Soziale Aspekte bei Demenz

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Abkürzungsverzeichnis

BPSD	Behavioral and Psychological Symptomes of Dementia (deutsch: Verhaltensbezogene und psychologische Symptome bei Demenz)
DSM-5	Diagnostic and Statistical Manual of Mental Disorders
ICD-10	International Classification of Diseases, Version 10
MCI	Mild Cognitive Impairment (deutsch: leichte kognitive Beeinträchtigung)
SF-DEM	Sozialfunktionen bei Demenz Fragebogen
TOM	Theorie of Mind (deutsch: Theorie des Mentalen)

1. Einleitung

Demenz ist ein neuropsychiatrisches Syndrom, das vor allem infolge einer degenerativen Erkrankung des Gehirns auftritt (ICD-10-Code F00-F03; WHO, Dilling H, Mombour W, et al., 2008). Es ist eine der häufigsten und schwersten Erkrankungen im Alter und verkürzt die Lebensspanne erheblich (Roehr et al., 2015). Zu Beginn macht sich die Erkrankung vor allem durch den Verlust des Kurzzeitgedächtnisses bemerkbar (Soria Lopez et al., 2019). Im weiteren Krankheitsverlauf können zeitliche und örtliche Desorientierung auftreten (Soria Lopez et al., 2019). Die Sprache kann ebenfalls im weiteren Krankheitsverlauf eingeschränkt werden (Soria Lopez et al., 2019). Darüber hinaus kommt es aufgrund der kognitiven Defizite häufig zu Beeinträchtigungen in grundlegenden alltäglichen Aktivitäten. Zu den funktionellen Veränderungen gehören unter anderem Schwierigkeiten bei der Körperhygiene, Nahrungsaufnahme und Mobilität, aber auch bei instrumentellen Tätigkeiten, wie z. B. dem Einkauf, der Regelung finanzieller Geschäfte oder der Bewältigung des Haushalts (Soria Lopez et al., 2019).

In der fünften Auflage des *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) wurden sozialkognitive Veränderungen als Merkmal demenzieller Erkrankungen, die dort als neurokognitive Störungen aufgeführt sind, erstmals berücksichtigt (Falkai, 2018). Diese treten i. d. R. neben den Hauptmerkmalen, d. h. kognitiven und funktionellen Beeinträchtigungen bei Demenzerkrankungen auf. Die Änderung der Diagnosekriterien beruht auf der Beobachtung, dass typische neuropathologische Veränderungen im Gehirn nicht nur zunehmende Beeinträchtigungen der kognitiven und alltäglichen Funktionen, sondern auch Beeinträchtigungen der Sozialfunktionen auslösen können.

Mit dem Anstieg der Lebenserwartung und der damit einhergehenden Alterung der Gesellschaft steigt die Zahl der Menschen, die weltweit mit Demenz leben, stetig an (Prince et al., 2016). Bisher gibt es keine wirksame Behandlung oder Heilung für Demenz. Im Zuge des demografischen Wandels, der die Bevölkerungsalterung vorantreibt, werden immer höhere Kosten für die Gesundheitssysteme entstehen (Heinrich & Wübker, 2016). Daher wird die Bedeutung der Demenzprävention und -früherkennung immer größer. Denn nur so

kann der Entwicklung oder dem Fortschreiten einer Demenzerkrankung entgegengewirkt werden.

Dieses Kapitel gibt einen Überblick über die Definition und die Charakteristika demenzieller Erkrankungen, insbesondere im Hinblick auf Veränderungen im sozialen Kontext; es stellt epidemiologische Fakten dar und geht dabei auf die Krankheitskosten, Risikofaktoren und Konsequenzen in Bezug auf soziale Aspekte ein. Es beschreibt zudem Instrumente zur Beurteilung der Sozialkognitionen und der *Behavioral and Psychological Symptomes of Dementia* (deutsch: verhaltensbezogene und psychologische Symptome bei Demenz; BPSD). Abschließend wird ein kurzer Überblick über die Ziele der Arbeiten gegeben, aus denen sich diese Dissertation zusammensetzt.

1.1. Demenz: Definition und Charakteristika

Unter dem Begriff Demenz werden verschiedene Symptome und Merkmale zusammengefasst, die sich im International Classification of Diseases, Version 10 (ICD-10), definieren als *„[…] Folge einer meist chronischen oder fortschreitenden Krankheit des Gehirns mit Störung vieler höherer kortikaler Funktionen, einschließlich Gedächtnis, Denken, Orientierung, Auffassung, Rechnen, Lernfähigkeit, Sprache, Sprechen und Urteilsvermögen im Sinne der Fähigkeit zur Entscheidung*“ (WHO, Dilling H, Mombour W, et al., 2008). Die Symptome müssen über mindestens sechs Monate bestehen, wobei das Bewusstsein typischerweise nicht getrübt ist.

Demenzielle Erkrankungen beginnen i. d. R. langsam und machen sich zu Beginn vor allem durch den Verlust des Kurzzeitgedächtnisses bemerkbar. Es werden drei Stadien unterschieden: die präklinische Phase, die leichte kognitive Beeinträchtigung (englisch: Mild Cognitive Impairment, MCI) und Demenz. Symptome sind dabei nur in den letzten beiden Stadien vorhanden („2019 Alzheimer's Disease Facts and Figures”, 2019). Bei MCI zeigen sich bei den betreffenden Personen in kognitiven Tests Ergebnisse unterhalb der alters- und geschlechtsspezifischen Norm, wobei ihre Alltagsaktivitäten nicht beeinträchtigt sind. Angehörige bemerken zum Teil Veränderungen im Denkvermögen. Neben einem Verlust kognitiver Funktionen kommt es im Zuge der größer werdenden Gedächtnisschwierigkeiten im dritten Stadium der Demenz auch zu Beeinträchtigungen in grundlegenden alltäglichen

Aktivitäten (Dening & Sandilyan, 2015). Dazu zählen unter anderem Schwierigkeiten bei der Körperhygiene, Nahrungsaufnahme und Mobilität, aber auch bei instrumentellen Tätigkeiten, wie z. B. der Erledigung von Einkäufen, finanzieller Geschäfte oder des Haushaltes (Soria Lopez et al., 2019).

Neben diesen kognitiven und den daraus resultierenden funktionellen Beeinträchtigungen treten bei demenziellen Erkrankungen häufig auch nicht-kognitive Symptome auf. Dazu zählen Veränderungen der emotionalen Kontrolle und des Sozialverhaltens (Dening & Sandilyan, 2015), aber auch Veränderungen der Persönlichkeit und der Stimmung (BPSD). Dazu gehören: Agitation, Angst, Depression, Apathie, Wahnvorstellungen, Schlaf- und Essstörungen, Euphorie, Reizbarkeit, Enthemmung und Halluzinationen. In Längsschnittstudien mit in Gemeinschaft lebenden Demenzpatienten waren bis zu 97% von mindestens einem BPSD-Symptom betroffen, am häufigsten Depression oder Apathie, wobei Wahnvorstellungen, Unruhe und abweichendes motorisches Verhalten bei etwa einem Drittel der Patienten auftraten (Kales et al., 2015). BPSD sind somit ein zentrales Element demenzieller Erkrankungen. Der Schweregrad der BPSD nimmt im Krankheitsverlauf zu.

Auf die Veränderungen des Sozialverhaltens bei demenziellen Erkrankungen wird im Folgenden genauer eingegangen. Die Diagnosekriterien DSM-5 sind in Tabelle 1 zusammengefasst.

1.1.1. Soziale Veränderungen

Zwischenmenschliche Beziehungen sind bedeutend für das geistige und körperliche Wohlbefinden (Umberson & Montez, 2010). Sie sind ein menschliches Grundbedürfnis (Maslow, 1943). Grundlage für erfolgreiche soziale Interaktionen sind z. B. sozialkognitive Fähigkeiten. Defizite in diesem Bereich beeinträchtigen die Fähigkeit, zwischenmenschliche Beziehungen aufzubauen und aufrechtzuerhalten (Henry et al., 2016).

Als bedeutsam für die Sozialkognitionen hat sich vor allem die „Theorie of Mind“ (deutsch: Theorie des Mentalen; kurz: TOM) herausgestellt. Unter TOM wird die Fähigkeit verstanden, den geistigen Zustand anderer zu verstehen und zu begreifen, dass dieser sich vom eigenen Zustand unterscheiden kann (Henry et al., 2016). Weiter wird zwischen der affektiven TOM und der kognitiven TOM unterschieden. Die affektive TOM erfordert ein Verständnis der

Tabelle 1: Diagnosekriterien nach DSM-5.

DSM-5 (Mild Neurocognitive Disorder)
a. Rückgang in einem oder mehreren kognitiven Bereichen (Komplexe Aufmerksamkeit, exekutive Funktionen, Lernen und Gedächtnis, Sprache, Sensomotorik, Sozialkognition) basierend auf: a1. Besorgnis der betroffenen Person, eines Angehörigen oder des Arztes über Verschlechterungen der kognitiven Funktionen und a2. eine deutliche Beeinträchtigung der kognitiven Leistungsfähigkeit, die vorzugsweise durch standardisierte neuropsychologische Tests oder, falls die Durchführung solcher Tests nicht möglich ist, durch eine andere valide klinische Bewertung nachgewiesen wird.
b. Kognitive Defizite beeinträchtigen die Unabhängigkeit bei alltäglichen Aktivitäten (d. h. es wird mindestens Unterstützung bei komplexen instrumentellen Aktivitäten des täglichen Lebens wie dem Bezahlen von Rechnungen oder der Verwaltung von Medikamenten benötigt).
c. Die kognitiven Defizite treten nicht in Zusammenhang mit Delirium auf.
d. Beeinträchtigungen der Kognition lassen sich nicht auf eine andere psychische Störung zurückführen (z. B. Depression oder Schizophrenie).

Emotionen, affektiven Zustände oder Gefühle anderer, während die kognitive TOM ein Verständnis der Zustände, Überzeugungen, Gedanken oder Absichten anderer voraussetzt (Henry et al., 2016). Ersteres entspricht demnach einem emotionalen Nachempfinden und Letzteres einem rationalen Erschließen von mentalen Zuständen anderer.

Reiter et al. (2017) fanden in einer Studie mit 55 jüngeren (18-30 Jahre) und 52 älteren, gesunden Erwachsenen (65-80 Jahre) heraus, dass die kognitive TOM im Alter beeinträchtigt ist, wohingegen die affektive TOM auch im Alter gut funktioniert. Auch Schild et al. (2021) konnten zeigen, dass mit einem Fortschreiten der kognitiven Beeinträchtigung die kognitive TOM stärker eingeschränkt ist als die affektive TOM.

Yi et al. (2020) zeigten anhand einer Metaanalyse, dass die TOM-Fähigkeit bei Patienten mit Demenz und MCI im Vergleich zu gesunden Kontrollpersonen signifikant beeinträchtigt war. Dieser Unterschied zeigte sich bei Patienten mit Demenz stärker als bei denen mit MCI.

Auch die Ergebnisse der Metaanalyse von Kessels et al. (2021) kommen zu diesem Ergebnis. Sowohl bei MCI als auch bei Demenz waren die TOM-Fähigkeiten im Vergleich zu gesunden Kontrollpersonen signifikant herabgesetzt.

In Folge der Einschränkungen in den Sozialkognitionen und den damit verbundenen beeinträchtigten Sozialfunktionen ziehen sich Menschen aus dem Umfeld von Personen mit Demenz häufig aus den Beziehungen zu ihnen zurück. Dadurch verringern sich die sozialen Kontakte und die sozialen Aktivitäten der Personen mit Demenz. Beeinträchtigungen im Sozialverhalten haben damit das Potenzial, BPSD zu verstärken und zu einer Verschlechterung der psychischen Gesundheit beizutragen (Porcelli et al., 2019). Einige Beispiele für Verhaltenssymptome, die aus Beeinträchtigungen sozialkognitiver Fähigkeiten resultieren können, sind in Tabelle 2 aufgeführt.

Zusammenfassend lässt sich festhalten, dass sich soziale Aspekte im Verlauf demenzieller Erkrankungen verändern können. Sozialkognitive Fähigkeiten können mit abnehmender kognitiver Leistungsfähigkeit abbauen, i. d. R. sind vor allem die Fähigkeiten der kognitiven TOM betroffen. Folglich verändert sich das Sozialverhalten der Personen mit Demenz, was zu Schwierigkeiten bei zwischenmenschlichen Interaktionen und in zwischenmenschlichen Beziehungen führen kann. Neue Kontakte aufzubauen und bestehende Kontakte zu pflegen, gestaltet sich für Erkrankte zunehmend schwieriger. Soziale Aspekte wurden daher in die Diagnosekriterien des DSM-5 aufgenommen. Momentan ist jedoch nur wenig über soziale Aspekte (z. B. Qualität und Quantität sozialer Beziehungen, soziale Aktivitäten, soziales Engagement) bei Demenz bekannt. Hier werden weitere Studien benötigt. Die Arbeiten dieser Dissertation schaffen eine wichtige Grundlage für weitere Untersuchungen mit Fokus auf soziale Aspekte bei Demenz.

1.2. Epidemiologie

Die Zahl der Menschen, die weltweit mit Demenz leben, nimmt ständig zu (Prince et al., 2016). Im Jahr 2015 gab es 46,8 Millionen Demenzfälle (Heinrich & Wübker, 2016) und die Zahl wird bis 2050 voraussichtlich auf 152 Millionen ansteigen (Alzheimer's Disease International, 2019). In Ländern mit niedrigem und mittlerem Einkommen sind mehr Menschen betroffen als in Ländern mit hohem Einkommen (Livingston et al., 2020). Rund zwei Drittel aller Menschen mit Demenz leben in Ländern mit niedrigem bzw. mittlerem Einkommen (Livingston et al., 2020). In wohlhabenden Ländern wird die Prävalenz auf rund 6-9 % geschätzt (Robert Koch Institut, 2015).

In Deutschland lebten 2020 insgesamt rund 1,6 Millionen Menschen mit einer Demenzerkrankung (Glaeske, 2020). Bei den 65-69-Jährigen sind etwas mehr als 1 % und bei den über 90-Jährigen über 30 % von einer demenziellen Erkrankung betroffen (Robert Koch Institut, 2015). Die Neuerkrankungsrate lag 2013 bei rund 300.000 Fällen (Robert Koch Institut, 2015).

Tabelle 2: Beispiele für Verhaltensweisen, die auf Beeinträchtigungen der Sozialkognition zurückzuführen sind (nach Henry et al., 2016).

Typische Verhaltensweisen von Personen mit sozialkognitiven Einschränkungen:	
• Sozialer Rückzug und Meidung sozialer Kontakte • Verlust sozialer Umgangsformen (inadäquates Verhalten) • Meidung von Blickkontakt • Unhöfliche oder beleidigende Bemerkungen, welche die Gefühle anderer verletzen können • Verlust der Manieren in Bezug auf Nahrungsaufnahme oder andere körperliche Funktionen • Halten langer Reden, denen es an Fokus und Schlüssigkeit fehlt • Vernachlässigung des äußeren Erscheinungsbildes, ohne dass dies z. B. auf eine Depression zurückzuführen ist • Missachtung des Leidens oder Schadens von anderen • Unfähigkeit, an der Freude oder den Unternehmungen anderer teilzuhaben, wenn dies erwartet oder erbeten wird	• Unfähigkeit zu sozialer Wechselseitigkeit, selbst wenn offensichtliche soziale Signale gegeben werden • Mangelhafte Gesprächsführung • Offensichtlich vorurteilsbehaftetes oder rassistisches Verhalten • Vermehrte oder inadäquate zwischenmenschliche Grenzverletzungen • Witze oder Wortspiele, die allgemein verständlich sind, werden nicht erfasst • Unfähigkeit, eindeutige soziale Signale wie Langeweile oder Ärger in Gesprächen zu erkennen • Mangelnde Einhaltung sozialer Normen in Bezug auf Kleidung oder Gesprächsinhalte • Übermäßige Fokussierung auf bestimmte Aktivitäten unter Vernachlässigung wichtiger sozialer oder beruflicher Aufgaben

Da es bisher noch keine Heilungsmöglichkeiten für demenzielle Erkrankungen gibt, sterben Personen mit Demenz mit oder an der Erkrankung selbst. In Deutschland waren demenzielle Erkrankungen im Jahr 2020 die zweithäufigste Todesursache (Statistisches Bundesamt, 2019).

1.2.1. Krankheitskosten

Die Versorgung der Patienten mit Demenz ist mit enormen Kosten verbunden. Weltweit wurden im Jahr 2010 schätzungsweise mehr als 600 Milliarden US-Dollar dafür ausgegeben. Davon fallen 70 % der Kosten auf die Staaten Westeuropas und Nordamerikas (Wimo et al., 2013). Weltweit (Wimo et al., 2013) und auch in Deutschland (Michalowsky et al., 2019) steigen die jährlichen Kosten, die aufgrund demenzieller Erkrankungen verursacht werden, stetig an. Im Jahr 2002 wurden 8 Millionen Euro und 2008 rund 11 Millionen Euro für die Versorgung von Menschen mit Demenz in Deutschland aufgebracht (siehe Abb. 1; Statistisches Bundesamt, 2010). Daten von Hausarztpatienten in Deutschland zeigen, dass im Krankheitsverlauf immer höhere Nettokosten entstehen, die sich je nach Stadium der

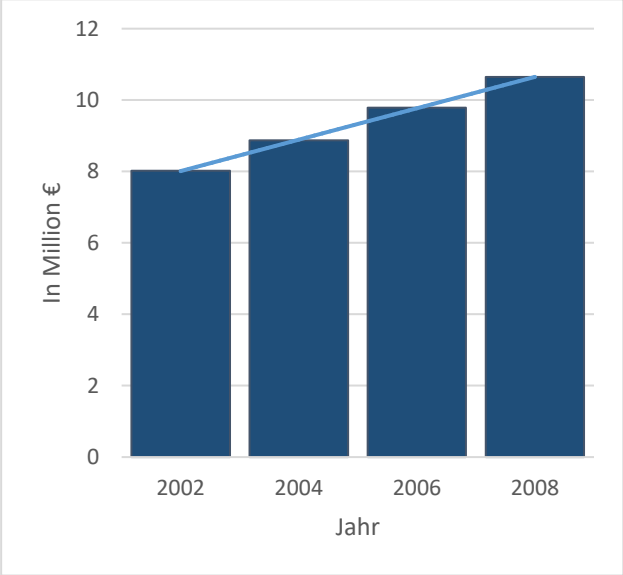

Abbildung 1: Gesamtkosten für Demenzerkrankungen in Million Euro (Quelle: Statistisches Bundesamt (2010); Eigene Darstellung).

Erkrankung mehr als verdoppeln. Bei leichten demenziellen Erkrankungen liegen sie bei 15.215 Euro, bei mittelschweren bei 30.948 Euro und bei schweren bei 41.130 Euro pro Jahr. Einen Großteil macht dabei der Bereich Pflege aus. Er beansprucht etwa drei Viertel der Gesamtkosten, während ein Viertel die medizinische Versorgung betrifft (Leicht et al., 2011).

Die Versorgung von Patienten mit demenziellen Erkrankungen ist damit mit enormen gesellschaftlichen und ökonomischen Herausforderungen verbunden (Robert Koch Institut, 2015). Im Einzelnen fallen z. B. Kosten für die stationäre Gesundheitsversorgung, die

Primärversorgung, Arzneimittelversorgung, Sozialfürsorge und die Pflege (bezahlt und unbezahlt) an (siehe Abb. 2; DAK (2017); Alzheimer's Disease International (2019)). Getragen werden diese Kosten nicht nur vom Gesundheits- und Sozialfürsorgesystem, sondern auch von den Angehörigen der Person mit Demenz.

Die Pflege an Demenz erkrankter Personen kann für die Pflegenden eine Belastung darstellen (Zwerling et al., 2016). Studien haben beispielsweise ein erhöhtes Stressniveau und andere negative Folgen für die Gesundheit und Lebensqualität pflegender Ehepartner nachgewiesen (Pinquart & Sörensen, 2003; Vitaliano et al., 2003). Bei etwa 50 % der Pflegenden ist die eigene Gesundheit und die Arbeit durch die Pflege beeinträchtigt (Alzheimer's Disease International, 2019). Zudem nimmt das Mortalitätsrisiko und das Risiko für kognitive Beeinträchtigungen zu (Zwerling et al., 2016). Die Pflege kann darüber hinaus einen Einfluss auf das Sozialleben der Pflegenden haben. Etwa zwei Drittel berichten von Beeinträchtigungen im Sozialleben durch die Übernahme von Aufgaben in der Pflege der Person mit Demenz (Alzheimer's Disease International, 2019).

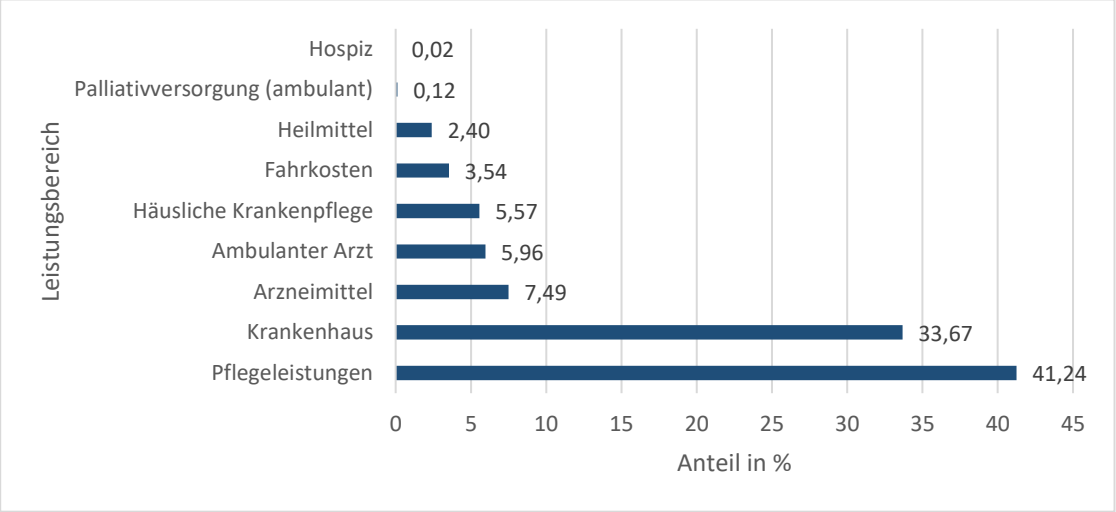

Abbildung 2: Kostenverteilung bei Demenzpatienten nach Leistungsbereich ein Jahr nach der Diagnose (Quelle: DAK (2017); Eigene Darstellung).

