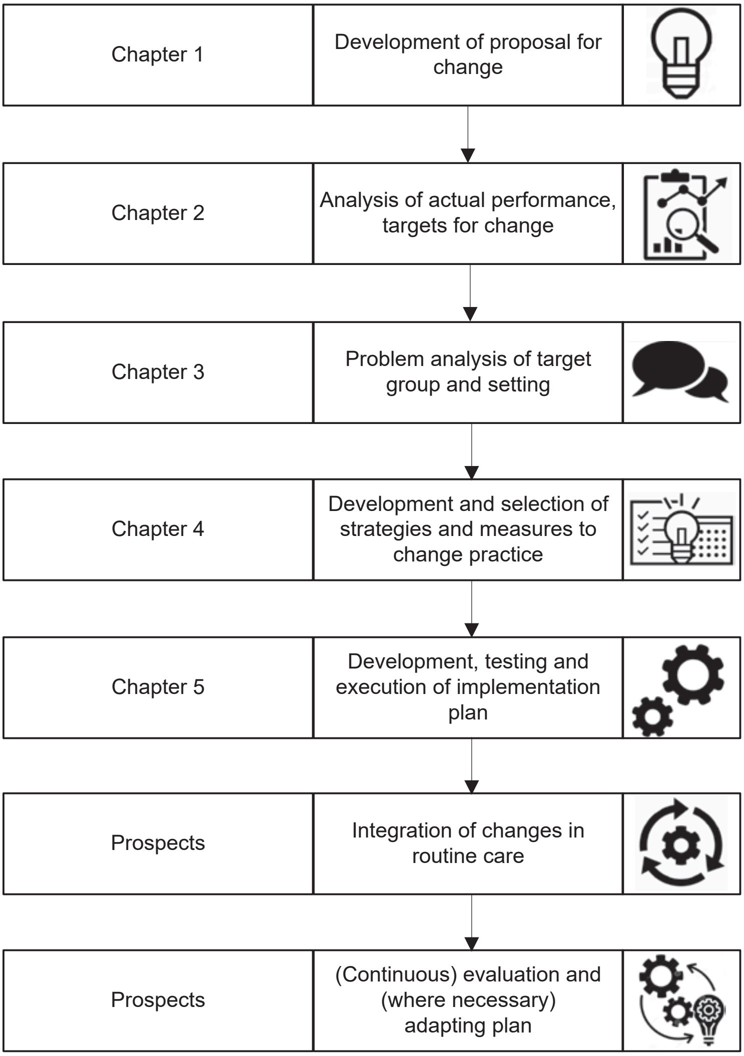


Figure 3. Implementation of change model by Grol and Wensing[5], which was used as guiding principle for the de-adoption of low-value basal cell carcinoma follow-up care

sary. The claims data analysis (Chapter 2) will be repeated to monitor the effects and to detect any possible unwarranted practice variation.

After successfully implementing the personalised letter in routine care for BCC, this intervention could also be adapted to other diseases. Squamous cell carcinoma patients will be the easiest to adapt the letter to first, as it they show many similarities with BCC patients (Chapter 3). For now, patients preferred to have the letter on paper (Chapter 4), but as new generations will be diagnosed with skin cancer, at a certain point the letter will be digitalised. I believe that in the future, all patient information for any disease will be tailored to the individual and presented in a way each individual patient prefers.

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Chapter 7

Summary / Samenvatting

SUMMARY

Chapter 1 is a general introduction based on skin cancer practices of general practitioners (GPs) and dermatologists. It exposes opportunities for improvement of care and provides the main objectives of this thesis.

Skin cancer is the most common type of cancer in the Netherlands and its incidence is still rising. The two most common subtypes of skin cancer are basal cell carcinoma (BCC) and squamous cell carcinoma (SCC), both commonly referred to as keratinocyte carcinoma (KC). About 48,000 inhabitants being diagnosed for the first time with BCC and 12,000 with SCC in 2017. Although KC is usually not deadly, it could cause considerable functional and cosmetic morbidity, as it is typically found on sun-exposed areas such as the face. More than one-third of KC patients develops at least one subsequent KC. These high incidence rates put pressure on healthcare systems.

In order to identify areas for improvement, clinical practices of GPs and dermatologists were described by using the Integrated Primary Care Information database and the Netherlands Cancer Registry (secondary care). A random selection was made of patients who consulted their GP for suspicious or confirmed KC (n = 1597) and for secondary care 1569 patients were randomly selected with a histologically confirmed KC. All patients were diagnosed between 2009 and 2013 and followed up until 2016. Details on diagnosis, treatment and follow-up care were described. The descriptive analyses revealed that one-third of lesions suspected for KC by GPs were indeed skin malignancies, leading to unnecessary referrals. GPs treated almost a third of all suspected KC lesions, but one-third of those treatments were not primarily directed at KC (e.g. antibacterial and/or antimycotic ointments). In the analyses regarding secondary care, it was noted that low-risk BCC patients received more follow-up than recommended in the guidelines. Strengthening the diagnostic pathway for KC in primary care and reduction of low-risk BCC follow-up visits were suggested as potential areas for improvement in KC care. As initiatives focussing on primary care seemed unfeasible at the moment, the focus of this thesis was placed on the low-value BCC follow-up visits.

Therefore the main aim of this thesis was to develop a strategy to reduce the number of low-value BCC follow-up visits, while maintaining quality of care. This was done by following the Grol and Wensing Implementation of Change Model. The first step was to develop a proposal for change, which was done in this chapter.

