Full-Length Research Report

Well Advised

The Need for Counseling in Early Stages of Alzheimer's Disease

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Abstract: Societal and scientific interest in the prediction and early diagnosis of Alzheimer's disease is growing. However, decisions regarding early diagnosis must be well-considered. The decision-making process requires specific counseling for concerned individuals, which is currently missing. In our project "Well Advised," we investigate the needs and expectations of people concerned about their memory regarding counseling services in Germany. Using a mixed-methods approach, we analyze the evaluative interviews from telephone counseling (n = 44) and one expert focus group with 4 participants. Our evaluation shows a great need for information; the low-threshold telephone counseling service is appreciated. The topics of interest of those seeking advice concern medical-ethical issues of autonomy, the right (not) to know, and risk-benefit considerations. From these findings, we developed a training module and counseling guideline.

Keywords: cognitive impairment, Alzheimer's disease, counseling, affected individuals, ethics

The Early Diagnosis of Alzheimer's Disease

The number of people with dementia is continuously increasing because of demographic aging (WHO, 2022). The neuropathology of Alzheimer's disease (AD) is the most common cause of dementia and can be identified by biomarker diagnostics that detect amyloid- and tau-pathology long before the first clinical symptoms appear (Scheltens et al., 2021). While biomarker-based tests for the prediction and early diagnosis of Alzheimer's dementia have been relevant in the scientific context for some time, they are now increasingly being requested in the clinical context, for example, when individuals are concerned about first mild symptoms (Caprioglio et al., 2022), such as slight short-term memory disorders.

A diagnosis of mild cognitive impairment (MCI) and prodromal AD/MCI because of AD has been considered clinically useful by European clinicians (Bertens et al., 2019). Currently, biomarker diagnostics are performed through cerebrospinal fluid (CSF) or nuclear medicine examinations. However, blood-based biomarkers are becoming increasingly reliable in detecting Alzheimer's pathology, even at preclinical or prodromal stages (Klafki et al., 2022; Nakamura et al., 2018). It is conceivable that, when blood-based biomarkers become routinely used in clinical practice, the tests will become more readily available and accessible (Largent et al., 2021). To date, there are no approved treatment options for preclinical phases, and no drug for the prodromal phases of AD has achieved full approval in Europe. When diagnosed, individuals are commonly referred to more general preventive measures (Petersen et al., 2018).

Decisions for Early Diagnostics and Need for Counseling

Diagnosing possible AD in preclinical or prodromal phases can fundamentally affect a person's life. This touches upon, for example, areas such as further life planning and care decisions but also relationships with relatives and friends and the person's quality of life (Porsteinsson et al., 2021). The use of biomarker diagnostics in this context also poses ethical challenges. For example, the issues of patient autonomy, the right to know/not know, and the weighing of potential risks and benefits are important in determining whether and to what extent a concerned individual wants to undergo diagnostics (Porteri et al., 2017; Smedinga et al., 2018; van der Schaar et al., 2022). Early screening and diagnosis should be well considered, and there is a need to inform patients and concerned individuals about the potential implications a diagnosis may have to enable self-determined, well-reflected decisions (Grill et al., 2017).

Thus, predicting and diagnosing dementia in the early stages of suspected AD are regarded as challenges requiring targeted counseling services for patients and concerned

individuals. Counseling can help in supporting well-informed decisions about whether a diagnosis is desired regarding an early stage of AD (Alpinar-Sencan & Schicktanz, 2020; Grill et al., 2017; Porteri et al., 2017; Rostamzadeh & Jessen, 2020). By taking a holistic view, including relevant ethical aspects, one can weigh the potential implications not only biomarker testing itself but also an AD diagnosis at an early stage may have on individuals and their families (Vanderschaeghe et al., 2018). Comprehensive counseling and appropriate communication strategies should address potential effects and benefits up front (Frederiksen et al., 2021).

The relevant ethical issues mentioned above show that counseling in the context of prediction and early diagnosis has high standards regarding individual considerations and involves the aspect of complex risk assessment (Rostamzadeh et al., 2021; van Maurik et al., 2019). As early as 2011, researchers initiated a consensus process to establish a common ethical framework for the use of biomarkers in neurodegenerative diseases to provide patients and the healthcare system with the best possible diagnostic measures as early as possible and in a safe and responsible manner (Prvulovic & Hampel, 2011). However, there remains the urgent need for clinical guidelines (Schweda et al., 2018) as well as the need for counseling, including both pre- and postbiomarker testing.

Current Lack of Counseling Services and Concrete Guidelines

There are few concrete guidelines on implementing counseling services with ethical standards for dementia prediction (Rostamzadeh & Jessen, 2020; Schicktanz et al., 2021). Specifically, there is a pressing need for guidelines on the ethical and social aspects of risk communication in dementia prediction (Alpinar-Sencan & Schicktanz 2020; Rostamzadeh & Jessen, 2020). Research has highlighted the current lack of counseling services directed at people in the early stages of memory disorders (Lingler et al., 2018).

Regarding the German context, the "Dementia" guideline (DGPPN et al., 2016) provides little information on counseling in the context of diagnostics for prodromal phases of dementia. Regarding counseling, when a person seeking advice with MCI desires risk assessment for the prediction of Alzheimer's dementia, the guideline recommends that information about possible procedures, including predictive strength and consequences of various outcome possibilities, be provided by an expert before performing testing. It does not provide further details on the content of such counseling. The German Medical Association offers similar information in its 2018 statement on dealing with predictive testing for the risk of Alzheimer's dementia (Bundesärztekammer, 2018).

