



Health literacy and shared decision-making in predictive medicine — professionals' perceptions and communication strategies

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Abstract

Aim This contribution empirically analyses and theoretically reflects health literacy (HL) and shared decision-making (SDM) in the context of predictive medicine, taking in the perspective of healthcare professionals (HCPs). The aim is to identify ways to promote HL of persons dealing with disease risk, and to support SDM in predictive consultations.

Methods The perspectives of HCPs consulting patients at early prediction centers and advising them with respect to preventive therapies or further diagnostic procedures were examined using semi-structured, qualitative expert interviews and a complementary survey.

Results The data reveal resources and challenges regarding risk communication and the empowerment of patients for informed and health-literate decisions upon their disease risk. They also show potentially useful communication strategies and prerequisites for demand-oriented decision-making in the predictive setting. Furthermore, the findings highlight that risk communication and patient information in predictive medicine are considered to be underrepresented in medical education and training. Therefore, this contribution provides implications and suggestions for educational concepts and practical tools for medical education and predictive practice.

Conclusion We emphasize communication and interaction between HCPs and patients as crucial for health-literate decision-making in the specific context of predictive medicine. This study's results indicate relevant aspects of social and communicational skills that need to be considered in consultation guides and integrated into medical education and training, to provide individual-sensitive consultation and HL promotion for people at risk.

Keywords Health literacy · Shared decision-making · Predictive medicine

Introduction

With continuous medical–technical progress, individual disease risks prediction is getting increasingly advanced; likewise does the scope of preventative therapeutical

options in predictive medicine¹. Patients confronted with disease risk are challenged to navigate complex risk information, needing to decide upon anticipated health developments. Health literacy (HL)² is crucial for risk-adjusted decision-making (Schmidt-Kaehler 2016; Sørensen et al. 2012). Being able to critically evaluate risk information is necessary to make informed choices towards preventive

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¹ Predictive medicine or early diagnostic procedures refer to consultations, assessments, diagnostics, and therapeutic interventions to identify and respond to disease risk factors or early disease states, to prevent disease development or to moderate its onset.

² HL describes the ability to critically access, understand, appraise, and apply health information (Sørensen et al. 2012). It addresses the individual, organizational, and system levels (Schaeffer et al. 2018; Sørensen et al. 2012). Additionally, we share the understanding of HL as a form of multidimensional knowledge and social (Samerski 2019) and communicative practice (Harzheim et al. 2020).

measures or health-promoting lifestyles (Oliveira et al. 2018). This requires HCPs to inform their patients extensively on disease probabilities and enable them to make sound decisions. Especially in the context of predictive medicine, HL and shared decision-making (SDM)³ are interwoven (Altin and Stock 2016; Hauser et al. 2015; Joseph-Williams et al. 2014). Simultaneously, there is a shift from traditional medical consultation models towards co-creative encounters between patients and HCPs (Clayman et al. 2017; Stiggelbout et al. 2015), emphasizing the demand for promoting HL and SDM in medical consultations (Altin and Stock 2016; Shen et al. 2019; Smith et al. 2009). Therefore, an individual-sensitive communication culture needs to be practiced (Jorm 2015), for which HCPs need to be equipped by incorporating communication skills into their education (Clayman et al. 2017; Schmidt-Kaehler 2016; Shen et al. 2019; Stiggelbout et al. 2015). While there is a lot of teaching material on general patient information in medical education (Langewitz 2012), literature does not provide specific concepts of teaching risk communication in predictive medicine, nor is there research on what resources HCPs resort to when communicating with patients in the context of risk. There are studies investigating aspects of HL (Wagner et al. 2009) and SDM (Woudstra et al. 2019) in the context of medical screenings. However, studies like these focus on the perspective of patients, examining correlations of educational levels or objectively defined HL states with the utilization of screening procedures. What has not been investigated to this date is the perspective of HCPs on the challenges and requirements of risk communication and decision-making in the field of predictive medicine. While HL and SDM are mostly investigated quantitatively and standardized⁴, there is a lack of qualitative–inductive research, exploring what aspects are relevant from the perspective of HCPs.

Building upon a study on the perspective of patients (Harzheim et al. 2020), this contribution investigates the perceptions and experiences of HCP's regarding HL and SDM in predictive medicine, focusing especially on risk communication, patient information, and decision-making.

Aim & research questions

This study's aim is to enhance HL of persons partaking in early diagnostic procedures, to support SDM in predictive medicine, to provide empirically grounded recommendations for communication in the predictive setting⁵, and to suggest strategies to translate the findings into practice and medical education.

Research questions addressed are: (1) how can HL of individuals facing disease risks be promoted, (2) what aspects are relevant with respect to SDM, and (3) which communication strategies have proven to be beneficial from the perspective of HCP consulting patients about disease risk predictions?

Methods

To inductively explore HCP's perspectives, a qualitative research design was chosen.

First, semi-structured expert interviews (Helfferrich 2011) were conducted, followed by a short, complementary survey. The interview guide contained questions about HCP's experiences and perceptions about HL- and SDM-relevant aspects in predictive consultations. HCPs were asked about how they experienced communicating with patients about disease risks, what aspects they considered relevant to support patient's HL, and what challenges they faced in the decision-making process about disease-preventing measures. Due to its open structure, the interview guide allowed for participants to address any other subject of relevance to them in the context of the research topic. The guide was conceptualized incorporating findings from the preceding study on the patient's perspective, where risk communication, patient information, and decision-making were central aspects for patients with respect to HL and SDM in predictive procedures (Harzheim et al. 2020). Therefore, these categories were used as focus themes in the conceptualization and the analysis of this study (Kuckartz 2018). The additional survey was conducted to learn about participants' professional background and their experiences and needs regarding medical education and training on patient information, risk communication, and SDM. It comprised a combination of multiple-choice questions and free text fields on participant's professional profile and work experience, as well as their experiences and wishes regarding training and further education within these domains.

³ This work aligns with the definition of SDM as a process in health-care where patients and HCPs mutually find health-relevant decisions by critically negotiating treatment options and possible outcomes (Hauser et al. 2015).

⁴ An investigation of the HL in German society, for instance, used the HLS-EU-Q47, consisting of 47 questions on self-estimated ('inadequate' to 'excellent' HL) differences in dealing with information on health-related activities and tasks (Hurrelmann et al. 2020).

⁵ Predictive communication or consultations mean the medical encounters between patients (and their relatives) and HCPs in the course of the medical determination of individual disease risk. The communication of the diagnosis determines therapeutic interventions or preventive measures, and is a key situation for people affected and their future health decisions (Harzheim et al. 2020).

The interviews were audio recorded, transcribed, and analyzed using qualitative content analysis; for the purpose of this study, a topic-centered cross-case analysis was chosen (Kuckartz 2018). Following this method, in a first step the interviews were summarized, disclosing key aspects and contexts. The transcripts were then coded, using a category-based, deductive–inductive approach. For resource-efficient reasons, the coding procedure was conducted by the first author (LH). Triangulation between researchers (Flick 2011) was applied to ensure the quality of data analysis; the codes and all following analysis steps were critically reviewed by the co-authors (LH, SS, SJ) and discussed among all authors. With this open yet thematically oriented process, key categories and subcategories were identified, which will be introduced in the following. The survey was analyzed using descriptive statistics.

Recruitment & data collection

In line with the study design, recruitment followed a criteria-based sampling strategy (Kuckartz 2018). Included were HCPs who conducted risk diagnostics and consultations in specialized early prediction centers and medical teaching practices of the University Hospital Cologne. This setting was chosen because it is one option for people seeking medical advice concerning disease risk to get diagnosed, informed, and advised with respect to preventive alternatives. It represents one encounter between patients and HCPs, where HL and SDM can be investigated and promoted; with university hospitals being a linkage for evidence-based practice, this setting also provides a ground for research–practice–transfer. As examples of indicational fields, the disease risk prediction of Alzheimer’s disease (AD), coronary heart disease (CHD), familial breast and ovarian cancer (FBOC), and psychosis (PSY) were chosen. The selection of these clinical fields is rooted in their epidemiological relevance and in how their prediction or early detection affect future healthcare services. They cover a broad clinical spectrum (psychiatry, neuropsychiatry, oncology, and cardiology) and imply different preventive and therapeutic options (surgical, medicinal, psych-educative, behavioural). Also, they reveal diverse notions of risk (bodily, as in the case of FBOC, where risk is located in certain organs, vs abstract, as, for instance, in PSY, where risk is related to mental manifestation of the disease. This makes it possible to observe the understanding of and dealing with risk-probability statements about physical as well as mental disease manifestations.

In total, 262 HCPs were invited to partake in the study (interviews and surveys). They were contacted in cooperation with the collaborating institutions.⁶ Recruitment and

data collection took place from December 2020 to April 2021. While the survey was conducted via online-inquiry, the interviews were carried out via telephone or face-to-face at the respective center or with video-telephony.

Results

Of the contacted HCPs, seven agreed to being interviewed and to completing the survey (one FBOC, three AD, three PSY), 32 filled in the survey (one FBOC, three AD, two PSY, 26 CHD). Lack of time, the small number of professionals conducting predictive consultations at the respective clinic, and pandemic-related adjustments were reasons named by contacted HCPs who did not participate in the study or who only agreed to complete the survey. Strengths and limitations of the sample size will be addressed in the discussion of this study.

Main findings from expert interviews

Based on the participants’ experiences, three thematic foci were identified: (1) the communication of risk, challenges, and strategies, (2) HL in predictive medicine, communicating risk and negotiating previous knowledge, and (3) the decision-making on disease risk, recommended communication tools. A selection of pseudonymized quotes shall illustrate these categories introduced in the following.

The communication of risk — challenges and strategies

HCPs reported recurring challenges when communicating risk to patients. Explaining disease probabilities to medical lay people was described as being complex, requiring medical knowledge and emotional sensitivity in equal measure. HCPs stated that there are disease-specific facts but also individual concerns and emotions that need to be addressed. Risk perceptions thereby differed. HCPs pointed out that they faced extended requirements in communication skills, considering a dynamic development of the HCP–patient relationship, patient empowerment, and individual-sensitive communication:

“It’s essential, that people are fundamentally different in how they deal with situations like this. [...] Whether a glass is half full or half empty depends on someone’s character.” (Expert Interview (EI) 07)

The potential of stoking fear when communicating disease risks to patients was also emphasized. Especially regarding particularly stigmatized diseases such as psychosis or Alzheimer’s disease, patients attended predictive consultations with strong preconceptions or trauma. Rigid disease images were described as potentially hindering constructive

⁶ The collaborating institutions were the (1) Centre for Memory Disorders (AD) and the (2) Early Detection and Therapy Center for Mental Crises (PSY) of the Clinic and Polyclinic for Psychiatry and Psychotherapy, the (3) clinic for general medicine (CHD), and the (3) Center for Hereditary Breast and Ovarian Cancer (FBOC) the at the University Hospital Cologne.

dealing with risk information. The ‘risk of knowing’ was depicted, when fearing risk led to the progression of symptoms or the onset of a disease:

“We witness patients [...] getting into mental crises. Such as depression, anxiety, isolation [...]. And that [...] has a negative effect on the onset of the disease. [...] It compromises the quality of life. It worsens the course of disease.” (EI 02)

Disagreements between patients and their relatives were also mentioned as having a complicating effect on predictive consultations. Differences in self- and external perception challenged HCPs to mediate, needing to conciliate both parties. In cases of low symptom understanding or motivation on behalf of the patient, communication was experienced as being harder than with proactive and intrinsically motivated patients whose perceptions aligned with those of their relatives:

“It’s rather [challenging] with patients who don’t recognize any symptoms, coming to us because their family members [...] asked them to. [...] and then they come here with a bunch of symptoms but without being motivated for any treatment.” (EI 05)

The interviewees shared communication strategies they had developed to navigate the challenges named: considering the emotional level, communicating in an opportunity-oriented manner, and using imagery language had proven to be beneficial in their practice. Mediating a diagnosis carefully, asking about the patient’s fears and worries, and being transparent and empathic helped to constructively convey communication. Building a trusted environment and responding to individual needs before communicating a diagnosis were explained as putting patients at ease and preparing them best for discussions on how to proceed:

“First, it is about building trust. [...] You have to mediate very carefully.” (EI 01)

The earlier disease probabilities are identified, the more preventive options there are — from medical or surgical interventions to psychotherapeutic or educative approaches. HCPs described it as being essential to emphasize the chance that lies within risk prediction. An opportunity-oriented communication style helped to focus on possibilities, encouraging patients to preventive measures:

“I always try to come to therapeutic options as soon as possible. ‘All right, what can we do about it?’” (EI 02)

HCPs used imagery language, illustrations, or pictures to decrypt complex statistical risk parameters. Self-made drawings, graphs, or prints from imaging techniques were used

to communicate medical findings. Metaphors also helped to make certain conditions more acceptable for patients:

“And I always try to destigmatize by naming neurobiological causes [...]. I have my standard metaphor of a broken leg [...]. The comparison with a physical condition is often easier to accept for people.” (EI04)

Health literacy in predictive medicine — communicating risk and negotiating previous knowledge

According to the interviewees, challenges in navigating risk information lie in the complexity of health information in general and in explaining and understanding risk probabilities in particular. ‘Incorrect’ self-gained knowledge and pre-assumptions based on, for instance, stigma, hindered a constructive communication and challenged the HCP to realign patients’ perceptions of risk.

“With all that information available it is really hard [to distinguish good and bad sources]. And all this external information has a strong impact on patients [...]. During the consultations you only contribute a small part as an expert.” (EI 01)

“People do their research on the internet. And it’s difficult because they name symptoms they have read [...], they adopt a terminology that isn’t correct, and they use certain buzz words but the content behind those is actually different.” (EI 04)

HCPs stated that in general, disease prognoses, preventive options, and symptom characteristics were pieces of information asked for in predictive consultations. When disclosing a positive risk finding, HCPs found themselves being asked about the next steps, potential courses of the disease, and available preventive options. Patients also showed relief when having their symptoms explained and being introduced to preventive and therapeutic measures:

“People want to know what they can do to prevent the disease from breaking out.” (EI 04)

“Many of them are relieved that their symptoms are explicable. That they then finally know, their symptoms are nothing totally out of the ordinary.” (EI 04)

Individual resources and competencies of patients were also named as being central components in the communication and negotiation of risk. HCPs experienced patients’ risk perceptions as depending on internal and external resources and competencies: intuition, self-reflection, and motivation were named as important internal resources. Individuals’ social environment and being appropriately informed were external resources HCPs associated with a constructive dealing with risk:

'Some know the factors that aren't good for them. They intuitively know that they should quit smoking weed and that stress does no good for them. A lot of them know what they need right now.' (EI 04)

'I feel like those who came here motivated by themselves, [...] are well reflected and have observed themselves over a longer period of time.' (EI 05)

"One of the most important things is family, the social situation. When patients are settled, it's one of the best preconditions." (EI 01)

Decision-making on disease risk — recommended communication tools

Depending on the clinical field, HCPs were involved to a different extent in the decision-making process on preventive measures. In an early prediction center that is specialized on the diagnostic process alone, the communication between patients and HCPs is limited to the diagnosis disclosure. However, when there are follow-up concepts, the encounters involve further decision steps. Yet the decision-making was described as resting more strongly on part of the patients, once the HCPs had introduced them to different treatment options:

"You name all options to the patient and then they decide for themselves." (EI 04)

"And I ask them what option they prefer from the bouquet I introduce to them. And I always say that we make a recommendation but as a reasonable, mature person, they need to make the decision themselves." (EI 05)

Interviewees reported communication tools such as brochures to help in disease risk consultations. They recommended differentiating between the factual, indication-specific level and the communication-strategical level. As examples, they named standardized guidelines/protocols with information about the predictive procedure, disease characteristics, treatment options, and topics such as social and legal issues. As well as adaptive, situational coaching tools for individual-sensitive communication:

"It is important to differentiate between the content and the way you communicate. [...] How to communicate can be learned in non-specific communication-training sessions. [...] Basic information about disease, treatment options and everything around it should be standardized." (EI 01)

Although teaching material was stated not to replace experience, participants emphasized that risk communication had been neglected in their academic studies or further education. There were training elements in medical education on delivering diagnoses in general, but not on communicating risk in predictive medicine in particular:

"In medical practice, there is a lot about learning by doing. You can be trained to a certain extent, but in the end, it is about professional experience..." (EI 01)

"I would benefit from some training on how to talk to relatives in this context." (EI 03)

Depending on the academic background (psychological vs medical education) and the specification of the institution with respect to risk communication and SDM in the predictive setting, the awareness of and the need for tools and education regarding risk communication skills varied between participants. It was also indicated that aspects such as communication, empathy, and sensitivity are of varying relevance in medical and psychological curricula:

"The training in psychology, especially when it comes to communication, empathy, and sensitivity for people, is completely different from what you can learn in medical school." (EI06)

Main findings from the survey

Complementary to the interviews, the survey made it possible to highlight HCPs' experiences, needs, and impulses with respect to professional training and further education on the three topics (1) patient information, (2) risk communication, and (3) SDM in the context of disease risk prediction (Table 1). It discloses implications for the operationalization of the study findings in medical practice.

Participants specified: "Consultations [about risk] and how to conduct them should be trained intensively" (Question (Q) 20). Participants who stated that there was not enough respective education in their professional field, added that "too little practical training" was offered or that "frequent training would be desirable". "I didn't realize that the offer for professional training was so scarce." (Q 15).

Wishing for more professional training and further education on risk communication, SDM, or general patient information, one participant added: "I find it useful to be taught basic communication skills and competencies that can be transferred to various clinical fields in the [medical] studies. Indication-specific training sessions should be offered by the respective professional association." (Q 20).

Table 1 Main findings from the survey

Survey participants	
In total	32
Clinical field during data collection...	
CHD	26
AD	3
PSY	2
FBOC	1
Educational background	
Studied medicine	31
Studied psychology	1
Did NOT get input on the three topics during education	17
Did get theoretical (not practical) input	1
Studied more than 10 years ago	19
Studied 5–10 years ago	3
Studied less than 5 years ago	2
Professional training and further education experience	
Frequently take part in training and further education	16
Training and further education they received were offered by...	
External providers (e.g., medical association)	15
The clinic they worked for (e.g., guest lecture)	10
Others (not specified)	4
Training and further education they attended covered the topics...	
SDM	13
Patient information in general	8
Risk communication in particular	5
The input was provided in form of...	
Presentations	11
Articles, digital and print media	10
Practical exercises and simulations	6
Need for training and further education for disease risk consultations	
Education on the three topics is missing in their profession	7
Wish for more training/education with respect to...	
SDM	13
Risk communication in particular	10
General patient information	6

The following table (Table 2) summarises all findings and implications. It provides suggestions on how to implement the findings and implications introduced into (medical) education and predictive practice.

Discussion

In the following, the findings and implications will be discussed in the light of previous research and existing literature. With this work's overall aim to contribute to promoting HL of people confronted with disease risk and to support SDM in predictive medicine, there is a need

to critically reflect whether the implications derived from the results are suitable for operationalization and transfer into practice — are the suggested approaches appropriate to support HL and SDM in predictive medicine, especially with respect to their practicability and their effectiveness? What does previous research indicate with respect to the implications derived? To address these questions, the benefit of tools in medical practice as well as the effectiveness of incorporating communication and interaction skill training into medical education should be critically discussed.

Communication tools and medical training as suitable for HL and SDM promotion in predictive medicine

Recommending tools such as prompts, checklists, handouts, and explanation instruments can only be fruitful if they can be incorporated into medical practice effectively. While there is a lot of research on instruments to *assess* HL, there is no systematic evaluation on how to *promote* HL or SDM in predictive consultations in particular. However, there are a few studies that address questions about whether it is reasonable to offer communication tools in medical encounters, and whether they show a positive effect on patient's HL and/or the SDM. An interview study investigating HCPs' perceptions with regard to communication and SDM with patients with limited HL in the palliative setting revealed that teaching communicational skills and using tools in consultations were concepts that effectively supported HL and SDM (Roodbeen et al. 2020). A review on the effectiveness of question prompt lists in general medical consultation, in terms of patients actively partaking/asking questions in consultations, showed that more content was shared in consultations when using such a tool. However, the quality of the consultation or the effect of a question aid on the HL of patients was not evaluated (Sansoni et al. 2015). In addition, using tools to visualize risk probabilities and to introduce possible outcomes to patients is recommended for use in a trusted environment and for informed choices about disease risk (Paling 2003). With tools potentially being an effective measure, HCPs' resources to implement them need to be considered. The work environment needs to provide structures for the use of tools (e.g., management support, time, coaching, supervision, etc.).

With regard to our recommendations for medical training and further education, we wish to discuss (a) the potential of teaching-to-practice transfer in general, and (b) the benefit of training and education for HL and SDM promotion in particular. Participants wished for input on risk communication, SDM, and patient information. But even if the curriculum of medical studies would cover these areas, there is the risk that input on communication, interaction, and mediation skills is given little priority by medical students,

Table 2 Summary of findings, implications, and suggestions for implementation

General findings	<p>The results give an orientation on aspects HCPs find to be relevant with respect to HL, SDM, and communication concerning disease risk prediction. They highlight the needs of HCPs with regard to professional training and education in predictive medicine.</p> <p>(Medical) education and training is important for individual-sensitive and demand-oriented communication in predictive medicine.</p>
Implications for education and training	<p>There is a wish for input on risk communication, SDM, and patient information in (medical) education, professional training, and further education for predictive consultations.</p> <p>Input on communication in predictive medicine should be two-levelled, addressing ‘facts & feelings’: standardized, indication-specific material as well as adaptive guidance on communication strategies</p>
Communication resources and strategies	<p>As equally beneficial for medical practice as education and training, tools such as guides, protocols, and handouts were named.</p> <p>For fruitful communication strategies and HL-/SDM-promotion in predictive consultations, approaches such as (1) considering informational and emotional needs of patients and relatives, (2) incorporating previous knowledge, fear, and stigma, (3) communicating in an opportunity-oriented manner, (4) using imagery language, (5) providing time and empathy, and (6) enabling for informed choices were suggested.</p>
Transfer to practice	<p>Shared perceptions and experiences (e.g., the duality of risk communication, the ‘risk of knowing’, the need for mediating competencies, the relevance of emotions, pre-assumptions, and internal resources) should be incorporated into the conceptualization of teaching materials and tools.</p> <p>Findings should be integrated into a training concept for medical curricula and further education programs. For example, by the development of practical exercises, focusing on risk prediction (simulations of predictive consultations) in different clinical areas, and on communication with patients alone and with their relatives.</p> <p>Examples of tools could be: prompts or checklists for HCPs, handouts and questions lists for patients, graphs, figures, and explanation instruments to draw on in a medical encounter.</p>
Implementation	<p>A 3-moduled pilot project could be developed: (1) a teaching concept for the undergraduate medical curriculum, (2) a further education program for practicing HCPs (indication-specific, using the example of one clinical field at first), and (3) tools and materials for patients and HCPs in medical practice.</p> <p>Following a participatory approach, the pilot project would need to be co-created by scientists (conceptual framework, evaluation, transfer to medical curriculum), patients (content and assessment), and HCPs (content, assessment, and implications with regard to medical practice).</p> <p>During and after implementation, materials and teaching concepts needed to be empirically evaluated. For example, with a mixed-method approach, incorporating interviews, surveys, participatory observations, and/or workshops with students, HCPs, and patients.</p> <p>The evaluation study should be re-incorporated in further developments of the materials and teaching concepts. After that, the modules might be expanded to other universities/training facilities/clinics/medical offices to cover a broader variety of clinical fields.</p>

considering the massive amount of material to be learned and the biomedical focus of the curriculum. Our participants’ engagement with these subjects possibly correlates with their specification in predictive medicine and their work at an early diagnostic center. Yet, an educational concept focusing on competencies in the named areas could be beneficial for medical students, preparing them for individual-sensitive communication and SDM. To our knowledge, there are no evidence-based teaching concepts for the training of HL competencies in HCPs, nor have there been investigations on how professionals manage to incorporate acquired competencies into their medical practice (Lippke et al. 2020). There is, however, a study showing that teaching risk communication and SDM skills in clinicians is effective, meaning that participants engaged more confidently and that they showed a higher objective knowledge on SDM and risk

communication after having undergone some online teaching (Hoffmann et al. 2021).

There are theories on the practice transfer of learned contents and thereby on the effectiveness of further education and professional training. Literature primarily discusses the learning–practice–transfer in a business educational context (Tonhäuser 2017). Yet, general theories can be transmitted to the medical practice as well. The theory of identical elements by Thorndike and Woodworth (1901), for instance, suggests that in order for learned material to be translated successfully into practice, the learning and application situation need to be as similar as possible (Woodworth and Thorndike 1901). So, when wanting to sensitize HCPs in predictive consultation for both the informational and emotional needs of patients and relatives, communication simulations need to replicate a patient–relative–HCP interaction as truly as possible to

the original. Experiences shared in this study could serve to replicate sample scenarios, e.g., by creating case vignettes for simulated advice seekers, to confront students or professionals with challenges in risk communication. Behaviorist approaches such as this focus on stimulus–response processes mostly depend on external components of environment. Cognitivist transfer theories, however, centralize inner processes/mechanisms of the learner. With regard to individual problem-solving strategies, general principles are introduced to the learner, who then deductively interprets and transfers these general sets of rules to the practice (Singley and Anderson 1989). Following this theory, introducing general information on aspects such as fear or stigma to (medical) students and HCPs, may enable them to transfer this knowledge into their practice. Grounding on these and other theoretical approaches, Tonhäuser (2017) summarizes three categories that determine a positive learning–practice–transfer process: personal factors (motivation, volition, cognitive capacity etc.), organizational factors (such as supporting colleagues and superiors or application opportunities in the workplace), and measure-specific factors (e.g., similarity of learning material to practice reality and applicability). Simplified, this means that teaching materials need to be target group-oriented, applicable, and close to reality. The module-box for the development of culture-sensitive communication trainings in predictive and preventive medicine by Lorke (2021) offers one possibility for a complementary conceptual framework, empirically covering patients' perceptions in the context of health, risk, and culture.

When delving into the literature about medical education and HCP training on HL and SDM, '*professional health literacy*' is a central term one may come across. The concept includes the competence of a HCP to communicate and listen in a way that centers the patient's individual interests (Lippke et al. 2020). There is a reciprocal effect implied, demanding health-literate professionals in healthcare in order to provide an environment to support a patient's HL (Mullan et al. 2017). It is emphasized that a health-literate interaction with patients should be taught in medical education and training, and that teaching communication skills may enable HCPs to appraise and respond to their patients' HL (Lippke et al. 2020). Educational concepts that are considered beneficial in teaching HL competencies of HCPs are, for instance, interactive communication loops (Schillinger et al. 2003), motivational interviewing (Miller and Rollnick 1991) or the health action process approach (Schwarzer et al. 2011).

Previous research and theoretical concepts on implications

We address the duality of risk communication respecting factual and emotional aspects that need to be considered when communicating about disease risk; also, emphasis is placed on the requirement for predictive consultations to be

individualized and preference-sensitive, incorporating previous knowledge, fears, and needs.

The two-levelled approach of addressing facts (standardized) and feelings (individualized) in a medical consultation has already been addressed by others. Studies have shown that emotions often outweigh statistical aspects in decision-making processes and therefore need to be taken seriously in medical encounters (Holmberg et al. 2015; Lorke et al. 2021). Recognizing and replying to emotions potentially creates an environment for more productive interactions. Respecting emotions as valuable in decision-making eases the decision-making process and comforts people in their choices, reducing relational conflicts (Gengler 2020). Meeting the emotional element in medical encounters is also considered to be beneficial with respect to people's HL (Roodbeen et al. 2020). With predictive medicine being primarily grounded on statistical and numerical information, a balanced risk communication is needed, considering facts and feelings individually. Kaldjian (2017) gives valuable focus on the duality of communication in healthcare by discussing different concepts of health in SDM processes. He opposes the biostatistical concept of health (such as absence of disease, objective, value-free) and the well-being concept of health (such as value-oriented, socially determined, individual-specific), arguing that attributes of both systems need to be negotiated in SDM processes, where care goals have to be identified individually (Kaldjian 2017). Chirchirez and Purcărea (2018) go beyond encouraging HCPs to be trained in incorporating feelings of patients, but to analyze and consider the complexity of their mindsets, emotions, and reactions to "[...] diagnose not only the health state but also the patient's typology level [meaning the set of a patients' personal characteristics], their cultural and mental state." (Chirchirez and Purcărea 2018). We share the idea that medical encounters should be a sensitive, nurturing environment where beneath the communication of facts, personal issues, and concerns are integrated for effectively promoting HL and SDM. Going beyond this, we suggest encouraging HCPs also to analyze and consider *their own* mindsets, emotions, and cultural and mental state. This would be a prerequisite for critically reflecting on one's own fears, values, and preferences, since it has been shown that it is hardly possible to present decision-relevant medical information in a neutral manner (Molewijk et al. 2003). Moreover, it would be a means to overcome the strict separation of 'physicianhood' and 'patienthood', allowing for truly 'shared' decision-making (DasGupta and Charon 2004), since it can be argued that in medical encounters, not only the patient has emotions and culture (Napier et al. 2014).

We consider stigma, fear, and previous knowledge to be potentially relevant for predictive consultations. Conditions affecting the mental state (e.g. Psychosis or Alzheimer's disease) are especially stigmatized. With predictive

procedures alone being a potentially fearful event (Chiolero 2014), needing to deal with health-related stigma or fear may facilitate negative health outcomes (Jessen et al. 2014), less participation in healthcare services in general, and preventive measures in particular (Kane et al. 2019). Being sensitive towards what is known about or feared about a disease may help to counteract misconceptions. This reciprocity of risk/disease perceptions and health outcomes implies the importance of understanding factors such as stigma, fear, and previous knowledge in predictive consultations. This consideration interrelates with the above mentioned ‘risk of knowing’ which is being given credit by the controversial debate on potential harms of risk prediction and ‘the right not to know’ in predictive medicine. In genomic research and the prediction of life-altering diseases for instance, ethically highly relevant impulses with regard to aspects such as individualized communication, patients’ autonomy, and normativity in healthcare are contributing to the mentality of future healthcare (Andorno 2004; Berkman and Hull 2014; Cook and Bellis 2001; Davies and Savulescu 2021).

When recommending an opportunity-oriented communication style (e.g., using imagery language or practicing empathy), questions for communication strategies that have proven to be effective in predictive medicine arise. Although there is literature on communication in medicine in general and on concepts such as individualized and preference-sensitive communication, publications rather indicate research desiderata than empirical evaluation of communication models with practical implications (Balducci 2014; King and Hoppe 2013; Koul 2017). There is, however, evidence concerning the use of graphical images in medical consultations showing that patients who saw explanatory images when being consulted about disease were more satisfied with the encounter (Vilallonga et al. 2012). Complementing the use of graphical images, imagery language (metaphors) may be a relevant tool for explaining disease risk. Schwegler (Schwegler 2021) has described the risk consultation encounter as a novel communication genre that confronts both advice seekers and HCPs with new and particular challenges. Future research on HL and SDM in predictive medicine could therefore benefit from linguistic approaches, analyzing the effectiveness of imagery language in predictive encounters for patients and HCPs alike.

In order to operationalize this study’s results, deductive concepts and practical tools integrating the abovementioned implications should be developed, introduced to patients and HCPs in the predictive practice, and systematically evaluated — most preferably using a participatory research approach. Respecting the idea of medical reality being co-created by patients and HCPs (Cherry 1996), previous research on patients’ perceptions (Harzheim et al. 2020; Lorke et al. 2021) should be included in conceptualizing tools and teaching material.

Strengths and limitations

Due to the heterogeneity of HCP’s specialty (e.g., CHC vs FBOC) and the varied data corpus (more surveys than interviews), an overarching data analysis, without the intention to provide indication-specific findings, was conducted. The focus was based on identifying similarities across clinical fields, so that early predictive procedures in general may benefit from the findings. The sample size is adequate for the research question, the study design, and the given project resources, following the principles of purposive/theoretical sampling (Corbin and Strauss 1990). This study’s sample allowed for HCPs to share experiences and views on the topics of interest, and for deriving theoretical approaches and orienting cornerstones for further research. However, all participants worked at specialized early prediction centers and therefore were sensitized to the topics addressed. Investigating the perceptions of HCPs consulting about risk in less specialized environments might reveal insights which a broader audience in predictive medicine could relate to.

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Availability of data and material All data used for this contribution are available to the journal upon request and in a pseudonymized form.

Declarations

Ethics approval Ethics approval to this study was granted by the ethics committee of the Medical Faculty of the University of Cologne on December 8, 2020 (registration number: 20-1290_1). The study aligns with the Helsinki Declaration of 1964, as revised in 2013, respective human and animal rights. All participants consented their participation verbally and in writing.

Consent to participate and for publication Informed consent to participate in this study and to having their data published was obtained from all participants included in this study.

Conflicts of interests There are no conflicts of interests to declare.

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