


SPECIAL ISSUE ARTICLE

iKNOWgynetics – A web-based learning concept to empower primary care gynecologists to participate in the care of patients with a family history of breast and ovarian cancer

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Abstract

Familial cancer burden and genetics play an increasingly important role in the early detection and prevention of gynecological cancers. However, people with hereditary cancer risks are often identified late when they already have cancer. We aimed at developing and evaluating a training concept for primary care gynecologists—iKNOWgynetics—to improve their knowledge and awareness of genetic cancer syndromes and their ability to identify patients with increased familial cancer risks based on up-to-date evidence and current guidelines (in Germany, primary care includes all doctors treating patients on an outpatient basis without a clear separation of the expertise of the doctor or of their specialty). Starting off with a needs assessment among primary care gynecologists, we developed and evaluated an online training concept—using a web-based learning platform in combination with a live virtual seminar—to convey practice-relevant knowledge about familial cancer. After registration, participants get access to the web-based learning platform (www.iknowgynetics.de) to prepare for the virtual seminars and to use it as online reference to re-access the contents after the training. Evaluation included multiple-choice (MC) questions on knowledge and participants' self-efficacy to implement the acquired knowledge, which were administered in a pre-post design. Of 109 participants, 103 (94.5%) filled out pre- and post-questionnaires. Eighty-five participants were gynecologists in primary care from Berlin (81.2%) and Brandenburg (18.8%) and had an average of 24.1 years (SD=8.5 years) of professional experience. After the training, participants answered significantly more knowledge questions correctly ($M=15.2$ of 17, $SD=1.3$) than before ($M=13.8$ of 17, $SD=1.7$) ($p<0.01$) and felt more confident to be able to apply referral criteria for specialized counseling in practice ($p<0.001$). The online-based training iKNOWgynetics considers the busy schedule of primary care gynecologists and supports them in acquiring practice-relevant information on familial cancer risks and on how to identify healthy persons at risk, which may ultimately help to improve the prevention of gynecological cancers. In future studies, the reported concept could be transferred to other entities.

Dorothee Speiser and Friederike Kendel are shared first authors.

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KEYWORDS

digital learning, education, familial cancer risk, genetic counseling, primary care, transsectoral care

1 | INTRODUCTION

Precision medicine using genetics as important biomarkers is on the rise to improve prevention and prognosis for people with increased cancer risks. To realize the potential of precision medicine, all health sectors should ideally be involved in the care of women at risk for familial cancer. Yet, studies show that community-based gynecologists often lack the necessary knowledge and skills (Haga et al., 2019) to routinely carry out initial risk assessments as part of the family history or to sensitize patients with increased cancer risks to this topic and refer them to specialized centers for genetic counseling (Cohen et al., 2019). Given that patients with increased cancer risks often remain undetected until they develop cancer, gynecologists in primary care may play an important role in identifying healthy high-risk patients *before* they develop cancer (Kne et al., 2017; Meyer et al., 2010; van Riel et al., 2012). Thus, the aim of this project was to develop and evaluate a guideline-based training module for gynecologists in primary care to convey the necessary knowledge about hereditary breast and ovarian cancer which could be useful in their daily routine.

In recent years, knowledge about genetic causes of cancer has increased rapidly. At least 5%–15% of all breast and ovarian cancers are caused by pathogenic genetic variants (Owens et al., 2019). Awareness of germline genetics is crucial not only for intensified diagnostics, but increasingly also for therapeutic decisions. This does not only apply for advanced cancers, but increasingly also for curable early stages of cancer. The development toward oncological precision medicine based on pathogenic germline variants is accompanied by the discovery of more and more genes with clinical relevance for cancer diseases. Apart from the impact on cancer patients, early identification of pathogenic variants in high-risk genes enables early detection and prevention strategies in healthy carriers to effectively reduce cancer risks in affected families (Ritchie et al., 2021; Xiao et al., 2019). However, studies and practical experience show that a large proportion of affected individuals with increased hereditary cancer risks are not identified or are identified too late, that is, after cancer has already developed (Fussman et al., 2016; Knerr et al., 2019). Results of recent studies conclude that currently only about 10%–20% of the affected persons are genetically counseled and examined (Evans & Manchanda, 2020; Kne et al., 2017; Manchanda et al., 2018; Meyer et al., 2010; van Riel et al., 2012).