The Present Study "Well Advised"

The starting point of our research project "Well Advised" was the increasing relevance of biomarkers and the increasing social and scientific interest in early diagnosis of AD and dementia prediction. Regarding the German context, a preceding research project established that dementia prediction and presymptomatic diagnosis are considered special challenges that require targeted counseling services for patients and concerned individuals. The project concretely developed a joint statement that put forward, for a future in which relevant test procedures are offered clinically, the ethical-legal bases as well as that concrete counseling services must be prepared, for which counseling should contain medical as well as psychosocial elements (Ad Hoc Working Group, 2018; Schicktanz et al., 2021).

Our research project "Well Advised" aimed to develop an implementable counseling system to analyze the social, legal, and financial framework conditions, and to develop guidelines for counseling as well as a training module for counseling professionals in specialized memory clinics[1]. It was funded by the German Alzheimer Association[2] for the duration of 2 years (2020–2022).

The project included the conception of a website with relevant content regarding the (early) diagnosis of AD, an analysis of the socio-legal framework of early diagnosis and counseling in this context, and the initiation of a telephone counseling service for people with initial memory disorders and worried relatives. This paper focuses on the content of the evaluative interviews with concerned people who called the telephone counseling service and on an expert focus group on dementia prediction and early diagnosis.

Research Questions

We examined the current needs and expectations of affected people with initial memory disorders or people concerned about their memory toward respective counseling services in Germany. We analyzed evaluative interviews

[1] The term "memory clinic" is used in this text to describe medical facilities, mainly outpatient clinics, that specialize in the early diagnosis, therapy, and counseling of dementia patients. In most cases, specialists from different fields work together in these facilities. In other countries, the terminology may differ including, for example, the term "memory center."

[2] In German: *Deutsche Alzheimer Gesellschaft e. V. Selbsthilfe Demenz*. We received funding for our pilot project as part of the 2019 research grant (Forschungsförderung 2019).

regarding a telephone counseling service we initiated at a university hospital's Department for Psychiatry and Psychotherapy with a geriatric-psychiatric focus, including a memory clinic, for this specific target group. Further, we examined the views of interdisciplinary counseling professionals in the context of memory clinics toward relevant aspects of counseling in the early diagnosis of AD. To this end, we analyzed a focus group conducted with four counseling professionals. In our analysis, we address the following research questions:

- What are the concrete needs and expectations of affected people in low-threshold counseling for early AD detection?
- What fears, concerns, and chances do affected people have regarding early AD detection and counseling?
- What content is relevant in early AD counseling?
- Is the telephone an appropriate medium for communication and counseling in this context?
- How can counseling services be established in the future according to practical-ethical requirements?

Methods

To establish a counseling system, we initiated our telephone service on 25 January 2021. The free consultation service was offered twice a week for 2 hours as part of the project and was targeted at people with initial memory disorders or individuals concerned about their memory as well as worried relatives, caretakers, or friends. We announced the telephone counseling service over various channels, including an article and advertisement in a local newspaper, screen advertising in a public place, and distribution of information postcards to the offices of physicians, psychotherapists, and pharmacies. Our website (https://beratung-demenz.de[3]), with further information about the project as well as more general information about dementia, early cognitive disorders, diagnostic approaches, and relevant links to existing support, also promoted the telephone counseling service. The website was launched on 14 December 2020 and has since been developed and updated continuously.

Participants

Focus Group

Before initiating the telephone counseling service, we conducted a focus group with four counseling professionals. The participating experts stem from psychiatry, psychology, geriatric psychiatry, social work, and family counseling. The counseling professionals are from two different German university hospitals, and three out of four were recruited through the Ethics Working Group of the German Network of Memory Clinics (Deutsches Netzwerk Gedächtnisambulanzen – DNG). All participants had numerous years of work experience treating individuals with cognitive deficits and counseling dementia patients (see Table 1). This focus group explored the current situation of counseling regarding early diagnosis at German memory clinics and collected ideas about how future counseling in this field can be established and expanded. For structuring the focus group, we developed a guideline with 13 questions under four overriding themes: Experience and Background Knowledge, the Practice of Counseling, the Financing and Implementation of Flexible Counseling, and the Development of Training Modules for Counseling (see Electronic Supplementary Material [ESM 1]). The focus group was conducted online over video conferencing software because of the COVID-19 pandemic and lasted 115 minutes and 40 seconds. It was moderated by a researcher with experience conducting focus groups, documented by a research assistant, and recorded and subsequently transcribed verbatim (Liamputtong, 2011); the data was pseudonymized. Focus groups represent an established and recognized social-empirical method for investigating perceptions, attitudes, and patterns of argumentation, which allows participants to openly and directly discuss with each other a variety of opinions, arguments, ambiguities, and contradictions (Green & Thorogood, 2014; Liamputtong, 2011).

