Determinanten der informellen Pflege in Deutschland: Gesundheitsökonomische Beiträge zur Untersuchung von Bereitschaft und Präferenzen

Von der Wirtschaftswissenschaftlichen Fakultät der
Gottfried Wilhelm Leibniz Universität Hannover
zur Erlangung des akademischen Grades

Doktorin der Wirtschaftswissenschaften
– Doctor rerum politicarum –

genehmigte Dissertation
von

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2022

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Tag der Promotion: 04.10.2022

Zusammenfassung

Aufgrund des demografischen Wandels wird die Zahl pflegebedürftiger Menschen in Deutschland weiter steigen. Im Jahr 2019 wurden 80% der Pflegebedürftigen in Deutschland zu Hause versorgt; die Mehrheit davon durch Angehörige, Freunde oder Nachbarn (56%). Diese sogenannte informelle Pflege ist mit deutlichen Kostenvorteilen für die Pflegeversicherung verbunden und entspricht den Wünschen der meisten Älteren. Aufgrund bestehender Mängel an professionellen Pflegekräften und Pflegestrukturen in Deutschland ist mit einem Anstieg des Bedarfs an informeller Pflege zu rechnen. Die Sicherstellung der künftigen Pflege hängt somit unter anderem von der Bereitschaft nahestender Personen ab, diese Art der Pflege zu übernehmen. Das informelle Pflegepotenzial könnte jedoch in Zukunft abnehmen, unter anderem durch Veränderungen der Voraussetzungen für die Übernahme der Pflege, wie beispielsweise ein abnehmendes Pflichtgefühl in der Gesellschaft.

Das Ziel dieser Dissertation liegt in der Untersuchung der Pflegepräferenzen und erwarteten Pflegebereitschaft der deutschen Allgemeinbevölkerung. Hierbei werden mithilfe von neun Modulen zentrale Determinanten der informellen Pflege untersucht, methodische Aspekte bei der Ermittlung von Pflegepräferenzen aufgezeigt und die Bedeutung einer Lohnersatzleistung für informell Pflegende, als geeignetes Instrument zur Erhöhung der Pflegebereitschaft, diskutiert. Eingeordnet werden die eingeschlossenen Publikationen in das *Informal Care Model* von van Groenou und de Boer (2016) und in Deutschland in Hinblick auf die Modelldimensionen untersucht.

In den letzten Jahren zeigt sich als Vorgehensweise eine zunehmende Nutzung von wahlbasierten „stated-preference“ Methoden, wie dem Discrete Choice Experiment (DCE) zur Ermittlung und Quantifizierung von Pflegepräferenzen. Umfangreiche Vorstudien (systematische Literaturrecherchen, qualitative Interviews) wurden in dieser Dissertation zur Problemdefinition und Identifikation relevanter Entscheidungskriterien für die Präferenzerhebung mittels DCE angewandt. Erstmals wurde die erwartete Pflegebereitschaft der Allgemeinbevölkerung in Deutschland mittels dieser Methodik erhoben. Dabei konnten wichtige Erkenntnisse relevanter Einflussfaktoren auf die Pflegebereitschaft generiert sowie Präferenzheterogenitäten aufgezeigt werden. Der Einbezug einer Lohnersatzleistung hat die Berechnung monetärer Mindestsätze für die Erbringung informeller Pflege in Deutschland ermöglicht. Die Ergebnisse der Analysen haben gezeigt, dass ein finanzieller Ausgleich die Pflegebereitschaft bestimmter Subgruppen erhöhen könnte, während andere den Pflegeumfang oder die Häufigkeit einer professionellen Unterstützung als wichtiger einstuften. Somit bedarf es flexibler Ansätze zur Erhöhung der Pflegebereitschaft. Die neun Publikationen konnten zudem den wachsenden Stellenwert der Präferenzerhebung im Bereich der Langzeitpflege ganzheitlich aufzeigen.

Schlagwörter: Informelle Pflege, Präferenzen, Bereitschaft, Discrete Choice Experiment, Versorgungsforschung, Gesundheitsökonomie, Lohnersatzleistung, Informal Care Model

Abstract

The number of people in need of care will continue to rise in Germany due to demographic changes. In 2019, 80% of those in need of care in Germany were cared for at home, the majority by relatives, friends or neighbors (56%). This so-called informal care is associated with significant cost benefits for the long-term care insurance and corresponds to the wishes of most older adults. Due to existing shortages of professional caregivers and care structures in Germany, the need for informal care is expected to increase in the future. Securing future care thus depends, among other aspects, on the continued willingness of close relatives to provide informal care. However, the potential for informal care could decrease in the future due to, amongst others, changes in the prerequisites for taking on the role of informal caregiver, for example a decreasing sense of obligation in the society.

The aim of this dissertation is to investigate care preferences and expected willingness to provide informal care in the German general population. With the help of nine modules, central contributing factors of informal care are examined, methodological aspects when eliciting care preferences are highlighted, and the significance of a monetary compensation for informal caregivers as a suitable instrument for increasing willingness to care is discussed. The included publications are classed in the *Informal Care Model* by van Groenou and de Boer (2016) and examined with regard to the model dimensions in Germany.

In recent years, choice-based "stated-preference" methods such as the Discrete Choice Experiment (DCE) have been increasingly utilised to conduct and quantify care preferences. Extensive preliminary studies (systematic literature reviews, qualitative interviews) were applied in this dissertation to specifically define the problem at hand and identify relevant decision-criteria for eliciting preferences using a DCE. For the first time, the expected willingness to provide care in the German general population was surveyed using this methodology. Important insights into relevant factors that influence willingness to provide informal care were generated and preference heterogeneities were identified. The inclusion of a monetary compensation enabled the calculation of minimum rates that were accepted for the provision of informal care in Germany. The results of the analyses showed that a financial compensation could increase the willingness to care of certain subgroups, while others rated the extent of care or the frequency of professional support as more important. Thus, flexible approaches are needed to increase readiness to care. The nine publications were also able to demonstrate the growing importance of preference elicitation in the field of long-term care in a holistic manner.

Keywords: Informal care, Preferences, Willingness, Discrete choice experiment, Health services research, Health economics, Monetary compensation, Informal Care Model

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1. Motivation und Zielsetzung

1.1. Status Quo und Rahmenbedingungen

Die Alterung der Gesellschaft, insbesondere in den Industrienationen, wird schon lange als globales Phänomen erkannt. Die Geschwindigkeit der anteiligen Zunahme der älteren Menschen wird je nach Land jedoch unterschiedlich beobachtet und erwartet [1]. Da ein höheres Alter mit einer steigenden Wahrscheinlichkeit pflegebedürftig zu werden einhergeht, stellt die Bereitstellung und Finanzierung von Langzeitpflege eine große Herausforderung für nationale Gesundheitssysteme dar. Die deutsche Bevölkerung gehört heutzutage bereits zu einer der ältesten Bevölkerungen weltweit [1]. Schätzungen zufolge lag der Anteil pflegebedürftiger Personen Ende 2019 bei 4,1 Millionen. Der Großteil der deutschen Pflegebedürftigen ist 65 Jahre und älter (80%) und die Mehrheit sind Frauen (62%) [2]. Für das Jahr 2030 werden aktuellen Schätzungen zufolge 6 Millionen Pflegebedürftige prognostiziert. Diese Zahl überschreitet somit die bisher angenommenen Vorhersagen [2, 3]. Aufgrund der Zunahme chronischer Erkrankungen und der wachsenden Zahl pflegebedürftiger Personen werden ebenfalls steigende Kosten erwartet, während infolge niedriger Fertilitätsraten mit sinkenden Einnahmen für die Pflegeversicherung zu rechnen ist [4]. Derzeitige Prognosen erwarten bei einem konstant bleibenden Leistungsspektrum der Pflegeversicherung jährliche Mehrausgaben im Jahr 2030 in Höhe von 13,4 Milliarden Euro im Vergleich zum Jahr 2020 [3]. Der Großteil der 4,1 Millionen Pflegebedürftigen (80%) in Deutschland wurde 2019 zu Hause versorgt, entweder alleine durch Angehörige, Freunde oder Nachbarn (56%) und/oder durch ambulante Pflegedienste (24%) [2].

