Full-Length Research Report

Predementia Counseling

Informed Decision-Making and Postcounseling Reflection

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Abstract. Improving risk prediction of Alzheimer's dementia poses challenges to healthcare professionals, patients, and their social environment. Moreover, predictive diagnosis faces limited operationalized clinical recommendations. In this study, we developed manuals for counseling individuals with mild cognitive impairment on their biomarker-based dementia risk prediction; we interviewed 16 participants postcounseling. The interview analysis examines sources of knowledge concerning the decision regarding risk prediction. Subsequently, an interdisciplinary interpretation discusses implications for practice. By focusing on sources of the participants' knowledge, we identified epistemic authorities, such as (former) medical-related professional background or previous disease experiences. The findings provide information on cues and conversational elements for improving counseling sessions. Sensibly integrated language-based and legal considerations may achieve a targeted and efficient joint decision-making process.

Keywords: Alzheimer's disease, dementia risk prediction, risk communication, counseling recommendation, informed-decision making

Prediction and Early Diagnosis of Alzheimer's Dementia

Alzheimer's disease (AD) starts decades before the onset of neurocognitive symptoms and eventually leads to Alzheimer's dementia. Current AD research criteria and new diagnostic methods allow early AD diagnosis in the predementia stages (Jack et al., 2018). The prodromal phase of AD is characterized by mild cognitive impairment (MCI) in the presence of mild cognitive deterioration with preserved activities of daily living (Albert et al., 2011). MCI is a heterogeneous state, and only about 30 % of MCI patients develop Alzheimer's dementia within 3 years after an MCI diagnosis (Mitchell & Shiri-Feshki, 2009). However, MCI with evidence of an AD biomarker is a high-risk condition for Alzheimer's dementia, as up to 90% eventually develop dementia within approximately 5 years (Vos et al., 2015). The application of biomarker information in clinical practice involves several uncertainties regarding the interpretation of biomarker test results, counseling, disclosure, and clinical management. Healthcare professionals and patients therefore face complex and partially conflicting recommendations regarding the diagnostic process. The use of biomarkers raises unresolved ethical, legal, social, and medical questions, such as how to carry out a valid risk assessment or how patients and their close others deal with their risk knowledge in their future life planning. But it also touches on practical questions, for example, whether an increased risk of dementia should be communicated to insurance carriers when taking out an insurance policy. Against this background, people interested in biomarker diagnostics should seek comprehensive advice beforehand to make an informed decision for or against such diagnostics.

Guidelines for Counseling and Risk Disclosure

Because of the limited therapeutic options in predementia stages, individuals at risk for Alzheimer's dementia are challenged to judge the potential benefits of biomarker-based dementia risk prediction. In this context, most potential benefits are associated mainly with individual

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attitudes, beliefs, personal resources, and social support systems. The ambiguity and uncertainty of an MCI diagnosis and its prognosis may cause distress in both patients and their close others. It may motivate some individuals to obtain more information on their brain health status, whereas, on the other hand, it may also result in their refraining from further predictive diagnostic work-up (Vanderschaeghe et al., 2018).

To date, the guidelines for counseling and risk disclosure are not well developed and based mostly on research protocols or expert consensus processes for cerebrospinal fluid (CSF)-biomarker and positron emission tomography (PET)-biomarker testing for AD in predementia stages (Alpinar-Sencan & Schicktanz, 2020; Frederiksen, Nielsen, Appollonio et al., 2021; Frederiksen, Nielsen, Winblad et al., 2021; Harkins et al., 2015; Herukka et al., 2016; Karlawish, 2011; Lingler et al., 2016; Roberts et al., 2013a; Rostamzadeh et al., 2021; Shaw et al., 2018). The current literature on guidelines for biomarker test disclosure to symptomatic individuals in predementia stages emphasizes the importance of determining the degree of certainty and uncertainty when communicating the biomarker test results. Porteri et al. (2010) recommend that the patient's personal and environmental conditions should drive the physician to partial or full diagnostic disclosure – or delay communication. There are arguments in favor of involving healthcare professionals with expertise in education and counseling when developing guidelines. Roberts et al. (2013b) recommended guidelines for "pretest counseling sessions, post-test disclosure procedures, and longer-term follow up" of predictive AD diagnosis, including reflections on psychological consequences, consequences for family members, financial and legal matters, and transfer of contacts who might help in case of emergency. In light of these factors, counseling on AD detection and dementia risk prediction emerges as a complex process that recognizes the heterogeneity and insecurity among healthcare professionals regarding counseling practices during the informed decision-making process (Schwegler, 2021).

