

Dementia Care-Toolbox: Verbesserung der Versorgung von Migranten mit Demenz in deutschen Hausarztpraxen

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Inhaltsverzeichnis

Abkürzungsverzeichnis	7
1. Deutsche Zusammenfassung	8
1.1 Einleitung	8
1.2 Material und Methoden	10
1.3 Ergebnisse	12
1.4 Diskussion	15
1.5 Zusammenfassung	19
1.6 Literaturverzeichnis der deutschen Zusammenfassung	20
2. Veröffentlichung A	25
Abstract	25
Introduction	25
Materials and Methods	26
Results	28
Discussion	29
References	31
Veröffentlichung B (Ko-Autorenschaft)	33
Abstract	33
Introduction	34
Materials and Methods	34
Results	37

Discussion	38
References	41
3. Danksagung	45
4. Publikationen	46

Abkürzungsverzeichnis

CI	Confidence Interval = Konfidenzintervall
DCT	Dementia Care-Toolbox
GEE	Generalized Estimating Equations = Generalisierte Schätzgleichungen
GP	General Practitioner = Hausarzt
MFA	Medizinische Fachangestellte
NRW	Nordrhein-Westfalen
OR	Odds Ratios
PrA	Practice Assistant = MFA

1. Deutsche Zusammenfassung

1.1 Einleitung

Demenz stellt die Gesundheitsversorgung in Deutschland wegen der zunehmenden Alterung der Gesellschaft vor eine relevante Herausforderung. Weltweit sind 55 Millionen Menschen an Demenz erkrankt (Gauthier et al., 2022), wovon 1,8 Millionen in Deutschland leben (Deutsche Alzheimer Gesellschaft e.V., 2022). Es ist davon auszugehen, dass sich die Zahl der Demenzerkrankten in Deutschland bis 2050 auf 2,8 Millionen erhöhen wird (Deutsche Alzheimer Gesellschaft e.V., 2022). Morbus Alzheimer ist mit 50-70 % die häufigste Demenzform und äußert sich in einer langsamen, progredienten Gedächtnisstörung mit Orientierungsverlust insbesondere in Ort und Zeit (DGPPN und DGN, 2016). Das Langzeitgedächtnis und die Persönlichkeitsstruktur bleiben hierbei über einen langen Zeitraum intakt und sind erst im Spätstadium betroffen (Deutsche Alzheimer Gesellschaft e.V., 2019). Als Ursache werden neben einer Hirnatrophie, die insbesondere im Bereich des parieto-temporalen und frontalen Kortexes stattfindet, auf histopathologischer Ebene Eiweißablagerungen in Form von extrazellulären senilen Amyloid-Plaques (β -Amyloidproteine) und intrazellulären Alzheimer Fibrillen (Phospho-Tauproteine) angenommen (DGPPN und DGN, 2016; Reitz und Mayeux, 2014). Bis dato bestehen keine kurativen Therapieansätze. Durch den Einsatz von Acetylcholinesterasehemmern und NMDA-Antagonisten können lediglich eine Symptommilderung und ein Hinauszögern des Erkrankungsprogresses erreicht werden (DGPPN und DGN, 2016). Studien zeigen den größten Nutzen bei Etablierung der Pharmakotherapie im frühen Krankheitsverlauf (Geldmacher, 2007; Wattmo et al., 2016). Um Demenzerkrankten und deren Angehörigen eine frühzeitige optimale Planung hinsichtlich erwünschter Interventionen und Therapien zu ermöglichen und Gefühle der Unsicherheit und Angst zu reduzieren, ist laut Dubois et al. (2016) eine Detektion von Demenzsymptomen bereits im Frühstadium sinnvoll. Hierbei spielen in Deutschland Hausärzte eine entscheidende Rolle, da sie die erste Anlaufstelle für Betroffene und deren Angehörige sind und zudem ihre Patienten meist über einen langen Zeitraum betreuen. Weltweit durchgeführte Studien unter Hausärzten weisen jedoch auf Wissenslücken über Demenz und deren Abgrenzung zu anderen kognitiven Störungsbildern (Cahill et al., 2006; Mitchell et al., 2011), Unsicherheiten in der Demenzdiagnostik

(Cahill et al., 2006; Dubois et al., 2016; van Hout et al., 2007; Turner et al., 2004) und unzureichende Kenntnisse über Unterstützungsmöglichkeiten (Pathak und Montgomery, 2015; Turner et al., 2004) und Kommunikationsstrategien hin (Kaduszkiewicz et al., 2008; Pathak und Montgomery, 2015; Turner et al., 2004). Infolgedessen ist von einer Unterdiagnostizierung der Demenz insbesondere in der Frühphase auszugehen (Eichler et al., 2014; Mitchell et al., 2011). Eine besondere Herausforderung stellt hierbei die Versorgung von Migranten mit Demenz dar (Sagbakken et al., 2018).

Deutschland ist ein Land mit einem hohen Anteil an multinationalen Zuwanderern. Im Jahr 2021 lebten in Deutschland 22,3 Millionen Menschen mit Migrationshintergrund, von denen die meisten in Nordrhein-Westfalen (NRW) leben. Sie stammen meist aus der Türkei (12 %), Polen (10 %) oder der Russischen Föderation (6 %) (Destatis, 2022a). In Deutschland sind schätzungsweise 2,2 Millionen Menschen mit Migrationshintergrund älter als 65 Jahre und haben somit ein erhöhtes Erkrankungsrisiko für Demenz (Destatis, 2022b; DeZIM, 2022). Es ist daher davon auszugehen, dass die Prävalenz der Demenz bei Menschen mit Migrationshintergrund unter Berücksichtigung der steigenden Lebenserwartung ebenfalls ansteigt, was Hausarztpraxen vor zusätzliche Herausforderungen stellen wird. In einer Querschnittsstudie konnte durch das Institut für Hausarztmedizin gezeigt werden, dass 96 % der befragten Hausärzte schon einmal Barrieren in der Demenzdiagnostik erlebt haben vor allem aufgrund einer Sprachbarriere (89,3 %) und Unsicherheiten in der Demenzdiagnostik (70,9 %) bei Patienten mit Migrationshintergrund (Tillmann et al., 2019). Einen Ansatz, um diese Barriere zu überwinden, stellt die Dementia Care-Toolbox (DCT) dar, die für Hausärzte, medizinische Fachangestellte (MFA), Demenzerkrankte mit und ohne Migrationshintergrund und deren Angehörige entwickelt wurde. Diese umfasst neben Informationsmaterial multiple diagnostische Hilfsmittel in den Sprachen Deutsch, Türkisch und Russisch, entsprechend der Häufigkeitsverteilung der Herkunftsländer in NRW. In unserer ersten Studie konnte eine hohe Akzeptanz der DCT (82 %) gezeigt werden. Hierbei wurden insbesondere die Broschüren (52,1 %), gefolgt von der Informationskarte (44,9 %) und dem Poster (28,6 %) von den befragten Hausärzten und MFAs als hilfreich bewertet (Filbert et al., 2020).

Die hier dargestellte Folgestudie hatte zum Ziel, Effekte der DCT auf die Selbsteinschätzung der Sicherheit von deutschen Hausärzten und MFAs in der Demenzversorgung, insbesondere von Patienten mit Migrationshintergrund zu identifizieren (Jäger et al., 2021). Die Selbsteinschätzung wurde anhand verschiedener Aspekte bestehend aus der Informationsvermittlung, der Beantwortung von Nachfragen, der Kommunikation, der Interaktion und dem Wissen über lokale Unterstützungsangebote untersucht. Darüber hinaus wurde die Sicherheit in der Kommunikation mit Demenzpatienten im Allgemeinen betrachtet.

1.2 Material und Methoden

Die Studie wurde als 2-armige Cluster-randomisierte, kontrollierte Studie durchgeführt und adressierte Hausarztpraxen in NRW. Die Teilnehmerkohorte umfasste 46 Praxen, wovon 24 der Interventions- und 22 der Kontrollgruppe zufällig zugeteilt wurden. Alle teilnehmenden Praxen waren bei der Kassenärztlichen Vereinigung Nordrhein als aktiv praktizierende Hausärzte gelistet, wobei Pädiater und Lehrärzte des Institutes für Hausarztmedizin ausgeschlossen wurden. Von September bis November 2018 stand der Interventionsgruppe die DCT zur Anwendung zur Verfügung, die aus einer Demenz-Informationsbroschüre für Patienten und Angehörige, einem Poster für das Wartezimmer, einer Informationskarte für Hausärzte und MFAs, sowie einem praktischen Tool (Anamnesebögen auf Deutsch-Englisch/Türkisch/Russisch, Heft über Informationen zur Gesundheitskompetenz und Tipps zur Kommunikation mit Patienten mit Migration, Easy-Kurztest) für Hausärzte bestand und zuvor per Post zugesendet wurde. Die Kontrollgruppe erhielt zu diesem Zeitpunkt kein Interventionsmaterial. Im Anschluss wurden soziodemografische Charakteristika der Ärzte und MFAs (Alter, Geschlecht, Migrationshintergrund, Beruf, Dauer der Beschäftigung in der Praxis), sowie Fragen zur Selbsteinschätzung der Sicherheit in der Demenzdiagnostik und Behandlung von Demenzerkrankten mit und ohne Migrationshintergrund mittels eines standardisierten Evaluationsfragebogens anhand einer 5-Punkte Likert-Skala von der Interventions- und Kontrollgruppe erfasst (Jäger et al., 2021). Zusätzlich wurde die Akzeptanz und Nutzung des Informationsmaterials der DCT anhand einer 5-Punkte Likert-Skala und Multiple-Choice-Feldern erhoben (Filbert et al., 2020). Die Daten ausgefüllter Fragebögen wurden in IBM SPSS Statistics Version 26 übertragen,

aufgearbeitet und anschließend analysiert. Frühzeitige Studienabbrüche, sowie unvollständig ausgefüllte Fragebögen wurden aus den statistischen Analysen ausgeschlossen, sodass die Interventionsgruppe aus 15 Praxen (14 Hausärzte, 36 MFA) und die Kontrollgruppe aus 17 Praxen (16 Hausärzte, 57 MFA) bestand (Abb. 1). Zur deskriptiven Analyse wurden relative Häufigkeiten, Mittelwerte, Quartile, Chi-Quadrat-Tests und t-Tests berechnet. Die Analysen zur Selbsteinschätzung der Sicherheit von Hausärzten und MFAs in der Demenzdiagnostik und Behandlung von Demenzkranken mit und ohne Migrationshintergrund wurden mittels generalisierter Schätzgleichungen (GEE) mit einer autoregressiven Beziehung der ersten Ordnung (AR1) unter Berücksichtigung der Faktoren Kondition, Berufsgruppe, Geschlecht und Migrationshintergrund durchgeführt (Jäger et al., 2021). Anhand von Odds Ratios (OR), einem 95 % Konfidenzintervall (CI) und einem Signifikanzniveau von 0,05 konnten anschließend die Effekte der Intervention im Vergleich zur Kontrollgruppe berechnet werden.