Die erbrachte Pflege und Versorgung ausschließlich durch nahestehende Personen wird auch als informelle Pflege bezeichnet und geschieht in der Regel ohne finanzielle Entschädigung oder Bezahlung [5]. Diese Art der Pflege ist eine zentrale Säule sowohl in der deutschen als auch in der Pflegeversorgung anderer Länder [5, 6]. Die informelle bzw. häusliche Pflege wird in Deutschland auch von Seiten der Politik gestärkt und ist fest im Sozialgesetzbuch (§3 SGB XI) verankert [7]. Eine verpflichtende Pflegeversicherung wurde 1995 für die gesamte deutsche Bevölkerung eingeführt und ist entweder an eine gesetzliche oder private Krankenversicherung gekoppelt [8]. Die pflegerische Versorgung in Deutschland ist als gesamtgesellschaftliche Aufgabe definiert (§8 SGB XI). Die Pflegekassen tragen dabei die Verantwortung für die Sicherstellung der strukturellen Voraussetzungen (§12 SGB XI). Seit Einführung der Pflegeversicherung haben diverse Gesetzesänderungen zur Weiterentwicklung der sozialen Pflegeversicherung beigetragen. Drei Pflegestärkungsgesetze (PSG I, II und III) haben seit Anfang 2015 unter anderem eine Umstellung des Pflegebegutachtungsverfahrens bewirkt, in dem eine Einteilung in fünf Pflegegrade vollzogen wurde. Auf Basis von sechs Modulen wird auf einer Skala von 0 bis 100 Punkten die Einstufung in einen dieser Pflegegrade vorgenommen, wobei ein höherer Pflegegrad mit einem höheren verfügbaren Budget an Geld- und/oder Pflegesachleistungen einhergeht [9, 10].

Die häusliche bzw. informelle Pflege ist zum einen mit deutlichen Kostenvorteilen für die deutsche Pflegeversicherung verbunden und entspricht zum anderen den Präferenzen und Wünschen der meisten Älteren [11]. Eine Versorgung in der vertrauten Umgebung wird oftmals mit der Erhaltung sozialer Kontakte und einem hohen Grad an Selbstständigkeit und Unabhängigkeit verbunden. Im Vergleich hierzu wird von vielen Betroffenen die Versorgung in einer stationären Pflegeeinrichtung hingegen mit einem Verlust von Freiheit und Unabhängigkeit in Verbindung gebracht [12]. In einer repräsentativen deutschen Stichprobe gaben 87% der Befragten an, dass sie in Zukunft im Falle einer Pflegebedürftigkeit in ihrer vertrauten Umgebung bleiben möchten [13]. Ein weiterer Grund für die zunehmende Bedeutung der informellen Pflege ist der bereits bestehende Mangel an professionellen Pflegekräften in Deutschland, welcher die Gewährleistung einer ausreichenden ambulanten und stationären Pflegeversorgung erschwert [14].

Durch den Anstieg der Pflegebedürftigen sowie der strukturellen und finanziellen Herausforderungen des aktuellen Pflegesystems ist mit einer Zunahme des Bedarfs an informeller Pflege zu rechnen [15]. Die Sicherstellung der künftigen Pflege hängt daher weiterhin von der Bereitschaft Familienangehöriger, informell zu pflegen, ab. Umfragen haben jedoch gezeigt, dass vor allem jüngere Befragte eine geringere familiäre Zugehörigkeit und ein weniger ausgeprägtes Pflichtgefühl für die Pflege ihrer älteren Angehörigen empfinden [16]. Zudem haben sich die Voraussetzungen für die informelle Pflege verschlechtert [17]. Dazu zählen gesellschaftliche Veränderungen wie eine steigende Erwerbstätigkeit von Frauen sowie die Abnahme der Geburtenrate bzw. die Zunahme kinderloser Familien. Darüber hinaus führen Auswirkungen der Globalisierung, insbesondere die zunehmende berufliche Mobilität, häufig zu größeren geografischen Distanzen zwischen Familienmitgliedern [15, 17]. Daher könnte das Potenzial der informellen Pflege in Zukunft abnehmen, während davon ausgegangen wird, dass die Nachfrage weiter steigen wird [18].

Die Übernahme informeller Pflegetätigkeit geht oftmals mit erheblichen Veränderungen für die pflegende Person einher. Studien berichten von Auswirkungen auf die Gesundheit, Lebensqualität sowie auf die berufliche Tätigkeit und finanzielle Situation der pflegenden Person [3, 19]. Am häufigsten wird von psychischen und physischen Symptomen wie Rückenschmerzen, Schlafmangel und Depression sowie Lohneinbußen in Folge einer reduzierten oder vollständig pausierten Berufstätigkeit berichtet [3, 20]. Die Vereinbarkeit von Pflege- und Berufstätigkeit stellt für viele pflegende Angehörige eine besondere Herausforderung dar und kann infolgedessen die Wahrscheinlichkeit einer Vollzeitbeschäftigung nachhaltig senken [21]. Vor diesem Hintergrund gibt es unterschiedliche Studien sowie ökonomische Theorien, welche Erklärungsansätze für die Entscheidung, informell zu pflegen, ausarbeiten. Aus ökonomischer Sicht ist die Entscheidung, einen Angehörigen zu pflegen, nur dann rational, wenn der Nutzen (bspw. erhöhtes Selbstwertgefühl) die Kosten überwiegt. Das Modell des altruistischen Verhaltens nimmt an, dass die pflegende Person einen Nutzen aus dem Wohlbefinden der pflegebedürftigen Person zieht und dieser Nutzen größer ist als die empfundenen Belastungen. Weitere ökonomische Modelle beruhen auf einem strategischen Austauschmotiv zwischen Eltern und ihren Kindern in Form von finanziellen Anreizen oder Erbschaften, um den Entscheidungsprozess zu erklären [22]. Eine Einbeziehung informeller Pflege in ökonomische Analysen ist in Form von monetären Bewertungen oder Feststellung der Auswirkungen auf die pflegende Person möglich [23].

Die Erhebung von Präferenzen im Bereich der Langzeitpflege hat in den letzten Jahren stark zugenommen, insbesondere mithilfe quantitativer Präferenzmessmethoden wie dem Discrete Choice Experiment (DCE) oder der Conjoint Analyse [12]. Das DCE gehört zu den multi-attributiven Methoden und wird zunehmend in der Gesundheitsökonomie eingesetzt, um die Präferenzen von Individuen zu ermitteln und zu quantifizieren. Hierbei werden die Befragten gebeten, sich in mehreren Situationen jeweils zwischen zwei Alternativen zu entscheiden. Dabei liegt jedem DCE die Annahme zugrunde, dass Gesundheitsmaßnahmen und -produkte in eine Reihe von Merkmalen (Attributen) zerlegt und durch diese beschrieben werden können und dass die Individuen diese Merkmale je nach Ausprägung unterschiedlich bewerten [24]. Die getroffenen Entscheidungen können anschließend mithilfe unterschiedlicher Regressionsmodelle analysiert werden und ermöglichen somit eine Schätzung der Bedeutung der einzelnen Attribute sowie der Abwägungsentscheidungen (*Trade-offs*). Hier besteht die Annahme, dass Individuen sich für die Alternative mit dem aus subjektiver Sicht maximalen Nutzen entscheiden.