Ethical and Legal Considerations Regarding Risk Prediction

Considering that people at risk of Alzheimer's dementia face progressive deterioration of cognitive functioning and may already be cognitively impaired, these individuals face unique challenges in health-related informed consent and counseling. Also, geriatric individuals are more likely to suffer from medical conditions (e.g., sight disorder, hearing loss) impairing their communication and the informed-decision process. These considerations affect health literacy skills and health-related competencies, so it is crucial to consider options to enhance healthcare professionals' skills, for example, by communication training, and to offer individual support for patients (Ivashkov & Van Norman, 2009; Poth et al., 2021; Rostamzadeh et al., 2020).

From an ethical and legal point of view – and from clinical experience – ideally the decision for or against a predictive AD diagnosis is a step-wise, shared decision-making process by an ensemble of a healthcare professional, the patient, and close others (Alpinar-Sencan & Schicktanz, 2020; Prvulovic & Hampel, 2011; Visser et al., 2012). In particular, it is crucial to give information on possible outcomes of biomarker testing and the implications of the various test results. The individuals at risk should be informed about the advantages and disadvantages of the diagnostic steps, and that, apart from lifestyle changes, specific therapeutic opportunities with early AD diagnosis at the stage of MCI are still absent. While raising the question of *which information* or *how many details* to give, other aspects of the – very complex – decision-making process may disappear from the scientific focus. However, the shared decision-making process depends on various critical *soft* factors, such as the patient's emotional situation and context, the doctor-patient relationship (empathy, sympathy), and the patient's (coincidental) experience, role models, and previous/lay knowledge on the respective topic impacting the decision-making. Because of the focus on informational content, contextual aspects of the process may be overlooked. It is very challenging to truly and empirically identify the latter, since parts thereof concern an inner process built on questions of credibility, authenticity, and emotions (Gigerenzer, 2008; Samerski, 2015).

The PreDADQoL Study

This article presents the qualitative analysis of interview data from the PreDADQoL study (Ethical and Legal Framework for Predictive Diagnosis of AD Dementia: Quality of Life of Individuals At-Risk and Their Close Others). The interdisciplinary study investigates risk perception and expectations toward predictive AD diagnostics as well as the effects of biomarker-based dementia risk prediction on MCI patients and their close others, the goal being to improve counseling and risk disclosure in the context of predictive AD diagnostics (Rostamzadeh et al., 2021). The study was conducted at two sites (Fundació ACE Barcelona, Spain; Center for Memory Disorders, University Hospital Cologne, Germany) with the contribution of experts in the fields of ethics, law, clinical neurology, psychiatry, linguistics, and the social sciences. The present article (1) outlines aspects of PreDADQoL's counseling session, (2) introduces details on the participants' knowledge stocks and sources that occurred in the postcounseling interviews, and (3) reflects these in an interdisciplinary manner as implications for clinical (counseling) practice and legal requirements during the informed decision-making process of predictive AD diagnostics.

Methods

Study Participants

MCI patients who went through the routine diagnostic work-up, including neuropsychological testing (CERAD, Morris et al., 1989), cerebral magnetic resonance imaging (MRI), and blood test, and fulfilled the NIA-AA criteria for MCI (Albert et al., 2011) were recruited together with one close other for the PreDADQoL study. Additional inclusion criteria were: age $\geq$ 55 years, lack of contraindication for lumbar puncture, and a reliable close other. The anticipated close other should be in regular contact with the patient and be able to accompany the patient to all study visits and contribute to the study. The close others needed to perform $\geq$ 27 points in the Mini-Mental State Examination (MMSE). Severe depression, anxiety, and suicidality were exclusion criteria for all subjects. Furthermore, all study participants were assessed with the structured interview for DSM-IV Axis I Disorders to rule out major or minor depressive episodes or a general anxiety disorder. A detailed description of the overall study design was previously published (Rostamzadeh et al., 2021). For the present analysis, we considered qualitative data from narrative interviews with eight MCI patients and their corresponding eight close others, who were recruited for PreDADQoL at the site of Cologne. Each participant was interviewed twice (= 16 × 2 interviews).

Informed Consent to Research

The PreDADQoL study was approved by the local Ethics Committees of the Medical Faculty of the University of Cologne and the Hospital's Clinic Ethical Committee Barcelona. The reference number is 17–016. Written informed consent was obtained from all study participants before their participation in the study; the consent process was documented. Participants unable to give written informed consent were not enrolled in the study. Study participants were informed of all risks and were able to withdraw from the study at any time for any reason.