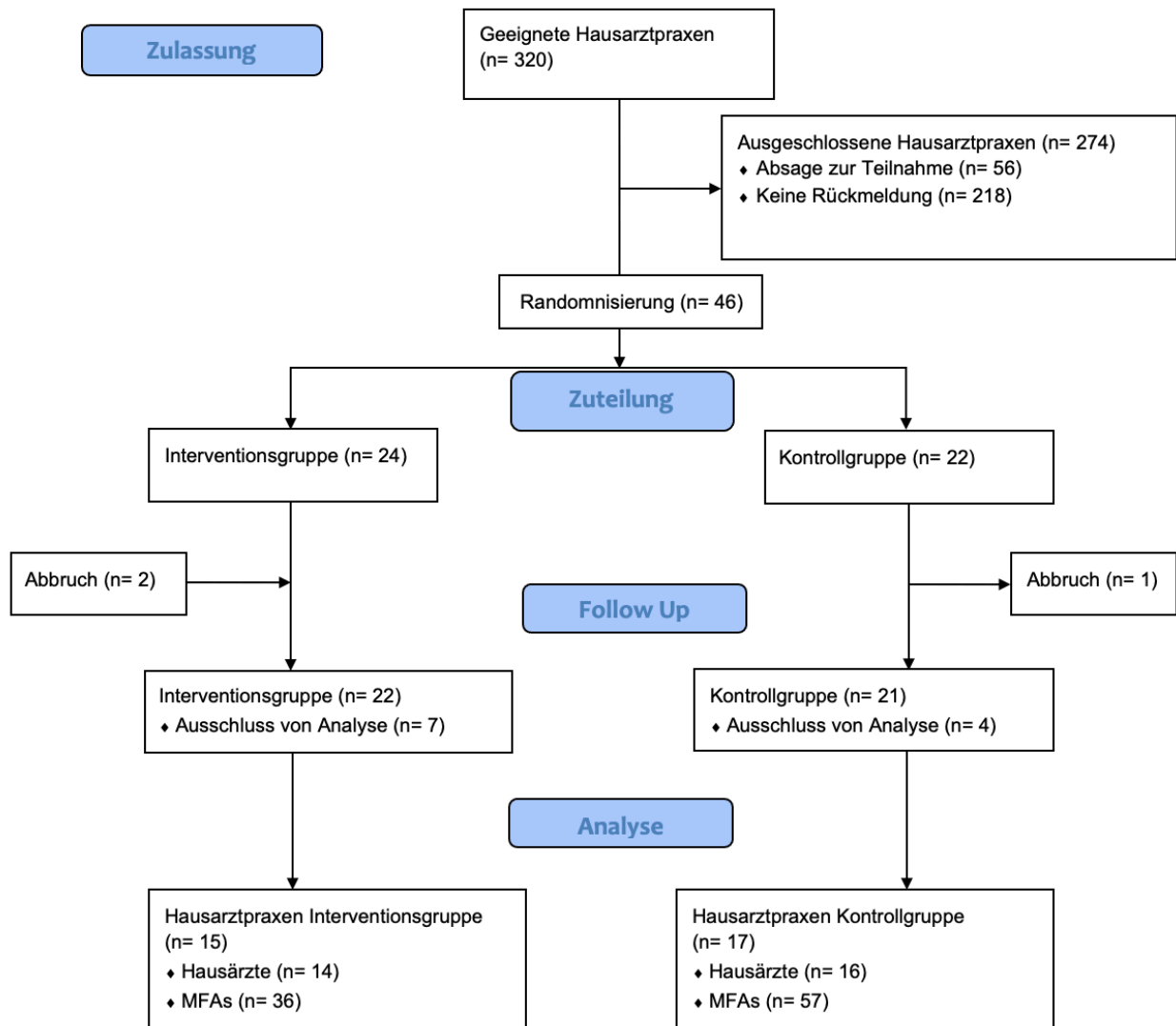


Abb. 1: Flussdiagramm zum Auswahlprozess der Studienteilnehmer (Modifikation Figur 1 aus Filbert et al., 2020)

1.3 Ergebnisse

Die deskriptiven Analysen zeigten unter Hausärzten und MFAs sowohl in der Interventions- (Abb. 2) als auch Kontrollgruppe (Abb. 3) Unsicherheiten 1) im Umgang, 2) in der Informationsvermittlung des Krankheitsbildes, 3) in der Beantwortung von Nachfragen,

sowie 4) allgemeine Wissenslücken über lokale Unterstützungsmöglichkeiten für Demenzpatienten mit Migrationshintergrund.

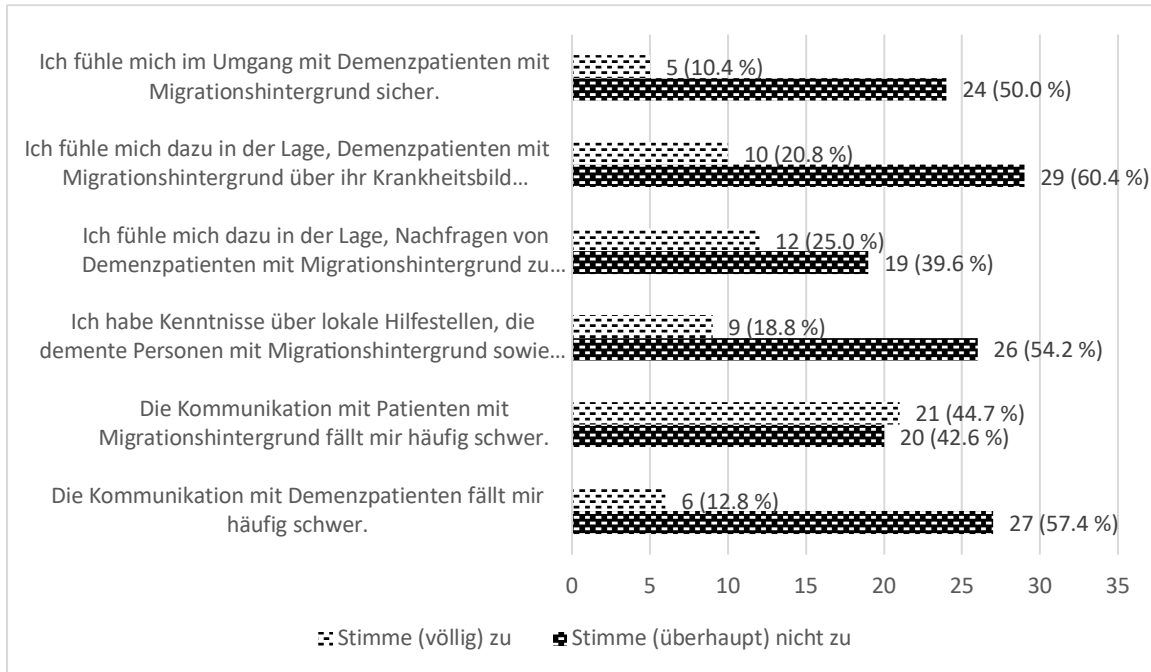


Abb. 2: Selbsteinschätzung der Sicherheit im Umgang mit der Demenzversorgung von Migranten: Häufigkeitsverteilungen verschiedener Versorgungsaspekte (nur Interventionsgruppe) (n= 14 Hausärzte und n= 36 MFA)

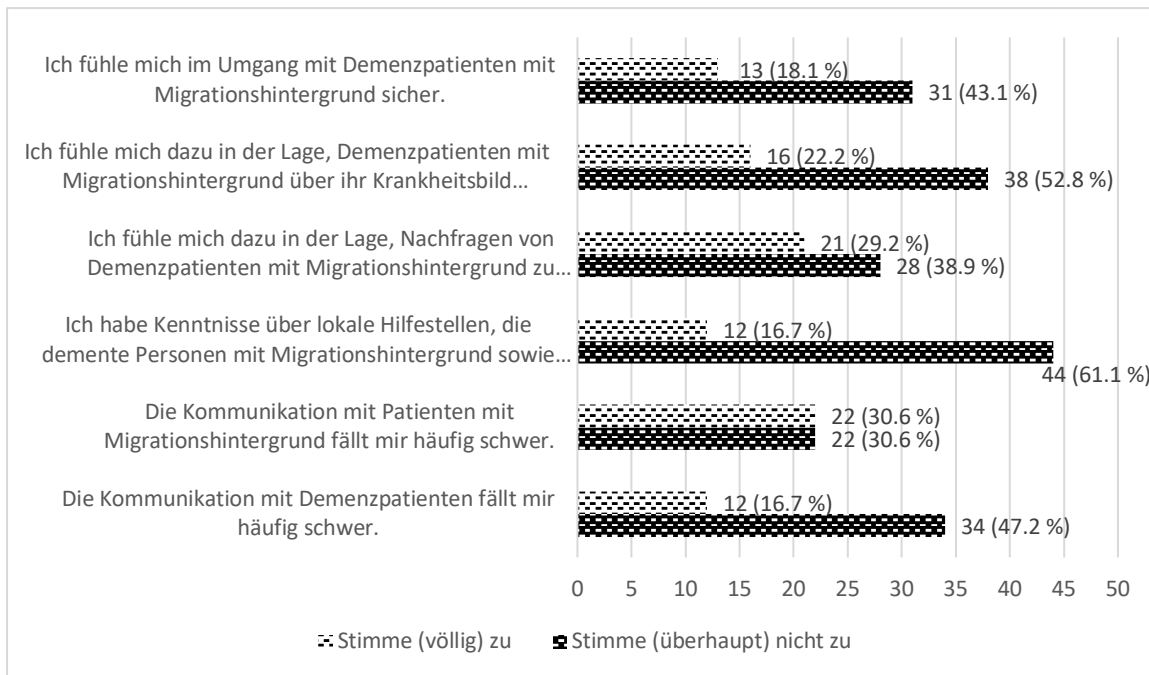


Abb. 3: Selbsteinschätzung der Sicherheit im Umgang mit der Demenzversorgung von Migranten: Häufigkeitsverteilungen verschiedener Versorgungsaspekten (nur Kontrollgruppe, n= 16 Hausärzte und n= 57 MFA)

Insgesamt hatte die DCT keinen signifikanten Effekt auf die Selbsteinschätzung der Sicherheit von deutschen Hausärzten und MFAs in der Demenzversorgung (OR 1.01, 95 % 0.72-1.43, $p=0.95$). Auch die GEE Analysen der 6 Teilaspekte zeigten keine signifikanten Ergebnisse. Es fanden sich zwischen der Interventions- und Kontrollgruppe keine signifikanten Unterschiede im Wissensstandes über geeignete Unterstützungsmöglichkeiten für Demenzpatienten mit Migrationshintergrund (OR 1.43, 95 % CI 0.68-3.03, $p=0.35$) und hinsichtlich Kommunikationsschwierigkeiten mit Demenzerkrankten im Allgemeinen (OR 0.72, 95 % CI 0.33-1.56, $p=0.40$) oder spezifisch mit Demenzerkrankten mit Migrationshintergrund (OR 1.63, 95 % CI 0.65-4.10, $p=0.30$). Zudem konnten keine signifikanten Effekte der DCT-Intervention auf den Umgang mit Migranten mit Demenz (OR 0.57, 95 % CI 0.26-1.23, $p=0.15$), die Informationsvermittlung über das Krankheitsbild Demenz (OR 0.60, 95 % CI 0.25-1.45, $p=0.26$) oder die Beantwortung von Nachfragen (OR 0.82, 95 % CI 0.36-1.86, $p=0.64$) gezeigt werden (Tab. 1).

Tab. 1: Selbsteinschätzung der Sicherheit in der Demenzversorgung von Migranten durch Hausärzte und MFA (Ergebnisse des GEE-Modells) (Modifikation Tabelle 5 aus Jäger et al., 2021)

	Sig	OR	95% CI
Gesamteffekt Selbsteinschätzung der Sicherheit in der Demenzversorgung.	0.95	1.01	0.72-1.43
Ich fühle mich im Umgang mit Demenzpatienten mit Migrationshintergrund sicher.	0.15	0.57	0.26-1.23
Ich fühle mich dazu in der Lage, Demenzpatienten mit Migrationshintergrund über ihr Krankheitsbild aufzuklären / zu informieren.	0.26	0.60	0.25-1.45
Ich fühle mich dazu in der Lage, Nachfragen von Demenzpatienten mit Migrationshintergrund zu beantworten.	0.64	0.82	0.36-1.86
Ich habe Kenntnisse über lokale Hilfestellen, die demente Personen mit Migrationshintergrund sowie ihre Familien unterstützen.	0.35	1.43	0.68-3.03
Die Kommunikation mit Patienten mit Migrationshintergrund fällt mir häufig schwer.	0.30	1.63	0.65-4.10
Die Kommunikation mit Demenzpatienten fällt mir häufig schwer.	0.40	0.72	0.33-1.56

Referenz: Kontrollgruppe, kontrolliert für Berufsgruppe (Hausarzt, MFA), Geschlecht (männlich, weiblich), Migrationshintergrund (ja, nein)