1.2.2. Risikofaktoren

Das Risiko an Demenz zu erkranken ist für Frauen größer als für Männer und nimmt im Alter zu (siehe Abb. 3; Deutsche Alzheimer Gesellschaft e.V. Selbsthilfe Demenz (2022)). Ursache für diese geschlechtsspezifischen Differenzen sind zum einen genetische Unterschiede und zum anderen die höhere Lebenserwartung von Frauen (Soria Lopez et al., 2019). Der wichtigste genetische Risikofaktor ist das Apolipoprotein E4 (ApoE4) (Soria Lopez et al., 2019). Neben diesen nicht veränderbaren Risikofaktoren hat die Lancet-Kommission zur Prävention, Intervention und Pflege von Demenzerkrankungen insgesamt 12 modifizierbare Risikofaktoren identifiziert (Geringe Bildung, Bluthochdruck, Probleme beim Hören, Rauchen, Übergewicht, Depression, körperliche Inaktivität, Diabetes, ein Mangel an sozialen Kontakten, Alkoholmissbrauch, Schädel-Hirn-Traumata, Luftverschmutzung), die für ca. 40 % aller Demenzfälle auf der ganzen Welt verantwortlich sind (Livingston et al., 2020). Auf die sozialen Risikofaktoren soziale Isolation und Einsamkeit soll an dieser Stelle gesondert eingegangen werden.

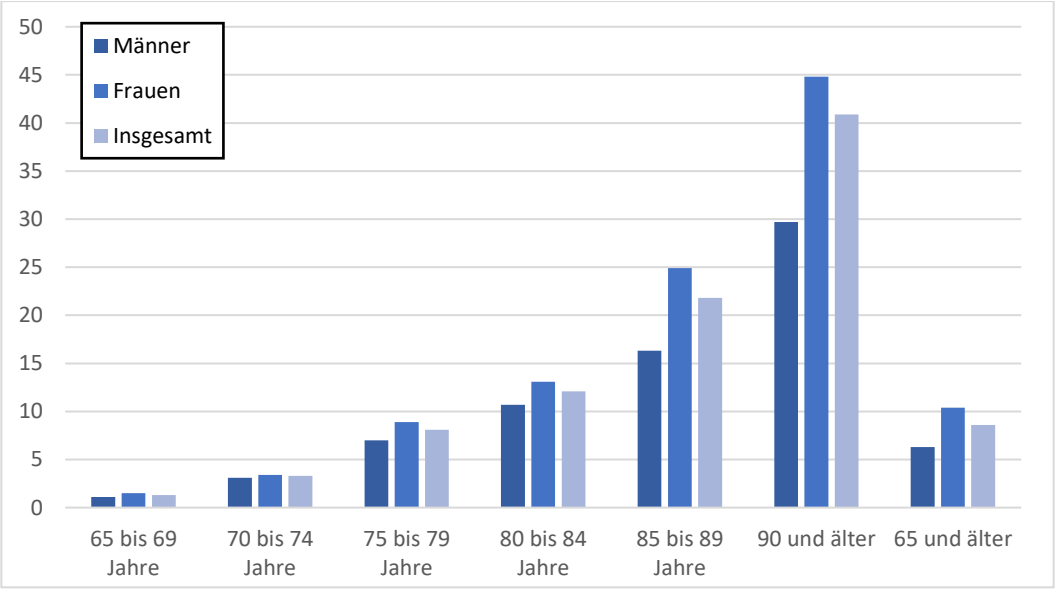

Abbildung 3: Prävalenzrate von Demenzerkrankungen in Deutschland nach Alter und Geschlecht 2018 (Quelle: Deutsche Alzheimer Gesellschaft e.V. Selbsthilfe Demenz (2022); Eigene Darstellung).

Soziale Isolation und Einsamkeit als Risikofaktoren

Der Anteil sozial isoliert Lebender nimmt mit dem Alter zu (Jong Gierveld et al., 2006). Unter den in Gemeinschaft lebenden älteren Erwachsenen reicht die Prävalenz von 10 % bis 43 % (Nicholson, 2012). Soziale Isolation wird definiert als eine geringe Anzahl und Häufigkeit von Kontakten zu Anderen (Nicholson, 2009). Es handelt sich um ein objektives Maß und kann durch die Quantifizierung des sozialen Netzwerks einer Person bewertet werden (Luhmann & Hawkley, 2016). Abzugrenzen ist davon der Begriff Einsamkeit. Darunter wird eine gefühlte soziale Isolation, nicht aber eine objektiv quantifizierbare soziale Isolation verstanden (Luhmann & Hawkley, 2016). Menschen können relativ wenige soziale Kontakte haben, ohne sich einsam zu fühlen. Umgekehrt ist es auch möglich, dass viele soziale Kontakte bestehen, die Person sich aber dennoch als einsam einschätzt. Einsamkeit wird definiert als ein belastendes Gefühl, das mit der Wahrnehmung verbunden ist, dass die eigenen sozialen Bedürfnisse nicht durch die Anzahl oder die Qualität der sozialen Beziehungen befriedigt werden können (Luhmann & Hawkley, 2016).

Zum Einsamkeitsempfinden unter älteren Erwachsenen gibt es nur wenige Zahlen. Aus der Europäischen Erhebung zur Lebensqualität geht hervor, dass sich 6 % der Älteren (65+) meistens oder die ganze Zeit einsam fühlen (European Quality of Life Survey, 2016). Zudem ist bekannt, dass vor allem die Gruppe der Hochaltrigen stark von Einsamkeit betroffen ist (Luhmann & Hawkley, 2016).

Eine Reihe von Studien haben einen Zusammenhang zwischen Merkmalen und Aspekten des sozialen Netzwerkes (z. B. soziale Teilhabe, Alleinleben und weniger häufige Kontakte) und der kognitiven Leistungsfähigkeit sowie dem Auftreten von Demenz belegt (Evans et al., 2019; Kuiper et al., 2015). Lammer et al. (2021) zeigten in ihrer Analyse der Daten von 1992 kognitiv gesunden Personen im Alter von 50 bis 82 Jahren, dass soziale Isolation zum Abbau bestimmter Gehirnstrukturen und einem kognitiven Rückgang im hohen Lebensalter beitragen kann (Lammer et al., 2021). Die Auswirkungen sozialer Isolation auf das Gehirn wurden auch in einem Experiment mit Mäusen untersucht. Smith et al. (2018) zeigten, dass das alternde Gehirn durch größere soziale Netzwerke positiv beeinflusst werden kann. Diese Ergebnisse unterstützen die Annahme, dass das soziale Netzwerk mit der Gehirnstruktur

verbunden ist und somit kognitive Funktionen und die Entwicklung von Demenz beeinflussen kann.

Momentan gibt es nur wenige Forschungsarbeiten zu verschiedenen Altersgruppen, insbesondere zu den Hochbetagten, bei denen die soziale Isolation besonders häufig ist. Je nach Altersgruppe können die Auswirkungen der Risikofaktoren unterschiedlich sein. Daher ist es wichtig, verschiedene Altersgruppen in Bezug auf das Demenzrisiko und die Demenzhäufigkeit zu untersuchen. Die Forschung zur sozialen Isolation als Risikofaktor für Demenz wird mit dieser Dissertation erweitert, indem der Zusammenhang zwischen sozialer Isolation und dem Auftreten von Demenz längsschnittlich in einer Gruppe von Hochaltrigen untersucht wird.

Es gibt zwei Mechanismen, die den Zusammenhang zwischen sozialer Isolation und Demenz erklären – Social Bridging und Social Bonding. Beide werden im Folgenden kurz vorgestellt.

Social Bridging

Social Bridging beschreibt lose Kontakte bzw. schwach ausgeprägte Beziehungen einer Person mit Demenz aus verschiedenen Gruppen. Social Bridging führt zur Identitäts- und Perspektiverweiterung, da Personen mit vielen solchen Kontakten mit einer Vielzahl anderer Menschen unterschiedlichen Alters, unterschiedlicher Herkunft und unterschiedlicher politischer Zugehörigkeit Umgang haben. Diese Personen führen ein aktives Leben, mit einer Vielzahl an Unternehmungen. Somit umgibt sie eine heterogene Gruppe von Freunden und Bekannten. (Perry et al., 2021)

Diese eher zufälligen Beziehungen setzen neue soziale Reize in Form von Ideen, Informationen, Aktivitäten, verbalen und nonverbalen Zeichen, aber auch vielen Gesichtern und Sprachmustern. Im Zuge dessen sind lose Kontakte und schwache ausgeprägte Beziehungen vermutlich kognitiv bereichernder als vertraute, sich wiederholende Interaktionen mit guten Freunden und nahen Verwandten. (Perry et al., 2021)

Die Wirkung von Social Bridging auf die Gehirngesundheit erfolgt über einen direkten und einen indirekten Weg. Direkt beeinflusst wird, wie Studien zeigen, die Auslösung von Genexpressionen und die Unterstützung funktioneller Verknüpfungen des neuronalen

Wachstums und der Gehirnregeneration (Perry et al., 2021). Indirekt führt Social Bridging zur Bildung einer kognitiven Reserve (Perry et al., 2021).

Social Bonding

Unter Social Bonding werden enge, vertraute Kontakte verstanden wie z. B. Partnerschaften oder Elternschaft. Sie wirken identitätsvertiefend und bieten bei Bedarf Begleitungen, emotionale Unterstützung sowie Hilfe bei alltäglichen Aufgaben. Ein hohes Maß an Social Bonding vermittelt ein Gefühl von Lebenssinn, Wertschätzung und Zugehörigkeit und fördert die Selbstbestimmung, das Selbstwertgefühl, die Sicherheit und Verhaltensführung. (Perry et al., 2021)

Der Einfluss von Social Bonding auf die Gehirngesundheit erfolgt über einen direkten und einen indirekten Weg. Social Bonding wirkt sich direkt auf zahlreiche Körper- und Gehirnfunktionen aus und reduziert Einsamkeit, wohingegen die wahrgenommene soziale Unterstützung steigt. Daraus ergeben sich Effekte auf den Cortisol- und Oxytocin-Spiegel, was positive Auswirkungen auf die Gehirngesundheit hat (Perry et al., 2021).

Indirekt schützt ein hohes Maß an sozialer Bindung vor kognitiven Rückgang, indem die biologischen Auswirkungen von Stress auf das Gehirn gemindert werden (Stress-Buffering-Hypothese; Perry et al., 2021).

1.2.3. Konsequenzen im Kontext sozialer Aspekte

Momentan ist nur wenig darüber bekannt, wie sich soziale Beziehungen im Verlauf demenzieller Erkrankungen verändern. Man weiß, dass es infolge dieser Erkrankungen zu einer Abnahme der sozialen Beziehungen kommen kann. Basierend auf einer qualitativen Erhebung zeigte sich, dass Personen mit Demenz weniger gut sozial eingebunden sind. Eine Ursache können Stigmatisierungen sein. Personen mit Demenz können beispielsweise von ihrem Umfeld ignoriert, nicht auf Treffen eingeladen und von Aktivitäten, an denen sie sich gern beteiligt haben, ausgeschlossen werden wie beispielsweise in Vereinen, wo sie zuvor aktiv oder ehrenamtlich tätig waren. Personen mit Demenz berichten auch, dass sie das Gefühl haben nichts beitragen zu können. Sie haben Angst, dass sie nicht mithalten können oder dass andere Menschen sich durch ihre Anwesenheit unwohl oder gar gestört fühlen könnten. Den Verlust der sozialen Anbindung bemerken die betroffenen Personen auch

dadurch, dass immer weniger Freunde und Kollegen den Austausch mit ihnen suchen (Alzheimer's Disease International, 2019).

Zu diesem Punkt sind weitere Forschungen nötig, die klären, wie sich das soziale Umfeld im Zuge einer Demenzerkrankung verändert. Gibt es im Krankheitsverlauf typische Auswirkungen, z. B. auf qualitative und quantitative Netzwerkcharakteristika oder soziale Aktivitäten? Wie wirken sich solche Veränderungen auf den weiteren Krankheitsverlauf aus? Können ein stabil bleibendes soziales Umfeld und vielfältige soziale Aktivitäten vor einem schnelleren Krankheitsverlauf schützen? Ist es so, dass mit der Abnahme der sozialen Kontakte die Person mit Demenz weniger Reizen und Eindrücken ausgesetzt ist, sich ihre kognitive Leistungsfähigkeit infolgedessen zunehmend verschlechtert und die Krankheit schneller voranschreitet, als wenn das soziale Netzwerk stabil bleibt? Gibt es dann beispielsweise weniger Einweisungen in eine Pflegeeinrichtung? Und wie wirken sich Veränderungen in den sozialen Beziehungen im Krankheitsverlauf auf die Lebensqualität der Personen mit Demenz und deren Angehörigen aus?

1.3. Diagnose und Screening

Um die oben dargestellten Diagnosekriterien zu überprüfen, gibt es zahlreiche Tests. Diese umfassen Instrumente zur Erfassung der kognitiven Leistungsfähigkeit, der Unabhängigkeit in instrumentellen Alltagsaktivitäten und den Sozialkognitionen. Diese Instrumente können sowohl zur Diagnostik als auch zur Verlaufsbeschreibung und Evaluation von Behandlungs- und Interventionseffekten eingesetzt werden. In dieser Arbeit liegt der Fokus auf sozialen Aspekten. Daher wird aus Kapazitätsgründen ausschließlich auf die Diagnostik der Sozialkognition und BPSD eingegangen.

1.3.1. Beurteilung der sozialen Kognitionen und BPSD

Gemäß den S3-Leitlinien (S3-Leitlinien „Demenz") existiert derzeit kein Goldstandard zur Beurteilung der Sozialkognitionen bei Personen mit Demenz für die klinische Praxis. Es werden aber Empfehlungen zur Erfassung von BPSD gegeben.

Diese umfassen das Neuropsychiatrische Inventar (Cummings, 1997; NPI), die Behavioral Pathology in Alzheimer`s Diseases Rating Scale (Reisberg et al., 1996 und Harwood et al.,

1998; BEHAV-AD), die Behavior Rating Scale for Dementia of the Consortium to Establish a Registry for Alzheimer's Disease (Tariot, 1996 und Tariot et al., 1995; CERAD-BRSD) und die Nurses Observation Scale for Geriatric Patients (Brunner & Spiegel, 1990; NOSGER) zur Erfassung syndromübergreifender Symptome. Darüber hinaus gibt es noch Instrumente zur Erfassung spezifischer BPSD, wie Depression (Cornell Depression bei Demenz Skala von Alexopoulos et al., 1988; CDDS; Geriatrische Depressionsskala von Sheikh and Yesavage, 1986, die Hamilton Depressionsskala von Hamilton, 1960; HAM-D und das Beck-Depressions-Inventar von Beck et al., 1961; BDI), Apathie (Apathie Evaluation Skala von Marin et al., 1991; AES) und Agitation (Cohen-Mansfield Agitation Inventory von Cohen-Mansfield et al., 1995; CMAI).

In der Forschung hingegen wird eine Vielzahl an Instrumenten verwendet, um die Sozialkognition von Studienteilnehmern zu beurteilen. Tabelle 3 gibt einen Überblick.

Tabelle 3: Instrumente zur Erfassung sozialkognitiver Funktionen.

Domäne der Sozialkognition	**Instrumente zur Erfassung**
TOM	False-Belief Aufgaben
	The Awareness of Social Inference Test
	Strange Stories Test
	Faux-Pas Test
	Reading the Mind in The Eyes Test
Empathie	Empathic Concern
	Empathy Quotient
	Multifaceted Empathy Test
Soziale Wahrnehmung	Ekman Faces
	Facial Expressions of Emotion – Stimuli and Tests
	Comprehensive Effect Testing System
	Florida Affect Battery
	The Awareness of Social Interference Test Part 1: Emotion Evaluation Test
Auffälligkeiten im sozialen Verhalten	Frontal Systems Behavior Scale
	Frontal Behavioral Inventory
	Socioemotional Dysfunction Scale
	Peer-Report Social Functioning Scale
	Social Impairment Rating Scale

Aktuell existiert für den deutschen Sprachraum kein geeignetes Instrument zur Erfassung der Sozialfunktionen speziell bei Demenz. Die Forschung zu diesem Punkt wird im Rahmen dieser Arbeit erweitert, indem ein geeignetes Instrument recherchiert und für den deutschen Sprachraum verfügbar gemacht wird.

1.4. Ziele der Dissertation

Bisher gibt es keine wirksame Behandlung oder Heilung für Demenz. Im Zuge des demografischen Wandels, der die Bevölkerungsalterung vorantreibt, werden höhere Kosten für die Gesundheitssysteme entstehen. Daher wird die Bedeutung der Demenzprävention und -früherkennung immer größer. Valide Messinstrumente bilden eine Grundlage zur Prävention und Früherkennung von Demenz.

Um ein besseres Verständnis über Veränderungen in sozialen Beziehungen und den damit verbundenen Ereignissen bei Patienten, Angehörigen und Pflegekräften zu erzielen, ist es wichtig, die sozialen Aspekte bei Demenz valide erfassen zu können. Sie können bei der Bewertung von Interventionseffekten hilfreich sein und die Entwicklung psychosozialer Therapien einerseits, aber auch die Entwicklung von Präventionsmaßnahmen andererseits vorantreiben. Daher wurde in einer **ersten Arbeit** eine systematische Literaturrecherche durchgeführt, um einen Überblick über geeignete Instrumente zur Erfassung der sozialen Funktionsfähigkeit speziell bei Personen mit Demenz zu geben. Die Social Functioning in Dementia Scale (SF-DEM; Sommerlad et al., 2017) hat sich als besonders geeignet herausgestellt.

In einem **zweiten Schritt** wurde die SF-DEM aus dem Englischen ins Deutsche übersetzt und anhand einer Pilotstudie psychometrisch überprüft. Dazu wurden Dyaden, bestehend aus Personen mit leichter Demenz und jeweils einem Angehörigen, zu zwei Befragungszeitpunkten befragt.

Die **dritte Arbeit** legt den Schwerpunkt auf soziale Isolation als einen Risikofaktor für Demenz. Es wurde eine Analyse mit Berücksichtigung des konkurrierenden Risikos Mortalität durchgeführt, um den Zusammenhang zwischen sozialer Isolation und dem Auftreten von Demenz längsschnittlich bei Hochaltrigen zu untersuchen. In Anbetracht der unterschiedlichen Profile von Risikofaktoren für Demenz bei Frauen und Männern, über die

bereits berichtet wurde (siehe Kapitel 1.2.2.), wurde zusätzlich eine nach Geschlecht stratifizierte Analyse durchgeführt. Diese erfolgte unter der Annahme, dass das Risiko eine Demenz zu entwickeln bei Personen, die sozial isoliert leben größer ist als bei jenen, die nicht sozial isoliert leben.

2. Empirische Studien

2.1. Instruments to assess social functioning in individuals with dementia: a systematic review

Grothe, J., Schomerus, G., Dietzel, J., Riedel-Heller, S., & Röhr, S. (2021). Instruments to Assess Social Functioning in Individuals with Dementia: A Systematic Review. *Journal of Alzheimer's Disease*, 80(2), 619–637.

Background: Social functioning is an important parameter for the early detection and diagnosis of dementia, as well as the description of its course and the assessment of intervention effects. Therefore, valid and reliable instruments to measure social functioning in individuals with dementia are needed.

Objective: We aimed to provide an overview of such instruments including information on feasibility and psychometric properties.

Methods: The review is informed by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. Relevant literature was identified using a pre-specified search string in the databases MEDLINE, PsycINFO and Web of Science. Information on the characteristics, feasibility and psychometric properties of the identified instruments were extracted, summarized and discussed.

Results: Out of 5,307 articles, 8 were selected to be included in the study, describing a total of three instruments for measuring social functioning in individuals with dementia: the Nurses' Observation Scale for Geriatric Patients (NOSGER; dimension "social behavior"), the Socioemotional Dysfunction Scale (SDS) and the Social Functioning in Dementia Scale (SF-DEM). The validity of all the three instruments was overall acceptable. Reliability was high for the NOSGER scale "social behavior" and the SF-DEM. Information on the usability of the instruments tended to be scarce.

Conclusion: There are a few valid and reliable instruments to assess SF in individuals with dementia. Further considerations could comprise their feasibility with regard to measuring changes in social functioning over time, in additional target groups, e.g. different types and stages of dementia, and adaptions to different languages and cultural backgrounds.

Für den Volltext siehe Seite 18.

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Instruments to Assess Social Functioning in Individuals with Dementia: A Systematic Review

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Conclusion: There are a few valid and reliable instruments to assess social functioning in individuals with dementia. Further considerations could comprise their feasibility with regard to measuring changes in social functioning over time, in additional target groups, e.g., different types and stages of dementia, and adaptions to different languages and cultural backgrounds.

Keywords: Assessment, dementia, instrument, measurement, psychometric properties, reliability, social functioning, systematic review, validity

INTRODUCTION

Dementia is a neuropsychiatric syndrome that mainly occurs as a result of a degenerative disease of the brain. It is one of the most common and most severe disorders in old age and shortens the life span considerably [1]. The number of people living with dementia worldwide is constantly increasing [2]. In 2015, there

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were 46.8 million dementia cases [3], and the number is projected to increase to 152 million by 2050 [4]. This development will pose major challenges for public health and old age care systems in countries all over the world [5]. There is no effective treatment or cure for dementia yet. In the course of demographic changes that drive population aging, higher costs for health care systems will emerge [3]. Therefore, the importance of dementia prevention and early detection is growing.

The core symptom of dementia is acquired cognitive impairment that limits the independent performance of everyday functional activities. In addition to cognitive decline and functional loss, changes in social functioning (SF) frequently occur in the course of dementia [6].

By showing repeated inappropriate social behavior—typically being unaware of it—people around individuals with dementia often withdraw from relationships with them. This reduces the individuals' social contacts and social activities. Social behavior comprises "the readily observable interactions between an individual and other people, while "social functioning" is broader than social behavior in that it consist in the long-term and contextualized ability of an individual to interact with others" [7]. It is about how someone interacts in relationships with others, in social relationships, "how individuals associate and interact, both in society at large and their own personal environment", such as loss of interest in previously valued hobbies or changes within close relationships [8]. Therefore, impairments in SF, showed as a disengagement from social activities that lead to impoverished interpersonal relationships, can contribute to increased psychiatric symptoms and worse mental health [6]. Behavioral problems such as disinhibition, apathy, or loss of empathy do not belong to SF by our definition. They are neuropsychiatric symptoms and are rather a prerequisite for SF. Supplementary Table 1 gives an overview of the definitions of the terms social cognition, social behavior, and social functioning.