Procedures

All study participants received a standardized 1-hour counseling session with a trained neurologist or psychiatrist, who provided information about MCI, AD, Alzheimer's dementia, biomarkers, AD biomarker-based dementia risk prediction, and preventive measures in a standardized and manual-guided manner. Each dyad – the MCI patient and the corresponding close other – received an offer of a counseling session. The baseline visit, where the patient gave the final notice of decision for or against biomarker testing, took place 7–10 days after the counseling session. MCI patients willing to undergo biomarker testing received an appointment for a lumbar puncture. Approximately 2 weeks after the lumbar puncture, the 1-hour disclosure session (visit 0) followed, during which the individual biomarker results and dementia risk were communicated by a trained neurologist or a psychiatrist, following a manual-guided procedure. The effects and outcomes of the procedures (counseling and disclosure of biomarkers with communication of dementia risk) were assessed at three (Barcelona) to four (Cologne) different time points. Figure 1 presents the study flowchart. The qualitative interviews occurred at baseline (7–10 days after the counseling session) and at visit 2 (3 months postdisclosure or postdecision against biomarker testing).

Materials: Development of Manuals for the Counseling and Disclosure Sessions

For the development of the standardized manuals, we considered the current body of literature as well as the existing legal requirements and principles, keeping in mind that the informed decision-making process is a crucial element in the context of AD biomarker application (Grill et al., 2017; Herukka et al., 2016; Lingler et al., 2016; Shaw et al., 2018; Visser et al., 2012). We aimed to ensure our study participants' comprehension. Therefore, we used plain language, avoided medical terminology where possible, and applied the teach-back method to confirm whether patients and close others understood the most important information (Genske, 2020; Mejia et al., 2019). We encouraged them to reflect the pros and cons, such as possible consequences, before deciding to undergo Alzheimer's dementia risk assessment (Gertz & Kurz, 2011; Porteri & Frisoni, 2014; Visser et al., 2012). The objective of the counseling session was to provide general information and establish a "knowledge basis" (Deppermann, 2018) to ascertain that patients and close others had experienced an informed decision-making process. The content of the counseling sessions' first section was a general introduction and education on diagnostic work-up in memory clinics and clinical symptoms regarding MCI syndrome, AD, and Alzheimer's dementia. The subsequent part included information on AD biomarkers, lumbar puncture, and the potential risks and benefits of CSF-based AD biomarker assessment (Albert et al., 2011; Deuschl & Maier, 2016; Herukka et al., 2016). The more general introduction served to