1.4 Diskussion

Ziel der Dissertation war es, die Wirksamkeit der neu entwickelten DCT auf die Selbsteinschätzung der Sicherheit von Hausärzten und MFAs in der Demenzversorgung von Migranten mithilfe einer Cluster-randomisierten Interventionsstudie zu evaluieren. Durch die DCT konnte hierbei ein erster Forschungsbeitrag zu möglichen Strategien zur Optimierung der hausärztlichen Versorgung von Patienten mit Migrationshintergrund geleistet werden. Es wurden keine signifikanten Effekte auf die Selbsteinschätzung der Sicherheit von Hausärzten und MFAs in der Demenzversorgung von Migranten nach 3 Monaten gefunden. In Filbert et al. konnte gezeigt werden, dass Hausärzte am häufigsten die Informationskarte verwendeten, die konkrete Hilfsangebote mit Kontaktadressen und Kommunikationshinweise für Demenzerkrankte enthielt. Im Vergleich bevorzugten MFAs die Broschüren, die ebenfalls Hilfsangebote mit Kontaktadressen auf verschiedenen Sprachen für Patienten mit Migrationshintergrund beinhalteten. Es ist möglich, dass diese Unterschiede auf verschiedene Lernpräferenzen und Arbeitsweisen beider Berufsgruppen zurückzuführen sind. Hausärzte könnten möglicherweise durch ihren zeitlich eng getakteten und hochfrequenten Patientenkontakt, in dem hohe medizinische Anforderungen an sie

gestellt werden, die kurze, prägnante Materialgestaltung der Informationskarte mit Verweisen auf detaillierte Informationen bevorzugt haben. Hingegen sind MFAs meist der erste Praxiskontakt für Anliegen der Patienten und deren Angehörige, sodass diese möglicherweise häufiger die Broschüren einsetzten, um Patienten mit ausführlichen Informationen zum Krankheitsbild Demenz, abgestimmt auf deren Bedürfnisse, zu versorgen. Dies könnte darauf hindeuten, dass durch die Verwendung des Materials das Bewusstsein für patientenzentrierte Themen unter den Studienteilnehmern geschärft und das eigene Vertrauen in eine zufriedenstellende Patientenversorgung gestärkt wurde, um alltäglichen Herausforderungen in der Demenzversorgung besser zu begegnen. Diese Annahme ist im Einklang mit vorherigen Studien, wo ein positiver Einfluss auf Wissen, Bewusstsein und Einstellung durch den passiven Gebrauch von gedrucktem Aufklärungsmaterial gezeigt wurde (Bull et al., 2001; Coumou und Meijman, 2006; Janamian et al., 2011). In unserer Intervention zur hausärztlichen Demenzversorgung wurden Leistungserbringer von Menschen mit Migrationshintergrund adressiert. Dass die Interventionsgruppe trotz der DCT Unsicherheiten im Umgang, in der Kommunikation und Informationsvermittlung mit Demenzpatienten mit Migrationshintergrund angab, lässt darauf schließen, dass Studienteilnehmern durch die Intervention die Komplexität der Demenzversorgung von Migranten und eigene Defizite bewusst wurden. Möglicherweise deckte das Interventionsmaterial diese Aspekte unzureichend ab, um das Selbstvertrauen der Studienteilnehmer zu stärken. Hinweise hierfür finden sich in der Bewertung einzelner Aspekte der Informationskarte. Hausärzte bewerteten diese am wenigsten hilfreich bei Sprachproblemen und MFAs bei Herausforderungen im Praxisalltag (Filbert et al., 2020). Vergleichbare Defizite in der Versorgung von Migranten konnten von Sagbakken et al. (2018) in einer Umfrage unter norwegischem medizinischem Fachpersonal identifiziert werden. Hierbei stellten im klinischen Alltag wenig Erfahrung, Sprachbarrieren und Wissenslücken in der Demenzdiagnostik bei Patienten mit Migrationshintergrund die größten Herausforderungen dar (Sagbakken et al., 2018). Zu vergleichbaren Ergebnissen kam ein Review europäischer Studien zu Barrieren in der Gesundheitsversorgung von Demenzerkrankten ethnischer Minderheiten (Duran-Kıraç et al., 2022). Schlussfolgernd postulieren die Autoren die Notwendigkeit von Trainingsprogrammen zur Verbesserung der Kommunikationsfähigkeiten und den Gebrauch von transkulturellen Erhebungsinstrumenten in der Demenzversorgung von Migranten (Duran-Kıraç et al., 2022; Sagbakken et al.,

2018; Teunissen et al., 2017). Ein hohes Interesse an solchen Weiterbildungsmöglichkeiten über Demenz äußerten Hausärzte in mehreren ausländischen Studien (Lee et al., 2020; Robinson et al., 2001). Dass die DCT von der Mehrheit der Hausärzte genutzt und mehrheitlich angenommen wurde, unterstützt die Annahme einer hohen Bereitschaft und Motivation unter Hausärzten für Weiterbildung, um eigene Kenntnisse und Fähigkeiten auf diesem Gebiet zu erweitern. Die DCT greift dieses Interesse auf und stellt einen ersten Ansatz dar diese Defizite durch die Verwendung von Diagnostikinstrumenten für medizinisches Personal in verschiedenen Fremdsprachen anzugehen. Darüber hinaus wurde versucht, die Kritik an der Inkompatibilität von Ansätzen für den alltäglichen Praxisgebrauch zu überwinden (Muijsenbergh et al., 2014), indem der Inhalt auf zuvor identifizierte Wissensbedürfnisse der MFAs sowie Hausärzte abgestimmt wurde (Tillmann et al., 2019). Weiterhin wurde durch eine übersichtliche Materialgestaltung (Überschriften, Stichpunkte, hervorgehobenen Kernaussagen) und die Verwendung einer einfachen Sprache versucht, komplexe Aspekte des Krankheitsbildes „Demenz“ Patienten und deren Angehörigen verständlich nahezubringen und deren Aufmerksamkeit für das Krankheitsbild zu schärfen. Letztere spielen nämlich in der Detektion und Versorgung eine entscheidende Rolle. Studien liefern Evidenz dafür, dass die Einbindung von Angehörigen in Schulungs- und Interventionsprogramme langfristig zu einer verbesserten Demenzversorgung und Lebensqualität führt (Nielsen et al., 2022; Xiao et al., 2016). Kritisch hierbei zu betrachten bleibt die Bereitschaft der Patienten und deren Angehörigen für eine frühzeitige Unterstützung, da in anderen kulturellen Kreisen als hierzulande kognitive Defizite und Demenz häufig mit Stigmata und Scham besetzt sind (Sagbakken et al., 2018; van Wezel et al., 2018), keine offene Kommunikation über Demenz besteht (van Wezel et al., 2018) und Patienten mit deren Angehörigen dementsprechend nicht ausreichend durch Interventionen erreicht werden. Dies ist im Einklang mit aktuellen Studiendaten, die darauf hindeuten, dass Migranten weniger Gesundheitsangebote in Anspruch nehmen und Erkrankte sowie deren Familienangehörige erst im Spätstadium der Krankheit medizinische Hilfe aufsuchen (Mukadam et al., 2011; Nielsen et al., 2011; Segers et al., 2013). Demzufolge übernehmen bis dahin häufig Familienangehörige in Gemeinschaften mit Migrationshintergrund die alleinige Verantwortung und intensive Betreuung ihrer erkrankten Familienmitglieder resultierend in einer starken physischen und psychischen Belastung (Farina et al., 2017; Mukadam et al., 2011; Nielsen et al., 2021). Ein erster Schritt hierbei ist die

Sensibilisierung der Angehörigen für das Krankheitsbild und für entsprechende Unterstützungsangebote. Die Toolbox griff dies durch den Einsatz von multilingualen Informationsbroschüren mit konkreten Anlaufstellen für Erkrankte und deren Angehörige auf. Inwieweit diese von Betroffenen in Anspruch genommen wurden und einen Effekt auf Barrieren von pflegenden Angehörigen hatten bleibt offen, da hierzu keine Daten in der Studie erhoben wurde. Mehrere Studien deuten jedoch darauf hin, dass die Inanspruchnahme solcher Unterstützungsangebote und Teilnahme an kultur-sensiblen Managementprogrammen die Kompetenz im Umgang mit Herausforderungen in der Demenzversorgung stärken (Xiao et al., 2016) und die Lebensqualität und den Gesundheitszustand der Angehörigen verbessern (Nielsen et al., 2022).

Limitationen und Ausblick

Eine Stärke unserer Studie stellt die Berücksichtigung beider Berufsgruppen (Hausärzte, MFA), die in der Demenzversorgung von Hausarztpatienten involviert sind, dar. Da es sich jedoch bei dieser Studie um eine explorative Studie mit kleiner Stichprobengröße handelte, sind folgende Limitationen zu beachten. Es wurden alleinig Daten der Studienteilnehmer nach Interventionsablauf und nicht zusätzlich zu Beginn der Intervention erhoben, sodass ein Vergleich der Effekte zur Selbsteinschätzung der Sicherheit von Ärzten und MFAs in der Demenzversorgung von Patienten mit Migrationshintergrund nur zwischen Interventions- und Kontrollgruppe möglich ist. Zudem ist anzunehmen, dass insbesondere Hausarztpraxen mit Forschungsinteresse oder Interesse am Thema Demenz von unserer Studie angesprochen wurden, was die Generalisierbarkeit unserer Ergebnisse einschränkt. Des Weiteren umfasste der Fragebogen Fragen zur Selbsteinschätzung, welche anfällig für Antwortverzerrungen sind und möglicherweise nicht die tatsächlichen Leistungen der Studienteilnehmer widerspiegeln. Da eine Verbesserung der Selbsteinschätzung der Sicherheit in der Demenzversorgung von Migranten nicht unmittelbar eine verbesserte Patientenversorgung bedeutet, sollten zukünftige Studien die Effekte der DCT auf Patientenebene wie Lebensqualität, Inanspruchnahme von Hilfsangeboten und Belastung der Angehörigen erfassen. Auch wurden keine qualitativen Fragen zur Nutzung der DCT erhoben, lediglich vorgenommene Änderungen oder der Unterstützungswert der DCT in der hausärztlichen Versorgung seitens der Studienteilnehmer wurden erfasst. In-

wiefern Langzeiteffekte der DCT bestehen und ob bisherige Studienergebnisse in größeren Stichproben repliziert werden können, gilt es nun in Folgestudien zu untersuchen. Hierbei sollte ein verstärkter Fokus auf den aktuellen Unterstützungsbedarf in der hausärztlichen Demenzversorgung von Patienten mit Migrationshintergrund gelegt werden, um die DCT in Hinblick auf diese Bedürfnisse weiter zu modifizieren.

1.5 Zusammenfassung

Diese Studie verdeutlicht die Notwendigkeit von Unterstützungsmöglichkeiten für Ärzte und MFAs in der hausärztlichen Demenzversorgung von Patienten mit und ohne Migrationshintergrund. Hierbei steht die Stärkung der Kompetenzen und Sicherheit des medizinischen Personals im Fokus, um eine situationsgerechte Betreuung dieses Patientenkollektivs zu gewährleisten. Die DCT stellt einen neuartigen Ansatz für Hausärzte und MFAs dar. Zusammengefasst deuten die Ergebnisse dieser Dissertation darauf hin, dass die DCT von Hausarztpraxen mehrheitlich angenommen wurde. Nichtsdestotrotz hatte die Nutzung der DCT keinen signifikanten Effekt auf die Selbsteinschätzung der Studienteilnehmer in der hausärztlichen Demenzversorgung. Es gilt nun die DCT weiter auf den Bedarf von Hausärzten und MFAs anzupassen, um dann Erkenntnisse in einer größeren Stichprobe zu gewinnen und medizinisches Personal durch weitere praxisorientierte Ansätze auf zukünftige Herausforderungen in der Demenzversorgung adäquat vorzubereiten.

1.6 Literaturverzeichnis der deutschen Zusammenfassung

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RESEARCH

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Effects of the dementia care toolbox on personnel's self-reported confidence in patient care: a CRT in general practices

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Abstract

Background: In rapidly aging populations, general practitioners (GPs) are challenged in dementia care of patients with and without migration background. Uncertainties in treating dementia in migrant patients due to language barriers or information deficits are reported. To address these deficits, we developed the Dementia Care Toolbox which was judged helpful by GP practice personnel. This two-armed cluster-randomised trial (CRT) investigated the effects of this toolbox on German GPs' and practice assistants' (PrAs) attitudes and confidence in dementia care, especially in patients with migration background.

Methods: A total of 32 GP practices were recruited and randomised into intervention (toolbox use for 3 months) and waiting-list control (toolbox after follow-up). After 3 months all participating GPs and PrAs received a standardised questionnaire addressing their levels of self-reported confidence in dementia care for patients with and without migration background. A generalized estimating equation model that took practice cluster effects into account was applied to assess GPs and PrAs self-reported confidence in dementia care in patients with and without migration background.

Results: Overall, the intervention had no significant effect on self-reported confidence in dementia care. However, the use of the dementia care toolbox showed a tendency for a learning effect on knowledge about local support structures for migrant patients with dementia (odds ratio 1.43; 95% CI 0.68-3.03, $p = 0.35$) and for less communication difficulties with dementia patients in general (odds ratio 0.72; 95% CI 0.33-1.56; $p = 0.40$). Moreover, intervention practices showed a tendency towards more awareness of own limitations: less self-confidence regarding answering questions (odds ratio 0.82; 95% CI 0.36-1.86, $p = 0.64$) and providing information for patients with migration background (odds ratio 0.60; 95% CI 0.25-1.45, $p = 0.26$).