In **Chapter 2** we measured performance of the target for change, which was the second step in the implementation of change model. In order to measure performance, first quality indicators have to be defined. Therefore, all skin cancer related claims were extracted from the nationwide Vektis claims database. For over 220,000 patients a skin cancer claim was reimbursed in 124 healthcare centres. It showed large practice variation in both treatments and follow-up visits. On average, skin cancer patients received

1.8 follow-up visits in 2016. The analysis demonstrated that claims data may be a valid and feasible dataset to extract quality indicators for skin cancer. It is still to be investigated whether the detected practice variation is unwarranted.

In **Chapter 3** the target groups were analysed by obtaining the views of stakeholders. In **Chapter 3.1** we identified the needs and preferences of BCC and SCC patients regarding their care by the means of six focus groups with 42 patients in total. Both BCC and SCC patients expressed the following needs and preferences: (I) the need to receive all relevant, tailored information; (II) a physician who takes you seriously and communicates well; (III) a short waiting period and the best treatment with direct results; (IV) to be seen by the same physician; a preference for a dermatologist during (V) treatment and (VI) follow-up; (VII) a general need for structured follow-up care and (VIII) a full-body skin examination during follow-up. Patients with BCC additionally expressed the need for openness and transparency and wanting to participate in shared decision making. These results could be used to tailor skin cancer care to the needs of KC patients. It is advocated to add the patient's perspective to guidelines.

In **Chapter 3.2** the factors that influenced low-value BCC follow-up practices were identified among dermatologists and suggestions were made to de-adopt this care. In addition, the views of low-risk BCC patients were explored. A qualitative study was conducted consisting of 18 semistructured interviews with dermatologists and three focus groups with in total 17 low-risk BCC patients. Factors influencing current follow-up care practices among dermatologists included complying with patients' preferences, lack of trust in GPs, financial incentives and force of habit. Patients reported varying needs regarding periodic follow-up visits, preferred to be seen by a dermatologist and indicated a need for improved information provision. Suggested strategies by dermatologists to de-adopt the low-value care encompassed educating patients with improved information, educating GPs to increase trust of dermatologists, realising appropriate financial reimbursement and informing dermatologists about the low value of care. This mixture of factors contributing to low-value BCC follow-up practices indicate that in order to de-adopt this care strategies should be aimed at all stakeholders.

In **Chapter 3.3** the other side of the spectrum was investigated: the experiences and needs of complex skin cancer patients. These are patients who had undergone surgical treatment for skin cancer by a dermatologist with a subsequent reconstruction by a plastic surgeon. Their care process is often more complicated and psychological and social problems may play a larger role. Sixteen complex skin cancer patients were interviewed on their experiences and needs regarding care using a predefined topic list. They reported a need for a skilled and friendly physician who tailors information and communication to their individual situation. A need for continuity of care and improved collaboration between healthcare providers was also emphasised. Furthermore, patients experienced complications and unmet expectations and expressed a need for shared decision-making at various steps throughout the treatment process (depending on age). Patients also considered completeness of tumour removal, follow-up visits with multiple specialists to be planned the same day and recognition of the psychological impact of the disease on the partner important. These results advocate for efforts to be undertaken to improve continuity of care and collaboration for this patient group. Furthermore, physicians should take the individual needs of patients and their partner into account and adjust information, communication and (supportive) care accordingly.

In **Chapter 4** the qualitative results from the previous chapters were quantified. First, in **Chapter 4.1** a ranking list was developed, based on the results of the focus groups. The list consisted of five items regarding the patient-physician relationship, five disease-specific items and two external items (costs and travel time). The items were ranked by 101 BCC patients from 1 (most important) to 12 (least important). They scored patient-physician related factors as most important, with 'explanation of the seriousness of the skin cancer' as the most important factor regarding BCC care. The second most important factor to patients is the 'feeling that the physician listens well to the patient'. Patients ranked patient-physician related factors higher than disease-specific factors. The external factors were considered least important. This study emphasises the importance of integrating patient-physician relationship factors with traditional medically orientated aspects of BCC care.

Subsequently, in **Chapter 4.2**, the most important items were used in a discrete choice experiment in order to learn which trade-offs BCC patients and dermatologists are willing to make to accept fewer low-value follow-up visits. Eighty-four dermatologists and 266 BCC patients completed the discrete choice experiment. A panel latent class model was used for analysis. The results showed that the acceptance of having no additional follow-up visits (i.e. following the guidelines) would increase from 55% to 77% by patients if the post-treatment visit was performed by the same person as treatment provider and a printed hand-out was provided to patients containing personalised information. Female patients and older dermatologists are less willing to accept the guidelines and prefer additional follow-up visits. This study revealed that a personalised hand-out would be a feasible strategy to substantially reduce costs, while maintaining quality of care.

In **Chapter 5** the strategy, a personalised discharge letter for patients based on all the previous research, was tested in one academic hospital, three general hospitals, and two independent sector treatment centres. The efficacy, the cost-effectiveness and the budget impact of the personalised letter on the number of follow-up visits for patients following a low-risk BCC compared with usual care were studied by the means of a model-based cost-effectiveness analysis using individual patient data gathered via surveys. The study included 473 first-time BCC patients. The personalised discharge letter decreased the number of follow-up visits at the dermatologist by 13% in one year. The incremental costs after five years were -€26.04 per patient. The budget impact was -€2,9 million after five years in the Netherlands. These results show that distribution of a personalised discharge letter decreases the number of follow-up visits and implementing the intervention in the eligible population results in large cost savings and contributes to restrain the growing skin cancer costs.