SF needs to be differentiated from similar terms, such as social activities, social participation, or social engagement, which are frequently measured, for example, by collecting information on the frequency of contacts or meetings with family and friends or attending events [9]. Also, closely related is the construct of social network. It can be defined as "the web of social relationships that surrounds an individual" [10]. The assessment of the social network includes network size, the relationship between members and their frequency of contact [9]. These constructs are also important in surveys about individuals with dementia, and have been studied extensively [11, 12].

Changes in SF can occur early in the course of cognitive decline [13], in various types of dementia [14], including dementia due to Alzheimer's disease (AD) [15], behavioral variant frontotemporal dementia (bvFTD) [16] and Lewy body dementia (LBD) [17]. In bvFTD, changes in SF are best described, because associated changes occur specifically in brain areas such as frontal lobes, anterior temporal lobes, and the amygdala being pivotal for SF [16, 18]. Studies also have shown that SF is already perceptibly altered in dementia pre-stages, e.g., in mild cognitive impairment [14]. In addition to cognitive and functional impairment, SF is thus not only an important criterion in the prediction and diagnosis of dementia but also a significant target variable for assessing treatment effects in prevention and intervention studies [8].

The fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) also takes into account new research findings on the development and course of dementia which are explicitly reflected in expanded diagnostic criteria [19]. In addition to key characteristics, i.e., cognitive and functional impairment, social cognitive changes are now part of the diagnostic criteria of dementia, which are referred to as major neurocognitive disorder in the DSM-5. This is based on the observation that typical neuropathological changes in the brain trigger not only increasing impairment of cognitive and everyday functions, but also SF disorders [20]. Social cognition includes, e.g., aspects of social perception, social memory processes, socially influenced emotions, and thinking and acting [7, 15] and can be tested with standardized tests (for an overview, see [21]). SF needs to be assessed through self- and other-report questionnaires.

The significance of assessing SF in dementia consists in its usefulness for a better understanding of changes in relationships and associated outcomes in patients, relatives, and caregivers. It can be useful in the evaluation of intervention effects. As such, it can facilitate the development of effective psychosocial therapies and prevention interventions. This presumes valid and reliable measures of SF.

Therefore, the aims of the study were:

1. to systematically review the literature to identify instruments for assessing SF in individuals with dementia;

2. to provide an overview of the characteristics of the identified instruments and the feasibility of their application in individuals with dementia;
3. to provide an overview of the psychometric properties (e.g., reliability, validity, and responsiveness) of the identified instruments;
4. to provide recommendations for future research regarding instruments for assessing SF in individuals with dementia.

METHODS

Literature search

This study was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [22]. We performed a systematic search for eligible articles in October 2019 in the electronic databases MEDLINE, PsycINFO, and Web of Science. The search included the following search algorithm: (questionnaire OR instrument OR tool OR measure OR scale OR assessment* OR inventory) AND (dementia OR "cognitive function*" OR "cognitive impairment*" OR "cognitive decline" OR "neurocognitive disorder*" OR Alzheimer) AND ("social function" OR "social behavior" OR "social activity" OR "social life" OR "social participation" OR "social cognition" OR "social impairment" OR "social resources" OR "social appropriateness" OR "social inappropriateness" OR "socioemotional function"). The search was not limited regarding years of publication.

Eligibility criteria

Published articles were included if 1) the studies explained the development or psychometric testing of an instrument designed to assess SF in 2) individuals with dementia and 3) were published in English or German language in a peer-reviewed journal.

Single items were assigned to the domain of SF if the overall questionnaire, subscales of a questionnaire, or individual items addressed aspects of SF in the broader context of social interactions of individuals with dementia.

Study selection

The search results were uploaded to a reference management software (Citavi 6). First, duplicates were removed. Two reviewers (JG, SR) independently assessed the titles and abstracts of all identified articles in order to check their relevance for the study. Articles selected based on title and abstract screening were then read in full, specifically if the eligibility criteria were not clear yet. In case of disagreement, both reviewers discussed the articles until a consensus was reached.

Data extraction and data synthesis

The data were extracted by one researcher (JG). The following data were inventoried and described: 1) characteristics of the instrument (e.g., domains, number of items, scoring), 2) feasibility (administration, duration of application, ease of use, the latter indicating the ease with which the items are understood by or explained to the person with dementia, caregiver, or the interviewer and the availability of the instruments), and 3) psychometric properties (reliability, validity, and responsiveness, the latter defined as the ability to reflect changes in cognitive functions).

RESULTS

The search in the MEDLINE, PsycINFO, and Web of Science databases revealed 5,296 references. In total, 1,667 duplicates were eliminated. Additionally, 11 potentially suitable articles were identified after checking the reference lists of potentially eligible full-text articles. Finally, the study selection resulted in 8 articles describing three relevant instruments. Figure 1 illustrates the selection process.

In addition to the three relevant instruments, a number of other instruments were identified, which included single items of relevance as part of other constructs. Such instruments were not the focus of the study; however, Table 2 provides a brief overview of these instruments. Moreover, Supplementary Table 2 lists further instruments that were not included in the systematic review with reasons for exclusion.

Instruments for assessing social functioning in individuals with dementia Characteristics and feasibility of the instruments

The identified instruments for assessing SF in individuals with dementia were the Nurses' Observation Scale for Geriatric Patients (NOSGER) [23], the Social Functioning in Dementia Scale (SF-DEM) [8], and the Socioemotional Dysfunction Scale (SDS) [24]. Table 1 shows the characteristics and feasibility of the instruments.

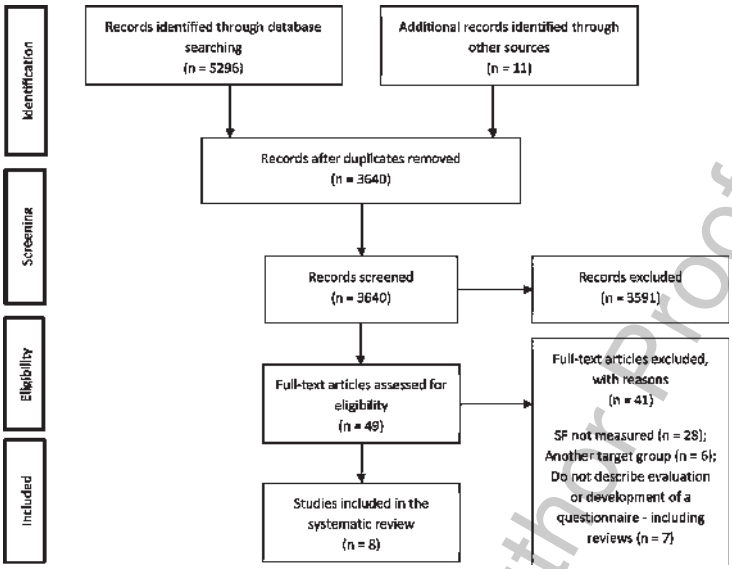

Fig. 1. PRISMA Flow chart of literature references on instruments for social functioning (SF) included in the review.

The NOSGER is a 30-item questionnaire which is completed by a close caregiver. The screening tool was developed for outpatients and inpatients with suspected age-related dementia to detect behavioral changes in clinically relevant areas. Each area is assessed by one domain: memory, instrumental activities of daily living (IADL), activities of daily living (ADL), mood, social behavior, and disturbing behavior. Only one of the six domains, social behavior, taps into SF with five items (e.g., "Is interested in what is going on around him/her", "Makes contact with people around"; cf. [25]). The scale is scored on a five-point Likert scale (1 to 5; "all the time" to "never"). The questions apply to the last four weeks.

The SDS is a 40-item scale for socioemotional dysfunction that can be completed by an informant (spouse, family member, caregiver, or other). The questionnaire reflects social interpersonal phenomena and socioemotional changes. Collective clinical features (disinhibition, apathy, social disengagement, poor social awareness, and difficulty discerning negative feelings in others) are represented in the content of the SDS items. This makes it especially relevant for clinicians, because these are the most promising discriminatory clinical markers of bvFTD [24]. Thirty-one items of the SDS were modified from the Social Competency Questionnaire (SCQ) [26]. The items are scored on a five-point Likert scale (1 to 5; "very inaccurate" to "very accurate"). A higher score indicates greater social dysfunction.

The SF-DEM assesses SF as the main construct and was developed specifically for individuals with dementia. It can be completed as a face-to-face interview with the individuals with dementia or with a proxy (e.g., caregiver or clinician). Both versions (self- and proxy report) consist of four domains: 1) Spending time with other people (e.g., "gone on trips or events like cinema or talks" or "seen friends and family in your own home"), 2) Communicating with other people (e.g., "talk to other people about your feelings or concerns" or "found it difficult to think of something to say to others"), and 3) Sensitivity to other people (e.g., "been very outspoken about what you really think" or "had argument or shouted at other people"). Altogether, the questionnaire includes 17 items. They are scored using a four-point Likert scale (0 to 3; "Very often" to "Never") with a higher score indicating better SF. Three unscored summary questions assess overall impressions of SF in the individuals with dementia. These questions include recent change and willingness to make future social changes. Recent changes are recorded by comparing the current SF with the situation one year ago. Changes can be rated using a five-point ordinal scale.

Table 1
Characteristics and feasibility of instruments for assessing social functioning in individuals with dementia

Measure	Characteristics of the Instrument				Feasibility	
	Domains	No. Items	Scoring	Administration	Completion Time	Ease of use and acceptability
Nurses' Observation Scale for Geriatric Patients (NOSGER)	6 Scale "social behavior"	30 5	5-point Likert scale	Administration by a close caregiver	Not reported	Rated by N = 42 raters as understandable and acceptable in terms of content [23]. Acceptance by relatives and caregivers was very good [27].
Socioemotional Dysfunction Scale (SDS)	1	40	5-point Likert Scale	Proxy-report	Not reported	Not reported
Social Functioning in Dementia Scale (SF—DEM)	4	20	4-point Likert scale	Self-report and carer-report	**Persons with dementia:** 13 minutes [8]; **Carer:** 11 minutes [8]; 5 minutes [28]	**Availability:** Freely available online **Acceptability:** 62% rated the instrument as acceptable or very acceptable (38%) [8] **Floor or celling effects:** None [8] **Ease of use:** No missings and no problems. All study participants could answer the questions of the self- and carer-report [8]; 95,3% could answer all questions in the carer-report [28]

Table 1
Psychometric properties of instruments for assessing social functioning in individuals with dementia

Authors	Target Population	Reliability	Validity	Responsiveness
Nurses' Observation Scale for Geriatric Patients (NOSGER) - Scale "social behavior'				
Brunner and Spiegel (1990) [23]		Not reported for subscales of the NOSGER.	Not reported for subscales of the NOSGER.	Not reported for subscales of the NOSGER.
Spiegel et al. (1991) [25]	Close relatives or nursing staff of older individuals living in the community	High interrater and test-retest reliability. Refers to Brunner and Spiegel (1990) [23]: **Interrater reliability:** $r_s = 0.74$ **Test-retest reliability:** $r_s = 0.80$ **Population:** N = 32 older individuals (Age: 56–96[1])	**Concurrent validity:** High and meaningful correlations Refers to Brunner and Spiegel (1990) [23]: with "social dysfunction[2]" ($r_s = 0.84$), "extraversion[3]" ($r_s = 0.75$)	Not reported
	Individuals with Alzheimer disease, living in the community and institutions	Refers to not published article: **Interrater reliability:** $r_s = 0.89$ **Test-retest reliability:** $r_s = 0.87$ **Population:** *N* = 27 patients with Alzheimer (Age: No detailed information available)	Refers to not published article: "memory disturbance[4]" ($r_s = 0.76$), "confusion[4]" ($r_s = 0.75$), "activity/communication" ($r_s = 0.64$)	
	Patients in a multicenter drug trail	Refers to Tremmel and Spiegel (1993) [30]: **Interrater reliability:** $r_s = 0.86$ **Test-retest reliability:** $r_s = 0.86$ **Population:** N = 28 patients (Age: No detailed information available)	Refers to Tremmel and Spiegel (1993) [30]: "apathy[5]" ($r_s = 0.62$) and "interpersonal relations[5]" ($r_s = 0.52$)	
Tremmel and Spiegel (1993) [30]	Patients in a multicenter drug trail	Refers to Spiegel et al. (1991) [25]: high test-retest and interrater reliability in very different settings	Refers to Spiegel et al. (1991) [25]: satisfactory concurrent validity	**Sensitive to change**: Changes in "social behavior" correlated with independent physicians overall assessments of treatment efficacy ($r = 0.41$). Low correlation between "social behavior" change scores and MMSE change scores ($r = -0.19$). **Population:** *n* = 123 individuals with mild to moderate dementia severity
Wahle et al. (1996) [27]	Older individuals	**Interrater reliability:** $r = 0.68$ **Test-retest reliability**[a]: $r_s = 0.87$; $r^* = 0.88$	**Content validity:** close correlation with the first dimension of PLUT ("disturbed social behavior") ($r_s = 0.74$) and statistically significant correlations with the dimensions memory (r_s between –59 and –38), IADL ($r_s = -56$) and self-care[6] ($r_s = 54$).	Not mentioned

Table 1
(Continued)

Authors	Target Population	Reliability	Validity	Responsiveness
			Discriminant validity: Significant differences between the four groups (H = 48.21). Differences between healthy subjects and all other groups.	
		Population: healthy old subjects ($n = 50$), patients with mild dementia ($n = 25$), patients with serve dementia ($n = 25$), elderly patients with depression ($n = 25$) (Age: 65–90)	**Population:** healthy old subjects, patients with mild dementia, patients with serve dementia, elderly patients with depression	
Bläsi et al. (2005) [29]	Older individuals without dementia and with probable AD (Age: No detailed information available).		Correlation with MMSE $r_s = -0.25$ for the Alzheimer disease-Sample. Correct classification rate at acceptable level: 71.5%	NOSGER revealed good discriminatory power in those behavioral dimensions affected in early stages on AD and is suitable for monitoring behavioral changes as a function of disease progression. Its use in combination with the MMSE for dementia screening purposes is recommended.
Socioemotional Dysfunction Scale (SDS)				
Barsuglia et al. (2014) [24]	Individuals with dementia and their caregivers	**Internal consistency:** excellent ($\alpha = 0.98$)	**Preliminary validity:** acceptable level **Divergent validity:** no correlation with: NPI: –depression –anxiety –delusion CDR: –memory –orientation **Convergent validity:** strong correlation with conceptual assessments: NPI: –disinhibition ($r = 0.82$) –appetite/eating changes ($r = 0.71$) –disinhibition ($r = 0.68$) –aberrant motor behaviors ($r = 0.65$) –agitation ($r = 0.65$) –elation ($r = 0.62$) –elation/euphoria ($r = 0.60$) –apathy ($r = 0.59$) –agitation/aggression ($r = 0.55$) –irritability ($r = 0.47$)	Discriminating between bvFTD and EOAD.

(Continued)

Table 1
(Continued)

Authors	Target Population	Reliability	Validity	Responsiveness
			CDR: –BEHAV ($r = 0.86$) –community affairs ($r = 0.67$) –judgment and problem solving ($r = 0.64$) –home and hobbies ($r = 0.50$) –personal care ($r = 0.63$) FrSBe (r between 0.54 and 0.77) DKEFS design fluency repetitions ($r = 0.70$) **Correct classification rate:** 83%.	
Social Functioning in Dementia Scale (SF-DEM)				
Sommerlad et al. (2017) [8]	Individuals with mild dementia and their caregivers	**Internal consistency:** Patient rated instrument ($\alpha = 0.62$) and caregiver rated instrument ($\alpha = 0.64$) at an acceptable level. **Interrater reliability:** Very high for overall scores on the patient rated SF-DEM (ICC = 0.99) and the caregiver rated version (ICC = 0.99) **Test-retest reliability:** Very strong for the patient rated (ICC = 0.80) and caregiver rated version (ICC = 0.89). **Population:** N = 30 dyads of individuals with dementia and family caregivers (Age_{PmD}: 66–92; Age_{carer}: 43–76)	**Content validity:** Based on qualitative expert opinions **Population:** N = 18 for focus group interview ($n = 9$ individuals with dementia interview ($n = 9$ individuals with dementia and $n = 9$ caregivers) **Construct validity:** Significant positive correlation between SF-DEM and QOL—AD in both versions at Follow-Up 2 (patient rated: $r_s = 0.47$; caregiver rated $r_s = 0.49$) **Concurrent validity:** Both SF-DEM versions demonstrated moderate concurrent validity against a single item rating overall social functioning (patient rated r = 0.42; caregiver rated r = 0.59) **Convergent validity:** moderate correlation ($r = 0.59$) between overall scores from our patient rated and caregiver rated instruments **Population:** N = 30 dyads of individuals with dementia and family caregivers	The mean patient rated SF-DEM score decreased by 1.2, whereas the caregiver rated SF-DEM increased by 0.1 points on average over a time period of 6 to 8 months, indicating responsiveness to change. Change in MMSE score for the person with dementia was not associated with SF-DEM change.
Budgett et al. (2019) [28]	Carers of individuals with dementia	Refers to Sommerlad et al. (2017) [8]: high reliability **Internal consistency:** Acceptable for each of the factors ($\alpha = 0.72 – 0.79$)	Refers to Sommerlad et al. (2017) [8]: moderate concurrent validity **Construct validity – "spending time with other people":** ADL ($r = –0.48$);	Not reported

Table 1
(Continued)

Authors	Target Population	Reliability	Validity	Responsiveness
		Population: N = 299 carers of individuals with dementia (n = 31 very mild, n = 108 mild, n = 99 moderate, n = 61 severe) Age_{PmD}: 55–98; Age_{carer}: 21–90	NPI (r = –0.23) **Construct validity – "communication with others":** ADL (r = –0.66); NPI (r = –0.36); DEMQOL-proxy (r = –0.13) **Construct – "sensitivity to others":** NPI (r = –0.45); DEMQOL-proxy (r = 0.35) **Population:** N = 299 carers of individuals with dementia (n = 31 very mild, n = 108 mild, n = 99 moderate, n = 61 severe)	

[1]refers to Brunner and Spiegel (1990); [2]from the Geriatric Rating Scale; [3]from the "semantic differential"; [4]from the Götestam scale; [5]SCAG factors which are similar in meaning and content to social behavior; [6]PLUT scale "Reduced bodily care behavior", [a]time between both interviews: 2 weeks. *results from variance component analysis; α, Cronbachs Alpha; ADL, Activities of Daily Living; bvFTD, behavioral variant frontotemporal dementia; CDR, Clinical Dementia Rating Scale; DEMQOL, Dementia Quality of Life Scale; DKEFS, Delis-Kaplan Executive Function System; EOAD, Early onset Alzheimer's Disease; FrSBe, Frontal Systems Behavior Scale family version; H, Kruskal-Wallis H test; ICC, Interclass correlation coefficient; MMSE, Mini-Mental Status Examination; NPI, Neuropsychiatric Inventory; PmD, Person with Dementia; PLUT, Geriatric observation scale of Plutchik; QoL-AD, Quality of Live in Alzheimer Disease (three social questions); r, Pearson's correlations coefficient; r_s, Spearman's Rank coefficient.

Table 2
Instruments that include items to assess social functioning (SF) in individuals with dementia

Instrument	Construct	Domains/Scales *Items that cover SF*[#]	No. Items (total/SF)	Number of response categories	Validity	Test-Retest Reliability	Interrater Reliability	Internal Consistency	Completion time[*]
Behavioral Assessment Scale [35]	Adaptive Functioning	1. Daily Living Skills **2. Communication and Social Skills** *Oral comprehension; Oral expression; Nonverbal expression; Contact with others; Awareness of Familiar Persons* 3. Problem Behavior 4. Global Functioning	32/5	for 9 items 2[1]					
Behavioral and Emotional Activities Manifested in Dementia [36]	Troublesome and disruptive behavior	**1. Target behaviors** *Hostility/Aggression; Disruption of other´s activities; Uncooperativeness* 2. Inferred behaviors	16/3	4; exception one item 3	X		X		
Behavioral Pathology in Alzheimer's Disease Rating Scale [37, 38]	Behavioral disturbance	1. Paranoid and delusional ideation 2. Hallucinations 3. Activity disturbances **4. Aggressiveness** *Verbal outburst; Physical threats and violence* 5. Diurnal rhythm disturbances 6. Affective disturbances 7. Anxieties and phobias	25/2	4	X		X		
Behavior Rating Scale for Dementia [39]	Behavioral pathology	1. Psychotic Symptoms 2. Depressive Symptoms 3. Behavioral Dysregulation 4. Irritability/Aggression *Uncooperative; Verbal aggression* 5. Inertia 6. Vegetative	48/2	for 26 items 5; for 11 items 6, for 8 items 2				X	
Behavioral Syndromes Scale for Dementia [40]	Behavioral symptoms and syndromes	**1. Disinhibition** *Has he been verbally abusive? Has he been swearing or yelling?; Has he been physically abusive toward you or others?; Has he tied to hit you or someone else?* **2. Apathy-Indifference** *Has he been interested in being with friends and relatives as he used to be?* 3. Catastrophic reactions 4. Sundowning 5. Denial 6. Other clinical features	24/3	7, except for "denial" 5	X		X	X	20–30

Table 2
(Continued)

Instrument	Construct	Domains/Scales *Items that cover SF*[#]	No. Items (total/SF)	Number of response categories	Validity	Test-Retest Reliability	Interrater Reliability	Internal Consistency	Completion time[*]
		7. Most distressing behavioral problem[2]							
CERAD Behavior Rating Scale for Dementia [41]	Psychopatho-logic signs and symptoms	1. Depressive Features 2. Psychotic Features 3. Defective Self-Regulation 4. Irritation/Agitation 5. Vegetative features 6. Apathy **7. Aggression** *Verbal aggression; Physical aggression* 8. Affective lability	51/2	for 5 items 2; for 46 items 7	X	X			20-45
Dementia Behavior Disturbance Scale [42, 43]	Behavioral symptoms	*Makes physical attacks (e.g., hits, bites, scratches, kicks, or spits)*	28/1	5	X	X		X	
Disruptive Behavior Rating Scale [44]	Disruptive Behavior	**1. Physical aggression** *Hitting; Kicking; Biting; Spitting; Other physical Aggression* **2.Verbal aggression** *Other verbal aggression* 3. Agitation 4. Wandering	21/6	5	X		X		
Empirical Behavioral Pathology in Alzheimer's Disease Rating Scale [45]	Behavioral symptoms	1. Paranoid and delusional ideation 2. Hallucinations 3. Activity disturbance **4. Aggressively** *Verbal outburst; Physical threats and violence* 5. Affective disturbance 6. Anxieties and phobias	12/2	4			X		20
Geriatric Rating Scale [46]	Level of functioning	*The patient communicated in any manner (by speaking, writing, or gesturing) well enough to make himself easily understood; The patient will begin conversations with others; Without being asked, the patient physically helps other patients; The patient talks with other people on the ward; The patient verbally threatens to harm other patients or staff; The patient physically tries to harm other patients or staff*	31/6	3	X		X		