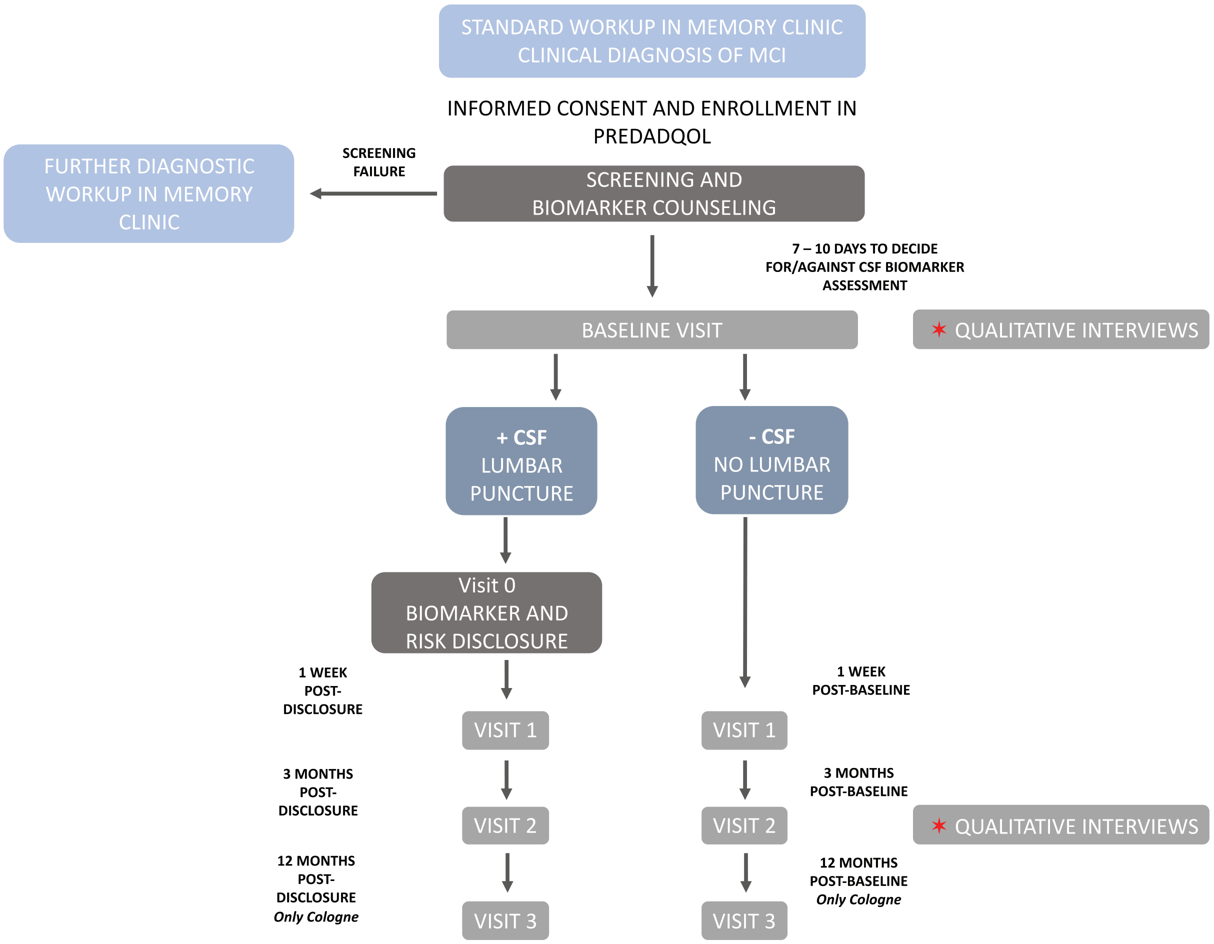

Figure 1. Study flowchart. MCI = mild cognitive impairment; CSF = cerebrospinal fluid; +CSF = MCI patients consented to lumbar puncture/biomarker assessment; −CSF = MCI patients not consented to lumbar puncture/biomarker assessment.

establish a "common ground" (Stalnaker, 2002) as a knowledge basis and address misconceptions, before continuing with the topic of dementia risk estimation based on AD biomarker status (Gertz & Kurz, 2011; Lingler et al., 2016; Visser et al., 2012).

Hereinafter, the main focus lay on different scenarios of possible AD biomarker profiles and the derived 3–5-year risks of developing dementia. Biomarker-based risk estimates for developing dementia within 3–5 years after the MCI diagnosis were obtained from the meta-analysis by Vos et al. (2015), and the overall risk estimation for developing dementia, based on the clinical MCI diagnosis, was taken from the meta-analysis by Mitchell (2008) as well as Mitchell and Shiri-Feshki (2009). We aimed to carve out the implications of four different scenarios and discuss their personal relevance together with the dyads: normal biomarker status ($A^- N^-$), abnormal biomarker status ($A^+ N^+$, meaning full AD profile with amyloid and tau pathology), conflicting biomarker status ($A^+ N^-$ or $A^- N^+$, meaning only amyloid or only tau pathology present), and unknown biomarker status (meaning no CSF biomarker testing performed when patients decided against it). Here, we opposed the possibilities of dementia risk prediction without knowledge of the AD biomarker status and the changes of prognosis when AD biomarker testing was performed. The information material with written and graphical aids was developed under consideration of the cognitive impairment of the participants and the challenge of providing complex probabilistic numerical risk information. The communication of health-related risk information is particularly challenging, as in the current study, cognitive impairment and lack of numeracy may bias good decision-making, but also, because the literature indicates that inappropriate information presentation by healthcare professionals may complicate the communication of medical information (Fagerlin et al., 2007; Garcia-Retamero & Galesic, 2013).

For depicting the different dementia risk scenarios, we developed oral, written, and graphical (icon arrays, bars, and line charts) information, including take-home material, guided by a literature review on risk-communication techniques (Figure 2) (Garcia-Retamero & Cokely, 2017;