Chapter 6 is the general discussion of the thesis, in which an overview of the main findings is provided and placed into perspective of existing literature. In the first part of the general discussion the care pathway of BCC is evaluated from prevention until follow-up, with suggestions for improvements in each step of the pathway. This determines the place of the personalised letter in current BCC care. The second part of the discussion reflects on the position of patients in research. It advocates to make benefit of patients' unique, diverse and complementary experiential expertise in all the steps of the research process, from prioritisation of research until implementation of care. Finally, the implementation of change model is completed by including the prospects.

SAMENVATTING

Hoofdstuk 1 is een algemene inleiding, gebaseerd op de dagelijkse praktijk van huisartsen en dermatologen op het gebied van huidkankerzorg. In dit hoofdstuk worden de mogelijkheden voor verbetering van de huidkankerzorg blootgelegd en worden de belangrijkste doelstellingen van dit proefschrift beschreven.

Huidkanker is de meest voorkomende vorm van kanker in Nederland en de incidentie neemt nog steeds toe. De twee meest voorkomende subtypen van huidkanker zijn basaalcelcarcinoom (BCC) en plaveiselcelcarcinoom (PCC), beiden worden algemeen aangeduid als keratinocyt carcinoom (KC). Ongeveer 48.000 Nederlanders werden in 2017 voor het eerst gediagnosticeerd met BCC en 12.000 met PCC. Hoewel KC meestal niet dodelijk is, kan het wel aanzienlijke functionele en cosmetische schade veroorzaken, omdat het meestal wordt aangetroffen op aan de zon blootgestelde gebieden zoals het aangezicht. Meer dan een derde van de KC-patiënten ontwikkelt ten minste nóg een KC. Deze hoge incidentiecijfers zetten de gezondheidszorg onder druk.

Om verbeterpunten te identificeren is de dagelijkse praktijk van huisartsen en dermatologen beschreven met behulp van de 'Integrated Primary Care Information' database en de Nederlandse Kankerregistratie. Er werd een willekeurige selectie gemaakt van patiënten die hun huisarts hebben geraadpleegd voor een voor maligniteit verdachte huidafwijking of bevestigde KC (n = 1597) en voor de dermatologische zorg zijn 1569 patiënten willekeurig geselecteerd met een histologisch bevestigde KC. Alle patiënten werden gediagnosticeerd tussen 2009 en 2013 en opgevolgd tot 2016. Details over de diagnose, de behandeling en de zorg tijdens de nacontroles werden beschreven. Uit de analyses bleek dat een derde van de door de huisartsen voor KC verdachte huidafwijkingen daadwerkelijk huidkanker was, wat leidde tot onnodige verwijzingen. Daarnaast behandelden huisartsen bijna een derde van alle verdachte KC, maar een derde van die behandelingen was niet primair gericht op KC (bijv. antibacteriële en/of antimycotische zalven). In de analyses van de dermatologische zorg werd opgemerkt dat laag-risico BCC-patiënten meer nacontroles kregen dan in de richtlijnen werd aanbevolen. Op basis van de resultaten werden versterking van het diagnostische zorgtraject voor KC in de eerstelijnszorg en vermindering van laag-risico BCC nacontroles gesuggereerd als mogelijke verbeterpunten in de KC-zorg. Omdat initiatieven gericht op de eerstelijnszorg op dit moment onhaalbaar leken, lag de focus voor dit proefschrift op de onnodige BCC nacontroles.

Het hoofddoel van dit proefschrift was het ontwikkelen van een strategie om de hoeveelheid onnodige laag-risico BCC nacontroles te verminderen, met behoud van de kwaliteit van de zorg. Dit werd gedaan aan de hand van het model van Grol en Wensing voor implementatie en verandering. De eerste stap was het ontwikkelen van een voorstel voor verandering, wat in dit hoofdstuk is gedaan.

In **Hoofdstuk 2** werd de feitelijke zorg van het veranderingsdoel gemeten, dit was de tweede stap in het model. Om deze zorg te meten moeten eerst kwaliteitsindicatoren worden gedefinieerd. Daarom zijn alle zorgdeclaraties met betrekking tot huidkanker uit de Vektis-declaratie-database geëxtraheerd en geanalyseerd. Voor meer dan 220.000 patiënten werd in 124 zorgcentra een declaratie voor huidkanker vergoed. Het toonde een grote praktijkvariatie in zowel de behandelingen als de nacontroles. In 2016 kregen huidkankerpatiënten gemiddeld 1,8 nacontroles. De analyse toonde aan dat de Vektis-declaratie-database een valide en bruikbare dataset kan zijn om kwaliteitsindicatoren voor huidkanker te meten. Er moet nog worden onderzocht of de gedetecteerde praktijkvariatie ongewenst is.

In **Hoofdstuk 3** zijn de standpunten van de belanghebbende doelgroepen geanalyseerd. In **Hoofdstuk 3.1** hebben we de behoeften en voorkeuren van BCC- en PCC-patiënten met betrekking tot hun zorg in kaart gebracht aan de hand van zes focusgroepen met in totaal 42 patiënten. Zowel BCC- als PCC-patiënten hebben de volgende behoeften en voorkeuren kenbaar gemaakt: (I) de noodzaak om alle relevante informatie op maat te ontvangen; (II) een arts die hen serieus neemt en goed communiceert; (III) een korte wachttijd en de beste behandeling met direct resultaat; (IV) gezien worden door dezelfde arts; een voorkeur voor de dermatoloog tijdens (V) behandeling en (VI) nazorg; (VII) een algemene behoefte aan gestructureerde nazorg en (VIII) een volledig huidonderzoek tijdens de nacontrole. Patiënten met BCC gaven bovendien aan dat er behoefte is aan openheid en transparantie en dat zij willen deelnemen aan de gezamenlijke besluitvorming. Deze resultaten kunnen worden gebruikt om de huidkankerzorg af te stemmen op de behoeften van KC-patiënten. Er wordt gepleit om het patiëntperspectief in de huidige richtlijnen te integreren.