There are two main reasons for why so many at-risk persons are currently underdiagnosed: Affected persons often show psychological resistance to engage with the topic and, more importantly in the context of this article, family histories, which help to gauge familial cancer risks, are often omitted or performed inadequately during routine check-ups (McCain et al., 2022). A first explanation for this observation is that taking a complete family history is a

What is known about the topic?

Precisely because the importance of family history and genetic cancer risks is increasing over the last years for early detection, prevention and therapy of cancer, awareness and application of genetic knowledge among primary care gynecologists still need to be improved.

What this paper adds to the topic?

We developed and evaluated a targeted training concept for primary care gynecologists on how to identify hereditary cancer risks. In future studies, the reported concept could be transferred to other entities.

lengthy and time-consuming task. Thus, family histories are often only carried out incompletely in the primary care sector due to extremely limited time and a focus on patients' more urgent concerns (Bellcross et al., 2011; Welch et al., 2018). A second explanation is that, although most guidelines are complex and frequently updated (McCain et al., 2022), the scope and form of family histories and the conclusions to be drawn based on them are not specified (Sussner et al., 2011). It is therefore up to the individual doctor whether and how family histories are taken. Most physicians may have briefly learned about how to take family histories in medical school but often lack strategies for doing so efficiently (Sussner et al., 2011). Finally, expert knowledge on genetic cancer is rapidly changing. If keeping up with the scientific progress is challenging, gynecologists in primary care may prefer not to talk about hereditary cancer risks with their patients to avoid conveying outdated or incorrect knowledge (Van Riel et al., 2010).

Although primary care gynecologists may currently lack time and efficient strategies to identify high-risk patients, they are ideally suited to help improve the care of these patients. Due to very close and long-standing relationships with patients and their families, primary care gynecologists are particularly well positioned to identify familial cancer burden at an early stage (Frank et al., 2015), to address this issue sensitively, and to refer them to specialized centers for genetic counseling. To be able to correctly identify high-risk patients at an early stage and without breaking their tight time budget, primary care gynecologists require up-to-date, practice-relevant knowledge on hereditary cancer syndromes – in particular, on hereditary breast and ovarian cancer (HBOC) – and on how to apply it efficiently. Targeted training for primary care physicians is therefore necessary to ensure that more high-risk patients receive the best possible diagnosis and treatment as early as possible (McCarthy

et al., 2013). To our knowledge, no training on how to identify hereditary cancer risks currently exists in German-speaking countries, that is explicitly targeted at primary care gynecologists (for a pilot study on a related training in Australia see Meiser et al., 2022). To fill this gap, we developed the continuing education project iKNOWgynetics and obtained funding from the German Cancer Aid (GCA) (70113238).

2 | MATERIALS AND METHODS

2.1 | Development of iKNOWgynetics

The project iKNOWgynetics was supported by the GCA under the funding priority "patient orientation" between 01/2019 and 03/2021. In an interdisciplinary team of gynecologists, genetic counselors, psychologists, ergonomists, and expert patients (members of the BRCA-Netzwerk e.V.) we developed, implemented, and evaluated the iKNOWgynetics training concept to convey skills and knowledge about familial cancer burden to primary care gynecologists using a web-based learning platform www.iknowgynetics.de combined with live virtual seminars. To understand and meet the specific needs and (time) constraints of primary care gynecologists, we first performed a needs assessment as basis for developing and evaluating a user-centered training concept.

2.1.1 | Needs assessment among primary care gynecologists

For the needs assessment, we developed an online questionnaire divided into five sections: (1) relevance of the topic 'hereditary cancer risks' for primary care gynecologists (three items); (2) current practice of taking and documenting family histories (three items); (3) current knowledge and perceived self-efficacy concerning assessments of hereditary cancer risks and inclusion criteria for specialized counseling on the topic (two items); (4) as well as the process to refer patients to specialized centers were discussed ("If you identify high-risk patients in your office, where do you send them for specialized counseling?") and (5) interest in a continuing education training on hereditary cancer risks, including the possibility to register for such a training with their e-mail address. The online questionnaire was implemented using Questback Unipark EFS surveys and took about 3–4 min to complete.