Interviews

Between January 2021 and July 2022, we conducted 66 telephone consultations. The counselor was a specialist in psychiatry and psychotherapy with many years of experience in the (early) diagnosis of AD and the treatment of people with dementia. The same physician conducted all consultations. During the consultation, we first informed those seeking advice that no medical diagnosis or treatment is intended or would be made during such a telephone consultation. The physician collected the callers' sociodemographic data, the reason for the call, and briefly documented the procedure discussed. The length of the conversations ranged between 2 and 30 minutes; if a consultation actually took place, it ranged between 20 and 30 minutes. On average, the consultations lasted 18.5 minutes. After the consultation, we asked the callers if they would be willing to participate in an evaluative interview: 44 people (18 directly affected people and 26 relatives, caretakers, or friends, see Table 2) agreed to participate. On average, the evaluative

[3] Last accessed on 31 May 2023.

Table 1. Occupation and work experience of focus group participants

Occupation and specialization	Approximate years of work experience in counseling for AD patients
Psychiatrist and psychotherapist Focus on (early) detection of AD and effects of dementia prediction	6
Psychologist Focus on neuropsychology	12
Social worker Focus on counseling regarding dementia	21
Psychiatrist and psychotherapist Focus on (early) detection of AD and effects of dementia prediction	10

Table 2. Sociodemographic data of participants in evaluative interviews

	Directly affected people (n = 18)	Relatives, caretakers, friends (n = 26)
Gender		
Female	11	23
Male	7	3
Age		
Over 90 years	–	3
80–89 years	5	8
70–79 years	3	8
60–69 years	7	4
50–59 years	3	2
Not specified	–	1
Residential area		
Urban	14	18
Rural	4	8
Educational level		
No school-leaving qualification	–	1
8–9 years of schooling (German *Hauptschulabschluss*)	2	16
10 years of schooling (German *Realschulabschluss*)	3	4
12–13 years of schooling (German *Abitur* equivalent to A levels)	11	4
Not specified	2	1

interviews lasted 16.57 minutes. We obtained written informed consent from all subjects.

The interview was conducted over the telephone and usually took place on the day of consultation or a few days thereafter. The conversation was guided by a semi-standardized questionnaire with 28 question items. The interviewer documented the interview by filling out the questionnaire, while the conversations were also audio-recorded and subsequently transcribed verbatim (Halcomb & Davidson, 2006); the data was pseudonymized. Those who voluntarily participated in the evaluative interview received a financial reimbursement (15 Euros) as a thank-you for their invested time.

We received ethical approval for both the study with experts and the study with affected people (see IRB information below). Both the focus group and the evaluative interviews took place in German. The illustrative quotations in the Results section below were translated into English by a native speaker of both languages.

Mixed-Methods Analysis

We evaluated the open-ended questions of the focus group using qualitative thematic analysis (Mayring, 2000). The focus group transcript of the open-ended questions was peer-coded and revised by two research team members. We conducted the evaluation of the focus group transcripts by structuring the focus group material deductively with previously identified themes according to the focus group guideline. We considered the focus group a preliminary step to gathering initial insights into the challenges of the current counseling process for our target group of the research project.

We evaluated the interview material using a mixed-methods approach, i.e., a combination of several methods from qualitative and quantitative research (Schoonenboom & Johnson, 2017). We based the closed questions on a 5-point response scale (Likert scale), which we analyzed quantitatively by means of frequency analysis (Au, 2017). We evaluated the open-ended questions using qualitative thematic analysis (Mayring, 2000). The interview transcripts of the open-ended questions were peer-coded and revised by three members of the research team. We used an exploratory approach to evaluate these questions. We structured the interview material deductively with previously identified themes according to the semistandardized questionnaire and combined it with an inductive analysis of the empirical material. The inductive approach was guided by category formation, which structured the material with a focus on satisfaction, comprehension, inferred steps of action, attitudes toward diagnostic testing, and attitudes toward counseling. The inductive procedure helped us to infer underlying concepts, themes, or patterns that may impact concrete needs and could not be captured by the deductive approach (Bingham & Witkowsky, 2022; Boyatzis, 1998). The research team discussed the codes and their meanings before coding to guarantee intercoder reliability.

During the evaluative interviews, we concretely inquired about the topics depicted in Table 3. The following results

Table 3. Topic list of evaluative interviews

Topics
Motivation for the call
Perceived quality of counseling during the call
Comprehension of discussed content as well as handling of the content or, if applicable, indications of missing content
Concerns and fears regarding (diagnostic) examinations
If applicable, derived steps of action
Relative distance to a memory clinic/university hospital (as we were interested in the sense of a telemedicine offer, whether our counseling service covered rural areas)
Attitudes toward the form of consultation (telephone vs. video consultation vs. personal contact), i.e., inquiring whether the telephone is perceived as a suitable medium for such a service

refer to the themes of the topic list and the focus group guideline.

Results

Demographics

This study included one focus group with four experts as participants and 44 evaluative interviews. Although we collected empirical data both on directly affected people and their relatives, caretakers, and friends, in the following, we focus on the perceptions of the directly affected people and the perceptions of the counseling professionals. Because the topics of the expert focus group and the evaluative interviews with people who had called the counseling service overlapped, it seemed fitting to present both together in the Results section.

Lack of Standardization of Counseling Processes in the Context of Early AD

According to the experts in the focus group, only informed consent procedures for CSF punctures are currently standardized in memory clinics, and the therapeutic steps, in the case of abnormal findings, are coordinated within the medical center or are specified, for example, in the S3 guidelines on dementia (DGPPN et al., 2016). There is great variability concerning the question of whether biomarkers are determined within a diagnostic process. How quickly CSF examinations are offered in the diagnostic process also varies from center to center.