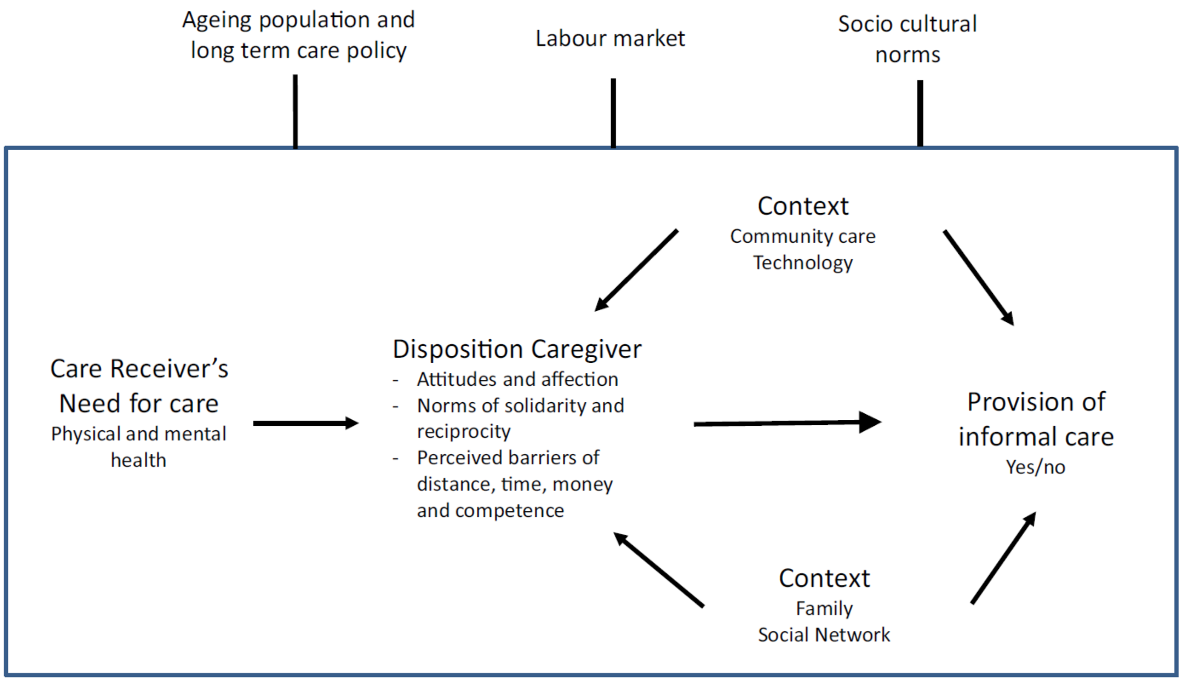
Im Bereich der informellen Pflege wird oftmals die Contingent Valuation Methodik angewandt, um einen monetären Wert für eine Stunde informeller Pflege zu berechnen, entweder durch die Schätzung der Zahlungsbereitschaft (*Willingness-to-pay/WTP*) für die Reduzierung einer Pflegestunde oder des akzeptierten Mindestlohns für eine zusätzliche Stunde informeller Pflege (*Willingness-to-accept/ WTA*). Die Ermittlung von Präferenzen kann wichtige Erkenntnisse liefern, wie Leistungen und Pflegestrukturen an die Bedürfnisse, Erwartungen und Wünsche der Nutzer präferenzbasiert angepasst und optimiert werden können. Im Bereich der informellen Pflege ist neben der Ermittlung von Präferenzen auch die Untersuchung der Pflegebereitschaft bedeutend. Dieses Wissen über die Pflegebereitschaft in der Allgemeinbevölkerung kann gezielte Hinweise auf die Tragfähigkeit der aktuellen Pflegesysteme, die Verfügbarkeit von informellen Pflegepersonen sowie auf die Einordnung von Unterstützungsaspekten, die für potenziell pflegende Personen besonders relevant sind, liefern.

1.2. Theoretischer Bezugsrahmen und Ableitung der Forschungsfragen

Zur Erläuterung der Einflussfaktoren auf die Entscheidung, informell zu pflegen, wurde 2016 von den Autorinnen van Groenou und de Boer ein theoretisches Modell („*Informal Care Model*“) erstellt. Theoretische Konzepte im Bereich der informellen Pflege konzentrieren sich meist auf deren Folgen (insbesondere Gesundheit und Belastung) und weniger auf die Prozesse und Determinanten, welche die

Erbringung der informellen Pflege beeinflussen. Diese Forschungslücke hat das *Informal Care Model* geschlossen. Das Modell konzentriert sich auf die Perspektive der pflegenden Person und beinhaltet drei zentrale Komponenten: (1) informelle Pflege beginnt mit der Vorstellung bzw. dem Eintritt einer Pflegebedürftigkeit im sozialen Netzwerk, (2) individuelle Einstellungen bestimmen die Wahrscheinlichkeit, mit der die potenziell pflegende Person tatsächlich informell pflegen wird und (3) die Übernahme oder Ablehnung der informellen Pflege hängt von äußeren Bedingungen ab. Die Übernahme informeller Pflege wird als Prozess dargestellt, welcher sowohl von individuellen als auch kontextuellen und relationalen Faktoren beeinflusst wird (s. Abbildung 1). Des Weiteren wurden drei politische bzw. gesellschaftliche Bereiche identifiziert, welche sich auf den gesamten Prozess der informellen Pflege auswirken können: (1) die Alterung der Bevölkerung und die Langzeitpflegestrukturen im jeweiligen Land, (2) der Arbeitsmarkt (bspw. höheres Renteneintrittsalter), (3) der soziokulturelle Kontext im jeweiligen Land (bspw. Veränderungen der Werte und Normen in der Gesellschaft).

Abbildung 1: *„Informal Care Model: determinants of informal care provision at the individual level“*



Quelle: van Groenou & de Boer (2016) [25]

Die individuelle Einstellung bzw. die Bereitschaft der potenziell pflegenden Person wird in dem Modell als Konsequenz der zugrundeliegenden Motivationen, Werte sowie potenziellen Barrieren verstanden. Häufig genannte Motivationen und Werte sind die emotionale Bindung zur pflegebedürftigen Person, Liebe und Zuneigung, Pflichtgefühl oder Familienzusammenhalt [26, 27]. Mögliche Barrieren umfassen größere geografische Distanzen zwischen Familienangehörigen, Kosten als Konsequenz der Pflegetätigkeit sowie fehlende Kompetenzen oder Zeit. Die Übernahme der Pflege kann von kontextuellen Faktoren wie der Familienstruktur und -dynamik, dem sozialen Netzwerk, den angebotenen ambulanten Pflegeleistungen und der Pflegeinfrastruktur positiv oder negativ beeinflusst werden.

In der vorliegenden Dissertation sollen alle eingeschlossenen Publikationen in das *Informal Care Model* eingeordnet und die Modelldimensionen anhand empirischer Beispiele untersucht werden. Dabei verfolgt die Dissertation folgende Fragestellungen:

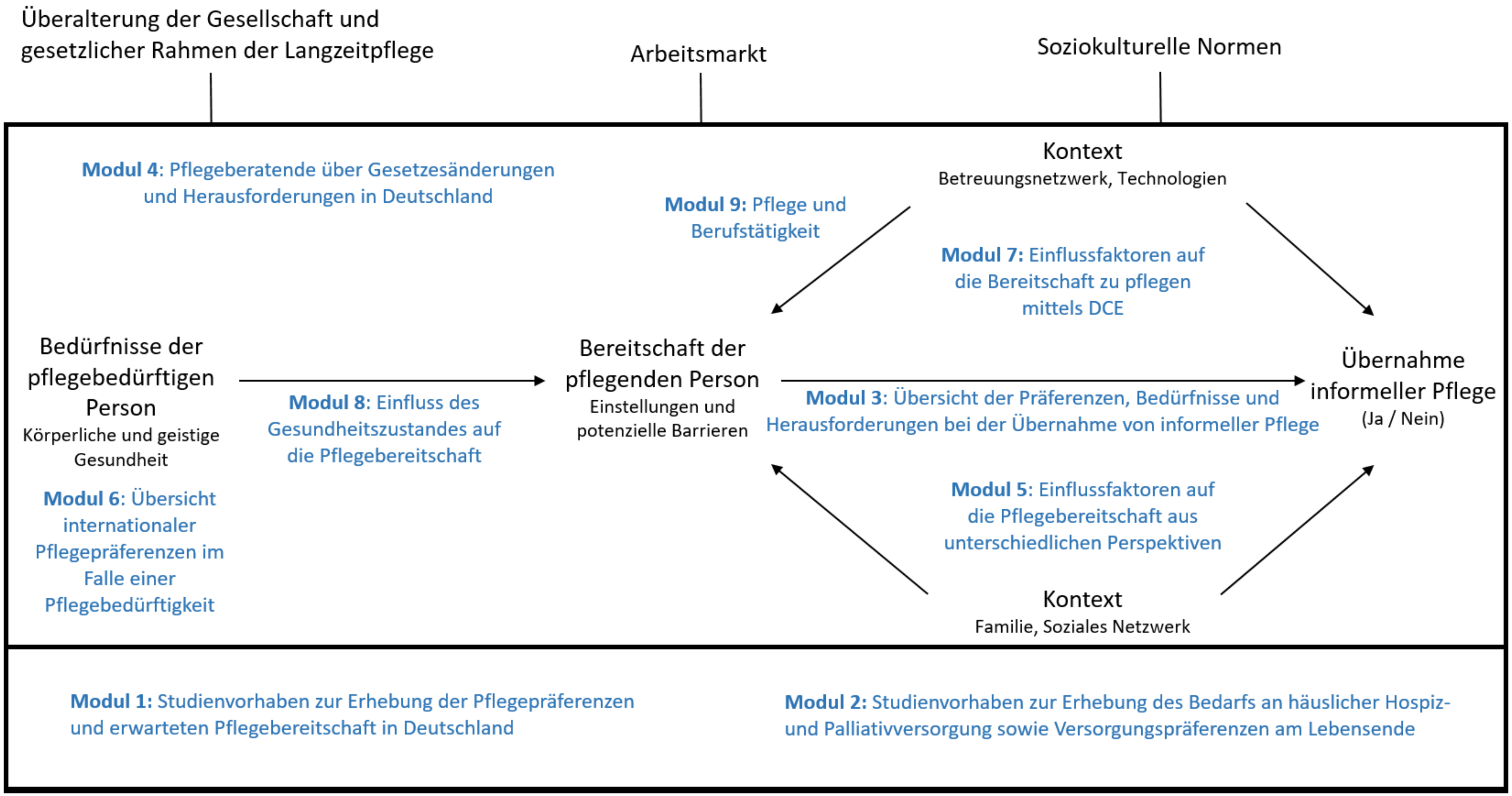
1. *Welche Faktoren beeinflussen die informelle Pflege?*
2. *Welche methodischen Aspekte müssen bei der Ermittlung von Pflegepräferenzen beachtet werden?*
3. *Unter welchen Bedingungen stellt eine Lohnersatzleistung für informell Pflegende ein geeignetes Instrument zur Erhöhung der Pflegebereitschaft in der Allgemeinbevölkerung dar?*

2. Beitrag der vorliegenden kumulativen Dissertationsarbeit

2.1. Einordnung der Module

Die vorliegende Dissertation gliedert sich in neun Module, die aufeinander aufbauend die Schritte einer mehrstufigen Präferenzerhebung darstellen. Die eingeschlossenen Module konnten alle in das *Informal Care Model* eingeordnet werden und beleuchten den Prozess der informellen Pflege aus unterschiedlichen Perspektiven. PflegeberaterInnen, pflegende Angehörige sowie Stichproben der Allgemeinbevölkerung wurden in den eingeschlossenen Veröffentlichungen befragt und können wichtige Einblicke liefern. Module 1 bis 6 umfassen ausgiebige Vorstudien mit dem Ziel der Problemdefinition sowie der Identifikation relevanter Entscheidungskriterien für die Präferenzerhebung mittels DCE. Dies erfolgt vor allem mithilfe systematischer Literaturrecherchen und qualitativer Einzelinterviews (Kapitel 2.2). Module 7, 8 und 9 befassen sich hingegen mit der Präferenzerhebung mittels DCE (Kapitel 2.3). Aus den Ergebnissen der Module werden zentrale Einflussfaktoren bzw. Determinanten der informellen Pflege mithilfe des *Informal Care Models* aufgezeigt. Abbildung 2 stellt die Einordnung der eingeschlossenen Module in das theoretische Modell dar. Die Relevanz der zentralen Modelldimensionen des *Informal Care Models* konnten ebenfalls in den eingeschlossenen Modulen nachgewiesen werden.

Abbildung 2: Determinanten der informellen Pflege anhand des Informal Care Models



Quelle: Eigene Darstellung in Anlehnung an van Groenou & de Boer (2016) [25]

2.2. Problemdefinition und Identifikation relevanter Entscheidungskriterien

Zur transparenten Darstellung der Zielsetzung sowie des Studienvorhabens ist ein Studienprotokoll zu Beginn des Projektes elementar. Dies dient vor allem der Qualitätsprüfung im Rahmen eines Peer-Review-Verfahrens und der genauen Erläuterung der Studienschritte. Des Weiteren wird die Angemessenheit und Relevanz der ausgewählten Methodik zur Beantwortung der Forschungsfragen verdeutlicht. Eine detaillierte Beschreibung und Begründung zweier Studiendesigns, inklusive Stichproben (Rekrutierungswege, Stichprobenmerkmale, Umfang), Datenauswertung sowie datenschutzrechtlicher und ethischer Aspekte finden sich in den Modulen 1 und 2. In der Publikation „Informal and formal care preferences and expected willingness of providing elderly care in Germany: protocol for a mixed-methods study" (Modul 1) wurde der Studienablauf zur Ermittlung von Pflegepräferenzen und der erwarteten Pflegebereitschaft beschrieben. In der Publikation „Exploring the status of and demand for palliative day-care clinics and day hospices in Germany: a protocol for a mixed methods study" (Modul 2) wurde der Studienablauf zur Ermittlung des Bedarfs an palliativmedizinischen Tageshospizen und Tageskliniken sowie Versorgungspräferenzen am Lebensende dargelegt. Beide Projekte befassen sich mit häuslichen Versorgungspräferenzen in Deutschland und folgen einem Mixed-Methods-Studiendesign, in dem sowohl qualitative als auch quantitative Methoden angewandt werden. In beiden Studien werden zur Problemdefinition und Konkretisierung des Forschungsgegenstands zunächst Literaturrecherchen (Module 3, 6) und qualitative Interviews (Module 4, 5) durchgeführt.

Eine ausführliche Übersicht der Präferenzen, Wünsche und Bedürfnisse pflegender Angehörige wurde durch eine systematische Literaturrecherche in der Publikation „Needs and preferences of informal caregivers regarding outpatient care for the elderly: a systematic literature review" (Modul 3) erstellt. Auf Basis ausgewählter Datenbanken und zusätzlicher Handrecherche konnten insgesamt 44 Studien aus 17 Ländern identifiziert und eingeschlossen werden. Die meisten der eingeschlossenen Studien haben eine qualitative Methodik in Form von Interviews, Fokusgruppen oder Gruppendiskussionen für die Präferenzerhebung verwendet. Die Ergebnisse konnten in fünf Themenfelder eingeordnet werden: (1) Präferenzen für die Struktur von Langzeitpflege, (2) Organisatorische Bedürfnisse, (3) Informationsbedürfnisse, (4) Unterstützungsbedarf und (5) Bedürfnisse nach gesellschaftlicher Anerkennung. In den eingeschlossenen Studien zeigte sich die häusliche Pflege als präferierte Pflegeoption. Die Wahl der Pflegeoption wurde von unterschiedlichen Faktoren wie dem gesundheitlichen Zustand, der finanziellen Situation und den Wünschen der pflegebedürftigen Person beeinflusst. Im Rahmen der organisatorischen Bedürfnisse war vor allem der Wunsch nach einer besseren Vereinbarkeit von Pflege- und Berufstätigkeit sowie Entlastungsangeboten von Bedeutung. Zudem wurde in vielen der eingeschlossenen Studien ein erheblicher Informationsbedarf auf Seiten pflegender Angehöriger identifiziert. Dieser Bedarf beinhaltet Informationen hinsichtlich ambulanter Pflegeleistungen sowie diverser Unterstützungs- und Beratungsangebote. Informationen wurden zudem in Bezug auf Herausforderungen der informellen Pflege sowie der Art und dem Schweregrad der Pflegebedürftigkeit gefordert. Bei den Unterstützungsbedürfnissen besteht der Wunsch nach finanzieller, sozialer, emotionaler und professioneller Unterstützung sowie Möglichkeiten der Inanspruchnahme von technischen Assistenzsystemen und Pflegerobotern. Ein großer Wunsch pflegender Angehöriger war es zudem, Respekt und gesellschaftliche Anerkennung für ihre Pflegetätigkeit und den geleisteten gesellschaftlichen Beitrag zu erhalten.