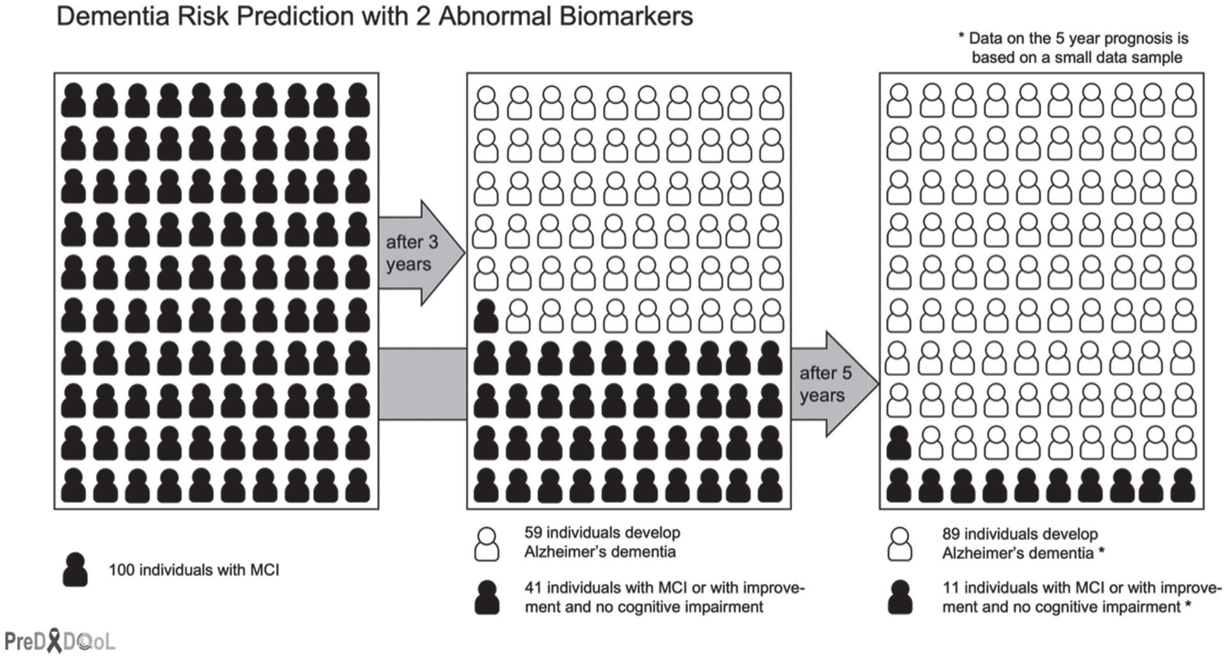

Figure 2. Example of take-home material for patients and close others.

Garcia-Retamero & Galesic, 2013; Gigerenzer et al., 2007; Lingler et al., 2016; Lipkus, 2007). We dedicated a subsequent section to therapeutic options and preventative measures at the stage of MCI to inform about modifiable dementia risk factors and measures, how to optimize lifestyle to reduce the individual dementia risk (Deuschl & Maier, 2016; Livingston et al., 2017). After the discussion on the previous topics, the session concluded with open-ended questions to allow time for a reflection on predictive AD diagnosis. The study participants were encouraged to defer their decision for or against the predictive biomarker testing to a later time and first discuss it with their close others, close friends, or other professionals (e.g., their general practitioner).

Interview Conduction

During the baseline visit (7–10 days after the counseling session), we collected interviews of 30–60 minutes each in the form of episodic interviews (Flick, 2011) in which participants could narrate rather freely. Every participant was interviewed twice postcounseling, 1 week after and 3 months after the counseling session (= 16 × 2 interviews). Eight patients and their eight corresponding close others were interviewed separately. The three different interviewers had a professional background in the academic fields of medical humanities and the social sciences. The episodic interview chosen as method of data collection consists ideally of episodic parts (narratives on life events) and of semantic parts, that is, it includes questions about specific situations from the participants' everyday life as well as questions about their understanding of certain concepts. The main topic of the interview was the risk prediction of Alzheimer's dementia, to gain insights into the participants' respective attitudes and expectations (Rostamzadeh et al., 2021). The interviewer guided the participants through their narrations of specific occasions in the context of their symptom development and the diagnostic process of dementia risk prediction in the memory clinic. The questioning started with the past and finished with future imaginations. Questions about (trustworthy) knowledge and the personal sources of knowledge were explicitly not asked.

Data Analysis

We recorded the interviews as audio files and transcribed the data according to the GAT2 minimal transcript (Couper-Kuhlen & Barth-Weingarten, 2011) to allow a thematic and interactional linguistic approach. During the qualitative linguistic analysis of the transcribed interviews (Deppermann, 2008), it became apparent that the participants were elaborating alternative sources of knowledge and implicit knowledge stocks (Schwegler et al., 2023). This knowledge occurred in two linguistic ways: directly, by explicitly mentioning the sources of knowledge, and indirectly, by sources and knowledge stocks that become visible through the interviewee's *(self-)positioning*. *Positioning* is a linguistic practice with which people produce and

Table 1. Demographic data of the interviewed MCI patients and close others

Dyads	Age/gender	MMSE	Relation	Years of education	Family history of dementia	CSF biomarker status
Patient A	75 years, m	28	Spouse	13 years	Mother, 2 brothers	A^{+} N^{+}
Close other A	73 years, f	30	Spouse	13 years	/	A^{+} N^{+}
Patient B	71 years, m	22	Spouse	13 years	/	A^{+} N^{+}
Close other B	N/A, f	28	Spouse	10 years	/	A^{+} N^{+}
Patient C	76 years, f	28	Spouse	11 years	3 sisters	A^{+} N^{+}
Close other C	59 years, f	29	Spouse	19 years	Mother	A^{+} N^{+}
Patient D	68 years, m	30	Spouse	15 years	Mother, aunt, uncle	A^{-} N^{+}
Close other D	66 years, f	30	Spouse	13 years	/	A^{-} N^{+}
Patient E	80 years, m	28	Spouse	19 years	Brother	Not tested
Close other E	77 years, f	30	Spouse	19 years	/	Not tested
Patient F	77 years, m	28	Spouse	9 years	Sister	Not tested
Close other F	69 years, f	30	Spouse	11 years	/	Not tested
Patient G	80 years, f	27	Spouse	13 years	/	Not tested
Close other G	84 years, m	30	Spouse	13 years	/	Not tested
Patient H	75 years, f	27	Spouse	9 years	/	Not tested
Close other H	75 years, m	27	Spouse	11 years	/	Not tested