The type and extent of a consultation during a diagnostic process also varies among physicians, even within a center, meaning there are no clear guidelines on a specific procedure. However, there is consensus not to usually communicate concrete percentages for risk assessment. In the future, it is emphasized that visualization could help communicate risk information. There are also differences in the length of time allotted for initial contacts, informed consent procedures, and counseling sessions at the experts' facilities.

Decisions for Early Diagnostics and Need for Counseling

The focus group discussed the decision for or against diagnostics in the preclinical and prodromal phases of AD. The experts emphasized that needs regarding a differential diagnosis strongly vary in practice. While some individuals do not want diagnostic measures carried out even when concerned, for example, because they are afraid of stigmatization, for some individuals, it is very important to be able to correctly assess their potentially very subtle memory disorders and prepare for further potential deterioration in the future. The experts stressed that a staged diagnosis is often useful in practice: Concerned individuals can be reassured by a normal result of a neuropsychological test, while others may not be satisfied and demand further examinations. This is where individualized and person-centered approaches to counseling procedures become necessary.

However, a visit to a memory clinic may pose a major hurdle or may not be necessary, especially for people with initial cognitive disorders or concerned individuals. An initial contact provided by a telephone counseling service allows for an easy access point, especially for persons who otherwise would not have even contacted the memory clinic for an appointment. To establish the perceived need and satisfaction with such a telephone counseling service, in the following, we refer to perceptions shared during the evaluative interviews by people concerned about memory impairment.

Perceived Need for Low-Threshold Counseling Services

Concerned individuals in the evaluative interviews expressed a high need for information and advice in the case of increasing memory problems and previous experience

Figure 1. Perceived satisfaction with counseling service, *N* = 44.

with dementia within the family. This included a perceived wish to obtain information about early detection and diagnostic measures and potentially make use of them. The callers of the telephone counseling service only knew of few alternative counseling services relevant to their particular situation or that they could have otherwise considered. Our provided service gave the callers a reason to become active and to take responsibility for their future, as the following quotations from the evaluative interviews illustrate:

> "Most [people] would not yet react when they experience what I am experiencing, but I told myself, I'll start early and see what the assessment of professionals is like." (66-year-old man)

> "[. . .] I am just interested to know about my situation or about my future, to put it carefully." (58-year-old woman)

There was a high level of satisfaction with the length of the telephone counseling, which according to the callers' own assessment varied from 6 to 37 minutes. Overall, there was also a high level of gratitude for the low-threshold counseling service. Figure 1 depicts a general assessment of the counseling service (light grey bar) and satisfaction with the way information was conveyed (dark grey bar), including both directly affected people as well as relatives, caretakers, or friends.

Matters of Interest and Concrete Needs of Affected People

Most callers shared a worry about their memory or about potential worsening of symptoms, which was accompanied by the fear of losing autonomy in the future. Many callers expressed the hope of gaining certainty through possible diagnostics. Some also expressed the hope that the consultation would give them access to therapies and prevention options, and provide them with information on how to possibly slow down the process of memory decline, as the following quotations illustrate:

> "I would like to receive information including how one can perhaps do this or that better – or even better information on the status of one's memory, i.e., is that still tolerable or does something more have to be done." (77-year-old man)

> "Well, I am now 86, and I have noticed that I forget a lot and have a lower drive. Above all, I sometimes have problems finding words, so I thought I would like to prevent dementia or rather delay it a bit." (86-year-old woman)

The experts in the focus group shared similar needs they experienced during the counseling procedures with individuals seeking advice, such as how to provide prevention options and recommendations for a healthy lifestyle.

Regarding the general reception of the content provided during the telephone counseling, there were similarities to the experiences shared by the experts in the focus group: Most callers said the telephone consultation had a reassuring effect based on the information received and potentially formulated steps that could be undertaken, even if it confirmed their potential fears, as the following quotations illustrate:

> "Of course, one is scared that a diagnosis of Alzheimer's will be confirmed, as it was with my mother. However, the conversation yesterday stilled my fears in this respect." (65-year-old woman)

> "[. . .] the consultation was rather a confirmation of what I have suspected all along, [. . .] I have many symptoms that have worsened [. . .] and [I] thought:

No, this is not a severe form of dementia, if anything, early dementia [...] Basically, it was about confirming my fears or concerns, and that is helpful for me [...]. I have my own assessment, but the assessment of an outsider perspective who consulted me [...] and whose assessment corresponded to mine gave me a perspective on how I can continue to deal with it." (66-year-old man)

"I just want to know. I'm not worried short-term but rather long-term [...] My mother turned 93 and had severe dementia, and I don't want to get that old because I worry that I will also have severe dementia. It starts with very common forgetfulness of old age and then spreads, at least that's how it was with my mother [...] This means I'm curious about the result; maybe it will give me some reassurance." (75-year-old woman)

In addition to the needs expressed in the evaluative interviews regarding information, the experts in the focus group emphasized that the following needs are routinely addressed by concerned individuals in counseling sessions: information about exchanging with people who are in the same situation as they are, the possibility to have follow-up consultations, and the possibility to address psychosocial stress, including how to address potential issues at the workplace. Further, there was an interest in obtaining information about discussing the role of relatives and possible social and legal implications of early diagnostics. Also, there was a need for very practical issues, such as receiving information about fitness to drive.

Concerns, Opportunities, and Derived Steps of Action

On the one hand, most callers expressed strong concerns about a potential diagnosis or confirmation of their memory disorder. This entailed – or may also have strengthened – their worry about the future and uncertainty about planning for a life with a cognitive disorder. Here, most callers concretely referred to issues of dependency as well as to more abstract fears put forward by an imagined life with dementia, as the following quotations illustrate:

"Because of the experiences of other people I know who had dementia, I am, of course, afraid that I will get dementia at some point, which is also associated with a loss of autonomy." (66-year-old man)

"It depends on whether it's clearly dementia or possibly dementia or whether it's TGA[4]. I'm very worried about that, yes, I'm very worried about both [...] A bit scared of dementia that's looming because of TGA, but also TGA itself makes me feel very worried." (69-year-old woman)

On the other hand, many callers said that the counseling may have provided them with the chance to intervene or even counteract the progression with early detection, including treatment with medication or potentially the exploitation of preventative measures. Some callers expressed seeing opportunities for diagnostic testing, such as an improvement in their quality of life strengthened by clarification of symptoms and confirmation that something is not in order, as the following quotations illustrate:

"[...] I have hope that there may be preventive or diagnostic things that can help me cope better now and especially in the future to prevent dementia, severe dementia – or to at least moderate it a bit – to prevent or mitigate it." (66-year-old man)

"I think they are still in the early stages – these disorders – and I know that this is not yet very advanced, but at a stage where one can already intervene, by inhibiting possibly [...] My mother had severe dementia. There is also a general fear of having to suffer something like that, but, primarily, I have a certain hope that a little something can be done." (76-year-old man)

While some callers, with the help of the counseling service, were able to make decisions for concrete follow-up appointments at a memory clinic or specialist doctor, other callers perceived the counseling service as a confirmation that strengthened their decision not to take any further steps at the moment. Some callers in the evaluative interviews mentioned or noticed difficulties in remembering the concrete content of the counseling and concretely derived steps of action. This is either based on the progression of their cognitive impairment, but in some cases it also depends on the length and breadth of information provided.

Satisfaction and Dissatisfaction with Telephone Counseling

Satisfaction was primarily based on the callers' feeling of empowerment, which allowed them to take control of their current situation as well as giving them a feeling of being informed by receiving information that was previously lacking or had caused uncertainty among people with initial memory disorders or people concerned about their memory. Many callers expressed feeling recognized and

[4] TGA (transient global amnesia) is a temporary, acutely occurring memory impairment.

receiving attention as well as support through the telephone counseling service and also through the evaluative interviews. Some expressed relief because of obtaining concrete ideas of how to proceed. Most callers appreciated the professionalism of the counseling service, meaning that high quality was attributed to the counseling service provided. Great satisfaction was expressed regarding the low-threshold offer, meaning there were no hurdles or specific requirements to access the service.

Dissatisfaction was based mainly on a feeling of time pressure, which was mentioned only in very few cases, while others stressed their appreciation of the specialist spending so much time during the consultation. One caller mentioned that insufficient information had been provided during counseling.

Perspectives on the Appropriate Medium of Counseling Services

Most callers indicated a clear preference for the telephone as a form of communication for such a counseling service. Two out of 18 directly affected indicated that there were topics they did not want to address over the telephone but would have addressed in personal contact or a video call. Of the 18 directly affected people, only 8 mentioned that, instead of telephone counseling, communication over e-mail or a website would be possible, albeit with added specific qualifiers, as the following examples illustrate:

> "That's difficult. Maybe young people can do that quite well, but I, for example, have difficulties with WhatsApp. I'm way too slow with my fingers [. . .] People two generations below me already innately have these skills, I can't imagine that." (76-year-old man)

> "I personally would not find that appealing. I think, at least, I'm still of the old school. I prefer to pick up the phone, and it is not so important to me whether I see my counterpart or not [. . .] [The telephone] is very personal, and when you have to write sentences – I also find that cumbersome [. . .] that takes too long, at least for me, I'm also very slow in that way. The telephone is a great device." (65-year-old woman)

This also corresponds to the expert views in the focus group that counseling on the telephone is useful because it can provide a low-threshold offer for people who live far away from memory clinics or have reservations about going to a memory clinic in person. Video counseling is considered feasible and useful when face-to-face counseling is impossible. The experts do not consider e-mail counseling to be useful. Information compiled on a website can provide a basis and allow the individual seeking advice to follow up on conversation content on their own later.

Discussion

This study examined the perceptions of counseling professionals and of directly affected people regarding the need and expectations for a counseling service focusing on initial memory disorders and early AD. Through a combination of findings from a focus group with experts and evaluative interviews with concerned individuals regarding our provided counseling service, we could integrate complementary views for initiating a counseling setting that currently lacks concrete guidelines and standardization. This provided impulses on how counseling in this context could and should prospectively be structured and delivered in Germany.

Specifications for a Target-Group-Specific Counseling System

Concerns about cognitive performance often precede decisions or thoughts about contacting professional help, including decisions about possible diagnostics. This transitional phase between perceiving initial memory issues, worrying about them, to making decisions about diagnostics calls for an appropriate support system. In our research project "Well Advised" we aimed at providing and piloting a low-threshold counseling service that could be expanded across memory clinics in Germany to address the needs and expectations of this target group currently lacking such a support system.

Regarding worries and concerns, our findings show that the reassurance of those affected is an important factor. For affected individuals, this can include gaining certainty by learning about possible diagnostics, access to therapeutic approaches, prevention options, or also by concretely formulating steps that can be undertaken.

Tasks of Counseling in the Context of Early Diagnosis of AD and Dementia Prediction

Our initiated telephone counseling service enabled us to demonstrate a high need for counseling in the early phases of cognitive impairment. The callers' assessment of the counseling service shows that gaining information predominantly leads to a feeling of empowerment and self-determination, which can be especially important in the context of cognitive impairment (e.g., van Corven et al., 2021). Concretely, our findings highlight that counseling for individuals with initial memory disorders or other concerned individuals should accompany them in making decisions for or against diagnostics or other examinations by providing pertinent information and thereby enabling self-determined decision-making. Counseling should further

address the right to know and the right not to know from different perspectives and address secondary and tertiary prevention options, as other authors have found in the context of considering a diagnosis of AD (e.g., van der Schaar et al., 2022).

Our findings suggest that counseling in the context of prediction and early diagnosis has high standards regarding individual considerations, as other authors such as Rostamzadeh et al. (2021) and van Maurik et al. (2019) have also indicated. If possible and if desired, counseling should involve family members and relatives in appointments at memory clinics and also offer or refer to training for family members.

Wishes such as wanting to be informed, being able to make self-determined decisions, and knowing of one's right to know contribute to formulating ethical framework conditions of how to practically shape counseling for people in the early stages of AD. Further, assessments regarding the need for support, reassurance based on knowledge of the following steps to be taken, and accessibility based on counseling offered without major hurdles or requirements can guide practical approaches for future counseling procedures.

Telephone Counseling as a Low-Threshold Prediagnostic Counseling Solution

The positive assessment of our counseling service underscores the relevance of implementing and expanding such counseling services throughout Germany. The assessment of the interviewed individuals regarding the content and form of the counseling service confirms the assessment of the counseling professionals in the focus group that remote counseling in the form of telephone counseling is an appropriate approach for this target group. Telephone counseling is useful and feasible for providing low-threshold access to counseling services. The preference for remote counseling supports the practicability of providing such services at other memory clinics. People who do not live in the proximity of a memory clinic or people who have reservations about coming to a memory clinic in person can obtain information and advice in this uncomplicated way. But counselors and those seeking advice should be aware of the limitations, as counseling via telephone cannot capture the situation of the individual seeking advice as comprehensively as face-to-face counseling can, and it is difficult to include relatives and present important content and results as a visualized reminder in one-to-one telephone contact. Here, counseling via an internet video platform could be a useful addition to a follow-up appointment. Especially regarding the issue of patient concerns, psychosocial support on dealing with issues such as feared dependency should be incorporated in such counseling services.

To provide such a service more comprehensively throughout Germany in the future, we need information on how individuals became aware of the existence of the counseling service for people with initial cognitive impairment and early AD. Although not systematically surveyed, 36 of 44 respondents provided information on this during or at the end of the interview: Most of the callers became aware of our counseling service through our advertisement in a local newspaper (n = 21), six through a search on the internet/website of the memory clinic, four through a recommendation, four through a medical institution/place where we had laid out information, and one came across our service by chance.

Need for Support to Retain Information

To implement counseling services for concerned individuals, we need to determine any emerging difficulties in remembering the concrete content of counseling and highlight concretely derived steps of action that innovative approaches offer. This could entail exploring how to sustainably stimulate cognitive memory and provide support through targeted visualization and specific communication approaches if visualization is not possible in the counseling setting. For example, reference to websites with valid information, such as we created in our research project (https://beratung-demenz.de), can provide basic details and visualization, enabling individuals seeking advice to follow up on conversation content at their leisure. Also, further ideas such as sending information after a telephone counseling session and offering a follow-up call could solve the issue of retaining received information.

Differences Between Affected Individuals and Worried Relatives, Caretakers, and Friends

Although we did not systematically record the degree of cognitive impairment, the counselor had the lasting impression that relatives calling the counseling service were more likely to call because of loved ones who were significantly more advanced in their cognitive impairment or who had already developed dementia, while directly affected or concerned individuals calling on their own behalf were much less impaired. One should consider such needs assessments or points of departure of the target groups when establishing and expanding counseling services in the future. Initially, the main aim of our research project and the initiated telephone counseling service was to address directly affected people. The unexpected number of relatives calling this provided service shows that this target group also requires its

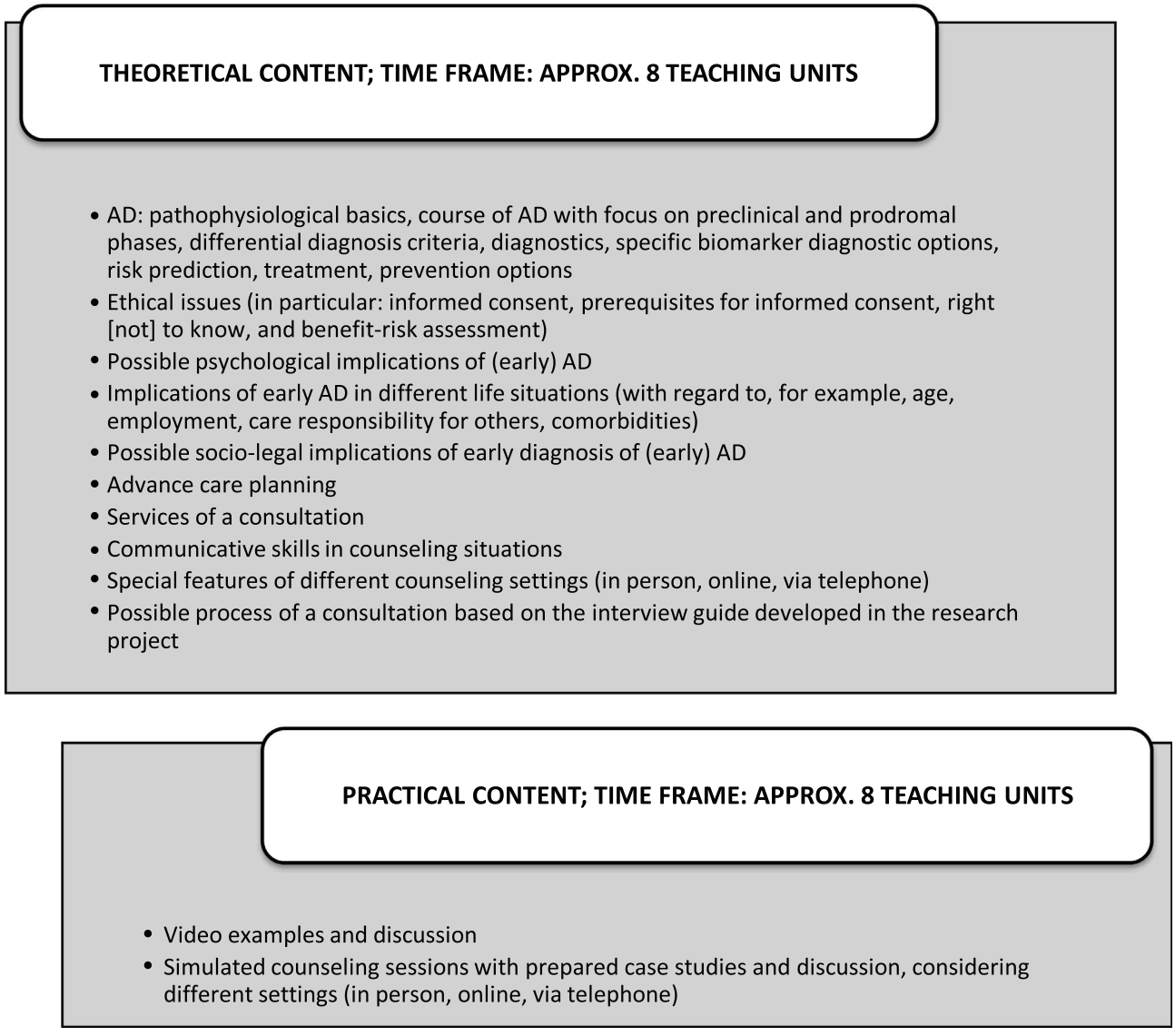

Figure 2. The Well-Advised Training Module for counseling professionals in the context of early diagnosis of AD and dementia prediction.

own counseling service. We plan to analyze and present the perspectives of this specific target group in a more differentiated manner in an additional research paper.

Limitations

This qualitative study refers to a small sample size, especially regarding the number of directly affected individuals included in the evaluative interviews. Also, we conducted only one focus group. Further research is needed to more systematically assess the needs and expectations regarding counseling in a larger sample size. We aimed to provide advice related to the early detection of AD. A limitation of our study is that we could not systematically record the degree of cognitive impairment – if any – and therefore could not track whether we actually reached our target group.

Material for Clinical Practice – the "Well-Advised Training Module"

Counseling procedures for the context of early diagnosis of AD and dementia prediction have not been standardized in medical practice. Based on the empirical results of our project, we developed a concept for a training module containing specific content-related, communicative, and context-related skills for counseling patients on early diagnosis of AD, and we developed a guideline for counseling in the context of early detection of AD. The training module is aimed at professionals in memory clinics and other medical

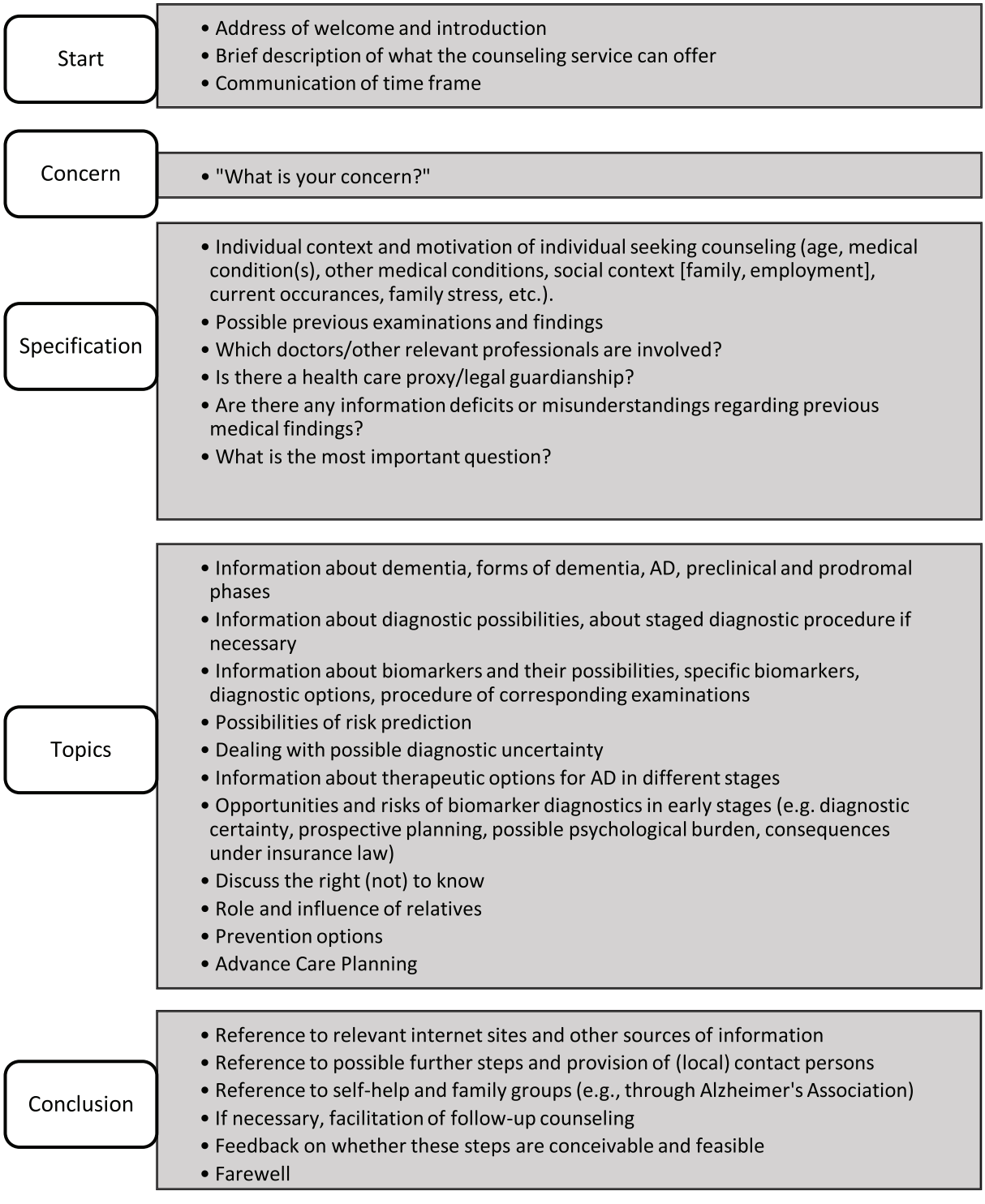

Figure 3. Interview guidelines for counseling on early diagnosis of AD.

institutions specializing in early diagnosis of AD. It was designed as a workshop over 2 days, including approx. 16 teaching units with two facilitators and 12–18 participants.

The material should be regarded as drafts based on the empirical results of our project and input from experts with experience in (early) detection of AD and the effects of dementia prediction. To ensure high-quality consultations, counseling specialists must respond to scientific innovations in diagnosing and treating AD (Liss et al., 2021). Moreover, the future availability of blood-based biomarkers encourages the use of direct-to-consumer AD blood tests (Largent et al., 2021). Healthcare professionals must

anticipate this change in clinical practice by including respective counseling in such cases (Erickson et al., 2022). These considerations should be addressed in the further development of training modules and guidelines for counseling. Figure 2 depicts an overview of the course content.

We also developed a counseling guideline in the context of early AD detection. Figure 3 depicts an overview of the guideline content.

Conclusions

The present results enhance the current landscape of provided counseling services in Germany and highlight the lack of target group-specific counseling for phases of initial cognitive impairment and early AD. With new upcoming treatment options for the early stages of AD, the demand for counseling services regarding early diagnosis will potentially increase. The empirical findings provide concrete reference points regarding the needs and expectations of affected individuals for counseling. Unfortunately, we did not systematically collect data on how callers found out about our counseling service. However, many callers nonetheless provided us with this information during or at the end of the interview. We mainly advertised through local newspapers, which seems to have been highly effective in reaching individuals with worries and initial memory disorders. Also, information provided at medical practices in the form of flyers and posters seems to have been effective.

Further, our findings point to how the respective counseling services can be implemented and expanded more comprehensively in the future, namely, by directing patients to concrete existing resources, such as those in specialized clinics or caregiver support groups, and expanding their services by implementing a low-threshold phone counseling service. Content provided by the counseling service should reflect the worries and needs described by the target group. Relevant informational resources, as provided on our project website, can serve as a further access point for this target group.

Based on our empirical findings, we developed the "Well-Advised Training Module" and a guideline for counseling on the (early) diagnosis of AD. These materials can guide the future development of concrete counseling services. Regarding potential future developments of clinical availability of blood-based biomarkers, it will be useful to consider framework conditions for biomarker application in early diagnosis of AD. Target group-oriented, quality-assured, low-threshold counseling services that include ethical aspects represent an important element in this process.

Electronic Supplementary Material

The electronic supplementary material is available with the online version of the article at https://doi.org/10.1024/1662-9647/a000318

ESM 1. Focus group guideline in the research project "Well Advised."

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