(Continued)

Table 2
(Continued)

Instrument	Construct	Domains/Scales *Items that cover SF*[#]	No. Items (total/SF)	Number of response categories	Validity	Test-Retest Reliability	Interrater Reliability	Internal Consistency	Completion time[*]
Manchester and Oxford Universities Scale for the Psychopathological Assessment of Dementia [47]	Psychopathological and behavioral changes	1. Delusion 2. Hallucinations 3. Misidentifications 4. Reduplications 5. Walking 6. Eating 7. Sleep 8. Sexual behavior **9. Aggression** *Has she been physically or verbally aggressive since onset of memory problems (more aggressive than before onset of dementia)?* 10. Other types of behavior in the last month	59/1	4	X	X	X		
Nursing Home Behavior Problem Scale [48]	Behavioral problems	**11. Uncooperative or aggressive behavior** *Fights or is physically aggressive: hits, slaps, kicks, bites, spites, pushes, pulls* **12. Irrational or restless behavior** *Says things that do not make sense* 13. Sleep problems 14. Annoying behavior 15. Inappropriate behavior 16. Dangerous behavior	29/2	5	X		X		3–5
Present Behavioral Examination [49]	Abnormal behavior	1. Mental health 2. Walking (activity disturbance) 3. Eating 4. Diurnal rhythm **5. Aggressive behavior**[○] 6. Sexual behavior 7. Incontinence 8. Individual behavioral abnormalities	187 [3]/[4]	7		X	X		
Problem Behavior Inventory [50]	dementia-related problem behavior	1. Mood **2. Verbal** *Being verbally aggressive or abusive to you or others* 3. ADL Related **4. Physical** *Seeking attention; Being physically aggressive to you or others*	24/3 21/19	5 4	X 	 X	 X		20

Table 2
(Continued)

Instrument	Construct	Domains/Scales *Items that cover SF*[#]	No. Items (total/SF)	Number of response categories	Validity	Test-Retest Reliability	Interrater Reliability	Internal Consistency	Completion time[*]
Rating Scale for aggressive Behavior [51]	Aggressive Behavior	*Been demanding or argumentative; Shouted, yelled or screamed; Sworn or used abusive language; Disobeyed ward rules, e.g., deliberately passed urine outside the commode; Been uncooperative or resisted help, e.g., while being given a bath or medication; Been generally in a bad mood, irritable or quick to fly off the handle; Been critical, sarcastic or derogatory, e.g., saying someone is stupid or incompetent; Been impatient or got angry if something does not suit him/her; Threatened to harm or made statements to scare others; Indulged in antisocial acts, e.g., deliberately stealing food or tripping someone; Pushed or shoved others; Destroyed property or thrown things around angrily, e.g., towels, medicines; Been angry with him/herself; Attempted to kick anyone; Attempted to hit others; Attempted to bite, scratch, spit at, or pinch others; Used an object (such as a towel or a walking stick) to lash out or hurt someone); In the past 3 days, has the patient inflicted any injury on others?; Taking all factors info consideration, do you consider the patient's behavior in the last 3 days to have been aggressive?*							
Revised Index for Social Engagement [52]	Social engagement	*At ease interacting with others; Initiates interaction with others; Reacts positively to interactions by others*	6/3	2	X	X	X		
Revised Memory and Behavioral Problem Checklist [53]	Behavioral problems	1. Memory related 2. Depression **1. Disruptive behaviors** *Threats to hurt others; Aggressive to others verbally; Arguing, irritability, and/or complaining*	24/3	5	X			X	

(Continued)

Table 2
(Continued)

Instrument	Construct	Domains/Scales *Items that cover SF*[#]	No. Items (total/SF)	Number of response categories	Validity	Test-Retest Reliability	Interrater Reliability	Internal Consistency	Completion time*
Revised Memory and Behavioral Problem Checklist – Nursing Home [54]	Problem behavior	Behavior problem frequency questions: 1. Memory related 2. Emotional **3 Disruption** *e.g., How often has your resident engaged in combative behavior (hitting, scratching, or biting)?* [4] Burden questions: 1. Care-related 2. Social-emotional	42/[4]	6 for behavior frequency questions and 5 for burden questions	X	X	X	X	
Social-Adaptive Functioning Evaluation [55]	Crucial adaptive functions	*Conversational skills; Social Appropriateness/Politeness; Social engagement; Friendships*	17/4	4	X	X	X	X	
The Columbia University Scale for Psychopathology in Alzheimer's disease [56]	Neuropsy chiatric symptoms	1. Delusion 2. Hallucinations 3. Illusions **4. Behavioral Disturbances** *Has he/she made verbal outbursts?; Has he/she physical threats and/or violence?* Depression	56/2	2, except for "depression" 5	X		X		10–25
Ward Function Inventory [57]	Self help and other skills relevant to the geriatric inpatient population	*Socialization; Inappropriate behavior; Verbal skills*	12/3	5, except for two items 3	X		X		

SF, social functioning; [#] Domains and/or subscales are listed in numbered order. Below them, items relevant for SF are listed in italics. Individual items are separated by a semicolon. If an instrument has no subscales, only the items are listed (in italics). Subscales that contain relevant items are printed in bold; *in minutes; X: indicate quality criterion was tested; [1]No information about the number of answer categories of the other items; [2]qualitative question; [3]121 main questions and 66 nested questions; [4]detailed list of items is not freely available.

The will to change is assessed by asking if the individual desires to change their SF on a three-point Likert scale. The SF-DEM refers to the past four weeks.

Information on the instruments' ease of use for individuals with dementia were found for NOSGER and SF-DEM. Regarding the NOSGER, short interviews with 42 relatives and caregivers were conducted to determine user acceptance and feasibility. In short discussions, it was determined to what extent the format of the NOSGER was acceptable and whether there were concerns or objections to individual terms. No concerns were expressed about the scale "social behavior" [23]. Wahle et al. (1996) confirmed these findings. The percentage of positive feedback given by individuals with mild dementia (87% acceptance) and individuals with moderate dementia (79% acceptance) was very high [27] Regarding the SF-DEM, based on a survey of 30 dyads, consisting of a person with dementia and a relative each, Sommerlad et al. (2017) showed that 62% rated the SF-DEM acceptable and 38% very acceptable. There were no floor or ceiling effects, and all study participants were able to answer the questions of the self- and proxy version, respectively [8]. The acceptance of the proxy version of the SF-DEM was confirmed in a second study [28].

Psychometric properties

Psychometric properties concerning reliability, validity, and responsiveness were available for all three instruments in regard to the application in individuals with dementia. Details are given in Table 2.

The validity (concurrent) and reliability (test-retest and interrater) of the NOSGER scale "social behavior" have been tested. Spiegel et al. (1991) show high and meaningful correlations of the "social behavior" scale with external criteria measuring the same or related areas indicating concurrent validity [25], as summarized in Table 1. The interrater and the test-retest reliability showed high values in very different settings and groups of patients. Wahle et al. (1996) showed significant differences in the results of the scale "social behavior" between healthy older individuals, individuals with mild dementia, individuals with serve dementia and elderly patients with depression [27]. The classification rate was at an acceptable level for this scale [29]. Responsiveness of individuals with dementia was demonstrated for the NOSGER. The study of Tremmel and Spiegel (1993) showed a moderate correlation between changes in the NOSGER scale "social behavior" and independent physicians' overall assessments of treatment efficacy following a multicenter drug trail. In addition, they reported a moderate correlation between changes in the scale "social behavior" and the Mini-Mental Status Examination (MMSE) score, a test for cognitive impairment, assessed at baseline and at least three months later [30]. The rather short follow-up period may indicate that several different factors rather than the cognitive decline contribute to change in SF in individuals with dementia.

There was evidence for the validity (convergent and divergent) and reliability (internal consistency) of the SDS. The scale demonstrated preliminary evidence for discriminating between individuals with bvFTD and early-onset Alzheimer's disease (EOAD). Furthermore, the SDS correlated strong with measures of conceptually similar constructs like judgment, community involvement, personal care, behavior, personality, apathy, disinhibition, elation, agitation, and irritability, which indicates convergent validity. The SDS also shows divergent validity as it can be differentiated from other concepts such as depression, anxiety, and delusion. The SDS total score did not correlate with proxy reports of measures of memory or orientation. Furthermore, the SDS did not significantly correlate with the majority of a range of cognitive tests except for one subscore of repetition errors on design fluency [24].

There was evidence for the validity (convergent, construct, content, and concurrent) and reliability (test-retest, interrater, and internal consistency) of the SF-DEM (see Table 1 for an overview). Sommerlad et al. (2017) found a moderate positive correlation between the SF-DEM total score and questions that measure a conceptually similar construct for both, the self-report and the proxy version [8]. This finding is an indication for convergent validity of both versions of the SF-DEM. Testing the construct validity of the proxy version, the domains "spending time with other people" and "communicating with other people" were correlated with levels of dependence as measured by the Bristol Activities of Daily Living (B-ADL) scale. All three domains were inversely correlated with neuropsychiatric symptoms. Only the item "sensitivity to others" was significantly correlated with quality of life. But this correlation was inversely as expected. Content validity was measured for both versions of the SF-DEM. They have shown to be good and reasonable, respectively based on qualitative opinions by interviewing study participants, both individuals with dementia and caregivers, in a focus group. Sommerlad et al. (2017) reported a

moderate correlation between the patient or caregiver rated total score of the SF-DEM and their overall impression of the person's "social life" indicates SF-DEM's concurrent validity [8]. The agreement between patient and caregiver ratings supports the validity of the instrument. Moreover, they found preliminary evidence for the responsiveness of the instrument to measure changes in SF over time (repeated testing after an average of 7.2 months). In addition, there were indications that the question of the change in SF compared to a year ago predicts the SF-DEM score. However, changes in MMSE scores, i.e., cognitive impairment, in persons with dementia were not associated with changes in SF-DEM scores.

Instruments with relevant items

In addition to the three instruments presented, we have identified a number of other instruments that include SF as part of more comprehensive constructs, such as neuropsychiatric symptoms, problem behavior, and inappropriate behavior. These instruments cover SF either with single items or a number of items. Mostly, single items cover aggressive behavior. In all but one instrument, SF only plays a minor role. Table 2 provides an overview about these instruments with emphasize on the SF items.

DISCUSSION

We systematically reviewed the literature for instruments that are applicable for the assessment of SF in individuals with dementia. Such instruments are important in order to support a timely diagnosis of dementia and to better understand the course of the disorder. Reliable and valid instruments are also important for evaluating the effectiveness of different interventions.

Our systematic review identified three instruments to assess SF in individuals with dementia (NOSGER Scale "social behavior" [23, 25, 29, 27, 30], SDS [24], and the SF-DEM [8, 28]). Detailed information regarding the feasibility and the psychometric properties of the instruments were provided, if available.

The scale "social behavior" from the NOSGER is short, which allows for quick assessments. Furthermore, the NOSGER was psychometrically tested (concurrent validity, test-retest, and interrater reliability) in different settings with different groups of elderly, which supports a broad application. It can be used to assess SF in individuals with any degree of dementia and is particularly helpful for individuals with AD. However, SF is not assessed as comprehensive as in the other two questionnaires: First, the SF-DEM consists of various subscales that comprehensively assess SF. It is the only questionnaire that can be completed by the individual with dementia or a proxy. In addition, it is the only questionnaire that also records changes in SF over time and asks about satisfaction with social life and the desire for change. This instrument was developed for individuals with dementia of any subtype. Specifically, it has been tested in individuals with mild dementia in regard to the self-report version, while the proxy-report version has also been tested in moderate to severe dementia. Comprehensive information about validity (convergent, construct, content, and concurrent) and reliability (test-retest, interrater and internal consistency) is available. The SF-DEM can be used for and the evaluation of interventions. It is also possible to track decline in SF in the context of disease progression. In addition to the SF-DEM, the SDS also provides comprehensive coverage of SF, whereby some of its items rather represent prerequisites for SF by covering socio-emotional changes including theory of mind. It can be used to assess SF in individuals with mild dementia. Therefore, it is possible to distinguish between individuals with EOAD and bvFTD on the basis of the results from SDS, which is not feasible using the SF-DEM. The SDS questionnaire is thus primarily relevant for clinical and diagnostic use. Currently there are estimates on the convergent and divergent validity and internal consistency, but there are no findings on test-retest reliability and interrater reliability of the SDS. The NOSGER and SF-DEM showed high values for the test-retest and interrater reliability. These instruments thus measure SF independently of the rater.

Besides the above discussed instruments, we have found a number of other instruments that include items to assess SF as part of a more comprehensive construct. The majority of these instruments address a range of neuropsychiatric symptoms (e.g., aggression, agitation, wandering, yelling, repetitive behavior, etc.). Because single items of these instruments may only cover aspects of SF as opposed to measures such as the SF-DEM, which provide a comprehensive understanding of multiple facets of SF, these instruments may give rather limited information about SF in individuals with dementia. Therefore, instruments like the NOSGER scale "social behavior" and the SF-DEM seem more suitable, specifically as these instruments have been psychometrically tested.

Strengths and limitations

Our systematic review is, to the best of our knowledge, the first to provide an overview about instruments to assess SF in individuals with dementia. Our literature search was broadly diversified by using three databases. This ensured that as many relevant articles as possible were found. Only articles from peer-reviewed journals were considered. This procedure should make sure that the basic scientific quality of the studies that were included was given.

Nevertheless, there are also limitations in our study. First, it is possible that we missed relevant articles that were not covered by our search terms. Therefore, we additionally searched the references of potentially eligible articles. A second limitation concerns the restriction of the language of the selected articles: we were only able to consider articles in English or German language. Consequently, we may have missed instruments or versions of instruments published in different languages.

Further research and recommendations

Overall, the number of instruments to assess SF or aspects of SF in individuals with dementia was small. Moreover, the SF-DEM and the SDS are currently only available in English language. However, valid and reliable instruments to assess SF in individuals with dementia should also be available in different languages, for assessment in culturally different populations. Therefore, it is necessary to make progress toward adapting original instruments with promising psychometric properties for different languages. Moreover, specific inspection of the applicability of promising instruments could be tested in regard to different stages of disease progression, including more severe dementia, but also pre-stages and prodromal stages. This would be especially interesting to describe change in SF in relation to disease progression. Different types of dementia should be targeted as well. Currently, there is no instrument for SF specifically for individuals with AD. This is despite the fact that this is the most common of all dementias. It would be worthwhile to consider whether such a specific instrument would be useful. It could include aspects of personality and social changes, such as rigidity, self-centeredness, and limitations of social control, but also limitations in emotional recognition. There is evidence that such changes can occur in the preclinical and prodromal stages of AD [31, 32].

CONCLUSION

There are a few instruments to comprehensively assess SF in individuals with dementia, of which two instruments have been found to be psychometrically sound in regard to the considered populations (the NOSGER and the SF-DEM). Further reliability and validation studies would be useful in regard to instrument applicability in individuals at different stages of dementia including pre- and prodromal stages as well as different types of dementia. Studies that inspect the reliability of SDS would be valuable. Adaptations of standardized original instruments into other languages and cultural settings would be highly useful. Such adaptations should include examining the content of the questions in the questionnaire with regard to cultural differences, as social conventions and habits can differ in different societies [33, 34]. Having reliable standardized instruments to measure SF in individuals with different types of dementia is a prerequisite to driving our understanding and knowledge about the role of SF in any type of dementia. Research on the social aspects, especially SF in different types of dementia, is still incipient (except for bvFTD and LBD). Further questionnaires to assess specific aspects of SF depending on the type of dementia are necessary to gain a comprehensive understanding of this largely unexplored topic.

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SUPPLEMENTARY MATERIAL

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2.2. Psychometric evaluation of the German version of the Social Functioning in Dementia Scale (SF-DEM)

Grothe, J., Luppa, M., Dietzel, J., Schomerus, G., Sommerlad, A., Riedel-Heller, S. G., & Röhr, S. (2022). Psychometric Evaluation of the German Version of the Social Functioning in Dementia Scale (SF-DEM). *Journal of Alzheimer's Disease*, 7, 1–11.

Background: Dementia is one of the most common and most severe disorder in old age. In addition to cognitive decline and functional impairment, changes in social functioning occur in the course of dementia. Currently, there is no valid instrument in German language to assess social functioning in individuals with dementia.

Objective: We aim to adapt and psychometrically evaluate a German version of the Social Functioning in Dementia Scale (SF-DEM).

Methods: First, a multi-step and team-based translation process based on the TRAPD model was performed. Second, we interviewed dyads of individuals with mild dementia and caregivers to test the internal consistency, test-retest reliability, interrater reliability, construct validity and acceptance of the German version of the SF-DEM.

Results: The internal consistency of the patient-rated ($\alpha = 0.72$) and the caregiver-rated ($\alpha = 0.76$) SF-DEM is at an acceptable level. The interrater reliability was excellent for both versions (patients: ICC = 0.98, CI [0.95-0.99]; caregiver: ICC = 0.95, CI [0.89-0.98]) and the test-retest reliability was moderate (patients: ICC = 0.57, CI [0.26-0.77]; caregiver: ICC = 0.58, CI [0.27-0.78]). Caregiver-rated SF-DEM correlated strong with LSNS-6 ($r_s = 0.60$, $p < .01$), QoL-AD (marriage: $r_s = 0.61$, $p < .01$; friends: $r_s = 0.51$, $p = .01$). In addition, the SF-DEM was accepted by the participants.

Conclusion: The German SF-DEM is a valid, reliable and acceptable instrument to assess social functioning in individuals with dementia. Further research should address the psychometric properties in individuals with more severe dementia.

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Psychometric Evaluation of the German Version of the Social Functioning in Dementia Scale

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Abstract.
Background: Dementia is one of the most common and most severe disorder in old age. In addition to cognitive decline and functional impairment, changes in social functioning occur in the course of dementia. Currently, there is no valid instrument in German language to assess social functioning in individuals with dementia.
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Conclusion: The German SF-DEM is a valid, reliable, and acceptable instrument to assess social functioning in individuals with dementia. Further research should address the psychometric properties in individuals with more severe dementia.

Keywords: Acceptance, dementia, measure, psychometrics, questionnaire, reliability, scale, SF-DEM, social functioning, validity

INTRODUCTION

In addition to cognitive impairment that limits the independent performance of everyday functional activities, social functioning (SF) is a characteristic feature of dementia and is defined as "how individuals associate and interact, both in society at large and their own personal environment" [1]. It causes the

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patient to lose interest in previously enjoyed hobbies or to experience changes in their close relationships [2], which are distressing for both the patient and their family and friends. The COVID-19 pandemic has renewed the focus on the importance of social functioning for all people, but especially those with dementia who are at a greater risk of isolation [3].

The assessment of SF in dementia is important for early detection, diagnosis, description of the course of disease, and evaluation of intervention effects. It also facilitates the development of psychosocial therapies and preventive interventions. However, this assessment requires valid and reliable instruments. Currently, measures, specifically designed to assess SF in individuals with dementia, are lacking [4].

To fill this gap, Sommerlad et al. developed and psychometrically evaluated the Social Functioning in Dementia Scale (SF-DEM) [2], a patient- or caregiver-reported scale to measure SF in individuals with mild dementia. Both versions of the assessment include 3 sections, derived from factor analysis, on different aspects of SF [5]. The first section, "spending time with other people" includes the frequency of contact with family members and participation in activities or events with others. The second section, "communication with other people", includes frequency of general and personal conversations with others. The third section, "sensibility to other people" includes possible difficulties in interaction with others, such as problems following conversations, arguments, and aggression, or a desire for social withdrawal. An additional and overarching section asks global questions about SF: How about your social life as a whole? How is it compared to a year ago? Is a change in your social life desired? Altogether, the questionnaire comprises 20 items for patient- and/or caregiver-report. All questions are simple and precise and are answered via pre-defined four-point Likert scale answering categories. The reference period is one month.

Currently, no comparable psychometrically tested instrument exists to assess SF in individuals with dementia in German language, and our previous systematic review found the SF-DEM to be the most promising social functioning instrument in dementia [4]. Germany has one of the oldest and fastest aging populations in the world [6] and therefore a high number of people living with dementia as well as a projected increase of cases over the coming decades. While currently 1.6 million Germans are living with dementia, this is expected to almost double by 2050 [7]. Already, this is associated with high health care costs [8]. Instruments to assess SF are thus needed in Germany as well as other German speaking regions with similar demographic developments (i.e., Austria and Switzerland).

Therefore, the aims of this study were: 1) translation of the SF-DEM into German and 2) psychometric evaluation of the German version ("Sozialfunktionen bei Demenz–Fragebogen"/SF-DEM).

METHODS

Ethics

This work was approved by the Ethics Committee of the Medical Faculty of the University of Leipzig (ref: 401/19-ek). Participants were informed about the aims of the study. They provided written informed consent prior to enrolment.

Translation process

We performed a multi-step and team-based translation process using the TRAPD model (Translation, Review, Adjudication, Pretesting, and Documentation) (Fig. 1) [9, 10]. Several individuals were involved over several stages for optimization of the translation process. First, the original English SF-DEM was translated into German and back into English by two independent professional translators certificated according to the norms DIN EN 15038 and ISO 1700. Second, these two versions were reviewed, discussed, and agreed upon by SR and JG. This resulted in a preliminary German version.

As part of the pretesting, the content validity of the preliminary version was evaluated, and we con-

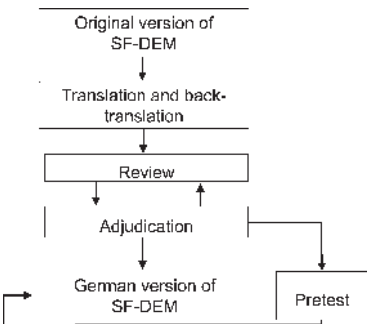

Fig. 1. Translation of the SF-DEM based on the TRAPD-model (according to Harkness [9]).

sidered the need for changes to the SF-DEM to make suitable for application to individuals with mild dementia. For this purpose, the research team members were interviewed. However, no adjustments were found to be necessary.

Recruitment and participants

Participants were enrolled at the memory day clinic of the University Hospital, Leipzig (Germany), with the goal to reach a sample size of 30 dyads. We included individuals with mild dementia of any subtype (clinical diagnosis was made by a physician according to ICD-10 [11]), of mild severity (Mini-Mental State Examination (MMSE) score $\geq$ 20), aged $\geq$ 65 years. Individuals with moderate severity of dementia were also included (MMSE score $\geq$ 18), if they are able to answer the questions. We excluded those with severe physical conditions or mental disorders, limiting their participation in the interviews, or those who were unable to give informed consent. For each individual with dementia, we included a German-speaking caregiver, aged $\geq$ 18 years, in contact with the patient at least weekly, so that they could give an accurate appraisal of the patient's current level of social functioning.

