# Ansätze zur Verbesserung der hausärztlichen Versorgung von Menschen mit Migrationshintergrund mit Fokus auf die Demenzdiagnostik

#### Dissertation

zur Erlangung des Doktorgrades (PhD)

der Medizinischen Fakultät

der Rheinischen Friedrich-Wilhelms-Universität

Bonn

**Judith Tillmann** 

aus Troisdorf 2021

Angefertigt mit der Genehmigung							
der Medizinischen Fakultät der Universität Bonn							
Gutachter: Prof. Dr. med. Klaus Weckbecker							
2. Gutachterin: Prof. Dr. Hürrem Tezcan-Güntekin							
Tag der Mündlichen Prüfung: 10.05.2021							
Aus dem Institut für Hausarztmedizin							
Direktor: Prof. Dr. med. Klaus Weckbecker (bis 28.02.2018),							
Direktorin: Prof. Dr. med. Birgitta Weltermann, MPH(USA) (ab 01.03.2018)							

## **Table of Contents**

List of Abbreviations	4
1. Abstract	5
2. Introduction and aims	6
2.1 People with a migration background in Germany	6
2.2 Dementia: causes, epidemiology and diagnosis	7
2.2.1 The part of general practitioners in diagnosing dementia	8
2.2.2 Dealing with people with a migration background in dementia diagnos	itics9
2.3 Research questions and aims	11
References	12
3. Publications	18
3.1 Publication 1	18
3.2 Publication 2	25
3.3 Publication 3	36
4. Discussion	47
4.1 Intercultural opening of healthcare and general practice	47
4.2 Political focus on healthcare for people with a migration background	49
4.3 Healthcare research on people with a migration background	50
4.4 Limitations	51
References	52
5. Acknowledgement	56
6. Statement	57
7. List of publications	61

#### **List of Abbreviations**

AD = Alzheimer's disease

ADI = Alzheimer's Disease International

aOR = adjusted Odds Ratio

BaDeMi = Reducing barriers in general practitioners' dementia diagnostics among

people with a migration background (study)

CDT = Clock-drawing testCI = Confidence Interval

DEGS1 = the first wave of the German health interview and examination survey for

adults

Destatis = German Federal Statistical Office

DGN = German Society for Neurology

DGPPN = German Society for Psychiatry and Psychotherapy, Psychosomatics and

Neurology

DRKS = German Clinical Trials Registry

*EFTA* = European Free Trade Association

*EU* = European Union

*GP* = general practitioner

*MCI* = Mild cognitive impairment

MMSE = Mini-Mental State Examination

*MoCA* = Montreal Cognitive Assessment Test

NRW = North Rhine-Westphalia

RKI = Robert Koch Institute

RUDAS = Rowland Universal Dementia Assessment Scale

TFDD = Test for early diagnosis of dementia with differentiation from depression

UK = United Kingdom

US = United States

WHO = World Health Organization

#### 1. Abstract

Introduction and aims: People with a migration background represent more than a quarter of the German population and are increasingly at risk of suffering from dementia due to demographic change. Diagnosing dementia depends on language skills, cultural backgrounds, knowledge and access of patients to the healthcare system. Although general practitioners (GPs) hold a key role in diagnosing dementia in Germany, it is unknown whether they face challenges and are in need of support to interact with patients with a migration background. In addition, the access of people with a migration background to GP services is unclear. This thesis aims to address these gaps in research.

**Methods:** A cross-sectional survey in a random sample of 339 GPs in North Rhine-Westphalia (NRW) was conducted from October 2017 to January 2018 (response rate: 34.5 %). A self-developed, standardized questionnaire was used to gather GPs' experience in diagnosing dementia and analysed performing descriptive and multiple logistic regression analyses. The connection of a migration background and further factors and having no GP was analysed among the 7755 participants of the representative "German Health Interview and Examination Survey for Adults". Descriptive analyses and multiple logistic regression models were conducted.

**Results:** A share of 96 % of GPs reported having experienced barriers in diagnosing dementia in their patients with a migration background at least once. Uncertainties in this field were stated by 70.9 % with no significant association to GPs' sociodemographic characteristics. Language barriers (89.3 %), information deficits (59.2 %) and shameful interaction or lack of acceptance of the syndrome (55.5 %) on the part of patients were reported most frequently. A demand for information on the topic was expressed by 70.6 % of GPs. In DEGS1, an increased share of 14.8 % of people with a migration background had no GP, especially those with a two-sided background (aOR: 1.90, 95 % CI: 1.42–2.55).

**Discussion:** To prevent unequal health opportunities, GPs should be supported in providing healthcare and especially in performing dementia diagnostics in their patients with a migration background. Intercultural opening of the healthcare system through language und culturally sensitive information, intercultural competence training of GPs and a focus in politics and research could be useful to improve healthcare.

#### 2. Introduction and aims

International migration has reached an unprecedented extent, dynamics and patterns worldwide leading to social, political and public health challenges. In Germany, more than every fourth person had a so-called "migration background" in 2019 (Statistisches Bundesamt [Destatis], 2020). Like the entire population, people with a migration background are affected by demographic ageing and the resulting increased risk of suffering from age-related diseases and conditions associated with symptoms of dementia. However, access and quality of health care, especially regarding diagnostics of dementia, can differ between people with and without a migration background, leading to unequal health opportunities. There are findings that people with a migration background in Germany are not receiving sufficient and adequate healthcare due to systemic and individual barriers (Razum et al., 2004). General practitioners (GPs) are usually the first point of contact in case of any health issue in Germany but it is unknown, if they face barriers and challenges in assessing dementia in patients with a migration background and if there is a need for support or measures. The special situation of people with a migration background and needs of GPs to ensure high quality dementia services for these people are tasks with increasing present and future relevance but not yet appropriately considered in healthcare and research.

### 2.1 People with a migration background in Germany

The German Federal Statistical Office defines the term "migration background" as follows: Either the person him- or herself or at least one parent was not born with German nationality (Destatis, 2020). However, it is important to stress that people with a migration background are a heterogeneous group with different socioeconomic circumstances, language skills, cultural backgrounds and healthcare needs (Kurth and Razum, 2019). Information and research results cannot be generalized. In 2019, 26 % of the German population (21.2 million) had a migration background, the tendency is rising strongly (Destatis, 2020). Among them, 47.6 % do not have and 52.4 % do have German citizenship, 64.4 % have experienced immigration themselves (Destatis, 2020). With 5.45 million out of 17.67 million people, NRW reports the highest number and one of the highest proportions (30.8 %) of people with a migration background in the state

(Destatis, 2020). The most common countries of origin are Turkey (13.3 %), Poland (10.6 %) and Russia (6.5 %) (Destatis, 2020). A number of 2.07 million are at least 65 years and thus belong to the age group defined by a rising risk of developing dementia (Destatis, 2020; Weyerer, 2007).

#### 2.2 Dementia: causes, epidemiology and diagnosis

Dementia is a collective term for a wide range of symptoms associated with a decline in memory, thinking skills, emotion and behaviour that are often progressive and so severe that they can reduce a person's ability to perform everyday life (World Health Organization [WHO], 2017, 2018). There are several diseases and conditions associated with dementia symptoms, Alzheimer's disease (AD) is the most common (60-70 %), followed by vascular dementia (15-20 %) (Raz et al., 2016; Weyerer, 2007; WHO, 2017). There is also a small amount of reversible conditions like thyroid problems or vitamin B12 deficiency, so-called "secondary dementias" (WHO, 2019). Age is the strongest risk factor for the onset of dementia (WHO, 2017). There is no curative treatment available for the most common types of dementia like AD (WHO, 2019). Nevertheless, there are possibilities to support and improve life of patients and carers like drug therapies, especially for symptomatic improvement of cognitive impairment, physiological interventions to improve well-being and quality of life and social interventions (Weyerer, 2007). However, their effectiveness is often not sufficiently empirically proven (Weyerer, 2007).

Alzheimer's Disease International (ADI) and the World Health Organization (WHO) predict a global increase from about 50 million people suffering dementia in 2018 to 74.7 million in 2030 and 131.5 million in 2050 (Alzheimer's Disease International, 2015; WHO, 2017, 2018). In Germany, a rise from 1.59 million in 2018 to 1.81 million in 2025 and 2.75 million in 2050 is estimated (Alzheimer Europe, 2019). The Robert Koch Institute (RKI) even predicts 3.5 Million people affected in Germany until 2050 (Robert Koch-Institut [RKI] and Destatis, 2015). The WHO addressed dementia as a public health priority and emphasizes the need to raise awareness (WHO, 2018).

Diagnosing dementia usually includes taking the medical history of the person's problems from the patient him- or herself and a close friend or relative in combination with an examination of the patient's physical and mental state with a cognitive testing instrument

(Weyerer, 2007). For the latter, the MMSE (Mini Mental State Examination), the Dem-Tect (Dementia Detection), the TFDD (Test for early diagnosis of dementia with differentiation from depression) and the MoCA (Montreal Cognitive Assessment Test) are recommended in Germany (Deutsche Gesellschaft für Psychiatrie und Psychotherapie, Psychosomatik und Nervenheilkunde [DGPPN] and Deutsche Gesellschaft für Neurologie [DGN], 2016; Ihl et al., 2000; Kalbe et al., 2004; Mitchell, 2009; Nasreddine et al., 2005). The clock-drawing test (CDT) can be used in combination with one of these instruments (Cullen et al., 2007; DGPPN and DGN, 2016). In addition, imaging techniques, electrophysiological methods and blood tests can be used (Weyerer, 2007). Despite the lack of cure and treatment options for most types of dementia, early detection can be beneficial for people affected as well as their relatives and carers (WHO, 2017): reversible causes can be identified and treated, patients and relatives get the opportunity to prepare for the future, to fulfil dreams, get information, arrange support and care measures as long as the affected person can still be involved in decisions (Hinton et al., 2004; Turner et al., 2004). Preparing a living will and power of attorney do also play a role at this stage (Tillmann et al., 2020). Nevertheless, the psychological consequences of the diagnosis have to be observed (Aminzadeh et al., 2007).

### 2.2.1 The part of general practitioners in diagnosing dementia

GPs play a crucial role in healthcare and dementia assessment in Germany. As usually the first point of contact in case of any health issue, GPs see a large number of patients every day and often have a long term trust relationship with their elderly patients (Weyerer, 2007). According to the RKI, over 90 % of dementia patients are treated by their GP in Germany (Weyerer, 2007). They are thus in the best position to raise awareness of dementia symptoms and identify the causes at an early stage of the disease. There is evidence of dementia being underdiagnosed and frequently diagnosed at a late stage with missing or fragmentary care pathways worldwide (WHO, 2017). International research especially discloses lacking diagnostics in the primary care setting: According to data analyses by Connolly et al. (2011), less than half of the expected patients over 65 years with dementia are recognised by GPs in the UK. Iliffe et al. (2009) confirm that share in the UK and Boustani et al. (2003) report an undiagnosed share of 50 to 66 % in primary care samples studied in the US. In Germany, the RKI reports 40 to 60 % of de-

mentia cases being unnoticed by GPs (Weyerer, 2007). Overall, little is known about the contact of people with a migration background and GPs in Germany, especially in assessing dementia. Differences in the use of the German healthcare system between people with and without a migrant background have been identified (RKI, 2008). For example, more frequent first contacts of women with migrant background with rescue services instead of the GP practices have been revealed in a German study (David et al., 1998). A qualitative study among German and Russian-speaking patients showed that migrants are less satisfied with GPs than Germans, resulting in frequent doctor change (Bachmann et al., 2014).

# 2.2.2 Dealing with people with a migration background in dementia diagnostics

Providing healthcare for people with dementia-related diseases in general is a major public health challenge. Symptoms of normal ageing, mild cognitive impairment (MCI) and dementia are sometimes difficult to distinguish (Cahill et al., 2006; Stewart et al., 2014). Dementia is often met with stigma and shameful behaviour on the part of patients and relatives (Nielsen and Waldemar, 2016; van Wezel et al., 2018; Werner and Heinik, 2008; WHO, 2017). Insecurities in diagnostics, management and sensitive communication (Pathak and Montgomery, 2015; Phillips et al., 2012), lack of training among GPs despite a huge demand (Cahill et al., 2006) and frequently missing knowledge about regional services (Pathak and Montgomery, 2015) have been reported in international studies among GPs. Hansen et al. (2008) call for support for patients and targeted information for doctors. However, if patients have a migration background, the diagnostic process may be accompanied by following further hurdles.

#### Access to the healthcare system

Access to healthcare can be limited for people with a migration background (Razum et al., 2004). Delayed consultation and help-seeking of immigrants with cognitive problems in Belgium (Segers et al., 2013), delayed help-seeking of minority ethnic carers of people with dementia in the UK (Mukadam et al., 2011a), lower use of mental health services of immigrants in Europe (Lindert et al., 2008) and deviating pathways to a diagnosis of dementia of ethnically diverse family dementia caregivers in the US have been

identified (Hinton et al., 2004). Thus, it can happen that these patients consult a physician late after the onset of symptoms and in an advanced stage (Haralambous et al., 2014; LoGiudice et al., 2001; Segers et al., 2013).

#### Language skills and communication

Poor language skills can hamper the access to healthcare and diagnostic processes (Razum et al., 2004). In a study in 15 European clinical dementia centres, diagnostic evaluation of dementia in ethnic minority patients was indicated to be challenging because of communication problems and lack of adequate tools (Nielsen et al., 2011). Apart from that, people with a migration background can be affected in a particularly severe way: Since dementia causes memory loss of the newer phases of life more quickly, especially people with a migration background of the first generation likely lose their memories of life in Germany and German language skills and lapse into their mother tongue (Söderman and Rosendahl, 2016). And since assessment is strongly language-based, poor or forgotten language skills complicate or impede this process (Daker-White et al., 2002; Segers et al., 2013; Söderman and Rosendahl, 2016).

#### Cultural perception of health and illness

The perception, acceptance and handling of diseases and especially conditions affecting the psyche can be culturally shaped. In some cultures, associated symptoms are tabooed, denied, and strongly associated with shame (Liu et al., 2008; Mukadam et al., 2011a; Yildirim-Fahlbusch, 2003). They may be hidden at the doctor's office. For example, van Wezel et al. (2018) identified barriers within Turkish and Moroccan communities against talking openly about dementia. In some cultures, illness is perceived as fate or punishment from god you cannot change, in others, dementia is seen as a part of normal ageing (Braun et al., 1995; Graham et al., 2003; Liu et al., 2008; Mukadam et al., 2011a). Besides, diseases and symptoms may be expressed different than in European medicine, e.g. in a more holistic way (RKI, 2008; Yildirim-Fahlbusch, 2003). As the importance of the family in caring for the elderly is high in many cultures, this may be accompanied by a situation in which help from "outside" the family and community is rejected (Deardorff, 2009; Mukadam et al., 2011b; Shanley et al., 2012).

Health literacy and access to information

Knowledge about dementia can sometimes be low due to cultural perceptions or limited health literacy (Mukadam et al., 2011b). Schaeffer et al. (2016) emphasizes that particularly people with a migration background and people of old age have an on average lower health literacy level than the general population. That comprises a lack of resources to operate easily in the healthcare system due to language hurdles and missing knowledge (Schaeffer et al., 2016; Spallek and Razum, 2008).

#### 2.3 Research questions and aims

The aim of this thesis is to gain new insights into GP care of people with a migration background in Germany, especially regarding the diagnosis of dementia. General knowledge about the use patterns of GP services of people with a migration background should be gained. Besides, the aim is to identify challenges involved in diagnosing dementia in patients with migration background from the perspective of GPs. The annexed publications aim to shed light on these topics by examining the following research questions:

- Are there any barriers or challenges in diagnosing dementia in patients with a migration background in Germany from the perspective of GPs? And if so, which barriers exist and how do GPs deal with them?
- Is there a need for support or information about the topic among GPs?
- Does having no GP differ between people with and without a migrant background in Germany?

#### Ethics vote, data protection and study registration

The BaDeMi cross-sectional study was approved by the Ethics Committee of the Medical Faculty of the University of Bonn with reference number 251/17. In addition, a positive data protection vote was obtained for the implementation of the BaDeMi-study. The project has been registered in the German Clinical Trials Registry (DRKS) (No. DRKS00012503) and the Clinical Registry of the University Hospital of Bonn (ID530).

#### References

- Alzheimer Europe, 2019: Dementia in Europe. Yearbook 2019. Estimating the prevalence of dementia in Europe. https://www.alzheimer-europe.org/content/download/19 5515/1457520/file/FINAL%2005707%20Alzheimer%20Europe%20yearbook%20201 9.pdf (Access date: 14.10.2020)
- Alzheimer's Disease International, 2015: World Alzheimer Report 2015. The Global Impact of Dementia. An analysis of prevalence, incidence, cost and trends. https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf (Access date: 14.10.2020)
- Aminzadeh F, Byszewski A, Molnar FJ, Eisner M. Emotional impact of dementia diagnosis: Exploring persons with dementia and caregivers' perspectives. Aging & Mental Health 2007; 11(3): 281–290
- Bachmann V, Völkner M, Bösnerr S, Donner-Banzhoff N. The experiences of Russian-speaking migrants in primary care consultations. Dtsch Arztebl Int 2014; 111(51-52): 871–876
- Boustani M, Peterson B, Hanson L, Harris R, Lohr KN. Screening for dementia in primary care: A summary of the evidence for the U.S. Preventive Services Task Force. Ann Intern Med 2003; 138(11): 927–937
- Braun KL, Takamura JC, Forman SM, Sasaki PA, Meininger L. Developing and testing outreach materials on Alzheimer's disease for Asian and Pacific Islander Americans. Gerontologist 1995; 35(1): 122–126
- Cahill S, Clark M, Walsh C, O'Connell H, Lawlor B. Dementia in primary care: The first survey of Irish general practitioners. Int J Geriatr Psychiatry 2006; 21(4): 319–324
- Connolly A, Gaehl E, Martin H, Morris J, Purandare N. Underdiagnosis of dementia in primary care: Variations in the observed prevalence and comparisons to the expected prevalence. Aging & Mental Health 2011; 15(8): 978–984
- Cullen B, O'Neill B, Evans JJ, Coen RF, Lawlor BA. A review of screening tests for cognitive impairment. Journal of Neurology, Neurosurgery & Psychiatry 2007; 78(8): 790–799

- Daker-White G, Beattie AM, Gilliard J, Means R. Minority ethnic groups in dementia care: A review of service needs, service provision and models of good practice. Aging & Mental Health 2002; 6(2): 101–108
- David M, Pette G, Kentenich H. Unterschiedliche Inanspruchnahme einer gynäkologischen Notfallambulanz durch deutsche Patientinnen und Migrantinnen. Geburtsh Frauenheilk 1998; 58(6): 319–323
- Deardorff DK. The Sage handbook of intercultural competence. Thousand Oaks, California: Sage Publications, 2009
- Deutsche Gesellschaft für Psychiatrie und Psychotherapie, Psychosomatik und Nervenheilkunde, Deutsche Gesellschaft für Neurologie, 2016: S3-Leitlinie "Demenzen". https://www.awmf.org/uploads/tx\_szleitlinien/038-013I\_S3-Demenzen-2016-07.pdf (Access date: 14.10.2020)
- Graham N, Lindesay J, Katona C, Bertolote JM, Camus V, Copeland JRM, Mendonça Lima CA de, Gaillard M, Gély Nargeot MC, Gray J, Jacobsson L, Kingma M, Kühne N, O'Loughlin A, Rutz W, Saraceno B, Taintor Z, Wancata J. Reducing stigma and discrimination against older people with mental disorders: A technical consensus statement. Int J Geriatr Psychiatry 2003; 18(8): 670–678
- Hansen EC, Hughes C, Routley G, Robinson AL. General practitioners' experiences and understandings of diagnosing dementia: Factors impacting on early diagnosis. Social Science & Medicine 2008; 67(11): 1776–1783
- Haralambous B, Dow B, Tinney J, Lin X, Blackberry I, Rayner V, Lee S-M, Vrantsidis F, Lautenschlager N, Logiudice D. Help seeking in older Asian people with dementia in Melbourne: Using the Cultural Exchange Model to explore barriers and enablers. J Cross Cult Gerontol 2014; 29(1): 69–86
- Hinton L, Franz C, Friend J. Pathways to dementia diagnosis: Evidence for cross-ethnic differences. Alzheimer Disease & Associated Disorders 2004; 18(3): 134–144
- Ihl R, Grass-Kapanke B, Lahrem P, Brinkmeyer J, Fischer S, Gaab N, Kaupmannsennecke C. Entwicklung und Validierung eines Tests zur Früherkennung der Demenz mit Depressionsabgrenzung (TFDD). Fortschr Neurol Psychiatr 2000; 68(9): 413–422