Conclusion: The Toolbox Dementia Care increased awareness on the respective topic. Given a small sample size, further studies on its effectiveness in primary care are needed.

Trial registration: German Clinical Trials Register, DRKS00014632. Registered 02/08/2018.

Keywords: Dementia care, Dementia, General practitioners, Self-reported confidence in primary care, Intervention, Migration background

Background

Dementia is a worldwide challenge due to a lack of curative therapies for most forms of the syndrome [1]. It is estimated that 46.8 million people suffer from dementia and this number is expected to triple by 2050 [2].

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Especially in aging populations, this represents a considerable economic, medical, and social challenge for health care systems [3–6]. Although an issue of debate [1], it is believed that the (early) detection of dementia benefits the patient and their next of kin in terms of optimal treatment, reduction of psychological stress and the possibility of living in a familiar environment as long as possible [7–10]. British studies from primary care by Cahill et al. [11] and Iliffe et al. [12] showed that detection can be challenging as early symptoms are difficult to distinguish from those of other cognitive impairments and normal ageing processes, testing is time-consuming [13, 14] and diagnostic skills may be insufficient [14, 15]. Surveys among general practitioners (GPs) from Ireland [11, 16], Nepal [15] and England [17] indicate a lack of knowledge on dementia [18] and support services available for patients and their next of kin [14, 19], as well as uncertainties in communicating the diagnosis [14, 18], especially when dealing with migrant populations [20]. The authors of these studies recommended information and support strategies for both physicians as well as patients and their care givers [14, 18, 11].

In Germany, 21.2 million inhabitants have a migration background of whom 2.07 million are aged over 65 years and are at risk for dementia [21]. European studies from Nielsen et al. indicate that diagnosing dementia in migrants is considered difficult by two thirds of physicians [20]. Therefore, researchers from Belgium and Norway assumed that dementia is underdiagnosed in migrants [22, 23]. Currently, there is no data from Germany indicating an outcome-relevant deficit in dementia care for migrants, but this may differ from other countries as all patients have health coverage and access to primary and further level neuro-psychiatric care. For medical and ethical reasons, the German guideline on dementia recommends dementia diagnostic only in patients agreeing on this [1]. Aiming to better understand potential difficulties of German GPs in dementia care for patients with and without migration background, we had performed a physician questionnaire survey among 326 GPs: 96% experienced barriers at least once mostly due to language barriers or information deficits for migrants, 70.9% reported difficulties in diagnosing dementia in migrants [24]. To provide focussed information for GP practices, we developed a dementia care toolbox with material for physicians and practice assistants (PrAs) (information card, diagnostic tool). In addition, information media for patients and their next of kin (poster for the waiting room, brochure) was provided in German, Turkish and Russian. This is in accordance with the distribution of migrants in the German North Rhine region, where most migrants have a Turkish (17.7%) or Russian (8.1%) background [25]. The effects

of the toolbox on GPs self-reported care for dementia care patients with and without migration background was studied in the intervention arm of this study [26]. In a first analysis, we showed that the toolbox was generally well accepted (82%) by GPs and PrAs. In descending order, both professions rated the brochures (52.1%), the information card (44.9%) and the poster (28.6%) as helpful [26]. Here we report the effects of the toolbox on the self-reported confidence of German GPs and PrAs when dealing with dementia patients with and without a migration background.

Methods

Study design and participants

This two-armed cluster-randomised trial (CRT) targeted GPs and PrAs in the German North Rhine region. The intervention comprised the Dementia Care Toolbox for GP practices [26]. Details of the study protocol for the cross-sectional study are published [27]; the study protocol for this CRT was submitted to the Ethics Committee of the Medical Faculty of the University of Bonn and is detailed in this manuscript. In short, a total of 320 general practices were invited to participate: 1) 230 GPs from the random sample of the prior cross-sectional study and 2) 90 practices from the institute's teaching practice network with known research interested were asked for participation in the study [24]. A total of 46 practices participated either in the intervention or control group with follow-up data available for 32 practices [26]. Due to the novelty of the intervention, sample size was estimated based on prior CRTs in general practices. Practices were allocated to intervention or wait list-controlled group by random number generator. Intervention practices received the Dementia Care Toolbox by mail after randomisation. Practices in the waiting list-control arm received the intervention after the follow-up data collection was completed. Scientists involved in the project were responsible for study conduct, including randomisation, enrolment of participants and assignment to intervention groups. No blinding was performed. The study took place from September 2018 to April 2019, with the intervention being conducted from September to November 2018.

Intervention: description of dementia care toolbox

All practices who provided written informed consent were randomised and received the Dementia Care Toolbox by mail with the offer to use the materials for the subsequent 3 months. After 3 months, physicians and PrAs received a questionnaire to assess for the use in the toolbox [26] and effects on self-reported confidence in patient care.

The Dementia Care Toolbox comprised the following material:

1 Patients and next of kin

- Brochures: The 8-page brochure gave an overview on dementia and included a definition of dementia and core symptoms, contact addresses of support services as well as the further procedure after first dementia symptoms appeared. It was available in German, Turkish and Russian.
- Poster (30 cm × 42 cm): The poster was hung up in the waiting room of the practice to raise awareness of dementia among patients and next of kin. Short questions and statements about core symptoms of dementia were printed on the poster in German, Turkish and Russian.

2 GPs and PrAs:

- Information card: The double-sided information card contained general information on dementia as well as assistance for challenges, communication, cultural sensitivity for dementia patients with and without a migration background and contact addresses in case of language barriers.

3 GPs

- Practical tool: To facilitate the diagnostic of dementia in patients with and without a migration back-

ground, the practical tool included double-sided printed medical history sheets in Turkish/German, English/German and Russian/German, a non-verbal, culturally sensitive screening test for cognitive impairment and a 20-page booklet on dementia.

Details of the intervention material are published [26] and shown in Table 1.

Questionnaires

GPs and PrAs were asked to fill a standardised, self-administered questionnaire after 3 months. In addition to sociodemographic data (age, gender, migration background), the level of agreement with the following six statements on self-reported confidence in dementia care were requested. Answer options ranged from “totally disagree” to “totally agree” on a 5-point Likert scale:

- I feel confident in dealing with dementia patients with migration background.
- I feel confident to inform dementia patients with migration background about their disease.
- I feel confident in answering question from dementia patients with migration background.
- I have enough knowledge about local help centres that support dementia patients with a migration background and their families.
- I often have difficulties communicating with patients with migration background.
- I often have difficulties communicating with dementia patients.

Table 1 Description of the intervention toolbox

Target group	Item	Aim of the material	Topic/Content	Layout	Language
Patients, next of kin	8-page brochure	Provide overview and support	<ul style="list-style-type: none"> • Definition of dementia and symptoms • Contact addresses • Procedural steps (GPs) 	<ul style="list-style-type: none"> • Symbols • Diagram • Pictures • Highlighted keywords • Websites 	Common language: German Russian Turkish
Patients, next of kin	Poster (30 cm × 42 cm)	Creating awareness	<ul style="list-style-type: none"> • Questions about key symptoms of dementia 	<ul style="list-style-type: none"> • Symbols 	Common language: German Russian Turkish
GP, PrA	2-page information card	Information on how to deal with patients with and without a migration background	<ul style="list-style-type: none"> • Support services for language barriers • Cultural sensitivity • Contact addresses • Communication advice 	<ul style="list-style-type: none"> • Symbols • Highlighted keywords • Websites 	German
GP	Practical tool	Facilitation of diagnostics for people with and without a migration background	<ul style="list-style-type: none"> • Medical history sheet • EASY test • 20-page booklet 	<ul style="list-style-type: none"> • Highlighted keywords • Symbols • Interviews • Diagrams • Websites 	German-English German-Turkish German-Russian

Target group: GP General practitioner, PrA Practice assistant

Practices were reminded once by mail and twice by phone. An access limited masterfile contained the name of the physician and contact data of the practice, which was used for pseudonymization. The names of the participating PrAs were not requested. Each GP had provided the number of participating PrAs and a respective number of questionnaires for these team members.

Statistical methods

Questionnaires had been read in with TeleForm data capture system with subsequent visual control. Relative frequencies, means and quartiles were used to describe the characteristics of the intervention and control arm. Chi-square tests were used to compare the categorical variables such as gender, occupation, and migration background between both groups, while the t-test was applied for continuous variables. i.e., age and working years. Generalized Estimating Equation (GEE) models [28] that took practice cluster effects into account were applied to examine effects of the Dementia Care Toolbox on GPs' and PrAs' levels of self-reported confidence in dementia care of patients with and without migration background (primary outcome). Responses on the 5-point Likert scale were merged into 3 categories: fully disagree/ disagree, neutral and agree/fully agree. The GEE model was run with a first order autoregressive relationship (AR-1) working correlation matrix including the factors condition, occupation, gender, and migration background to determine the overall effects on self-reported confidence in dementia care (all six items) with a Poisson distribution (log link) and each item separately with a multinomial distribution (logit link). Effects were assessed on the base of Odds Ratios (OR) with a 95% confidence interval (CI). IBM SPSS Statistics, Version 26, was used for statistical analysis with a significance level set at $p = 0.05$.

Ethics statement

The study was approved by the Ethics' Committee of the Medical Faculty of the University of Bonn. It was registered in the German Clinical Trials Register on 02/08/2018 (DRKS-ID: DRKS00014632) [29].

Results

Participants' characteristics

The intervention group comprised 50 participants, of whom 14 were GPs and 36 PrAs whereas the control group consisted of 16 GPs and 57 PrAs. Most respondents had no migration background (intervention: 85.4%, control 83.6%). The majority of physicians were male (intervention: 71.4%, control: 56.3%), while the majority of PrAs were female (intervention: 97.2%, control: 100%). The mean age of the participants in the control group was 44.97 years ($SD \pm 11.71$) and in the intervention group

45.44 years ($SD \pm 13.70$). After dichotomizing age into < 50 years and ≥ 50 years, the distribution of the intervention group was balanced (< 50 years: 50%, ≥ 50 years: 50%), whereas 58.3% participants of the control group were aged < 50 years. Most GPs and PrAs of both groups worked in their general practice for more than 15 years (intervention: 46.9%, control: 40.3%). Both groups did not show any significant difference in age ($p = 0.10$), working years ($p = 0.41$), sex ($p = 0.15$), occupation ($p = 0.44$) and migration background ($p = 0.78$). The practice teams comprised one to eight participants (at least one GP per practice with differing numbers of PrAs). For details see Table 2 and [26].

Regarding levels of self-reported confidence in dementia care most GPs and PrAs in both groups agreed with one of the six statements (intervention: 27.1%, control: 31.9%), followed by agreeing with none (intervention: 22.9%, control: 23.6%) and with two items (intervention: 22.9%, control: 19.4%). Particularly, more participants in the intervention group did not agree on feeling confident in dealing with (intervention: 50.0%, control: 43.1%) or providing information about dementia to migrants

Table 2 Characteristics of the study participants

	Intervention group		Control group	
	n	(%) ^a	n	(%) ^a
Total participants	50	(40.6)	73	(59.4)
Total practices	15	(46.9)	17	(53.1)
	n	(%) ^{a,b}	n	(%) ^{a,b}
Profession				
GPs	14	(28.0)	16	(21.9)
Male	10	(71.4)	9	(56.3)
Female	4	(28.6)	7	(43.8)
PrAs	36	(72.0)	57	(78.1)
Male	1	(2.8)	0	(0)
Female	35	(97.2)	57	(100.0)
Gender				
Male	11	(22.0)	9	(12.3)
Female	39	(78.0)	64	(87.7)
Was your mother or father or were you yourself born abroad?				
Yes	7	(14.6)	12	(16.4)
No	41	(85.4)	61	(83.6)
Age				
< 50	25	(50.0)	42	(58.3)
≥ 50	25	(50.0)	30	(41.7)
Duration of employment in this family practice				
< 5 years	12	(24.5)	17	(23.6)
≤ 15 years	14	(28.6)	26	(36.1)
> 15 years	23	(46.9)	29	(40.3)

^a Column percentages

^b Percentages reported for valid cases

Table 3 Overall self-reported confidence in dementia care: frequency of answer options 'agree/ fully agree' per participant

	Intervention group		Control group	
	n	(%) ^{a,b}	n	(%) ^{a,b}
0	11	(22.9)	17	(23.6)
1	13	(27.1)	23	(31.9)
2	11	(22.9)	14	(19.4)
3	7	(14.6)	9	(12.5)
4	3	(6.3)	5	(6.9)
5	3	(6.3)	4	(5.6)
6	0	(0)	0	(0)
Mean ± SD	1.73 ± 1.46		1.64 ± 1.44	

^a Column percentages

^b Percentages reported for valid cases

compared to the control group (intervention: 60.4%, control: 52.8%). In contrast, more respondents of the control group indicated a lack of knowledge about local support opportunities for migrants with dementia and their families compared to the intervention (intervention: 54.2%, control: 61.1%). For details see Tables 3 and 4. In the intervention group, 57.4% of the participants rated the communication with dementia patients in general as uncomplicated, as did 47.2% of the control group. Communication with dementia patients with migration background was rated either as difficult (intervention: 44.7%, control: 30.6%) or non-problematic in equal proportions (intervention: 42.6%, control: 30.6%). For details see Table 4.