Im Rahmen der Vorstudie wurden in zwei weiteren Publikationen die Pflegebereitschaft sowie die gesetzlichen Rahmenbedingungen und Pflegeinfrastruktur in Deutschland mittels qualitativer Methoden beleuchtet. Das Ziel der Publikation „„Aber vielfach scheitert man dann an Besonderheiten“ – Pflegeberater über Gesetzesänderungen und die Herausforderungen ihrer Arbeit: Eine qualitative Untersuchung“ (Modul 4) war es, eine Einschätzung von PflegeberaterInnen zu aktuellen Pflegereformen und deren Auswirkungen in Deutschland zu erhalten. Grundlage der Analyse sind 14 leitfadengestützte, semi-strukturierte Einzelinterviews. Diese wurden aufgenommen, wörtlich transkribiert und mit der Software MAXQDA nach Mayring inhaltsanalytisch ausgewertet. Die PflegeberaterInnen haben seit der Einführung der PSG I, II und III spürbare positive Auswirkungen auf den Leistungsumfang für die Pflegebedürftigen und pflegenden Angehörigen wahrgenommen, jedoch mit dem Verweis auf bestimmte Umsetzungsgrenzen. Unwissenheit bei pflegenden Angehörigen und Pflegebedürftigen bezüglich Art und Umfang der Leistungen führe dazu, dass diese erst spät oder gar nicht in Anspruch genommen werden. Zudem fehle es vor allem an struktureller Umsetzung, welche zu stark abweichenden länderspezifischen und regionalen Unterschieden in der Inanspruchnahme führten. Weiterer Reformbedarf wurde identifiziert, jedoch erst nach einer stabilisierenden Phase der Umsetzung bestehender Reformen. Die Häufigkeit gesetzlicher Neuregelungen wurde als besonders herausfordernd empfunden. Ein Wunsch nach bundeseinheitlichen gesetzlichen Regelungen für die Leistungsinanspruchnahme sowie einer zentralen Informationsplattform für Pflegeangebote wurde verhäuft ausgesprochen. Ebenfalls wurde ein öffentlicher Diskurs zu den Themen Eigenverantwortung, Gerechtigkeit und einer flächendeckenden Versorgung gefordert.

Um die Dimensionen der Pflegebereitschaft aus unterschiedlichen Perspektiven zu erfassen, wurden im Rahmen der Publikation „Willingness and preparedness to provide care: interviews with individuals of different ages and with different caregiving experiences“ (Modul 5) PflegeberaterInnen (n = 14), pflegende Angehörige (n = 12) und Menschen ohne Pflegeerfahrungen (n = 7) befragt. 33 semi-strukturierte, leitfadengestützte Interviews wurden insgesamt durchgeführt. Die Interviews wurden aufgenommen, wörtlich transkribiert und mit der Software MAXQDA nach dem Verfahren von Mayring inhaltsanalytisch ausgewertet. Die Ergebnisse haben gezeigt, dass fast alle Befragten bereit waren, die

Pflege für einen älteren, nahen Angehörigen zu übernehmen. Die Pflegebereitschaft hing von unterschiedlichen Faktoren ab, bspw. der Beziehung zu der pflegebedürftigen Person oder dem Bedürfnis, unerwünschte Pflegeoptionen wie stationäre Pflegeeinrichtungen, auszuschließen. Ein negatives Bild von stationären Pflegeeinrichtungen mit mangelnder Qualität wurde vor allem in den Medien wahrgenommen. Auch die große Belastung der informellen Pflege wurde häufig als Argument aufgeführt, sodass einige TeilnehmerInnen die Pflegeübernahme als nicht erstrebenswert, aber verpflichtend wahrgenommen haben. Die Pflegebereitschaft der TeilnehmerInnen wurde jedoch nicht als absolut angesehen. Einflussfaktoren wie größere geografische Distanzen zwischen Familienangehörigen, junge Kinder im Haushalt oder die Notwendigkeit, in Vollzeit berufstätig zu sein, zeigten sich als potenzielle Barrieren für die Übernahme der Pflegetätigkeit.

Obwohl fast alle TeilnehmerInnen bereit waren Pflege zu leisten, waren die meisten zurückhaltend im Falle einer eigenen, hypothetischen Pflegebedürftigkeit Hilfe von Familienangehörigen anzunehmen, um Angehörigen nicht zur Last zu fallen. Die Interviews haben aber auch gezeigt, dass einige TeilnehmerInnen sich wünschen Unterstützung von Familienangehörigen zu erhalten, damit eine Versorgung in der Häuslichkeit möglich ist. TeilnehmerInnen gaben an, sich gut für den Fall einer Pflegebedürftigkeit vorbereitet zu fühlen, wenn der Wohnraum bereits barrierefrei umgebaut wurde, Kinder in der Nähe von ihren Eltern wohnten und die Kommunikation über die Wünsche für das Alter offen geführt wurde. Ausreichende Informationen über Pflegeoptionen und Unterstützungsangebote zu haben wurde als sehr wichtig eingestuft, damit frühzeitig Hilfe in Anspruch genommen werden kann. Ebenfalls haben die Interviews gezeigt, dass die Unterstützung durch die eigene Tochter nicht nur erwünscht, sondern meist konkret erwartet wurde und häufig zu Gefühlen der Erleichterung geführt hat. Dies deutet weiterhin auf eine traditionsgebundene Rolle von Frauen hin, welche die Versorgung naher Angehöriger beinhaltet.

Die Erstellung einer umfassenden inhaltlichen sowie methodischen Übersicht internationaler Pflegepräferenzen über einen langen Zeitraum war Mittelpunkt der Publikation „A systematic review to identify the use of stated preference research in the field of older adult care” (Modul 6). Es wurden ausschließlich Studien, die mittels quantitativer „stated preference“ Methoden erhoben wurden, eingeschlossen. Die detaillierte Übersicht der gewählten Attribute und Ausprägungen in den wahlbasierten Erhebungsverfahren können einen wichtigen Eindruck der Operationalisierung von Langzeitpflege in den unterschiedlichen Ländern vermitteln, da deren Auswahl in der Regel durch umfangreiche Literaturrecherchen und/oder qualitative Interviews untermauert wurde. Insgesamt konnten 68 Studien aus 19 verschiedenen Ländern identifiziert und in einer umfangreichen Übersicht inkludiert werden. Eingeschlossen wurden Publikationen, die im Zeitraum von 2000 bis 2020 veröffentlicht wurden. Die Mehrheit der Studien (57%) hat eine Stichprobe der Allgemeinbevölkerung befragt. 48% der Studien haben Single bzw. Binary choice, Ranking oder Rating Methoden zur Präferenzerhebung verwendet. Von den wahlbasierten „stated preference“ Methoden wurde das DCE am häufigsten angewandt und ermöglicht dadurch eine Einstufung der Relevanz unterschiedlicher Attribute sowie der Trade-offs zwischen Attributen. Die Nutzung von wahlbasierten Erhebungsverfahren (DCE, Conjoint Analyse, Best-Worst-Scaling) ist eine relativ neue Entwicklung - die überwiegende Mehrheit der Studien wurde zwischen den Jahren 2015 und 2020 veröffentlicht.