- Iliffe S, Robinson L, Brayne C, Goodman C, Rait G, Manthorpe J, Ashley P. Primary care and dementia: 1. Diagnosis, screening and disclosure. Int J Geriatr Psychiatry 2009; 24(9): 895–901
- Kalbe E, Kessler J, Calabrese P, Smith R, Passmore AP, Brand M, Bullock R. DemTect: a new, sensitive cognitive screening test to support the diagnosis of mild cognitive impairment and early dementia. Int J Geriatr Psychiatry 2004; 19(2): 136–143
- Kurth BM, Razum O. Editorial: Gesundheitsmonitoring muss die Vielfalt der Bevölkerung berücksichtigen. Journal of Health Monitoring 2019; 4(3): 1–6
- Lindert J, Schouler-Ocak M, Heinz A, Priebe S. Mental health, health care utilisation of migrants in Europe. Eur Psychiatr 2008; 23(1): 114-120
- Liu D, Hinton L, Tran C, Hinton D, Barker JC. Reexamining the relationships among dementia, stigma, and aging in immigrant Chinese and Vietnamese family caregivers. J Cross Cult Gerontol 2008; 23(3): 283–299
- LoGiudice D, Hassett A, Cook R, Flicker L, Ames D. Equity of access to a memory clinic in Melbourne? Non-English speaking background attenders are more severely demented and have increased rates of psychiatric disorders. Int J Geriatr Psychiatry 2001; 16(3): 327–334
- Mitchell AJ. A meta-analysis of the accuracy of the mini-mental state examination in the detection of dementia and mild cognitive impairment. Journal of Psychiatric Research 2009; 43(4): 411–431
- Mukadam N, Cooper C, Basit B, Livingston G. Why do ethnic elders present later to UK dementia services? A qualitative study. Int Psychogeriatr 2011a; 23(7): 1070–1077
- Mukadam N, Cooper C, Livingston G. A systematic review of ethnicity and pathways to care in dementia. Int J Geriatr Psychiatry 2011b; 26(1): 12–20
- Nasreddine ZS, Phillips NA, Bédirian V, Charbonneau S, Whitehead V, Collin I, Cummings JL, Chertkow H. The Montreal Cognitive Assessment, MoCA: A Brief Scree-ning Tool For Mild Cognitive Impairment. Journal of the American Geriatrics Society 2005; 53(4): 695–699
- Nielsen TR, Vogel A, Riepe MW, Mendonça A de, Rodriguez G, Nobili F, Gade A, Waldemar G. Assessment of dementia in ethnic minority patients in Europe: A European Alzheimer's Disease Consortium survey. Int Psychogeriatr 2011; 23(1): 86–95

- Nielsen TR, Waldemar G. Knowledge and perceptions of dementia and Alzheimer's disease in four ethnic groups in Copenhagen, Denmark. Int J Geriatr Psychiatry 2016; 31(3): 222–230
- Pathak KP, Montgomery A. General practitioners' knowledge, practices, and obstacles in the diagnosis and management of dementia. Aging & Mental Health 2015; 19(10): 912–920
- Phillips J, Pond CD, Paterson NE, Howell C, Shell A, Stocks NP, Goode SM, Marley JE. Difficulties in disclosing the diagnosis of dementia: A qualitative study in general practice. Br J Gen Pract 2012; 62(601): e546-53
- Raz L, Knoefel J, Bhaskar K. The neuropathology and cerebrovascular mechanisms of dementia. J Cereb Blood Flow Metab 2016; 36(1): 172–186
- Razum O, Geiger I, Zeeb H, Ronellenfitsch U. Gesundheitsversorgung von Migranten. Dtsch Ärztebl 2004; 101(43): A-2882-2887
- Robert Koch-Institut, 2008: Migration und Gesundheit. Schwerpunktbericht der Gesundheitsberichterstattung des Bundes. Gesundheitsberichterstattung des Bundes. https://www.rki.de/DE/Content/Gesundheitsmonitoring/Gesundheitsberichterstattung/GBEDownloadsT/migration.pdf? blob=publicationFile (Access date: 14.11.2020)
- Robert Koch-Institut, Statistisches Bundesamt, 2015: Gesundheit in Deutschland. Gesundheitsberichterstattung des Bundes gemeinsam getragen von RKI und Destatis. https://www.rki.de/DE/Content/Gesundheitsmonitoring/Gesundheitsbericht erstattung/GesInDtld/gesundheit\_in\_deutschland\_2015.html;jsessionid=B20F3669D A861080B74E6DCC2833A965.internet061?nn=2379316.pdf (Access date: 14.10.2020)
- Schaeffer D, Vogt D, Berens E-M, Hurrelmann K, 2016: Gesundheitskompetenz der Bevölkerung in Deutschland: Ergebnisbericht. https://pub.uni-bielefeld.de/download/2908111/2908198/Ergebnisbericht\_HLS-GER.pdf (Access date: 14.11.2020)
- Segers K, Benoit F, Colson C, Kovac V, Nury D, Vanderaspoilden V. Pioneers in migration, pioneering in dementia: First generation immigrants in a European metropolitan memory clinic. Acta Neurol Belg 2013; 113(4): 435–440
- Shanley C, Boughtwood D, Adams J, Santalucia Y, Kyriazopoulos H, Pond D, Rowland J. A qualitative study into the use of formal services for dementia by carers

- from culturally and linguistically diverse (CALD) communities. BMC Health Serv Res 2012; 12(1)
- Söderman M, Rosendahl SP. Caring for Ethnic Older People Living with Dementia Experiences of Nursing Staff. J Cross Cult Gerontol 2016; 31(3): 311–326
- Spallek J, Razum O. Erklärungsmodelle für die gesundheitliche Situation von Migrantinnen und Migranten. In: Bauer U, Bittlingmayer UH, Richter M, eds. Health inequalities: Determinanten und Mechanismen gesundheitlicher Ungleichheit. Wiesbaden: VS, Verlag für Sozialwissenschaften, 2008: 271–288
- Statistisches Bundesamt, 2020: Bevölkerung und Erwerbstätigkeit. Bevölkerung mit Migrationshintergrund Ergebnisse des Mikrozensus 2019. https://www.destatis.de/DE/Themen/Gesellschaft-Umwelt/Bevoelkerung/Migration-Integration/Publikationen/Downloads-Migration/migrationshintergrund-2010220197004.pdf?\_\_blob=publicationFile (Access date: 08.10.2020)
- Stewart TV, Loskutova N, Galliher JM, Warshaw GA, Coombs LJ, Staton EW, Huff JM, Pace WD. Practice patterns, beliefs, and perceived barriers to care regarding dementia: A report from the American Academy of Family Physicians (AAFP) national research network. J Am Board Fam Med 2014; 27(2): 275–283
- Tillmann J, Schnakenberg R, Weckbecker K, Just J, Weltermann B, Münster E. Hausärztlicher Umgang mit Patientenverfügung und Vorsorgevollmacht bei Demenzpatienten Eine Querschnittsstudie unter deutschen Hausärzten. Das Gesundheitswesen 2020; 82(2): 188–195
- Turner S, Iliffe S, Downs M, Wilcock J, Bryans M, Levin E, Keady J, O'Carroll R. General practitioners' knowledge, confidence and attitudes in the diagnosis and management of dementia. Age Ageing 2004; 33(5): 461–467
- van Wezel N, Francke AL, Kayan Acun E, Devillé WL, van Grondelle NJ, Blom MM. Explanatory models and openness about dementia in migrant communities: A qualitative study among female family carers. Dementia 2018; 17(7): 840–857
- Werner P, Heinik J. Stigma by association and Alzheimer's disease. Aging & Mental Health 2008; 12(1): 92–99
- Weyerer S, 2007: Altersdemenz. Gesundheitsberichterstattung des Bundes. Heft 28. Gesundheitsberichterstattung des Bundes. http://www.gbe-bund.de/gbe10/owards.

- prc\_show\_pdf?p\_id=9663&p\_sprache=d&p\_uid=gast&p\_aid=1933234&p\_lfd\_nr=1 (Access date: 15.10.2020)
- World Health Organization, 2017: Global action plan on the public health response to dementia 2017 2025. http://apps.who.int/iris/bitstream/10665/259615/1/978924151 3487-eng.pdf (Access date: 14.10.2020)
- World Health Organization, 2018: Towards a dementia plan: a WHO guide. http://apps.who.int/iris/bitstream/handle/10665/272642/9789241514132-eng.pdf (Access date: 14.10.2020)
- World Health Organization, 2019: Risk reduction of cognitive decline and dementia. WHO guidelines. https://www.who.int/publications/i/item/risk-reduction-of-cognitive-decline-and-dementia (Access date: 02.11.2020)
- Yildirim-Fahlbusch Y. Türkische Migranten: Kulturelle Missverständnisse. Dtsch Ärztebl 2003; 100(18): A-1179-1181

- 3. Publications
- 3.1 Publication 1

#### **STUDY PROTOCOL**

**Open Access** 



# Barriers in general practitioners' dementia diagnostics among people with a migration background in Germany (BaDeMi) - study protocol for a cross-sectional survey

Judith Tillmann<sup>1\*</sup>, Rieke Schnakenberg<sup>1</sup>, Marie-Therese Puth<sup>1,2</sup>, Klaus Weckbecker<sup>1</sup>, Johannes Just<sup>1</sup> and Eva Münster<sup>1</sup>

#### **Abstract**

**Background:** Considering the targeted general practitioner-centred healthcare in Germany, general practitioners (GPs) are in the best possible position to increase awareness of all sorts of dementia, an age-related syndrome with rising relevance in the future. In Germany, a doubling of the number of cases from 1.55 million up to 3 million in 2050 is predicted. Diagnostics can be challenging, especially among patients with a migration background. Complicating factors include: Language-based diagnostic tools, cultural differences in handling the syndrome and its underlying diseases as well as a differing use of the healthcare system. Because of missing research in this field in Germany, the type, frequency and intensity of barriers as well as the way GPs cope with them is unknown. That is why it's crucial to focus research on diagnostics in total and especially among this population group.

**Methods:** A cross-sectional study among a random sample of 1000 general practitioners in Germany is conducted in October 2017. A self-administered standardized questionnaire was developed, evaluated and send to the GP practices. A response rate of 30% is expected with one reminder letter. Descriptive statistics as well as, depending on the results, multivariable analyses will be executed. Based on these results and the stated needs, a cluster-randomized intervention study will be constructed to improve healthcare.

**Discussion:** This study is the first in Germany focusing on how dementia diagnostics in general practice is performed, what problems occur, especially because of a migration background of patients, and how GPs cope with them. Depending on the results, it should emphasize the necessity of dementia diagnostics to be adjusted to the needs of the rising amount of people with a migration background (22.5% in Germany, 2016) like concluded from international studies.

**Trial registration:** German Clinical Trials Register: DRKS00012503, date of registration: 05.09.2017. Clinical register of the study coordination office of the University hospital of Bonn: ID530, date of registration: 05.09.2017.

**Keywords:** Dementia diagnostics, Family medicine, Migration background, Culture and health, Public health, Epidemiology, GP

<sup>&</sup>lt;sup>1</sup>Institute of General Practice and Family Medicine, Medical Faculty of the University of Bonn, Sigmund-Freud-Str. 25, 53127 Bonn, Germany Full list of author information is available at the end of the article



<sup>\*</sup> Correspondence: judith.tillmann@ukbonn.de

#### **Background**

Rising life expectancy in the course of demographic change causes a steep increase in the number of people with age-related diseases, notably dementia. A rise of actually 35.6 million patients with dementia worldwide (2010) up to 42 million patients till 2040 is predicted [1, 2]. In Germany, a country with 82.4 Million citizen, a doubling of the number of cases from 1.55 million up to 3 million in 2050 is predicted [3, 4], resulting in costs of 85 up to 142 billion € [2]. Above all, the growing number of people suffering from dementia is a huge public health challenge. Within the framework of action plans at national level, the World Health Organization (WHO) points out that awareness of dementia should be sharpened and early diagnosis should be supported [5]. General Practitioners (GPs) should generally be the first point of contact for people with health problems in Germany. This includes possible first symptoms of dementia like problems with short-term memory, concentration, orientation, mood or mental capacity [6]. Therefore GPs are in the best position to increase awareness of all types of dementia. Besides they can detect treatable reasons of the syndrome best to prevent permanent health impairment.

Because symptoms are difficult to distinguish from beginning forgetfulness due to aging and Mild Cognitive Impairment (MCI), diagnostics is challenging for many GPs, even among patients without a migration background. Moreover, limited consultation timeframes of GPs are likely to prevent precise diagnostics. Another aspect described in international literature is restricted knowledge of GPs about a good personal interaction with their dementia patients as well as existence of regional services to support people who are concerned [7–9].

Especially people with a migration background require particular attention because diagnostic tools of dementia are language-based, cross-cultural adaption is missing and the syndrome and underlying diseases are tabooed or handled differently in some cultures. Moreover a less frequent use of health services is reported in international as well as European studies [10–18]. The German Federal Statistical Office (Destatis) defines migration background as follows: Either a person itself or at least one parent is born without German nationality [19]. According to the Microcensus 2016, 22.5% of the population in Germany share this characteristic; a further increase in future is predicted [4]. Among this group, Turkey (15.1%), Poland (10.1%) and Russia (6.6%) represent the most common countries of origin [4].

Within European studies of Nielsen et al., two thirds of doctors describe diagnostics and classification of dementia among ethnic minorities as problematic [17]. There are further international hints that dementia is underdiagnosed among migrants [11, 16, 20]. In total, this topic has hardly been explored, especially in the

European area, and requires particular attention [17, 21]. Hence this project is the first of its kind in Germany and represents a great step towards closing the research gap and improving healthcare of people suffering from dementia.

The following research question should be answered: Are there any barriers in dementia diagnostics in general practice, especially between GPs and patients with a migration background? And if so, what kind of barriers exist and how do GPs deal with them? In order to identify underlying causes, common methods and diagnostic tools used by GPs in the course of dementia diagnostics as well as their experiences with patients showing symptoms of dementia should be determined. Moreover it is of high relevance to gather what actions GPs suggest to remove barriers.

#### **Methods**

#### Study aim

The project "Barriers in general practitioners' dementia diagnostics among people with a migration background" (BaDeMi) aims at improving dementia diagnostics in general practice through a reduction of barriers among doctors and patients. In the course of the cross-sectional study, experiences, potential barriers on the doctors' and patients' side as well as possibilities to improve dementia diagnostics should be detected. Special focus is laid on patients with a migration background since they could have special needs due to language barriers, lack of knowledge about the syndrome and the health system as well as cultural differences. Based on these results, information material will be developed and evaluated in the course of a cluster-randomized intervention study with the aim to reduce barriers and improve healthcare of people with dementia or related symptoms. All in all, health inequalities among people with and without a migration background regarding dementia care should be reduced.

#### Design

The BaDeMi-project consists of two studies, a cross-sectional survey of general practitioners and a following cluster-randomized intervention study; the first one is central to this protocol: It is a cross-sectional survey among a random sample of 1,000 GPs in North Rhine-Westphalia, the most populous state of Germany (17.87 million inhabitants) [22]. The period of the whole project is set from May 2017 up to April 2019, the cross-sectional study will be conducted in the period of September 2017 to December 2017, while the survey takes place in October 2017. The standardized self-administered written survey includes questions about procedures of general practitioners used within the scope of dementia diagnostics as well as their experiences with patients with

a migration background (Fig. 1). Finally, ways to improve diagnostics and support doctors in their practices are inguired. As response categories, five-point Likert-type scales with responses varying from strongly disagree to strongly agree as well as multiple choice response fields were used.

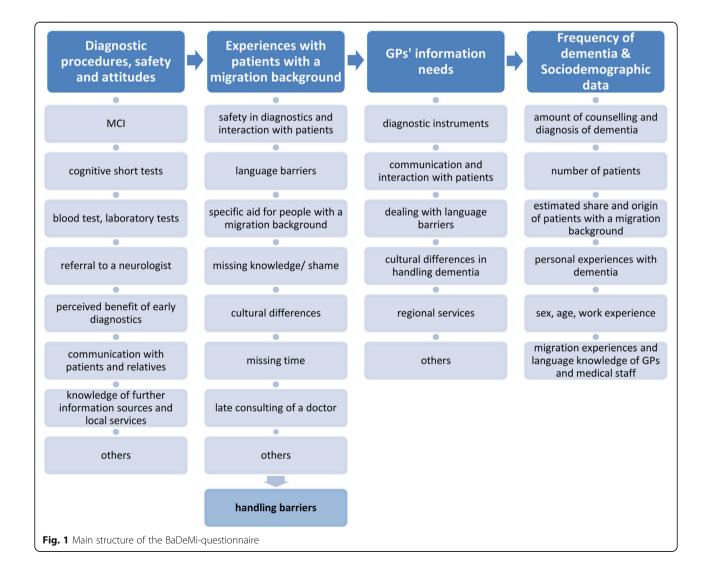
Tillmann et al. BMC Medical Research Methodology

The questions were developed based on systematic literature research on the topic in medical databases (PubMed, Livivo) and Google Scholar. The most common problems in the diagnostic process and in dealing with patients with a migrant background described in the international literature were taken up as questions/ answer options in the questionnaire. In addition, free text fields have been added to name additional aspects not yet described.

Eight questions about methods in diagnostics and physicians' attitudes towards dementia at the beginning of the questionnaire are based on a survey developed by Australian researchers of Wicking Dementia Research & Education Centre (University of Tasmania) within the scope of collaboration [23]. Questions were translated using the method of back-translation by an English native speaker to ensure comparability.

#### Setting and eligibility criteria

Primary target group of this study are general practitioners in North Rhine-Westphalia who practiced at the time of study execution. They have to be registered in the data of the Association of Statutory Health Insurance Physicians North-Rhine (Kassenärztliche Vereinigung Nordrhein (KVNO)) as a general practitioner on the 28th of July 2017 (n = 6,313). Doctors have to be approved in the KVNO in Germany to be allowed to treat patients with a statutory health insurance (87.7% of the population) [24]. These doctors are allowed to treat privately insured patients as well. This group of doctors contains GPs specialized on general medicine, practical physicians as well as internists. They work in practices,



ambulatory healthcare centers (MVZ) or group practices. Pediatricians have been excluded because of lack of relevance for dementia research. All other doctors who are not labeled as GPs have been excluded (n = 15,007). Also, GPs who have exclusively private paying patients and are therefore not registered in the KVNO have not been included.

#### Study endpoints

The aim of this cross-sectional study is the identification of barriers in dementia diagnostics in general practice among people with and without a migration background from physicians' point of view. Using predefined categories and additional free text fields (Fig. 1), occurring problems should be defined, for example into problems caused by poor applicability of diagnostic instruments, missing knowledge of patients and/or GPs, communication or differences in culture. Second aim is the identification of established methods of dementia diagnostics in general practice as well as possible ways to support GPs in diagnostics of patients suffering from dementia.

#### Sample size and recruitment

Among 6313 general practitioners fitting the inclusion criteria, a random sample of 1000 doctors was enclosed in the study (Fig. 2). Before, GPs connected with the research institute like teaching doctors (n = 170), GPs working in the project (n = 2), being connected with research projects (n = 53) as well as GPs included in the pretest (n = 9) were excluded. This random sample has been contacted at the beginning of October 2017 with a letter that contains a covering letter, instructions, the

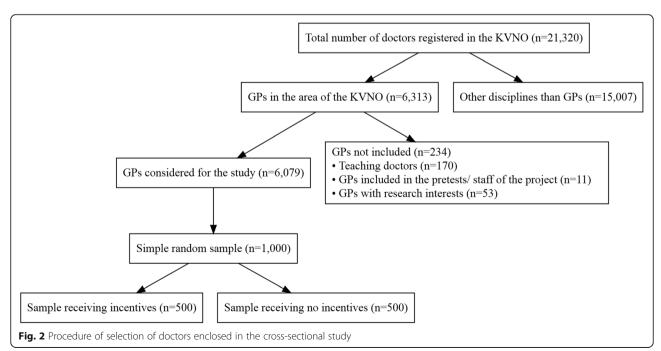
pseudonymised questionnaire and an already addressed and postpaid envelope. They were asked to participate and send it back in the annexed envelope. Half of the study population (n = 500), randomly chosen, also received an incentive, typical sweets from the city of the study, in the envelope. Non-responders were contacted again in writing after two weeks and asked to participate with the questionnaire enclosed again.

#### Pretesting

Before conducting the study, the questionnaire has been pretested among four general practitioners to ensure content validity and to identify possible sources of error. The GPs have not been contacted before. They received the questionnaire and a standardized evaluation sheet and were asked to evaluate the questionnaire following the categories on the evaluation sheet. They commented on comprehensibility and construction, relevance and quality, design and duration. The results of this pretest have been used to adapt the questionnaire to ensure suitability for daily use.

#### Statistical analysis

The software IBM SPSS Statistics (Version 22) will be used for data analyses [25]. The questionnaires will be scanned by the data capture system TeleForm. All GPs who answer and resend the questionnaire will be included. Simple descriptive statistics including frequencies with 95% confidence intervals, medians, means and standard deviations will be used to describe the various parameters covering the evaluations of GPs of dementia and its diagnostics as well as sociodemographic determinants.



Multivariable analyses, comprising multiple logistic regressions, will be conducted. Missing data will be coded and summarized. To reduce potential sources of bias, the study sample was randomly chosen and the questionnaire was standardised. Sociodemographic data like age, gender, migration background and other characteristics of GPs are gathered in the questionnaire and analyses will be adjusted for these characteristics. Moreover logistic regression analyses will be conducted stratified by gender and other characteristics of GPs to control the influence of this characteristic and avoid effect modification.