Effects of the dementia care toolbox on self-reported confidence in dementia care

The intervention Dementia Care Toolbox had no significant effects on self-reported confidence in dementia care, neither on the single six aspects addressed nor the summarizing item ($p=0.95$; Table 5). However, a tendency was found among the intervention group who showed a learning effect in terms of increased knowledge about local support options for migrant patients and their families compared to the control group (OR=1.43; 95% CI=0.68-3.03, $p=0.35$). In addition, intervention practices were more likely to experience less communication difficulties with dementia patients in general (OR=0.72; 95% CI=0.33-1.56, $p=0.40$). In comparison to these learning effects, practices of the intervention group showed a tendency of feeling less confident in answering questions of migrants with dementia compared to the control group (OR=0.82; 95% CI=0.36-1.86, $p=0.64$). Both groups also differed in terms of the fact that the intervention group showed a tendency to experience more communication difficulties with patients

Table 4 Frequencies of self-reported confidence in dementia care for all six questions separately

	Intervention group		Control group	
	n	(%) ^{a,b}	n	(%) ^{a,b}
I feel confident in dealing with dementia patients with migration background				
(Fully) Disagree	24	(50.0)	31	(43.1)
Neutral	19	(39.6)	28	(38.9)
(Fully) Agree	5	(10.4)	13	(18.1)
I feel confident to inform dementia patients with migration background about their disease				
(Fully) Disagree	29	(60.4)	38	(52.8)
Neutral	9	(18.8)	18	(25.0)
(Fully) Agree	10	(20.8)	16	(22.2)
I feel confident in answering question from dementia patients with migration background				
(Fully) Disagree	19	(39.6)	28	(38.9)
Neutral	17	(35.4)	23	(31.9)
(Fully) Agree	12	(25.0)	21	(29.2)
I have enough knowledge about local help centres that support dementia patients with a migration background and their families				
(Fully) Disagree	26	(54.2)	44	(61.1)
Neutral	13	(27.1)	16	(22.2)
(Fully) Agree	9	(18.8)	12	(16.7)
I often have difficulties communicating with patients with migration background				
(Fully) Disagree	20	(42.6)	22	(30.6)
Neutral	6	(12.8)	28	(38.9)
(Fully) Agree	21	(44.7)	22	(30.6)
I often have difficulties communicating with dementia patients				
(Fully) Disagree	27	(57.4)	34	(47.2)
Neutral	14	(29.8)	26	(36.1)
(Fully) Agree	6	(12.8)	12	(16.7)

^a Column percentages

^b Percentages reported for valid cases

with a migration background (OR = 1.63; 95% CI = 0.65-4.10, $p=0.30$). In addition, they showed a higher chance of feeling less confident to inform this group of patients sufficiently about dementia (OR=0.60; 95% CI=0.25-1.45, $p=0.26$) and to deal with them (OR=0.57; 95% CI=0.26-1.23, $p=0.15$). For details see Table 5.

Discussion

This cluster-randomised controlled intervention trial aimed at raising awareness and perceived self-confidence on dementia care for patients with and without migration background in German GPs and PrAs by providing the newly developed Dementia Care Toolbox. Based on a sample with 32 GP practices only, our toolbox did not show a significant effect on self-reported confidence in dementia care after 3 months,

Table 5 Results GEE model on the overall effects and all six aspects separately on self-reported confidence

Item	Sig	OR	95% CI
Overall effect on self-reported confidence in dementia care.	0.95	1.01	0.72-1.43
I feel confident in dealing with dementia patients with migration background.	0.15	0.57	0.26-1.23
I feel confident to inform dementia patients with migration background about their disease.	0.26	0.60	0.25-1.45
I feel confident in answering question from dementia patients with migration background.	0.64	0.82	0.36-1.86
I have enough knowledge about local help centres that support dementia patients with a migrant background and their families.	0.35	1.43	0.68-3.03
I often have difficulties communicating with patients with migration background.	0.30	1.63	0.65-4.10
I often have difficulties communicating with dementia patients.	0.40	0.72	0.33-1.56

Control group reference; controlled for occupation (GPs, PrAs), sex (male, female), migration background (yes, no)

yet there were positive tendencies indicating learning effects regarding knowledge on local support centres and self-reported communication skills with dementia patients. The latter findings are in line with previous studies stressing an educational need for increasing GPs' self-confidence in dementia care [11, 18]. Several studies from various countries addressed this problem and studied interventions aiming to improve dementia care in primary care. In a large, nationwide dementia-focused Continuing Medical Education program with 1352 GPs from Australia, Casey et al. 2020 found a significant increase in dementia awareness and self-reported confidence directly after the intervention and at 6 to 9 months follow-up measured with a self-report survey using mainly Likert scales [30]. In comparison to our 3-months intervention with printed materials only, the former-mentioned program offered at least 6 h online or face-to-face education including case studies and discussions to GPs. Likewise, 29 American primary care physicians, who participated in a one-day dementia care training program, showed a significantly increase in dementia care competency after 6 months assessed with a baseline, post-training, and follow-up questionnaire [31]. Similar improvements of interventions in dementia care were shown in some European GP populations [32]. Foley et al. conducted a study with 104 GPs from Ireland who participated in small-group dementia workshops resulting in increased knowledge and confidence in dementia care measured with post-intervention questionnaires using Likert-style response options [32]. As questionnaires of these studies differed, comparisons on dementia related attitudes and self-reported confidence need to be considered with caution. Our study used the validated and reliable General Practitioner Attitudes and Confidence Scale for Dementia (GPACS-D) developed by Mason et al. for measuring Australian GPs attitudes and confidence in dementia care [33]. In contrast to these studies, our study is the first survey targeting GP practices'

dementia care in patients with migration background. Although no significant differences were found in the limited sample, we showed tendencies of reduced self-reported confidence in dementia care of patients with migration background in the intervention group. This might suggest that our intervention "dementia care toolbox" might have increased GPs' and PrAs' awareness of their limitations in care for patients with migration background. Reported difficulties and challenges of GPs addressed communication with and information of dementia patients with migration background which highlights the need for special interventions. Similar difficulties in dementia care for patients with migration background were shown in previous studies. In a study of 27 health professionals from Norway, Sagbakken et al. (2018) found that language barriers and a lack of appropriate diagnostic tools represented main barriers for GPs in dementia care for migrants [34]. These authors recommended that communication and diagnostic skills should be improved by offering educational trainings to GPs. Similar conclusions were drawn from a Swiss survey among 4460 GPs of whom 15% reported a lack of confidence in diagnosing dementia in patients with a migration background [35]. Likewise, a survey of 36 clinical dementia centres from 15 European countries showed that 64% reported difficulties in diagnosing dementia in migrants due to communication problems and insufficient diagnostic tools [20]. Our toolbox addressed these deficits by offering practical tools for GPs in several languages. In addition, the toolbox included information brochures for patients and next of kin in several languages as families play a major role in early dementia detection. Such an approach is supported by a 2020 published study from Norway addressing barriers and facilitators for dementia care service in eight family caregivers of migrants with dementia [36]: a lack of knowledge on dementia and insufficient awareness of care services for migrants with dementia were identified as key barriers.

Also, intercultural differences need to be respected as dementia is not socially accepted as a neurological disease in all cultures and initial symptoms may be misinterpreted as normal aging [37].

Strengths and limitations

This cluster-randomised study addressed both professional groups involved in GP practices' care for dementia patients, namely GPs and PrAs which is a major strength of our study. Due to limited project resources, this exploratory study has several limitations. First, no studies with reliable outcomes addressing knowledge and confidence of German GPs in dementia care for migrants were available for a formal sample size calculation. The focus was a comparison of the toolbox effects between intervention and control arm at follow-up as this information was not assessed at baseline. Second, no qualitative information on changes in practices and the use of the toolbox was obtained. Third, the intervention might have drawn attention to general practices with particular interest in dementia care, so that results on self-reported confidence in dementia care might not be representative for all GPs. German GPs complete at least 5 years of postgraduate training prior to licensing, while GP training comprises 3 years in many other countries. Therefore, generalizability of the present findings might be limited. Fourth, our questionnaire was a modified version of the Australian GPACS-D which is not validated in German yet. As we showed a high acceptance of the toolbox materials in our prior publication [26], a larger study is reasonable. Future research should include direct educational approaches involving team education rather than print-materials only.

Conclusion and perspectives

Prospectively, GP practices will be increasingly confronted with dementia in patients with migration background. Therefore, our dementia care toolbox is a promising approach to facilitate and potentially improve dementia care especially for patients with migration background. However, further studies are needed to investigate the effectiveness of the dementia care toolbox in a larger sample of GP practices.

Abbreviations

CI: Confidence interval; CRT: Cluster-randomised trial; GEE: Generalized estimating eq.; GP: General practitioner; GPACS-D: General practitioner attitudes and confidence scale for dementia; OR: Odds ratio; PrA: Practice assistant; SD: Standard deviation.

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Authors' contributions

SJ, AF, TW and BW developed the data analysis plan. SJ and AF performed the raw data management. SJ performed further data management and the data analysis supported by AF and TW. SJ prepared the first version of the manuscript, AF, BW and TW revised the manuscript. All authors read and approved the final version.

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Availability of data and materials

The datasets used and/or analysed for the current study are available from the corresponding author on reasonable request and with permission of the responsible ethics' committee.

Declarations

Ethics approval and consent to participate

The study was approved by the Ethics Committee of the Medical Faculty of the University of Bonn (reference number: 172/18). Additionally, the project was registered in the German Register of Clinical Studies (DRKS, No. DRKS00014632). All physicians provided written informed consent for study participation of the practice. Filling of the anonymous questionnaire by practice assistants was regarded as consent. All methods were performed in accordance with the relevant guidelines and regulations (Declaration of Helsinki).

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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RESEARCH ARTICLE

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Acceptance and self-reported use of a dementia care toolbox by general practice personal: results from an intervention study in German practices



Anna-Liesa Filbert , Sabine Christine Jäger and Birgitta Weltermann

Abstract

Background: Dementia is an age-related syndrome that is estimated to affect 46.8 million people worldwide (2015). In ageing populations, the prevalence of dementia is expected to increase. General practitioners (GPs) are often the first to be contacted when signs of dementia appear. This cluster-randomised trial (CRT) investigates the effects of a dementia care toolbox mailed to GP practices to facilitate dementia care. It contained patient brochures and posters for the waiting room in three languages, information cards for professionals and practical tools in three languages. The GPs' and practice assistants' (PrAs) use of and opinion about the toolbox is reported here.

Methods: Three months after receiving the toolbox, participating GPs and PrAs were sent a standardised, self-administered questionnaire asking about the use and helpfulness of the various toolbox items by mail.

Results: A total of 50 GPs and PrAs (14 GPs and 36 PrAs) from 15 practices completed the questionnaire. Of the participants, 82.0% reported using at least one of the tools, while 18.0% had used none. In descending order, the patient brochures (70.0%), the information card (58.0%) and the poster (40.0%) were used. In general, the brochures (52.1%), the information card (44.9%) as well as the poster (28.6%) were perceived as helpful.

Conclusion: Overall, the dementia toolbox was widely accepted by both professional groups. Future research should investigate long-term effects of information strategies for GP practice settings.

Trial registration: German Clinical Trials Register, [DRKS00014632](https://www.drks.de/DRKS00014632). Registered 02 August 2018. Clinical register of the study coordination office of the University hospital of Bonn. Registered 05 September 2017.