After approval by the ethics committee of the Department of Psychology and Ergonomics (IPA) at Technische Universität Berlin (AR_01_20200608), we e-mailed the questionnaire to registered primary care gynecologists in Berlin and Brandenburg, whose contact details were publicly available through the Association of Statutory Health Insurance Physicians in these states (as of 09/2019).

Additionally, focus group interviews with four primary care gynecologists and five expert patients were performed. In these interviews, we focused on patients' and gynecologists' experience

with family history taking considering the respective points of view. Another aspect of the interview was the process to schedule appointment at specialized centers.

2.1.2 | Learning goals and training formats

To address the needs identified via the questionnaire, e.g. knowledge on family history taking and applying inclusion criteria for specialized counseling, we set out to develop a training concept that conveys practically relevant knowledge and skills to apply this knowledge in a way that takes as little time out of gynecologists' already busy schedule as possible. To do so, we formulated the following learning objectives: after completing training, participants should be able to reliably identify their patients' eligibility for specialized counseling in a center of the German Consortium Hereditary Breast and Ovarian Cancer (GC-HBOC) according to guidelines; they should know the basics of genetics associated with gynecologic diseases as well as relevant legal aspects related to the Genetic Diagnostics Act (Gendiagnostikgesetz). Finally, after completing the training, participants should show increased self-efficacy expectations with respect to their ability to identify patients at risk of a genetic cancer syndrome. By conveying this knowledge and skills via the iKNOWgynetics training, we aim to better connect primary care institutions with specialized counseling services, strengthen transsectoral care networks, and ultimately, improve care for patients with hereditary cancer risks.

To define the contents to be conveyed via the platform, a scoping literature research was performed. After having defined the learning objectives and contents, we identified and iteratively refined suitable teaching formats with regard to the specific needs of primary care physicians: a blended learning format consisting of (1) a *web-based learning platform* (www.iknowgynetics.de) to enable easy access to basic knowledge and skills whenever and wherever convenient for busy primary care gynecologists and (2) *live seminars* to allow participating physicians to ask follow-up questions and share their experiences and best practices (peer learning). That is, participating physicians first obtained access to the learning platform to familiarize themselves with the knowledge and skills provided. They were invited to a follow-up live seminar 2 weeks later to give them opportunity to consolidate the acquired knowledge and skills in discussions with experts in the field and their peers.

2.1.3 | Development of the web-based learning platform

Addressing the identified needs of primary care gynecologists, e.g. knowledge about completing family history and inclusion criteria, the navigation menu of the web-based learning platform consists of five main categories of information that convey the following clinically relevant topics: (1) inclusion criteria for specialized counseling, (2) basics of genetics, (3) early detection measures, (4) options for

risk reduction, and (5) information about patient flow management. For each content area, we provided short, easy-to-understand texts, complemented by mnemonic boxes and/or interactive graphics to help readers prioritize learning contents and to facilitate retrieval and retention of basic knowledge units and how to apply them in practice. To support different learning preferences, we also provided audio files with the most important contents. Scroll-over elements on the website were used to prevent information overload and provide additional information and a glossary only when needed. To implement these principles and as form of quality assurance of the development process, we engaged in an iterative, interdisciplinary, and user-centered development process. This way, we managed to not only implement relevant guidelines and literature from a medical perspective, but also the necessary didactic principles to guarantee comprehensibility, esthetics, and practical relevance of the platform contents.

2.1.4 | Development of the live seminars

To allow participating physicians to consolidate the information they obtained via the learning platform, live seminars were developed. These seminars were designed to take 2 h and cover three main parts. First, from a medical perspective, the essential gynecologic-genetic knowledge and skills were repeated and discussed in the same order as they were provided on the learning platform. The second part of the live seminars provided the psychological background knowledge and communication techniques needed to discuss emotionally stressful issues with patients. Detailed information on this module will be described elsewhere. At the end of each seminar, practical aspects of the patient flow management between gynecologists in private practice and specialized Hereditary Breast and Ovarian Cancer Centers were discussed.

To date, a total of five interactive live seminars have been held. Originally, all seminars were planned as face-to-face events. Due to the Sars-Cov19 pandemic we had to replan and change to virtual live seminars. Links to the virtual ZOOM® events were sent to the participants after they had completed the pre-seminar evaluation survey.

2.2 | Evaluation

The main goal of the iKNOWgynecetics training is to increase primary care gynecologists' knowledge about hereditary breast and ovarian cancer, psychologically sensitive (risk) communication techniques, and their skills to implement this knowledge in practice. To evaluate the effect of the training, we administered online questionnaires (using Questback Unipark EFS surveys) in a pre/post-design. Both pre- and post-training questionnaires were identical, except for demographic data, which were only surveyed as part of the pre-training questionnaire, and questions asking participants to evaluate the training overall, which were only asked in the post-training survey.

Both questionnaires contained questions tapping participants' self-efficacy expectation and 13 multiple choice (MC) questions assessing knowledge of inclusion criteria for specialized counseling, basic gynecologic-genetic facts and psychosocial communication skills which added up to 17 possible points. The MC questions were designed by gynecologists and geneticists of the Hereditary Breast and Ovarian Cancer Center of Charité according to the standards of board examination in Germany (IMPP, 2020). After completing the pre-training questionnaire, participants received access to the web-based learning platform. The live virtual seminar was scheduled 10–14 days later, after which participants were asked to complete the post-training questionnaire.

2.2.1 | Data analyses

We used SPSS from IBM Statistics (version 27) for the descriptive summaries and statistical analysis of the questionnaire data. The t-test for dependent samples was used to test changes in knowledge, multiple linear regression was used to examine associations of knowledge with gender, age, professional experience, the type and the urban versus rural location of the participating physicians' offices. A p -value <0.05 was defined as statistically significant.

3 | RESULTS

We were able to reach out to $n=427$ licensed gynecologists in Berlin and $n=136$ in Brandenburg between 19/09/19 and 19/11/19 when the needs assessment questionnaire was closed. Overall, 97 gynecologists (17%) completed the needs assessment survey (for complete results see Fechner et al., 2020). Whereas 87 gynecologists (89.7%) reported to take family history on a regular basis, only 13 (13.4%) felt completely confident to assess hereditary tumor risks according to guideline and only 37 (38.1%) to identify patients who should be referred to specialized counseling centers. Conversely, 74 respondents (76.3%) stated that comprehensive knowledge about hereditary cancer risks could improve their patient care, 89 (91.8%) were interested in continuing education on the topic and 86 gynecologists (88.7%) immediately registered for a training course.

Altogether, $n=109$ physicians accessed both the iKNOWgynecetics platform and participated in one of the live virtual seminars with an average group size of $M=21.8$ [range 14–31]. Of these, 103 participants (94.5%) filled out both pre- and post-training questionnaires and were included into the analyses (See Table 1). The average age of participants was 50.8 ± 9.0 years [range 26–71], 89% (92/103) were female. 85 of the participants were gynecologists in primary care who had on average 24.1 [range 0–50] of professional experience. About 56.5% of the gynecologists (48/85) worked in a solo practice, whereas 43.5% (37/85) were part of a group practice. Physicians from the federal state of Berlin made up 81.2% (69/85) of the participants whereas those from the federal state of Brandenburg made up 18.8% (16/85). Overall, 92.9%

TABLE 1 Sociodemographic characteristics of participants.

Participants		Total sample (N = 103)	Target group (n = 85)
Gender	Male/Female/Divers	92/11/0	77/8/0
Age in years	M ± SD	50.8 ± 9.0	52.3 ± 8.3
Department	Gynecologists in primary care	85	85
	Gynecologists in hospitals	13	—
	Others ^a	5	—
Years of professional experience	M ± SD	—	24.1 ± 8.5
Type of physicians' office	Solo practice	—	48
	Group practice	—	37
Location of physicians' office	Urban environment	—	79
	Rural environment	—	6

^a Research, oncology, radiology.

TABLE 2 Knowledge test before and after training, N = 103 (T-test).

Categories	Max. score	Before training		After training		t(102)	p	Cohen's d
		M	SD	M	SD			
Overall results	17	13.80	1.74	15.17	1.32	-9.418	0.000	1.475
Inclusion criteria	10	8.83	1.10	9.46	0.84	-5.808	0.000	1.086
Basic gynecologic-genetic facts	3	2.63	0.61	2.71	0.51	-1.269	0.207	0.621
Psychosocial communication skills	4	2.32	1.01	3.00	0.82	-7.246	0.000	0.952

(79/85) came from an urban and 7.1% (6/85) from a rural environment (79/85) came from an urban and 7.1% (6/85) from a rural environment (79/85) came from an urban and 7.1% (6/85) from a rural environment.