Of the 40 dyads contacted, 33 agreed to participate in the study. A total of five dyads were excluded from the analysis because of the high severity of cognitive impairment (MMSE score < 18) (Fig. 2 and Supplementary Table 1). This resulted in a final sample of 28 participating dyads. All participants, except for one dyad, consented to their interviews being audio recorded to allow assessment of scale reliability. For this purpose, the SF-DEM was completed by another interviewer, based on audio records.

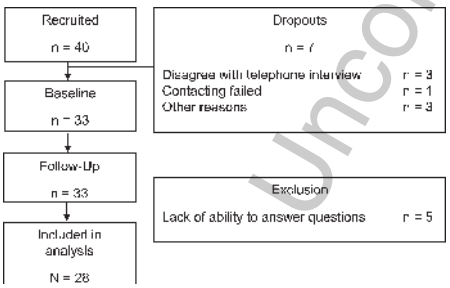

Fig. 2. Flowchart - Flowchart - recruitment and analytic sample selection.

The recruitment period was from October 2019 to December 2020, with face-to-face data collection from December 2019 to March 2020. Due to the COVID-19 pandemic, interviews were conducted by telephone (from April 2020; baseline: $n = 11$; follow-up: $n = 13$; Supplementary Table 2).

Measures

Structured interviews were conducted twice (baseline and after four weeks). During the interviews, the section containing the SF-DEM was audio-recorded. The baseline interviews included standardized questions on sociodemographic data, the SF-DEM, cognitive and functional tests, as well as questions related to SF, detailed below.

Sociodemographic data included age, sex, marital status, education, and living situation, among others. In order to evaluate the content validity, participants were asked Likert-scale questions about the acceptance of the SF-DEM (very acceptable, acceptable, unacceptable, and very unacceptable) and its clarity, length, and structure of the total questionnaire, and whether the length of single items was acceptable (yes/no; comments). They were also invited to make general comments about the questionnaire.

BASELINE MEASURES FOR PEOPLE WITH MILD DEMENTIA

The MMSE was used to gather information about the cognitive status [12, 13]. It consisted of 11 questions and tasks regarding orientation, recall, and visual construction. Higher scores indicated better overall cognitive function. The maximum score was 30.

For the patient's everyday functions or functional independence, the Barthel index was determined by questioning individuals with mild dementia about 10 basic activities of daily living (ADL) (for example, personal hygiene, food intake, and toilet use). The maximum score of 100 reflected maximum independence [15].

Moreover, eight Instrumental Activities of Daily Living (IADL) were assessed using the Lawton & Brody IADL scale [16], which included the ability to use a telephone and transportation (car, bus, train), and the ability to manage financial matters. The score ranged from 0–8; a higher score indicated higher independence.

Baseline measures for people with mild dementia and their caregivers

The short version of the Lubben Social Network Scale (LSNS-6) was used to get information about the social network size [17]. It contained the number and frequency of contacts with friends and family and the support received by them. Each of the six items had scores ranging on a scale of 0–5, and the total score ranged from 0–30; higher scores indicated larger social networks.

Selected questions from the ENRICHD Social Support Inventory (ESSI) [18] were used to measure perceived emotional social support. The five questions were rated on a five-point Likert scale. The score was calculated as the sum of all items and could have values between 5 and 25. Higher values represented a stronger level of social support.

Furthermore, selected questions of the Quality of Life in Alzheimer's Disease (QoL-AD) [19] were used to assess the patient's current social situation with family, marriage, and friends using a four-point Likert scale ("poor" to "excellent").

Impairments in social activities due to memory difficulties were rated using questions of the health status questionnaire (SF-36). Ratings were based on a five-point Likert scale ("always" to "never") [20].

Assessments at follow-up

The follow-up interviews after four weeks contained the SF-DEM and a question on whether anything considered significant by the person with dementia or caregiver had occurred between baseline and follow-up. Individuals with mild dementia conducted the MMSE again.

Analysis

Descriptions of sample characteristics were calculated. We assessed internal consistency using Cronbach's α. Spearman's rank coefficient was calculated to determine item-total and item-item reliability. We tested inter-rater and test-retest reliability for the total SF-DEM score based on the intraclass correlation coefficient (ICC) [21], using the (2,1) model for inter-rater reliability, the (1,1) model [22] for test-retest reliability, and inter-rater and test-retest agreement on item level using Cohen's k [23].

In order to determine construct validity, we calculated Spearman's rank coefficient based on the correlation of SF-DEM scores and ordinal data from SF-36, QoL-AD, LSNS-6, and ESSI. Moreover, we calculated ICC for agreement between the patient and the caregiver.

STATA 16 was used for statistical analysis [24]. All analyses employed an α-level for statistical significance of 0.05 (two-tailed).

RESULTS

Sample characteristics

Table 1 shows sociodemographic and clinical characteristics of the 28 dyads included in the analysis. Individuals with mild dementia had a mean age of 77.54 (SD = 4.53) years, and 57.14% were women. Majority of the participants were married at the time of the interview (82.14%) and lived with their respective partner or spouse in private households (64.29%). The majority of them had completed polytechnic secondary school and half had completed an apprenticeship (78.57%; 50.00%). Functional ability was largely intact ($M_{ADL} = 94.64$, $SD_{ADL} = 8.81$; $M_{IADL} = 5.28$, $SD_{IADL} = 2.24$). The mean MMSE score was 21.21 (SD = 2.36).

Caregivers were mostly spouses of the individuals with mild dementia (75.00%) and were in daily contact with them (89.29%). Their mean age was 69.14 (SD = 11.56) years, and 57.14% were females, married (85.17%), and had completed polytechnic secondary school (64.29%) and an apprenticeship (42.86%).

SF-DEM results

Table 2 shows details of the mean and range of response scores of the participants to the SF-DEM items. Individuals with mild dementia used the full range of possible responses for eight and the caregivers for seven questions of the SF-DEM. The overall rating by individuals with mild dementia was higher than that of the caregivers' (mean difference = 2.07, 95% CI [0.28–3.86], $p = 0.02$). A significant difference was found only in the subscale "sensitivity to other people" (mean difference = 1.07, 95% CI [0.22–1.92], $p = 0.02$). The scores of the other two subscales of caregiver ratings did not differ significantly from patient ratings.

Acceptability

Across all dyads, the SF-DEM was rated as acceptable or very acceptable. Moreover, all dyads rated the questionnaire as clearly understandable. The major-

Table 1
Characteristics of participants

Characteristics	Patients ($n = 28$)	Caregivers ($n = 28$)
Female sex *(n (%))*	16 (57.14)	16 (57.14)
Age (*M* (*SD*))	77.54 (4.53)	69.14 (11.56)
Marital status (*n (%)*)		
Married	23 (82.14)	24 (85.71)
Single	0 (0)	2 (7.14)
Divorced	1 (3.57)	2 (7.14)
Widowed	4 (14.29)	0 (0)
Living situation of patient (*n (%)*)		
Lives alone	8 (28.57)	–
Living with spouse/partner	18 (64.29)	–
Living with other family	1 (3.57)	–
Living with others	0 (0)	–
Assisted living	0 (0)	–
Retirement homes	1 (3.57)	–
Nursing home	0 (0)	–
Level of education (*n (%)*)		
No school graduation	0 (0)	0 (0)
General elementary education	1 (3.57)	1 (3.57)
Polytechnic secondary	22 (78.57)	18 (64.29)
Advanced technical college High school graduation	5 (17.86)	9 (32.14)
Other	0 (0)	0 (0)
Level of professional education (*n (%)*)		
None	3 (10.71)	0 (0)
Completed apprenticeship	14 (50.00)	12 (42.86)
Specialists/technicians or master school	3 (10.71)	5 (17.86)
Polytechnic degree or university degree	8 (28.57)	10 (35.71)
Postgraduate degree or doctorate	0 (0)	1 (3.57)
Other	0 (0)	0 (0)
Cognitive status* (*M* (*SD*))	21.21 (2.36)	–
ADL (*M* (*SD*))	94.64 (8.81)	–
I-ADL (*M* (*SD*))	5.28 (2.24)	–
Relationship to caregiver		
Spouse	–	21 (75.00)
Child, child-in-law	–	7 (25.00)
Frequency of contact between patient and caregiver *(n (%))*		
Daily	–	25 (89.29)
More than 2-3 times/week	–	1 (3.57)
2-3 times/week	–	2 (7.14)
1 time/week	–	0 (0)
2-3 time/month	–	0 (0)
1 time/month	–	0 (0)
Rarer than 1 time/month	–	0 (0)

*Mini-Mental Status Examination. ADL, Activities of Daily Living; I-ADL, Instrumental Activities of Daily Living; M, Mean; SD, standard deviation.

ity of participants stated that the overall length of the questionnaire was adequate (individuals with mild dementia: 96.43%; caregivers: 92.86%). The length of the items was judged as appropriate by all respondents. The majority approved the four response options as being adequate (individuals with mild dementia: 96.43%; caregivers: 89.29%).

The average time to complete the SF-DEM was 11.56 minutes (SD = 5.24) for the patient-report and 9.21 minutes (SD = 4.12) for the caregiver-report.

Only a few participants made additional comments. For example, it was noted that the SF-DEM might be unsuitable for individuals with more severe dementia (due to the length and language of the SF-DEM). However, the comments did not give enough reason to make adjustments to the SF-DEM.

Internal consistency

Consistency of the patient-rated ($\alpha = 0.72$) and caregiver-rated ($\alpha = 0.76$) instruments was acceptable (see Supplementary Table 3 for internal consistency of subscales) [25]. A total of five items in the patient-rated instrument (1, 3, 4, 12, 14) and five in the

Table 2
Summary of participants' responses to the German SF-DEM at baseline

SF-DEM domain: How often in the past month have you/they . . .	Patient version ($n = 28$)				Caregiver version ($n = 28$)			
	n (%)				*n (%)*			
	Very often	Often	Occasionally	Never	Very often	Often	Occasionally	Never
Spending time with other people								
1. Seen friends or family in own home	20 (71.43)	8 (28.57)	0 (0)	0 (0)	19 (67.86)	7 (25.00)	1 (3.57)	1 (3.57)
2. Visited friends or family at their homes	1 (3.57)	7 (25.00)	10 (35.71)	10 (35.71)	0 (0)	11 (39.29)	8 (28.57)	9 (32.14)
3. Attended community or religious meetings*	0 (0)	0 (0)	2 (7.41)	25 (92.59)	0 (0)	26 (92.86)	1 (3.57)	1 (3.57)
4. Gone shopping with friends or family	1 (3.57)	18 (64.29)	4 (14.29)	5 (17.86)	0 (0)	18 (64.29)	3 (10.71)	7 (25.00)
5. Gone on trips or to events like the cinema or talks	0 (0)	7 (25.00)	5 (17.86)	16 (57.14)	0 (0)	6 (21.43)	8 (28.57)	14 (50.00)
6. Gone to a cafe, restaurant, pub, or social club	0 (0)	8 (28.57)	5 (17.86)	15 (53.57)	0 (0)	11 (39.29)	7 (25.00)	10 (35.71)
7. Exercised, walked, or played sport with others	7 (25.00)	13 (46.43)	2 (7.14)	6 (21.43)	5 (17.86)	15 (53.57)	4 (14.29)	4 (14.29)
Communication with other people								
8. Contacted friends or family by phone or computer	3 (10.71)	13 (46.43)	9 (32.14)	3 (10.71)	5 (17.86)	12 (42.86)	4 (14.29)	7 (25.00)
9. Started or taken part in a conversation	24 (85.71)	4 (14.29)	0 (0)	0 (0)	22 (78.57)	6 (21.43)	0 (0)	0 (0)
10. Talked to others about your/their feelings or concerns	5 (17.86)	7 (25.00)	5 (17.86)	11 (39.29)	2 (7.14)	8 (28.57)	10 (35.71)	8 (28.57)
11. Asked other people about their feelings or concerns	0 (0)	8 (28.57)	8 (28.57)	12 (43.86)	0 (0)	8 (28.57)	9 (32.14)	11 (39.29)
12. Found it difficult to think of something to say to others	0 (0)	2 (7.14)	2 (7.14)	24 (85.71)	0 (0)	7 (25.00)	6 (21.43)	15 (53.57)
13. Found other people's conversation unclear	2 (7.14)	1 (3.57)	2 (7.14)	23 (82.14)	2 (7.14)	3 (10.71)	10 (35.71)	13 (46.43)
Sensibility to other people								
14. Been outspoken about what you/they really think	2 (7.14)	5 (17.86)	3 (10.71)	18 (64.29)	1 (3.57)	11 (39.29)	4 (14.29)	12 (42.86)
15. Found that other people are irritating	0 (0)	3 (10.71)	3 (10.71)	22 (78.75)	1 (3.57)	4 (14.29)	6 (21.43)	17 (60.71)
16. Had an argument or shouted at other people	0 (0)	1 (3.57)	4 (14.29)	23 (82.14)	0 (0)	8 (28.57)	3 (10.71)	17 (60.71)
17. Found they don't want to do things you/they would usually	1 (3.57)	4 (14.29)	10 (35.71)	13 (46.43)	0 (0)	7 (25.00)	6 (21.43)	15 (53.57)
	M (SD)		Range		*M (SD)*		Range	
Summary scores								
Section 1 "Spending time with other people" (1–7)	8.48 (2.68)		4 – 14		8.64 (2.67)		4 – 13	
Section 2 "Communication with other people" (8–13)	11.93 (2.26)		7 – 16		10.86 (3.22)		5 – 17	
Section 3 "Sensibility to other people" (14–17)	10.04 (2.06)		4 – 12		8.96 (1.95)		5 – 12	
Total	30.43 (4.62)		20 – 40		28.36 (4.79)		19 – 36	
	Patient rated ($n = 28$)				Caregiver rated ($n = 28$)			
	n (%)				*n (%)*			
	Excellent	Good	Fair	Poor	Excellent	Good	Fair	Poor
Thinking about your/their social life as a whole, how is it now?	2 (7.14)	21 (75.00)	5 (17.86)	0 (0)	1 (3.57)	12 (42.86)	12 (42.86)	3 (10.71)
	A lot better	A bit better	No change	A bit worse	A lot better	A bit better	No change	A bit worse	A lot worse
How is it now compared to 1 year ago?	4 (14.29)	2 (7.14)	14 (50.00)	6 (21.43)	2 (7.14)	0 (0)	3 (10.71)	9 (32.14)	10 (35.71)	6 (21.43)
	Rather do more		No change needed		Rather do less	Rather do more		No change needed		Rather do less
Would you like your/their social life to change?	14 (50.00)		14 (50.00)		0 (0)	19 (67.86)		9 (32.14)		0 (0)

*missing values: $n = 1$. SF-DEM, German version of SF-DEM; M, mean; SD, standard deviation. For each question, higher score indicates better social functioning. For questions 1–11:0 = never, 1 = occasionally, 2 = often, 3 = very often. 12–17:0 = very often, 1 = often, 2 = occasionally, 3 = never.

Table 3
Summary of psychometric properties for items of the German SF-DEM

Psychometric property	Item-total correlation		Interrater reliability		Test-retest reliability		Convergent validity: patient-caregiver agreement
Statistic	Spearman's *r*		Cohen's *k*		Cohen's *k*		Cohen's *k*
SF-DEM domain	Patient rated	Caregiver rated	Patient rated	Caregiver rated	Patient rated	Caregiver rated	
Spending time with other people							
1. Seen friends or family in own home	*0.19*	*0.08*	*0.74*	0.77	*0.10*	*0.22*	0.52
2. Visited friends or family at their homes	0.47	0.35	0.89	0.89	0.63	*0.26*	*0.11*
3. Attended community or religious meetings	0.33	*0.45*	0.85	0.86	0.59	0.66	*0.32*
4. Gone shopping with friends or family	*0.44*	0.62	1.00	0.88	*0.18*	0.51	*0.36*
5. Gone on trips or to events like the cinema or talks	*0.38*	0.26	1.00	0.89	*0.19*	*0.25*	*0.40*
6. Gone to a cafe, restaurant, pub, or social club	*0.51*	0.28	0.89	1.00	*0.15*	*0.30*	*0.36*
7. Exercised, walked or played sport with others	0.08	0.38	0.83	0.95	*0.11*	0.54	0.09
Communicating with other people							
8. Contacted friends or family by phone or computer	0.19	*0.25*	*0.65*	1.00	0.74	*0.31*	0.47
9. Started or taken part in a conversation	0.22	*0.10*	0.84	1.00	0.64	0.47	0.76
10. Talked to others about your/their feelings or concerns	0.50	0.63	0.95	0.90	*0.20*	*0.38*	*0.13*
11. Asked other people about their feelings or concerns	0.32	0.50	0.95	0.95	*0.13*	*0.21*	*0.08*
12. Found it difficult to think of something to say to others	0.14	0.15	1.00	1.00	*0.02*	*0.21*	*0.09*
13. Found other people's conversation unclear	0.45	*0.48*	0.89	1.00	0.42	*0.21*	*0.08*
Sensibility to other people							
14. Been outspoken about what you/they really think	*0.15*	0.15	0.87	1.00	*0.20*	*0.21*	*0.16*
15. Found that other people are irritating	0.36	0.22	1.00	1.00	*0.04*	*0.26*	*0.19*
16. Had an argument or shouted at other people	0.34	0.19	0.87	0.86	*0.15*	*0.31*	*0.25*
17. Found they don't want to do things you/they would usually	0.32	0.38	1.00	1.00	*0.28*	*0.26*	*0.05*
Total	0.72	0.76	0.98	0.95	0.57	0.58	0.46
95% CI			0.95, 0.99	0.89, 0.98	0.26, 0.78	0.28, 0.78	0.11, 0.71
Statistic for total score	Cronbach's α		Intraclass correlation coefficient for total score				

SF-DEM, German version of SF-DEM. Statistics in italicized type indicate low reliability or agreement: item-total reliability: Cronbach's' α would increase if item were deleted; interrater reliability: Cohen's quadratic-weighted $k \leq 0.75$; test-retest reliability: Cohen's quadratic-weighted $k \leq 0.40$; and convergent validity: Cohen's quadratic-weighted $k \leq 0.40$.

caregiver-rated instrument (1, 7, 12, 14, 16) had low item-total reliability (Table 3). The other items did not result in an alpha increase when they were removed.

Inter-rater reliability

Inter-rater correlation between the two interviewers was very high for overall scores in the patient-rated (ICC = 0.98, 95%CI [0.95–0.99]) and the caregiver-rated version (ICC = 0.95, 95%CI [0.89–0.98]). Inter-rater agreement was good for item one in the patient-rated and the caregiver-rated version and for item three in the patient-rated SF-DEM. For all other items, the inter-rater agreement was very good (Table 3 and Supplementary Table 3 for subscales).

Test-retest reliability

We repeated the assessment of the SF-DEM after an average of 29.36 with patients and 29.50 days with caregivers ($SD_P = 3.11$; $range_P$ 24–39; $SD_A = 3.04$; $range_A$ 24–39).

Test-retest correlation was moderate for the patient-rated (ICC = 0.57, 59% CI [0.26–0.77]) and the caregiver-rated versions (ICC = 0.58, 95% CI [0.27–0.78]). Significant agreement ($\kappa \geq 0.4$) was found for items four and nine of both versions, as well as item two, three, and 13 of the patient-rated and item five and eight of the caregiver-rated SF-DEM (Table 3 and Supplementary Table 3 for subscales).

Validity

There is no German measure of SF against which SF-DEM can be compared in order to evaluate validity. We did not find a significant correlation between the patient ratings and LSNS-6 ($r_s = 0.20$, $p = 0.31$), ESSI ($r_s = 0.19$, $p = 0.32$), QoL-AD (family: $r_s = 0.09$, $p = 0.66$; marriage: rs = 0.12, $p = 0.55$; friends: r_s=–0.08, $p = 0.68$), and the SF-36 items (r_s=–0.13, $p = 0.50$; $r_s = 0.00$, $p = 0.99$).

Strong correlations were found with respect to the caregiver-rated instrument and LSNS-6 ($r_s = 0.60$, $p < 0.01$) and QoL-AD (marriage: $r_s = 0.61$, $p < 0.01$; friends: $r_s = 0.51$, $p = 0.01$). Moderate correlations occurred between QoL-AD family ($r_s = 0.37$, $p = 0.05$) and the SF-36 items ($r_s = 0.39$, $p = 0.04$ and $r_s = 0.33$, $p = 0.09$). No significant correlation was observed between the SF-DEM and ESSI ($r_s = 0.28$, $p = 0.15$). See Table 4 and Supplementary Table 4 for subscales.

Table 4
Correlation analysis to test the validity of the SF-DEM

	Patients		Caregiver	
	r_s	p	r_s	p
LSNS-6	0.20	0.31	**0.60**	< 0.01
ESSI	0.19	0.32	0.28	0.15
QoL-AD				
Family	0.09	0.66	**0.37**	0.05
Marriage	0.12	0.55	**0.61**	< 0.01
Friends	– 0.08	0.68	**0.51**	0.01
SF-36				
	– 0.13	0.50	**0.39**	0.04
	0. 00	0.99	*0.33*	0.09

ESSI, ENRICHD Social Support Inventory [18]; LSNS-6, Lubben Social Network Scale [17]; r_s, Spearman's rank correlation coefficient; SF-36, Questionnaire about health status [20], modified question about SF (6 and 9); SF-DEM, German version of the Social Functioning in Dementia Scale [2]; QoL-AD, Quality of Life in Alzheimer´s Disease [19]. **Bold print** = significant on level 5%; *in italics* = significant on level 10%.

No significant correlation was found between the total SF-DEM score and the 3 global social behavior questions in the patient version. In the caregiver version, the overall score correlated moderately with item 18 assessing overall social behavior ($r_s = –0.45$; $p = 0.02$). See Supplementary Table 5 for correlations between SF-DEM subscale scores.

DISCUSSION

We aimed to provide a German version of the originally English SF-DEM scale to assess social functioning in individuals with mild dementia. The original scale was validated in individuals with mild dementia and their caregivers and has been found to have good psychometric properties [2]. Second, Budgett et al. showed that the caregiver-rated original English SF-DEM has satisfactory psychometric properties in all severities of dementia [5].

In our study, the first step was to translate the scale according to the TRAPD model. In the second step, we evaluated the reliability, validity, and acceptability of the German version.