Keywords: Dementia, Dementia care, General practitioner, General practices, Family medicine, Migration background

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Background

Dementia has become an increasing challenge worldwide especially among the rapidly growing elderly population. With an estimated prevalence of 46.8 million, it is expected that 131.5 million people will suffer from dementia by 2050 [1]. As no specific treatment exists yet, it is ranked the fifth most common cause of death worldwide [2, 3].

Dementia is age-related and describes a progressive neurodegenerative disorder. It is characterised by a decline in memory and cognitive deficits in learning ability, concentration and orientation persisting for at least 6 months [4]. These cognitive deficits gradually impair the affected persons' ability to perform activities of daily living. In Germany, 1.2 million people suffer from dementia, Alzheimer's Disease (AD) being the most common subtype [5]. AD is a neuropathological disorder characterised by an abnormal cerebral accumulation of intraneuronal hyper-phosphorylated tau protein (p-tau) and extra-neuronal beta-amyloid plaques (A β) causing cerebral atrophy [3]. Vascular dementia (VD), which accounts for about 10% of dementia cases, results from micro or macro brain strokes due to damages or blockages of cerebral vessels [5, 6]. However, AD and VD often coexist and cannot always be separated [5]. Research has shown that the prevalence of dementia after a first stroke increases to 10% and even exceeds 30% after stroke recurrences [7]. Therefore, in order to lower the overall risk of dementia it is important to prevent recurrent strokes and to manage prominent cerebrovascular risk factors associated with AD and VD such as hypertension, atrial fibrillation, diabetes, hypercholesterolaemia, lack of physical activity and obesity [8].

Because dementia progresses slowly over many years from an asymptomatic stage to a full clinical manifestation, and early symptoms are often misinterpreted and advanced symptoms are recognised only in the late stage, diagnosing the disease is challenging [9]. This is reflected in the fact that mild dementia is often underdiagnosed [10]. However, there is an urgent need for early diagnosis in order to ensure the earliest possible access to treatment options and adequate intervention programs for patients and to support caregivers [10–12]. Moreover, keeping patients in their familiar environment, reducing feelings of anxiety and uncertainty, improving quality of life and independence as well as reducing psychological distress have all been shown to be beneficial for patients, as it gives them more time to cope with the diagnosis [13–15]. In Germany, general practitioners (GPs) are usually the first point of contact when signs of dementia occur. However, overall there has been a decline in the number of general practitioners [16]. The situation is further complicated by the fact that GPs are confronted with challenges due to demographic change and multimorbidity [17].

Several studies among GPs worldwide have shown that the above-mentioned difficulties are due to lack of confidence in the diagnosis, time, case complexity, fear of early labelling and uncertainty about which instruments and tests are useful [18–21]. Training on the use of testing tools was therefore considered useful especially for young professionals [19, 20]. Providing materials in different languages to improve the diagnosis of dementia in migrants is also considered expedient [19, 20].

In order to facilitate dementia care in German general practices for patients with and without a migrant background, the effects of a toolbox consisting of four tools for GPs and practice assistants (PrAs) were investigated. The intervention group was asked about their use and perceived helpfulness of the toolbox.

Methods

Study design

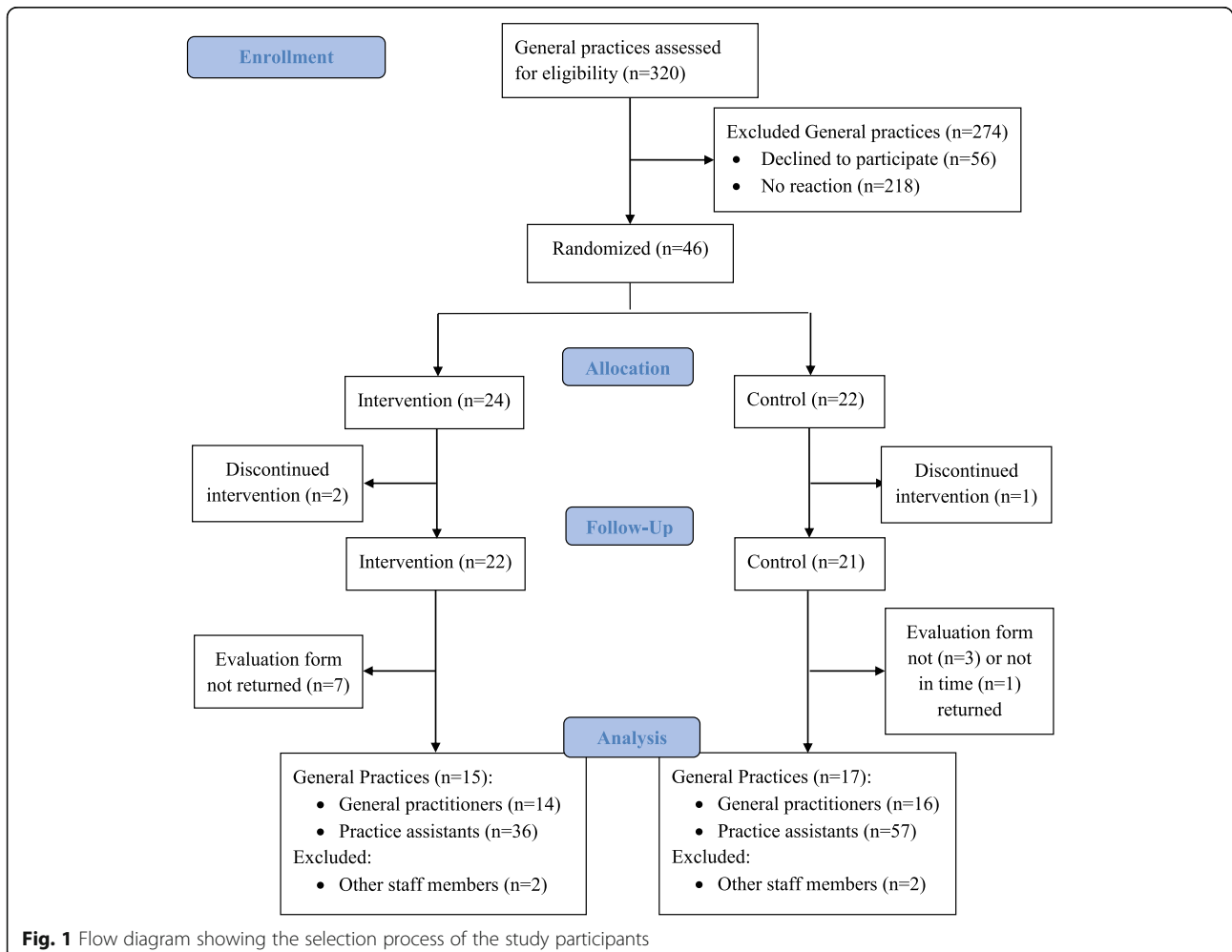
A cluster-randomised, wait list-controlled intervention study was conducted on the basis of the previously published exploratory baseline survey, which showed that GPs were interested in receiving further information on how to deal with dementia patients [22]. Thirty-two out of 320 general practices across North Rhine-Westphalia in Germany were recruited as shown in Fig. 1. The study was conducted between September 2018 and April 2019. Practices were randomly allocated to receive the dementia care toolbox at baseline or after 3 months.

A standardised, self-administered, written evaluation survey was used to ask for details relating to confidence and/or professional dementia care, dementia care in the last 3 months and opinions on education material with its perceived effect. In addition, GPs and PrAs were asked to provide their sociodemographic data, including age, sex, language skills, duration of employment and migrant background. The study was registered with the German Clinical Trials Register (DRKS) (DRKS-ID: DRKS00014632) and the clinical register of the study coordination office of the University Hospital Bonn [23].

Participants

The target group of this study were GPs and their PrAs in the North Rhine region. Two hundred thirty practices from the previous random sample in the cross-sectional study as well as 90 practices from the Institute's network of teaching physicians or practices from which a research interest was known, were contacted [22]. Actively practicing practices whose physician was registered as a contract physician in the database of the Association of Statutory Health Insurance Physicians of North Rhine-Westphalia (KVNO) on 28 July 2017 and was listed in the KVNO database as a family physician were included.

Physicians with the designation paediatrician in the KVNO database were excluded.



Intervention and control conditions

After obtaining written informed consent for study participation by fax or mail, the information material was sent by mail to the GP practices randomised to the intervention group. At the same time, the practices of the control group received a short letter on the further procedure. The intervention material was then used for 3 months, following which the physicians and PrAs of the intervention and control groups were interviewed by means of a standardised, self-administered evaluation form.

Intervention condition: toolbox

The toolbox materials were developed according to the needs identified by the GPs in a prior baseline survey and the experience of regional contact points for dementia patients and their next of kin obtained via telephone contact. Furthermore, the practical tools of the toolbox contain already existing materials so that the composition of the individual components is newly developed. The baseline survey documented that GPs experience

language barriers in the diagnosis of dementia, especially among patients with a Turkish or Russian background [22]. This result was plausible, as migrants from European countries account for 30.4% of the population in the North Rhine region, with most of them coming from Turkey (5.34%) and Russia (2.18%) [24].

The toolbox consisted of four different materials (Table 1):

- 1 Brochures: The eight-page brochure was written for patients and their next of kin in three languages (German, Turkish, Russian) to sensitise them for dementia. In addition to a definition of dementia, it included typical symptoms and a description of the general procedure after first symptoms appear. Moreover, contact addresses (website and telephone numbers) of support services for patients and their next of kin as well as contact points specifically for people with a migrant background were provided. The brochure was written in a common, understandable language, and symptoms as well as the

Table 1 Description of the intervention toolbox

Item	Target group	Aim of material	Topic/Content	Layout	Language
8-page brochure	Pat, next of kin	Provide overview and support	<ul style="list-style-type: none"> • Definition of dementia and symptoms • Contact addresses • Procedural steps (GPs) 	<ul style="list-style-type: none"> • Symbols • Diagram • Highlighted keywords • Websites 	Common language: Ger, Rus, Tur
Poster (30 cm × 42 cm)	Pat, next of kin	Creating awareness	<ul style="list-style-type: none"> • Questions about key symptoms of dementia 	<ul style="list-style-type: none"> • Symbols 	Common language: Ger, Rus, Tur
2-page information card	GP, PrA	Information on how to deal with patients with and without a migrant background	<ul style="list-style-type: none"> • Support services in case of language problems • Cultural sensitivity • Contact addresses • Communication advice 	<ul style="list-style-type: none"> • Symbols • Highlighted keywords • Websites 	Ger
Practical tool	GP	Facilitation of diagnostics for people with and without a migrant background	<ul style="list-style-type: none"> • Medical history sheet • EASY test • 20-page booklet 	<ul style="list-style-type: none"> • Highlighted keywords • Symbols • Interviews • Diagrams • Websites 	Ger-Eng Ger-Tur Ger-Rus

Target group: GP General Practitioner, Pat Patients, PrAs Practice Assistants, Language: Eng English, Ger German, Tur Turkish, Rus Russian

- further steps taken by the physicians were graphically illustrated in the form of symbols and diagrams.
- Poster: The poster (30 cm × 42 cm) with the headline “Are you or your next of kin familiar with these situations?” was provided for the practices’ waiting rooms. The aim was to make patients and their next of kin aware of typical symptoms of dementia and to encourage them to consult their GP if any such symptoms occurred. The symptoms were presented in the form of short questions and statements, such as “Where am I?” and “I often misplace objects”. Additionally, these sentences were supported by the same symbols as in the brochure. The original German poster was translated into Turkish and Russian.
 - Information card: The target group of the information card were the GPs and their PrAs. The double-sided printed card was written in German. In addition to a definition of migrant background and epidemiological facts on dementia diagnostics, it contained assistance on the following aspects: challenges, communication advice, support services in case of language problems, cultural sensitivity and contact addresses for dementia patients with and without a migrant background. For example the paragraph on support services in case of language problems includes tips such as online translators or a homepage on which it is possible to search for GPs according to language skills.
 - Practical tool: The practical tool consisted of three parts: a double-sided printed medical history sheet in Turkish/German, English/German and Russian/

German (supplied by Setzer Verlag), the standardised EASY test, a non-verbal, culture-fair screening procedure for the detection of cognitive impairment, and a booklet. The booklet “Diversity in the practice” published by the National Association of Statutory Health Insurance Physicians was given to GPs in German and included information on health competence and tips for communication, especially for patients with a migrant background. In addition to examples and tips for cultural sensitisation, the booklet contained various interviews with specialists, legislation for treatment and further service addresses. The booklet consisted of 20 pages and was designed with pictures, diagrams, symbols, highlighted headlines as well as subheadings.

Control condition

Practices randomised to the control group did not receive any intervention, i.e. treatment as usual. After the follow-up data were collected in the intervention and control groups, the practices in the waiting-list control group received the toolbox.

Data collection

After the toolbox was used in the intervention group for 3 months, all practices (intervention and control group) received the evaluation survey. GPs and PrAs completed the form to assess the acceptance and use of the toolbox materials and returned it to the study coordinator. Reminders to complete and return the questionnaire were given once in writing and twice by telephone.

The questionnaire used at follow-up comprised a total of 13 questions supplemented by eight questions for the intervention group only. For comparison, about a third of the questions were identical to the questionnaire, which was used for our prior cross-sectional survey [22, 25]. The additional questions addressed the acceptance and use of the toolbox, e.g. role/duties in the practice, how they used/liked the toolbox materials, and estimated frequency of contacts to dementia care patients/migrants in last 3 months.

The physicians' data were pseudonymized; those of the PrAs were anonymous.

For the purposes of this paper, the answers to the following questions translated in German were included in the descriptive analyses of the intervention group. The answer categories were 5-point Likert scales ranging from "not helpful" to "very helpful" (a), multiple answers with or without additional free text fields (b) as well as closed questions (yes/no) (c):

To what extent did you use the information material provided?^(b)

How helpful do you find the information card that was developed for you?^(a)

Which sections of the information card do you find particularly helpful?^(b)

How helpful do you find the poster for your patients/family?^(a)

How helpful do you find the information brochure for your patients/family members?^(a)

Do you find the practical material (multilingual medical history sheets, EASY short test, booklet) helpful?^(c)

Data management and statistical methods

The questionnaires were scanned using the TeleForm data capture system. Extracted data were checked visually through a comparison with the original questionnaires. All data were analysed using descriptive statistics in IBM SPSS-Statistics for Windows, version 25. All above mentioned questions answered by GPs and PrAs were included in the analysis whereas missing data were not considered. Absolute and relative frequencies, means and standard deviations are reported for valid cases. To control for confounding, descriptive statistics adjusted for age, gender, duration of employment in this family practice and migration background were computed for all participants.

Results

The distribution of participants varied between one and six in the 15 practices. For a detailed distribution, see Table 2.

Characteristics of the study population

A 10.0% response rate was achieved. Thirty-two practices, 15 of which were randomised to the intervention

Table 2 Distribution of participating GPs and PrAs among the individual practices

Practices	Intervention group	GP	Medical assistant
1	2	1	1
2	2	1	1
3	6	1	5
4	3	1	2
5	2	1	1
6	2	1	1
7	4	1	3
8	6	1	5
9	3	1	2
10	1	1	0
11	1	1	0
12	3	0	3
13	6	1	5
14	5	1	4
15	4	1	3

group and 17 to the control group, returned the questionnaire. The following analyses considered only the data of the intervention group, which consisted of 14 GPs (28.0%) and 36 PrAs (72.0%). Of the 14 family doctors, 71.4% were male and 28.6% were female. Among the PrAs the distribution was 97.2% female and 2.8% male. The participants' mean age was 45.6 years (SD \pm 13.7), 55.6 years (SD \pm 6.5) in GPs and 41.5 years (SD \pm 13.8) in PrAs. If the age is dichotomized into < 50 years (50.0%) and \geq 50 years (50.0%), the age distribution was balanced. The average duration of employment in this family practice was 16.7 (SD \pm 11.4) years. Among the participating GPs, two (14.2%) indicated having a migration background, and five (14.7%) among the PrAs. Considering the number of languages apart from German that can be spoken fluently, 13 (40.6%) of the PrAs did not speak any, which is not the case for any of the GPs. 17 (53.1%) PrAs spoke one foreign language fluently, two (6.3%) PrAs spoke two foreign languages and none of the PrAs spoke three foreign languages. Among the GPs, six (42.9%) spoke one foreign language fluently, four (28.6%) spoke two and another four (28.6%) spoke three foreign languages fluently. Characteristics of the study population are summarised in Table 3.

Use of intervention material

Overall, GPs used the toolbox materials more often than PrAs. 82.0% of the participants used at least one of the four intervention tools, whereas 18.0% did not use any. 30.0% of the participants stated that they had used three out of four information materials. No participant applied

Table 3 Characteristics of the study population

	Total study population		Intervention group	
	n	(%) ^a	n	(%) ^a
Total participants	123	(100)	50	(40.6)
Total practices	32	(100)	15	(46.9)
	n	(%) ^{a,b}	n	(%) ^{a,b}
Profession				
GPs	30	(24.4)	14	(28.0)
PrAs	93	(75.6)	36	(72.0)
Gender				
Female	103	(83.7)	39	(78.0)
Male	20	(16.3)	11	(22.0)
Age				
< 50	67	(54.5)	25	(50.0)
≥ 50	56	(45.5)	25	(50.0)
Duration of employment in this family practice				
< =5 years	29	(24.0)	12	(24.5)
< =15 years	40	(33.1)	14	(28.6)
> 15 years	52	(43.0)	23	(46.9)
Was your mother or father or were you yourself born abroad?				
Yes	19	(15.7)	7	(14.6)
No	102	(84.3)	41	(85.4)
Which languages apart from German do you speak fluently that you are able to treat a foreign-language patient in your family doctor's practice?				
0	30	(26.3)	13	(28.3)
1	59	(51.8)	23	(50.0)
2	19	(16.7)	6	(13.0)
3	6	(5.3)	4	(8.7)

^a Column percentages^b Percentages are reported for valid cases

all four information tools (Table 4). In descending order, the brochures (70.0%), the information card (58.0%) and the poster (40.0%) were used. 70% of both professional groups used the brochures. More precisely, GPs used the information card (85.7%) most often and the poster

Table 4 Information materials used by the study participants with different functions

	Intervention group		GPs		PrAs	
	n	(%) ^a	n	(%) ^a	n	(%) ^a
Quantity of intervention material used						
0	9	(18.0)	2	(14.3)	7	(19.4)
1	13	(26.0)	1	(7.1)	12	(33.3)
2	13	(26.0)	3	(21.4)	10	(27.8)
3	15	(30.0)	8	(57.1)	7	(19.4)
4	0	(0)	0	(0)	0	(0)

^a Column percentages

(64.3%) the least. In comparison, PrAs used the brochures most often (69.4%) and the posters (30.6%) the least. 85.0% of GPs, but only about half of PrAs, used the information card (Fig. 2).

Opinion about the intervention material

In descending order, the brochures (52.1%), the information card (44.9%) and the posters (28.6%) were considered helpful. More precisely, the following aspects, listed in descending order, were considered helpful: support for patients with and without a migrant background (41.7%), support services in case of language problems (27.1%), communication advice (22.9%), cultural sensitivity (6.3%) and challenges (4.2%). GPs as well as PrAs rated the support for patients with and without a migrant background as most helpful (GPs: 38.5%, PrAs: 42.9%). The least helpful aspect among GPs was support services in case of language problems (7.7%), whereas among PrAs it was support for cultural sensitivity (2.9%) (Table 5).

Discussion

Key findings and interpretation

The purpose of this study was to facilitate dementia care in German general practices by using a newly developed toolbox. With a setting-related approach, the toolbox addressed different target groups in the GP practice setting (GPs, PrAs, patients and next of kin) and included a wide variety of intervention materials. Overall, the toolbox was well accepted (82.0%) and considered helpful; in particular the brochure was rated as helpful by both professions. Our result was to be expected, as 50–80% of physicians use printed materials to obtain information [26]. This passive use of printed educational materials may be used to improve knowledge, awareness, attitudes and patient outcomes in different settings [26–29]. Although various studies have shown a positive effect of information material in practices on the health of patients, the design, content and writing style are criticised [30, 31]. This shows that the characteristics of the intervention material (source of the information, content and channel through which it is delivered) are of importance with regard to its effectiveness [32]. In this study, brochures for patients and next of kin were found to be helpful by GPs and PrAs alike. In fact, brochures are widely used in patient education and are greatly appreciated by patients as a means of obtaining information on health issues [33]. The same applies to the poster for the waiting rooms and the brochures, which PrAs considered helpful. Both are suitable information strategies for GPs practice, especially PrAs, as they require little effort in a work scenario which tends to be challenging, multi-tasking and – at least sometimes – stressful for personal [34]. Providing such brochures and posters to patients

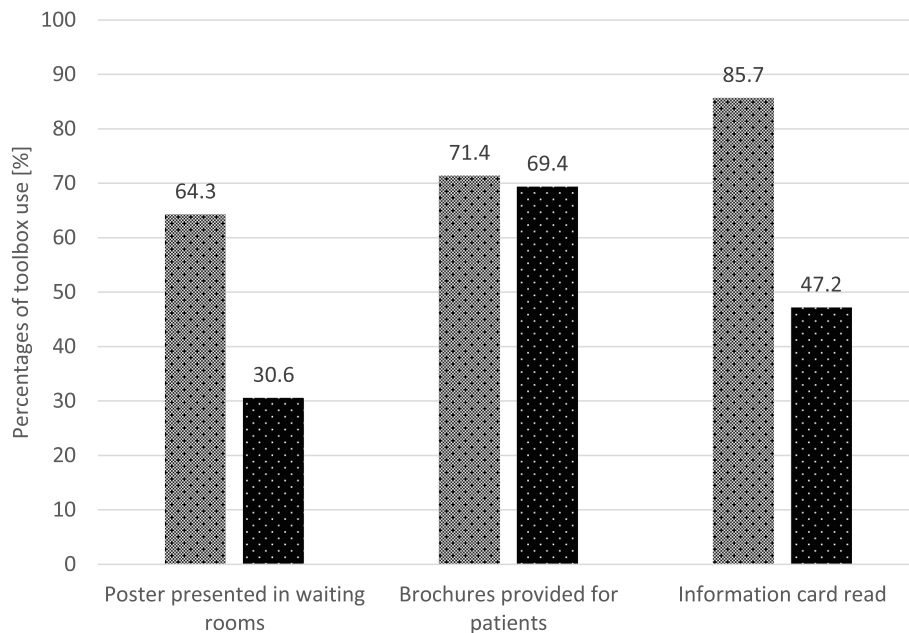


Fig. 2 GPs' and PrAs' use of the toolbox materials

gives them the opportunity to strengthen their right of self-determination and self-control as well as to make independent decisions on relevant health issues [35]. At the same time, it addresses the desire of many next of kin for more information material [36]. This is of major relevance, as the diagnosis dementia also affects the family and has a significant impact on the future family life. Also, it follows the recommendations of previous studies to involve and support the next of kin in dementia care [32]. As described above, dementia patients also reported that they themselves felt insufficiently informed about the disease [36]. Our intervention materials address this imbalance. Furthermore, as Protheroe et al. (2015) showed in their latest study that three out of four patient information leaflets in general practices were judged too complex to read by 15% of the English population [30], our study paid particular attention to a patient-friendly design, specific content and readability of the material. In our study, this was generally achieved through the use of headlines, bullet points, highlighted key messages, the division of topics into sub-topics, a simple design, the use of common language, specific contact addresses and sources of detailed information.

Regarding the information card for GPs and PrAs, the effectiveness of these design and content elements of the printed educational material are in line with the results of an earlier qualitative study by Grundniewicz et al. (2016) among Canadian GPs [31]. In their study, they investigated physicians' preferences regarding the design and content of printed educational materials. Physicians

preferred short, simple and concise materials with references for more detailed information not least due to lack of time. They also emphasised the significant impact of design and content selection on the perceived usability and actual usability of the materials. Furthermore, physicians use training materials to manage and reduce the diversity of new guidelines and evidence [31]. The fact that PrAs rated the aspect "support services in case of language problems" higher may indicate that they are more often in the situation of not being able to communicate with a patient as desired or required due to language barriers. This might be due to the fact that PrAs speak fewer languages than GPs or that PrAs are often the first contact person for the patient.

As mentioned in the introduction section, this topic is becomingly increasing important due to the ageing population. In general, the diagnosis of dementia should be critically reviewed and after information has been provided to those affected [5, 32]. The principle that there is a right not to know must always be considered [5]. Our materials are intended to provide psychosocial support for patients and families; this is particularly important in the case of dementia, as there is evidence that the integration of psychosocial elements is of similar importance to medication [5, 37, 38].

