Full-Length Research Report

The Promotion of Health Literacy

An Ethical Task in the Prediction of Alzheimer's Dementia Risk

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Abstract: Progress in predictive medicine has increased the challenges to navigating complex risk information for patients and healthcare professionals. This contribution investigates how people facing the risk of developing Alzheimer's dementia perceive risk, what aspects are relevant to their health literacy, and how to promote individual health literacy in predictive medicine. We conducted a qualitative study analyzing narrative interviews, body maps, and sociodemographic data from persons who had undergone early predictive procedures in a memory clinic. We understand the promotion of health literacy as an ethical task in predictive medicine and argue for (1) emphasizing personal resources to promote subjective health literacy, (2) reframing communication and decision-making about disease risk, and (3) teaching skills for value-sensitive, individualized risk communication.

Keywords: Alzheimer's disease, risk prediction, health literacy, ethical aspects

In an aging population, age-related neurodegenerative diseases are becoming more prominent in medical research and care (Albert et al., 2011). Ongoing medical-technical progress allows the prediction of the risk for the development of neurodegenerative diseases as well as the detection of their early stages to enable preventive measures (Jessen, 2019). This opportunity means people undergoing early prediction procedures are particularly challenged in dealing with risk information (Newsholme, 2015). Understanding and critically evaluating risk information is important to making informed choices about preventive interventions or adopting a health-promoting lifestyle (Harzheim et al., 2020; Sørensen et al., 2012). Likewise, healthcare professionals (HCPs) are challenged to establish an environment adequate for shared decision-making (SDM) in predictive consultations, although there are presently no well-established communication models for this setting (Rostamzadeh & Jessen, 2020). To promote a health-literate approach to risk information, empirical research on health literacy (HL)-relevant factors in the context of neurodegenerative disease could substantiate implications for predictive practice.

The aim and methodological approach of this study stem from the predictive diagnosis of Alzheimer's disease (AD) as an example of a neurodegenerative disease, the relevance of HL in the context of cognition, and ethical issues in the field of predicting Alzheimer's dementia risk.

The Predictive Diagnosis of Alzheimer's Disease

AD is the most common neuropathologic etiology of dementia, with an increasing prevalence in older age. Along with demographic developments, a growing incidence of AD implies a substantial public health challenge (Ferri et al., 2005). AD is characterized by amyloid and tau pathology as well as consecutive neurodegeneration, which finally leads to a progressive cognitive decline (Blennow et al., 2006). Its pathophysiological processes can be detected in early disease stages using biomarker-based analysis (Rostamzadeh & Jessen, 2020; Sanroma et al., 2017). Subjective cognitive decline (SCD) and mild cognitive impairment (MCI) may be Alzheimer's dementia at-risk stages

(Albert et al., 2011; Jessen et al., 2014).[1,2] There are increasing efforts to predict dementia risk at preclinical or prodromal stages of AD to enable preventive actions: People affected can adapt their life plans, address modifiable lifestyle aspects (e.g., diet, physical activity, cognitive training) to decelerate disease progression (Basu et al., 2019; Li et al., 2020; Livingston et al., 2020; Ngandu et al., 2015), or decide for early medical interventions, which are hoped to slow disease courses by maintaining cognitive functions (Jessen, 2019). Decision-making in the context of early AD detection and risk prediction hence implies particular demands on health literacy (HL) in terms of navigating and appraising complex health information (Rostamzadeh et al., 2020; Sørensen et al., 2012).

Health Literacy and Cognition

HL refers to assessing, understanding, appraising, and applying health information. Given the growth of predictive medicine, risk-related HL[3] is essential for health promotion (Sørensen et al., 2012). HL and decision-making in predicting Alzheimer's dementia risk are challenged by the complexity of information about anticipated health events and by (beginning) cognitive constraints. Also, knowledge about being at risk itself can impact health-related outcomes (Harzheim et al., 2020) and increase the risk of disease progression (Jessen et al., 2014; Roehr et al., 2017). It, therefore, constitutes an ethical challenge in risk communication (Davies & Savulescu, 2021; Götzelmann et al., 2021).

For cognitively impaired individuals, the challenge of dealing with complex health information amplifies since they may face more difficulties than nonimpaired persons in applying the above-mentioned attributes of HL (Rostamzadeh et al., 2020). Studies have distilled a bidirectional relationship between cognitive functions and HL: Deterioration of memory is associated with regressive HL (Federman et al., 2009; Liu et al., 2019), and a "low HL" may increase the risk of cognitive impairment (Oliveira et al., 2019).