The German SF-DEM was highly acceptable to the target population, i.e., individuals with mild dementia, as well as their caregivers. The internal consistency was acceptable, the inter-rater reliability was very high, and test-retest reliability was moderate for both versions.

The total score of the German SF-DEM showed higher values for the patient version than for the caregiver version. These differences were mainly found in the subscale "sensitivity to other people". The

subscale included items about socially undesirable behaviors, such as aggression and arguing. It is well known that individuals with dementia may have low disease insight and often tend to underestimate or trivialize deficits [26]. Low insight, also referred to as anosognosia, increases during the course of dementia [27, 28]. Similar patterns have been identified for quality of life [29, 30].

The evaluation of construct validity was not straightforward, because there is no suitable German assessment to compare the SF-DEM; therefore, we chose instruments of constructs which we hypothesized to be correlated, such as social network size, perceived social support, and quality of life. However, we found that patient ratings of SF did not correlate with these constructs, which may further reflect the impairment of insight. However, using proxy concepts, the caregiver version showed that a higher SF-DEM score was associated with a larger social network of patients. The satisfaction of the individual with mild dementia with family, marriage, and friends, as assessed in the QoL-AD, was also positively related to the SF-DEM score. Higher SF was evident if the caregiver reported less impairments due to the patient's memory problems. The total result of the caregiver-rated SF-DEM was associated with better satisfaction of the overall social life of the patient.

Overall, our results are largely in line with those of the original English version [2]. Acceptability of the German version was consistent with the original English version. The duration of the interviews in the German version was 1 minute shorter in the patient-rated and 2 minutes shorter in the caregiver-rated version. It is most likely that these discrepancies were due to language. The internal consistency of the German SF-DEM was slightly higher than in the original English SF-DEM. The reason for this difference could be that a third subscale was added to the English version after initial psychometric evaluation, thus improving the internal consistency. Our analysis showed slightly lower values in inter-rater reliability. This may be a result of having 2 interviewers in our study, while one interviewer was involved in the evaluation of the original English version. In the study by Sommerlad et al. in 2017, inter-rater reliability was determined by recording the interviews on a voice recorder and then having them rated again by another person.

Notably, we found lower values regarding test-retest reliability. This may be associated with the COVID-19 pandemic, which began during our data collection period. The public health interventions to curb the spread of the virus caused significant restrictions on social life. The average SF-DEM score was lower at participant's follow-up interviews, which largely took place during the pandemic, and this is likely due to these restrictions reducing the availability of social contacts and activities. Some of the participants were interviewed face-to-face prior to the onset of the pandemic and by telephone at follow-up after the onset of the pandemic. We cannot rule out that the change in survey mode led to a change in response behavior.

The emergence of the COVID-19 pandemic is probably also the reason why the full range of answers was not used for all questions in the SF-DEM. This was precisely because trips and visits to cafés were not possible during this period. Ceiling or floor effect for the scales were not evident.

Strengths and limitations

Our work provides a validated instrument to assess SF in individuals with mild dementia in German language. Individuals of different educational backgrounds and of both sexes could be included. All participants were interviewed twice without dropouts.

Interviewing individuals with cognitive impairment carries the risk of cognitive fatigue. A total of 5 individuals with dementia experienced difficulties during the interview. To counteract these difficulties, the questions were rephrased and explained, if required. It cannot be ruled out that caregivers also had difficulties in answering our questions. This was not noticed by the interviewers. Bias in the answers cannot be ruled out. Caregivers were not subjected to screening. Possibly, some caregivers among the interviewees had cognitive deficits and probably could not answer questions reliably. Interviewers were trained to minimize such biases. Explanations were given in case of comprehension problems, and questions were re-formulated, if necessary.

CONCLUSION

Our results provide promising evidence that the German SF-DEM can be used as a valid and reliable patient- and caregiver-report to assess SF in individuals with mild dementia. Further studies are required to assess its applicability in moderate and severe dementia, pre-stages of dementia, and in different settings, such as in nursing homes or among community-dwelling individuals. Furthermore, the

German SF-DEM should be tested in other German-speaking regions to test the generalizability of our findings. For the same reason, testing of a larger sample is also desirable with confirmatory factor analysis of the factor structure of the scale. Further research is also required to test the responsiveness of the German SF-DEM. Finally, the German SF-DEM should be used in future studies to assess changes in SF especially in individuals with dementia. Furthermore, an application in clinical and care settings is also explicitly desired to evaluate the scale's role in early detection of dementia, to facilitate conversation about distressing changes in SF, and supporting individuals with dementia and their caregivers to improve SF.

The instrument is available for free: https://www.ucl.ac.uk/psychiatry/research/mental-health-older-people/projects/social-functioning-dementia-scale-sf-dem

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SUPPLEMENTARY MATERIAL

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2.3. Social isolation and incident dementia in the oldest-old – A competing risk analysis

Grothe, J., Röhr, S., Luppa, M., Pabst, A., Kleineidam, L., Heser, K., Fuchs, A., Pentzek, M., Oey, A., Wiese, B., Lühmann, D., van den Bussche, H., Weyerer, S., Werle, J., Weeg, D., Bickel, H., Scherer, M., König, H.-H., Hajek, A., Wagner, M. & Riedel-Heller, S. G. (2022). Social Isolation and Incident Dementia in the Oldest-Old—A Competing Risk Analysis. *Frontiers in Psychiatry*, 13, Article 834438, 535.

Purpose: Social isolation is considered a risk factor for dementia. However, less is known about social isolation and dementia with respect to competing risk of death, particularly in the oldest-old, who are at highest risk for social isolation, dementia and mortality. Therefore, we aimed to examine these associations in a sample of oldest-old individuals.

Methods: Analyses were based on follow-up (FU) 5 to 9 of the longitudinal German study AgeCoDe/AgeQualiDe. Social isolation was assessed using the short form of the Lubben Social Network Scale (LSNS-6), with a score ≤ 12 indicating social isolation. Structured interviews were used to identify dementia cases. Competing risk analysis based on the Fine-Gray model was conducted to test the association between social isolation and incident dementia.

Results: Excluding participants with prevalent dementia, n = 1,161 individuals were included. Their mean age was 86.6 (SD = 3.1) years and 67.0% were female. The prevalence of social isolation was 34.7% at FU 5, 9.7% developed dementia and 36.0% died during a mean FU time of 4.3 (SD = 0.4) years. Adjusting for covariates and cumulative mortality risk, social isolation was not significantly associated with incident dementia; neither in the total sample (sHR: 1.07, 95%CI 0.65-1.76, p = .80), nor if stratified by sex (men: sHR: 0.71, 95%CI 0.28-1.83, p = .48; women: sHR: 1.39, 95%CI 0.77-2.51, p = .27).

Conclusion: In contrast to the findings of previous studies, we did not find an association between social isolation and incident dementia in the oldest-old. However, our analysis took into account the competing risk of death and the FU period was rather short. Future studies, especially with longer FU periods and more comprehensive assessment of qualitative social network characteristics (e.g. loneliness and satisfaction with social relationships) may be useful for clarification.

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Social Isolation and Incident Dementia in the Oldest-Old—A Competing Risk Analysis

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Purpose: Social isolation is considered a risk factor for dementia. However, less is known about social isolation and dementia with respect to competing risk of death, particularly in the oldest-old, who are at highest risk for social isolation, dementia and mortality. Therefore, we aimed to examine these associations in a sample of oldest-old individuals.

Methods: Analyses were based on follow-up (FU) 5–9 of the longitudinal German study AgeCoDe/AgeQualiDe. Social isolation was assessed using the short form of the Lubben Social Network Scale (LSNS-6), with a score ≤12 indicating social isolation. Structured interviews were used to identify dementia cases. Competing risk analysis based on the Fine-Gray model was conducted to test the association between social isolation and incident dementia.

Results: Excluding participants with prevalent dementia, $n = 1{,}161$ individuals were included. Their mean age was 86.6 ($SD = 3.1$) years and 67.0% were female. The prevalence of social isolation was 34.7% at FU 5, 9.7% developed dementia and 36.0% died during a mean FU time of 4.3 ($SD = 0.4$) years. Adjusting for covariates and cumulative mortality risk, social isolation was not significantly associated with incident dementia; neither in the total sample (sHR: 1.07, 95%CI 0.65-1.76, $p = 0.80$), nor if stratified by sex (men: sHR: 0.71, 95%CI 0.28-1.83, $p = 0.48$; women: sHR: 1.39, 95%CI 0.77-2.51, $p = 0.27$).

Conclusion: In contrast to the findings of previous studies, we did not find an association between social isolation and incident dementia in the oldest-old. However,

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our analysis took into account the competing risk of death and the FU period was rather short. Future studies, especially with longer FU periods and more comprehensive assessment of qualitative social network characteristics (e.g., loneliness and satisfaction with social relationships) may be useful for clarification.

Keywords: social isolation, incident dementia, oldest-old, epidemiology, competing risk analysis, longitudinal study

INTRODUCTION

Around 17% of the world population will be 65 years old or older in 2050 (1). The fastest growing group above 65 years of age is the oldest-old, i.e., individuals over 85 years of age (2). Population aging is associated with an increase of age-related disorders, especially dementia (3). Dementia is a neuropsychiatric syndrome that mainly occurs as a result of a degenerative disease of the brain. It is one of the most common and most severe disorders in old age and shortens the life span considerably (4). The number of individuals living with dementia worldwide is constantly increasing (5). In 2015, there were 46.8 million dementia cases (6) and the number is projected to increase to 152 million by 2050 (7). This development will pose major challenges for public health and old age care systems in countries all over the world (8). As there is no effective treatment or cure for dementia yet, increasing costs for health systems and societies at large will emerge (6). Therefore, the importance of dementia risk reduction and prevention is growing.

It is also well known that social isolation increases with age (9). The prevalence of social isolation in community-dwelling older adults ranges from 10 to 43% (10). Social isolation is defined as a low number and frequency of contacts with others (11). It is an objective measure and can be assessed by quantifying an individual's social network. Social isolation is associated with increased mortality (12, 13), an increased risk of developing coronary heart disease and stroke (14).

A number of studies demonstrated a relationship between characteristics and aspects (e.g., social participation, living alone, and less frequent contact) of social network size and cognitive performance as well as incident dementia (15, 16).

Moreover, Holt-Lunstadt et al. (12) showed that individuals with adequate social relationships had a 50% higher probability of survival compared to those with poor or insufficient social relationships. The extent of this effect was comparable to that of smoking cessation and it exceeds many other known risk factors for mortality (e.g., overweight, lack of exercise) (12, 17).

The effect of social isolation on the brain were studied in an experiment with mice. Smith et al. (18) showed that the aging brain can be positively influenced by larger social networks. These findings support the assumption that the social network is associated with brain structure and could thus affect cognitive function and the development of dementia.

In this context, we aimed to longitudinally assess the association between social isolation and incident dementia in oldest-old individuals. To the best of our knowledge, no competing risk analysis has been performed in the oldest-old to investigate the association of social isolation and incident dementia. However, it is important to consider competing events when analyzing survival data in old and oldest-old individuals (19). In particular, mortality is a relevant competing risk in oldest-old individuals when studying the association of health outcomes, including dementia (20).

We study the group of the oldest-old, as they are different from younger older age groups (21). For example, among individuals 90 years of age and older, incidence dementia increases exponentially (2). The oldest-old are at high risk for several risk factors associated with incident dementia (e.g., sensory deficits, frailty, physical disability, malnutrition, and unintentional weight loss) (21). In addition, the risk of social isolation is specifically high in the oldest-old (21).

We assume that those who are not socially isolated are less likely to develop dementia over the course of the study.

We aimed to assess the association between social isolation and incident dementia in the oldest-old longitudinally, taking mortality risk into account.

MATERIALS AND METHODS

This work is informed by the STROBE (22) guidelines for reporting observational studies in epidemiology.

Study Design and Sampling

Analyses were carried out using data of the German study on Aging, Cognition, and Dementia in Primary Care Patients (AgeCoDe), a prospective longitudinal cohort study on mild cognitive impairment (MCI) and dementia, and its extensioncontinuation, the study on Needs, Health Service Use, Costs, and Health-related Quality of Life in a large sample of oldest-old primary care patients (AgeQualiDe). Participants were recruited by 138 general practitioners (GP) in six cities (Bonn, Duesseldorf, Hamburg, Leipzig, Mannheim, Munich) between January 2003 and November 2004. GP patients were eligible for the AgeCoDe/AgeQualiDe-study, if they were aged 75 years or older, dementia-free, and had at least one GP contact within the last year. Patients who only saw their GP at their homes, lived in a nursing home, had a serious illness that was expected to be fatal within 3 months, did not have sufficient knowledge of the German language, were deaf or blind, or were unable to give informed consent, were excluded from participation in the study. The study design has previously been described elsewhere (23).

Initially, 3,327 individuals constituted the AgeCoDe/AgeQualiDe cohort at baseline. Nine follow-up assessments were scheduled every 1.5 years up to follow-up seven and then every 10 months up to follow-up nine. In this

study, waves five to nine were used for the analysis because social network data were only assessed from FU5. At this time, 1,342 individuals were interviewed. For analysis, 181 participants were excluded, because of a diagnosis of dementia at follow-up five ($n = 166$; 91.7%) and missing information on social network, measured by Lubben Social Network Scale (LSNS-6) ($n = 15$; 8.3%). The resulting analytic sample included data from $n = 1{,}161$ participants. A flowchart of sample selection and attrition is shown in **Figure 1**.

Ethics

The ethics committees of all six study centers approved the study. The study was performed in accordance with the ethical standards of the Declaration of Helsinki (24). Patients and/or their proxies provided written informed consent prior to their study participation.

Instruments

Social Isolation

Social isolation was determined by measuring the social network size, using the short form of the Lubben Social Network Scale (LSNS-6). The LSNS correlates with other measures of social integration and thus has good validity (25). It contains questions about the number and frequency of contacts with friends and family as well as social support received by them (25). Each of the six LSNS-6 questions is scored from zero to five. The total score ranges from zero to 30. Higher scores indicate larger social networks. A score below 12 is considered an indicator of social isolation and a score of 12 or higher indicates social integration (25). For this cutoff, the LSNS demonstrates concordant validity for identifying individuals with risk for social isolation (25).

Incident Dementia

To identify dementia cases in the AgeCoDe/AgeQualiDe cohort, the Structured Interview for Diagnosis of Dementia of Alzheimer's type, Multi-infarct Dementia and Dementia of other Etiology according to DSM-IV and ICD-10 (SIDAM) interview was used. It contains a neuropsychological test battery (largely comprising the MMSE) and a 14-item scale for the assessment of activities of daily living (SIDAM-ADL-Scale) (26). Dementia was diagnosed in a consensus conference with the interviewer and an experienced geriatrician or geriatric psychiatrist according to the criteria of DSM-IV, which are implemented as a diagnostic algorithm in the SIDAM. Date of follow-up assessment was the point of incident dementia diagnosis.

Covariates

Information on several covariates was collected to control for possible confounding effects. Sociodemographic data included age, sex, education (according to the Comparative Analysis of Social Mobility in Industrial Nations (CASMIN) criteria (27)), marital status and living situation. Cognitive function was measured using the Mini-Mental State Examination (MMSE) (28). It consists of 11 questions and activities regarding, e.g., orientation, recall, and visual construction. Higher scores indicate better overall cognitive function. The maximum score is 30. The MMSE was administered as part of the SIDAM (26).

In order to determine the individual's everyday function or functional independence, eight Instrumental Activities of Daily Living (IADL) were collected using the Lawton & Brody IADL scale (29). This scale included, among others, the ability to use a telephone and transportation (car, bus, train), and the ability to manage financial matters. The score ranged from zero to eight. A higher score indicated higher independence.

Cognitive and physical activities were assessed according to Verghese et al. (30) with some small modifications. Activities of the past 4 weeks were collected using an ordinal scale of frequency (four—daily, three—several times per weeks, two—once per weeks, one—less than once per weeks, and zero—never). Physical activities included seven questions, for example on bicycling, walking, swimming, gymnastics, chores/gardening, and a category of other physical activities (e.g., bowling, dancing, bicycling, walking, or golfing). Cognitive activities included eight items, e.g., doing crossword puzzles, memory training/brainteasers, games (card games, board games, or individual games), reading, writing, and playing a musical instrument. For analysis, two sum scores were calculated. One for cognitive and one for physical activities. The score for cognitive activities ranged from zero to 32. The maximum score for physical activities was 28. Higher scores indicated higher activity level.

Health Characteristics

Mobility, vision, and hearing impairments were assessed with a self-report question for each domain. Specifically, we asked participants, "Do you have difficulty walking/hearing/seeing?" Responses were recorded using an ordinal scale of severity: (1) no difficulty, (2) some difficulty, (3) significant difficulty, and (4) extreme difficulty or unable to walk/blind/deaf. For analysis, variables were dichotomized (yes/no).

Depressive symptoms were measured using the short version of the Geriatric Depression Scale (GDS) (31). The GDS consists of 15 questions specific to older age, e.g., "have you dropped many of your activities and interests?." The maximum score is 15 (score $>$ five indicates increased depressive symptomatology; score >10 indicates severe depressive symptomatology).

Information on whether participants had a history of stroke, diabetes mellitus, and hypertension was obtained from standardized questionnaires completed by the participants' general practitioners at each wave of the study.

Statistical Analyses

Group differences between socially isolated and socially integrated individuals at follow-up five were inspected using Pearson chi-square tests, rank sum tests or Wilcoxon two-sample tests. We used the Fine and Gray (competing risk) regression model to calculate the risk of incident dementia, taking into account the competing event (mortality) over time (19). Fine and Gray's model modifies the Cox proportional hazard model to account for competing risks. A competing risk is understood as an event that hinders the occurrence of the event of interest (32, 33). First, we ran a competing risk analysis without adjustment. In a second step, our competing risk analysis was adjusted for all above named covariates.

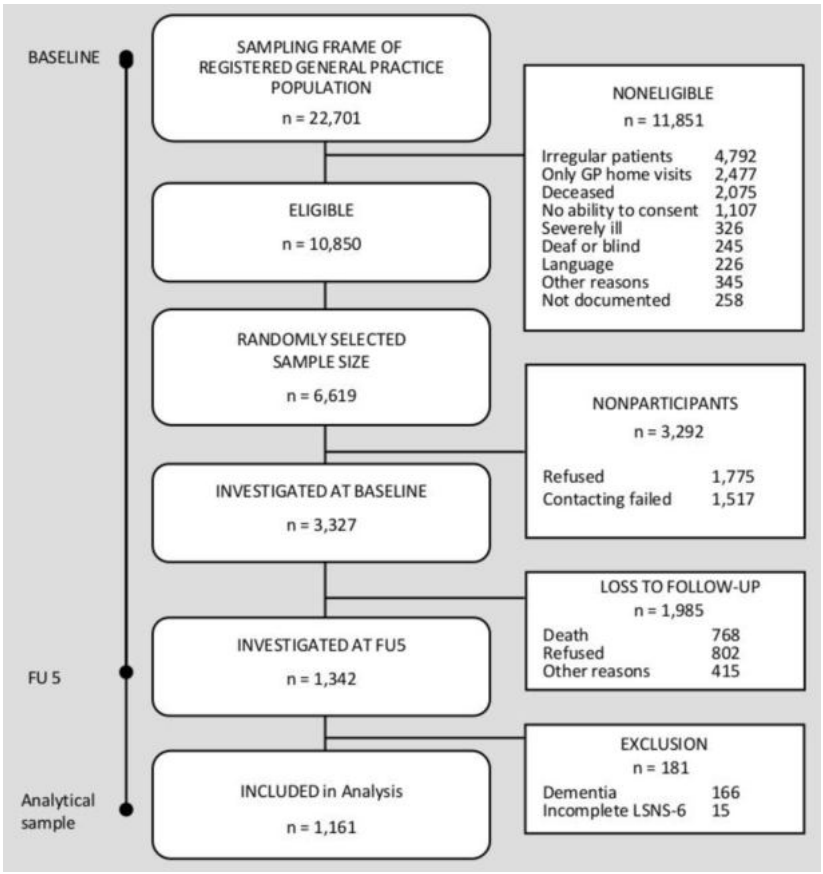

FIGURE 1 | Sample selection flowchart.

In view of the different profiles of risk factors of dementia between women and men previously reported (34), we additionally aimed to conduct analysis stratified by sex.

Results were presented as a sub-distribution hazard ratio (sHR) with a 95% confidence interval (CI). All events except the two of interest (incident dementia and mortality) were censored.

In a sensitivity analysis, we ran all competing risk regression models with social isolation as a time-varying variable.

STATA 16 was used for statistical analysis (35). All analyses employed an α-level for statistical significance of 0.05 (two-tailed).

RESULTS

Sample Characteristics

In total, 1,161 dementia-free individuals were included in the analytic sample. Their mean age was 86.57 (*SD* = 3.1) years and $n = 778$ (67.0%) were female. Prevalence of social isolation was 34.7% ($n = 403$) at FU 5, $n = 113$ (9.7%) developed dementia and 418 (36.0%) died during a mean follow-up time of 4.26 (*SD* = 0.35) years. The mean survival time was 3.86 years (*SD* = 1.26). Mortality was higher in socially isolated compared to socially integrated individuals [$n = 174$ (43.2%) vs. $n = 244$ (32.2%); $p < 0.001$].

The average social network size, measured using the LSNS-6 score was 8.07 (*SD* = 2.70) for socially isolated individuals and 17.14 (*SD* = 3.87) for socially integrated participants ($t = 41.93$, $p < 0.001$). Socially isolated individuals were significantly older, less often married, and more often living alone than socially integrated individuals. In addition, they had lower MMSE scores, higher depressive symptoms, less often performed cognitive and physical activities and were more often impaired in vision and mobility. Socially isolated and socially integrated individuals did not differ regarding sex, IADL, history of stroke, history of diabetes mellitus, hypertension and hearing impairment.

Baseline characteristics of the analytical sample are shown in **Table 1**.

TABLE 1 | Sociodemographic and health characteristics of the study sample.