In general, there is a gap between previous studies on dementia care and the populations studied. Migrants have thus far received little attention in this context, therefore it can be assumed that dementia is underdiagnosed in migrants [39]. Our study has considered this

Table 5 Opinions of GPs and PrAs about the dementia care toolbox

	Intervention group		GPs		PrAs	
	n	(%) ^{a,b}	n	(%) ^{a,b}	n	(%) ^{a,b}
How helpful was the poster?						
Unhelpful	0	(0)	0	(0)	0	(0)
Slightly helpful	18	(36.7)	5	(38.5)	13	(36.1)
Helpful	14	(28.6)	3	(23.1)	11	(30.6)
Very helpful	3	(6.1)	2	(15.4)	1	(2.8)
Not applicable	14	(28.6)	3	(23.1)	11	(30.6)
How helpful was the brochure?						
Unhelpful	1	(2.1)	0	(0)	1	(2.9)
Slightly helpful	8	(16.7)	1	(7.7)	7	(20.0)
Helpful	25	(52.1)	6	(46.2)	19	(54.3)
Very helpful	7	(14.6)	3	(23.1)	4	(11.4)
Not applicable	7	(14.6)	3	(23.1)	4	(11.4)
How helpful was the information card?						
Unhelpful	4	(8.2)	2	(15.4)	2	(5.6)
Slightly helpful	12	(24.5)	3	(23.1)	9	(25.0)
Helpful	22	(44.9)	6	(46.2)	16	(44.4)
Very helpful	3	(6.1)	1	(7.7)	2	(5.6)
Not applicable	8	(16.3)	1	(7.7)	7	(19.4)
Which aspect in particular did you find helpful?						
Challenges	2	(4.2)	2	(15.4)	0	(0)
Communication advice	11	(22.9)	4	(30.8)	7	(20.0)
Support services in case of language problems	13	(27.1)	1	(7.7)	12	(34.3)
Support for cultural sensitivity	3	(6.3)	2	(15.4)	1	(2.9)
Support for patients with and without a migrant background	20	(41.7)	5	(38.5)	15	(42.9)

^a Column percentages^b Percentages are reported for valid cases

problem by compiling the toolbox material in different languages according to the distribution of migrants in North Rhine-Westphalia.

GPs play a key role in optimising outpatient care, which is of major importance as most dementia patients hope to be able to stay in their familiar environment for as long as possible [40]. However, it has been shown that the provision of advice and information via the family doctor is problematic [41].

Limitations

The key strength of the current study is its physician and practice assistant approach which indirectly addressed patients and families. As our intention was to provide an initial overview of the usefulness and opinion about the newly developed toolbox, the validity and reliability of the self-administered questionnaires were not further investigated. In terms of validity, it should be noted that the answer options for the practical tools differ from the other items in the toolbox and that not all

parts of the practical tool were tested individually for usefulness. A response bias cannot be excluded for two reasons: First, it can be assumed that mainly GP practices participated with a general interest in research and/or the topic of dementia. Second, despite our efforts (e.g. reminders), the proportion of non-respondents was high. To counteract the problem of validity, we used an anonymised/pseudonymised self-administered paper questionnaire. We did not obtain any information on the acceptance of the toolbox items on behalf of the end users. Self-reported outcomes and the associated socially desirable responses represent a potential bias. The study addressed acceptance of toolbox materials, the effectiveness of patient-related outcomes needs to be evaluated in future. Due to the small sample size the results need to be interpreted with caution.

Conclusion

The mere diagnosis of dementia is a threat to the livelihood of the patient and his family. The toolbox helps to

avoid feeling alone and closes the gap between the diagnosis and further support.

Further research is needed to identify the long-term effects of information strategies for the setting of GP practices. Our study documented the need for and acceptance of the concept of the dementia care toolbox, especially the information brochures, in the setting of general practitioners' practices.

Abbreviations

AD: Alzheimer's disease; A β : Beta-amyloid plaques; GP: General practitioner; KVNO: Association of statutory health insurance physicians of North Rhine-Westphalia; p-tau: Hyperphosphorylated tau protein; PrA: Practice assistant; VD: Vascular dementia

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Authors' contributions

A-LF, SJ and BW developed the data analysis plan, AF and SJ performed the data management, data analysis and prepared the first version of the manuscript, BW revised the manuscript. AF, SJ and BW drafted the manuscript. All authors read and approved the final version.

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Availability of data and materials

The datasets used and/or analyzed for the current study are available from the corresponding author on reasonable request and with permission of the responsible ethics' committee.

Ethics approval and consent to participate

The study was approved by the Ethics Committee of the Medical Faculty of the University of Bonn (reference number: 172/18). Additionally, the project was registered in the German Register of Clinical Studies (DRKS, No. DRKS00014632) as well as the study register of the University Hospital Bonn. All practices provided written informed consent for study participation.

Consent for publication

No identifiable material is published.

Competing interests

The authors declare that they have no competing interests.

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<input type="checkbox"/> Hausarzt/-ärztin	<input type="checkbox"/> Medizinische/r Fachangestellte/r	<input type="checkbox"/> weitere/r Mitarbeiter/in			
2. Inwieweit haben Sie die zur Verfügung gestellten Informationsmaterialien eingesetzt?					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ich habe das Poster in der Praxis aufgehängt	Ich habe die Broschüren für Patienten in verschiedenen Sprachen ausgelegt	Ich habe die Informationskarte für Ärzte und MFA gelesen	Ich habe die praktischen Tools verwendet	Ich habe nichts davon getan, weil: _____	
3. Wie hilfreich finden Sie die für Sie entwickelte Informationskarte?					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gar nicht hilfreich	Etwas hilfreich	Hilfreich	Sehr hilfreich	Trifft nicht zu	
4. Welche Abschnitte der Informationskarte finden Sie besonders hilfreich?					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Herausforderungen	Kommunikationshinweise	Hilfen bei Sprachbarrieren	Hilfen zu Kultursensibilität	Hilfestellen für Patienten mit und ohne Migrationshintergrund	Trifft nicht zu
5. Wie hilfreich finden Sie das Poster für Ihre Patienten/ Angehörige?					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gar nicht hilfreich	Etwas hilfreich	Hilfreich	Sehr hilfreich	Trifft nicht zu	
6. Wie hilfreich finden Sie die Informationsbroschüre für Ihre Patienten und deren Angehörige?					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gar nicht hilfreich	Etwas hilfreich	Hilfreich	Sehr hilfreich	Trifft nicht zu	
7. Finden Sie das praktische Material (mehrsprachige Anamnesebögen, EASY-Kurztest) hilfreich?					
<input type="checkbox"/> Nein	<input type="checkbox"/> Ja. Falls ja: Welches Material würden Sie Kollegen empfehlen? _____				<input type="checkbox"/> Trifft nicht zu
8. Haben Sie Verbesserungsvorschläge?					
<input type="checkbox"/> Nein	<input type="checkbox"/> Ja, und zwar: _____				
9. Wurden Sie in den letzten 3 Monaten vermehrt von Patienten auf das Thema Demenz angesprochen?					
<input type="checkbox"/> Nein	<input type="checkbox"/> Ja	<input type="checkbox"/> Weiß ich nicht			
10. Bitte geben Sie an, inwieweit Sie den folgenden Aussagen zustimmen:					
	stimme überhaupt nicht zu				stimme völlig zu
Ich fühle mich im Umgang mit Demenzpatienten mit Migrationshintergrund sicher.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ich fühle mich dazu in der Lage, Demenzpatienten mit Migrationshintergrund über ihr Krankheitsbild aufzuklären/ zu informieren.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ich fühle mich dazu in der Lage, Nachfragen von Demenzpatienten mit Migrationshintergrund zu beantworten.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ich habe Kenntnisse über lokale Hilfestellen, die demente Personen mit Migrationshintergrund sowie ihre Familien unterstützen.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Die Kommunikation mit Patienten mit Migrationshintergrund fällt mir häufig schwer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Die Kommunikation mit Demenzpatienten fällt mir häufig schwer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Bitte schätzen Sie: Wie häufig war die „dementielle Veränderung“ (Gedächtnisstörung, Orientierungslosigkeit usw.) im letzten Quartal Beratungsanlass bei der Gesamtheit Ihrer Patienten?					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nie	1-3 mal	4-6 mal	7-9 mal	10-12 mal	13-15 mal
					≥16 mal

12. Bitte schätzen Sie: Wie häufig war die „dementielle Veränderung“ (Gedächtnisstörung, Orientierungslosigkeit usw.) im letzten Quartal Beratungsanlass bei Ihren Patienten mit Migrationshintergrund?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nie	1-3 mal	4-6 mal	7-9 mal	10-12 mal	13-15 mal	≥16 mal

13. Wie häufig kam es im letzten Quartal vor, dass Sie aufgrund von Hürden und Sprachprobleme einen Patienten mit Migrationshintergrund in Bezug auf Demenz nicht optimal behandeln bzw. mit ihm/ ihr umgehen konnten?

Nie Selten Manchmal Oft Sehr oft Ich hatte noch nie Probleme

14. Welche Art von Kontakt haben Sie zu Demenzpatienten in Ihrer Praxis? (Mehrfachnennungen möglich)

<input type="checkbox"/> Ich führe kognitive Kurztests durch.	<input type="checkbox"/> Ich nehme Blut ab.
<input type="checkbox"/> Ich kläre den Patienten über Demenz auf.	<input type="checkbox"/> Ich beantworte Fragen zu Demenz.
<input type="checkbox"/> Ich gebe dem Patienten Informationsmaterial über Demenz mit.	<input type="checkbox"/> Ich fungiere als Dolmetscher.
<input type="checkbox"/> Als Arzt frage ich meine Mitarbeiter nach Demenzsymptomen der Patienten bzw. als MFA berichte ich dem Arzt von Demenzsymptomen der Patienten.	<input type="checkbox"/> Ich leite Demenzpatienten an Hilfestellen weiter, z.B. zur Beratung, Betreuung oder Pflege.
<input type="checkbox"/> Sonstiges, und zwar: _____	<input type="checkbox"/> Ich habe keinen Kontakt.

15. Welches Geschlecht haben Sie?

Weiblich Männlich

16. Wie alt sind Sie?

Jahre

17. Wie lange sind Sie schon in der Hausarztpraxis tätig?

Jahre

18. Ist Ihre Mutter oder Ihr Vater oder sind Sie selbst im Ausland geboren?

Ja Nein

19. Welche Sprachen außer Deutsch sprechen Sie so gut, dass Sie einen fremdsprachigen Patienten in der Hausarztpraxis behandeln/ mit ihm umgehen können? (Mehrfachantworten möglich)

Englisch Französisch Russisch Polnisch Spanisch Italienisch
 Türkisch Arabisch Griechisch Keine Sonstige, und zwar: _____

20. Gibt es weitere Themen, die Sie in Ihrer Praxis beschäftigen, zu denen Sie Unterstützung benötigen oder und zu denen Sie einen Forschungsbedarf sehen?

Falls Sie als Arzt tätig sind, bitten wir Sie um Beantwortung der folgenden 4 Fragen:

21. Bitte geben Sie an, inwieweit Sie den folgenden Aussagen zustimmen:

	stimme überhaupt nicht zu				stimme völlig zu
Ich fühle mich in der Demenzdiagnostik sicher.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ich fühle mich in der Demenzdiagnostik bei Menschen mit Migrationshintergrund sicher.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ich konnte schon einmal kognitive Kurztests aufgrund von sprachlichen Problemen zwischen dem Patienten mit Migrationshintergrund und mir nicht anwenden.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ich fühle mich sicher darin, die Demenzdiagnose einem Patienten mit Migrationshintergrund mitzuteilen.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Herzlichen Dank für Ihre Unterstützung!

3. Danksagung

Mein besonderer Dank gilt Frau Univ.- Prof. Dr. med. Weltermann für die Überlassung des Themas, die ausgezeichnete Betreuung der Arbeit und die überaus angenehme Zusammenarbeit.

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4. Publikationen

Jäger SC, Filbert AL, Welchowski T, Weltermann B. Effects of the dementia care toolbox on personnel's self-reported confidence in patient care: a CRT in general practices. *BMC Fam Pract* 2021; 22: 231. DOI: 10.1186/s12875-021-01577-8

Filbert AL, Jäger SC, Weltermann B. Acceptance and self-reported use of a dementia care toolbox by general practice personal: results from an intervention study in German practices. *BMC Fam Pract* 2020; 21: 264. DOI: 10.1186/s12875-020-01345-0