Die Übersichtsarbeit hat die Studien sowohl nach ihrem inhaltlichen Schwerpunkt sowie nach der verwendeten Erhebungsmethode kategorisiert. Die PRISMA Checkliste diente der Überprüfung der Qualität der systematischen Literaturrecherche und die PREFS Checkliste der Überprüfung der Qualität der eingeschlossenen Studien. Vier thematische Schwerpunkte konnten identifiziert werden: (1) Präferenzen für unterschiedliche Pflegeoptionen und ihre Einflussfaktoren, (2) Einschätzungen der Eignung verschiedener Pflegesettings für hypothetische Patientenoutcomes, (3) Präferenzen für die Gestaltung und Struktur spezifischer Pflegeoptionen und Pflegeleistungen sowie (4) Auswirkungen von Pflegeleistungen auf die Lebensqualität oder Instrumente der Pflegequalitätsmessung. Mit Ausnahme von zwei Studien, die Präferenzen im Zeitverlauf untersuchten, haben die Studien ein Querschnittsdesign verwendet. Ungeachtet der großen Heterogenität der Studien in Bezug auf die befragte Studienpopulation, Stichprobengröße und auf das Studiendesign ergaben sich einige einheitliche Ergebnisse. Bei einer Entscheidung zwischen mehreren Pflegeoptionen zog es die Mehrheit vor, informelle und ambulante Pflege in der eigenen Häuslichkeit in Anspruch zu nehmen. Mit zunehmendem Schweregrad der kognitiven und/oder körperlichen Beeinträchtigungen verschoben sich Präferenzen in Richtung einer ausschließlichen Inanspruchnahme formeller Pflege. In den eingeschlossenen Studien wurde der Einfluss einer Vielzahl von unabhängigen Variablen (Alter, Geschlecht, Bildung, Einkommen etc.) auf die Präferenzen der Befragten untersucht, wobei keiner der Variablen konsistente Auswirkungen in allen Studien aufzeigte.

2.3. Präferenzerhebung mittels Discrete Choice Experiment

Die Erkenntnisse aus den unterschiedlichen Modulen der Vorstudie wurden in den folgenden Publikationen im Rahmen der Hauptbefragungen angewandt. In dem Modul 7 „Willingness to provide informal care to older adults in Germany – a discrete choice experiment” wurde erstmals mittels DCE die Pflegebereitschaft in Deutschland ermittelt. Der postalische Fragebogen wurde über die AOK Niedersachsen an eine Zufallsstichprobe der Allgemeinbevölkerung versendet. Obwohl die Art und der Schweregrad der Pflegebedürftigkeit sowie die Beziehung zu der pflegebedürftigen Person wichtige Determinanten für die Pflegebereitschaft sind, wurden im DCE ausschließlich relevante Attribute eingeschlossen, die eine informelle Pflegesituation beschreiben. Fünf quantitative Attribute mit jeweils drei Ausprägungen wurden final ausgewählt: die erwartete Dauer der Pflegesituation, der Pflegeumfang, eine professionelle Unterstützung, Entlastung sowie eine Lohnersatzleistung. Letztere wurde als finanzieller Ausgleich pro Pflegestunde definiert und in das DCE zur Berechnung von WTA-Werten und zur Untersuchung der Relevanz dieser als möglicher Hebel oder Instrument zur Erhöhung der Pflegebereitschaft integriert. TeilnehmerInnen wurden gebeten, sich jeweils zwischen zwei hypothetischen Pflegesituationen zu entscheiden. Bei der Auswahl der Attribute und Level war es wichtig, dass die Pflegesituationen realistisch sind, aber die Befragten auch zwingen zwischen Alternativen abzuwägen. 280 TeilnehmerInnen konnten final in die Datenanalyse eingeschlossen werden. In den multivariaten Datenanalysen wurden Conditional Logit Modelle (CLM) und Latent Class Modelle (LCM) angewandt. Die CLM wurden mit und ohne Interaktionseffekte geschätzt und verglichen. Die LCM ermöglichen die Untersuchung von Präferenzheterogenitäten, in dem für jede Klasse die Relevanz der Attribute sowie soziodemografische Variablen, die eine Klassenzugehörigkeit bestimmt haben, herausgestellt wurden.

Die Ergebnisse der Datenanalyse haben gezeigt, dass für die Entscheidung zwischen zwei Pflegesituationen alle Attribute für die Befragten relevant waren. Eine Erhöhung des Pflegeumfangs pro Tag hatte in der Gesamtstichprobe den größten negativen Einfluss auf die Bereitschaft zu pflegen. Bei einem Pflegeumfang von acht im Vergleich zu zwei Stunden pro Tag, würden die Befragten ein Minimum von 14,54€ pro Pflegestunde akzeptieren. Dieser Wert ist höher als der nationale Mindestlohn von 9,82€ pro Stunde bzw. der geplante Mindestlohn von 12€ ab dem 01.10.2022. Datenbasiert wurden mittels der LCM drei Klassen (Subgruppen) identifiziert. Obwohl eine Lohnersatzleistung politisch diskutiert wird, um die Pflegebereitschaft in der Allgemeinbevölkerung zu erhöhen, haben die Ergebnisse gezeigt, dass eine solche Maßnahme nur für bestimmte Subgruppen entsprechende wirksame Anreize setzt. Eine höhere Lohnersatzleistung pro Stunde hatte den größten positiven Einfluss auf die Pflegebereitschaft in einer der drei Gruppen. Diese Gruppe ist gekennzeichnet durch ein geringeres Haushaltseinkommen, einen höheren Anteil an Personen mit Pflegeerfahrungen und einen größeren Wunsch, später ebenfalls von Familienangehörigen gepflegt zu werden.

Die Auswertung der postalischen Befragung (Modul 7) hat gezeigt, dass die Befragten die Kenntnis der Art und des Schweregrads der Pflegebedürftigkeit als relevant eingestuft haben, um ihre Bereitschaft im Voraus einschätzen zu können. Daher sollte der Gesundheitszustand in das DCE integriert werden. Das Ziel der Publikation „The impact of different care dependencies on people’s willingness to provide informal care: A discrete choice experiment in Germany“ (Modul 8) war es deshalb, die Relevanz des Gesundheitszustandes der pflegebedürftigen Person auf die Pflegebereitschaft der deutschen Allgemeinbevölkerung zu untersuchen. Dafür wurden zwei Gesundheitsbeschreibungen (kognitive vs. körperliche Beeinträchtigungen) in die Fallbeschreibung vor den DCE Entscheidungssets integriert. Die fünf Attribute mit jeweils drei Ausprägungen aus Modul 7 wurden in dieser Publikation identisch verwendet. TeilnehmerInnen wurden gebeten sich insgesamt sechsmal zwischen zwei informellen Pflegesituationen zu entscheiden. In den ersten drei Entscheidungssets wurde ein überwiegend kognitiv beeinträchtigter Angehöriger beschrieben und für die restlichen drei Entscheidungssets ein überwiegend körperlich beeinträchtigter Angehöriger. Für die Befragung wurde ein Online-Fragebogen in der Software SurveyEngine erstellt und über soziale Netzwerke, mithilfe von Flyern und per Schneeballprinzip, an Personen aus der Allgemeinbevölkerung verschickt bzw. weitergeleitet. Neben den DCE Entscheidungssets wurden, identisch zu Modul 7, auch hier eine Reihe von soziodemografischen Fragen sowie zusätzliche Fragen zu Einflussfaktoren auf die Pflegebereitschaft gestellt. 260 TeilnehmerInnen konnten in die Datenauswertung eingeschlossen werden. Für die multivariaten Analysen wurden mehrere CLM geschätzt.