#### Ethic approval, data management and funding

The BaDeMi study has been approved by the Ethics Committee of the Medical Faculty of the University of Bonn (no. 251/17). Moreover, it has been registered at the German Clinical Trials Register (DRKS) (no. DRKS00012503) and the clinical register of the study coordination office of the University Hospital of Bonn (ID530). Participation is optional for all doctors. By means of a covering letter, they get informed about the study, its importance and aims as well as benefits for healthcare. Person-identifying data, such as names and birthdays, have not been collected. Anonymity is ensured after receiving the questionnaires. All data will be stored under lock for at least ten years. The project is financially supported by the German Alzheimer Society (https://www.deutsche-alzheimer.de/). The study is conducted independently from the funder and competing interests. It is ensured that only staff members of the project get access to the collected data.

The results of this study will be published in articles in national and international medical journals and presented to healthcare professionals of the German Alzheimer Society. They will also be used to construct the following cluster-randomized intervention study.

#### **Discussion**

This study aims at closing several gaps in dementia and migration research. Especially in Germany, only little has been done in general practice to improve care of people with dementia, especially with a migration background. It is unknown with what kind of barriers GPs are confronted, how frequently they occur and how they deal with them. In Germany, the overall proportion of people with a migration background is high. In the most populated state North Rhine-Westphalia, where the study is conducted, it is even higher (27,2%) [4]. Considering the rising amount of asylum seekers and refugees, who have not been in contact with the German healthcare system at all, it's even more urgent to set adjustments on the doctor's and patient's side. Research in other parts of the world like Denmark and Australian is much more advanced. It already highlights the importance of adjusted medical approaches and dementia diagnostics in particular on the needs of the population with a migration background or so called "ethnic minorities" [11, 16, 17, 20, 21]. Nevertheless, setting the focus on GPs has not been done so far. Based on these results, information material will be developed and evaluated in a cluster-randomized intervention study at family medicine practices.

Results might differ between GPs because of different patient bases as well as the region of the practice and connected differing amount of patients with or without a migration background. GPs' own migration background might also influence responses. Patients might rather consult GPs with the same migration background to feel comfortable and well understood. For this reason it is essential to gather these aspects in the survey and to consider them in the analyses.

Since study execution is limited to GPs registered in the Association of Statutory Health Insurance Physicians North-Rhine, results might differ from private doctors. Because 87.7% of the German population is insured in a statutory health insurance, that aspect won't have large effects [24]. Furthermore there are other health professionals like neurologists and nursing staff that routinely interact with patients suffering from dementia, who should be researched in future regarding their experiences with people with a migration background. A response bias cannot be excluded as the responding GPs may be more interested in the topic. However, since characteristics of GPs, such as the age patterns, are quite similar to the average of GPs in Germany, the results may allow generalisation. Barriers and problems identified in this study may not be transferable to all migrant populations because of heterogeneous cultures, religions and views existing even within the barriers of a country. To improve diagnostics and therefore healthcare of people with dementia, the findings of this study will be used in the next step to develop information material for GPs as well as their patients.

#### Abbreviations

Destatis: German Federal Statistical Office; DRKS: German Clinical Trials Register; GP: General Practitioner; MVZ: ambulatory healthcare center; WHO: World Health Organization

#### Acknowledgements

Many thanks to R. Nielsen (Danish Dementia Research Centre, University of Copenhagen) and D. Pond (University of Newcastle, Australia) for the professionally and informative exchange and to A. Robinson and R. Mason (Wicking Dementia Research and Education Centre, University of Tasmania) for the collaboration within constructing the questionnaire. Many thanks to the German Alzheimer Society for financially supporting the project.

#### Funding

The project is funded by the German Alzheimer Society.

#### Availability of data and materials

The dataset generated and analyzed during the current study is available from the corresponding author on reasonable request.

#### Authors' contributions

JT performed study coordination, mainly developed the questionnaire, conducted pretesting, study execution, data analysis and prepared the manuscript. EM is the project leader and advised in all important steps. MP enriched the project and especially data analysis with her statistical knowledge. RS designed the project and raised external funds KW acted as an advisor with medical and practical knowledge and experiences. JJ designed the project and raised external funds. All authors have read and approved the final manuscript.

#### Ethics approval and consent to participate

The University of Bonn Medical Faculties Ethics Committee reviewed and approved this study (Reference Number: 251/17).

#### Consent for publication

Not applicable.

#### Competing interests

The authors declare that they have no competing interests.

#### **Publisher's Note**

Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

#### **Author details**

<sup>1</sup>Institute of General Practice and Family Medicine, Medical Faculty of the University of Bonn, Sigmund-Freud-Str. 25, 53127 Bonn, Germany. <sup>2</sup>Department of Medical Biometry, Informatics and Epidemiology (IMBIE), University Hospital of Bonn, Sigmund-Freud-Str. 25, 53127 Bonn, Germany.

#### Received: 11 October 2017 Accepted: 18 October 2018 Published online: 06 November 2018

#### References

- Ferri CP, Prince M, Brayne C, Brodaty H, Fratiglioni L, Ganguli M, et al. Global prevalence of dementia: a Delphi consensus study. Lancet. 2005;366:2112–7. https://doi.org/10.1016/S0140-6736(05)67889-0.
- Doblhammer G, Schulz A, Steinberg J, Ziegler U. Demografie der Demenz. 1st ed. Bern: Huber; 2012.
- Doblhammer G, Scholz R. Ageing, Care Need and Quality of Life. Wiesbaden: Springer Fachmedien; 2010.
- Statistisches Bundesamt. Bevölkerung und Erwerbstätigkeit: Bevölkerung mit Migrationshintergrund. Ergebnisse des Mikrozensus 2016. 2017.
- World Health Organization. Dementia: a public health priority. United Kingdom: World Health Organization; 2012.
- Deutsche Alzheimer Gesellschaft e. V Die Häufigkeit von Demenzerkrankungen: Informationsbatt 1. 2016.
- Cahill S, Clark M, Walsh C, O'Connell H, Lawlor B. Dementia in primary care: the first survey of Irish general practitioners. Int J Geriatr Psychiatry. 2006;21: 319–24. https://doi.org/10.1002/gps.1464.
- Stewart TV, Loskutova N, Galliher JM, Warshaw GA, Coombs LJ, Staton EW, et al. Practice patterns, beliefs, and perceived barriers to care regarding dementia: a report from the American Academy of family physicians (AAFP) national research network. J Am Board Fam Med. 2014;27:275–83. https:// doi.org/10.3122/jabfm.2014.02.120284.
- Pathak KP, Montgomery A. General practitioners' knowledge, practices, and obstacles in the diagnosis and management of dementia. Aging Ment Health. 2015;19:912–20. https://doi.org/10.1080/13607863.2014.976170.
- Liu D, Hinton L, Tran C, Hinton D, Barker JC. Reexamining the relationships among dementia, stigma, and aging in immigrant Chinese and Vietnamese family caregivers. J Cross Cult Gerontol. 2008;23:283–99. https://doi.org/10. 1007/s10823-008-9075-5.
- Daker-White G, Beattie AM, Gilliard J, Means R. Minority ethnic groups in dementia care: a review of service needs, service provision and models of good practice. Aging Ment Health. 2002;6:101–8. https://doi.org/10.1080/ 13607860220126835.
- Eh K, McGill M, Wong J, Krass I. Cultural issues and other factors that affect self-management of type 2 diabetes mellitus (T2D) by Chinese immigrants in Australia. Diabetes Res Clin Pract. 2016;119:97–105. https://doi.org/10. 1016/j.diabres.2016.07.006.

- Mukadam N, Cooper C, Basit B, Livingston G. Why do ethnic elders present later to UK dementia services? A qualitative study. Int Psychogeriatr. 2011; 23:1070–7. https://doi.org/10.1017/S1041610211000214.
- Mukadam N, Cooper C, Livingston G. A systematic review of ethnicity and pathways to care in dementia. Int J Geriatr Psychiatry. 2011;26:12–20. https://doi.org/10.1002/gps.2484.
- Lindert J, Schouler-Ocak M, Heinz A, Priebe S. Mental health, health care utilisation of migrants in Europe. European Psychiatry. 2008;23:14–20. https://doi.org/10.1016/S0924-9338(08)70057-9.
- Segers K, Benoit F, Colson C, Kovac V, Nury D, Vanderaspoilden V. Pioneers in migration, pioneering in dementia: first generation immigrants in a European metropolitan memory clinic. Acta Neurol Belg. 2013;113:435–40. https://doi.org/10.1007/s13760-013-0245-z.
- Nielsen TR, Vogel A, Riepe MW, de MA, Rodriguez G, Nobili F, et al. Assessment of dementia in ethnic minority patients in Europe: a European Alzheimer's disease consortium survey. Int Psychogeriatr. 2011;23:86–95. https://doi.org/10.1017/S1041610210000955.
- Boughtwood D, Shanley C, Adams J, Santalucia Y, Kyriazopoulos H, Pond D, Rowland J. Dementia information for culturally and linguistically diverse communities: sources, access and considerations for effective practice. Aust J Prim Health. 2012;18:190–6. https://doi.org/10.1071/PY11014.
- Statistisches Bundesamt. Bevölkerung und Erwerbstätigkeit. Bevölkerung mit Migrationshintergrund: Ergebnisse des Mikrozensus 2015. Wiesbaden: Destatis; 2016.
- Diaz E, Kumar BN, Engedal K. Immigrant patients with dementia and memory impairment in primary health care in Norway: a national registry study. Dement Geriatr Cogn Disord. 2015;39:321–31. https://doi.org/10.1159/ 000375526.
- Piechotta G, Matter C. Die Lebenssituation demenziell erkrankter türkischer Migranten/–innen und ihrer Angehörigen. Zeitschrift für Gerontopsychologie & -psychiatrie. 2008;21:221–30. https://doi.org/10.1024/ 1011-6877.21.4.221.
- Statistisches Bundesamt. GENESIS-Online Datenbank: Fortschreibung des Bevölkerungsstandes. Ergebnisse auf Grundlage des Zensus 2011. Berlin: Statistisches Bundesamt: 2017.
- Mason RL, Annear MJ, Lo A, McInerney F, Tierney LT, Robinson AL. Development and preliminary psychometric properties of the general practitioner attitudes and confidence scale (GPACS-D) for dementia. BMC Fam Pract. 2016;17:105. https://doi.org/10.1186/s12875-016-0506-z.
- Statistisches Bundesamt. Sozialleistungen. Angaben zur Krankenversicherung: Ergebnisse des Mikrozensus. Wiesbaden: Statistisches Bundesamt (Destatis); 2016.
- 25. IBM Corp. IBM SPSS statistics. Armonk: IBM Corp; 2016.

#### Ready to submit your research? Choose BMC and benefit from:

- fast, convenient online submission
- thorough peer review by experienced researchers in your field
- rapid publication on acceptance
- support for research data, including large and complex data types
- gold Open Access which fosters wider collaboration and increased citations
- maximum visibility for your research: over 100M website views per year

#### At BMC, research is always in progress.

Learn more biomedcentral.com/submissions



# 3.2 Publication 2

#### **RESEARCH ARTICLE**

**Open Access** 



# Challenges in diagnosing dementia in patients with a migrant background - a cross-sectional study among German general practitioners

Judith Tillmann<sup>1\*</sup>, Johannes Just<sup>1</sup>, Rieke Schnakenberg<sup>1,2</sup>, Klaus Weckbecker<sup>1</sup>, Birgitta Weltermann<sup>1</sup> and Eva Münster<sup>1</sup>

#### **Abstract**

**Background:** Diagnosing dementia, a syndrome affecting 35.6 million people worldwide, can be challenging, especially in patients with a migrant background. Language barriers and language-based diagnostic tools, cultural differences in the perception of the syndrome as well as restricted access to healthcare can influence medical care. For the first time in Germany, this study investigates whether German general practitioners (GPs) feel prepared to meet the diagnostic needs of these patient groups and whether there are challenges and support needs.

**Methods:** A cross-sectional study among a random sample of 982 general practitioners in Germany was conducted from October 2017 to January 2018 (response rate: 34.5%). A self-developed, written, standardised questionnaire was used. Descriptive statistics as well as multiple logistic regression analyses were performed using data of 326 GPs.

**Results:** Ninety-six percent of GPs reported having experienced barriers at least once. Uncertainties in diagnosing dementia in patients with a migrant background were indicated by 70.9%. There was no significant association between uncertainties in diagnosing dementia and GPs' sociodemographic characteristics. The most frequently reported barriers were language barriers that affected or prevented diagnostics (89.3%) and information deficits in patients with a migrant background (59.2%). Shameful interaction or lack of acceptance of the syndrome was also common (55.5%). A demand for more information about the topic was expressed by 70.6% of GPs.

**Conclusions:** Public health measures supporting GPs in their interaction with patients with a migrant background as well as information and services for dementia patients are needed. Efforts to facilitate access to interpreting services and to focus on people with a migrant background in healthcare are necessary.

**Trial registration:** German Clinical Trials Register: DRKS00012503, date of registration: 05/09/2017 (German Institute of Medical Documentation and Information. German Clinical Trials Register (DRKS) 2017). Clinical register of the study coordination office of the University hospital of Bonn: ID530, date of registration: 05/09/2017 (Universitätsklinikum Bonn. Studienzentrum. UKB-Studienregister 2017).

Keywords: General practitioner, Dementia, Diagnostics, Migration, GP, Public health

<sup>&</sup>lt;sup>1</sup>Institute of General Practice and Family Medicine, Medical Faculty of the University of Bonn, Bonn, Germany





<sup>\*</sup> Correspondence: judith.tillmann@ukbonn.de

Tillmann et al. BMC Family Practice (2019) 20:34 Page 2 of 10

#### **Background**

#### Scientific background and relevance

Diagnosing dementia in individuals with a migrant background can be associated with various difficulties from the perspective of the diagnosing person: people with a migrant background often do not speak the national language fluently or forget the second language. Hence, difficulties in applying language-based diagnostic instruments may arise [1-4]. Cultural facors may influence attitudes and coping with dementia. Dementia and mental diseases that are often tabooed, induce feelings of shame and are therefore difficult to address. Diagnosis, therapy options and help from outside the family is sometimes not accepted [5-9]. In some cultures, family plays a central role in caring for sick family members [8-10]. According to international and European studies, migrant background was associated with reduced access to health care [3, 8, 9, 11]. Associations between low health literacy and socio-economic standing and migrant status have already been shown [12].

The increasing life expectancy associated with the ongoing demographic change is causing a steep increase in the number of people with age-related diseases like dementia. An increase of currently 35.6 million patients with dementia worldwide (2010) to 42 million patients by 2040 is predicted [13, 14]. In Germany, a country with 82.4 million inhabitants, it is likely that the number of cases will increase from 1.55 million to 3 million in 2050 [15, 16]. At the same time, the number of people with a migrant background is growing rapidly in Germany (currently 18.56 million, 22.5%). This population group is also ageing steadily and is increasingly affected by dementia as well [16]. The German Federal Statistical Office (Destatis) defines a migrant background as follows: Either the person in question or at least one parent is born without German nationality [17]. Within this group, Turkey (15.1%), Poland (10.1%) and Russia (6.6%) are the most common countries of origin in Germany [16]. However, there is no official, uniform definition at global level. Destatis reports that there are 1.86 million people with a migrant background who are aged 65 years or older and are therefore at risk of developing dementia [16]. More specifically, the "Dementia Service Centre for People With Immigration History" reports that there are 108,000 individuals with a migrant background suffering from dementia in Germany (2015) [18].

GPs play a key role in diagnostics in Germany and are in the best position to raise awareness for all types of dementia. They examine a large number of patients and are generally the first point of contact for people with any health complaints. Therefore, they are able to identify treatable causes of the syndrome

at an early stage to prevent irreversible health impairment.

According to European studies conducted by Nielsen et al., two thirds of physicians describe the diagnostics and classification of dementia in ethnic minorities as problematic [1]. On an international level, there is also evidence suggesting that dementia is underdiagnosed in immigrants and minority ethnic groups [3, 6, 19]. Despite the described increase in affected people worldwide and identified barriers in international studies, it is unknown whether doctors in Germany and other European countries are prepared to meet the diagnostic needs of these patient groups [1, 20]. Hence, the study "Barriers in GPs' dementia diagnostics in patients with migration background" (BaDeMi) is the first of its kind in Germany to focus on identifying challenges in diagnosing dementia in people with a migrant background.

#### **Objectives**

The aim of the study was to examine challenges in diagnosing dementia in patients with a migrant background in German GP practices. And if so, what challenges exist and are there information needs? Are sociodemographic characteristics of GPs associated with their confidence in diagnosing dementia in patients with a migrant background?

#### **Methods**

#### Study design

A cross-sectional study in a simple random sample without replacement of 982 GPs (response rate 34.5%; 339 GPs) was conducted. The exploratory study took place in general practitioners' practices in North Rhine-Westphalia, the most densely populated state in western Germany (17.87 million inhabitants), from October 2017 to January 2018. North Rhine-Westphalia is by far the federal state with the highest number of people with a migrant background (5,036,000; 28.4%) [21]. The definition of a migration background of the German Federal Statistical Office was used: Either the person or at least one parent is born without German nationality [17]. The standardised, self-administered, written survey included questions about GPs' experience in diagnosing dementia in patients with a migrant background and ways to improve diagnostics and support physicians. Sociodemographic data of GPs, including age, sex, language skills and migration background was collected. Five-point Likert-type scales with responses ranging from 'strongly disagree' to 'strongly agree' as well as multiple-choice questions were used as response categories. The questions were developed based on a systematic literature search in medical databases and Google Scholar. The most common

Tillmann et al. BMC Family Practice (2019) 20:34 Page 3 of 10

problems in the diagnostic process and in dealing with patients with a migrant background described in the international literature were included in the guestionnaire as questions or answer categories. In addition, free text fields were added to describe further aspects. Few questions were based on a survey developed by Australian researchers of Wicking Dementia Research & Education Centre (University of Tasmania) within the scope of a collaboration [22]. The questions were translated using the method of back-translation by an English native speaker to ensure comparability. Before conducting the study, the questionnaire was pretested by general practitioners to identify possible sources of error. Validity and reliability were not further investigated. More detailed information on the process of questionnaire develop ment are provided in the methods paper [23]. Address data of the physicians were provided by the 'Association of Statutory Health Insurance Physicians North-Rhine' upon request. The target population was contacted by the institute of general practice using a postal mail with the questionnaires enclosed. Two written, postal reminder procedures were carried out, each with a waiting period of 4 weeks. Informed consent to participate in the study was documented by answering and returning the pseudonymised question naire. The study has been registered at the German Clinical Trials Register (DRKS) (no. DRKS00012503) [24] and the clinical register of the study coordination office of the University hospital of Bonn (ID530) [25].

The following questions of the questionnaire were included in the analysis for the present study (translated from the German questionnaire). 5-point Likert scales ranging from "I don't agree at all" to "I fully agree" <sup>(a)</sup> or "never" to "very frequently" <sup>(b)</sup> as well as multiple responses with additional free-text fields <sup>(c)</sup>, multiple-choice-fields <sup>(d)</sup> and free-text fields <sup>(e)</sup> were used as response catagories:

- I feel confident in diagnosing dementia. a
- I feel confident in diagnosing dementia in people with a migrant background. <sup>a</sup>
- I feel confident about communicating the dementia diagnosis to a patient.
- I feel confident about communicating the dementia diagnosis to a patient with a migrant background. <sup>a</sup>
- I have enough knowledge about local help centers that support dementia patients and their families. <sup>a</sup>
- I have enough knowledge about local help centers that support dementia patients with a migrant background and their families.
- I have not been able to use cognitive short tests at least once due to these language difficulties between the patient with a migrant background and myself.

- What barriers have you ever experienced during dementia diagnostics?
- How have you so far dealt with language problems in dementia diagnostics between you and your patients with a migrant background?
- How often did these barriers and language problems prevent you from optimally treating a patient with a migrant background for dementia?
- Would you like to get more information on how to deal better with dementia patients with a migrant background?
- Which information are you personally interested in?
- Sociodemographic and practice-related paramaters:
   How old are you? <sup>e</sup>, Which gender do you have? <sup>d</sup>,
   Is your mother or father or were you born abroad?
   <sup>d</sup>, How long have you been working as a general practitioner so far? <sup>e</sup>, Please estimate: how high is the percentage of people with a migrant background among your patients? <sup>e</sup>

#### **Participants**

The target group of this study were general practitioners in North Rhine-Westphalia who were actively practicing medicine when the study was conducted. In order to meet the inclusion criteria, GPs had to be registered in the 'Association of Statutory Health Insurance Physicians North-Rhine' as a general practitioner on July 28th, 2017. In Germany, physicians have to be members of this association to be allowed to treat patients with statutory health insurance (87.7% of the population) [26].

#### Statistical methods

The questionnaires were scanned using the data capture system TeleForm [27]. The software IBM SPSS Statistics (Version 22) was used for data analyses [28]. Descriptive statistics including frequencies with 95% confidence intervals, medians, means and standard deviations were calculated to evaluate GPs' data. Multiple logistic regression analysis was conducted to examine the association between sociodemographic characterisitcs and GPs' confidence in diagnosing dementia in patients with a migrant background. The dependent variable was dichotomised into the categories "I fully/rather agree/ neutral" and "I fully/rather disagree". The sociodemographic variables shown in Table 1 were used as independent variables to analyse whether characteristics of GPs and their practices are associated with problems in diagnosing dementia. Variables were included in the analysis simultaneaously. All independent variables were dichotomised to reduce the degrees of freedom (Table 2). Missing data in the dependent variable were excluded from analysis. Missings in independent variables were allocated to the reference category (largeste group)

Tillmann et al. BMC Family Practice (2019) 20:34 29 Page 4 of 10

**Table 1** Characteristics of the study population and prevalence of not feeling confident in dementia diagnostics in patients with a migrant background n= 326).