Note. A = Amyloid; CSF = cerebrospinal fluid; f = female; m = male; MMSE = Mini Mental State Examination; N = neurodegeneration; years = years.

represent themselves and others in linguistic interactions relative to each other as persons (Lucius-Hoene & Deppermann, 2004). The interactional function of positioning is to make the conversation partner understand how one wants to be seen. Analyzed linguistically, positioning depicts those attributes, roles, characteristics, and motives persons claim and ascribe to their actions. Within respective interview utterances, direct and indirect reference was very regularly made to bearers of *epistemic authority*. We analyzed the interview data linguistically, categorized utterances thematically (epistemic authorities), and afterward interpreted the findings interdisciplinarily in a discussion that included implications for the clinical practice.

Results

We interviewed 8 MCI patients and corresponding close others – in total 16 study participants; Table 1 presents the collected demographic data of the dyads.

Each participant A–H (see Table 1) was interviewed twice postcounseling (30–60 minutes duration). During the thematic analysis of the interviews, which mainly served to search for attitudes toward risk prediction (Rostamzadeh et al., 2021), we found only on very few occasions that the counseling session or counseling physician was actively mentioned as a source of knowledge. When that was the case, it mainly depended on the individual personality and empathy of the physician, who was emphasized positively. Moreover, in some interviews, the pictograms of the counseling documents were actively remembered (see Figure 2). On the other hand, it was interesting that unsolicited indications of other (or nonmedical) sources of knowledge from the individuals' daily life occurred frequently. For this reason, we collected, analyzed, and categorized them as presented in the following. Sensibly integrated, such insights can provide helpful additional elements to improve counseling and may contribute to a better targeted and more time-efficient access to joint meaning-making and appropriate knowledge generation in counseling sessions. Also, such integration fulfills a number of legal requirements that to date aren't universally clear, thus safeguarding the rights of both patients and close others as well as legal certainty for physicians and care personnel.

The analysis allowed us to identify five categories of relevant epistemic authorities (knowledge stocks and sources of knowledge) besides the authority of the counseling physician (Schwegler et al., 2023). They are displayed in a summarized manner in the following five subchapters: (1) (former) medical-related professional background, (2) dementia in the social environment, (3) experiences with other diseases, (4) generalizations and universalities, and (5) media and public discourse.

Knowledge Stocks and Sources of Knowledge Concerning the Risk Prediction of AD Dementia

(Former) Medical-Related Professional Background

A central, directly and indirectly, mentioned source of knowledge is the (former) professional or honorary background of the participants, their partners, or other close family members. This knowledge is presented as very trustworthy. It is characteristic that statements about the (former) medical profession are included as (self-)positionings in health-related conversations, because they have a relevant function in linguistic adaptation processes and the negotiation of knowledge (a)symmetry with the respective conversation partners in a healthcare context (Graf & Spranz-Fogasy, 2018). Thus, addressing knowledge serves not only the transmission of knowledge; the corresponding stock of knowledge is associated with social categories (Deppermann, 2018, p. 119). This type of epistemic status can sometimes include (prior) knowledge about clinical procedures and interventions that may no longer correspond to the current state of practice in the case of geriatric participants. Misunderstandings may arise during the consultation and persist for longer if presumed shared procedural knowledge is not explicitly reconciled. The latter applies not only to outdated information but also to precounseling medical knowledge and general medical terminology (linguistic knowledge).

Dementia in the Social Environment

Participants report exemplarily about individuals with dementia from their social environment, which extends beyond close family members (Table 1, demographic data on family history of dementia). Considered a source of knowledge, persons with dementia in the social environment are a very experience-based category. Those contacts count as first-person experiences with dementia, which implies participants have made real-world experiences by themselves (in contrast to secondary experiences from narrations, newspapers, books, or films). Interestingly, not only family members are cited as sources of knowledge in this category but also more distant relatives and neighbors. In this category, epistemic authority is primarily claimed for the speed, frequency, or certainty with which dementia occurs in the respective family or social environment. Especially in narrative sequences about their experiences with (some other/formerly known) dementia patients, those who participated as close others expressed utterances such as "bad," "cruel," or "unbelievable." This may indicate the (anticipated) stressful situation that nowadays possibly becomes an earlier personal experience because of predictive AD diagnostics (Largent & Karlawish, 2019).

Experiences with Other Diseases

Illness experiences used as a source of knowledge and for comparison but have nothing to do with AD, Alzheimer's dementia, or any other form of dementia tend to positively affect the participants' attitude, in contrast to the previous category. Experienced life-threatening diseases or successfully treated diseases of close family members were mentioned (i.e., positive outcomes despite a poor initial situation). Such positive experiences with previous (other) diseases contribute to establishing an individual positive perception of the concepts of health and illness. Knowledge from experience is comprehensively trustworthy for the participants. In addition to engendering general hope, the experiential knowledge from this category also contains references to belief in medical solutions and reliance on medical recommendations. In the context of dementia risk prediction, no general and clear recommendations for or against risk prediction are actively made by the counseling healthcare professionals, since predictive testing for Alzheimer's dementia has no major impact on disease progression and clinical management as long as disease-modifying therapies are not available yet. Nonetheless, evaluative connotations can still be understood as recommendations if there is a strong basis of trust – even though those recommendations are very passive.

Generalizations and Universalities

The appearance of *the other* as a generalized quantity is also a typical epistemic category we identified. The forms with which epistemic stance is indicated here are often presumptive (*I suspect*, *I could imagine*, *maybe*). Generalizations (*one*, *them*, *others*) are used primarily to represent vague knowledge about dealing with dementia or dementia patients. Vague general knowledge tends to contain (aspects of) prejudices, biased ideas, and stereotypes that can be addressed and reduced during counseling. In this category, our data do not reveal exactly where the vague knowledge comes from or whether it is considered credible. However, vague, generalized knowledge is described in less detail and is thus less concrete and firmly fixed in the knowledge stocks of the participants.

Media and Public Discourse

The knowledge source of the media discourse, which enables access to everyday knowledge, can likely appear combined with expressions of generalizations (see the previous category). However, the specific indicator of this category is the reference to concrete media sources, discursive contents, and medial quotations. Commonly mentioned sources are newspaper articles on risk prediction of Alzheimer's dementia, public interviews with healthcare workers from memory outpatient clinics, or, more generally, the internet (and active internet research). Furthermore, books that deal with dementia in a literary form were mentioned in a few cases.

Discussion

The results show details of the participants' knowledge stocks and sources that occurred in the postcounseling interview and can be classed in five categories. These findings may help us to gain a new perspective on the counseling session and respective professional requirements – particularly because there are certain knowledge asymmetries between patients and physicians in the healthcare context (Linell & Luckmann, 1991). However, knowledge asymmetries exist first and foremost between the knowledge stocks, that is, between expert or specialized knowledge and (among other things, personal) experiential knowledge, biographical knowledge, or even everyday and worldly knowledge (Graf & Spranz-Fogasy, 2018). This article shows that factual medical information is only one kind of important knowledge that directly affects decision-making. In our counseling session, we consider this in a general introduction as the first part of the session (see Materials – Development of Manuals for the Counseling and Disclosure Sessions). This part of the session serves to establish a "common ground" (Stalnaker, 2002) as a knowledge basis (before going on to the risk-prediction details); this is elaborated further according to the following legal, ethical, and language-based interpretation of our findings.

Common Ground, Knowledge, and Information – Legal Implications

The concept of knowledge and the establishment of common ground are closely related to the legal requirement that affected persons must be provided with basic information to freely decide whether to give consent to medical treatment, including diagnostic procedures. This requirement of *informed consent* can be considered a universal principle in legal jurisdictions worldwide (WHO, 2021). It raises the question of what information needs to be present in the affected person and how it is to be conveyed (Schmitz-Luhn & Chandler, 2022). As an expert, the physician must communicate those aspects exclusive to their professional knowledge, which are normally not present with the patient. In particular, this includes not only a risk clarification about the dangers of a medical intervention (e.g., the medical risks associated with CSF sampling or PET; WMA, 2006), but in a much broader sense, all information needed to freely decide whether or not to undergo medical treatment (Schmitz-Luhn et al., 2012). From an ethical point of view, *comprehension* must also be secured appropriately. In light of the above-mentioned five categories, our study underlines the importance of reaching an optimized situation for decision-making and establishing the necessary legal basis for consent, which can be achieved by an interactive general introduction session to establish common ground.

However, the extent of the physician's legal duty to provide information and secure comprehension regarding even remote effects of a diagnostic procedure, for example, psychosocial implications that are relevant to decision-making but not specifically medical, has not yet been conclusively clarified (Schmitz-Luhn & Chandler, 2022). Many such lifestyle-related and social implications of risk knowledge depend on the individual patient's situation and preferences, for which the patient must ideally be prepared. That includes the expected significance of the diagnosis, the understanding of the probabilities achieved with the diagnosis as well as the effects of that knowledge on the personal lifestyle and future life planning. This knowledge naturally reaches beyond medical circumstances, which has so far been the focus of the legal duty to inform. Accordingly, legal frameworks have yet to integrate how healthcare professionals can best convey the increasing plethora of information about far-reaching consequences, which are equally important for decision-making as purely medical information, and what legal consequences derive from any shortcoming. Today, much of the underlying knowledge needed for the complex decision-making process of risk prediction is instead associated with other information sources than the actual counseling process by the healthcare institution. Our study indicates that decisions by patients and their close others rely on various backgrounds, experiences, and knowledge stocks that have not yet been considered by healthcare professionals. Integrating these into the consent process not only can ease access to this much-needed information but also ensures compliance with possible heightened standards of information as a legal duty of healthcare professionals.

Sources of Knowledge and Language-Based Considerations for Clinical Practice

As category (1) on medical-related backgrounds of participants illustrates, medical terminology suggests a presumably high degree of knowledge symmetry. Especially in conversations with geriatric participants, language could be a slippery slope fallacy since respective participants might not be familiar with the current state of (predictive) medicine. Ultimately, medical terminology says little about a patient's understanding of risk predictions or probabilities. If presumed shared procedural knowledge is not explicitly reconciled, misunderstandings can arise and be amplified. Attention should be paid to casual and incidental expression of medical knowledge and terminology. If this emerges during counseling sessions, it is helpful to explicitly inquire and include the participants' backgrounds in a meaningful common ground. Category (2) on previous dementia experiences in the social environment encourages the idea that participants might seek out examples in their social environment with dementia more intensively, since they may anticipate a similar outcome in the future. First-person knowledge in combination with the expression of negative evaluations should be monitored closely during the counseling process: It may indicate distress because of anticipation of a challenging future. Here, the situation of the "pre-caregiver" (Largent & Karlawish, 2019) may be addressed in the counseling session to encourage specific precaregiver support established in analogy in the context of dementia caregiver support. Category (3) concerns knowledge from experiences with other diseases, underlining participants' active use of other exemplary diseases compared to AD. They should be carefully considered during the counseling session, even though they are highly individual and, at first glance, might deviate from a regular AD-related counseling topic. Differences between the respective disease and AD, Alzheimer's dementia, or other forms of dementia should be actively addressed by the physician to avoid transfer errors by the participants. One can possibly detect indicators for category (4) regarding generalizations and universalities when making efforts to create an interactional conversation, that is, when asking more questions and paying attention to generalizations in the language of the patients and close others. Vague and generalized knowledge is described in less detail and is thus less concrete and firmly fixed in the knowledge stocks. This provides a means of joint knowledge generation, establishing a common ground, and possibly reducing prejudices that could lead to (self-)stigmatization during the disease. As category (5) illustrates, media and public discourse are important information sources and epistemic authorities. The nonmedical everyday language of regular media leads to semantic issues between certain societal understandings and the respective medical terminology. Furthermore, it is characteristic of medical journalism to exaggerate the results of basic research (Busch, 2015), which may turn into exaggerated or unrealistic expectations among laypeople. A desirable introduction to the counseling session might lie in an explicit conversation about media and their exaggerated character, which could be embedded during the appraisal of previous knowledge about dementia, AD, and prediction.

Interview data revealed that wording should be reflected and formulated as neutral as possible, while avoiding evaluative connotations, since connotatively emphasized information can be understood as recommendations if there is a strong basis of trust. In the research context, it may be feasible to survey basic information concerning the categories (1), (2), and (3) with an attentive style of conversation and an extended demographic questionnaire; "extended" because personal experiences with people with dementia can include very distant relatives and even neighbors. Such results could be used to improve the counseling process in a truly interactional manner.

Conclusion

The specifically developed information and counseling manuals of the PreDADQoL study include a variety of relevant structural and content-related aspects to be considered when patients are initially confronted with dementia risk prediction. The analysis of the postcounseling interviews demonstrated that decision-making for dementia risk prediction might rely on a number of knowledge sources of high importance for the participants, beside the information conveyed by healthcare professionals. In the end, both approaches must be combined for a successful counseling, preferably by starting the session by establishing a common ground as a knowledge basis, according to the legal considerations and language-based specifications mentioned above. We recommend surveying data on experiences with dementia and AD in the social environment, applying an attentive style of conversation, and paying attention to the outlined linguistic cues during counseling, which may indicate nonmedical epistemic authorities or even (mis-)understandings. Existing knowledge stocks may be a crucial factor for decision-making and therefore highly influence future life and well-being. Finally, ensuring a comprehensive understanding of the situation and the implications of risk prediction for one's own future is decisive to ensuring a truly self-determined decision, which is both an ethical and legal requirement.

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