Ethical Aspects

A vivid ethical debate is going on about the predictive diagnosis of AD (Gauthier et al., 2013; Porteri & Frisoni, 2014; Schicktanz et al., 2021). Conducting genomic research or analyzing biomarkers to predict a life-altering disease raises questions about patients' well-being, normativity, autonomy, and self-determination (Götzelmann et al., 2021). With all the benefits of risk prediction, its potential harm and the possible psychological effects of a risk diagnosis are being discussed in the scientific literature (Andorno, 2004; Berkman & Hull, 2014; Cook & Bellis, 2001; Davies & Savulescu, 2021). This also results from the normative potential of predictive medicine: Predicting disease risk potentially shifts the perception of being healthy to being ill (Lorke, 2021; Meier et al., 2017); especially in the context of neurodegenerative diseases, diagnostic labeling entails the risk of stigmatization and discrimination (Götzelmann et al., 2021). Autonomy and self-determination in the context of AD research are especially delicate subjects in the face of (beginning) cognitive constraints (Burlá et al., 2014; Cascio & Racine, 2018; Silva et al., 2020). The ethical asset of informed consent needs to be preserved by guaranteeing the patient's understanding of disease risk information and enabling them to make informed choices (Kim, 2011). These ethical aspects are elements of communicating about and dealing with the disease risk inherent to HL (Harzheim et al., 2020). They need to be empirically investigated and theoretically reflected when conducting research on HL and risk prediction of Alzheimer's dementia.

Aim

Concerning the epidemiological and ethical relevance of the risk prediction of Alzheimer's dementia, the importance of HL in dealing with complex risk information, and the lack of patient-centered, inductive HL research in the context of predictive medicine, this contribution aims at identifying the patient perspective. The research questions we address are as follows: (1) How do people facing Alzheimer's dementia risk perceive disease risk? (2) What HL-relevant aspects are important to them? (3) How to best promote the HL of people facing Alzheimer's dementia risk?

Methodological Approach

We employed a qualitative, mixed-methods research design, including narrative interviews, body maps, and sociodemographic data. The data stem from a research

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[1] While MCI is defined by a slight functional impairment without yet meeting dementia criteria (Petersen, 2004), SCD is described as a state of self-perceived cognitive deterioration that cannot be objectively identified. SCD may represent the earliest manifestation of Alzheimer's dementia or other forms of dementia (Jessen et al., 2014; Roehr et al., 2017).

[2] Alzheimer's disease (AD) refers to the pathological changes addressed by early diagnosis procedures; Alzheimer's dementia refers to the clinical syndrome investigated in risk prediction.

[3] Risk-related HL in terms of self-efficient management of risk information and risk-adjusted decision-making and behavior (Sørensen et al., 2012).

project about HL in predictive medicine, analyzing HL-relevant aspects for people facing disease risk in four exemplary clinical fields (Harzheim et al., 2020).[4]

Sampling and Recruitment

Participants had been diagnosed with SCD (Jessen et al., 2014) or MCI (Albert et al., 2011) during the diagnostic work-up at the Centre for Memory Disorders of the Department of Psychiatry and Psychotherapy at the University Hospital Cologne. We recruited them in collaboration with the Centre for Memory Disorders according to predefined inclusion and exclusion criteria[5] and provided written and verbal informed consent. The interviews were conducted between April 2018 and August 2019 by one of the authors (LH, SJ, or ML).[6] Ethical approval was granted by the medical faculty of the University Hospital Cologne.[7]

Data Collection and Analysis

The mixed-methods approach (Kelle, 2014) enabled a comprehensive analysis of the participants' perceptions: A triangulation of data sources served for a more in-depth analysis of different layers of risk appraisal (verbal and nonverbal; declarative, procedural, and embodied). Therefore, we conducted 10 narrative interviews (Nohl, 2017) and asked participants about their experiences with and perception of disease risk and predictive procedures. To investigate HL-relevant aspects from the interviewees' perspectives, we asked in-depth questions concerning their access, understanding, appraising, and application of risk information. At the end of each interview, we invited the participants to draw their dementia risk perception on a body sketch.[8] Body-mapping, as "the process of [. . .] using drawing, painting, or other art-based techniques to visually represent aspects of people's lives, their bodies and the world they live in" (Gastaldo et al., 2018, p. 5), proved helpful for nonverbally assessing perceptions of people experiencing cognitive constraints or difficulties with verbal descriptions (Dew et al., 2018). We also assessed sociodemographic data like age, living conditions, and healthcare experiences to contextualize the participants' personal situations.

We analyzed the verbal (interviews), visual (body maps), reflexive (field notes), and contextual (sociodemographic questionnaire) data following the principles of the reflexive grounded theory[9] (Breuer et al., 2010; Corbin & Strauss, 1990). We transcribed audio recordings of the interviews verbatim and analyzed them line by line (open coding), abstracting the codes and condensing them into categories and subcategories (axial and selective coding). This category system illustrates the main findings of this study (Table 2). We used the field notes for documenting, disclosing, and minimizing the subjectivities of the researchers and for reflecting upon their role in the research process (Breuer et al., 2017). We analyzed the body maps together with the verbal explanatory information provided by participants, analyzing the sociodemographic data using descriptive statistics (Table 1).