Variable	Total ($n = 1.161$)	Socially isolated individuals* ($n = 403$)	Socially integrated individuals* ($n = 758$)	*p*-value
Age, M (*SD*)	86.6 (3.1)	87.1 (3.1)	86.3 (3.0)	<0.001
Sex, *n* (%)				0.192
Female	778 (67.0)	280 (69.5)	498 (65.7)	
Male	383 (33.0)	123 (30.5)	260 (34.3)	
Education, *n* (%)				0.363
Low	655 (56.4)	232 (57.6)	423 (55.8)	
Middle	357 (30.8)	127 (31.5)	230 (30.3)	
High	149 (12.8)	44 (10.9)	105 (13.9)	
Marital status, *n* (%)				<0.001
Married	346 (29.8)	85 (21.1)	261 (34.4)	
Not married	814 (70.1)	317 (78.7)	497 (65.6)	
Missings	1 (0.1)	1 (0.3)	0 (0.0)	
Living situation, *n* (%)				0.015
Living alone	604 (52.0)	230 (57.1)	374 (49.3)	
Not living alone	557 (48.0)	173 (42.9)	384 (50.7)	
Cognitive function (MMSE), M (*SD*)	27.9 (1.8)	27.6 (2.0)	28.0 (1.7)	<0.001
Missings	7 (0.6)	2 (0.5)	5 (0.7)	
IADL, M (*SD*)	6.5 (1.9)	6.2 (2.09)	6.6 (1.7)	0.052
Cognitive activities, M (*SD*)	12.4 (4.2)	10.8 (3.99)	13.3 (4.1)	<0.001
Missings	20 (1.7)	9 (2.2)	11 (1.5)	
Physical activities, M (*SD*)	6.4 (3.9)	5.4 (3.7)	6.9 (3.9)	<0.001
Missings	25 (2.2)	8 (2.0)	17 (2.2)	
History of stroke, *n* (%)				0.889
Yes	63 (5.4)	22 (5.5)	41 (5.4)	
No	831 (71.6)	283 (70.2)	548 (72.3)	
Missings	267 (23.0)	98 (24.3)	169 (22.3)	
History of diabetes mellitus, *n* (%)				0.278
Yes	252 (21.7)	93 (23.1)	159 (21.0)	
No	635 (54.7)	210 (52.1)	425 (56.1)	
Missings	274 (23.6)	100 (24.8)	174 (23.0)	
Hypertension, *n* (%)				0.425
Yes	761 (65.6)	255 (63.3)	506 (66.8)	
No	135 (11.6)	50 (12.4)	85 (11.2)	
Missings	265 (22.8)	98 (24.3)	167 (22.0)	
Mobility impairment, *n* (%)				<0.001
Yes	460 (39.6)	278 (69.0)	423 (55.8)	
No	701 (60.4)	125 (31.0)	335 (44.2)	
Hearing impairment, *n* (%)				0.694
Yes	567 (48.8)	200 (49.6)	367 (48.4)	
No	594 (51.2)	203 (50.4)	391 (51.6)	
Vision impairment, *n* (%)				0.042
Yes	304 (26.2)	283 (70.2)	184 (24.3)	
No	857 (73.8)	120 (29.8)	574 (75.7)	
Depressive symptoms (GDS), M (*SD*)	2.6 (2.5)	3.5 (2.8)	2.1 (2.2)	<0.001
Missings	16 (1.4)	10 (2.5)	6 (0.8)	
Mortality, *n* (%)	418 (36.0)	174 (43.2)	244 (32.2)	<0.001
Incident dementia, *n* (%)	113 (9.7)	44 (10.9)	69 (9.1)	0.321

GDS, geriatric depression scale (score range: 0-15); M, mean; MMSE, mini-mental state examination (score range: 0–30); SD, standard deviation.
**Based on the total score form the Lubben Social Network Scale (LSNS-6, scoring range: 0-30), which defines social isolation as a score below 12 and social integration as a score equal 12 or higher.*

TABLE 2 | Univariate and multivariate Fine and Gray (competing risk) regression model for the impact of social isolation on incident dementia.

	Model I		Model II	
	sHR	*p*	*sHR*	*p*
Social isolation (ref. socially integrated individuals)	1.24	0.260	1.07	0.800
Age*			1.04	0.320
Male sex (ref. female sex)			*0.55*	*0.057*
High education (ref. middle, low)			*1.64*	*0.003*
Married (ref. not married)			1.40	0.288
Living alone (ref. shared housing)			1.08	0.788
Cognitive function (MMSE)*			*0.71*	*<0.001*
Depressive symptoms*			1.03	0.596
IADL*			1.00	0.965
Physical activities*			1.00	0.943
Cognitive activities*			1.00	0.905
Vision impairment (ref. no impairment)			0.70	0.228
Hearing impairment (ref. no impairment)			0.91	0.712
Mobility impairment (ref. no impairment)			1.03	0.920
Hypertension (ref. no history of hypertension)			0.80	0.463
Diabetes (ref. no history of diabetes)			*0.50*	*0.020*
Stroke (ref. no history if stroke)			1.21	0.648
n		1.161		843

**Continuous scores; IADL, instrumental activities of daily living; MMSE, mini-mental state examination; sHR, subdistribution hazard ratio. Statistics in italicized type indicate significant results.*

Effects of Social Isolation on Incident Dementia

Table 2 presents the results of the competing risk analysis. Social isolation was not significantly associated with incident dementia, neither in the unadjusted (sHR: 1.24, $p = 0.26$) nor in the adjusted model (sHR: 1.07, $p = 0.80$). In separate models for women and men, a significant association between social isolation and incident dementia was found in the unadjusted model for women (sHR = 1.46, $p = 0.08$), but not for men (sHR = 0.68, $p = 0.38$; see **Table 3**). After adjusting for possible confounders, no significant results were found for both women (sHR: 1.39, $p = 0.27$) and men (sHR: 0.71, $p = 0.48$). In separate models for women and men, no significant results were found for both women and men in the unadjusted (women: sHR = 1.46, $p = 0.08$; men: sHR = 0.68, $p = 0.38$; see **Table 3**) and the adjusted model (women: sHR: 1.39, $p = 0.27$; men: sHR: 0.71, $p = 0.48$). Results of the sensitivity analysis did not differ (see **Supplementary Tables S1**, **S2**).

DISCUSSION

We aimed to longitudinally investigate effects of social isolation on incident dementia in a large sample of oldest-old individuals taking into account the competing risk of mortality. Social isolation was highly prevalent in our sample (34.7%). Moreover, mortality was higher in socially isolated individuals compared to socially integrated individuals. We did not find an association between social isolation and incident dementia in the oldest-old, when taking mortality into account. Moreover, there was no association between social isolation and incident dementia in men or women.

There are a few studies that have also examined the association between social isolation and dementia or cognitive functioning in the oldest old (23, 36, 37). A study also based on AgeCoDe/AgeQualiDe data examined oldest-old, healthy individuals over a period of 4.7 years with regards to social isolation and cognitive function. It was shown that smaller social networks, measured with the LSNS-6, were associated with lower cognitive function (23). In addition, Hajek et al. (37) studied oldest-old individuals based on AgeCoDe/AgeQualiDe data with the LSNS-6 over a 2-year period and found that a social network size was associated with functional deterioration in men. The different findings in comparison to our study could be explained by varying methodological approaches. For example, in both previous studies, continuous outcomes were used. For this study, however, a defined clinical disease (dementia) was used as outcome. In addition, in contrast to Röhr et al. (23) and Hajek et al. (37), our analyses was adjusted for mortality risk by performing a competing risk analyses.

Other studies rather investigated social isolation in younger old age groups in relation to cognitive function instead of incident dementia (38–40). The results contradict the findings of our study. For example, Crooks et al. (38) conducted a longitudinal study with older women (78 and older) over 4 years. They showed that a larger social network had a protective effect on cognitive function in older women (38). Findings from Evans et al. (40) suggested that being isolated in late life is detrimental to cognitive function. They conducted a longitudinal study over 2 years with individuals aged over 65 years (40).

A study by Rodriguez et al. (41) considered individuals aged 75 years or older over 9 years. The results showed, in contrast to our findings, that having a restricted social network, assessed using the Wenger's Practitioner Assessment of Network Type (PANT), doubled the risk for developing dementia (41).

In a study over a 10-years period with dementia-free individuals who were 50 years old or older, Rafnsson et al. (42) found no association between social isolation and the development of dementia, maybe due to the relatively young age of the participants. Social isolation was operationalized using an index which included the extent of contact with the individual's social network and involvement in social organizations (42).

It is wellknown that women are at increased risk of developing dementia (43, 44). The gender difference can be explained in that women live longer than men in general. However, as individuals get older, the risk of developing dementia also increases (45). In addition, hormonal differences between men and women may be another reason why women are more likely to develop dementia. Moreover, differences in brain networks as well as in social, economic and cultural norms as well as relationships may contribute to differential dementia risk between men and women

TABLE 3 | Univariate and multivariate Fine and Gray (competing risk) regression model for the impact of social isolation on incident dementia by gender.

	Women				Men			
	Model I		Model II		Model I		Model II	
	sHR	*p*	*sHR*	*p*	*sHR*	*p*	*sHR*	*p*
Social isolation (ref. socially integrated individuals)	*1.46*	*0.082*	1.39	0.274	0.68	0.375	0.71	0.479
Age*			1.03	0.487			1.08	0.279
High education (ref. middle, low)			*1.93*	*0.003*			1.42	0.170
Married (ref. not married)			1.03	0.948			*5.52*	*<0.001*
Living alone (ref. shared housing)			0.95	0.878			*5.43*	*0.003*
Cognitive function (MMSE)*			*0.70*	*<0.001*			*0.69*	*0.011*
Depressive symptoms*			1.04	0.497			0.89	0.264
IADL*			1.03	0.761			0.98	0.891
Physical activities*			0.94	0.256			1.06	0.444
Cognitive activities*			1.04	0.228			*0.85*	*0.011*
Vision impairment (ref. no impairment)			0.62	0.186			1.04	0.947
Hearing impairment (ref. no impairment)			0.83	0.547			1.18	0.731
Mobility impairment (ref. no impairment)			1.39	0.396			0.49	0.311
Hypertension (ref. no history of hypertension)			0.96	0.905			0.50	0.191
Diabetes (ref. no history of diabetes)			*0.41*	*0.022*			0.94	0.896
Stroke (ref. no history if stroke)			0.71	0.577			*3.06*	*0.073*
n		778		544		383		299

**Continuous scores; IADL, Instrumental activities of daily living; MMSE, Mini-Mental state examination; sHR, subdistribution hazard ratio. Statistics in italicized type indicate significant results.*

(45). There are also differences in the social networks of men and women. Because women live longer than men they are more likely to live without a spouse in old age (46). In addition, they have larger close, supportive networks as men (46). Schwartz et al. (46) found that the social networks of older European women grew over a time period of 4 years. Women have been shown to have greater relative increase in closer social relationships than men. This was despite the fact that there were no gender differences with the loss of number of confidants. Thus, women seem to tend to create new closer relationships, or add peripheral contacts to closer contacts (46). In a sample of older Koreans, Lee et al. (47) found that the cognitive function of women was influenced by social activity and the number of individuals they considered friends. Although these results might suggest that the influence of social network varies by gender, we did not find a significant association between social isolation and incident dementia in the unadjusted model as well as after adjusting for possible confounder for both oldest-old women and men.

Overall, most studies confirmed an association between social isolation and incident dementia or cognitive function. There may be several reasons why our results were not in line with previous studies. First, our follow-up period was rather short. A longer observation period may have provided differential insights. Second, our results may be explained by selective mortality (13, 48), i.e., individuals with a history of social isolation may not have reached oldest-old age in the first place. Thus, the individuals under investigation in this study may be rather resilient and have had a lifestyle that makes successful aging more likely. The four areas of preventing illness and disability; high cognitive, mental, and physical functioning; active participation in life; and good psychological adjustment in later life have been found to be important for successful aging (49). There is also evidence that physical activities (50), education, work life, leisure activities, stress, and diet are important factors for successful aging and health in late life (51). The difference in findings could be also explained due to heterogeneity of the study samples. In addition, previous studies have often used continuous score for cognition rather than dementia as a binary outcome. Cognitive scores can be used to detect more subtle changes than using a binary diagnostic outcome that represents solid clinical levels of impairment, such as the one used in our work.

Social isolation may not have been a phenomenon over the life course for many oldest-old individuals, but may rather be a correlate of the increasing age and survival, which is associated with decreasing social networks, for example, because of widowhood, the death of siblings and friends (52). With other words, social isolation may be more detrimental to cognitive function if it occurs during earlier late life and if it occurs over rather longer periods. This supports the general relevance for studying modifiable risk factors for dementia with regards to different age spans from a life course perspective in order to determine best practices of dementia risk reduction (53). Therefore, it would be useful if individuals were observed over a long period of time over the whole life-course, ideally starting in early life and continuing into oldest-old age to answer at what stage of life social isolation is a risk factor (e.g., adolescence); how long an individual must continuously live in social isolation before it becomes a risk factor; and whether the risk can be

reversed when the individual is no longer affected by social isolation after a certain period of time. An example of how risk for dementia varies depending on age are hypertension and obesity. For example, studies found that systolic blood pressure levels conveying the lowest dementia risk differ between age groups and have rather *U*-shaped relation with dementia risk (54). Similar findings have been reported for obesity in relation to dementia risk (55). We suggest there may be a similar relationship with regards to social isolation as a risk factor for dementia.

In this context, it would furthermore be important to investigate whether feelings of loneliness have a different effect on the development of dementia in the oldest-old. In general, a *U*-shaped relationship between age and loneliness can be observed (56, 57). Social interactions that provide a sense of satisfaction and sociability have been shown to be a protective factor for dementia over 15 years (58). The presence of a confidant also has a protective effect (58). The likelihood of developing dementia symptoms is twice as high in individuals who feel lonely (58). This effect is also seen the other way around: people with AD are more likely to be lonely (58). Therefore, loneliness may be the better indicator to investigate research questions about cognitive health in the oldest-old.

STRENGTHS AND LIMITATIONS

Strengths of the study include the large sample of oldest-old individuals who provide longitudinal data over an observation period of over 4 years. Second, comprehensive structured clinical interviews, and consensus conferences with clinical experts were conducted to diagnose incident dementia. Using competing risk analysis allowed us to adjust for cumulative risk of mortality (59). This is an important aspect in survival analyses, particularly in oldest-old individuals, and may yield more accurate risk associations with dementia. In our study, more than one third of the participants died during the study period ($n = 418$; 36.0%), with higher mortality in socially isolated oldest-old individuals. This finding highlights the methodological necessity to conduct competing risk analysis in survival analysis, in oldest-old populations, and may yield more accurate results.

The study has also limitations. First, the generalizability of the results might be limited because of a moderate response rate of individuals to the study and a substantial number of participants who could not be located or refused participation in follow-up assessments, which may bias our analytical sample toward healthier participants. Therefore, the results may represent an underestimation of the impact of social isolation and incident dementia. Second, our measure for social isolation, the LSNS-6, does not capture qualitative aspects of social isolation. Therefore, it cannot be clarified whether other aspects of a social network, for example, perceived social support or feelings of loneliness, have an effect on the development of dementia. It is known that there are individuals who prefer to be alone and may not be affected by having only few other people around them. They may not feel lonely, despite having a few social contacts. Other individuals may feel lonely even among a large social network. Without assessing qualitative aspects of a social network, conclusions remain limited. Third, the study group is dynamic in terms of social network characteristics. Therefore, we conducted a sensitivity analysis with social isolation as a time-varying variable. The results did not differ from the competing risk analysis.

Though we used a standardized screening measures to assess the risk of social isolation, it is difficult to compare the results with other studies because social isolation is operationalized differently in various studies.

Moreover, it was not possible for us to control the analysis for other potential variables that increase the risk of dementia.

CONCLUSION

In contrast to the findings of previous studies, we did not find an association between social isolation and incident dementia specifically in the oldest-old. Consequently, social isolation may not be a risk factor for dementia in the oldest-old. This finding could be explained by selective mortality on the one hand and by a rather short study period on the other hand. The results highlight the importance of studying modifiable risk factors for dementia concerning age, as the impact of a risk factor may vary depending on life stages, e.g., midlife, early late life, or oldest-old age. This has important implications for precise prevention of cognitive decline and dementias.

AUTHOR'S NOTE

The results of the manuscript were presented at the 56th Annual Meeting of the DGSMP on 23/09/2021. The abstract has already been published in an abstract collection in the journal "Das Gesundheitswesen" (Georg Thieme Verlag, issue 8/9 2021). It can be downloaded under the following link: https://www.thieme-connect.de/products/ejournals/conferencepdf/079613/10.1055/s-00000022.pdf

DATA AVAILABILITY STATEMENT

The data analyzed in this study is subject to the following licenses restrictions: the dataset is available for research purposes upon reasonable request to the Data Handling Center of the Agecode/Agequalide Study. Requests to access these datasets should be directed to BW, Wiese.Birgitt@MH-Hannover.de.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Ethics Committee of the Medical Faculty of the University of Leipzig (Germany). The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

SR, MS, MW, and SR-H: study concept and design. SR, KH, MP, AF, H-HK, BW, SW, JW, HB, DW, MS, MW, and SR-H: acquisition of data. SR, JG, AP, and SR-H: analysis and interpretation of data. JG and SR: drafting the manuscript. All authors: critical revision of the manuscript for important intellectual content. All authors contributed to the article and approved the submitted version.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2022.834438/full#supplementary-material

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3. Allgemeine Diskussion

Demenz ist eine der am häufigsten auftretenden Erkrankungen im Alter. Bisher ist allerdings nur wenig über soziale Aspekte in Bezug auf diese Erkrankung bekannt. Welche Rolle spielen sie bei deren Entstehung – welche sozialen Risikofaktoren gibt es? Wie entwickeln sich soziale Aspekte über das gesamte Krankheitsspektrum hinweg? Gerade da es aktuell keine wirksamen Behandlungsmöglichkeiten oder eine Heilung für demenzielle Erkrankungen gibt, sind Prävention und Intervention von großer Bedeutung. Wir müssen verstehen, welche modifizierbaren Risikofaktoren es gibt und wie sie funktionieren. Nur so lassen sich wirksame Konzepte entwickeln.

Das Ziel dieser Dissertation war es, zum einen ein Instrument zur Erfassung von Sozialfunktionen bei Personen mit Demenz für den klinischen Bereich und für die Forschung im deutschen Sprachraum zur Verfügung zu stellen und zum anderen soziale Isolation als einen Risikofaktor für demenzielle Erkrankungen bei Hochaltrigen längsschnittlich zu untersuchen. Daraus ergaben sich insgesamt drei Arbeiten.

1. In einer systematischen Literaturrecherche fanden wir heraus, dass es nur wenige Instrumente gibt, die zur Erfassung der Sozialfunktionen bei Personen mit Demenz geeignet sind. Der SF-DEM ist dabei der einzige Fragebogen, der speziell zur Erfassung von Sozialfunktionen bei Personen mit Demenz entwickelt wurde. Es ist ein strukturierter Interview-Fragebogen, der über zwei Versionen verfügt: einen Selbstbericht zur Befragung von Betroffenen und einen Fremdbericht zur Befragung von Angehörigen oder anderen Bezugspersonen. Beide Versionen des SF-DEM umfassen jeweils vier Sektionen zu unterschiedlichen Aspekten des Sozialverhaltens. Die erste Sektion „Zeit mit anderen Menschen verbringen“ umfasst die Häufigkeit von Kontakten zu Familienmitgliedern, Freunden und weiteren Personen im persönlichen Umfeld und wie häufig an Unternehmungen oder Veranstaltungen mit anderen teilgenommen wurde mit einem Bezugsrahmen über den vergangenen Monat. In der zweiten Sektion „Kommunikation mit anderen Menschen“ werden vor allem mögliche Schwierigkeiten in der Kommunikation mit anderen Personen im vergangenen Monat erfasst, wie zum Beispiel Probleme Gesprächen zu folgen, Schwierigkeiten ein Gesprächsthema mit anderen zu finden, über Sorgen und Gefühle zu sprechen oder wie häufig allgemeine und persönliche Unterhaltungen geführt

wurden. Die Sensibilität gegenüber anderen Menschen wird in der dritten Sektion erfasst. Diese umfasst beispielsweise Streit und Aggressionen oder den Wunsch nach sozialem Rückzug. Die vierte Sektion erfragt globale Einschätzungen zum Sozialverhalten: „Wenn Sie Ihr Sozialleben im Großen und Ganzen betrachten, wie beurteilen Sie es jetzt?“; „Wie ist es jetzt im Vergleich zu einem Jahr zuvor?“; „Würden Sie gern etwas an Ihrem Sozialleben verändern?“ Insgesamt umfasst der Fragebogen 20 Fragen je Version, die sich durch eine einfache und kurze Formulierung auszeichnen und über vorgegebene abgestufte Kategorien beantwortet werden. Insbesondere die zweite, dritte und vierte Sektion des Fragebogens umfassen Aspekte, die typischerweise für Personen mit Demenz relevant sind und in dieser Form in anderen Fragebögen nicht spezifisch erfasst werden.

2. In der zweiten Studie wurde der SF-DEM zunächst anhand des Translation, Review, Adjudication, Pretesting and Documentation (TRAPD)-Modells übersetzt und anschließend anhand einer Pilotstudie psychometrisch überprüft. Es konnte gezeigt werden, dass der SF-DEM für die Zielpopulation, d. h. für Personen mit leichter Demenz und deren Angehörige, sehr akzeptabel ist. Die interne Konsistenz war auf einem akzeptablen Niveau, die Interrater-Reliabilität sehr hoch und die Test-Retest-Reliabilität moderat für beide Versionen. Die Bewertung der Konstruktvalidität war nicht einfach, da es kein geeignetes deutsches Instrument gibt, mit dem der SF-DEM verglichen werden konnte. Es wurden daher Instrumente ausgewählt, von denen angenommen werden konnte, dass sie mit dem SF-DEM korrelieren. Darunter waren z. B. die Größe des sozialen Netzwerkes, die wahrgenommene soziale Unterstützung und die Lebensqualität. Es stellte sich heraus, dass die Ergebnisse des SF-DEM in der Selbstberichtversion nicht mit diesen Konstrukten korrelieren. In der Fremdberichtversion zeigten sich vereinzelt Zusammenhänge. Insgesamt liefern die Ergebnisse dieser Studie vielversprechende Hinweise darauf, dass die deutsche Version des SF-DEM als valider und zuverlässiger Selbst- und Fremdbericht zur Beurteilung der SF bei Personen mit leichter Demenz verwendet werden kann.