Die Datenauswertung der Online-Befragung hat gezeigt, dass alle Attribute mit Ausnahme der Entlastung relevant für die Entscheidung zwischen den unterschiedlichen Pflegesituationen waren. Eine Erhöhung des Pflegeumfangs sowie der erwarteten Dauer der Pflegesituation hatten einen negativen Einfluss auf die Pflegebereitschaft in der Stichprobe. Bei einem Pflegeumfang von acht im Vergleich zu zwei Stunden wurde ein Minimum von 56,18€ pro Stunde akzeptiert. Dieser Wert liegt deutlich über dem Mindestlohn in Deutschland sowie den berechneten WTA-Werten in Modul 7. Eine mögliche Erklärung könnte hier das durchschnittliche junge Alter der Stichprobe sowie der hohe Anteil an TeilnehmerInnen ohne Pflegeerfahrungen sein. Ein negativer Zusammenhang zwischen jüngerem Alter und Pflegebereitschaft zeigte sich auch in anderen Studien [16, 28]. Die Erläuterung des Gesundheitszustandes der pflegebedürftigen Person hatte einen statistisch signifikanten Einfluss auf die Entscheidungen der Befragten. Die Pflege eines nahen Angehörigen mit kognitiven Einschränkungen wurde der Pflege eines Angehörigen mit körperlichen Beeinträchtigungen leicht vorgezogen. Es konnte jedoch auch gezeigt werden, dass bei der Pflege einer Person mit kognitiven Beeinträchtigungen jegliche Form an professioneller Unterstützung als positiv eingestuft wurde und die Pflegebereitschaft erhöht hat. Bei der Pflege einer Person mit körperlichen Beeinträchtigungen hatte nur die tägliche professionelle Unterstützung einen statistisch signifikanten positiven Einfluss auf die Steigerung der Pflegebereitschaft.

Ein großer Belastungsfaktor für viele (potenziell) informell Pflegende ist die Vereinbarkeit von Pflege- und Erwerbstätigkeit. Ziel der Publikation „Pflegebereitschaft in Abhängigkeit von der beruflichen Situation“ (Modul 9) war es deshalb, die Pflegebereitschaft der deutschen Allgemeinbevölkerung zu untersuchen. Ein besonderer Fokus lag dabei auf der Bereitschaft, die Arbeitszeit zu reduzieren sowie der Dauer der Pflegesituation und einer Lohnersatzleistung für die geleistete informelle Pflege. Eine zweistufige Primärdatenerhebung mittels Fragebogen wurde durchgeführt. Zunächst wurde eine Stichprobe der Allgemeinbevölkerung postalisch über die AOK Niedersachsen angeschrieben und in einem zweiten Schritt online mit der Befragungssoftware SurveyEngine befragt. Es konnten final 543 TeilnehmerInnen eingeschlossen werden. Der Großteil der TeilnehmerInnen (90%) war bereit einen nahen älteren Angehörigen zu pflegen, wobei 82% diese Bereitschaft von unterschiedlichen Einflussfaktoren abhängig gemacht hat. Der Gesundheitszustand der pflegebedürftigen Person (89%) und die zu pflegende Person selbst (83%) hatten den stärksten Einfluss auf die Pflegebereitschaft in der Stichprobe. Bei den 53 TeilnehmerInnen, die nicht bereit waren selbst zu pflegen, ist der Großteil ledig (62%), ohne Kinder (70%) und ohne Pflegeerfahrungen (60%). Ein jüngeres Alter sowie der Wunsch, später nicht von Familienangehörigen gepflegt zu werden, hat die Wahrscheinlichkeit, dass Befragte nicht bereit waren zu pflegen, signifikant erhöht.

134 TeilnehmerInnen (34%) würden ihre Arbeitszeit nicht für die Übernahme informeller Pflege reduzieren, der Großteil gab hierfür finanzielle Gründe an. 52% der Befragten war bereit die eigene Arbeitszeit zu reduzieren, wollte jedoch zumindest 10 bis 30 Stunden wöchentlich arbeiten. 14% der Stichprobe würde ihre Arbeitszeit für einen Zeitraum von bis zu 6 Monaten bzw. 2 Jahren komplett pausieren. In dieser Subgruppe zeigte sich ein höherer Anteil von TeilnehmerInnen mit Kindern (76%). Insgesamt haben die Ergebnisse gezeigt, dass zwei Faktoren die Wahrscheinlichkeit in Zukunft bereit zu sein die Arbeitszeit zu reduzieren, signifikant gesenkt haben. Diese waren ein geringeres Haushaltseinkommen und ein geringerer Wunsch von Angehörigen selbst gepflegt zu werden. Personen mit einem höheren Haushaltseinkommen würden eher ihre Arbeitszeit für die Pflege reduzieren oder vollständig pausieren. In der Gruppe der Befragten, die nicht bereit waren ihre Arbeitszeit zu reduzieren, war die erwartete Dauer der Pflegesituation sowie eine Lohnersatzleistung während der Pflegezeit am wichtigsten im Vergleich zu den anderen beiden Subgruppen.

3. Kritische Würdigung und Diskussion

3.1. Beantwortung der Forschungsfragen und Limitationen

Aufgrund des demografischen Wandels der Gesellschaft wird die informelle Pflege weiterhin eine wichtige Säule in der deutschen Pflegeversorgung bleiben, vor allem auch aufgrund mangelnder Pflegekräfte und Pflegestrukturen. Die in der vorliegenden Dissertation eingebrachten Module leisten einen bedeutsamen Beitrag zur Ermittlung von Pflegepräferenzen und der erwarteten Pflegebereitschaft in der Allgemeinbevölkerung. Zudem liefern die Module wichtige Hinweise hinsichtlich der Weiterentwicklung von Pflegeleistungen und -strukturen sowie der Verfügbarkeit informeller Pflegepersonen in Deutschland. Im Folgenden werden die zentralen Forschungsfragen beantwortet.

1. *Welche Faktoren beeinflussen die informelle Pflege?*

Die neun eingeschlossenen Module konnten alle in das *Informal Care Model* eingeordnet werden und die Ergebnisse der Module zeigen zentrale Einflussfaktoren bzw. Determinanten auf die informelle Pflege auf. Die Einordnung der Module in das theoretische Modell ist in Abbildung 2 erfolgt. Als Fundament des Modells sind die Module 1 und 2 an der Basis verortet und beschreiben jeweils in der Form eines Studienprotokolls die angewandten Methoden und die Relevanz dieser zur Untersuchung unterschiedlicher Aspekte von informeller Pflege. Ausgewählte externe Einflussfaktoren auf das informelle Pflegepotenzial in einem Land sind die nationalen Langzeitpflegestrukturen, Arbeitsmarktveränderungen und gesellschaftliche, demografische sowie kulturelle Veränderungen. Obwohl sich fast alle Module mit diesen externen Einflussfaktoren beschäftigen, werden die gesetzlichen Rahmenbedingungen und Pflegestrukturen in Deutschland vor allem in Modul 4 aus der Perspektive der PflegeberaterInnen näher beleuchtet. Bezogen auf den Pflegeleistungsumfang wurden positive Auswirkungen der aktuellen Pflegereformen hervorgehoben. Es fehle jedoch an Pflegestrukturen und Personal für eine weitere Umsetzung. Länderspezifische und regionale Unterschiede in den Angeboten beeinflussen somit stark die potenzielle Inanspruchnahme von ambulanten Pflegeleistungen und deshalb auch die mögliche Unterstützung für pflegende Angehörige. Diese strukturellen und gesetzlichen Bedingungen bestimmen den Bezugsrahmen der informellen Pflege und können die Übernahme dieser Art der Pflege vereinfachen oder erschweren.