Theoretical saturation (Breuer et al., 2017) was reached when the repeated examination and triangulation (Denzin, 2012) of the data did not lead to theoretical amplifications in the category system.

Results

We included 10 interviews in the data analysis[10]; five participants were diagnosed with MCI and five with SCD. MCI patients were communicated an increased Alzheimer's dementia risk compared to people of their age without signs of cognitive impairments; SCD patients were communicated that most people with SCD do not develop Alzheimer's dementia compared to a minority that does.

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[4] The project RisKomp (Health Literacy of Persons at Risk – From Information to Action) was conducted at the Cologne Center for Ethics, Rights, Economics, and Social Sciences of Health (CERES) of the University of Cologne from 2016 to 2019, in cooperation with clinics of the University Hospital of Cologne.

[5] Inclusion criteria met the NIA-AA guidelines for the diagnosis of MCI (Albert et al., 2011) and diagnostic criteria for SCD (Jessen et al., 2014). Exclusion criteria were, among others, a diagnosed dementia or an impairment stemming from a psychiatric or neurological condition.

[6] Laura Harzheim (LH), Saskia Jünger (SJ), Mariya Lorke (ML).

[7] Registration number from ethical approval: 18-014.

[8] With drawings showing participants' handwriting, the body maps were technically replicated true to the original for anonymity protection.

[9] The grounded theory methodology (GTM) is an approach of qualitative social research, describing a set of systematic procedures to generate inductively derived theories about certain phenomena. (Corbin & Strauss, 1990). Subjective relevancies uncovered through the interviewees' narrations can be abstracted into theoretical considerations about the phenomena of interest, following the assumption of social realities based on subjective relevance systems. This employs individuals' risk perceptions as a basis for theoretical considerations about HL-relevant aspects for people at risk.

[10] Despite a controversy discussion, there is no gold standard for the sample sizes in qualitative studies (Guest et al., 2016; Saunders et al., 2019). The sample size of this study is justified by the research question, the choice of the analysis method, the field access, and given research resources (Corbin & Strauss, 1990). In line with its design, this study does not aim for representativeness but for empirically founded theory building (Flick et al., 2010).

Table 1. Sociodemographic sample structure

Characteristic	Distribution
Sex	Male (3); female (7)
Age	$\geq$ 71 years (1); 61-70 (8); 51-60 (1)
Family status	Married (5); divorced (2); widowed (1); single (1); ns (1)
Living with …	Partner (5); partner and relatives (3); alone (2)
Cultural background	Bicultural (1); German (9)
Religious	Yes (6); no or ns (4)
Educational background	Higher (7); middle (1); lower (2) school graduation
Professional background	In health care (3); social services (2); science (1); administration (2); ns (2)
Experience with health conditions/involvement in the healthcare system	Have been medically treated (7); suffering from chronic disease (7)

Table 2. HL-relevant aspects in predictive diagnosis of AD

Risk interpretation	Information and knowledge
– Risk perception	– Seeking and reflecting
– Disease images	– Explanatory models, uncertainties, and meaning-making
Personal competencies and resources	Strategies
– Self-perception and -reflection	– Self-determination, proactive engagement
– Intuition	– Information, communication, interaction
– Disease experience	– Health-promoting lifestyle
– Personal environment	

Both groups were recommended to take all available preventive measures and to return every 6–12 months for check-ups. All participants completed the sociodemographic questionnaires, eight completed the body maps.

We identified four main categories that capture the participant's perceptions on accessing, understanding, appraising, and applying AD risk information (Table 2): individual ways of interpreting risk, dealing with risk information and knowledge, personal competencies and resources, and strategies for dealing with disease risk.[11] All categories touch on ethical aspects in predicting Alzheimer's dementia risk (discussed later on).

Risk Interpretation

How participants interpreted their Alzheimer's dementia risk was linked to their risk perceptions and disease images. Interviewees described perceiving the risk as a threat, as something omnipresent, or as something relative. They associated AD risk with degeneration, dysfunction, cognitive capacity loss ("[…] your body wears out," ADP02) and with declining social connection ("cut off," ADP02). Patients also referred to their risk with "fear" (ADP01),

"concern" (ADP05), and as a "safety warning [of something] the increase [of which] would be the worst" (ADP04). They visualized swirls and question marks around the heads and bodies, verbally expressing confusion and insecurity (Figure 1).

