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Quality, Readability, and Understandability of German Booklets Addressing Melanoma Patients

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Abstract

Booklets are the preferably used form among patient education materials and are often handed out during medical consultations in dermatological oncology settings. However, little is known about how beneficial they are and whether they correspond to essential quality characteristics. To assess the quality, readability, and understandability of currently freely available booklets written in German addressing melanoma patients (MP). Melanoma booklets in accordance with predefined criteria were searched and analyzed. Three reviewers independently assessed their quality and understandability by applying the DISCERN tool and PEMAT-P. The Flesch Reading Ease Score (FRES) was calculated to determine readability. Nine booklets addressing MP were analyzed. The overall median DISCERN score was 3.6 (interquartile range (IQR) 2.9–4.1), median PEMAT-P score was 91% (IQR 83–94.5), and median FRES was 43 (IQR 33.5–47.5), indicating a *medium* quality, a *high* application of understandability elements, but *low* readability in at least half of the booklets. Incomplete reporting on treatments and insufficient meta-information caused the main quality deficits. There is a need of content and didactic revision of German booklets for MP to raise their quality and to make them beneficial and understandable for more patients. An adaption in accordance with evidence-based criteria and an even stronger involvement of MP in assessment and development of patient education material are considered to be the best approaches.

Keywords Melanoma · Booklets · Qualitative evaluation · Readability · Patient education · Health communication · Information dissemination

Introduction

Melanoma incidence has been increasing worldwide [1]. In Germany, it accounts for about 4% of all cancers and is the fifth most common malignancy [2]. However, approvals of new effective therapies in recent years have substantially expanded the treatment spectrum, especially for melanoma patients (MP) with metastatic disease.

The increasing incidence and new treatments came along with an increased need to educate MP. Cancer patients in Germany prefer consultations with the physician to acquire information about their condition [3]. However, the physician's time is usually limited [4], and sometimes, many detailed medical facts are provided at once during medical consultations. In such cases, patients may have difficulty in understanding or be unable to absorb all the information and recall them correctly. This can lead to their feeling inadequately informed [5]. Another problem is that patients may fail to address all their concerns during medical consultations, and thus, some questions may remain unanswered.

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To compensate for information deficits, patients use sources of information outside of medical consultations [3, 6]. The range of available forms of cancer information is extensive and they vary in terms of their quality [7]. Patients therefore want clinicians [8–10] to complement medical consultations with written or visual information and to recommend sources that can be used by the patients themselves. Usually, verbal information is supplemented with booklets which are available from different institutions. Written information commonly aims to improve the patients' knowledge about the disease and its treatment and provide directions to supportive care. However, little is known about which of available German booklets are most appropriate to be handed out to melanoma patients.

Research repeatedly indicates that patients usually should have sufficient health literacy to understand, optimally use, and benefit from written information [11–13]. In almost half of the European population (47.6%) and in even 54% of the German population, however, health literacy is limited. This is especially the case in older and less-educated people [14]. One aim of the German National Cancer Plan is to optimize information provision and to make cancer information beneficial for more patients [15].

This study is part of the EBPIDASC project and the Skin Cancer Council Germany (www.nvkh.de). It was aimed at helping to explore how information provision in dermatological oncology works and to optimize the education of melanoma patients in Germany. As a first step, an inventory of information resources combined with a quality assessment was done. It was the aim to give an overview of what melanoma information are currently available and to identify existing shortcomings as potential starting points for improvement. This paper reports the assessment of freely available German booklets for melanoma patients (MP) in terms of their quality, readability and understandability.

Methods

Identification of Booklets

Booklets of interest had to meet the following criteria (Supplementary Figure 1): (1) melanoma is the main subject, (2) explicitly address patients and/or lay persons, (3) be available for free, (4) be available in German-speaking countries, (5) be written in German, and (6) be released not before 2011. Booklets were excluded if they solely considered melanoma prevention, if they considered only one medical treatment option (e.g., one specific medication), if they presented an institution (e.g., a skin cancer clinic) or self-help groups, or if they were just flyers (e.g., from medical practices) or brief information leaflets (< 3 pages of content).

To identify melanoma booklets in accordance with the predefined criteria we applied two different approaches: First, the first 20 hits on Google™, Bing™, and Yahoo™ were searched for combinations of the German synonyms for "melanoma," "booklet," "patient guideline," and "information." This is in accordance with the common information-seeking behavior of patients and lay people to search for information on cancer or health topics [16, 17]. Secondly, websites of established providers were visited, whose information is demonstrably used by cancer patients [3] and which are committed to making high-quality, evidence-based information available to them. Booklets on melanoma that were recommended on their websites at the time of exploration (05/2016) were compared with the findings of the first approach. Providers included:

- The German Cancer Society (called: DKG),
- The German Cancer Aid (called: DKH),
- The Association of the Scientific Medical Societies in Germany (called: AWMF)
- The Cancer Information Service of the German Cancer Research Center (called: KID),
- The Institute for Quality and Economic Efficiency in Health Care (called: IQWIG),
- The Medical Center for Quality in Medicine (called: ÄZQ),
- German skin cancer centers (certified by the German Cancer Society), and
- The Dermatological Cooperative Oncology Group (DeCOG; called: ADO).
- The booklets had to be both completely available for free as (printable) download and orderable directly from the providers in printed form.

Assessment of Quality

There is a variety of valid and reliable tools available to assess the quality of written or online patient information [18], including the IPDASi checklist [19], DISCERN [10], or EQIP [20] for instance. After profoundly exploring existing literature to identify the most appropriate tool for the booklet assessment, we decided to use DISCERN as it was previously found prior to other tools with regard to German patient information [21], there was an authorized German translation available published by the German Agency for Quality in Medicine [22] and it provided a scale for quantitative assessment.

The DISCERN tool (www.discern.de) is commonly used to evaluate *quality* of information addressing cancer patients [12, 23] and was developed for use by lay persons [10]. It contains 16 items to review: (1) a publication's *transparency* (items 1–8), (2) *content* (items 9–15), and (3) to give an intuitive *evaluation summary* (item 16). Items are scored on a 5-

point scale ranging from 1 (“criterion is not met at all”) to 5 (“criterion is fully met”). For our assessment, we omitted item 3 (“Is the publication important to you?”), since booklets which may be important to MP had already been selected by our inclusion criteria. For a booklet’s evaluation summary (item 16), the mean of all item ratings by one reviewer was calculated. A summary mean score of 5 corresponds to high quality.

Assessment of Understandability

For *understandability* assessment we applied the Patient Education Materials Assessment Tool for Printable Materials (PEMAT-P) [24]. It measures the utilization of elements in print media which may influence a person’s understandability of content, including the vocabulary, structure, use of numbers, layout, and use of visual aids. It contains 19 items of which each can be scored as 0 (“disagree”), 1 (“agree”) or N/A (“not applicable”). Then, percentages of fulfilled items are calculated. The higher the percentage value, the more elements to support understanding were found in a booklet.

Assessment by DISCERN and PEMAT-P was carried out independently by three reviewers (JB, MB, LR) with health research background. Ratings were based on the instructions of each tools’ handbook. For a booklet’s overall evaluation, the mean of item 16 ratings was calculated. Each reviewer additionally documented conspicuous positive and negative aspects of a booklet to give concrete examples for improvement.

Analysis of Readability

We determined the Flesch Reading Ease Score (FRES) by using an online tool for German texts [25] to assess *readability*. A booklet’s text was copied into a word document, checked for completeness, and then analyzed by the tool. Readability is mainly calculated from the length of sentences and the number of syllables per word. An FRES > 60 corresponds to *easy* text readability, scores between 46 and 60 correspond to readability in accordance with *average* reading levels, and texts with scores < 45 are considered to be *difficult* or *very difficult* to read.

Statistical Analyses

Data descriptions were used to summarize the quality, readability, and understandability ratings of the melanoma booklets. By applying SPSS Statistics (v. 23), an inter-rater reliability analysis of the three reviewers’ rating was performed by determining the intra-class correlation coefficient (ICC). The aim was to quantify consistency among reviewers for the DISCERN ratings and the strength of matches in the individual items as well. Furthermore, we examined associations between the overall DISCERN score of each booklet and the number of pages, readability, and understandability scores by means of the t test and the one-factor ANOVA. Statistical significance was set at $p \leq 0.05$.

Results

We identified eight booklets in accordance with the predefined criteria by online search engines and one additional by browsing the websites of non-commercial cancer information providers. A total of nine melanoma booklets were considered for assessment (Table 1). Of these, six were published by non-commercial and three by commercial providers (pharmaceutical companies). Seven of the booklets were published in Germany, one in Switzerland, and one in Austria. They contained between 28 and 90 pages dedicated to melanoma. Five booklets specifically addressed melanoma and four booklets addressed skin cancer in general, but melanoma had an own chapter.

Quality of Content

We rated an overall median DISCERN score of 3.6 (IQR 2.9–4.1) indicating that at least half of the nine booklets were of a *medium* to *medium-high quality.* However, none of the booklets achieved a *high-quality* rating (mean score > 4.5). Two booklets were scored > 4 (medium-high quality), five booklets were scored between 3 and 4 (medium quality), and two of the booklets reached a total DISCERN score between 2 and 3 (medium-low quality) (Table 1). We determined an ICC of 0.89 (95% CI 0.68, 0.96) and inter-item correlations r of 0.73–0.94, indicating a high overall and individual inter-rater agreement between the three reviewers in DISCERN assessment.

In detail, almost all melanoma booklets (8 out of 9) achieved a score of at least 4.0 for providing detailed information on supportive care (item 7) and for clearly indicating that there is more than one melanoma treatment option (item 14) as well. The same score ratings were given to seven booklets for clearly stating their aims at the beginning and for implementing them well in their content (item 1 and 2). However, one booklet failed to inform of who the booklet is for and only six booklets were rated highly for being written balanced and unbiased (item 6).

On four criteria, more than five booklets were mean scored ≤ 2 (indicating the criterion was *not* or *poorly* met). These criteria included clarity on sources used to compile a booklet (item 4), clarity on when the sources used were produced (item 5), reference to areas of lacking scientific evidence (item 8), and description of risks in each treatment described (item 11). Seven booklets scored ≤ 2 on information provided what would happen if no treatment is applied (item 12), but none

Table 1 Assessment summary of German booklets for melanoma patients

No.	Title (German title)	Edition	Publisher	Mean DISCERN score[a] (quality)	PEMAT-P[b] (understandability) (%)	FRES (German)[c] (readability)	Category of readability
1	"Patient Guidelines for Melanoma" (Patientenleitlinie Melanom)	07/2014	DKG, DKH, AWMF	4.4	91	43	Difficult
2	"Blue Guide for Skin Cancer Patients" (Hautkrebs. Die blauen Ratgeber)	05/2015	DKG, DKH	4.1	94	46	Average
3	"Melanoma. Black Skin Cancer" (Melanom. Schwarzer Hautkrebs)	10/2012	Krebsliga Schweiz	4.0	90	36	Difficult
4	"Patient Guide for Skin Cancer" (Patientenratgeber Hautkrebs)	11/2012	Landeskrebsgesellschaften	3.6	95	50	Average
5	"Black Skin Cancer. Information for Patients and Relatives" (Schwarzer Hautkrebs. Informationen für Patienten und Angehörige)	2013	Roche Pharma	3.6	89	44	Difficult
6	"Malignant Melanoma. Diagnosis and Therapy" (Malignes Melanom. Diagnose und Therapie)	08/2014	Bristol-Myers Squibb GmbH & Co. KGaA	3.5	95	31	Very difficult
7	"Skin Cancer. Diagnosis, Therapy, Post-treatment" (Hautkrebs. Diagnose-Therapie-Nachsorge)	04/2015	Österr. Gesellschaft für Dermatologie, Österreichische Krebshilfe	3.1	92	28	Very difficult
8	"Black Skin Cancer. Frequently asked Questions and Answers about Malignant Melanoma" (Der schwarze Hautkrebs. Die wichtigsten Fragen und Antworten zum malignen Melanom.	2011	HTC Charité/MSD Sharp & Dohme GmbH	2.7	77	49	Average
9	"Skin Cancer. Early Detection, Therapy, Post-treatment" (Hautkrebs. Früherkennung, Therapie, Nachsorge)	07/2012	Krebsgesellschaft Nordrhein-Westfalen	2.5	73	40	Difficult

Available in May 2016

DKG Deutsche Krebsgesellschaft (German Cancer Society); DKH Deutsche Krebshilfe (German Cancer Aid); AWMF Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften e.V. (Association of the Scientific Medical Societies in Germany); Krebsliga Schweiz (Swiss Cancer League); Landeskrebsgesellschaften (German Cancer Societies); Österreichische Gesellschaft für Dermatologie (Austrian Society of Dermatology); Österreichische Krebshilfe (Austrian Cancer Aid); HTC Hauttumorcentrum Charité (Skin Cancer Center Charité); Krebsgesellschaft Nordrhein-Westfalen (Cancer Society North Rhine-Westphalia)

[a] Mean DISCERN score of 5 indicates high quality

[b] PEMAT-P percentage indicates usage of understandability supporting elements

[c] FRES (Flesch Reading Ease Score) > 60 indicates easily readable text; calculated by www.schreiblabor.com

was scored ≥ 4 on this criterion. Furthermore, five booklets contained *no*, *poor*, or *incomplete* information on the effects of treatment choices on a patient's quality of life (item 13) and only five booklets were rated high as support for shared decision-making (item 14). An overall summary of the individual DISCERN item ratings is provided in Fig. 1.

Understandability

Six booklets achieved very good PEMAT-P ratings (> 90% of items were met) and three booklets achieved a score < 90% but > 70%, indicating overall high efforts to make a booklet's content understandable by applying supportive elements (e.g., visual aids, structure) [24]. Scores were especially reduced for equivocal and misleading use of terms or inadequate use of images (illustrations without relevant content and without reference to the text).

Readability

Text analyses resulted in an overall median FRE score of 43 (IQR 33.5–47.5). The score corresponds to a difficult readability in at least half of the nine melanoma booklets. Three booklets provided average reading levels, four were determined as difficult and two as even very difficult to read by lay persons.

Correlations Between Quality of Content, Understandability, and Readability

No significant differences were found between melanoma booklets of commercial and non-commercial providers in the DISCERN, PEMAT-P, FRE scores, and in the number of pages. We also detected no differences between *higher*, *medium*- and *low*-quality booklets (DISCERN score > 4; 3–4; < 3) in terms of their understandability and readability. But we found a significant difference between lower/medium quality (DISCERN ≤ 4) and higher quality booklets (DISCERN > 4) in the number of pages ($p = .048$) (Supplementary Figure 3), suggesting that higher quality booklets provided more information on melanoma.

Discussion and Conclusion

Discussion

By applying established assessment tools we found an overall medium quality, a high application of understandability elements, but a low readability in most of the analyzed German booklets for melanoma patients. The booklets had similar titles and expressed comparable aims. However, our assessment by three reviewers revealed heterogeneity in terms of the domains considered and illuminated shortcomings as base for optimization. Overall, the booklet providers were keen in naming the targeted audience of their booklets and in giving an introductive summary of the booklets' content. This holds also true for suggesting sources of supportive care and presenting different melanoma treatment options. However, we identified five aspects that were insufficiently met (DISCERN score < 3) by most of the booklets and diminished their quality. This was first; we often found *no* or *incomplete* information on the sources that were used to compile a booklet. Secondly, statements on areas of lacking scientific evidence were also limited. Both deficits have been depicted almost 20 years ago [26] and in recent literature again [13, 23], but are still present and are potential starting points to substantially optimize transparency and completeness of information for MP [27]. Third and fourth, while the mode and benefits of treatments were mostly described in detail, their risks as well as the potential consequences of treatments for the patient's quality of life were often addressed to a lesser degree (e.g., by

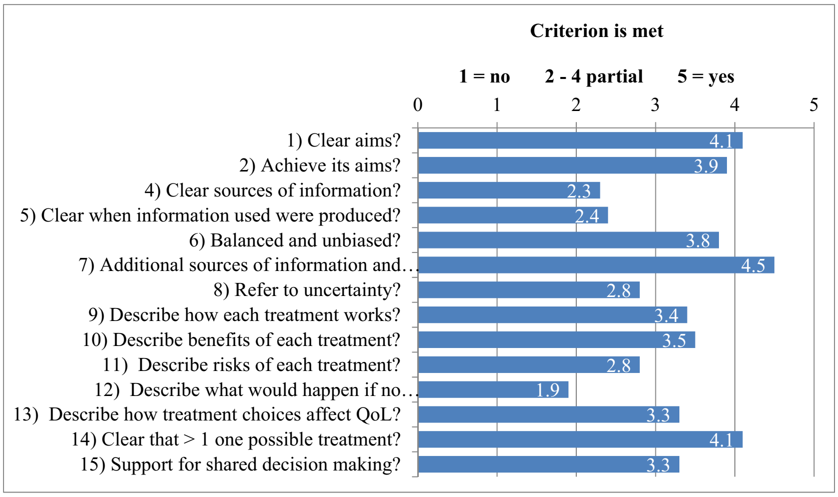

Fig. 1 Quality of information on melanoma of 9 booklets according to DISCERN instrument score. Values are depicted as mean scores for each of the items.(Mean score range 1–5: higher values correspond high quality); QoL = quality of life

imprecise information and risk description of only one treatment option). This is a fairly known problem with cancer information [13] which makes reporting one-sided and thus withholds important information. Finally, the most common problem in this field was, and still is, that information is lacking on what would happen if no treatment is administered at all [13, 23], although this is an important consideration MP should be informed about.

Providers were very keen to use several visual elements (e.g., tables, short headings, summary boxes, images) to make the booklets understandable, resulting in high understandability scores (> 70%). Nevertheless, we found elements that may rather contribute in raising questions. For instance, one booklet contained incorrect page references in the text which can lead to misinformation of the reader in the worst case [7]. Furthermore, we found images that were not self-explanatory or supportive (e.g., image of interferon structure), had no reference to the text or were merely used as an instrument of embellishment. In terms of skin cancer prevention, previous research demonstrated that the sensible use of images in patient education material increases attention, comprehension, and recall of health information and influence health behavior [28, 29]. However, there is a lack of evidence that demonstrates the cognitive use of images to explain clinical research outcomes and to illustrate the effects of skin cancer therapies. Bar graphs and pictographs are most likely to be recommended for use in patient education material for this purpose [27].

Another problem was that more than half of the melanoma booklets received low FRE scores corresponding to a difficult or even very difficult readability. Often, medical terms were used instead of more common German words (e.g., "kongenital" instead of "angeboren") and sometimes an explanation of the terms or a glossary was missing. It is fundamental that patients can easily read its text and understand the medical terms to benefit from a booklet. A patient who first gets a booklet to inform themselves without having pre-education could quickly feel overstrained.

We found significant correlations between the number of pages and the booklets' quality which confirms previous findings [13] and may reflect that booklets with more pages provide more information and thereby can meet more quality criteria. In addition, comprehensive information may meet the information needs of more patients. However, it has also to be pointed out that too many pages may be problematic for readers, who are less likely to locate relevant information and more likely to give up looking for desired information [30].

Limitations

Our assessment concentrated on a selection of nine booklets, written in German and dealing with melanoma per se. Although the sample size was quite small, each of the booklets was of considerable length. Another inclusion criterion was free of charge accessibility. Hence, our results cannot necessarily be generalized to booklets written in other languages, those which look more closely at single aspects of the disease and the melanoma booklets which are not available for free. The quality and understandability assessment were conducted by three reviewers and thus a result of subjectivity. However, the high inter-rater agreement suggests that most of the independently detected deficits were apparent to all of the reviewers and thus may be problematic for others. Furthermore, by the tools used, we primarily checked the completeness of aspects that should be addressed by patient information. Thus, further research is needed to determine which booklets for MP contain accurate and up-to-date information. This seems urgent, especially given the new treatment options for metastatic MP and the absence of recency indicators in some of the examined booklets. It is questionable whether booklets published more than 5 years ago and which are still available contain up-to-date treatment information. The Flesch formula was used to assess readability, indicating that measured reading levels were high across booklets. However, the utility of readability indices is limited since scores may have been artificially amplified because of medical terms. These receive low scores if they are polysyllabic, but high scores if they are just short terms, even if they are not commonly used or understood [27]. We determined a high understandability across the melanoma booklets, implying that all providers endeavored to apply helpful elements. However, given that the reading levels in many of the assessed booklets exceeded the average reading level, it is likely that a large proportion of MP may still experience difficulty in benefiting from the booklets' content. To account for this, an assessment of the quality, readability, and understandability by lay persons or focus groups of MP is desirable. A stronger patients' involvement in the development of information addressing them is recommended in general, as this can have positive effects on their perception, acceptance, and relevance [27].

Conclusions

Various providers are keen in making melanoma information available for patients in the form of booklets which is worthy of gratitude. Booklets are a very welcome and frequently used supplement source to educate MP about their disease. However, our assessment revealed shortcomings which should be considered for revision to enhance their quality and benefit. The booklets were mainly incomplete in terms of providing meta-information and reporting about treatments as well as informing about consequences of the disease for the patient's quality of life. In addition, most booklets were found to be difficult to read.

Practice Implications

For revision of German booklets addressing melanoma patients, to apply the guideline for developers of evidence-based health information [27] may be helpful as it contains evidence-based recommendations on how patient information should be structured, what content and meta-information should be provided, and what elements should be used to make them beneficial for more patients. A didactic revision is also recommended. This includes restructuring of texts to make them easier to understand, redesigning the layouts of some booklets to enhance their usability and applying more useful images that relate to the content and facilitate its understandability. In this context, the need to involve melanoma patients in the assessment and development of patient education material is worth to emphasize again, to reduce discrepancies between what is provided and what patients expect. Finally, the providers and physicians should also be familiar with the quality, content, and accuracy of the booklets they hand out. Our findings have been communicated with key stakeholders, including providers, and are being integrated into revised versions of some of the booklets assessed here.

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Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interests.

Ethics Approval This article does not contain any studies with human participants performed by any of the authors.

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