Der Prozess der informellen Pflege beginnt stets mit dem Eintritt einer Pflegebedürftigkeit im näheren Umfeld und den konkreten Bedürfnissen der pflegebedürftigen Person. Dabei spielen in dieser Arbeit die Determinanten der Pflegebedürftigkeit wie bspw. ein höheres Alter oder Komorbiditäten keine Rolle, sondern vor allem die Pflegepräferenzen im Falle einer Pflegebedürftigkeit. In den Ergebnissen der systematischen Literaturrecherche (Modul 6) zeigte sich in der Mehrheit der Studien eine klare Präferenz für die häusliche Pflege. Der Einfluss einer Vielzahl von unabhängigen Variablen (Alter, Geschlecht, Familienstand, Einkommen etc.) auf den Wunsch möglichst lange in der eigenen Häuslichkeit versorgt zu werden, wurde in den Studien untersucht und zeigte keine konsistenten Auswirkungen. Ein ausgesprochener Wunsch von Angehörigen im Falle einer Pflegebedürftigkeit häuslich versorgt zu werden, kann aber die Pflegebereitschaft und tatsächliche Übernahme von informeller Pflege erhöhen (Modul 5).

Ein zentraler Einflussfaktor für die Übernahme informeller Pflege ist die Bereitschaft zu pflegen. Der Gesundheitszustand der pflegebedürftigen Person (überwiegend kognitive vs. körperliche Beeinträchtigungen) wurde in einer Online-Befragung mittels DCE als eine Determinante der Bereitschaft zu pflegen identifiziert (Modul 8). Die Art und der Schweregrad einer Pflegebedürftigkeit erlauben es, bestimmte Vorhersagen über die Form der erforderlichen Pflegetätigkeiten (bspw. Grundpflege), die erwartete Dauer der Pflegesituation oder die mögliche Ausprägung der krankheitsbedingten Veränderungen zu treffen (Module 8, 9). Des Weiteren wurden mittels DCE Befragungen fünf Merkmale der informellen Pflege als statistisch signifikante Einflussfaktoren auf die Pflegebereitschaft ermittelt: (1) die erwartete Dauer der Pflegesituation, (2) der Pflegeumfang pro Tag, (3) die Häufigkeit einer professionellen Unterstützung, (4) die Entlastungszeiten pro Jahr und (5) eine Lohnersatzleistung pro informeller Pflegestunde (Modul 7). Weitere Einflussfaktoren auf die Bereitschaft zu pflegen wurden in einer qualitativen Studie (Modul 5) ermittelt. Diese hing in den qualitativen Interviews vor allem von der Person selbst bzw. der Beziehung zu dieser Person ab. Da alle befragten TeilnehmerInnen die erwartete Belastung informeller Pflege hervorgehoben haben, war der Großteil bereit, vor allem für ihre Eltern, die informelle Pflege zu übernehmen. Genannte Gründe dafür waren Zuneigung und Liebe, der Wunsch etwas zurückzugeben (Reziprozität), Verpflichtungsgefühle und die stationäre Pflegeeinrichtung als Ausschlussgrund aufgrund mangelnder Qualitätsvorstellungen. Vereinzelt haben hier auch Austauschmotive in Form von finanzieller Vergütung oder Erbschaften für die erbrachte Pflege zwischen Eltern und Kindern, vor allem im ländlichen Setting, eine Rolle gespielt. Bessere Möglichkeiten zur Vereinbarkeit von Pflege- und Erwerbstätigkeit wurden als zusätzlicher Einflussfaktor für die Pflegebereitschaft identifiziert und explizit erwünscht, um hohe Belastungen zu vermeiden (Modul 9).

Neben den nationalen Rahmenbedingungen in Bezug auf die möglichen Unterstützungsangebote für die informelle Pflege und der Pflegebereitschaft selbst, wurden potenzielle Faktoren bzw. Barrieren identifiziert, die eine tatsächliche Übernahme von informeller Pflege vereinfachen oder einschränken können. In den Interviews (Modul 5) zeigten sich größere geografische Distanzen zwischen Familienangehörigen sowie konkurrierende Verantwortungen wie kleine Kinder im Haushalt oder auch die Vollzeiterwerbstätigkeit als Schwierigkeit, da für die informelle Pflegetätigkeit bestimmte zeitliche und finanzielle Kapazitäten zur Verfügung stehen müssen. Trotz gesellschaftlicher Veränderungen wurde Töchtern noch immer eine größere Bedeutung in Bezug auf die Übernahme der Pflege in den Interviews zugeschrieben. Dies deutet auf eine weiterhin traditionelle Rolle von Frauen bezüglich der Übernahme informeller Pflege hin.

Die Ergebnisse der systematischen Literaturrecherche (Modul 3) zeigten, dass die meisten pflegenden Angehörigen in den inkludierten Studien ähnliche Bedürfnisse und Wünsche in Bezug auf die Übernahme der Pflege aufwiesen. Unter anderem wird eine bessere Vereinbarkeit von Pflege- und Erwerbstätigkeit, gesellschaftliche Anerkennung für die Pflegetätigkeit sowie finanzielle und professionelle Unterstützung gewünscht. Eine frühzeitige Einbindung von Präferenzen und Wünschen in die Gestaltung der gesetzlichen und strukturellen Rahmenbedingungen in Deutschland könnte die Pflege in der eigenen Häuslichkeit mithilfe von bedarfsgerechten Unterstützungsleistungen erleichtern. Hierbei geht es vor allem um die Vermeidung gesellschaftlicher Kosten (bspw. Arbeitsunfähigkeit) aufgrund von erheblichen gesundheitlichen Belastungen in der Gruppe der informell Pflegenden.

2. Welche methodischen Aspekte müssen bei der Ermittlung von Pflegepräferenzen beachtet werden?

Mittels einer ausführlichen Darstellung der zentralen Studienschritte sowie der Angemessenheit der verwendeten Methoden haben Module 1 und 2 gezeigt, dass die Erstellung eines Studienprotokolls zu Beginn eines Projektes die Transparenz und Qualitätsprüfung des Vorhabens deutlich erhöht. Die Module 3 und 6 verdeutlichen, dass eine systematische Literaturrecherche als erster Schritt bei Präferenzstudien zur Problemdefinition und einer ersten Übersicht von Pflegepräferenzen und methodischen Ansätzen essenziell ist. Die Qualität einer systematischen Literaturrecherche ist vor allem abhängig von der definierten Suchstrategie und Herangehensweise, wobei eine transparente Darstellungsform unverzichtbar ist. Eine Übersicht und Synthese der relevanten Erkenntnisse sowie eine Bewertung der Qualität und Limitationen der eingeschlossenen Studien können wichtige Hinweise für die darauffolgenden Projektschritte einer Präferenzerhebung geben. Studienergebnisse über Pflegepräferenzen, Bedürfnisse, Wünsche sowie Erwartungen waren die Grundlage der Leitfadenerstellung der Module 4 und 5. Die Operationalisierungen von Langzeitpflege, die Auswahl der Attribute und Level sowie die methodischen Herangehensweisen der quantitativen Präferenzmessmethoden in Modul 6 sind vor allem in die konkrete Erstellung des DCE (Module 7, 8) eingeflossen. Auch hier ist eine transparente und detaillierte Übersicht der Studienergebnisse sowie der methodischen Herangehensweise von besonderer Relevanz. Zudem ist es wichtig, Informationen zur Studienpopulation, Stichprobe, Art der Erhebung und Messung von Präferenzen (u.a. abhängige und unabhängige Variablen) zu extrahieren, um diese vergleichen zu können. Eine Ergebnisinterpretation von Pflegepräferenzen muss jedoch immer im Kontext der demografischen, kulturellen, strukturellen und gesetzlichen Rahmenbedingungen des Landes geschehen.

Die systematischen Literaturrecherchen haben deutlich gemacht, dass länderübergreifende Vergleiche von Präferenzen sich aufgrund der nationalen Pflegesysteme und Rahmenbedingungen schwierig gestalten. Qualitative Untersuchungen (Module 4, 5) eignen sich deshalb ergänzend als weitere Vorstudien, um explorativ Erfahrungen, Bedürfnisse und Meinungen im jeweiligen Forschungsland zu erheben. