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Provision of healthcare for culturally diverse populations: Insights from a qualitative study on dementia care with the members of the Turkish immigrant community in Germany

Abstract

Culture plays a crucial role in shaping a person's perceptions towards health-related phenomena. This gains importance in dementia care because the affected individuals become dependent on their caretakers as their faculties associated with self-determination and personhood is jeopardized. There is a danger that not all persons either affected with dementia or their caregivers from minority cultural groups will seek out or find access to care on par with those from the majority culture. The population of first-generation migrants in Germany are reaching an age where they are at risk of developing dementia. This chapter presents a pilot study focusing on the experiences on dementia care and expectations for counseling of caregivers and relatives of people with dementia of Turkish descent living in Germany. The study is based on qualitative research methodology. Seven face-to-face and telephone, semi-structured interviews were conducted. The preliminary analysis revealed four emerging themes: (1) the need for support, counseling and information about the disease and its course, (2) perception of discriminative behavior and neglect from healthcare staff, (3) the impact of migrant life on the initiation of the disease, and (4) the role of family in care. The results highlight the main needs of migrant groups and are further discussed in the context of culturally sensitive care.

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1. Introduction

1.1. Migration and dementia

Alzheimer's disease (AD), the most common cause of dementia, is a progressive and irreversible neurodegenerative brain disease that affects cognitive functions, including memory, orientation, planning, language comprehension and judgment.[1] AD/Dementia has recently been conceptualized as a continuum with a long asymptomatic, preclinical phase with the existence of slowly progressing pathological changes.[2] There is no cure for most forms of dementia and those affected become increasingly dependent on caretakers for undertaking activities of daily life. With the progressive worsening of cognitive functions, the disease affects the whole person, jeopardizing the faculties mostly associated with individuality, self-determination, and personhood.

The gradual, progressive, and irreversible nature of the disease raises pressing legal, economic, social, and ethical issues in treatment, support, and care of people with dementia. Family members and caregivers play a crucial role in identifying affected persons' needs or implementing their interests concerning counseling, communication, information, life planning, and care. Ethical issues in dementia and

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[1] Harald Hampel, David Prvulovic, Stefan Teipel, Frank Jessen, Christian Luckhaus, Lutz Frölich, Matthias W. Riepe, Richard Dodel, Thomas Leyhe, Lars Bertram, Wolfgang Hoffmann, Frank Faltraco, for the German Task Force on Alzheimer's Disease: The Future of Alzheimer's Disease: The Next Ten Years. In: Progress in Neurobiology 95 (2011), pp. 718–728; World Health Organization: Dementia (20.9.2022). https://www.who.int/news-room/fact-sheets/detail/dementia (accessed on 7.2.2023).

[2] Reisa A. Sperling, Paul S. Aisen, Laurel A. Beckett, David A. Bennett, Suzanne Craft, Anne M. Fagan, Takeshi Iwatsubo, Clifford R. Jack, Jeffrey Kaye, Thomas J. Montine, Denise C. Park, Eric M. Reiman, Christopher C. Rowe, Eric Siemers, Yaakov Stern, Kristine Yaffe, Maria C. Carrillo, Bill Thies, Marcelle Morrison-Bogorad, Molly V. Wagster, Creighton H. Phelps: Toward defining the preclinical stages of Alzheimer's disease: Recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. In: Alzheimer's & Dementia 7 (2011), pp. 280–292; Silke Schicktanz, Mark Schweda, Jesse F. Ballenger, Patrick J. Fox, Jodi Halpern, Joel H. Kramer, Guy Micco, Stephen G. Post, Charis Thompson, Robert T. Knight, William J. Jagust: Before it is too late: Professional responsibilities in late-onset Alzheimer's research and pre-symptomatic prediction. In: Frontiers in Human Neuroscience 8 (2014), https://doi.org/10.3389/fnhum.2014.00921; Annette Leibing: Situated Prevention: Framing the »New Dementia«. In: Journal of Law, Medicine and Ethics 46 (2018), pp. 704–716.

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dementia care are manifold and play out along a broad spectrum including not only the latest stage of the disease, i.e., when the capacity of self-determination is effectively lost, but also the earliest, pre-symptomatic stage, when the distinction between diagnosis and risk information is blurry.[3] Issues involve affected individuals, their families, caregivers, medical professionals, and society at large and include substitute decision-making, receiving and disclosing diagnostic or risk information, future life-planning, and information sharing. Dementia-related ethics is rife with culturally loaded ideas about family responsibilities, the good life, a good death and definitions of personhood. As the affected persons become increasingly dependent on their caretakers, dementia-related healthcare becomes an important context for reflecting healthcare provision for culturally diverse populations.

According to the German Alzheimer's Association around 1.6 million people with dementia live in Germany today, of which approximately 100.000 people have migration background.[4] Germany has the highest immigration rate in Europe.[5] About 20.8 million people living in Germany have migration background. Roughly 2.8 million individuals have Turkish migrant background and they constitute the

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[3] Sperling, Aisen, Beckett, Bennett, Craft, Fagan, Iwatsubo, Jack, Kaye, Montine, Park, Reiman, Rowe, Siemers, Stern, Yaffe, Carrillo, Thies, Morrison-Bogorad, Wagster, Phelps: Toward Defining (Note 2); Schicktanz, Schweda, Ballenger, Fox, Halpern, Kramer, Micco, Post, Thompson, Knight, Jagust: Before (Note 2); Bruno Dubois, Harald Hampel, Howard H. Feldman, Philip Scheltens, Paul Aisen, Sandrine Andrieu, Hovagim Bakardjian, Habib Benali, Lars Bertram, Kaj Blennow, Karl Broich, Enrica Cavedo, Sabastian Crutch, Jean-François Dartigues, Charles Duycaerts, Stéphane Epelbaum, Giovanni B. Frisoni, Serge Gauthier, Remy Genthon, Alida A. Gouw, Marie-Odile Habert, David M. Holtzman, Miia Kivipelto, Simone Lista, José-Luis Molinuevo, Sid E. O'Bryant, Gil D. Rabinovici, Christopher Rowe, Stephen Salloway, Lon S. Schneider, Reisa Sperling, Marc Teichmann, Maria C. Carrillo, Jeffrey Cummings, Cliff R. Jack, Jr: Preclinical Alzheimer's Disease: Definition, Natural History, and Diagnostic Criteria. In: Alzheimer's & Dementia 12 (2016), pp. 292–323.

[4] German Alzheimer's Association: Demenz und Migration: Neues Informationsangebot der Deutschen Alzheimer Gesellschaft in arabischer Sprache [Dementia and Migration: New information service from the German Alzheimer Society in Arabic] (15.3.2021). https://www.deutsche-alzheimer.de/artikel/demenz-und-migration-neues-informationsangebot-der-deutschen-alzheimer-gesellschaft-in-arabischer-sprache (accessed on 7.2.2023).

[5] International Organization for Migration: World Immigration Report 2020. https://publications.iom.int/system/files/pdf/wmr_2020.pdf (accessed on 7.2.2023).

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largest migrant group in Germany.[6] These individuals include those, whose parents were migrated from Turkey and who were either born in Germany or came to Germany as a kid – second-generation – or who were born in Turkey and has migrated themselves – first-generation.

The first-generation Turkish migrants came to Germany due to labor migration in the 1960s. Germany recruited workers from Turkey in 1961 as »guest workers«, as well as from other countries, such as Italy, Spain, Greece, Morocco, Portugal, Tunisia and the former Yugoslavia in the 1960, to boom postwar economy after World War II.[7] Due to the global oil crisis, German Government stopped the recruitment in 1973, however many decided to stay, brought their families and became permanent residents, which led to an increase of Turkish – and migrant – population in Germany.[8] The first-generation of Turkish migrants are now reaching an age at which age-related diseases, such as dementia, are more likely to occur. Hence, first-generation Turkish migrants now represent a large potential group for dementia-related healthcare services.[9]

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[6] Ümran Sema Seven, Inka Valeska Braun, Elke Kalbe, Josef Kessler: Demenzdiagnostik bei Menschen türkischer Herkunft – TRAKULA [Dementia diagnostics in people of Turkish origin – TRAKULA]. In: Olivia Dibelius, Erika Feldhaus-Plumin, Gudrun Piechotta-Henze (Eds.): Lebenswelten von Menschen mit Migrationserfahrung und Demenz [Living environments of people with migration experience and dementia]. Bern 2015, pp. 51–87; Federal Ministry of the Interior, Building and Community and Federal Office for Migration and Refugees: 2018 Migration Report: Key Results. Nürnberg: Bundesamt für Migration und Flüchtlinge [Federal Office for Migration and Refugees] (2019). https://www.bamf.de/SharedDocs/Anlagen/EN/Forschung/Migrationsberichte/migrationsbericht-2018-zentrale-ergebnisse.pdf?__blob=publicationFile&v=7 (accessed on 7.2.2023).

[7] Ann-Kristin Tlusty, Hasan Gökkaya, Julia Meyer: Guest Workers in Germany: »Germany Neglected My Parents«. In: Zeit Online (21.11.2019). https://www.zeit.de/gesellschaft/2019-11/gastarbeit-deutschland-nachkommen-vertragsarbeiter-ddr-anerkennung-english?utm_referrer=https%3A%2F%2Fwww.google.com%2F (accessed on 7.2.2023); Federal Ministry of the Interior, Building and Community: Labour Migration (2020). https://www.bmi.bund.de/EN/topics/migration/immigration/labour-migration/labour-migration-node.html (accessed on 7.2.2023).

[8] N.N.: Germany Looks Back at 50 Years of Turkish Immigration. In: The Local (26.10.2011). https://www.thelocal.de/20111026/38441 (accessed on 7.2.2023).

[9] Jessica Monsees, Wolfgang Hoffmann, Johen René Thyrian: Prävalenz von Demenz bei Menschen mit Migrationshintergrund in Deutschland [Prevalence of dementia among people with a migration background in Germany]. In: Zeitschrift für Gerontologie und Geriatrie 52 (2019), pp. 654–660.

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1.2. Provision of and access to dementia care for and by culturally diverse populations

Individual and familial immigration is a common cause of cultural diversity in healthcare systems. If the quality of provided dementia care depends on cultural affinity with the majority culture, this may create inequities in access to dementia care. Some studies indicate that there are gaps for minority groups in terms of dementia care access, in knowledge about the disease, and in how to address ethical, social, and practical issues related to dementia care and life planning.[10] A recent qualitative analysis of national dementia plans in Europe has shown that the topic of migration has only a minor role and that there is a lack of services and guidelines addressing the needs of people with migration background.[11] Some experts identified specific issues involving ethnic minority or immigrant groups in Europe. These revolved around communication problems with specific implications for assessments of cognitive function and for diagnosing people with dementia.[12] Recent studies conducted in Europe show that the preva-

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[10] Mary R. Janevic, Cathleen M. Connell: Racial, Ethnic, and Cultural Differences in the Dementia Caregiving Experience: Recent Findings. In: The Gerontologist 41 (2001), pp. 334–347; Dolores Gallagher-Thompson, Nancy Solano, David Coon, Patricia Arean: Recruitment and Retention of Latino Dementia Family Caregivers in Intervention Research: Issues to Face, Lessons to Learn. In: The Gerontologist 43 (2003), pp. 45–51; Jung Kwak, William Haley: Current Research Findings on End-of-Life Decision Making Among Racially or Ethnically Diverse Groups. In: The Gerontologist 45 (2005), pp. 634–641; Hürrem Tezcan-Güntekin, Oliver Razum: Pflegende Angehörige türkeistämmiger Menschen mit Demenz – Paradigmenwechsel von Ohnmacht zu Selbstmanagement [Caring relatives of Turkish people with dementia – paradigm shift from powerlessness to self-management]. In: Pflege & Gesellschaft: Zeitschrift für Pflegewissenschaft 23 (2018), pp. 69–83.

[11] Tim Schmachtenberg, Jessica Monsees, Wolfgang Hoffmann, Neeltje van den Berg, Ulrike Stentzel, Jochen R. Thyrian: Comparing National Dementia Plans and Strategies in Europe – Is there a Focus of Care for People with Dementia from a Migration Background? In: BMC Public Health 20 (2020), https://doi.org/10.1186/s12889-020-08938-5.

[12] T. Rune Nielsen, Asmus Vogel, Matthias W. Riepe, Alexandre de Mendonça, Guido Rodriguez, Flavio Nobili, Anders Gade, Gunhild Waldemar: Assessment of Dementia in Ethic Minority Patients in Europe: A European Alzheimer's Disease Consortium Survey. In: International Psychogeriatric 23 (2011), pp. 86–95; Mette Sagbakken, Ragnhild Storstein Spilker, T. Rune Nielsen: Dementia and Immigrant Groups: A Qualitative Study of Challenges Related to Identifying, Assessing, and Diagnosing Dementia. In: BMC Health Services Research 18 (2018), https://doi.org/10.1186/s12913-018-3720-7.

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lence of MCI (Mild Cognitive Impairment) and dementia is higher among the immigrant groups compared to the native population.[13] Moreover, these groups are less commonly diagnosed and are less likely to receive a drug therapy for slowing symptom progression or to be placed in a nursing home.[14] As some studies indicate, the insufficiency of the services is due to the language, cultural, religious and ethnic differences between the dominant culture and the persons with migration background.[15]

Access to adequate healthcare services and responsiveness of the provided service to the needs of the person seeking help often generate a challenging situation in culturally diverse societies. Many factors affect inadequate access to care, such as socio-economic background, e.g., type of education, occupation, immigration status, e.g., citizenship, country of origin, permanent residence permit holders, etc., language competence or proficiency, e.g., receiving important information, communication with the healthcare staff, as well as stigma and marginalization, e.g., differences in appearance, different cultural background, accent, etc. Healthcare services that are insensitive to these issues run the risk of reinforcing the perceptions of discriminative behaviors.[16] If these perceptions become prevalent, they can lead to a decrease in trust in medical services, and help-seeking behavior. Adequate access to healthcare is crucial, because poor health reduces people's range of opportunities.[17] Healthcare includes

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13 Kurt Segers, Florence Benoit, Cathérine Colson, Valérie Kovac, Delphine Nury, Valérie Vanderaspoilden: Pioneers in Migration, Pioneering in Dementia: First Generation Immigrants in a European Metropolitan Memory Clinic. In: Acta Neurologica Belgica, 113 (2013), pp. 435–440; Juliette L. Parlevliet, Özgul Uysal-Bozkir, Miriam Goudsmit, Jos P. van Campen, Rob M. Kok, Gerben ter Riet, Bernd Schmand, Sophia E. de Rooij: Prevalence of Mild Cognitive Impairment and Dementia in Older Non-Western Immigrants in the Netherlands: A Cross-Sectional Study. In: International Journal of Geriatric Psychiatry 31 (2016), pp. 1040–1049.

14 Lea Stevnsborg, Christina Jensen-Dahm, Thomas R. Nielsen, Christiane Gasse, Gunhild Waldemar: Inequalities in Access to Treatment and Care for Patients with Dementia and Immigrant Background: A Danish Nationwide Study. In: Journal of Alzheimer's Disease 54 (2016), pp. 505–514.

15 Seven, Braun, Kalbe, Kessler: Demenzdiagnostik (Note 6).

16 Roberto De Masi: Multiculturalism, Medicine and Health Part 1: Multicultural Health Care. In: Canadian Family Physician 34 (1988), pp. 2173–2177; Kathryn Pitkin Derose, José J. Escarce, Nicole Lurie: Immigrants and Health Care: Sources of Vulnerability. In: Health Affairs 26 (2007), pp. 1258–1268.

17 Norman Daniels: Health-Care Needs and Distributive Justice. In: Philosophy and Public Affairs 10 (1981), pp. 146–179.

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preventive, curative, and rehabilitative services and thus preserves our range of opportunities, which is needed for us to construct our conceptions of a good life.

1.3. Culture's role in healthcare ethics

Culture is a complex term. It is often described as standards if patterns of behavior and a system of beliefs that one acquires as a member of a particular group.[18] Moreover, the group's shared distinctive (cultural and religious) beliefs and values govern the conduct of their life and are exhibited in their rituals, social norms and behaviors.[19] Culture plays a significant role in shaping a person's attitudes towards risky and healthy behaviors and in influencing decision-making with respect to care, treatment and prevention. Therefore, culture has an impact on a person's perceptions of illness, health, responsibility and obligations towards one's family, etc.[20]

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18 De Masi: Multiculturalism, Medicine (Note 16); Toni Tripp-Reimer, Eunice Choi, Lisa Skemp Kelly, Janet C. Enslein: Cultural Barriers to Care: Inverting the Problem. In: Diabetes Spectrum 14 (2001), pp. 13–22; Matthew W. Kreuter, Stephanie M. McClure: The Role of Culture in Health Communication. In: Annual Review of Public Health 25 (2004), pp. 439–455.

19 David Miller: The Life and Death of Multiculturalism. In: Elizabeth Goodyear-Grant, Richard Johnston, Will Kymlicka, John Myles (Eds.): Federalism and the Welfare State in a Multicultural World. Kingston 2018, pp. 319–339.

20 Lucy M. Candib: Truth telling and advance planning at the end of life: Problems with autonomy in a multicultural world. In: Families, Systems, and Health 20 (2002), pp. 213–228; Evelyn Donate-Bartfield, Leonard Lausten: Why Practice Culturally Sensitive Care? Integrating Ethics and Behavioral Science. In: Journal of Dental Education 66 (2002), pp. 1006–1011; Leigh Turner: Bioethics in a Multicultural World: Medicine and Morality in Pluralistic Settings. In: Health Care Analysis 11 (2003), pp. 99–117; Michael Paasche-Orlow: The Ethics of Cultural Competence. In: Academic Medicine. 79 (2004), pp. 347–350; Cornela Betsch, Robert Böhm, Collins O. Airhihenbuwa, Robb Butler, Gretchen B. Chapman, Niels Haase, Benedikt Herrmann, Tasuku Igarashi, Shinobu Kitayama, Lars Korn, Ülla Karin Nurm, Bernd Rohrmann, Alexander J. Rothman, Sharon Shavitt, John A. Updegraff, Ayse K. Uskul: Improving Medical Decision Making and Health Promotion through Culture-Sensitive Health Communication: An Agenda for Science and Practice. In: Medical Decision Making. 36 (2016), pp. 811–833; Brenda Louw: Cultural Competence and Ethical Decision Making for Health Care Professionals. In: Humanities and Social Sciences 4 (2016), pp. 41–52.

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Following Kymlicka, culture provides a meaningful context for the range of options people have for implementing their values and preferences, which enable the execution of one's autonomy.[21] This allows one to form and revise one's own conception of a good or fulfilled life.[22] Culture »provides its members with meaningful ways of life across the full range of human activities, including social, educational, religious, recreational, and economic life, encompassing both public and private spheres.«[23]

Cultural membership shapes one's self-identity and provides a sense of belonging (pp. 89–90).[24] According to Taylor, what is central to the person's wellbeing, their notions of a good life (e.g. what is worthwhile, admirable or of value) and the cultural background of the society in which the person grew up informs their self-identity.[25] Cultures provide the conceptual framework that determines which values and life plans or aims inform how a person's conception of good life and self-identity is generated. Thus, insofar as conceptions of a good life inform an individual's health choices, culture and cultural diversity is a remarkably important category for analyzing dementia-related healthcare choices.

The qualitative study presented in this chapter aims to explore the experiences and expectations concerning dementia care and counseling of caregivers and relatives of people with dementia of Turkish descent living in Germany. This is a pressing issue because among the first-generation of migrants in Germany the occurrence of dementia is more prevalent, and therefore, they will likely become a potential group for seeking dementia-related healthcare.

2. Methods

This pilot study is conducted as a part of an international research project funded by the German-Israeli Foundation for Scientific

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21 Will Kymlicka: Multicultural Citizenship: A Liberal Theory of Minority Rights. Oxford 2013.

22 John Rawls: Justice as Fairness: A Restatement. Edited by Erin Kelly. Cambridge 2001.

23 Kymlicka: Multicultural Citizenship (Note 21), here p. 76.

24 Kymlicka: Multicultural Citizenship (Note 21), here pp. 89–90.

25 Charles Taylor: Sources of the Self. The Making of the Modern Identity. Cambridge 1989.

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Research and Development (G.I.F. grant no: G-1413–119.4/2017). The larger cross-sectional, qualitative study aimed at exploring how various stakeholders' moral and psychosocial attitudes regarding early diagnosis of dementia are embedded in social and cultural contexts in Germany and Israel. The study presented here is based on a qualitative research methodology. Seven face-to-face and telephone, semi-structured interviews with family caregivers and relatives of people with dementia of Turkish descent living in Germany were conducted from March 2020 to November 2021. The study's protocols were approved by the Ethics Committee in the University Medical Center Göttingen (Ref. Nr. 17/12/16). For the interviews, different from guest workers defined in the introduction, first-generation refers to those who were born in Turkey and came to Germany in the recent years to work or to study.

2.1. Recruitment process

The participants were recruited by using flyers and posters in Turkish, which were widely disseminated at collaborative memory clinics, one self-help organization and at one university as well as at supermarkets, mosques, public offices and societies. Also, an online advertisement was placed on one university's announcements' site. Additionally, in order to reach more people, mediators, who are working for special organizations, societies and help-centers for migrants, were contacted. The recruitment of participants was challenging and complicated as a whole. Although this was partly due to COVID-19 pandemic outbreak, people's hesitation to participate in a study played a huge role. Their hesitation was either due to being a foreigner in a country or due to their worry concerning sufficient anonymization, which likely led them to refrain from participating.

2.2. Study design

The interviews were conducted according to semi-structured interview guidelines. The guideline was developed to examine topics related to (a) participants' experiences, knowledge, and assessments of prediction and early diagnosis of dementia; (b) assessment of situations in which predictive results and diagnoses were disclosed; (c)

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the practical and social impact of these information on participants' lives; and (d) their expectations and experiences in terms of support and information.

2.3. Data collection and analysis

All interviewees were given a description of the study and afterwards they provided written informed consent. Every interviewee was free to withdraw from the study at any point in time. Each received 25€ for their contributions to the study. The interviewees were informed clearly about the procedure, recording, transcription, anonymization, and publications of the results. The interviews were conducted either in Turkish or in German and lasted about 30 to 45 minutes. All interviews were recorded and then transcribed verbatim. Transcriptions were fully anonymized to protect the interviewees' anonymity. Interview transcripts were analyzed following thematic content analysis.[26] The analysis software Atlas.ti™ supported coding and analysis.

3. Findings

In the following, the main findings of the study are presented. There was a homogeneity among the interviewees' expectations and experiences specifically for the need for more information and support at the early stages of the disease and the disease's course. Similar themes were found concerning lack of knowledge of the disease, the impact of living and working conditions on the initiation of the disease, and the importance of family care. A strongly emphasized sense of discrimination was found. The quotations given below are selected to illustrate the range of emerging themes.

[26] Virginia Braun, Victoria Clarke: Using Thematic Analysis in Psychology. In: Qualitative Research in Psychology 3 (2006), pp. 77–101.

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3.1. There is a need for support, guidance and information

Most participants mentioned that neither sufficient help nor information was provided. They therefore gathered all information themselves, for instance via the internet:

> WR2: »No, unfortunately not, no, not at all. I did in the first place, I search [for information on the disease as well as care and support services] on the internet all the time.« (Age: 36–50, caring daughter, second-generation)

> MR5: »(…) We had so many difficulties. We educated ourselves and gathered information. We did the research. We didn't get help and we had many difficulties. We obtained a lot of information from these difficulties. (…) When the first symptoms of dementia, such as forgetfulness, wetting himself or having difficulties with the bowel movement, were apparent, we went to the neurology outpatient clinic. They prescribed him with medicines. He [my father] was old, therefore they did not lend assistance. We obtained information on our own. We searched via internet.« (Age: 36–50, caring son, second-generation)

Some participants stated there was not enough aid, support, or guidance from the healthcare staff, while the doctors, for instance, neither had sufficient time nor informed concretely on what to do or how to proceed. Two participants expressed intensely that they were left alone:

> MR5: »As a simple example, I called the health insurance in order to ask about ›what to do‹, ›where to go‹, ›where to get support‹ or ›how to help‹. [I was being told that] ›we do not know that. Ask your doctor.‹ The doctors are like factories [machines], only the important things are taken care of. There cannot be a doctor with sufficient time. There cannot be.« (Age: 36–50, caring son, second-generation)

> WR2: »I feel so sad, because there should be more things posted for the relatives and for the sick person. Not any hints were given. Not at all. Also, for what we should pay attention to [in the course of the disease]. (…) Relatives [family members] need information. This could be very helpful. (…) They know the disease; [but], they do not know what to do with it. (…) There had to be more consultations [on what to expect in the course of the disease].« (Age: 36–50, caring daughter, second-generation)

It was also mentioned that sharing the experiences and the obtained information could be very helpful for others, who were in the same

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situation. This would be helpful to get sufficient information, which should instead be provided by the healthcare personnel, and to get emotional support from others. This idea was brought forward by an interviewee, who gave support to his neighbor, whose husband was diagnosed with early dementia:

> MR5: »I think her [his neighbor, whose husband was diagnosed with early dementia] German is not very good. They are now facing the same difficulty. They are not informed, they [doctors] do not tell much. They [affected neighbors] follow our suggestions: we did this, you should do this, too.« (Age: 36–50, caring son, second-generation)

As one interviewee stated having support through self-help groups, of which the members face the same difficulties and experiencing similar situations, would be quite helpful:

> WR7: »For every disease, it could be very helpful to know that the person is not alone having to face the disease. For instance, my mother-in-law does not partake in any activity and she feels very sad and even a bit embarrassed to be the only one who is affected among her friends. Therefore, joining to such groups [self-help groups], obtaining information from each other and support each other emotionally could be beneficial.« (Age: 36–50, wife of caring son, no information)

Predictive risk information was favored to prepare the family, as the disease burdens the family members, specifically those who are taking care of the affected person. Therefore, right at the beginning a need for support and counseling became apparent:

> MR5: »It [the disease] burdens the family most. We could be informed in advance. There are seminars, educations. We could have participated in those. We did not know that in advance. (…) The family members of the affected could be educated [informed] more in order to better communicate with the affected person and to get psychologically prepared [for the progress of the disease]. That would be very helpful. « (Age: 36–50, caring son, second-generation)
>
> WR7: »(…) [I]n such a disease not the affected person herself, but more importantly the persons taking care of the affected person should be informed more. The affected person normally forgets the situation [cannot recognize at all] and cannot prepare herself. Those who are close to the affected person should be informed about everything. « (Age: 36–50, wife of caring son, no information)
>
> WR2: »(…) My mom has dementia and our family suffers very much from it. Uh, I think my mother does not notice anything anymore.

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> One [can] say that it [the disease] has arrived. She has her own world. The children suffer. The spouse suffers. Sometimes we are helpless [clueless] with certain things, but yes that's just the way it is, right? « (Age: 36–50, caring daughter, second-generation)
>
> WR3: »(…) For the caretaker, it is a very difficult disease and the caretaker needs to have psychological support.« (Age: 36–50, relative, first-generation)

Getting earlier support and counseling was evaluated positively specifically when the need for preparing advance care directives became apparent to ensure that the affected persons make and carry out their own life decisions. Self-determination was valued by participants as the disease was associated with a diminished capacity for decision-making and hence, loss of control. However, without getting enough support or detailed information at an earlier stage, it is difficult to get prepared for the future, for instance by considering concrete options for care:

> WR2: »Definitely, definitely! We don't have any, but it [advance care directive] would be useful. (…) We were given little information. (…) We were not very well informed by the doctors. That must be changed in any case.« (Age: 36–50, caring daughter, second-generation)
>
> MR5: »We obtained information on that [advance care directives] on our own, too. Whenever we were in the hospital, they were asking us if we had any directives, but it was already too late, the disease was very advanced at that stage and he [my father] would not be able to decide. (…) I would recommend everyone to have an advance care directive, specifically for those who doesn't know German and who are from the same generation of my father while they are still in their right minds.« (Age: 36–50, caring son, second-generation)

An interviewee mentioned that they were informed about having an advance directive during one of their visits not related to dementia. The form was in German and the interviewee translated this document verbally to her mother. However, her mother was irritated and declined to have an advance care directive:

> WR1: »As I started to read the questions, like ›would you like to be connected to the machines?‹, ›would you like to be connected to the respiratory machine?‹, ›would you like to be resuscitated‹, she [my mom] told me that ›I am not that ill, I won't do this. I don't want this.‹ And we let it ride, she didn't want it.« (Age: 51–70, caring daughter, second-generation)

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3.2. The disease is not well-known

One of the participants stated that he was not aware before that dementia was a disease. He assumed that his grandfather had the disease; he was not diagnosed with it. The family assumed that it was senility due to advanced age. Generally, among the public, dementia is often known as senility and perceived as something normal rather than as a disease. After conducting some research on the internet on dementia, the participant thought his grandfather had it:

> MR6: »When I saw the announcement [for this study], it mentioned dementia. Up to now, I did not know anything about this disease. (…) I search for dementia on internet considering if one of my relatives could have the disease and I wondered about the disease itself. (…) I surprised to find out that I have a relative in that condition. I didn't know the medical name of the disease.« (Age: 26–35, relative, first-generation)

Other participants also mentioned that not only the disease, but also how it progresses was not well-known:

> WR2: »(…) [M]y mom, many acquaintances, they did not know what dementia is. Many relatives, friends and so many also laughed at her behavior. (…) I find that sad, because dementia is a disease that one [the affected] cannot see for herself. This is a disease and many cannot handle it. They have to be prepared (…) also one has [to show] a little respect for this person; respect in the sense that one should know that it is a disease, which one cannot help it.« (Age: 36–50, caring daughter, second-generation)

> WR3: »(…) It would be very helpful to have a booklet or something like that informing the patients' relatives step-by-step about what they could expect to see as the disease progresses.« (Age: 36–50, relative, first-generation)

3.3. Being a foreigner had led to a sense of discrimination

One participant very intensely and frequently stated that they were ignored and that the doctors did not pay enough attention or give sufficient information because his father was old and they were foreigners:

> MR5: »We were left alone. In every respect. Because he was old. Also, because he was a foreigner.« (Age: 36–50, caring son, second-generation)

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The same participant stated also concrete examples, where he felt they were treated differently and were discriminated against because they were foreigners. In the last couple of years, the participant's father was an inpatient a couple of times for a couple of days. The nurses were calling him to take care of his father. He had to go to the hospital and sometimes he was finding his father tied up from his hands and feet. He also mentioned that nurses were treating other inpatients differently. For instance, he found once that the diapers were not changed for about 16 to 17 hours. The nurses were changing the patient next door's, he stated, but not his father's. He also suspected that if he was not there to control the care his father received, the nurses would not connect his father to the oxygen tube:

> MR5: »(…) We suffered a lot, [because] they [the nurses] were treating us differently compared to the inpatients next door. (…) Since you are a foreigner, you recognize any different conduct. (…) We had suffered a lot. Different conducts, they look at [treat] my father differently. For instance, if we weren't there, they would not give him the oxygen. [Once] I found that his adult diapers were not changed for sixteen, seventeen hours. (…) They change the one next door. At night, before all went to bed, the nurses check everything. They change the adult diapers, but they would not change my father's. They were changing the next door, but not ours.« (Age: 36–50, caring son, second-generation)

The same interviewee gave another example concerning the provision of healthcare in terms of informing the person seeking help. He mentioned that the healthcare personnel did not show exactly how to make the insulin shots for his neighbor, who had diabetes. The person was about to have a shock due to very high blood sugar level. He stated that the healthcare personnel did not pay enough attention and the person was not informed well enough or sufficiently, even though the person's knowledge of German was well enough to communicate and express herself. However, it was not quite clear if the interviewee was specifically referring to being a foreigner or to the insufficiency of the information provided by the healthcare staff or a mixture of both.

3.4. Living and working conditions have an impact on the initiation of the disease

Some interviewees mentioned that having had to lead a stressful life had negative effects on one's mental health. Some interviewees

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stressed the difficulties their parents had to face as having to live in a foreign country as a migrant. According to some interviewees, leading a life with changes in one's living and working conditions was among stress factors initiating cognitive decline in one's later life:

> WR2: »I think stress factor also play a very big role [in developing dementia in the later years]. (…) How do I deal with a woman with dementia? How can I help her? What is feasible for her? (…) Also, [I would check for] stress factor. For example, has this woman had much stress in her life? (…) My mother had a lot of stress in her life, a lot.« (Age: 36–50, caring daughter, second-generation)

> MR5: »My father came to Germany in 1960s and worked in boiler making industry. Then in mid-1980s he opened a supermarket. His German was super [very good]. However, in 2003, we went bankrupt. With the bankrupt, we had to face psychological distress as a family. Then, he [my father] had a cerebral hemorrhage in 2004. Then, it began [cognitive decline]. Afterwards, he stopped talking in German and generally stopped talking at all.« (Age: 36–50, caring son, second-generation)

3.5. The care is offered by the family members

For all of the participants, it was so natural that the sons or daughters take care of the affected person. It is the family's choice. Mostly, it was expressed by the participants that no one else could take care of their affected parents as they did:

> WR3: »My aunt takes care of her [my grandmother]. My grandmother lives with my aunt and my mom helps my aunt three times a week.

> I: Was that the preference of your aunt and your mother? Or did your grandmother earlier told them that she did not want to be placed in a nursing home? Or was that rather the family's choice?

> WR3: More of a family choice. (…) For my aunt, taking care of her mother was so natural. Actually, she does not believe anyone else could take good care of her.« (Age: 36–50, relative, first-generation)

Very generally, getting professional support and help was evaluated quite positively. However, placing the affected relatives in a nursing home was quite unlikely:

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> WR2: »In our culture, one does not want to be placed in a nursing home willingly. However, it is a relief for the family and one should consider that.« (Age: 36–50, caring daughter, second-generation)

In Germany, the caretaker gets an allowance from the state. Also, a person is sent by the government as well to help in household. Since the mother of one interviewee could not speak German, she was present every time the attendant came. Such help was not evaluated as helpful in particular. This is not only because the affected person trusts her children (in this case, her daughter specially), but also there is the belief that the family knows the affected person better, i.e., not any help coming outside could be beneficial:

> WR1: »Actually, after the disease is recognized, one cannot expect anything. I do not expect anything from my mother. As I am not expecting anything, I am just helping her. What else can I expect for help? Solely, I can expect help from my sister. I do not think there can be any other help or support from outside. I do not think so. There cannot be.« (Age: 51–70, caring daughter, second-generation)

4. Discussion

The findings of the study presented in this chapter demonstrate the experiences and expectations of the participants with migration background regarding dementia care and counseling. Specifically, a culturally sensitive approach to care, the plausible role of culture shaping health-related phenomena, the impact of migrant life on the initiation of the disease and the importance of family care became apparent. In the following, the findings will be discussed and be compared with current studies.

4.1. Need for culturally sensitive care to promote better access and provision of healthcare

Language barriers lead to miscommunication, poorer understanding of the health condition, treatment options, and early termination of care.[27] In cases, where language is a barrier to access to care,

[27] Tripp-Reimer, Choi, Kelly, Enslein: Cultural Barriers (Note 18).

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usually a family member or, wherever possible, a professional staff member acts as an interpreter. However, family interpreters, as part of their cultural background, sometimes act as a protector by not totally informing the person about her condition.[28] Not informing the person accurately can harm the patient-doctor relationship, the person's autonomy, and the demand to keep information confidential.

This was not the case in the pilot study: none of the interviewees, who acted as a translator during the examination, mentioned misleading the affected relatives by hiding the diagnostic information.

Even though only one interviewee strongly emphasized it, having migration background can reinforce the perceptions of discrimination and stigmatization of culturally diverse groups. Such perceptions can lead to less help-seeking behavior, postponement of care and trust in medical services. Therefore, as some argued, culturally sensitive care can be considered a moral obligation.[29] Culturally sensitive care »means an openness for wishes and decisions that can be traced back to a patient's cultural or religious values.«[30] It aims to enhance patient satisfaction by improving the quality and outcome of healthcare services. Effectiveness of healthcare is not only due to individual's lack of information, language and communication difficulties, but also lack of sensitivity of the healthcare personnel for the cultural particularities, e.g., a different understanding of illness and a different way of dealing with it. These barriers hamper the doctor-patient relation, communication and the motivation to seek help and treatment. Culturally sensitive care does not only improve the quality and outcomes of healthcare services for cultural minorities but also promotes the principles of patient autonomy, beneficence and justice.[31] Lack of cultural sensitivity leads to violation of three biomedical principles, namely respect for autonomy, beneficence and justice, since it hinders communication, blocks some patients' ability

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28 Lucy M. Candib: Truth telling and advance planning at the end of life: Problems with autonomy in a multicultural world. In: Families, Systems, and Health 20 (2002), pp. 213–228.

29 Donate-Bartfield, Lausten: Why Practice (Note 20); Paasche-Orlow: The Ethics of Cultural Competence (Note 20).

30 Ilhan Ilkilic: Culture-Sensitive Advance Directives in a Multicultural Society and the Muslim Concept of Death. In: Walter Moczynski, Hille Haker, Katrin Bentele (Eds.): Medical Ethics in Health Care Chaplaincy. Berlin 2009, pp. 89–101, here p. 95 footnote.

31 Paasche-Orlow: The Ethics of Cultural Competence (Note 20).

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to realize their rights to make choices about their own treatment,[32] and diminishes the quality of care. Violation of these principles affects their willingness to seek further help and care, which limits their right to access to an adequate healthcare.

However, in making healthcare culturally sensitive, the danger of stereotyping and overgeneralization should be avoided. Limiting all considerations to culture runs the risk of reinforcing stereotypes about ethnic groups.[33] Attitudes within cultural groups can be diverse due to differing education levels, socio-economic backgrounds, gender, personal experiences, and acculturation or due to assimilation to a culture or cultural community, which can be observed, for instance, in the 3rd or 4th generation of people with migration background.[34] Thus, defining individuals by their cultural identity alone prevents adequate responses to the needs of individuals and their families.

4.2. Culture's role in shaping one's health-related phenomena

If individuals and their families from minority-cultural backgrounds bring their cultural perceptions and attitudes into culturally insensitive clinical settings,[35] culture-specific demands or practices can lead to conflicts between the medical system of the dominant culture and families from non-dominant or minority cultures.[36] For instance, ritual infant circumcision is a traditional religious practice among Jews

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32 Donate-Bartfield, Lausten: Why Practice Culturally Sensitive Care? (Note 20).

33 Silke Schicktanz, Sabine Wöhlke: Kulturelle Faktoren bei Entscheidungen zur Therapiebegrenzung. In: Andrej Michalsen, Christiane S. Hartog (Eds.): End-Of-Life Care in der Intensivmedizin. Berlin, Heidelberg 2013, pp. 133–137; Michael Coors, Tim Peters, Ilhan Ikilic: Kulturelle Differenz in der Gesundheitsversorgung [Cultural difference in healthcare]. In: Ethik in der Medizin 30 (2018), pp. 177–179.

34 Candib: Truth telling (Note 28); Leigh Turner: From the Local to the Global: Bioethics and the Concept of Culture. In: Journal of Medicine and Philosophy 30 (2005), pp. 305–320.

35 Leigh Turner: Bioethics in a Multicultural World: Medicine and Morality in Pluralistic Settings. In: Health Care Analysis 11 (2003), pp. 99–117.

36 Robert L. Schwartz: Multiculturalism, Medicine, and The Limits of Autonomy: The Practice of Female Circumcision. In: Cambridge Quarterly of Healthcare Ethics 3 (1994), pp. 431–441; Candib: Truth telling (Note 26); Sawitri Saharso: Feminist Ethics, Autonomy and the Politics of Multiculturalism. In: Feminist Theory 4 (2003), pp. 199–215; Kerry Bowman: What are The Limits of Bioethics in a Culturally Pluralistic Society? In: Journal of Law, Medicine and Ethics 32 (2004), pp. 664–669.

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and Muslims. In Germany, the practice was ruled as illegal because it was considered a violation of the child's right to bodily integrity and self-determination. The decision of the court was justified based on children's wellbeing (»Kindeswohl«), which cannot be overridden by parents' right to a religious upbringing of the children. The wellbeing of the child was held by the court in an individualistic and medical context, and not in a broader, culturally informed context, by which the best interest of the child can differ.[37]

In intercultural contexts, where the physician and the patient do not share the same cultural realm, ethical conflicts occur. Some cultural phenomena have ethical relevance because some health-related phenomena vary by culture.[38] For instance, including family members in decision-making can be an expression of traditional moral expectations including the traditional structure of authority within the family or faith and trust in one's family. Influence of family on decision-making might not necessarily be a breach of patient autonomy.[39] Although all the interviewees mentioned the importance of self-determination, making decisions for the affected family member was not seen as a breach of autonomy of the affected person. On the contrary, this showed strong bond of family ties, trust in family in making decisions as well as duty of responsibility of the descent to the parents.

4.3. Impact of migration experience on one's mental health

Having a migration experience is stressful and can affect the health of the person including cognitive decline, which might be due to the living and working conditions.[40] Working conditions, income, unemployment, etc. generated disadvantaged and stressful situations for the first-generation Turkish migrants.[41] This also shows consistency with the pilot study: the negative effects of stressful living and

[37] Ilhan Ilkilic: Islamische Aspekte der Beschneidung von Minderjährigen Jungen [Islamic aspects of circumcision of minor boys]. In: Zeitschrift für Medizinische Ethik 60 (2014), pp. 63–72.

[38] Ilhan Ilkilic: Interculturality and Ethics in Health Care. In: Ilhan Ilkilic, Hakan Ertin, Rainer Brömer, Hajo Zeeb (Eds.): Health, Culture and the Human Body. Istanbul 2014, pp. 697–709.

[39] Ilkilic: Culture-Sensitive (Note 30), here pp. 89–100.

[40] Seven, Braun, Kalbe, Kessler: Demenzdiagnostik (Note 6).

[41] Seven, Braun, Kalbe, Kessler: Demenzdiagnostik (Note 6).

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working conditions were also considered an initiating factor for the cognitive decline.

4.4. Willingness to care for the family

All interviewees mentioned that their affected relatives were taken care by their family members, namely by the affected person's daughters and sons. In Germany, there are well-developed aged-care services, such as residential aged-care facilities and aged-care cash allowance for the families. However, most elderly people with a Turkish immigrant background prefer to stay at home, to be taken care of by their family members and to receive the cash allowance, which might also generate a burden for the family as one study showed.[42] Another study also showed that the elderly Turkish migrants are mostly taken care by their families, however they often do not get professional support.[43] Although preferences in care are dependent on many other factors as well, such as costs, marital status and disease's severity, a Danish nation-wide study also showed that non-western immigrants were less likely to live in a nursing home.[44] There are also studies documenting in intergenerational relationships including the willingness to care for parents.[45] These results show consistency with the findings of the pilot study. However, it was also strongly

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42 Rosa Brandhorst, Loretta Baldassar, Richard Wilding: The Need for a »Migration Turn« in Aged Care Policy: A Comparative Study of Australian and German Migration Policies and Their Impact on Migrant Aged Care. In: Journal of Ethnic and Migration Studies 47 (2021), pp. 249–266.

43 Tezcan-Güntekin, Razum: Pflegende Angehörige (Note 10).

44 Lea Stevnsborg, Christina Jensen-Dahm, Thomas R. Nielsen, Christiane Gasse, Gunhild Waldemar: Inequalities in Access to Treatment and Care for Patients with Dementia and Immigrant Background: A Danish Nationwide Study. In: Journal of Alzheimer's Disease 54 (2016), pp. 505–514.

45 Helen Baykara-Krumme, Daniela Klaus, Anja Steinbach: Generationenbeziehungen in Deutschland. Ein Vergleich der Beziehungsqualität in einheimischen deutschen Familien, Familien mit türkischem Migrationshintergrund und Aussiedlerfamilien [Intergenerational relations in Germany. A comparison of the quality of relationships in native German families, families with a Turkish migration background and families with emigrants]. In: Josef Brüderl, Laura Castiglioni, Nina Schumann (Eds.): Partnerschaft, Fertilität und intergenerationale Beziehungen Ergebnisse der ersten Welle des Beziehungs-und Familienpanels [Partnership, fertility and intergenerational relationships Results of the first wave of the relationship and family panel]. Würzburg 2011, pp. 259–286.

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emphasized that having professional support was quite helpful, and at times quite informative as well. Even though in the current state some were not getting the professional help, they emphasized the importance of it, because they believed that it would relieve the burden a bit. However, most were hesitant to place their affected relatives to a nursing home. Additionally, lack of knowledge concerning the disease, i.e., seeing the disease as a natural course of life, as well as care and help structures was also apparent in the pilot study, which was also the case in another study.[46]

5. Limitations

There are a number of limitations of this study, which should be acknowledged. First, the pilot study is limited by a small sample, where the focus is on the caregivers and family members of people with dementia of Turkish descent living in Germany. Therefore, the findings of the study cannot be applied to the community of caregivers and family members with a Turkish descent or with migration background in Germany. Second, since qualitative research methods were referred to for this study, the validity of the results is based on the selected sample and can neither be claimed to be representative nor generalizable for the broader population.

6. Conclusion

The presented pilot study in this chapter focused on provision of dementia care for persons with migration background. The preliminary analysis of the pilot study revealed four emerging themes, which are the need for support and information, perception of discriminative behavior and neglect, the impact on migrant life on the initiation of the disease and the role of family in care. These findings highlighted some main needs of migrant groups: more information about disease management and social support as well as more accessibility and sensitivity for cultural differences from the healthcare personnel. These findings show consistency with existing studies as discussed above. The concerns participants raised supported in a limited way

[46] Tezcan-Güntekin, Razum: Pflegende Angehörige (Note 10).

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three working hypothesis: (1) the needs of immigrants affected with dementia are not always addressed satisfactorily; (2) this deficit is due to cultural differences; (3) decision-making is family-centered, even though individual autonomy is highly regarded.

The results of the presented study indicate a need for more research on the (plausible) impact of having migration background on shaping the perceptions regarding experiences of being a caretaker and the needs for counseling. Further comparative studies conducted with those without migration background could help to illuminate whether the perceptions of discriminative behaviors or neglect from healthcare personnel are due to having migration background. There is a lack of empirical ethics studies focusing on the influence of ethnic and cultural differences in family members and affected persons' attitudes in the context of dementia-related healthcare. This is at least partly due to lack of sufficient language skills and relevant cultural background knowledge among scholars. Such research would help to develop culture-sensitive guidelines for dementia-related care.

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