3.1 | Knowledge test and self-efficacy

Most participants (74/103, 71.8%) improved their knowledge after participating in iKNOWgenetics (see Table 2): before the training, participants reached $M_{pre} = 13.80 \pm 1.74$ on average of 17 possible points. After the training, the average scoring achieved through correct answers was $M_{post} = 15.17 \pm 1.32$ out of 17 points possible. Thus, after the training, participants reached an average of 1.37 more points (95% CI 1.1-1.7) of correctly answered questions than before the training ($t(102) = -9.42$; $p < 0.001$; $n = 103$). Looking at the different areas of knowledge in more detail, most participants showed good and similar basic knowledge on gynecologic-genetic topics both before and after the training (High-Score Basics = 3 Points, $M_{Basics-pre} = 2.63 \pm 0.61$, $M_{Basics-post} = 2.71 \pm 0.52$, $t(102) = -1.27$; $p = 0.207$). Questions about inclusion criteria and when to refer a patient to specialized counseling were answered correctly significantly more often after the training. Also knowledge about the regulatory aspects of the Gene Diagnostics Act increased: Whereas only 76% (78/103)

could answer questions correctly before the training, afterward, 89.3% (92/103) provided the correct answers. The percentage of participants who felt confident in their ability to correctly apply the referral criteria increased as a result of the training from 29.1% to 63.1% ($p < 0.001$) (see Figure 1).

Age, gender, and years of professional experience did not predict knowledge on HBOC/MC test results ($F(5,79) = 1.32$, $p < 0.265$, $n = 85$). That is, learning effects did not differ based on sociodemographic variables.

In the post-training questionnaire, participants were asked to evaluate the iKNOWgenetics training overall and with respect to individual aspects. The time to complete the training was described as appropriate by 88.3% of the participants (91/103). The majority of participants (82.5%, 85/103) reported using the learning platform up to 60min to prepare for the live seminar: only 17.4% (18/103) reported using it for more than 60min. The contents of both the learning platform and the live virtual seminar were evaluated to be relevant and applicable in everyday practice. The most relevant topic for participants was information on inclusion criteria (77/103; 74.8%). Overall, 91.3% (94/103) felt to have broadened their knowledge on HBOC through the learning platform, 98.1% (101/103) reported to have done so through the combination of the platform and the live virtual seminar. Also, 96.1% (99/103) of the participants were sure to use the iKNOWgenetics learning platform in the future as online reference.

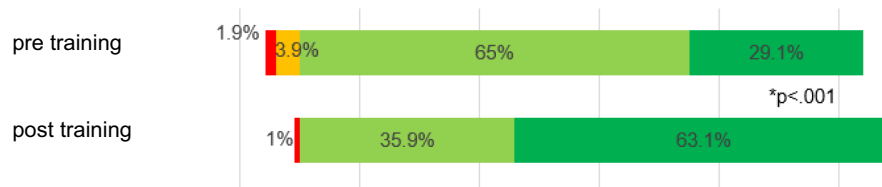


FIGURE 1 Diverging stacked bar chart – representation of the percentage of participants who felt confident in their ability to correctly apply the referral criteria increased as a result of the training ($N=103$) *asymptotic Wilcoxon test.

4 | DISCUSSION AND CONCLUSION

4.1 | Discussion

We developed iKNOWgenetics, an online-based learning platform combined with virtual live seminars to empower community-based gynecologists to identify patients with familial cancer risks and refer them to specialized counseling clinics early, that is, ideally, before they develop cancer. We worked with primary care gynecologists from Berlin and Brandenburg to evaluate this concept and could show that it improved knowledge on genetic cancer syndromes and self-efficacy regarding referral criteria. Finally, we hope that thus empowering them could lead to the referral of more patients at risk of familial cancer to specialized genetic counseling.

Although most primary care gynecologists indicated during the needs assessment that knowledge on hereditary cancer syndromes is important and could improve their patient care, most gynecologists reported difficulties in applying inclusion criteria to identify patients with hereditary cancer risks in their daily routine. On the other hand, most respondents clearly linked awareness and knowledge of hereditary cancer risks to the quality of care for their patient and thus reported a keen interest in continuous education on topics related to hereditary breast and ovarian cancer (HBOC).

With a pre-post design, we could show that the iKNOWgenetics training significantly improved participants' knowledge of the inclusion criteria needed to identify people with hereditary cancer risks and how to correctly apply them. As other studies have shown, the transfer of knowledge into practice is extremely important for primary care physicians (Bokkers et al., 2021). Thus, it is very encouraging that participants not only showed significantly improved knowledge, but also reported improved self-efficacy to correctly apply the referral criteria after having completed the training module. The training also increased knowledge of more abstract legal concepts such as the Genetic Diagnostics Act, which suggests that the complex topics surrounding hereditary cancer syndromes can be conveyed in a short and easy-to-grasp training format (Dekanek et al., 2020). In summary, based on our findings we suggest that the iKNOWgenetics learning platform helps to convey the basic skills, knowledge, and attitudes primary care physicians need to identify and refer people with hereditary cancer to specialized counseling clinics to, ultimately, help prevent cancer in the future. Future studies should show whether this expectation is actually met in clinical practice. Of course, results from both the needs assessment and the training course are limited by self-selection, that is, by the fact that

only physicians interested in the topic participated. Whereas our sample contained physicians at all stages of work experience, it did not allow us to differentiate physicians working in solo versus group practices. The mean age of participants was 50.8 years, which could reflect the long education period in Germany before doctors can work in private practice. Against this background, the willingness of the participants to take part in digital training and improve their skills was all the more impressive. The main difference we identified between physicians from urban versus rural areas reflects one of the main problems hampering care for patients with hereditary cancer risk: practitioners in rural areas do not always have good access to specialized care for their patients (Kühn et al., 2021). By providing the necessary knowledge about transfer procedures, and by involving these colleagues in transsectoral networks, we hope to contribute to improving the quality of precision care that can be provided in both urban and rural areas.

4.2 | Conclusion

With iKNOWgenetics we were able to show that a concise and easy-to-access web-based training is effective in conveying up-to-date knowledge about familial cancer burden and in increasing the perceived efficacy of primary care gynecologists to implement this knowledge in practice. The results also suggest that the web-based formats (i.e., the learning platform in combination with live virtual seminars) can do so in a time-effective manner. This way, iKNOWgenetics can help to integrate primary care providers into specialized networks that enable patients to undergo appropriate genetic counseling and analyses in a timely manner and ideally *before* they develop cancer. Identifying people with hereditary cancer risks early will help to realize the potential of precision oncology, with improved therapeutic options for cancer patients (Cohen et al., 2019; Stadler et al., 2021) but also with improved early detection and prevention measures.

4.3 | Practical implications and outlook

The iKNOWgenetics training concept conveys the essential knowledge and skills primary care gynecologists need to participate in and help improve the care of people with familial cancer risk, which has so far mainly been limited to specialized counseling centers. In future studies, we hope to show that involving community-based

physicians in the detection of people with familial cancer risks will increase the number of *healthy* counselees who are referred to specialized centers for genetic counseling and, ultimately, improve cancer prevention for these patients.

Given that the participating primary care gynecologists evaluated the iKNOWgenetics training so positively, we are planning to continue the trainings to reach community-based physicians also in other areas of Germany. Thanks to the fact that the training is web-based, we can easily update the contents of both the learning platform and the virtual life seminars to match the most recent evidence and guidelines. In addition, we offer the training concept and the easy-to-update learning platform to precision medicine physicians of other specialties to extend the platform's focus to other diseases such as familial colorectal cancer or prostate cancer.

AUTHOR CONTRIBUTIONS

All authors confirm that they had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. All of the authors gave final approval of this version to be published and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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CONFLICT OF INTEREST STATEMENT

Dorothee Speiser has received speaker honorarium from Astra Zeneca and Pfizer.

All other authors declare that they have no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ETHICS STATEMENTS

Human Studies and Informed Consent: This study was approved by and conducted according to the ethical standards of the ethics committee of the Department of Psychology and Ergonomics (IPA) at Technische Universität Berlin (AR_01_20200608). All applicable

international, national, and/or institutional guidelines were followed. Informed consent was obtained from all physicians for being included in the study.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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