	Total study population		Prevalence of not feeling confident					
	n	(%) <sup>a,b</sup>	n	(%; 95% CI) <sup>a,c</sup>				
Total	326	(100)	231	(70.9; 65.9–75.6)				
Gender								
Female	153	(46.9)	109	(71.2; 64.0–78.5)				
Male	173	(53.1)	122	(70.5; 63.7–77.4)				
Age								
< 50	105	(32.2)	69	(65.7; 56.5–74.9)				
>=50	221	(67.8)	162	(73.3; 67.4–79.2)				
GP has a migrant background								
No	278	(85.3)	200	(71.9; 66.6–77.3)				
Yes	48	(14.7)	31	(64.6; 50.6–78.6)				
Estimated percentage of patients with a migrant background in the practice								
1-20%	251	(77.0)	174	(69.3; 63.6–75.1)				
> 20%	75	(23.0)	57	(76.0; 66.1–85.9)				

<sup>a</sup>Missing cases were allocated to the reference category of logistic regression (age: n=9 (2.8%), gender: n=0, GP has a migrant background: n=4 (1.2%), estimated percentage of patients with a migrant background: n=10 (3.1%)). Missings in the dependent variables were excluded (n=11; 3.2%). <sup>b</sup>column percentages; <sup>c</sup> row percentages.

because they did not exceed a predetermined limit of 6%. Crude odds ratios (OR) with 95% confidence intervals (CI) were calculated. To control for confounding, odds ratios adjusted for age, gender, migration background and percentage of patients with a migrant background (aOR) with 95% CI were computed for all

participants. Crude and adjusted odds ratios stratified by gender were computed to consider potential effect modification. A p-value < 0.05 was considered significant.

#### **Results**

#### Characteristics of the study population

A response rate of 34.5% was achieved. Thirty percent of male and 36.2% of female GPs participated in the survey. A total of 326 GPs were included in the analyses as shown in Fig. 1. The mean age of participants was 53.5 years (SD =  $\pm 8.9$ ). The average duration of practicing as a GP was 16.9 years (SD =  $\pm 10.0$ ). The sex ratio of participants was nearly balanced (53.1% male, 46.9% female). GPs estimated the amount of their patients with a migrant background to be 16.7% on average. About 14.7% of GPs stated having a migrant background themselves. Characteristics of the study population are summarised in Table 1.

#### GPs' problems in diagnosing dementia

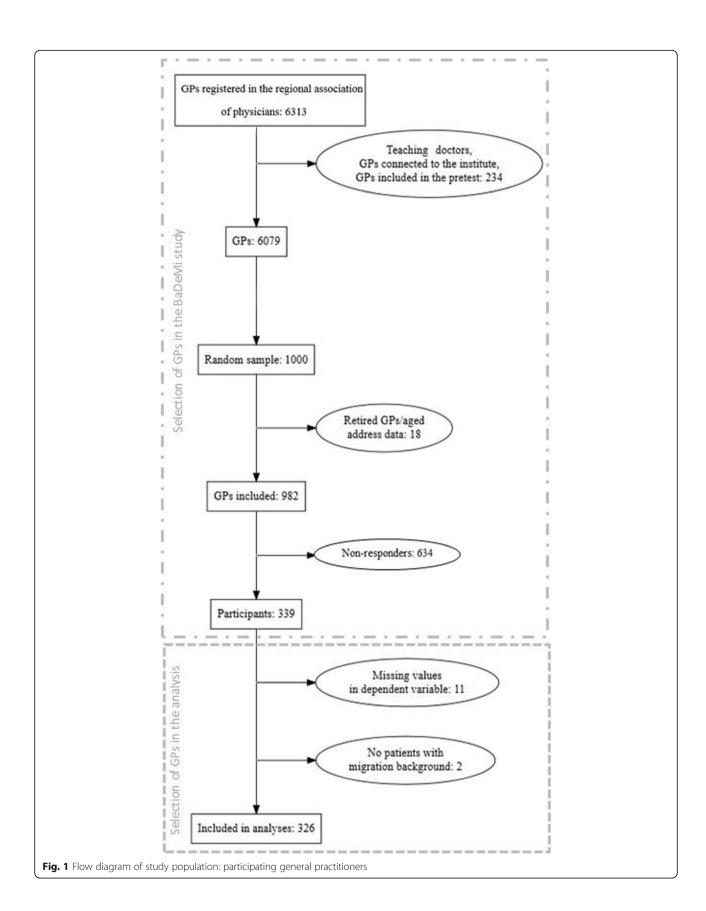
Ninety-six percent of GPs (n=326) experienced at least one barrier in the course of diagnosing dementia in their patients with a migrant background. Because of these barriers, 88.2% reported that they were not able to treat a patient with migrant background as they wished (18.1% of them answering "often" or "very often"). Feeling "not or rather not" confident in diagnosing dementia in people with a migration background was stated by 70.9%. Only 6.7% felt very confident (Fig. 2). The comparison of this value with the confidence in diagnostics among GPs' patients

Table 2 GPs lack of confidence in diagnosing dementia in patients with a migrant background

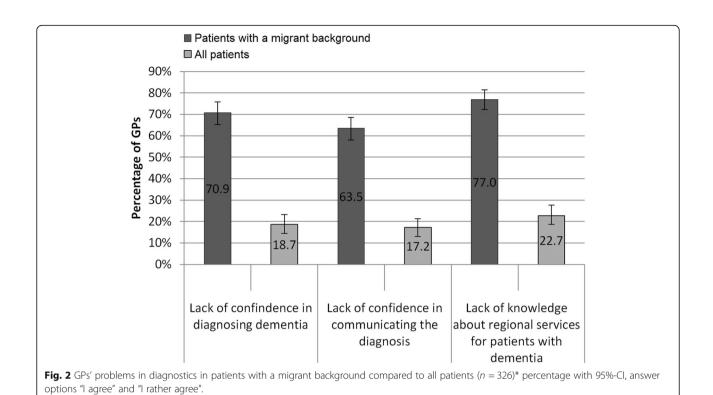
		2 2			,	
	OR (95% CI) total <sup>a</sup> (n = 326)	aOR (95% CI) total $^{\rm b}$ ( $n = 326$ )	OR (95% CI) men <sup>a</sup> $(n = 173)$	aOR (95% CI) men <sup>b</sup> (n = 173)	OR (95% CI) women $^{a}$ ( $n = 153$ )	aOR (95% CI) women <sup>b</sup> (n = 153)
Gender						
Female	1.04 (0.64–1.67)	1.06 (0.66–1.72)	-	-	-	-
Male	ref.	ref.	_	_	_	_
Age						
< 50	0.70 (0.42-1.15)	0.68 (0.40-1.13)	0.60 (0.30-1.20)	0.59 (0.29–1.21)	0.82 (0.40-1.69)	0.78 (0.38–1.64)
>=50	ref.	ref.	ref.	ref.	ref.	ref.
GP has a i	migrant background					
No	ref.	ref.	ref.	ref.	ref.	ref.
Yes	0.71 (0.37-1.36)	0.69 (0.36–1.33)	0.47 (0.20-1.12)	0.46 (0.19–1.13)	1.17 (0.43-3.20)	1.21 (0.44–3.34)
Estimated	percentage of patient	ts with a migrant backg	ground in the practice			
1-20%	ref.	ref.	ref.	ref.	ref.	ref.
> 20%	1.40 (0.77-2.54)	1.50 (0.82-2.74)	0.92 (0.43-2.01)	1.12 (0.50–2.52)	2.41 (0.92-6.27)	2.45 (0.94–6.40)

<sup>&</sup>lt;sup>a</sup>crude odds ratios with 95% confidence intervals (CI) estimated from logistic regression. Missing cases in the independent variables were allocated to the reference category (age: n = 9 (2.8%), gender: n = 0, GP has a migrant background: n = 4 (1.2%), estimated percentage of patients with a migrant background: n = 10 (3.1%)). Missings in the dependent variables were excluded (n = 11; 3.2%).

<sup>&</sup>lt;sup>b</sup>Adjusted odds ratios with 95% confidence intervals (CI) estimated from logistic regression (adjustment for the other sociodemographic and practice-related determinants of the model, method: enter).



Tillmann et al. BMC Family Practice (2019) 20:34 Page 6 of 10



overall shows lower values of 18.7% (not confident/rather not confident). GPs aged 50 years or older, without a migrant background themselves, and treating many patients with a migrant background reported being less confident in diagnosing dementia in patients with a migrant background (Table 1). Especially female GPs with more than 20% of patients with a migrant background reported uncertainties in diagnostics. However, these associations were not found to be significant in logistic regression analysis (Table 2). Moreover 69.9% experienced being unable to perform cognitive short tests because of communication problems with patients with a migrant background. Other values comparing GPs answers are

#### Most common barriers and information needs

shown in Fig. 2.

The most common barriers experienced at least once by GPs in diagnosing dementia in their patients with a migrant background are presented in Fig. 3: The most commonly reported problem was a language barrier that impeded the diagnostic process or made it impossible (89.3% of GPs). To deal with these communication problems, 90.5% of participants reported involving family members or friends of the patient as interpreters or practice staff (27.6%). 26.1% referred patients to a physician with necessary language knowledge. A share of 8.3% used the help of a professional interpreter. 8.0% provided information material in a foreign language and

7.1% referred their patient to a foreign-language service point (multiple answers possible).

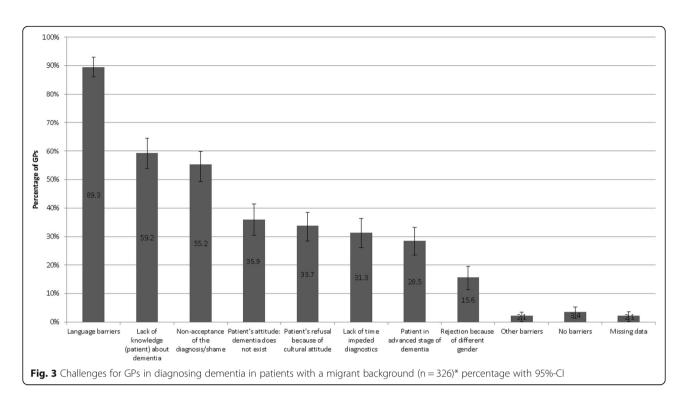
70.6% of GPs expressed a demand for more information on how to better treat patients with dementia and a migrant background. Specific diagnostic tools (39.9%), dealing with language barriers (45.7%) and cultural challenges as well specialised services for patients with a migrant background (53.7%) represented key interests.

#### **Discussion**

#### Key findings and interpretation

The present study revealed a wide range of unmet challenges that GPs face in diagnosing dementia in patients with migrant background. According to GPs, these problems lead to a lack of confidence in the diagnostic process and in communicating the diagnosis. Descriptive analysis found GPs aged 50 years or older, those without a migrant background themselves and those treating many patients with a migrant background in their practices to report uncertainties more frequently. However, no proof of significance of these differences was established in logistic regression analysis. Factors impeding diagnostics are multifaceted and include language barriers between GPs and patients with a migrant background but also lack of knowledge about the syndrome and possible non-acceptance in migrants. As a consequence, nearly 90% of GPs experienced personal limitations when treating patients with a migrant background. Over 70% of GPs expressed a demand for more

Tillmann et al. BMC Family Practice (2019) 20:34 Page 7 of 10



information on the topic. In line with international studies, our results clearly emphasise the need to support GPs in providing healthcare to patients with a migrant background.

Our study is the first in Germany to examine problems in diagnosing dementia in people with a migrant background in primary care. Results may be internationally transferable and may be an explanation for the potential underdiagnosis and late diagnosis of dementia in people with a migrant background described in former studies [3, 29, 30]. Uncertainties in diagnosing dementia and GPs' lack of knowledge about regional services have also been reported in other studies: Cahill et al. [31] found that 30% of Irish GPs showed lack of confidence and Pathak et al. reported that more than 46% of GPs were not or not at all confident in the process of diagnosing dementia in all patients[32]. Pathak et al. report that more than half of the 380 GPs in their study were unaware of any dementia care services in their local area [32]. Turner et al. also found that more than half of GPs in their study reported lack of knowledge about dementia patients' support groups in their area [33]. The results of the present study found an even higher proportion of GPs being uncertain in diagnosing dementia concerning patients with a migrant background. This finding suggests that these patients in particular require special attention. Our results highlight the need to prepare GPs for challenges linked to dealing with patients with a migrant background, to inform them about their options and ways of handling barriers. Cultural differences in dealing with the syndrome and risks of using non-professional interpreters should be highlighted. Ways to find information as well as regional, native-language services for patients with a migrant background should be clarified. The percentage of patients with a migrant background estimated by GPs is lower than the official statistics for the region. This result suggests that GP services are either used less frequently by patients with a migrant background in general or the migrant background of patients often goes unnoticed by GPs. There are international results that patients with a migrant background generally use healthcare services less often [6, 11, 34] and later after the onset of dementia symptoms [3, 8].

The lack of knowledge, acceptance and shame regarding dementia which physicians perceived in migrant patients is likely multicausal: the average level of education of people with a migrant background in Germany is lower than that of people without a migrant background. According to the Federal Office for Migration and Refugees (BAMF) and the German Institute for International Educational Research, number of individuals with a lower secondary education is three times higher among foreign nationals living in Germany than in German nationals. Only 23.7% (compared to 44.2% of Germans) graduate with an A level diploma, the highest school degree in Germany [35, 36]. Since a high level of education is needed to study medicine in Germany, the on average lower educational level may be a reason for the

Tillmann et al. BMC Family Practice (2019) 20:34 Page 8 of 10

relatively low proportion of healthcare providers with a migrant background in our study. However, there are also diverse cultural circumstances that must be taken into account: dementia and its connected diseases are often not accepted as medical problems or do not exist in some cultures [5-9]. "Forgetfulness" can be regarded as a normal consequence of aging and individuals may attempt to conceal it from others. The syndrome can be accompanied by the refusal of care, since this is regarded as a family duty [4, 8-10]. However, the role of the family in providing care can also be considered a resource as long as the family is able to deal with the situation. Feelings of shame associated with dementia and tabooing of the syndrome and other mental health impairments have already been identified in other studies [37, 38]. At this point, however, it should also be considered that cultural differences and other barriers mentioned by GPs reflect the subjective view of the GPs. Factors impeding the diagnosis of dementia such as shame and refusal may also be due to other factors such as a low level of education and poor health literacy. These barriers may be tackled by increasing knowledge about the disease [39]. In line with previous studies, these findings highlight a strong need for clear, accessible and understandable information for patients about dementia and underlying diseases [2, 10]. Providing material in different languages and native-language regional information centres and care facilities are necessary to ensure high-quality health care for the entire population. GPs could refer their patients to the centres for more information which may, in turn, reduce GPs' workload. Currently, these multilingual service centres for dementia patients are rare in Germany.

The frequently reported language barriers that impair the diagnosis of dementia in the present study are in accordance with Australian [2] Belgian [3], Swedish [4] and European [1] studies. Dementia screening instruments like cognitive short tests are primarily language -based and not suitable for all patient groups of other cultures and native languages [1, 6, 40]. Action should be taken to develop language- and culture-independent diagnostic tools and to facilitate access to professional interpreters. In our study mainly non-professionals were reported to act as interpreters during the diagnosis of dementia, more frequently than in other medical settings that have been studied thus far [1, 41]. Since mental symptoms or disorders are often tabooed or associated with shame [5–9], non-professional interpreters such as family members or friends may distort the translation and skip the unpleasant or burdensome diagnosis or symptoms [42]. The small number of GPs who worked with a professional interpreter may be due to the lack of reimbursement in general practitioners' practices [43]. It would be desirable to establish a pool of interpreters and to facilitate access in GP practices.

#### Limitations

Although our study addressed GPs who usually come into frequent contact with migrant patients [26], some study limitations must be taken into account: Other health professionals such as neurologists and nursing staff, were not included. A response bias cannot be excluded as the responding GPs may be more interested in the topic than non-respondents. Results might differ from other parts of Germany, for example areas with a lower proportion of people with a migrant background, differing patient populations and service infrastructure. However, since characteristics of GPs, such as the age patterns, are similar to sociodemographic characteristics of GPs at national level, the results may allow generalisation [44]. Barriers and problems identified in this study may not be transferable to all migrant populations because of heterogeneous cultures, religions and views existing even within countries.

#### **Conclusion**

Taking into account the increasing proportion of elderly people and individuals with a migrant background in the population, the development of public health measures and diagnostic tools suitable for all population groups to support GPs in their interaction with these patients is needed. The development of regional service points for dementia patients and strategies to disseminate information are desirable. Efforts to facilitate access to interpreting services and to support high quality healthcare for migrants are needed.

#### Abbreviations

aOR: Adjusted odds ratio; Cl: Confidence interval; Destatis: German Federal Statistical Office; DRKS: German Clinical Trials Register; GP: General practitioner; OR: Odds ratio; Ref: Reference category; SD: Standard deviation

#### Acknowledgements

Many thanks to the German Alzheimer Society for financing the study. Many thanks to all GPs who participated in the study. The authors thank the two reviewers for their valuable feedback that led to a significant improvement of the article.

#### Fundina

The project is funded by the German Alzheimer Society.

#### Availability of data and materials

The dataset generated and analysed during the current study is available from the corresponding author on reasonable request.

#### Authors' contributions

JT performed study coordination, mainly developed the questionnaire, conducted the study, data analysis and prepared the manuscript. EM is the project leader and advised on all important steps. KW, JJ and RS advised on planning and conducting the study and contributed parts of the discussion. BW enriched the study with her practical knowledge and contributed parts of the discussion. All authors have read and approved the final manuscript.

#### Ethics approval and consent to participate

The University of Bonn Medical Faculties Ethics Committee reviewed and approved this study (reference number: 251/17). A consent to participate is not applicable since it was voluntary, no identifiable material is published and a participation is regarded as an acceptance.

#### Consent for publication

No identifiable material is published and therefore no consent to publish is required.

#### Competing interests

The authors declare that they have no competing interests.

#### **Publisher's Note**

Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

#### **Author details**

<sup>1</sup>Institute of General Practice and Family Medicine, Medical Faculty of the University of Bonn, Bonn, Germany. <sup>2</sup>Department of Health Services Research, Carl von Ossietzky University Oldenburg, Oldenburg, Germany.

# Received: 20 September 2018 Accepted: 14 February 2019 Published online: 25 February 2019

#### References

- Nielsen TR, Vogel A, Riepe MW, de Mendonca A, Rodriguez G, Nobili F, et al. Assessment of dementia in ethnic minority patients in Europe: a European Alzheimer's disease consortium survey. Int Psychogeriatr. 2011;23:86–95. https://doi.org/10.1017/S1041610210000955.
- Boughtwood D, Shanley C, Adams J, Santalucia Y, Kyriazopoulos H, Pond D, Rowland J. Dementia information for culturally and linguistically diverse communities: sources, access and considerations for effective practice. Aust J Prim Health. 2012;18:190–6. https://doi.org/10.1071/PY11014.
- Segers K, Benoit F, Colson C, Kovac V, Nury D, Vanderaspoilden V. Pioneers in migration, pioneering in dementia: first generation immigrants in a European metropolitan memory clinic. Acta Neurol Belg. 2013;113:435–40. https://doi.org/10.1007/s13760-013-0245-z.
- Söderman M, Rosendahl SP. Caring for ethnic older people living with dementia - experiences of nursing staff. J Cross Cult Gerontol. 2016;31:311– 26. https://doi.org/10.1007/s10823-016-9293-1.
- Liu D, Hinton L, Tran C, Hinton D, Barker JC. Reexamining the relationships among dementia, stigma, and aging in immigrant Chinese and Vietnamese family caregivers. J Cross Cult Gerontol. 2008;23:283–99. https://doi.org/10. 1007/s10823-008-9075-5.
- Daker-White G, Beattie AM, Gilliard J, Means R. Minority ethnic groups in dementia care: a review of service needs, service provision and models of good practice. Aging Ment Health. 2002;6:101–8. https://doi.org/10.1080/ 13607860220126835.
- Eh K, McGill M, Wong J, Krass I. Cultural issues and other factors that affect self-management of type 2 diabetes mellitus (T2D) by Chinese immigrants in Australia. Diabetes Res Clin Pract. 2016;119:97–105. https://doi.org/10. 1016/j.diabres.2016.07.006.
- Mukadam N, Cooper C, Basit B, Livingston G. Why do ethnic elders present later to UK dementia services? A qualitative study. Int Psychogeriatr. 2011; 23:1070–7. https://doi.org/10.1017/S1041610211000214.
- Mukadam N, Cooper C, Livingston G. A systematic review of ethnicity and pathways to care in dementia. Int J Geriatr Psychiatry. 2011;26:12–20. https://doi.org/10.1002/gps.2484.
- Shanley C, Boughtwood D, Adams J, Santalucia Y, Kyriazopoulos H, Pond D, Rowland J. A qualitative study into the use of formal services for dementia by carers from culturally and linguistically diverse (CALD) communities. BMC Health Serv Res. 2012;12:354. https://doi.org/10.1186/1472-6963-12-354.
- Lindert J, Schouler-Ocak M, Heinz A, Priebe S. Mental health, health care utilisation of migrants in Europe. Eur Psychiatry. 2008;23:14–20. https://doi. org/10.1016/S0924-9338(08)70057-9.
- World Health Organization. Health literacy. In: The solid facts. Geneva: World Health Organization; 2013.
- Ferri CP, Prince M, Brayne C, Brodaty H, Fratiglioni L, Ganguli M, et al. Global prevalence of dementia: a Delphi consensus study. Lancet. 2005;366:2112–7. https://doi.org/10.1016/S0140-6736(05)67889-0.

- 14. Doblhammer G. Demografie der Demenz. 1st ed. Bern: Huber; 2012.
- Doblhammer G, Scholz R. Ageing, care need and quality of life. Springer Fachmedien: Wiesbaden: 2010.
- Statistisches Bundesamt. Bevölkerung und Erwerbstätigkeit: Bevölkerung mit Migrationshintergrund. In: Ergebnisse des Mikrozensus 2016; 2017.
- Statistisches Bundesamt (Destatis). Bevölkerung und Erwerbstätigkeit. In: Bevölkerung mit Migrationshintergrund: - Ergebnisse des Mikrozensus 2015. Wiesbaden: Destatis: 2016.
- Deutsche Alzheimer Gesellschaft e. V. Selbsthilfe Demenz. Demenz und Migration. Alzheimer Info Nachrichten der Deutschen Alzheimer Gesellschaft Selbsthilfe Demenz 2015;1.
- Diaz E, Kumar BN, Engedal K. Immigrant patients with dementia and memory impairment in primary health care in Norway: a national registry study. Dement Geriatr Cogn Disord. 2015;39:321–31. https://doi.org/10.1159/ 000375526.
- Piechotta G, Matter C. Die Lebenssituation demenziell erkrankter türkischer Migranten/–innen und ihrer Angehörigen. Z Gerontopsychol Psychiatrie. 2008;21:221–30. https://doi.org/10.1024/1011-6877.21.4.221.
- 21. Statistisches Bundesamt. Bevölkerung mit Migrationshintergrund. Ergebnisse des Mikrozensus: Fachserie 1 Reihe 2.2.
- Mason RL, Annear MJ, Lo A, McInerney F, Tierney LT, Robinson AL. Development and preliminary psychometric properties of the general practitioner attitudes and confidence scale (GPACS-D) for dementia. BMC Fam Pract. 2016;17:105. https://doi.org/10.1186/s12875-016-0506-z.
- Tillmann J, Schnakenberg R, Puth M-T, Weckbecker K, Just J, Münster E. Barriers in general practitioners' dementia diagnostics among people with a migration background in Germany (BaDeMi) - study protocol for a crosssectional survey. BMC Med Res Methodol. 2018;18:124. https://doi.org/10. 1186/s12874-018-0580-0.
- German Institute of Medical Documentation and Information. German Clinical Trials Register (DRKS) 2017. http://apps.who.int/trialsearch/Trial2. aspx?TrialID=DRKS00012503.
- Universitätsklinikum Bonn. Studienzentrum. In: UKB-Studienregister; 2017. https://www.studienzentrumbonn.de.
- Statistisches Bundesamt. Sozialleistungen. Angaben zur Krankenversicherung: (Ergebnisse des Mikrozensus). Wiesbaden: Statistisches Bundesamt (Destatis); 2016.
- 27. Electric Paper Informationssysteme GmbH. TeleForm. Lüneburg: Electric Paper
- 28. IBM Corp. IBM SPSS statistics. Armonk, NY: IBM Corp; 2016.
- LoGiudice D, Hassett A, Cook R, Flicker L, Ames D. Equity of access to a memory clinic in Melbourne? Non-English speaking background attenders are more severely demented and have increased rates of psychiatric disorders. Int J Geriatr Psychiatry. 2001;16:327–34.
- 30. Nielsen TR, Vogel A, Phung TKT, Gade A, Waldemar G. Over- and under-diagnosis of dementia in ethnic minorities: a nationwide register-based study. Int J Geriatr Psychiatry. 2011;26:1128–35. https://doi.org/10.1002/gps.
- Cahill S, Clark M, Walsh C, O'Connell H, Lawlor B. Dementia in primary care: the first survey of Irish general practitioners. Int J Geriatr Psychiatry. 2006;21: 319–24. https://doi.org/10.1002/gps.1464.
- 32. Pathak KP, Montgomery A. General practitioners' knowledge, practices, and obstacles in the diagnosis and management of dementia. Aging Ment Health. 2015;19:912–20. https://doi.org/10.1080/13607863.2014.976170.
- Turner S, Iliffe S, Downs M, Wilcock J, Bryans M, Levin E, et al. General practitioners' knowledge, confidence and attitudes in the diagnosis and management of dementia. Age Ageing. 2004;33:461–7. https://doi.org/10. 1093/ageing/afh140.
- Lindsay J, Hebert R, Rockwood K. The Canadian study of health and aging: risk factors for vascular dementia. Stroke. 1997;28:526–30.
- Deutsches Institut für Internationale P\u00e4dagogische Forschung. Bildung in Deutschland 2016 - Ein indikatorengest\u00fctzter Bericht mit einer Analyse zur Bildung und Migration. 2016.
- Bundesamt für Migration und Flüchtlinge. Schulische Bildung von Migranten in Deutschland. In: Integrationsreport. Berlin: Bundesamt für Migration und Flüchtlinge; 2008.
- Nielsen TR, Waldemar G. Knowledge and perceptions of dementia and Alzheimer's disease in four ethnic groups in Copenhagen, Denmark. Int J Geriatr Psychiatry. 2016;31:222–30. https://doi.org/10.1002/gps.4314.
- 38. van Wezel N, Francke AL, Kayan Acun E, Deville WL, van Grondelle NJ, Blom MM. Explanatory models and openness about dementia in migrant

- communities: a qualitative study among female family carers. Dementia (London). 2016. https://doi.org/10.1177/1471301216655236.
- 39. Seeleman C. Cultural competence and diversity responsiveness: How to make a difference in healthcare? [S.L.]. Amsterdam: BOXPress; Universiteit van Amsterdam [Host]; 2014.
- Parker C, Philp I. Screening for cognitive impairment among older people in black and minority ethnic groups. Age Ageing. 2004;33:447–52. https://doi. org/10.1093/ageing/afh135.
- Nielsen TR, Andersen BB, Kastrup M, Phung TKT, Waldemar G. Quality of dementia diagnostic evaluation for ethnic minority patients: a nationwide study. Dement Geriatr Cogn Disord. 2011;31:388–96. https://doi.org/10.1159/ 000327362.
- 42. Flores G. The impact of medical interpreter services on the quality of health care: a systematic review. Med Care Res Rev. 2005;62:255–99. https://doi.org/10.1177/1077558705275416.
- Meeuwesen L, Twilt S, ten TJD, Harmsen H. "ne diyor?" (what does she say?): informal interpreting in general practice. Patient Educ Couns. 2010;81:198– 203. https://doi.org/10.1016/j.pec.2009.10.005.
- Kopetsch T. Dem deutschen Gesundheitswesen gehen die Ärzte aus!: Studie zur Altersstruktur- und Arztzahlentwicklung. 5th ed. Köln: KBV; Bundesärztekammer; 2010.

#### Ready to submit your research? Choose BMC and benefit from:

- fast, convenient online submission
- thorough peer review by experienced researchers in your field
- rapid publication on acceptance
- support for research data, including large and complex data types
- gold Open Access which fosters wider collaboration and increased citations
- maximum visibility for your research: over 100M website views per year

#### At BMC, research is always in progress.

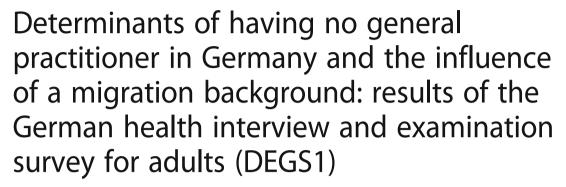
Learn more biomedcentral.com/submissions



# 3.3 Publication 3

## **RESEARCH ARTICLE**

**Open Access** 





Judith Tillmann<sup>1\*</sup>, Marie-Therese Puth<sup>1,2</sup>, Laura Frank<sup>3</sup>, Klaus Weckbecker<sup>1</sup>, Manuela Klaschik<sup>1</sup> and Eva Münster<sup>1</sup>

#### **Abstract**

**Background:** It is aspired in the German healthcare system that general practitioners (GPs) act as initial contact for patients and guide through at all steps of medical treatment. This study aims at identifying factors associated with the odds of having no GP within the general population and especially among people with migration background.

**Methods:** This cross-sectional analysis was based on the "German Health Interview and Examination Survey for Adults" (DEGS1) conducted by the Robert Koch Institute. Descriptive analyses as well as multiple logistic regression models were performed to analyse the impact of a migration background, age, gender, residential area, socioeconomic status (SES) and other factors on having no GP among 7755 participants.

**Results:** 9.5% of the total study population and 14.8% of people with a migration background had no GP, especially men, adults living in big cities and without chronic diseases. The odds of not having a GP were higher for people with a two-sided migration background (aOR: 1.90, 95% Cl: 1.42–2.55). Among the population with a migration background, particularly young adults, men, people living in big cities and having a private health insurance showed higher odds to have no GP.

**Conclusions:** It is necessary to investigate the causes of the differing utilization of healthcare of people with a migration background and, if necessary, to take measures for an equal access to healthcare for all population groups. Further research needs to be done to evaluate how to get young people into contact with a GP.

Keywords: Migration, General practitioner, Use of health services, DEGS

## **Background**

Ambulatory medical care in Germany is almost entirely carried out by registered physicians, comprising GPs as well as other specialized physicians [1]. These physicians treat patients, refer them to other specialists or send them to hospitals [1]. Although patients in Germany are generally free to choose their primary healthcare provider, this role should mainly be assumed by general practitioners (GPs). It is aspired that GPs act as guides

at all steps of treatment [2]. Better health outcomes through GP-centered healthcare in Germany, especially among older or chronically ill patients, have already been described [3, 4]. International research has been limited to the frequency of use of GPs by the general population [5–8]. Yet it is important to initiate research earlier to find out what drives or deters people to have a GP or not. Especially the establishment of contact by people with a migration background requires particular attention as a less frequent use of healthcare in general [9, 10] and delayed help-seeking behavior have been registered in international studies [11, 12].

Full list of author information is available at the end of the article



<sup>\*</sup> Correspondence: Judith.tillmann@ukbonn.de

<sup>&</sup>lt;sup>1</sup>Institute of General Practice and Family Medicine, University of Bonn, 53127 Bonn, Germany

The German Federal Statistical Office (Destatis) defines migration background as follows: Either a person his- or herself or at least one parent is born without German nationality [13]. According to the Microcensus 2016, a representative household survey of the official statistics in Germany, 22.5% of the population in Germany shares this characteristic. A further increase in future is predicted [14]. Among this group, Turkey (15.1%), Poland (10.1%) and Russia (6.6%) represent the most common countries of origin [14]. The establishment of contact with primary care by people with a migration background has not yet been analysed in Germany. Only very few findings about the use of healthcare services in general can be summarised: A less frequent utilization of preventative programs, for example medical examinations, preventive dentistry and flu vaccinations as well as rehabilitation measures by citizens with a migration background in Germany have already been described [15-17]. In Danish and Australian studies more visits of emergency departments by patients with a migration background have been reported [18, 19]. Barriers in access to primary care have been identified as the reason in a Danish study [19]. These findings indicate a probable misdistribution of citizens with foreign origin in the healthcare system that needs to be researched in more detail.

The aim of this study was to investigate determinants of not having a GP to visit first in case of any health problem. The focus was set on sociodemographic and health characteristics and their association with having no GP. Furthermore, it was examined whether having no GP differed between people with and without a migration background and which factors were connected to that.

### **Methods**

The German Health Interview and Examination Survey for Adults (DEGS) is part of the health monitoring carried out by the Robert Koch Institute (RKI) [20]. The RKI is the central federal institution responsible for disease control and prevention. The most current wave (DEGS1) was conducted between November 2008 and December 2011 and included examinations, interviews and tests among 18- to 79-year-olds living in Germany. A random sample from local population registries was combined with the participants of the German National Health Interview and Examination Survey 1998 (GNHIES98), who re-participated. In total, 8152 persons took part, among them 4193 newly invited participants (response 42%) and 3959 who had previously taken part in GNHIES98 (response 62%). The concept and design of DEGS1 have already been described in detail elsewhere [21-23]. The net sample (n = 7987) permits representative cross-sectional and time trend analyses. In order to compensate for the empirically lower participation rate of persons without German nationality, an oversampling by a factor of 1.5 was performed. In order to lower language barriers, translations of the consent forms and of the health questionnaires were offered in English, Russian, Serbo-Croatian and Turkish.

In the present analysis, having a GP or not was used as outcome measure and was assessed with the following question: "Do you have a GP to visit first in case of any health problems?". Only by answering in the affirmative it was assumed that participants had a GP.

The migration background of a participant was considered as potential influence factor on the outcome of having no GP. Within DEGS1, participants with migration background were distinguished between a one-sided and two-sided migration background. People who have immigrated from another country and have at least one parent who was not born in Germany or adults with both parents not born in Germany were regarded as participants with a two-sided migration background. People who were born in Germany and only have one parent who was not born in Germany were considered as participants with a one-sided migration background. Participants who immigrated themselves were considered to be migrants of the first generation. Those with a migration background who were born in Germany were assigned to the second generation. More details have already been published [24].

Further factors included in the analysis were age, gender, residential area, SES, marital status, longer working hours, general state of health, the presence of chronic diseases, type of health insurance and language skills. Knowledge of the German language was only considered for participants with migration background (Table 3). Age, residential area, marital status, general state of health and the presence of chronic diseases were classified as shown in Table 1. The SES was categorised into low, medium or high status depending on the value of a multidimensional index with information on education, professional status and net household income of the participants [23]. The usual number of working hours per week was used to generate a variable (long working hours) with a cut-point at 50 h per week. Health insurance was grouped into statutory health insurance, private health insurance and other (including no insurance, direct payer, foreign health insurance or any other kind of reimbursement). To enable logistic regression analyses among the smaller population group of adults with a migration background, categories of the independent variables have been dichotomised (except "chronic diseases" because of 6% missing values) to reduce the amount of degrees of freedom.

Absolute frequencies, percentages and 95% confidence intervals (CI) were determined. Bivariate differences

**Table 1** Characteristics of the study population and percentage with no GP (DEGS1)

	Study population (total) n <sup>a</sup> (% <sup>b</sup> )	% (95% CI) <sup>b</sup> of total population with no GP	p value <sup>c</sup>
Total	7755 (100)	9.5 (8.4–10.7)	
Migration background			***
One-sided	349 (4.8)	8.0 (5.1–12.2)	
Two-sided	753 (15.1)	16.9 (13.7–20.7)	
No	6552 (80.1)	8.1 (7.1–9.3)	
Gender			***
Male	3682 (49.7)	11.4 (10.0–13.0)	
Female	4073 (50.3)	7.6 (6.4–9.0)	
Age group (years)			***
18–29	1063 (19.1)	17.9 (14.8–21.4)	
30–44	1693 (25.4)	11.8 (9.9–14.1)	
45–64	3051 (36.5)	6.6 (5.5–8.0)	
65–79	1948 (19.0)	3.3 (2.4–4.6)	
Residential area (inhabitants)			***
Rural (< 5000)	1428 (16.2)	5.5 (4.2–7.1)	
Small town (5000 - < 20,000)	1904 (23.3)	7.3 (5.7–9.2)	
Medium-sized town (20,000 - < 100,000)	2244 (29.5)	8.0 (6.6–9.7)	
Big city (100,000+)	2179 (31.0)	14.6 (12.3–17.3)	
Marital status			***
Married	5051 (62.3)	7.4 (6.3–8.6)	
Single	1670 (26.5)	15.9 (13.5–18.6)	
Divorced/widowed	957 (11.2)	6.2 (4.4–8.6)	
SES			***
Low	1167 (18.9)	10.1 (7.9–12.7)	
Medium	4654 (60.6)	7.9 (6.7–9.2)	
High	1903 (20.4)	13.8 (11.4–16.5)	
Excess work (≥50 h/week)			***
Yes	592 (8.3)	13.7 (10.8–17.3)	
No	3839 (54.9)	10.6 (9.1–12.3)	
Non-working/65+ years	3196 (36.8)	6.9 (5.7–8.4)	
General state of health			***
Very good/good	5723 (75.2)	10.9 (9.6–12.4)	
Average/bad/very bad	2005 (24.8)	5.1 (3.8–6.7)	
Chronic diseases			***
Yes	2504 (30.4)	3.7 (2.8–5.0)	
No	4875 (69.6)	11.9 (10.4–13.6)	
Health insurance			***
Statutory	6749 (87.9)	8.3 (7.2–9.6)	
Private	527 (6.7)	19.6 (15.5–24.5)	
Others	468 (5.4)	16.0 (11.9–21.2)	

<sup>&</sup>lt;sup>a</sup>Unweighted n may not add up to total n due to missing responses <sup>b</sup> Weighted results to match the German population structure on 31th December 2010 <sup>c</sup>P values: Comparison between adults having a GP and having no GP, \*\*\* p < 0.001 \*\* p < 0.01 \* p < 0.05

between adults having and not having a GP were evaluated using Chi-square tests and a p-value < 0.05 was considered significant. Multiple logistic regression analyses with having no GP as dependent variable were performed. Logistic regression analysis was performed for the total study population, separately for men and women and additionally with focus only on participants with migration background. Adjusted odds ratios (aOR) with 95%-CI were computed. For all independent variables, missing responses were allocated to the reference category in the logistic regression analysis if they did not exceed 5% of cases. Additional analyses restricted to participants with valid data on all independent variables in regression (complete cases) showed similar results to the main analysis (see Additional files 1 and 2). To correct for any deviations of the DEGS1 study population from the German general population, analyses were weighted according to the standardised weighting factor by the Robert-Koch Institute [23]. To take into account both the weighting as well as the correlation of the participants within a community, the confidence intervals were determined with SPSS-25 procedures for complex samples [25].

#### **Results**

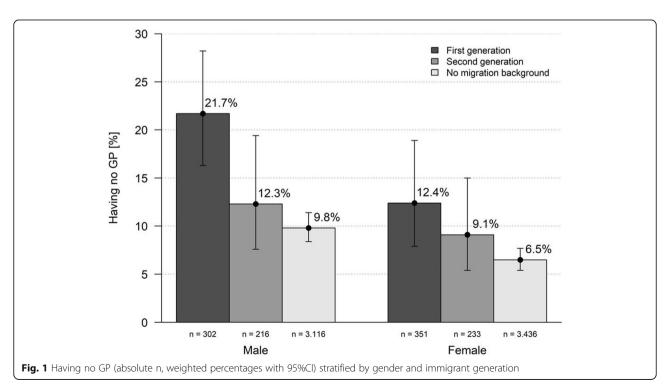
The total number of participants aged 18 to 79 years was 7987. Of those, 232 participants were excluded from the analysis due to missing responses regarding data on having a GP. The study population included 7755 participants with a balanced sex ratio and most participants

aged between 45 and 64 years; 1102 (19.9%) of them had a migration background (Table 1).

Having no GP was more common in adults with migration background (14.8% in total) than in adults without migration background (8.1%) (Table 3). Men (11.4%) showed significantly higher rates of having no GP than women (7.6%). Adults of the youngest age group (17.9%), adults living in big cities (14.6%) as well as single participants (15.9%) stated significantly more often to have no GP. People with low (10.1%) or high SES (13.8%) stated significantly more often to have no GP than people with a medium SES (7.9%). Having no GP was significantly less likely for adults with an average, bad or very bad general state of health (5.1%), for adults with chronic diseases (3.7%) and for adults with a statutory health insurance (8.3%) (Table 1).

People of the first or second generation of migration more frequently had no GP than people without a migration background, especially men (Fig. 1).

The odds of having no GP were higher for adults with a two-sided migration background than for adults without migration background (aOR: 1.90, 95%-CI: 1.42–2.55) (Table 2). Stratification for gender limited that significant effect to male participants with a migration background (aOR: 2.33, 95% CI: 1.54–3.55). Besides, significant effects could be identified in gender, age, residential area, SES, the presence of chronic diseases and the type of health insurance. Men stated more frequently to have no GP than women (aOR: 1.41, 95% CI: 1.15–1.74). Adults of the youngest age group were more than



**Table 2** Study population: having no GP with adjusted odds ratios (aOR) and 95% confidence intervals (CI) estimated from logistic regression stratified by gender (DEGS1)

	Having no GP			
	Total $(n = 7755)$	Men (n = 3682)	Women (n = 4073)	
	aOR (95% CI) <sup>a</sup>	aOR (95% CI) <sup>a</sup>	aOR (95% CI) <sup>a</sup>	
Migration background	***	***		
One-sided	0.86 (0.50-1.47)	0.84 (0.41–1.71)	0.94 (0.45-1.99)	
Two-sided	1.90 (1.42–2.55)	2.33 (1.54–3.55)	1.43 (0.92–2.22)	
No	ref.	ref.	ref.	
Gender	**			
Male	1.41 (1.15–1.74)	-	-	
Female	ref.	-	-	
Age group (years)	***		***	
18–29	3.63 (2.09–6.30)	2.63 (1.18–5.88)	5.20 (2.51–10.75)	
30–44	2.59 (1.56–4.30)	2.18 (1.06–4.51)	2.95 (1.56–5.57)	
45–64	1.78 (1.14–2.76)	1.66 (0.85–3.26)	1.80 (1.01-3.18)	
65–79	ref.	ref.	ref.	
Residential area (inhabitants)	***	***	***	
Big city (100,000+)	2.51 (1.83–3.45)	2.33 (1.53–3.57)	2.76 (1.77-4.31)	
Medium-sized town (20,000 - < 100,000)	1.31 (0.94–1.83)	1.12 (0.69–1.82)	1.65 (1.07–2.52)	
Small town (5000 - < 20,000)	1.35 (0.95–1.91)	1.29 (0.83–2.01)	1.41 (0.83–2.42)	
Rural (< 5000)	ref.	ref.	ref.	
Marital status				
Single	1.38 (1.01–1.90)	1.63 (1.02–2.61)	1.09 (0.69–1.74)	
Divorced/widowed	1.13 (0.75–1.70)	1.49 (0.83–2.70)	0.86 (0.50-1.48)	
Married	ref.	ref.	ref.	
SES	*		***	
Low	0.89 (0.62–1.28)	0.97 (0.59–1.61)	0.78 (0.49–1.27)	
Medium	0.68 (0.51-0.91)	0.90 (0.62-1.29)	0.47 (0.33-0.67)	
High	ref.	ref.	ref.	
Excess work (≥50 h/week)				
Yes	1.21 (0.88–1.67)	1.18 (0.81–1.74)	1.50 (0.70-3.22)	
Non-working/65+ years	1.13 (0.86–1.49)	1.03 (0.65–1.62)	1.24 (0.85–1.79)	
No	ref.	ref.	ref.	
General state of health				
Average/bad/very bad	0.81 (0.56–1.16)	0.70 (0.43–1.13)	0.96 (0.56–1.63)	
Very good/good	ref.	ref.	ref.	
Chronic diseases	***	**	**	
Yes	0.44 (0.31–0.63)	0.45 (0.28-0.71)	0.45 (0.26-0.80)	
No	ref.	ref.	ref.	
Health insurance	***	***		
Private	2.23 (1.60–3.12)	2.45 (1.67–3.61)	1.81 (0.96–3.39)	
Others	2.23 (1.51–3.31)	2.62 (1.63–4.22)	1.61 (0.89–2.91)	
Statutory	ref.	ref.	ref.	

<sup>&</sup>lt;sup>a</sup>Adjusted odds ratios estimated from logistic regression, missing responses were allocated to the reference category (n = 7755). P values: \*\*\* p < 0.001 \*\* p < 0.01 \* p < 0.05

three times as likely at risk compared to adults of the oldest age group (aOR: 3.63, 95% CI: 2.09–6.30), especially women. Men and women living in big cities showed odds of having no GP more than twice as high as men and women living in rural areas (men: aOR: 2.33, 95% CI: 1.53–3.57; women: aOR: 2.76, 95% CI: 1.77–4.31). Women with medium SES had lower odds of having no GP than women with high SES. The presence of chronic diseases reduced the odds of having no GP. Men with private (aOR: 2.45, 95% CI: 1.67–3.61) or any other health insurance (aOR: 2.62, 95% CI: 1.63–4.22) showed more than a two-fold higher odds for having no GP compared to participants with statutory health insurance (Table 2).

Characteristics of the population with a migration background (n = 1102) are summarised in Table 3. Two thirds were migrants of the first generation living in Germany. The larger part of the population (76.0%) had a two-sided background. 54.3% had another language than German as mother tongue but 85.9% of the participants were native speakers or rated their knowledge of the German language as very good or good. In general, participants with a migration background were younger than people without a migration background and more frequently living in big cities. The amount of people with a low SES was much higher among participants with a migration background (29.5%).

Logistic regression analyses including only people with a migration background showed significant associations between gender, age, residential area and type of health insurance and having no GP (Table 3). Male participants were again more likely to have no GP (aOR: 1.78, 95% CI: 1.11–2.85) as well as young people (18–44 years) (aOR: 1.67, 95% CI: 1.03–2.71), people with a private or other health insurance (aOR: 2.37, 95% CI: 1.06–5.26) and living in big cities (aOR:1.54, 95% CI: 1.01–2.37). In a model considering only gender, age, residential area, type of health insurance and subjective knowledge of the German language, all variables showed significant influences on having no GP. People without good German language skills had significant higher odds to have no GP in this model.

#### Discussion

As it is aspired in German healthcare that GPs are the first point of contact for people with health complaints and guide through at all steps of treatment, this study examines influencing factors on not having a GP for the first time in Germany. Especially people with a two-sided migration background, young adults, men and people living in big cities showed significant higher odds of having no GP.

A special focus has to be set on the result that people with migration background had odds of 1.61 to have no

GP compared to people without a migration background. There are several possible barriers this population group may be confronted with in order to find a GP: Migrants of the first generation have to adapt to a new and often different healthcare system. Especially the importance and function of the GP differs a lot depending on the country, e.g. in Turkey there was no family medicine-centered primary care till 2005 and it still differs from the German system [26]. In an Austrian study, a country with a healthcare system quite similar to the German one, the migration status of participants has also been identified as a predictor for consulting specialists without having seen a GP before. Especially men born in Turkey, also representing the most common migration background in Germany, used outpatient departments (OR = 3.05) or hospitals (OR = 5.00) instead of GP services [27]. It is necessary to investigate the causes and backgrounds of the differing utilization patterns of the population with a migration background for example if there is an information deficit about the healthcare system or if there are culturally manifested beliefs about healthcare use.

54.3% of participants with a migration background did not speak German as first language and especially the communication about medical symptoms and terminology might be complicated in another language [28]. In Germany the costs for professional interpreters are not reimbursed in GP practices and have to be paid by the patient [29]. That is why the use of non-professional interpreters like family members or friends is widespread but can cause problems: Shame to talk in front of trusted persons and therefore concealing health problems as well as wrong translations [30]. Since previous studies have already demonstrated the benefits of using professional interpreters in healthcare, it is necessary to build a pool of professional interpreters and to make it possible to bring their services to account in GP practices [31–35]. Culturally determined barriers could also impair to get in touch with physicians: Prejudices and tabooing as well as shame to talk about symptoms and diseases (especially mental diseases) as well as different levels of acceptance of care and therapy forms are widespread [11, 12, 36, 37]. It has to be researched if the use of other medical disciplines is also lower among people with a migration background, reflecting either a general barrier to healthcare or just a lower need, or if there is only a barrier to GPs which would suggest that there is a lack of information about pathways within the German healthcare system. The "Healthy migrant effect", describing an on average lower mortality and morbidity of immigrants (despite an on average lower socioeconomic status), can also be considered as a possible explanation for the lower amount of people with a migration background having a GP [38, 39]. As this effect mainly

**Table 3** Comparison of study population with and without a migration background and having no GP with adjusted odds ratios (aOR) and 95% confidence intervals (CI) estimated from logistic regression (DEGS1)

	study population (no migration background) $n = 6552$	study population (migration background) $n = 1102$	Having no GP (migration population only) $n = 1102$
	n <sup>a</sup> (%)	n <sup>a</sup> (% <sup>b</sup> )	aOR (95% CI) <sup>c</sup>
Having a GP			
Yes	6081 (91.9)	970 (85.2)	_
No	471 (8.1)	132 (14.8)	-
Migration background			
two-sided	-	753 (76.0)	2.02 (0.82–4.97)
one-sided	-	349 (24.0)	ref.
Migration generation			
First generation	-	653 (66.3)	1.01 (0.45–2.26)
Second generation	_	449 (33.7)	ref.
Knowledge of the German language (subjective	vely)		
Average/bad/very bad	_	111 (14.1)	1.64 (0.92–2.92)
Native speaker/very good/good	_	981 (85.9)	ref.
Gender			*
Male	3116 (50.0)	518 (49.1)	1.78 (1.11–2.85)
Female	3436 (50.0)	584 (50.9)	ref.
Age groups (years)			*
18–44	2220 (41.2)	509 (58.0)	1.67 (1.03–2.71)
45–79	4332 (58.8)	593 (42.0)	ref.
Residential area (inhabitants)			
Big city (100,000+)	1721 (28.2)	425 (42.0)	1.54 (1.01–2.37)
Rural/Small town/Medium-sized town (< 100,000)	4831 (71.8)	677 (58.0)	ref.
Marital status			
Single/divorced/widowed	2237 (38.0)	369 (36.7)	1.06 (0.62–1.83)
Married	4276 (62.0)	724 (63.3)	ref.
SES			
Low	886 (16.0)	253 (29.5)	0.79 (0.39–1.57)
Medium	4004 (62.3)	606 (54.4)	0.57 (0.28–1.15)
High	1656 (21.7)	241 (16.2)	ref.
Excess work (≥50 h/week)			
Yes	516 (8.7)	73 (6.7)	0.92 (0.43–1.97)
No/non-working/65+ years	5946 (91.3)	1012 (93.3)	ref.
General state of health			
Average/bad/very bad	1658 (24.5)	302 (24.9)	0.94 (0.46–1.92)
Very good/good	4872 (75.5)	796 (75.1)	ref.
Chronic diseases			
Yes	2137 (29.9)	322 (23.2)	0.42 (0.17–1.09)
Do not know	303 (5.3)	67 (6.5)	1.53 (0.63–3.73)
No	4112 (64.8)	713 (70.4)	ref.
Health insurance			
Private/others	904 (13.7)	84 (6.0)	2.37 (1.06–5.26)

**Table 3** Comparison of study population with and without a migration background and having no GP with adjusted odds ratios (aOR) and 95% confidence intervals (CI) estimated from logistic regression (DEGS1) (Continued)

	study population (no migration background) $n = 6552$	study population (migration background) n = 1102	Having no GP (migration population only) n = 1102
	n <sup>a</sup> (%)	n <sup>a</sup> (% <sup>b</sup> )	aOR (95% CI) <sup>c</sup>
Statutory	5640 (86.3)	1016 (94.0)	ref.

<sup>&</sup>lt;sup>a</sup>Unweighted n may not add up to total n due to missing responses

occurs in the first generation of immigrants and decreases over time [40] and our results showed no significant difference between migration generations, this effect will not have a large impact.

Differences in having no GP with respect to gender were also in line with previous findings and may be explained by a higher health awareness of women [41, 42]. Differences in the outcome depending on age may result from an insufficient transition process from a pediatrician to a GP and therefore more young people without a GP. Older adults may be more familiar with the German health care system and they are used to have a GP as regular point of contact in case of any medical problem. The difference between people living in urban or rural areas may be explained by the fact that medical specialists are rare in rural areas in Germany and people sometimes have no choice but to establish contact to a GP [43, 44]. A medically unjustified preference of patients in big cities to visit specialists instead of GPs would be a misallocation. In contrast to results reported in most of the literature, not only participants with a low SES but also those with a high SES were less likely to have a GP, especially women [5, 6, 45]. Those with a high SES may again prefer to approach medical specialists. For adults with a low SES, the requirement to pay a "practice fee" of ten Euro, which was raised at that time, may have kept them from getting in contact with a GP.

A new aspect uncovered by the analyses is that every fifth privately insured adult did not have a GP compared to only every twelfth person with statutory health insurance. Waiting times for an appointment at a specialist for privately insured patients are significantly shorter than for statutorily insured patients [46]. In line with this, privately insured adults were found to consult specialists instead of GPs more frequently in a previous analysis of DEGS1 [47]. Further research is necessary why this effect is more prevalent among men. This possible misallocation also manifests in the high number of people visiting emergency departments with minor complaints in Germany instead of making use of GP services [48]. It should also be taken into account that there may be participants who, although they have a GP, consult other health professionals first in the event of illness.

#### Limitations

DEGS1 provides a representative sample of the German population aged 18 to 79 years. Still, there is a chance that results are biased as all the information was based on self-reported data. As in many other populationbased surveys, chronically ill people might be underrepresented [22]. Besides having a GP to visit first in case of any health problems does not mean that a participant actually makes use of the services of a GP. There may also be participants who contact other medical specialists instead of a GP in case of health problems and therefore negotiating the question. It has to be considered that the DEGS1 dataset is not representative concerning the population with migration background. Despite an oversampling of this group and the application of translated questionnaires, people with migration background are underrepresented [23, 24]. Moreover, translated questionnaires have only been provided in a restricted number of other languages. However, according to weighting of the data, the proportion of persons with a migration background was almost the same as in the general population (weighted: 19.9%, microcensus: 19.2%) [14]. For some variables like immigrant generation the DEGS1 dataset is still biased, because people of the first generation are underrepresented. Stratifying for gender among people with migration background was not possible due to the small sample. The results concerning people with a migration background should not be generalised since there is no homogenous group. When comparing the results with international studies, attention should be paid to how migrant groups are defined because there are no uniform definitions of migration terms. In the present study only the immigrant generation and German language skills were considered as a differentiation of the migration background. Indicators such as country of origin, duration and status of stay and religious orientations should be given more attention.

#### Conclusions

This study, for the first time in Germany, examined the differences in frequency of having no GP among people with and without a migration background and characteristics

<sup>&</sup>lt;sup>b</sup>Weighted results to match the German population structure on 31th December 2010

<sup>&</sup>lt;sup>c</sup>Adjusted odds ratios estimated from logistic regression, missing responses were allocated to the reference category (n = 1102). P values: \*\*\* p < 0.001 \*\* p < 0.01

that keep people to have a GP. It is necessary to investigate the causes of the differing utilization of healthcare by people with a migration background and, if necessary, to take measures for an equal access to healthcare for all population groups. Besides young citizens, people living in urban areas and privately insured citizens have to be considered in detail. Further analyses are necessary to understand the patterns of health-seeking behaviour.

#### **Additional files**

**Additional file 1:** Study population: having no GP with adjusted odds ratios (aOR) and 95% confidence intervals (CI) estimated from logistic regression stratified by gender (DEGS1) – complete case analysis (n = 7111). Results of the complete case analysis (n = 7111) (DOCX 22 kb)

**Additional file 2:** Migration population: having no GP with adjusted odds ratios (aOR) and 95% confidence intervals (CI) estimated from logistic regression (DEGS1) – complete case analysis (n = 1001). Results of the complete case analysis (n = 1001) (DOCX 18 kb)

#### Abbreviations

aOR: Adjusted odds ratio; CI: Confidence interval; DEGS1: German Health Interview and Examination Survey for Adults (first wave); GP: General practitioner: SES: Socioeconomic status

#### Funding

Not applicable.

#### Availability of data and materials

The dataset analysed during the current study is available from the Robert Koch Institute for researchers who meet the criteria for access [49]. Data about the migration background of participants has to be requested separately.

#### Author's contributions

JT, EM and KW mainly devised the basic idea. JT wrote the manuscript, performed background research on the topic, wrote parts of the results and the discussion. MP wrote parts of the methods and results and performed the statistical analyses with contributions by JT and EM. LF wrote parts of the methods and methodical discussion and gave significant contribution to the interpretation of data. KW and MK wrote parts of the abstract and discussion and acted as advisors with medical knowledge. They gave significant contribution to the interpretation of data. EM gave substantial contributions to conception and design of the publication, advised in all important steps and revised the article critically. All authors read and approved the final manuscript and are accountable for all aspects of the work.

#### Ethics approval and consent to participate

Not applicable as the analysis is based on secondary data. However, DEGS1 was approved by the Charité-Universitätsmedizin Berlin ethics committee (No. EA2/047/08) and participants provided written informed consent prior to the interview and examination [22].

## Consent for publication

Not applicable.

## Competing interests

The authors declare that they have no competing interests.

#### **Publisher's Note**

Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

#### **Author details**

 $^1$ lnstitute of General Practice and Family Medicine, University of Bonn, 53127 Bonn, Germany.  $^2$ Department of Medical Biometry, Informatics and

Epidemiology (IMBIE), University Hospital of Bonn, 53127 Bonn, Germany. <sup>3</sup>Department of Epidemiology and Health Monitoring, Robert Koch Institute, 13353 Berlin, Germany.

Received: 24 July 2018 Accepted: 27 September 2018 Published online: 03 October 2018

#### References

- Döring A, Paul F. The German healthcare system. EPMA J. 2010;1:535–47. https://doi.org/10.1007/s13167-010-0060-z.
- Robert Koch-Institut, Statistisches Bundesamt. Health in Germany. Berlin: Robert Koch institute; Federal Statistical Office; 2008.
- Gerlach FM, Szecsenyi J. Hausarztzentrierte Versorgung. Inhalte und Qualität sind entscheidend. Deutsches Ärzteblatt. 2011;108:996–8.
- Freytag A, Biermann J, Ochs A, Lux G, Lehmann T, Ziegler J, et al. The impact of GP-centered healthcare. Dtsch Arztebl Int. 2016;113:791–8. https://doi.org/10.3238/arztebl.2016.0791.
- Fjær EL, Balaj M, Stornes P, Todd A, McNamara CL, Eikemo TA. Exploring the differences in general practitioner and health care specialist utilization according to education, occupation, income and social networks across Europe: findings from the European social survey (2014) special module on the social determinants of health. Eur J Pub Health. 2017;27:73–81. https:// doi.org/10.1093/eurpub/ckw255.
- Jørgensen JT, Andersen JS, Tjønneland A, Andersen ZJ. Determinants related to gender differences in general practice utilization: Danish diet, Cancer and health cohort. Scand J Prim Health Care. 2016;34:240–9. https://doi.org/10.1080/02813432.2016.1207141.
- Hessel A, Gunzelmann T, Geyer M, Brähler E. Inanspruchnahme medizinischer Leistungen und Medikamenteneinnahme bei über 60jährigen in Deutschland. Z Gerontol Geriatr. 2000;33:289–99. https://doi.org/10.1007/ s003910070049.
- Schlichthorst M, Sanci LA, Pirkis J, Spittal MJ, Hocking JS. Why do men go to the doctor? Socio-demographic and lifestyle factors associated with healthcare utilisation among a cohort of Australian men. BMC Public Health. 2016;16:1028. https://doi.org/10.1186/s12889-016-3706-5.
- Lindert J, Schouler-Ocak M, Heinz A, Priebe S. Mental health, health care utilisation of migrants in Europe. European Psychiatry. 2008;23:14–20. https://doi.org/10.1016/S0924-9338(08)70057-9.
- Hinton L, Franz C, Friend J. Pathways to dementia diagnosis: evidence for cross-ethnic differences. Alzheimer Dis Assoc Disord. 2004;18:134–44.
- Mukadam N, Cooper C, Basit B, Livingston G. Why do ethnic elders present later to UK dementia services? A qualitative study. Int Psychogeriatr. 2011; 23:1070–7. https://doi.org/10.1017/S1041610211000214.
- Mukadam N, Cooper C, Livingston G. A systematic review of ethnicity and pathways to care in dementia. Int J Geriatr Psychiatry. 2011;26:12–20. https://doi.org/10.1002/qps.2484.
- Statistisches Bundesamt. Bevölkerung und ErwerbstätigkeitBevölkerung mit Migrationshintergrund: - Ergebnisse des Mikrozensus 2015. Wiesbaden: Destatis; 2016.
- Statistisches Bundesamt. Bevölkerung und Erwerbstätigkeit: Bevölkerung mit Migrationshintergrund. Ergebnisse des Mikrozensus 2016. 2017.
- Razum O, Brzoska P. Menschen mit Migrationshintergrund in der Rehabilitation: Zugänglichkeit und Ergebnisse. Bonn: Friedrich Ebert Stiftung; 2016.
- Brzoska P, Voigtländer S, Spallek J, Razum O. Utilization and effectiveness of medical rehabilitation in foreign nationals residing in Germany. Eur J Epidemiol. 2010;25:651–60. https://doi.org/10.1007/s10654-010-9468-y.
- Rommel A, Saß AC, Born S, Ellert U. Die gesundheitliche Lage von Menschen mit Migrationshintergrund und die Bedeutung des sozioökonomischen Status: Erste Ergebnisse der Studie zur Gesundheit Erwachsener in Deutschland (DEGS1). Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz. 2015;58:543–52. https://doi.org/ 10.1007/s00103-015-2145-2.
- Mahmoud I. Immigrants and the utilization of hospital emergency departments. World J Emerg Med. 2012;3:245. https://doi.org/10.5847/wjem. j.issn.1920-8642.2012.04.001.
- Norredam M, Mygind A, Nielsen AS, Bagger J, Krasnik A. Motivation and relevance of emergency room visits among immigrants and patients of Danish origin. Eur J Pub Health. 2007;17:497–502. https://doi.org/10.1093/ eurpub/ckl268.
- 20. Kurth B-M, Lange C, Kamtsiuris P, Hölling H, Gesundheitsmonitoring am Robert Koch-Institut. Sachstand und Perspektiven. Bundesgesundheitsblatt

- Gesundheitsforschung Gesundheitsschutz. 2009;52:557–70. https://doi.org/10.1007/s00103-009-0843-3.
- Gößwald A, Lange M, Dölle R, Hölling H. The first wave of the German health interview and examination survey for adults (DEGS1). Participant recruitment, fieldwork, and quality assurance. Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz. 2013;56:611–9. https://doi.org/10. 1007/s00103-013-1671-z.
- Scheidt-Nave C, Kamtsiuris P, Gößwald A, Hölling H, Lange M, Busch MA, et al. German health interview and examination survey for adults (DEGS) design, objectives and implementation of the first data collection wave. BMC Public Health. 2012;12:730. https://doi.org/10.1186/1471-2458-12-730.
- Kamtsiuris P, Lange M, Hoffmann R, Schaffrath Rosario A, Dahm S, Kuhnert R, Kurth BM. The first wave of the German health interview and examination survey for adults (DEGS1). Sampling design, response, weighting, and representativeness. Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz. 2013;56:620–30. https://doi.org/10.1007/s00103-012-1650-9.
- Saß A-C, Grüne B, Brettschneider A-K, Rommel A, Razum O, Ellert U. Beteiligung von Menschen mit Migrationshintergrund an Gesundheitssurveys des Robert Koch-Instituts. Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz. 2015;58:533–42. https://doi.org/ 10.1007/s00103-015-2146-1.
- 25. IBM Corp. IBM SPSS statistics 25.0. Armonk: IBM Corp; 2017.
- Atun R. Transforming Turkey's health system--lessons for universal coverage. N Engl J Med. 2015;373:1285–9. https://doi.org/10.1056/NEJMp1410433.
- Hoffmann K, Stein KV, Maier M, Rieder A, Dorner TE. Access points to the different levels of health care and demographic predictors in a country without a gatekeeping system. Results of a cross-sectional study from Austria. Eur J Pub Health. 2013;23:933–9. https://doi.org/10. 1093/eurpub/ckt008.
- Giese A, Uyar M, Uslucan HH, Becker S, Henning BF. How do hospitalised patients with Turkish migration background estimate their language skills and their comprehension of medical information - a prospective crosssectional study and comparison to native patients in Germany to assess the language barrier and the need for translation. BMC Health Serv Res. 2013;13: 196. https://doi.org/10.1186/1472-6963-13-196.
- Deutscher Bundestag. Dolmetscher im Rahmen der gesundheitlichen Versorgung. Anspruch und Kostenübernahme: Sachstandsbeschluss WD 9-3000-021/17. 2017.
- Flores G. The impact of medical interpreter services on the quality of health care: a systematic review. Med Care Res Rev. 2005;62:255–99. https://doi. org/10.1177/1077558705275416.
- Jacobs EA, Shepard DS, Suaya JA, Stone E-L. Overcoming language barriers in health care: costs and benefits of interpreter services. Am J Public Health. 2004;94:866–9
- Karliner LS, Jacobs EA, Chen AH, Mutha S. Do professional interpreters improve clinical care for patients with limited English proficiency? A systematic review of the literature. Health Serv Res. 2007;42:727–54. https://doi.org/10.1111/j.1475-6773.2006.00629.x.
- Leanza Y, Boivin I, Rosenberg E. Interruptions and resistance: a comparison of medical consultations with family and trained interpreters. Soc Sci Med. 2010;70:1888–95. https://doi.org/10.1016/j.socscimed.2010.02.036.
- O'Donnell CA, Burns N, Mair FS, Dowrick C, Clissmann C, van den Muijsenbergh M, et al. Reducing the health care burden for marginalised migrants: the potential role for primary care in Europe. Health Policy. 2016; 120:495–508. https://doi.org/10.1016/j.healthpol.2016.03.012.
- Weinick RM, Krauss NA. Racial/ethnic differences in children's access to care.
   Am J Public Health. 2000;90:1771–4.
- Daker-White G, Beattie AM, Gilliard J, Means R. Minority ethnic groups in dementia care: a review of service needs, service provision and models of good practice. Aging Ment Health. 2002;6:101–8. https://doi.org/10.1080/ 13607860220126835.
- Eh K, McGill M, Wong J, Krass I. Cultural issues and other factors that affect self-management of type 2 diabetes mellitus (T2D) by Chinese immigrants in Australia. Diabetes Res Clin Pract. 2016;119:97–105. https://doi.org/10. 1016/j.diabres.2016.07.006.
- 38. Richter M, Hurrelmann K. Gesundheitliche Ungleichheit: Grundlagen, Probleme, Konzepte. 1st ed. Wiesbaden: VS Verlag für Sozialwissenschaften; 2006.
- Kliewer E. Epidemiology of diseases among migrants. Int Migr. 1992;30:141–65. https://doi.org/10.1111/j.1468-2435.1992.tb00781.x.

- Williams R. Health and length of residence among south Asians in Glasgow: a study controlling for age. J Pub Health. 1993;15:52–60. https://doi.org/10. 1093/oxfordiournals.pubmed.a042820.
- 41. Hurrelmann K, Kolip P. Geschlecht, Gesundheit und Krankheit: Männer und Frauen im Vergleich. 1st ed. Bern: Huber; 2002.
- 42. Lange C. Daten und Fakten: Ergebnisse der Studie "Gesundheit in Deutschland aktuell 2012". Berlin: Robert-Koch-Inst; 2014.
- 43. Bertelsmann Stiftung. Faktencheck Gesundheit: Regionale Verteilung von Arztsitzen (Ärztedichte). Gütersloh: Bertelsmann Stiftung; 2015.
- Hansen H, Pohontsch NJ, Bole L, Schäfer I, Scherer M. Regional variations of perceived problems in ambulatory care from the perspective of general practitioners and their patients - an exploratory focus group study in urban and rural regions of northern Germany. BMC Fam Pract. 2017;18:68. https:// doi.org/10.1186/s12875-017-0637-x.
- Kert S, Švab I, Sever M, Makivić I, Pavlič DR. A cross-sectional study of sociodemographic factors associated with patient access to primary care in Slovenia. Int J Equity Health. 2015;14:39. https://doi.org/10.1186/s12939-015-0166-y.
- Sundmacher L, Kopetsch T. Waiting times in the ambulatory sector—the case of chronically ill patients. Int J Equity Health. 2013;12:77. https://doi. org/10.1186/1475-9276-12-77.
- Rattay P, Butschalowsky H, Rommel A, Prütz F, Jordan S, Nowossadeck E, et al. Inanspruchnahme der ambulanten und stationären medizinischen Versorgung in Deutschland: Ergebnisse der Studie zur Gesundheit Erwachsener in Deutschland (DEGS1). Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz. 2013;56:832–44. https://doi.org/ 10.1007/s00103-013-1665-x.
- Scherer M, Lühmann D, Kazek A, Hansen H, Schäfer I. Patienten in Notfallambulanzen: Querschnittstudie zur subjektiv empfundenen Behandlungsdringlichkeit und zu den Motiven, die Notfallambulanzen von Krankenhäusern aufzusuchen. Deutsches Ärzteblatt. 2017;114:645–52.
- Robert Koch-Institut. Abteilung für Epidemiologie und Gesundheitsmonitoring. Gesundheit von Erwachsenen in Deutschland (DEGS1 2008-2012). Berlin: Robert Koch-Institut; 2015.

#### Ready to submit your research? Choose BMC and benefit from:

- fast, convenient online submission
- thorough peer review by experienced researchers in your field
- rapid publication on acceptance
- support for research data, including large and complex data types
- gold Open Access which fosters wider collaboration and increased citations
- maximum visibility for your research: over 100M website views per year

## At BMC, research is always in progress.

Learn more biomedcentral.com/submissions



## 4. Discussion

The presented results of the BaDeMi-study reveal a wide range of barriers and uncertainties among GPs in diagnostic processes and interaction with patients with a migration background. Language barriers, insufficient information, shame and culturally influenced views of patients were frequently reported to make dementia diagnostics difficult. As a consequence, nearly 90 % of GPs experienced personal limitations when treating patients with a migrant background, lacking confidence in the diagnostic process and in communication are common. This leads to huge information needs (70.6 %), especially about specialized services for patients, dealing with language barriers and specific diagnostic tools. These results should be viewed in the context of the presented results of the DEGS1 analyses that people with migration background in Germany have an on average higher odds ratio to have no GP compared to people without a migration background, ostensibly those with a two-sided background.

A detailed discussion of these results has already been presented in the three articles, which allows a focus on future needs and recommendations for action in the following parts. In order to provide the best possible healthcare for the target group, adjustments on the needs of the population with a migrant background and on the needs of GPs and other medical experts are worth supporting, similar to requirements in European and Australian research (Daker-White et al., 2002; Diaz et al., 2015; Nielsen et al., 2011; Sagbakken et al., 2018; Segers et al., 2013). Several stakeholders should be involved: policy players, research institutions, health professionals like GPs and medical assistants, self-help and migrant organisations. The participatory involvement of the target group in all steps is important to meet their needs and enable appropriate solutions.

# 4.1 Intercultural opening of healthcare and general practice

## Information and counselling

In line with previous studies, the presented findings of patient's missing knowledge, shame and culturally influenced views on dementia highlight the need for culturally-sensitive, mother-tongued and understandable, easy accessible and disseminated information and counselling (Boughtwood et al., 2012; Shanley et al., 2012). Pathways in

the German healthcare system should also be explained. Networks with GP practices should be established in order to improve the high demand stated in the BaDeMi-study (chapter 3.2) with simultaneous reduction of their workload. Currently, multilingual and culturally sensitive services for dementia patients are rare in Germany (Robert Koch-Institut [RKI], 2008). Training of special intercultural consultants would also be conceivable. Organizations like the German Alzheimer Society are currently making efforts in that area with their website www.demenz-und-migration.de or the project DeMigranz, aiming to launch a nationwide initiative to develop culturally sensitive offers and networks.

## Intercultural competence training for GPs

In order to overcome the frequently stated uncertainties in dealing with and diagnosing people with a migration background (BaDeMi-study), training of GPs' intercultural skills may be useful (Sagbakken et al., 2018). Awareness, learning and sensitivity towards differing values, life ways, perspectives and beliefs about health and illness can be reached through intercultural competence training (Deardorff, 2009). It can facilitate communication between healthcare providers and receivers and prevent misunderstandings that may lead to misdiagnosis and mistreatment (Ahmed, 2015). Sagbakken et al. (2018) emphasize training of primary care professionals in communication skills and use of cross-cultural assessment tools to build competence and confidence, which is in line with the needs stated in BaDeMi. Cahill et al. (2006) even call for a systematic approach to GP training in dementia care in general in Ireland. Rosenberg et al. (2007) recommend continuing education training of GPs. It may also be useful to integrate that topic earlier, in the medical curricula at universities (Rosenberg et al., 2007; Tillmann et al., 2018). Still, these offers should consider the lack of time of many GPs. A study in five European countries showed that training primary care teams on that topic led to more attention for patient's needs through a more tolerant attitude and more effective communication (Teunissen et al., 2017).

# 4.2 Political focus on healthcare for people with a migration background

Migration still plays a subordinate role in the national dementia plans and guides of European countries. Schmachtenberg et al. (2020) identified only eight of 23 dementia action plans in EU and EFTA countries to mention special needs of people with a migration background, only one with a chapter. In the German S3 dementia guideline, it is only mentioned that the socio-cultural background or language skills have to be considered in the choice of test instruments (Deutsche Gesellschaft für Psychiatrie und Psychotherapie, Psychosomatik und Nervenheilkunde [DGPPN] and Deutsche Gesellschaft für Neurologie [DGN], 2016). A national strategy may be necessary (Schmachtenberg et al., 2020).

## Interpreting services in general practice

The frequently reported language barriers in the BaDeMi-study (89.3 % of GPs) that impair the diagnosis of dementia have also been highlighted in Australian (Boughtwood et al., 2012) Belgian (Segers et al., 2013), Swedish (Söderman and Rosendahl, 2016) and European studies (Nielsen et al., 2011). The use of non-professional interpreters, reported in the BaDeMi-study, can facilitate medical consultations (Meeuwesen et al., 2010). But since mental symptoms or disorders are often tabooed or associated with shame (see chapter 2.2.2), non-professional interpreters may also distort the translation and skip unpleasant or burdensome content (Flores, 2005; Kirschbaum; Leanza et al., 2010; Salman, 2006). The use of professional interpreters in medical practice is recommended because of less mistakes and miscommunication and higher physician and patient satisfaction (Flores, 2005). However, there is still no legal basis for the reimbursement of interpreter costs in general practice (Federal Social Court, file no. 1RK 20/94), explaining the small share of 8.3 % in BaDeMi having ever worked with a professional. It is necessary to facilitate access and reimbursement of professional interpreter services in general practice and to point out to GPs what to be aware of when dealing with nonprofessional interpreters. Teunissen et al. (2017) figured out in their European study that migrants were more likely to trust the GP's diagnoses and GPs reported a better understanding of migrants' symptoms after implementation of interpreter services.

## 4.3 Healthcare research on people with a migration background

People with a migration background should actively be given greater consideration in healthcare research to improve lack of data (RKI and Statistisches Bundesamt [Destatis], 2015). In the health monitoring based on large representative surveys such as the DEGS1-survey included here, integration of people with migration background should be improved to obtain more robust and representative data. An example is the "Improving Health Monitoring in Migrant Populations (IMIRA)" project conducted by the RKI until 2019: necessary elements to reach people with migration background in health monitoring have been identified, for example development of the survey content, choice of different interview formats, personal contact, multilingual services and materials and cultural sensitive materials and training for the staff (Santos-Hövener et al., 2019).

## Definition of the target group

Setting a standard definition for the target group is desirable to make results more comparable (RKI and Destatis, 2015; Schmachtenberg et al., 2020). The present international research, for example, sometimes refers to people with a migration background, migrants, immigrants, ethnic minorities, non-English speaking background patients or culturally and linguistically diverse people.

## Dementia assessment tools

Dementia screening instruments like cognitive short tests are primary language-based and often not suitable for other cultures and native languages (Nielsen et al., 2011; Parker and Philp, 2004). This most likely explains the high demand among almost 40 % of GPs for suitable diagnostic tools in BaDeMi. In a survey conducted in clinical dementia centres in 15 European countries, 64 % of experts describe diagnostic evaluation of patients from minority ethnic groups as challenging because of communication problems and lack of adequate assessment tools (Nielsen et al., 2011). Parker and Philp (2004) report popular tools like the MMSE to be highly influenced by ethnicity and educational level. Diagnostic tools that are less dependent on language, literacy, education and culture may be useful. The Rowland Universal Dementia Assessment Scale (RUDAS) is an example for a screening instrument in multicultural populations (Storey et

al., 2004). So-called "culture-free tests" seem to be promising but further evidence is needed (Parker and Philp, 2004).

Access to the healthcare system

As the presented DEGS1 analyses can only provide initial indications of a differing use of GP services by people with and without a migration background, access and health-care pathways of people with a migration background should be further researched, for example whether specialists are visited more frequently instead. International results that they generally use healthcare services less often (Daker-White et al., 2002; Lindert et al., 2008) and later after the onset of dementia symptoms (Mukadam et al., 2011; Segers et al., 2013) should be considered. In a survey of citizens with Turkish origin in NRW, reasons for the low and late use of healthcare included a low subjective information status connected with a high demand for information material about the healthcare system in Turkish (Sauer, 2009), as already requested in this thesis.

## 4.4 Limitations

This thesis gives an insight into the results of research activities. All results could not be presented due to limitations of scope. Generalization of results, conclusions and messages has to be avoided. Barriers identified in this research are not transferable to all migration backgrounds because of heterogeneous cultures, religions and views existing even within the barriers of a country. It has to be considered that many people with migration background according to the definition were born and raised in Germany and do barely or not at all differ from people without a migration background in healthcare. When comparing the results with international studies, attention should be paid to non-uniform terms of definition. Since there are also other health professionals interacting with the target groups, it may be useful to research the entire healthcare chain regarding their experiences and needs. Perceptions and attitudes of people with a migration background should also be investigated, as perceptions of GPs may be subjective. Limitations of the cross-sectional study like differing patient bases, limitation to registered GPs and possible response bias have already been described in detail in the presented publications. Limitations of the secondary data analysis like potential bias, distinction be-

tween having and using a GP and underrepresentation of the target group, have also been described in the related publication.

## References

- Ahmed R. Intercultural Competence in Healthcare. In: Bennett JM, ed. The SAGE encyclopedia of intercultural competence. Los Angeles: SAGE, 2015: 487–490
- Boughtwood D, Shanley C, Adams J, Santalucia Y, Kyriazopoulos H, Pond D, Rowland J. Dementia information for culturally and linguistically diverse communities: Sources, access and considerations for effective practice. Australian Journal of Primary Health 2012; 18(3): 190–196
- Cahill S, Clark M, Walsh C, O'Connell H, Lawlor B. Dementia in primary care: The first survey of Irish general practitioners. Int J Geriatr Psychiatry 2006; 21(4): 319–324
- Daker-White G, Beattie AM, Gilliard J, Means R. Minority ethnic groups in dementia care: A review of service needs, service provision and models of good practice. Aging & Mental Health 2002; 6(2): 101–108
- Deardorff DK. The Sage handbook of intercultural competence. Thousand Oaks, California: Sage Publications, 2009
- Deutsche Gesellschaft für Psychiatrie und Psychotherapie, Psychosomatik und Nervenheilkunde, Deutsche Gesellschaft für Neurologie, 2016: S3-Leitlinie "Demenzen". https://www.awmf.org/uploads/tx\_szleitlinien/038-013I\_S3-Demenzen-2016-07.pdf (Access date: 14.10.2020)
- Diaz E, Kumar BN, Engedal K. Immigrant patients with dementia and memory impairment in primary health care in Norway: A national registry study. DEM 2015; 39(5-6): 321–331
- Flores G. The impact of medical interpreter services on the quality of health care: A systematic review. Med Care Res Rev 2005; 62(3): 255–299
- Kirschbaum KA. Intercultural Communication in Healthcare. In: Kim YY, Mckay-Semmler KL, eds. The international encyclopedia of intercultural communication. Hoboken (N.J.): Wiley Blackwell, 2018: 1–13

- Leanza Y, Boivin I, Rosenberg E. Interruptions and resistance: A comparison of medical consultations with family and trained interpreters. Soc Sci Med 2010; 70(12): 1888–1895
- Lindert J, Schouler-Ocak M, Heinz A, Priebe S. Mental health, health care utilisation of migrants in Europe. Eur Psychiatr 2008; 23(1): 114-120
- Meeuwesen L, Twilt S, Thije JD ten, Harmsen H. "Ne diyor?" (What does she say?): Informal interpreting in general practice. Patient Educ Couns 2010; 81(2): 198–203
- Mukadam N, Cooper C, Basit B, Livingston G. Why do ethnic elders present later to UK dementia services? A qualitative study. Int Psychogeriatr 2011; 23(7): 1070–1077
- Nielsen TR, Vogel A, Riepe MW, Mendonça A de, Rodriguez G, Nobili F, Gade A, Waldemar G. Assessment of dementia in ethnic minority patients in Europe: A European Alzheimer's Disease Consortium survey. Int Psychogeriatr 2011; 23(1): 86–95
- Parker C, Philp I. Screening for cognitive impairment among older people in black and minority ethnic groups. Age Ageing 2004; 33(5): 447–452
- Robert Koch-Institut, 2008: Migration und Gesundheit. Schwerpunktbericht der Gesundheitsberichterstattung des Bundes. Gesundheitsberichterstattung des Bundes. https://www.rki.de/DE/Content/Gesundheitsmonitoring/Gesundheitsberichterstattung/GBEDownloadsT/migration.pdf?\_\_blob=publicationFile (Access date: 14.11.2020)
- Robert Koch-Institut, Statistisches Bundesamt, 2015: Gesundheit in Deutschland. Gesundheitsberichterstattung des Bundes gemeinsam getragen von RKI und Destatis. https://www.rki.de/DE/Content/Gesundheitsmonitoring/Gesundheitsbericht erstattung/GesInDtld/gesundheit\_in\_deutschland\_2015.html;jsessionid=B20F3669D A861080B74E6DCC2833A965.internet061?nn=2379316.pdf (Access date: 14.10.2020)
- Rosenberg E, Kirmayer LJ, Xenocostas S, Dao MD, Loignon C. Gps' strategies in intercultural clinical encounters. Fam Pract 2007; 24(2): 145–151
- Sagbakken M, Spilker RS, Nielsen TR. Dementia and immigrant groups: A qualitative study of challenges related to identifying, assessing, and diagnosing dementia. BMC Health Serv Res 2018; 18(1)
- Salman R. Sprach- und Kulturvermittlung. Konzepte und Methoden der Arbeit mit Dolmetschern in therapeutischen Prozessen. In: Hegemann T, Salman R, eds.

- Transkulturelle Psychiatrie: Konzepte für die Arbeit mit Menschen aus anderen Kulturen. Bonn: Psychiatrie-Verlag, 2006: 169–190
- Santos-Hövener C, Schumann M, Schmich P, Gößwald A, Rommel A, Ziese T, Lampert T. Improving the information base regarding the health of people with a migration background. Project description and initial findings from IMIRA. Journal of Health Monitoring 2019; 4(1): 46–57
- Sauer, M. (2009). Türkeistämmige Migranten in Nordrhein-Westfalen und in Deutschland: Lebenssituation und Integrationsstand: Ergebnisse der neunten Mehrthemenbefragung. https://issuu.com/ufuq.de/docs/nrw-mehrthemenbefragung\_2008 (Access date: 29.10.2020)
- Schmachtenberg T, Monsees J, Hoffmann W, van den Berg N, Stentzel U, Thyrian JR. Comparing national dementia plans and strategies in Europe is there a focus of care for people with dementia from a migration background? BMC Public Health 2020; 20(1): 784
- Segers K, Benoit F, Colson C, Kovac V, Nury D, Vanderaspoilden V. Pioneers in migration, pioneering in dementia: First generation immigrants in a European metropolitan memory clinic. Acta Neurol Belg 2013; 113(4): 435–440
- Shanley C, Boughtwood D, Adams J, Santalucia Y, Kyriazopoulos H, Pond D, Rowland J. A qualitative study into the use of formal services for dementia by carers from culturally and linguistically diverse (CALD) communities. BMC Health Serv Res 2012; 12(1)
- Söderman M, Rosendahl SP. Caring for Ethnic Older People Living with Dementia Experiences of Nursing Staff. J Cross Cult Gerontol 2016; 31(3): 311–326
- Storey JE, Rowland JTJ, Basic D, Conforti DA, Dickson HG. The Rowland Universal Dementia Assessment Scale (RUDAS): A multicultural cognitive assessment scale. Int Psychogeriatr 2004; 16(1): 13–31
- Teunissen E, Gravenhorst K, Dowrick C, van Weel-Baumgarten E, Van den Driessen Mareeuw F, de Brún T, Burns N, Lionis C, Mair FS, O'Donnell C, O'Reilly-de Brún M, Papadakaki M, Saridaki A, Spiegel W, van Weel C, van den Muijsenbergh M, MacFarlane A. Implementing guidelines and training initiatives to improve cross-

cultural communication in primary care consultations: A qualitative participatory European study. Int J Equity Health 2017; 16(1): 16–32

Tillmann J, Krämer A, Fischer F. Medizinische Ausbildung zur Versorgung von Schutzsuchenden – Quantitative Bestandsaufnahme und Bedarfserhebung unter Medizinstudierenden in Deutschland. Z'flucht 2018; 2(1): 163–174

## 5. Acknowledgement

I thank Prof. Dr. Eva Münster warmly for her very professional and reliable support and advice regarding my doctorate and the studies I have conducted.

Furthermore, I would like to thank Prof. Dr. med. Klaus Weckbecker for his very competent support and for the great work experience that helped me to grow and implement these projects.

I also want to thank my friends, who have always supported me and believed in me.

Without all of you, this thesis and the experiences I was able to gather would not have been possible.

## 6. Statement

## Medizinische Fakultät der Universität Bonn

## Promotionsverfahren PhD und MD/PhD

# Erklärung über den Anteil des Bewerbers an den Publikationen nach § 6 (3) und § 7 (1) PromO.

Bei der Publikation, bei der der Promovend Erstautor ist, muss der Promovend den **überwiegenden Anteil an der Planung der wissenschaftlichen Arbeit, der Datenerhebung, der Auswertung und Interpretation** gehabt haben und die **erste Version des Manuskripts** selber verfasst haben.

Bei den Publikationen, bei denen der Promovend Koautor ist, muss er einen wesentlichen Anteil an der Planung der wissenschaftlichen Arbeit, der Datenerhebung, der Auswertung und Interpretation gehabt haben. Der Anteil des Promovenden an den Publikationen ist durch entsprechende Angaben gegenüber dem Herausgeber nachzuweisen.

Titel der Dissertation: Ansätze zur Verbesserung der hausärztlichen Versorgung von Menschen mit Migrationshintergrund mit Fokus auf die Demenzdiagnostik

Der Promovend/die Promovendin, Judith Tillmann, hat die oben genannte Dissertation in dem Institut für Hausarztmedizin unter der Betreuung von Herrn Prof. Dr. med. Klaus Weckbecker und Frau Dr. oec. troph. Eva Münster, apl.-Prof. der Universität Mainz, durchgeführt.

Bitte beschreiben Sie nun Ihren **Eigenanteil** sowie den Anteil, der von **anderen Personen** übernommen wurde, ausführlich für **jede Publikation** anhand der folgenden Kriterien.

(In einer Tabelle wird jeweils nur eine Publikation beschrieben.)

Titel der Publikation: Barriers in general practitioners' dementia diagnostics among people with a migration background in Germany (BaDeMi) – study protocol for a cross-sectional survey

Beschreiben Sie, wie sich Ihr **Eigenanteil** in den folgenden Teilbereichen zusammensetzt:

Beschreiben Sie den **Fremdanteil** in den folgenden Teilbereichen:

## Planung der wissenschaftlichen Arbeit:

Die Koordination und Umsetzung der BaDeMi-Studie (Förderung durch die Deutsche Alzheimer Gesellschaft) und dieser Publikation erfolgte von Beginn an durch die Promovendin. Die umfassende Literaturrecherche und -sichtung sowie Entwicklung des Fragebogens und der weiteren Studiendokumente erfolgte eigenständig durch die Promovendin. Kontakte zu internationalen Forschenden im Bereich Demenz und Demenz bei Menschen mit Migrationshintergrund bzw. "minority ethnic groups" aus Dänemark und Australien wurden durch die Promovendin aufgebaut. Diese Erfahrungswerte und Anteile von Studiendokumenten flossen in die Entwicklung der BaDeMi-Studienunterlagen ein. Die Promovendin erstellte den Antrag zum Erhalt der Kontaktdaten der zu befragenden Hausärztinnen und Hausärzte von der Kassenärztlichen Vereinigung Nordrhein. Die Pretestung des Fragebogens wurde durch die Promovendin organisiert, ausgeführt und ausgewertet. Der Ethikantrag wurde ei-

## Planung der wissenschaftlichen Arbeit:

Es erfolgten Rücksprachen mit Frau Dr. oec. troph. Münster, apl.-Prof. der Universität Mainz, zum Ablauf und der Entwicklung der Studienunterlagen. Hausärztliche Erfahrungswerte wurden von Herrn Prof. Dr. med. Weckbecker und Herrn Dr. med. Just eingebracht. Die Einwerbung der Drittmittel für das Projekt erfolgte im Vorfeld durch Frau Dr. oec. troph. Münster, apl.-Prof. der Universität Mainz, Frau Dr. Schnakenberg, Herrn Dr. med. Just und Herrn Prof. Dr. med. Weckbecker.

genständig durch die Promovendin erstellt. Ebenso erfolgten Registrierungen der Studie im Deutschen Register Klinischer Studien sowie im Studienregister des Universitätsklinikums Bonn durch die Promovendin. Ein Zeitungsartikel über die Querschnittsstudie wurde durch die Promovendin organisiert und im Rheinischen Ärzteblatt veröffentlicht. Die Publikation wurde von der Promovendin selbstständig unter Rücksprache mit den Co-Autorinnen und Co-Autoren verfasst. Datenerhebung: Datenerhebung: Die Studienkoordination & -durchführung inklusive Es erfolgten Absprachen mit Frau Dr. oec. troph. Münsder in der Publikation beschriebenen Pretests und ter, apl.-Prof. der Universität Mainz, und Herrn Prof. Dr. Datenerhebung mit Erinnerungsverfahren wurden med. Weckbecker zur Datenerhebung sowie Rückspravon der Promovendin selbstständig umgesetzt. chen bei Fragen. Dazu zählte auch die Ziehung der Stichprobe, Organisation des gesamten Studienablaufs und der Studienunterlagen, Zeitplanung und Klärung von Rückfragen als Ansprechpartnerin für die Teilnehmenden. Auswertung: Auswertung: Die Analysemethodik wurde durch die Promovendin Die Schwerpunkte der Datenanalyse wurden im Voraus festgelegt. Eine Auswertung von Daten ist in diesem mit Frau Dr. oec. troph. Münster, apl.-Prof. der Universität Studienprotokoll nicht beschrieben. Mainz, besprochen. Die Analysen wurden von Frau Dr. Puth (Mathematikerin) nach der Durchführung überprüft. Interpretation: Interpretation: Das Manuskript wurde eigenständig und federfüh-Das Manuskript wurde durch alle Co-Autorinnen & Co-Autoren Korrektur gelesen und weitere Diskussionspunkrend von der Promovendin erstellt. Die enthaltene Diskussion inklusive der Vergleiche mit internationate wurden eingebracht. len Erkenntnissen und Erläuterung der Limitationen der Studie wurde eigenständig von der Promovendin verfasst. Zutreffendes bitte ankreuzen: Promovend\*in ist Erstautor und hat die erste Version des Manuskripts selbst verfasst

Titel der Publikation: Challenges in diagnosing dementia in patients with a migrant background - a cross-sectional study among German general practitioners

Beschreiben Sie, wie sich Ihr **Eigenanteil** in den folgenden Teilbereichen zusammensetzt:

Promovend\*in ist Koautor

Beschreiben Sie den **Fremdanteil** in den folgenden Teilbereichen:

## Planung der wissenschaftlichen Arbeit:

Die Planung, Koordination und Umsetzung der Studie und der Publikation erfolgte von Beginn an durch die Promovendin. Die Literaturrecherche, die Entwicklung des Fragebogens und der weiteren Studiendokumente erfolgte eigenständig durch die Promovendin. Kontakte zu international tätigen Forschenden im Themenbereich der Demenz aus Australien und im Bereich Demenz bei Menschen mit Migrationshintergrund bzw. "minority ethnic groups" aus Dänemark wurden durch die Promovendin aufgebaut. Diese internationalen Erfahrungswerte und Teile von Studiendokumenten flos-

## Planung der wissenschaftlichen Arbeit:

Es erfolgten Rücksprachen mit Frau Dr. oec. troph. Münster, apl.-Prof. der Universität Mainz, bezüglich Ablauf der Studie und Entwicklung der Studienunterlagen. Die Planung des Ablaufs wurde ebenfalls mit Herrn Prof. Dr. med. Weckbecker, Frau Dr. Schnakenberg und Herrn Dr. med. Just besprochen. Die Einwerbung der Drittmittel für das Projekt erfolgte im Vorfeld durch Frau Dr. oec. troph. Münster, apl.-Prof. der Universität Mainz, Frau Dr. Schnakenberg, Herrn Dr. med. Just und Herrn Prof. Dr. med. Weckbecker.

sen in die Entwicklung der BaDeMi-Studienunterlagen ein. Die Unterlagen zur Beantragung der Kontaktdaten der zu befragenden Hausärztinnen und Hausärzte bei der Kassenärztlichen Vereinigung Nordrhein wurden durch die Promovendin erstellt. Die Pretestung des Fragebogens wurde durch die Promovendin organisiert, ausgeführt und ausgewertet. Der Ethikantrag wurde eigenständig durch die Promovendin erstellt. Ebenso erfolgten Registrierungen der Studie im Deutschen Register Klinischer Studien sowie dem Studienregister des Universitätsklinikums Bonn durch die Promovendin. Ein Zeitungsartikel über die Querschnittsstudie wurde durch die Promovendin organisiert und im Rheinischen Ärzteblatt veröffentlicht, um die Aufmerksamkeit in hausärztlichen Praxen zu erhöhen. Diese Publikation wurde von der Promovendin selbstständig verfasst.		
Datenerhebung:	Datenerhebung:	
Die Koordination und Durchführung der Querschnittsstudie inklusive der Pretests und Datenerhebung mit Erinnerungsverfahren wurden von der Promovendin selbstständig umgesetzt. Auch für die Ziehung der Stichprobe, die Organisation des Studienablaufs und der Studienunterlagen und die Zeitplanung war die Promovendin zuständig. Bei Rückfragen der Ärzteschaft oder Praxen war die Promovendin Ansprechpartnerin.	Es erfolgten Rücksprachen mit Herrn Prof. Dr. med. Weckbecker, Frau Dr. Schnakenberg und Herrn Dr. med. Just zur Durchführung der Datenerhebung.	
Auswertung:	Auswertung:	
Die Analysemethodik wurde durch die Promovendin festgelegt. Der Datensatz, der im Laufe der beschriebenen Querschnittsstudie generiert wurde, wurde eigenständig durch die Promovendin plausibilitätsgeprüft, aufbereitet und ausgewertet. Die Zusammenfassung und Darstellung der wichtigsten Ergebnisse der Studie im Rahmen dieser Publikation erfolgte ebenfalls durch die Promovendin. Der Zwischenbericht für die Deutsche Alzheimer Gesellschaft als Förderer des Projekts wurde durch die Promovendin geplant und geschrieben.	Es erfolgten Rücksprachen mit Frau Dr. oec. troph. Münster, aplProf. der Universität Mainz, und Herrn Prof. Dr. med. Weckbecker zu den Ergebnissen der Datenanalyse.	
Interpretation:	Interpretation:	
Die Promovendin hat das Manuskript eigenständig und federführend erstellt. Die enthaltene Interpretation und die Diskussion der Ergebnisse wurde eigenständig durch die Promovendin geschrieben. Dazu zählt auch der Vergleich mit internationalen Forschungsergebnissen, das Ableiten von Handlungsempfehlungen und Verfassen der Limitationen.	Das Manuskript wurde durch alle Co-Autorinnen & Co-Autoren Korrektur gelese und weitere Diskussionsbeiträge wurden von Herrn Prof. Dr. med. Weckbecker, Frau Dr. oec. troph. Münster, aplProf. der Universität Mainz, Frau Dr. Schnakenberg, Herrn Dr. med. Just und Frau Prof. Dr. med. Weltermann, MPH(USA) eingebracht.	
Zutreffendes bitte ankreuzen:		
X Promovend*in ist Erstautor und hat die erste Version des Manuskripts selbst verfasst		
Promovend*in ist Koautor		

Titel der Publikation: Determinants of having no general practitioner in Germany and the influence of a migration background: results of the German health interview and examination survey for adults (DEGS1)

Beschreiben Sie, wie sich Ihr **Eigenanteil** in den folgenden Teilbereichen zusammensetzt:

Beschreiben Sie den **Fremdanteil** in den folgenden Teilbereichen:

## Planung der wissenschaftlichen Arbeit:

## Die Promovendin hat das Forschungsthema dieser Publikation federführend entwickelt und eigenständig die Hintergrundrecherche zur Publikation und zu den entsprechenden Datenanalysen durchgeführt. Die thematische Schwerpunktsetzung inklusive Festlegung der zu untersuchenden Forschungsfragen, Planung der statistischen Analysen und des Aufbaus der Publikation erfolgte durch die Promovendin. Die Promovendin hat die Methodik mit den zu untersuchenden Variablen anhand von Recherchen und Rücksprachen mit der Co-Autorin des Robert Koch-Instituts festgelegt. Die Promovendin hat den Datenantrag an das Robert Koch-Institut erstellt, der notwendig war, um die zu analysierenden, migrationsspezifischen Variablen des DEGS1-Datensatzes zu erhalten. Im Zuge dessen war die Promovendin ebenfalls für die Korrespondenz mit einer Co-Autorin aus dem Robert Koch-Institut zuständig.

## Planung der wissenschaftlichen Arbeit:

Frau Dr. oec. troph. Münster, apl.-Prof. der Universität Mainz, und Herr Prof. Dr. med. Weckbecker unterstützten in der Entwicklung des Forschungsthemas. Frau Dr. med. Klaschik und Herr Prof. Dr. med. Weckbecker bereicherten die Planung durch ihre hausärztlichen Kenntnisse. Teile der Methodik der Publikation wurden von Frau Dr. Puth und Frau Dr. Frank ergänzt.

## Datenerhebung:

Der Antrag zum Erhalt der notwendigen Sekundärdaten (DEGS1) wurde durch die Promovendin geplant und erstellt. Die Korrespondenz mit der dazu verpflichtenden Co-Autorenschaft mit einer Mitarbeiterin aus dem Robert Koch-Institut erfolgte vor allem durch die Promovendin.

## Datenerhebung:

Der Datenantrag wurde durch Frau Dr. oec. troph. Münster, apl.-Prof. der Universität Mainz, und Herrn Prof. Dr. med. Weckbecker unterstützt.

## Auswertung:

Die Promovendin hat maßgeblich die in die Analysen einzuschließenden Variablen anhand der beschriebenen Recherchen und in Rücksprache mit der Co-Autorin aus dem Robert Koch-Institut festgelegt. Die Datenauswertung wurde gemeinsam mit einer Co-Autorin umgesetzt. Die Aufbereitung und Darstellung der zentralen Ergebnisse für die Publikation erfolgte durch die Promovendin.

## Auswertung:

Die Datenauswertung wurde gemeinsam durch Frau Dr. Puth (Mathematikerin) und die Promovendin unter Rücksprache mit Frau Dr. oec. troph. Münster, apl.-Prof. der Universität Mainz, umgesetzt.

## Interpretation:

Das Manuskript wurde federführend von der Promovendin geschrieben. Einzelne Abschnitte wurden von den Co-Autorinnen und Co-Autoren ergänzt. Ebenso wurde die Interpretation und Diskussion der Ergebnisse durch die Promovendin erarbeitet und in dieser Publikation geschrieben. Dies umfasst auch den Vergleich mit internationalen Studienergebnissen, das Ableiten von Handlungsempfehlungen und weiteren Forschungsbedarfen sowie das Zusammenstellen und Verfassen der Limitationen.

## Interpretation:

Alle Co-Autorinnen und Co-Autoren haben Beiträge zur Interpretation der Daten ergänzt und das Manuskript Korrektur gelesen.

## Zutreffendes bitte ankreuzen:

X	Promovend*in ist Erstautor und hat die erste Version des Manuskripts selbst verfasst
	Promovend*in ist Koautor

## 7. List of publications

- Bußkamp A, Vonstein C, Tillmann J, Roßmann C, De Bock F. Wissenstranslation: Aufbereitung von wissenschaftlichen Erkenntnissen für die kommunale Praxis Ergebnisse einer qualitativen Studie im Bereich Bewegungsförderung von älteren Menschen. Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz 2021; 64(1). DOI: 10.1007/s00103-021-03311-2
- Warth J, Beckmann N, Puth M-T, Tillmann J, Porz J, Zier U, Weckbecker K, Weltermann B, Münster E. Association between over-indebtedness and antidepressant use: A cross-sectional analysis. PLoS One 2020; 15(7). DOI: 10.1371/journal.pone.0236393
- Warth J, Puth M-T, Zier U, Beckmann N, Porz J, Tillmann J, Weckbecker K, Bosma H, Weltermann B, Münster E. Patient-physician communication about financial problems: A cross-sectional study among over-indebted individuals. PloS One 2020; 15(5). DOI: 10.1371/journal.pone.0232716
- Tillmann J, Schnakenberg R, Weckbecker K, Weltermann B, Münster E. Hausärztlicher Umgang mit Patientenverfügung und Vorsorgevollmacht bei Demenzpatienten Eine Querschnittsstudie unter deutschen Hausärzten. Das Gesundheitswesen 2020; 82(2): 188-195. DOI: 10.1055/a-1068-2348
- Tillmann J, Puth M-T, Weckbecker K, Klaschik M, Münster E. Prevalence and predictors of having no general practitioner analysis of the German health interview and examination survey for adults (DEGS1). BMC Fam Pract, 2019; 20(1). DOI: 10.1186/s12875-019-0976-x
- Warth J, Puth M-T, Tillmann J, Beckmann N, Porz J, Zier U, Weckbecker K, Weltermann B., Münster E. Cost-related medication nonadherence among over-indebted individuals enrolled in statutory health insurance in Germany: A cross-sectional population study. BMC Health Serv Res 2019; 19(1). DOI: 10.1186/s12913-019-4710-0
- Warth J, Beckmann N, Puth M-T, Tillmann J, Porz J, Zier U, Weckbecker K, Weltermann B, Münster E. Antidepressant use in over-indebted individuals compared to the general population in Germany. European Journal of Public Health 2019; 29. DOI: 10.1093/eurpub/ckz186.558

- Warth J, Puth M-T, Tillmann J, Porz J, Zier U, Weckbecker K, Münster E. Over-indebtedness and its association with pain and pain medication use. Prev Med Rep 2019; 16. DOI: 10.1016/j.pmedr.2019.100987
- Warth J, Puth M-T, Tillmann J, Porz J, Zier U, Weckbecker K, Münster E. Over-indebtedness and its association with sleep and sleep medication use. BMC Public Health 2019; 19(1). DOI: 10.1186/s12889-019-7231-1
- Tillmann J, Just, J, Schnakenberg R, Weckbecker K, Weltermann B, Münster E. Challenges in diagnosing dementia in patients with a migrant background A cross-sectional study among German general practitioners. BMC Fam Pract 2019; 20(1). DOI: 10.1186/s12875-019-0920-0
- Tillmann J, Puth M-T, Frank L, Weckbecker K, Klaschik M, Münster E. Determinants of having no general practitioner in Germany and the influence of a migration background: results of the German health interview and examination survey for adults (DEGS1). BMC Health Serv Res 2018; 18(1). DOI: 10.1186/s12913-018-3571-2
- Tillmann J, Schnakenberg R, Puth M-T, Weckbecker K, Just J, Münster E. Barriers in general practitioners' dementia diagnostics among people with a migration background in Germany (BaDeMi). Study protocol for a cross-sectional survey. BMC Med Res Methodol 2018; 18(1). DOI: 10.1186/s12874-018-0580-0
- Tillmann J, Krämer A, Fischer F. Medizinische Ausbildung zur Versorgung von Asylsuchenden und Geflüchteten Quantitative Bestandsaufnahme und Bedarfserhebung unter Medizinstudierenden in Deutschland. Zeitschrift für Flüchtlingsforschung 2018; 2(1): 3-14. DOI: 10.5771/2509-9485-2018-1-163