In **Hoofdstuk 3.2** werden de factoren die van invloed waren op de onnodige BCC nacontroles onder dermatologen geïdentificeerd en werden suggesties gedaan om deze zorg te verminderen. Daarnaast werd het perspectief van laag-risico BCC patienten onderzocht. Er werd een kwalitatief onderzoek uitgevoerd bestaande uit 18 semigestructureerde interviews met dermatologen en drie focusgroepen met in totaal 17 laag-risico BCC patiënten. Factoren die van invloed waren op de BCC nacontroles genoemd door dermatologen waren onder andere het voldoen aan de behoefte van patiënten, gebrek aan vertrouwen in de huisarts, financiële prikkels en de macht der gewoonte. Patiënten meldden uiteenlopende behoeften met betrekking tot periodieke nacontroles, ze gaven een voorkeur aan om gezien te worden door een dermatoloog en gaven aan dat er behoefte was aan betere informatievoorziening. De voorgestelde strategieën van de dermatologen om de laag-risico BCC nacontroles te verminderen waren het opleiden van patiënten met betere informatie, het opleiden van de huisartsen om het vertrouwen van de dermatologen te vergroten, het realiseren van een passende financiële vergoeding en het informeren van de dermatologen over de lage waarde van de laag-risico BCC nacontroles. Deze mix van factoren die bijdragen aan de laagwaardige BCC nacontroles geeft aan dat een strategie om deze zorg te verminderen gericht moeten zijn op alle belanghebbenden.

In **Hoofdstuk 3.3** werd de andere kant van het spectrum onderzocht: de ervaringen en behoeften van complexe huidkankerpatiënten. Dit zijn patiënten die chirurgisch zijn behandeld voor huidkanker door een dermatoloog met daaropvolgend een reconstructie door een plastisch chirurg. Hun zorgproces is vaak ingewikkelder en psychologische en sociale problemen kunnen een grotere rol spelen. Zestien complexe huidkankerpatiënten werden geïnterviewd over hun ervaringen en behoeften op het gebied van zorg aan de hand van een vooraf gedefinieerde onderwerpenlijst. Zij meldden behoefte te hebben aan een bekwame en vriendelijke arts die de informatie en communicatie op hun individuele situatie afstemt. Ook werd de behoefte aan continuïteit van zorg en een betere samenwerking tussen zorgverleners benadrukt. Verder ervoeren patiënten complicaties en onvervulde verwachtingen en gaven ze aan behoefte te hebben aan gedeelde besluitvorming in verschillende stappen van het behandelingsproces (afhankelijk van de leeftijd). De patiënten vonden ook het volledig verwijderen van de tumor, meerdere nacontrolebezoeken van verschillende specialisten op dezelfde dag plannen en de erkenning van de psychologische impact op de partner belangrijk. Deze resultaten pleiten ervoor om de continuïteit van de zorg en de samenwerking tussen specialisten voor deze patiëntengroep te verbeteren. Bovendien moeten artsen rekening houden met de individuele behoeften van patiënten en hun partner en de informatie, communicatie en (ondersteunende) zorg daarop afstemmen.

In **Hoofdstuk 4** werden de kwalitatieve resultaten van de vorige hoofdstukken gekwantificeerd. Allereerst is in **Hoofdstuk 4.1** een ranglijst ontwikkeld, gebaseerd op de resultaten van de focusgroepen. De lijst bestond uit vijf items met betrekking tot de patiënt-arts relatie, vijf ziektespecifieke items en twee externe items (kosten en reistijd). De items werden vervolgens gerangschikt door 101 BCC-patiënten van 1 (belangrijkste) tot 12 (minst belangrijke). Zij scoorden patiënt-arts gerelateerde factoren als belangrijkste, met 'uitleg over de ernst van de huidkanker' als belangrijkste factor met betrekking tot de BCC-zorg. De tweede belangrijkste factor voor patiënten is het 'gevoel dat de arts goed naar de patiënt luistert'. Patiënten hebben patiënt-arts gerelateerde factoren hoger ingeschat dan ziektespecifieke factoren. De externe factoren werden het minst belangrijk geacht. Deze studie benadrukt het belang van het integreren van patiënt-arts relatiefactoren in de huidige BCC-zorg.

Ten tweede werden in **Hoofdstuk 4.2** de belangrijkste items gebruikt in een 'Discrete choice experiment' (DCE) om te leren welke afwegingen BCC-patiënten en dermatologen bereid zijn te maken om minder laagwaardige nacontroles te accepteren. Vierentachtig dermatologen en 266 BCC-patiënten hebben de DCE ingevuld. De resultaten laten zien dat de acceptatie van geen extra follow-up bezoeken (d.w.z. het volgen van de richtlijnen) door patiënten zou toenemen van 55% tot 77% als de nacontrole werd uitgevoerd door dezelfde persoon als de behandelaar en er een hand-out werd gegeven aan patiënten met gepersonaliseerde informatie. Vrouwelijke patiënten en oudere dermatologen zijn minder bereid de richtlijnen te accepteren en geven de voorkeur aan extra vervolgbezoeken. Uit dit onderzoek bleek dat een gepersonaliseerde hand-out een realiseerbare strategie zou zijn om de kosten aanzienlijk te verlagen met behoud van de kwaliteit van de zorg.

In **Hoofdstuk 5** werd de strategie, een gepersonaliseerde ontslagbrief voor patiënten gebaseerd op al het voorgaande onderzoek, getest in één academisch ziekenhuis, drie algemene ziekenhuizen en twee zelfstandig behandelcentra. De effectiviteit, de kosteneffectiviteit en de budgettaire impact van de gepersonaliseerde brief op het aantal nacontroles voor laag-risico BCC patiënten werd vergeleken met de standaard zorg. Dit werd gedaan aan de hand van een modelgebaseerde kosteneffectiviteitsanalyse met behulp van individuele patiëntgegevens die via enquêtes werden verzameld. De studie omvatte 473 patiënten bij wie voor het eerst BCC werden gediagnosticeerd. De gepersonaliseerde brief verminderde het aantal nacontroles bij de dermatoloog met 13% in één jaar. De vermindering in kosten na vijf jaar bedroegen € 26,04 per patiënt. De budgettaire impact in Nederland bedroeg -€ 2,9 miljoen na vijf jaar. Uit deze resultaten blijkt dat de verspreiding van een gepersonaliseerde ontslagbrief het aantal nacontroles vermindert en dat de interventie bij implementatie in Nederland leidt tot een aanzienlijke kostenbesparing.

Hoofdstuk 6 is de algemene discussie, waarin een overzicht gegeven wordt van de belangrijkste bevindingen. Deze werden in het perspectief van de bestaande literatuur geplaatst. In het eerste deel van de algemene discussie wordt het zorgpad van BCC geëvalueerd vanaf de preventie tot en met de nazorg, met suggesties om elke stap van het traject te verbeteren. Dit toont de plaats van de gepersonaliseerde brief in de huidige BCC-zorg. Het tweede deel van de discussie reflecteert op de positie van patiënten in het onderzoeksproces. Er wordt gepleit om gebruik te maken van de unieke, diverse en complementaire ervaringsdeskundigheid van patiënten in alle stappen van het onderzoeksproces, vanaf de prioritering van onderzoek tot en met de implementatie in de zorg. Tot slot wordt het model van Grol en Wensing afgerond door de perspectieven voor de toekomst te beschrijven.

Chapter 8

Abbreviations
List of co-authors
List of publications
Curriculum vitae
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Dankwoord

ABBREVIATIONS

BCC	Basal cell carcinoma
BIA	Budget impact analysis
CEA	Cost-effectiveness analysis
DCE	Discrete Choice Experiment
DRG	Diagnosis-related group
FBSE	Full body skin examination
GP	General practitioner
ICER	Incremental cost-effectiveness ratio
ISTC	Independent sector treatment centre
KC	Keratinocyte carcinoma
LCA	Latent class analysis
LM	Lentigo maligna
MAR	Missing at random
MI	Multiple imputation
MMS	Mohs micrographic surgery
NMSC	Non-melanoma skin cancer
NP	Nurse practitioner
PA	Physician assistant or Probabilistic analysis
PDL	Personalized discharge letter
PDT	Photodynamic therapy
QALY	Quality-adjusted life year
QI	Quality-indicator
SCC	Squamous cell carcinoma
SRQR	Standards for Reporting Qualitative Research

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LIST OF PUBLICATIONS

M. Wakkee, **S. van Egmond**, M. Louwman, et al. Opportunities for improving the efficiency of keratinocyte carcinoma care in primary and specialist care: Results from population-based Dutch cohort studies. *Eur J Cancer 2019; 117: 32-40.*

S. van Egmond, L.M. Hollestein, C.A. Uyl-de Groot et al. Practice variation in skin cancer treatment and follow-up care: A Dutch claims database analysis. *Accepted for publication in Dermatology*

S. van Egmond, M. Wakkee, M. Droger, et al. Needs and preferences of patients regarding basal cell carcinoma and cutaneous squamous cell carcinoma care: a qualitative focus group study. *Br J Dermatol 2019; 180.1: 122-129.*

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S. van Egmond, M. Wakkee, M. Hoogenraad, et al. Complex skin cancer treatment requiring reconstructive plastic surgery: An interview study on the experiences and needs of patients. *Accepted for publication in Archives of Dermatological Research*

S. van Egmond, M. Lugtenberg, E.C. Noels, et al. What are the most important factors in basal cell carcinoma care? The patient perspective. *Accepted for publication in Skin Health and Disease*

S. van Egmond, E. de Vries, L.M. Hollestein, et al. What do patients and dermatologists prefer regarding low-risk basal cell carcinoma follow-up care? A discrete choice experiment. *Submitted*

S. van Egmond, E.D. van Vliet, M. Wakkee et al. Efficacy, cost-effectiveness and budget impact of a personalized discharge letter for basal cell carcinoma patients to reduce low-value follow-up care. *Manuscript in preparation*

E.C. Noels, L. Hollestein, **S van Egmond**, et al. Healthcare utilization and management of actinic keratosis in primary and secondary care: a complementary database analysis. *Br J Dermatol 2019; 181.3: 544-553.*

E.C. Noels, M. Lugtenberg, **S. van Egmond,** et al. Insight into the management of actinic keratosis: a qualitative interview study among general practitioners and dermatologists. *Br J Dermatol 2019; 181: 96-104.*

M. Wakkee, E. Noels, **S. van Egmond,** L. Hollestein. Cijfers over huidkanker zorg in Nederland. Ned Tijdschr Dermatol Venereol 2019

CURRICULUM VITAE

Sven van Egmond werd geboren op 13 september 1991 te Leiderdorp en groeide op in Oude Wetering. Na het afronden van het atheneum aan het Bonaventura college te Leiden heeft hij een jaar Life Science and Technology gestudeerd aan de Universiteiten Leiden en Delft. Echter bleek deze studie niet bij hem te passen en besloot hij het daaropvolgende jaar geneeskunde te gaan studeren, waar hij tot zijn geluk direct werd ingeloot bij de Universiteit Leiden. Tijdens zijn studie woonde hij in Leiden en heeft hij diverse bijbanen gehad. Het dermatologie coschap trok gelijk zijn interesse, waarna hij besloot zijn keuze-stages in deze richting te doen. Tijdens zijn wetenschapsstage werd naast de interesse voor de dermatologie, ook de interesse voor onderzoek gewekt. Na het behalen van zijn artsexamen in 2017 startte hij zijn promotieonderzoek bij de afdeling dermatologie van het Erasmus MC onder begeleiding van zijn promotor prof. dr. Tamar Nijsten en co-promotoren dr. Marlies Wakkee en dr. Esther W. de Bekker-Grob. Vanaf januari 2020 tot en met december 2020 was hij werkzaam als arts niet in opleiding tot specialist (ANIOS) bij de afdeling dermatologie van het Erasmus MC. Na een jaar met Laura Ouboter in Leiden gewoond te hebben, wonen zij sinds maart 2020 samen in Amsterdam Oost. Sinds januari 2021 is hij werkzaam als post-doctorale onderzoeker bij de afdeling dermatologie van Stanford University.

PHD PORTFOLIO

Name PhD Student:	Sven van Egmond
PhD period:	January 2017 – March 2021
Promotor:	Prof. dr. T.E.C. Nijsten
Co-promotoren	Dr. M. Wakkee Dr. E.W. de Bekker – Grob

	Year	Workload
Courses		
Molmed: Presenting Skills	2019	1.0 ECTS
Molmed: Photoshop and Illustrator CC 2019	2019	0.3 ECTS
Course Qualitative analysis	2018	16 hours
Erasmus Summer Programme: Introduction to Data-analysis	2018	0.7 ECTS
Erasmus Summer Programme: Health Economics	2018	0.7 ECTS
Good clinical practice: BROK	2018	1.5 ECTS
Measurement of Patient Preferences using Discrete Choice Experiments	2018	5.0 ECTS
Molmed: Basis introduction course on SPSS	2017	1.0 ECTS
Molmed: Biomedical English Writing Course	2017	2.0 ECTS
Research integrity	2017	7 hours
Limesurvey	2017	2 hours
Endnote	2017	4 hours
SPSS Dermatology workshop	2016	9 hours
(Inter)national presentations		
Strategic Planning - ECL Summer School, Ljubljana, Slovenia	2019	1.0 ECTS
De ins & outs van een patientenvereniging - PhD-Weekend Dermatology, Scheveningen, The Netherlands	2019	1.0 ECTS
Workshop 'Biopteren, verdoven en excideren' - Medisch Interfacultair Congres, Rotterdam, The Netherlands	2019	1.0 ECTS
What do dermatologists prefer in low-risk basal cell carcinoma follow-up care? A discrete choice experiment - LolaHESG, Almen, The Netherlands	2019	1.0 ECTS
Insight into the management of actinic keratosis (poster) - Annual meeting NVED, Lunteren, The Netherlands	2019	1.0 ECTS
Views and opinions of patients and providers on skin cancer care - Cells to Surgery, Rotterdam, The Netherlands	2019	1.0 ECTS
Basaalcelcarcinoom Follow-Up Study - Citrien Meet and Greet, Hilversum, The Netherlands	2018	1.0 ECTS
Follow-up care for skin cancer patients in The Netherlands: Analysis of nationwide claims data. - EDEN Forum Meeting, Berlin, Germany	2018	1.0 ECTS
Factors influencing current practices and suggested strategies to de-adopt low value follow-up care after basal cell carcinoma: a qualitative study - Annual meeting NVED, Lunteren, The Netherlands	2018	1.0 ECTS

Less is more. Deïmplementeren als kwaliteitsinstrument - NFU Masterclass, Nieuwegein, The Netherlands	2017	1.0 ECTS
Jonge Spruit - Skintermezzo Erasmus MC, Rotterdam, The Netherlands	2017	1.0 ECTS

	Year	**Workload**
Conferences attended		
Research meetings and journal clubs, Dermatology, Erasmus MC, The Netherlands	2017-2020	2.0 ECTS
Skintermezzo meetings, Dermatology, Erasmus MC, The Netherlands	2017-2020	1.0 ECTS
Leading the Change, Utrecht, The Netherlands	2020	5 hours
Doen of Laten work conference, Utrecht, The Netherlands	2019	3 hours
Lessons learned symposium, Erasmus MC, Rotterdam, The Netherlands	2018	3 hours
NVDV Scientific Meeting, Maastricht, The Netherlands	2018	1.0 ECTS
5 year Celcus, academy for affordable healthcare, The Hague, The Netherlands	2018	1.0 ECTS
Cells to Surgery, Rotterdam, The Netherlands	2017	1.0 ECTS
Choosing Wisely, Amsterdam, The Netherlands	2017	1.0 ECTS
PhD Weekend Dermatology, Den Bosch, The Netherlands	2017	1.0 ECTS
EDEN Forum. Madrid, Spain	2017	1.0 ECTS
PhD Weekend Dermatology, Antwerpen, Belgium	2016	1.0 ECTS

Teaching		
Supervising master thesis of Ella van Vliet	2020	2.0 ECTS
ICK education surgical skills and contribution to organisation of IWC education	2017-2020	2.0 ECTS
Research education: ‘Discrete Choice Experiment’	2019	1.0 ECTS
Supervising master thesis of Marit Hoogenraad	2019	2.0 ECTS
Research education: ‘Introduction to Discrete Choice Experiments’	2018	1.0 ECTS
Supervising master thesis of Anna Parfenkova	2018	2.0 ECTS
Skin cancer diagnostics course for general practitioners	2018	1.0 ECTS
Research education: ‘Linear regression’	2018	1.0 ECTS
Research education: ‘Multiple baseline design’	2017	1.0 ECTS

Organising committee		
Ski weekend 2020 Kirchberg, Dermatology, Erasmus MC	2019-2020	15 hours
‘Lief en Leed’ multiple activities, Dermatology, Erasmus MC	2018-2020	15 hours
PhD weekend Dermatology Erasmus MC, Breda, The Netherlands	2018	1.0 ECTS

Other		
‘Zonkracht Actie Plan’ member	2019-2020	5 hours
Co-founder ‘De Huidkanker Stichting’	2018-2020	60 hours
Occasional reviewer for the British Journal of Dermatology	2018	3 hours

DANKWOORD

Eindelijk is het af, het einde van een onvergetelijke periode in mijn leven komt in zicht. Een erg leuke en met name in het laatste jaar ook drukke periode. Dat het afgerond is en ook nog eens leuk was, is te danken aan een menigte personen, waarvan ik er een aantal in het bijzonder wil bedanken.

Mijn promotor, prof. dr. T.E.C. Nijsten. Beste Tamar, uiteraard gaat mijn eerste dank naar jou omdat je mij vier jaar geleden deze kans aangeboden hebt. Ik blijf mij na vier jaar nog steeds verbazen hoe gemakkelijk je in een oogwenk creatieve oplossingen en ideeën voor onderzoek bedenkt. Daarnaast heb ik veel mogen leren van jouw kritische blik en analytisch vermogen. Bedankt voor de begeleiding de afgelopen jaren en de betrokkenheid bij de volgende stap in mijn carrière.

Mijn eerste copromotor, Dr. M. Wakkee. Beste Marlies, wat ben ik blij dat ik onder jouw begeleiding mijn masteronderzoek mocht doen. Met name dankzij jouw bevlogenheid werd mijn interesse om verder onderzoek te doen gewekt en ben ik dit avontuur begonnen. Jouw altijd kritische blik heeft mijn promotieonderzoek naar een hoger niveau gebracht. Ik bewonder hoe goed je de kliniek en onderzoek combineert, ik hoop dit ook ooit zo goed te doen als dat jij dit doet. Helaas hadden we daardoor weinig tijd om bij te kletsen, maar het was fijn dat we hier soms in de auto naar congressen tijd voor hadden. Ik wil je uiteraard ook bedanken voor de kans die je mij gebracht hebt om mijn onderzoek verder voort te zetten in Stanford.

Mijn tweede copromotor, Dr. E.W. de Bekker – Grob. Beste Esther, ondanks dat we elkaar niet vaak gezien hebben de afgelopen jaren, wist ik wel dat je altijd voor mij klaar stond. Ik kreeg ondanks jouw drukte altijd direct antwoord op al mijn vragen. Je bent terecht copromotor van het jaar geworden, omdat je naast je deskundige inhoudelijke adviezen, ook altijd persoonlijke interesse toonde. Aangezien ik veel van mijn e-mails begon met 'Beste Esthers', moet ik natuurlijk hier ook dr. E. de Vries benoemen. Beste Esther, ik vond het erg fijn en gezellig om je vorig jaar eindelijk te ontmoeten in Bogota na elkaar alleen nog maar via videobellen gesproken te hebben. Ik hoop dat we binnenkort ergens op de wereld nog met zijn drieën een drankje gaan drinken.

Mijn onofficiële copromotor, Dr. M. Lugtenberg. Beste Marjolein, ik ben erg blij dat jij mijn eerste werken bijna geheel in het rood terugstuurde. Naast dat je mij bekwaam hebt gemaakt in het kwalitatieve onderzoek, heb je mij opnieuw leren schrijven. Zelfs voor het schrijven van mijn dankwoord gaf je mij nog advies. Daarnaast was het altijd erg gezellig om samen te werken, aangezien we altijd eerst begonnen met de (gedetailleerde) weekendbespreking, die we er nog steeds in hebben gehouden.

Mijn kleine promotiecommissie. Beste prof. dr. E.P. Prens, prof. dr. C.A. Uyl – de Groot en prof. dr. G.P. Westert, bedankt voor jullie bereidheid om mijn proefschrift te beoordelen en met mij van gedachten te wisselen tijdens de verdediging van mijn proefschrift.

Lieve Selma, één van de mooiste dingen die ontstaan is tijdens mijn promotieonderzoek is onze vriendschap. Ik ben heel erg blij dat wij tegelijk en in dezelfde onderzoekskamer zijn gestart in het GK gebouw. Met jou kan ik altijd alles delen en ik kan bij jou altijd terecht met al mijn problemen, van statistiek tot relatieadvies. Het is ongelofelijk dat we nog maar één keer onenigheid hebben gehad: omdat we allebei de deur niet open wilden doen. En dit was na 2 uur niet tegen elkaar praten alweer opgelost. We hebben al veel avonturen beleefd en het kan niet anders dan dat wij (samen met Bram en Laura) tot het einde der tijden blijven borrelen en kaasfonduen. Ik ben enorm blij dat jij straks achter mij staat als paranimf en ik zal niet veel later trots achter jou staan.

Lars, mijn grote broer. Ik ben blij dat we de afgelopen jaren meer naar elkaar toe gegroeid zijn. Ik bewonder hoe je, samen met Judith, je zonen Levi en Benja groot aan het brengen bent zonder dat het je enige moeite lijkt te kosten en dat naast je drukke baan. Ik realiseer mij nu weer dat ik vaker langs zou moeten komen en ik beloof bij dezen dat ik dat ga doen. Ik ben erg vereerd dat je achter mij zal staan als paranimf.

Lieve Eline, mijn sister from another mister, mijn mede-smurf. Het was mooi om te zien hoe je tijdens je promotieonderzoek steeds meer jezelf werd, waarbij je aanstekelijke lach steeds vaker door de muren te horen was. Ik ben heel erg dankbaar dat ik veel met jou samen heb mogen werken en dat je mijn oneindige geblaat, flauwe grappen en ongevraagde taalcorrecties tolereerde. Behalve dat het altijd erg gezellig was, ben je echt een powervrouw, het verbaast mij dan ook niet dat je nu al de directrice bent van de NVDV. En wat was ik trots op je toen ik achter jou stond bij je verdediging. Helaas mogen er maar twee, maar ik had jou erg graag als mijn derde paranimf gehad. Ik wil je nogmaals heel erg bedanken, en wens jou en Rik veel geluk en het allerbeste met alles en hopelijk kunnen we weer snel naar een wijnbar.

Alle (arts-)onderzoekers wil ik graag bedanken voor de leuke tijd inclusief wine-tastings en nuttige gedachtewisselingen over het werk, maar ook vaak over het leven. In het bijzonder wil ik Eline, Kirtie, Martijn, Merel, Minke, Selin, Selma en Sterre bedanken als mijn kamergenoten en buren in het GK-gebouw. Dankzij jullie voelde ik mij snel thuis. Daarnaast ben ik ook de uit-zijn-voegen-groeiende onco-groep onder leiding van Marlies en Loes zeer dankbaar voor de oneindige wekelijkse adviezen.

Ook alle A(N)IOS wil ik bedanken. Tijdens mijn ANIOS-jaar werd ik warm ontvangen als onderdeel van de groep. Dank ook aan alle dermatologen voor alle uitleg waardoor mijn dermatologische kennis een boost heeft gekregen. The Amsterdam Crew heeft er daarbij voor gezorgd dat zelfs het vele reizen leuk (en voedzaam) was.

Mijn onderzoek was niet mogelijk geweest zonder de deelname van patiënten aan mijn studies. Deze wil ik dan ook hartelijk hiervoor bedanken. Daarbij ook de (dermatologen van de) deelnemende ziekenhuizen voor het verlenen van de toegang tot hun patiënten.

Mijn dank gaat ook uit naar de ondersteuning, tijdens mijn klinische werkzaamheden en het onderzoek. In het bijzonder Barbera en Natasja, bedankt voor jullie hulp en de gezellige gesprekken tijdens het afwassen van de kopjes.

Prof. dr. E. Linos, dear Eleni, I would like to thank you for providing me the opportunity to conduct further research in your group. I hope that Covid-19 will allow us soon to work together in person.

Ik wil ook graag iedereen bedanken die geholpen heeft bij de oprichting van De Huidkanker Stichting (HUKAs). Ik wil hier in het bijzonder Jaap Touw bedanken voor zijn tomeloze inzet voor de stichting.

Lieve Vrienden en (Schoon)familie, allen heel erg bedankt voor jullie steun en afleiding. Jullie hadden vaak geen idee wat ik doe, maar misschien was daardoor de afleiding extra fijn. Thomas en Marco, jullie nog extra dank voor de gezellige samenwoontijd in Leiden. Schoonfamilie, ik ben blij dat ik jullie erbij heb gekregen.

Mama en papa, ondanks dat jullie niet meer samen zijn, noem ik jullie in één zin. Ik ben dankbaar voor de manier waarop jullie mij hebben gevormd tot waar ik nu ben. Mama, hartelijk dank voor de wekelijkse 'hoe gaat het?' en interesse. Papa, ik ben erg blij dat onze band het laatste jaar aan het versterken is en we elkaar weer vaker zien.

Liefste Laura, ik ben onbeschrijflijk blij dat ik jou tegen ben gekomen. Ondanks dat we totaal verschillend zijn, blijven we nog elke dag meer en meer naar elkaar toe groeien. Ik weet zeker dat ik met jou oud wil gaan worden en ik kijk er al naar uit om samen voor Gizzy te gaan zorgen (maar nu nog niet). Ik weet het, ik zeg het niet vaak genoeg, maar ik hou heel veel van je.

The printing and publication of this thesis had been financially supported by the department of Dermatology of the Erasmus University Medical Center Rotterdam. Further financial support for this dissertation was generously provided by:

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