3. In der dritten Studie wurde längsschnittlich untersucht, ob soziale Isolation bei Hochaltrigen das Demenzrisiko steigert. Die Berechnung wurde unter Berücksichtigung des konkurrierenden Risikos Mortalität anhand von Daten der multizentrischen Kohortenstudie AgeCoDe/AgeQualiDe durchgeführt. Wir konnten dabei keinen Zusammenhang zwischen

sozialer Isolation und dem Auftreten von Demenz bei Hochbetagten finden. Insgesamt bestätigten die meisten Studien einen Zusammenhang zwischen sozialer Isolation und dem Auftreten von Demenz oder kognitiven Funktionen. Es kann mehrere Gründe geben, warum unsere Ergebnisse nicht mit denen früherer Studien übereinstimmen. Erstens war der Nachbeobachtungszeitraum recht kurz. Ein längerer Beobachtungszeitraum hätte möglicherweise andere Erkenntnisse gebracht. Zweitens lassen sich die Ergebnisse möglicherweise durch Selektionseffekte erklären (Böger & Huxhold, 2018; Holt-Lunstad et al., 2015). Personen, die bereits im mittleren Erwachsenenalter sozial isoliert leben, erreichen möglicherweise nicht das höchste Alter. Vermutlich sind die in dieser Studie untersuchten Personen also widerstandsfähig und haben einen Lebensstil geführt, der ein erfolgreiches Altern wahrscheinlicher macht. Die Unterschiede in den Ergebnissen zu früheren Studien könnten zudem durch die Heterogenität der Studienstichproben erklärt werden. Aber auch die Form des Outcomes spielt eine entscheidende Rolle. Häufig wurden kontinuierliche Werte für die Kognition und nicht Demenz als binäres Ergebnis verwendet. Mit kontinuierlichen kognitiven Werten lassen sich subtilere Veränderungen eher erkennen als mit einem binären diagnostischen Ergebnis, das solide klinische Stufen der Beeinträchtigung darstellt, wie es in unserer Arbeit verwendet wurde. Die Ergebnisse früherer Studien zeigen, dass soziale Isolation die kognitive Funktionsfähigkeit negativ beeinflussen kann. Vermutlich zeigt sich dieser Zusammenhang vor allem dann, wenn soziale Isolation über längere Zeiträume auftritt.

Die Stärken der drei Arbeiten, aus denen sich diese Dissertation zusammensetzt, sind vielfältig. Die ersten beiden Arbeiten haben es ermöglicht, ein Instrument zur Erfassung von Sozialfunktionen bei Personen mit Demenz für den deutschen Sprachraum zur Verfügung zu stellen. Dazu wurde eine umfassende, sehr breit gefächerte Literaturrecherche in drei Datenbanken durchgeführt, die sicherstellt, dass möglichst viele relevante Artikel gefunden wurden. Um die wissenschaftliche Qualität der eingeschlossenen Studien zu gewährleisten, wurden nur Artikel aus Fachzeitschriften berücksichtigt, die vorab in einem Begutachtungsprozess beurteilt wurden. Unseres Wissens nach ist diese Arbeit die erste, die einen Überblick über Instrumente zur Bewertung der Sozialfunktionen bei Personen mit Demenz gibt. Auf Grundlage der Ergebnisse dieser Übersichtsarbeit wurde der SF-DEM nach wissenschaftlichen Kriterien übersetzt und psychometrisch anhand von Befragungen von 28

Dyaden überprüft. Dabei konnte ein breites Spektrum an Personen mit leichter Demenz und jeweils ein Angehöriger berücksichtigt werden. Zudem war die Dropoutrate sehr gering. Die besondere Bedeutung dieser Arbeit liegt in ihrem Neuigkeitswert und der hohen praktischen Relevanz für die Erforschung der Sozialfunktionen bei Demenz.

Die dritte Arbeit basiert auf einer längsschnittlichen Untersuchung des Einflusses sozialer Isolation auf das Auftreten von Demenz bei Hochaltrigen. Dabei konnte ein relativ langer Beobachtungszeitraum berücksichtigt werden. Die Datenqualität der zugrundeliegenden Daten ist hoch. Soweit es uns bekannt ist, ist dies die erste Untersuchung, die soziale Isolation als Risikofaktor für Demenz bei Hochaltrigen mittels Competing Risk-Analyse untersucht. Bei dieser Form der Analyse wurde die Mortalität als konkurrierendes Risiko berücksichtigt. Die Berücksichtigung konkurrierender Risiken ist besonders wichtig, wenn ältere Personen untersucht werden (Fine & Gray, 1999). Insbesondere die Sterblichkeit ist ein relevantes konkurrierendes Risiko bei Älteren, wenn die Assoziation von Gesundheitsfolgen, einschließlich Demenz, untersucht wird (Seshadri et al., 1997).

3.1. Implikationen für zukünftige Studien

Zukünftige Studien sollten die psychometrischen Gütekriterien des SF-DEM über das gesamte Krankheitsspektrum hinweg und bei verschiedenen Formen der Demenz untersuchen und dabei auch Demenzvorstufen mit einbeziehen. Zu klären ist auch, ob sich die Entwicklung der Sozialfunktionen bei verschiedenen Formen der Demenz unterscheidet. Der SF-DEM kann dann zur Verlaufsbeschreibung und zur Beschreibung der Sozialfunktionen über verschiedene Stadien und Typen demenzieller Erkrankungen hinweg beitragen. Diese Informationen können das Verständnis der Erkrankung verbessern und Anknüpfungspunkte für Präventions- und Interventionsmaßnahmen schaffen. Zudem ist eine Anwendung in der individuellen Diagnostik im klinischen und wissenschaftlichen Setting denkbar. Nicht zuletzt ermöglicht der SF-DEM die Erfassung der Sozialfunktionen als Outcome im Rahmen von Interventionsstudien. Zu untersuchen wäre auch, wie sich die Sozialfunktionen bei Personen mit Demenz in unterschiedlichen Settings unterscheiden (z. B. Leben im Pflegeheim vs. Leben im Privathaushalt).

Auch wenn soziale Isolation allgemein als ein Risikofaktor für Demenz gilt (Livingston et al., 2020), sind weitere Studien wünschenswert, die eine Lebenslaufperspektive einnehmen. Die Ergebnisse aus der dritten Arbeit dieser Dissertation unterstreichen, wie wichtig es ist, veränderbare Risikofaktoren für Demenz in Bezug auf verschiedene Altersgruppen aus einer Lebenslaufperspektive heraus zu untersuchen. Es muss geklärt werden, in welcher Lebensphase soziale Isolation einen Risikofaktor darstellt (z. B. im Jugendalter), wie lange eine Person dauerhaft in sozialer Isolation leben muss, bis soziale Isolation ein Risikofaktor für Demenz wird, und ob sich das Risiko umkehren lässt, wenn die Person nach einer bestimmten Zeit nicht mehr von sozialer Isolation betroffen ist. Nur so können optimale Verfahren zur Verringerung des Demenzrisikos ermittelt werden (Röhr & Riedel-Heller, 2021).

Sowohl zukünftige Studien zur Erforschung sozialer Isolation als Risikofaktor für Demenz als auch Studien zu den Sozialfunktionen im Verlauf von Demenzerkrankungen sollten Daten verschiedener Länder einbeziehen. Nur so können kulturelle Unterschiede Berücksichtigung finden. Zudem sollten innerhalb verschiedener Länder alle Bevölkerungsgruppen und alle Demenztypen vertreten sein.

3.2. Schlussfolgerung

Aktuell ist nur wenig über soziale Aspekte bei Demenz bekannt. Die Arbeiten, aus denen sich diese Dissertation zusammensetzt, greifen diese Lücke auf. Es wurde ein Instrument zur Erfassung von Sozialfunktionen speziell bei Personen mit Demenz für den deutschen Sprachraum verfügbar gemacht. Es bildet eine gute Grundlage, um mehr über Sozialfunktionen im Verlauf demenzieller Erkrankungen und bei Demenzvorstufen zu erfahren. Damit ist ein wichtiger Grundstein zur Erforschung sozialer Aspekte bei Demenz gelegt. Zudem wurde in einer weiteren Arbeit soziale Isolation als ein Risikofaktor für Demenz bei Hochaltrigen längsschnittlich untersucht. Dabei zeigte sich nach Berechnung von Competing Risk-Analysen kein Zusammenhang zwischen sozialer Isolation und Demenz.

Zukünftige Studien sollten soziale Aspekte demenzieller Erkrankungen möglichst aus einer Lebenslaufperspektive heraus untersuchen. Die deutsche Version des SF-DEM sollte über das gesamte Krankheitsspektrum hinweg, einschließlich der Demenzvorstufen, psychometrisch

und hinsichtlich ihrer Akzeptanz und Anwendbarkeit überprüft werden. Entsprechende Forschungsergebnisse sind von großer Bedeutung, da die Berücksichtigung sozialer Aspekte bei demenziellen Erkrankungen die Chancen für die Reduzierung des Demenzrisikos als auch die Verbesserung des Krankheitsverlaufs maximieren können.

Zusammenfassung

Kumulative Dissertation zur Erlangung des akademischen Grades Dr. rer. nat.

Soziale Aspekte bei Demenz

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Durch den demografischen Wandel, der mit einer Alterung der Gesellschaft einhergeht, wird es neue Herausforderungen in Bezug auf Alterserkrankungen geben. Demenz ist die am häufigsten vorkommende Erkrankung im Alter, bei der es zu einem zunehmenden Abbau der kognitiven Funktionsfähigkeit kommt. Dieser wiederum führt i. d. R. zu einem Verlust der Selbstständigkeit und zum frühzeitigen Tod. Aktuell gibt es keine Heilungsmöglichkeiten für demenzielle Erkrankungen. Daher ist es umso wichtiger, wirkungsvolle Präventions- und Interventionsmaßnahmen zu entwickeln. Grundvoraussetzung dafür ist ein umfassendes Verständnis über die Risikofaktoren der Erkrankung, aber auch über die Symptomatik in den verschiedenen Bereichen.

Aktuell ist nur wenig darüber bekannt, welche Rolle soziale Aspekte bei der Entstehung von Demenz spielen und wie sich soziale Aspekte über das gesamte Krankheitsspektrum hinweg

verändern. Ein Grund dafür ist, dass es kaum geeignete Instrumente zur Erfassung sozialer Aspekte, wie z. B. Sozialfunktionen, speziell für Personen mit Demenz gibt.

Daher wurde in einer ersten Arbeit eine umfassende Literaturrecherche nach der Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISAM)-Leitlinie durchgeführt, um geeignete Instrumente zur Erfassung der Sozialfunktionen bei Demenz zusammenzutragen. Von 5.307 gefundenen Artikeln wurden 8 für die Übersichtsarbeit ausgewählt, die insgesamt drei Instrumente zur Messung der sozialen Funktionsfähigkeit bei Menschen mit Demenz beschreiben: die Nurses' Observation Scale for Geriatric Patients (NOSGER; Skala „Sozialverhalten“), die Socioemotional Dysfunction Scale (SDS) und die Social Functioning in Dementia Scale (SF-DEM). Die Validität aller drei Instrumente war insgesamt akzeptabel. Die Reliabilität der NOSGER-Skala „Sozialverhalten“ und der SF-DEM war hoch. Informationen über die Benutzerfreundlichkeit der Instrumente waren kaum vorhanden. Insgesamt hat sich die im angloamerikanischen Raum entwickelte Social Functioning in Dementia Scale (deutsch: „Sozialfunktionen bei Demenz“-Fragebogen; kurz: SF-DEM) als besonders geeignet für die Erfassung von Sozialfunktionen bei Demenz herausgestellt.

Auf diesem Ergebnis fußt die zweite Arbeit. Ihr Ziel bestand darin, den SF-DEM für den deutschen Sprachraum zu adaptieren und ihn psychometrisch zu überprüfen. Dazu wurde zunächst ein mehrstufiger, teambasierter Übersetzungsprozess auf Grundlage des Translation, Review, Adjudication, Pretesting and Documentation (TRAPD)-Modells durchgeführt. Zweitens wurden Dyaden befragt, bestehend aus Personen mit leichter Demenz und jeweils einem Angehörigen, um die interne Konsistenz, Test-Retest-Reliabilität, Interrater-Reliabilität, Konstruktvalidität und Akzeptanz der deutschen Version des SF-DEM zu testen. Die interne Konsistenz der Selbst- und Fremdberichtversion liegt auf einem akzeptablen Niveau. Die Interrater-Reliabilität war für beide Versionen ausgezeichnet und die Test-Retest-Reliabilität moderat. Die Ergebnisse der Fremdberichtversion korrelierten stark mit der Größe des sozialen Netzwerkes, gemessen mit der Lubben Social Network Scale (Lubben et al., 2006; LSNS-6) und der Lebensqualität in Bezug auf Ehe und Freundschaften, erhoben mit dem „Lebensqualität bei Demenz“ - Fragebogen (Stypa et al., 2020; QoL-AD). Darüber hinaus wurde der SF-DEM von den Teilnehmern akzeptiert. Damit lässt sich zusammenfassend festhalten, dass die deutsche Version des SF-DEM ein valides, reliables

und akzeptables Instrument zur Erfassung der Sozialfunktionen bei Menschen mit Demenz ist. Weitere Untersuchungen sollten die psychometrischen Eigenschaften bei Personen mit mittleren und schweren Demenzen über das gesamte Krankheitsspektrum hinweg untersuchen.

Die dritte Arbeit untersucht den Zusammenhang zwischen sozialer Isolation und Demenz. Es wurden Competing Risk-Analysen anhand der Daten aus der AgeCoDe-Studie berechnet und kein Zusammenhang zwischen sozialer Isolation und dem Auftreten von Demenz bei Hochaltrigen gefunden. Damit weicht unser Ergebnis von denen anderer Untersuchungen ab. Die Unterschiede in den Ergebnissen lassen sich jedoch durch methodische Unterschiede erklären. Darunter zählen z. B. die verwendete Analysestrategie, die Form des Outcomes, die Länge des Nachbeobachtungszeitraumes und die Eigenschaften der untersuchten Stichprobe.

Zusammenfassend lässt sich festhalten, dass momentan nur wenig über soziale Aspekte in Bezug auf demenzielle Erkrankungen bekannt ist. Zukünftige Studien könnten vielversprechende Ergebnisse liefern, die wichtig sind für eine bessere Diagnostik und Früherkennung von Demenz, aber auch für die Entwicklung von Interventions- und Präventionskonzepten. Beide Punkte sind von großer Bedeutung, da es momentan noch keine Möglichkeit zur Heilung demenzieller Erkrankungen gibt. Die Arbeiten, aus denen sich diese Dissertation zusammensetzt, legen einen wichtigen Grundstein für zukünftige Untersuchungen auf diesem Gebiet.

Liste der Veröffentlichungen für die kumulative Dissertation:

1. Grothe, J., Schomerus, G., Dietzel, J., Riedel-Heller, S., & Röhr, S. (2021). Instruments to Assess Social Functioning in Individuals with Dementia: A Systematic Review. *Journal of Alzheimer's Disease*: JAD, 80(2), 619–637. https://doi.org/10.3233/JAD-200762.

2. Grothe, J., Luppa, M., Dietzel, J., Schomerus, G., Sommerlad, A., Riedel-Heller, S. G., & Röhr, S. (2022). Psychometric Evaluation of the German Version of the Social Functioning in Dementia Scale. *Journal of Alzheimer's Disease*, 7, 1–11. https://doi.org/10.3233/JAD-215557

3. Grothe, J., Röhr, S., Luppa, M., Pabst, A., Kleineidam, L., Heser, K., Fuchs, A., Pentzek, M., Oey, A., Wiese, B., Lühmann, D., van den Bussche, H., Weyerer, S., Werle, J., Weeg, D., Bickel, H., Scherer, M., König, H.-H., Hajek, A., . . . Riedel-Heller, S. G. (2022). Social Isolation and Incident Dementia in the Oldest-Old—A Competing Risk Analysis. Frontiers in Psychiatry, 13, Article 834438, 535. https://doi.org/10.3389/fpsyt.2022.834438

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Appendix A: Erklärung zum Promotionsbeitrag

Darstellung des wissenschaftlichen Beitrags der Promovendin Jessica Grothe zur folgenden Veröffentlichung im Rahmen einer kumulativen Promotion

Grothe, J., Schomerus, G., Dietzel, J., Riedel-Heller, S., & Röhr, S. (2021). Instruments to Assess Social Functioning in Individuals with Dementia: A Systematic Review. *Journal of Alzheimer's Disease: JAD*, 80(2), 619–637.

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- Entwicklung von Ein- und Ausschlusskriterien
- Entwurf einer Suchstrategie
- Auswahl der Studien auf Basis der Ein- und Ausschlusskriterien
- Ergebnisextraktion- und Darstellung
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Jessica Grothe, M.Sc.

Leipzig, 19.04.2022
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Jessica Grothe, M.Sc.

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Ort, Datum

Dietzel
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Dr. phil. Alexander Pabst

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Bonn, 10.05.2022 Ort, Datum	Luca Kleineidam
Ort, Datum	K. Heser Dr. Kathrin Heser, Dipl. Psych.
Ort, Datum	A Oey Anke Oey
Hannover, 03.05.2022 Ort, Datum	Birgitt Wiese Dipl.-Math. Birgitt Wiese
Ort, Datum	D. Lühmann Dr. med. Dagmar Lühmann

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Hiermit bestätige ich als Koautor/in der o.g. Veröffentlichung, dass die Promovendin Jessica Grothe den wesentlichen Beitrag zur Erstellung und Veröffentlichung der Publikation geleistet habe. Ihr Beitrag als Erstautorin umfasste dabei im Einzelnen:

- Datenaufbereitung
- Analyse der Daten
- Interpretation der Ergebnisse
- Manuskripterstellung
- Manuskripteinreichung und –überarbeitung im Gutachterprozess

Leipzig, 14.06.22
Ort, Datum

Grothe
Jessica Grothe, M.Sc.

Mannheim, 12.05.2022
Ort, Datum

Prof. Dr. Siegfried Weyerer

Ort, Datum

Dr. Jochen Werle

München, 10.05.2022
Ort, Datum

Dagmar Weeg
Dr. Dagmar Weeg

Ort, Datum

H. Bickel
Dr. Horst Bickel

Hamburg, 09.05.2022
Ort, Datum

Prof. Dr. Hans-Helmut König

Ort, Datum

Prof. Dr. André Hajek

Appendix B: Eigenständigkeitserklärung

Hiermit erkläre ich, dass ich die vorliegende Arbeit selbstständig und ohne unzulässige Hilfe oder Benutzung anderer als der angegebenen Hilfsmittel angefertigt habe. Ich versichere, dass Dritte von mir weder unmittelbar noch mittelbar eine Vergütung oder geldwerte Leistungen für Arbeiten erhalten haben, die im Zusammenhang mit dem Inhalt der vorgelegten Dissertation stehen, und dass die vorgelegte Arbeit weder im Inland noch im Ausland in gleicher oder ähnlicher Form einer anderen Prüfungsbehörde zum Zweck einer Promotion oder eines anderen Prüfungsverfahrens vorgelegt wurde. Alles aus anderen Quellen und von anderen Personen übernommene Material, das in der Arbeit verwendet wurde oder auf das direkt Bezug genommen wird, wurde als solches kenntlich gemacht. Insbesondere wurden alle Personen genannt, die direkt an der Entstehung der vorliegenden Arbeit beteiligt waren. Die aktuellen gesetzlichen Vorgaben in Bezug auf die Zulassung der klinischen Studien, die Bestimmungen des Tierschutzgesetzes, die Bestimmungen des Gentechnikgesetzes und die allgemeinen Datenschutzbestimmungen wurden eingehalten. Ich versichere, dass ich die Regelungen der Satzung der Universität Leipzig zur Sicherung guter wissenschaftlicher Praxis kenne und eingehalten habe.

Leipzig, Dezember 2022 Jessica Grothe

Appendix C: Lebenslauf

Aus Gründen des Datenschutzes ist mein Lebenslauf in der elektronischen Version der Doktorarbeit nicht aufgeführt.

Appendix D: Wissenschaftliche Beiträge

Publikationen

Grothe, J.; Röhr, S.; Luppa, M.; Pabst, A.; Kleineidam, L.; Heser, K. et al. (2022): Social Isolation and Incident Dementia in the Oldest-Old—A Competing Risk Analysis. In: Front. Psychiatry 13, S. 535. DOI: 10.3389/fpsyt.2022.834438. (IF: 4.86)

Grothe, J.; Luppa, M.; Dietzel, J.; Schomerus, G.; Sommerlad, A.; Riedel-Heller, S.G.; Röhr, S. (2022) Psychometric Evaluation of the German Version of the Social Functioning in Dementia Scale. In: Journal of Alzheimer's Disease. 7, S. 1–11. DOI: 10.3233/JAD-215557. (IF: 4.472)

Grothe, J.; Schomerus, G.; Dietzel, J.; Riedel-Heller, S.; Röhr, S. (2021): Instruments to Assess Social Functioning in Individuals with Dementia: A Systematic Review. In: Journal of Alzheimer's disease: JAD 80 (2), S. 619–637. DOI: 10.3233/JAD-200762. (IF: 4.472)

Gühne, U.; Dorow, M.; **Grothe, J.**; Stein, J.; Löbner, M.; Dams, J. et al. (2021): Valuing end-of-life care: translation and content validation of the ICECAP-SCM measure. In: BMC palliative care 20 (1), S. 29. DOI: 10.1186/s12904-021-00722-5. (IF: 2.93)

Konferenzbeiträge

Vorträge

2021

Grothe, J.; Röhr, S.; Luppa, M; Scherer, M.; Weyerer, S.; König, H-H; Wagner, M.; Riedel-Heller, SG. Social isolation and incident dementia in the oldest-old. A competing risk analysis. 20. – 22.09.2021, digital, DGEpi, Deutschland.

Grothe, J.; Röhr, S.; Luppa, M; Scherer, M.; Weyerer, S.; König, H-H; Wagner, M.; Riedel-Heller, SG. Social isolation and incident dementia in the oldest-old. A competing risk analysis. 22.-24.09.2021, dgital, DGSMP, Deutschland.

Grothe, J; Riedel-Heller, SG.; Dietzel, J.; Schomerus, G.; Röhr, S. SF-DEM: Veränderungen im Sozialverhalten im Verlauf dementieller Erkrankungen erfassen. Ein Instrument für Forschung und Klinik im deutschsprachigen Raum. 22.-24.09.2021, digital, DGSMP, Deutschland.

Grothe, J; Luppa, M.; Dietzel, J.; Schomerus, G.; Riedel-Heller, SG.; Röhr, S. SF-DEM: Veränderungen im Sozialverhalten im Verlauf dementieller Erkrankungen erfassen. Ein Instrument für Forschung und Klinik im deutschsprachigen Raum. 06. – 08.10.2021, digital, DKVF, Deutschland.

Posterpräsentation

2019

Grothe, J.; Dietzel, J.; Schomerus, G.; Riedel-Heller, SG.; Röhr, S. Assessing changes in social functioning in the course of dementia: an instrument for research and clinical practice in German-speaking areas. 18.01.2019, Leipzig, Research Festival, Deutschland.

Appendix E: Danksagung

Aus Gründen des Datenschutzes ist mein Lebenslauf in der elektronischen Version der Doktorarbeit nicht aufgeführt.