Participants perceived AD risk as multidimensional, locating it in the head and body (physical), affecting cognitive functions, as well as on a spiritual level (metaphysical), affecting and being affected by the mind (Figure 2).

Risk was perceived as omnipresent, affecting participants' well-being when they constantly worried about their families, about becoming a burden, and about not being able to live life as usual: "And I can't get this diagnosis out of my mind. It's in my every cell. […] I'm just terrified of getting dementia" (ADP01). The communicated estimated risk for developing Alzheimer's dementia (SCD vs. MCI) did not necessarily affect the degree to which participants perceived it as a threat or as omnipresent.

However, interpreting risk as something relative was a form of negotiating it: "Subjective cognitive decline – dear God, you've got your little aches and pains, and that is just one of them" (ADP02). Mentioning health-related contexts

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[11] Exemplary quotes from participants are presented to illustrate the anchoring of (sub)categories in the empirical data. Participants were pseudonymized (from ADP01 to ADP10).
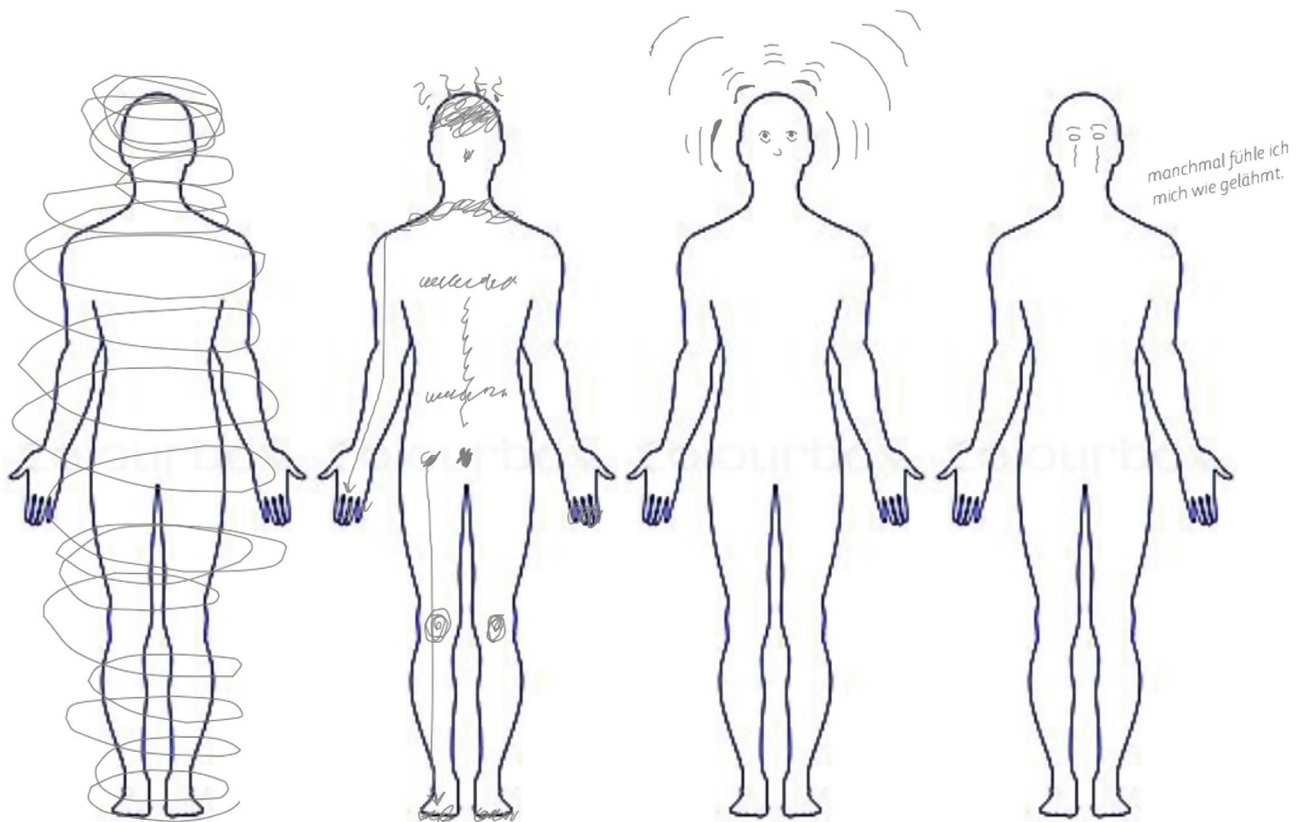
Figure 1. Body maps: emotional risk perception.

along with their Alzheimer's dementia risk indicated that risk was not interpreted separately: "When I took the first test [...], I was still in a job that really burdened me" (ADP08).

Participants' risk interpretations were also informed by their disease images – shaped by personal experiences (family history) or socially formed imprints (stigma), which induced fearful anticipation and preemptive strategies to regain control. For instance, participants associated AD with the loss of cognitive capacities and identity, but also – in most negative extremes – a life not worth living: "If I feel there's no way out, I'll go to Switzerland and kill myself" (ADP01).

Information and Knowledge

The participants' ways of searching for and assessing risk information, explanatory models, and uncertainties in the meaning-making (Park & Folkman, 1997) of risk information shed light on how they were dealing with risk information and knowledge of risk.[12]

Regarding seeking and reflecting on risk information, participants named public sources like online articles and TV broadcasts as well as their social environment. They furthermore emphasized being critical about risk information provided by their HCPs: "Well, it happened twice now that my medical report said something important my doctor hadn't even mentioned" (ADP05) and having difficulties with navigating through the variety of information on health, risk, and disease. Having worked in healthcare was reported as helping to deal more confidently with risk information.

Participants explained how they experienced divergences between the risk status communicated to them and their feeling of being at risk: "Well, I'm not really certain if I know for sure that I am not at risk" (ADP02). Not only when their perceptions contradicted the risk communicated to them did participants complement information from predictive consultations with (autobiographical) explanatory models: "[My job loss] bothers me constantly. [...] I think this is the main cause for my beginning dementia" (ADP06).

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[12] The term "information" describes the process of getting informed and the information itself, meaning bundled and contextualized data that contribute to gaining knowledge on a subject (Schreyögg, 1996; Seiffert, 1971); "knowledge" refers to the individual integration and interpretation of information (Schreyögg, 1996) when dealing with disease risk.
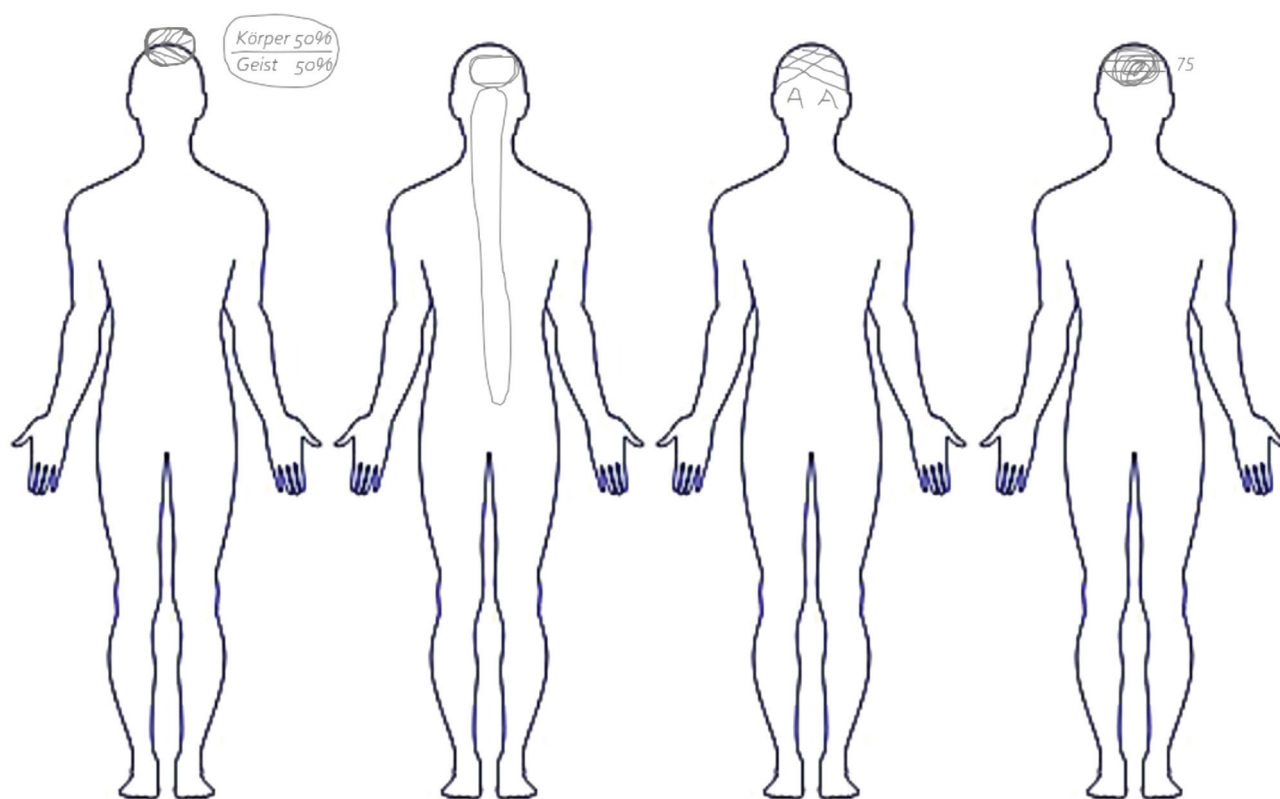
Figure 2. Body maps: location of risk perception.

Personal Competencies and Resources

Self-perception, intuition,[13] experience, and communication were personal competencies or resources participants restored when dealing with risk.

Observing changes in their cognitive capacity, for instance, led them to undergo predictive procedures: "It was my initiative actually. Because I had the feeling that I have become more forgetful" (ADP02). Intuitively feeling an imbalance between communicated and perceived risk contributed to the negotiation and inner communication about risk: "So, basically all the tests you can make [...] were all ok. [...] I just don't have a good feeling" (ADP05, SCD patient, no signs for an increased Alzheimer's dementia risk).

Having (directly or indirectly) experienced disease was described as influencing engagement in predictive procedures: "I witnessed [...] [my grandma's] condition getting worse [...], and that was also the reason why I came here" (ADP10). Interviewees seemed to project what they had witnessed to their future health vision: "And if you have witnessed the end of dementia [...] that cannot be a life goal for me" (ADP04). Disease experience, therefore, was either a competence (when leading to health-promoting choices) or a burden (when leading to approach risk in a fear-driven manner).

Participants designated their social environment as another personal resource in dealing with disease risk; relatives and friends served as a reflection and warning system, leading participants to seek professional advice: "That was when I started [noticing] – when my kids and my husband said something" (ADP07).

Strategies

Self-determination, information, communication, and a healthy lifestyle were strategies pursued by participants when dealing with disease risk.

Undergoing a predictive procedure was a form of proactively dealing with risk: "Everything you can do [...] against it needs to be done" (ADP04). With this, participants expressed autonomy, self-determination, and agency. A contrary example depicting the same principle is the choice to withdraw from risk information. Not wanting to know was described as a form of self-protection against the potential harm of knowing, when knowledge was perceived as a deterministic certainty about what to expect and a lack of

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[13] The term "intuition" is used in the sense of an intelligence not based on logic coherences or conscious reasoning (Gigerenzer, 2007).

hope for things to develop differently: "To know means knowing exactly how things will be. Not knowing [. . .] – I can lie to myself a bit longer" (ADP07). What may appear to be health illiterate was a well-considered, self-determined measure of protection against harm that subjectively outweighs the occurrence of alternative damage.

Communication and exchange with peers was a form of understanding, sorting, and coping with risk information: "Yes, we talk a lot about it. [. . .] Because really good friends are affected, too, you know?" (ADP05). Using another strategy of actively engaging with risk, participants consciously opted for a healthier lifestyle (e.g., memory training, physical activities, healthy diets, meditation): "Mindfulness training, meditation. [. . .] And I also read that cognitive training is helpful, right?" (ADP04).

Discussion

The main categories identified in this study showed various HL-relevant aspects in the course of Alzheimer's dementia risk prediction. HL has already been differentiated as multidimensional, situational, and a form of social practice, implying various forms and sources of health knowledge (Samerski, 2019). Expanding on these facets of HL, based on our findings, we wish to discuss the following implications for the promotion of HL in the context of risk prediction: (1) emphasizing personal competencies and resources, (2) reflecting the way of communication and decision-making in predictive procedures, and (3) incorporating preference-sensitive, individualized risk communication competencies into the education and training of HCPs. Concerning these implications, we elaborate on the significance of HL as an ethical task in predictive medicine.

Emphasizing Personal Competencies and Resources

The interviewees' perceptions showed the relevance of emotional-intuitive resources in the context of risk. Self-literacy in terms of a sense of personal well-being, discomfort, or physical and psychological changes determined the participants' decisions on preventive measures.

Indeed, that emotional-intuitive aspects are more relevant for health decisions than rational facts is already being discussed in HL research (Schaeffer et al., 2019). Situational awareness, "gut-feeling," and self-perception are considered at least as important as factual knowledge

for evaluating and making sense of health information (Champlin et al., 2017; Naccarella et al., 2016). Slovic et al. (2004) emphasized intuition as an equally relevant component of a rational-analytical approach (experiential vs. analytical) that people resort to when dealing with risk. To strengthen HL in the context of Alzheimer's dementia risk prediction, it is, therefore, crucial to consider individual resources – such as intuition – as essential parts of selfhood and identity (Brown, 2017), since identity and health may be regarded as interwoven[14]: A resource-oriented approach to promoting HL acknowledges and respects the patient's capacities and relevancies. Value-sensitive communication – e.g., by considering the degree to which patients desire to learn about their risk – may be understood as respecting their autonomy and self-determination. Therefore, social intuition and emotional intelligence on HCP's behalf are required.

Another means of resource-oriented HL promotion can be building on existing health, disease, and risk concepts. Since participants attended medical consultations with certain levels of knowledge, attitudes, and visions of their (future) health, ignoring these may lead to a preoccupation with statistics, which is known to be not necessarily decisive for decision-making (Holmberg et al., 2015; Reyna, 2008). Considering existing concepts may help to establish health-promoting strategies that already grew reasonable to patients. Asking "What do you know about Alzheimer's disease?" or "What is most important to you regarding your health?" or "What are your hopes and worries?" may help to incorporate preexisting knowledge into predictive consultations.

In other words, rather than operationalizing skills and competence levels with standardized criteria ("objective" HL), the focus of promoting and evaluating HL should lie on people's appraisal of their individual health-related resources (subjective HL) and on supporting them in critically appraising information (critical HL): "We need to change the focus of health literacy research by studying which approaches to dealing with health literacy result in the best outcomes for patients [. . .]" (Weiss, 2015).

Reframing Communication and Decision-Making

Following the assumption that HL forms and evolves in social interaction and communication (Harzheim et al., 2020), how risk is communicated can be key. Communicating with others and themselves helped participants to understand their risk. Therefore, intuitive-emotional

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[14] Identity potentially *affects* health – e.g., when identity-relevant changes lead to someone undergoing preventive measures (Strohminger & Nichols, 2015) – and identity potentially *is affected* by health – e.g., when cognitive decline impacts someone's perception of self and identity (Brown, 2017; Caddell & Clare, 2010).

aspects should be reflected in the way HCPs communicate in predictive encounters – how can intuition and biographical experience be acknowledged instead of being devalued as "irrational"?[15] Participants' struggling with understanding risk information may conflate with cognitive constraints or with an interview being a potentially stressful event. However, their difficulties need to be taken seriously, considering a more individualized, value-sensitive communication strategy for predictive procedures.

Irrespective of probabilities, risk can be perceived "[…] as highly normatively charged [and] as an emotionally significant threat" (Wöhlke et al., 2019, p. 1). This is connected to the suggestion of considering the ethically relevant risk of knowing along with the medically identified risk (Sarangi et al., 2003) as well as the potential epistemic confusion that may come along with risk information (Samerski, 2015).[16] Because AD is a disease that cannot yet be cured or prevented, predicting it may impact the psychosocial well-being of patients (Rostamzadeh & Jessen, 2020), which is of ethical relevance for the research field (Götzelmann et al., 2021).

HCPs who consult people facing Alzheimer's dementia risk are also familiar with communicating with relatives accompanying their partners or parents. Relatives and friends proved to be decisive for patients to undergo predictive consultation, suggesting the social environment to be an HL-relevant component. HCPs may consequently face the need to mediate the patient's and the relative's perceptions alike, needing to widen their communication spectrum, covering informational, emotional, and mediation-technique aspects, and considering the patient's cognitive capacities (Chiong, 2013; Wolfs et al., 2012).

Teaching Value-Sensitive, Individualized Risk Communication Competencies

Communication as a source for HL gets addressed more closely by Harzheim et al. (2020), particularly referring to Habermas' theory of communicative action (Hofmann, 2016). Cherry (1996) stated that patients and HCPs jointly construct medical-social reality. Key elements in this creational process are communication (information) and interaction (relationship), which is also in line with Samerski's (2019) notion of HL being co-created in social practice.

To operationalize this study's findings, we interpreted them with a focus on the setting of predictive consultations, where patient-HCP interaction and communication constitute a central encounter for individual HL promotion (Mullan et al., 2017).

The importance of teaching communication skills in HCPs' education has long been acknowledged (DasGupta & Charon, 2004). Yet, in predictive medicine, HCPs face a communicative situation for which no established orientation exists – the consultation for disease prediction (Schwegler, 2021). Specific communication guidance should therefore be offered for HCPs in predictive procedures. A two-level communication strategy (rational-analytical and emotional-intuitive) appears to be beneficial, since both systems operating in parallel are considered holistic and sufficient: "[…] each [system] seems to depend on the other for guidance. […] analytic reasoning cannot be effective unless it is guided by emotion and affect" (Slovic et al., 2004, p. 1).

Still, risk-communication training in medical education is considered underrepresented (Baessler et al., 2020), although this study and other research identified it as crucial for HL promotion in predictive medicine (PreDADQoL[17]). Communication guides, checklists, or HCP training could be offered, covering standardized, indication-specific information about risk and prevention, along with guidance on individually adaptable tips for preference- and capacity-sensitive communication.

Considering HL-Relevant Ethical Aspects in Predicting AD Risk

Risk perceptions, personal competencies, and strategies in dealing with risk are categories entangled with ethical issues in the context of AD research distilled by Götzelmann et al. (2021) and Silva et al. (2020).

In this study, we addressed the risk of the potential harm of Alzheimer's dementia risk prediction, its identity-relevant impact on individuals, their autonomy and self-determination, and their empowerment in decision-making are matters. We wish to reflect on this in light of the ethical

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[15] Greenhalgh et al. (2015) address low status of patient experience in evidence hierarchy as a potential bias in evidence-based medicine.

[16] Samerski (2015) describes the challenge of translating a statistically constructed risk status into an individual's life world as "epistemic confusion" and thereby also addresses the potential imbalance between risk communication and perception. Molewijk et al. (2008) shed light on the same potential confusion by pointing out the misinterpretation of statistically generated recommendations as "individualized" risk information.

[17] As part of the BMBF-funded research project (2016–2021), colleagues from CERES and the Centre for Memory Disorders are investigating the ethical and legal framework for carrying out predictive diagnostics of AD in order to develop guidance for informing, advising, and caring for patients dealing with an increased risk Alzheimer's dementia (Rostamzadeh et al., 2021).18Ethical debates in AD research may differentiate between genetic and biomarker-based risk prediction. We apprehend ethical considerations of predicting Alzheimer's dementia risk in general, to distillate recommendations for both directions of predictive practice.

guidepost for AD research (Götzelmann et al., 2021; Silva et al., 2020).[18] The ethical issue of potentially harming people with risk information lies within the nature of risk prediction, since communicating a risk entails imposing uncertainty upon a person (Davis, 2017). Information on biomarker testing is considered potentially harmful knowledge that can negatively affect patients' well-being, for instance, leading to depression or anxiety (Karlawish, 2011). It has been suggested to balance patients' desire to know their risk profile with the necessity to prevent harm resulting from this information (Karlawish, 2011). This implies the challenge of balancing patients' autonomy and well-being and the need to minimize the harm of risk disclosure by guiding patients through uncertainties (Götzelmann et al., 2021).

The status of being at risk has shown to be an identity-relevant shift from a person's self-perception as healthy to (soon-to-be) ill. This normative potential of risk prediction is addressed by "healthy-sick debates" (Meier et al., 2017) and elaborations on the power of definitional dynamics in risk prediction (Lorke et al., 2021). This is of high ethical relevance when a person's health and liberty are disregarded by overseeing psychological factors of public perceptions of at-risk statuses (Perhac, 1996). Silva et al. (2020) address the "acknowledgment of lived world," that is, calling for understanding and respecting the implications of risk diagnoses on an individual's life, their social experiences, and their interaction with others.

Respecting holistic personhood (Silva et al., 2020) also entails respecting autonomy and self-determination. Self-determination (living one's own will, making self-effective decisions; Burlá et al., 2014) implies respecting a person's choices, despite potential cognitive impairments (Cascio & Racine, 2018). When addressing self-determination in the context of dementia research, ethical debates on informed consent in medical practice are prominent (Kim, 2011). Because the potential compromising effect of memory loss on someone's cognition, their conscious self and thereby their decision-making can be impacted (Buller, 2015; Davis, 2017). Efforts to empower persons with (beginning) cognitive constraints should aim at maintaining their autonomy (Silva et al., 2020). Seeking "ongoing consent" is a strategy of continuously reassuring that diagnostic procedures and preventive options are being understood and agreed to (Silva et al., 2020). Relatives can be potentially valuable in negotiating solutions in line with the patients' values (Kim, 2011). At the same time, sensitivity is needed concerning the extent to which relatives may be included in the decision-making process, balancing out the patients' best interests with their relatives' concerns (Götzelmann et al., 2021).

Conclusion

This study's findings emphasize the complexity of HL-relevant factors in risk prediction, revealing crucial ethical aspects that need to be addressed in medical practice. Approaches to promote self-determined decision-making should incorporate individual experiences, perceptions, relevancies, and (cognitive) capacities. HL should be understood as a subjective concept, where "good" or "bad" HL is not defined mainly from an objective point of view but rather regarding the extent to which individual values are being met. Supporting subjective HL can be seen as an ethical task in the prediction of Alzheimer's dementia. For this, we consider the direct communication between patients and HCPs to be the smallest but most crucial unit in predictive medicine. Once the patient's perspective on the subject matter has been analyzed, experiences and perceptions of HCPs working with people seeking advice in predictive procedures must also be considered, to account for the bilateral co-emergence of HL.

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[18] Ethical debates in AD research may differentiate between genetic and biomarker-based risk prediction. We apprehend ethical considerations of predicting Alzheimer's dementia risk in general, to distillate recommendations for both directions of predictive practice.

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History

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Conflict of Interest

The authors declare no conflict of interest.

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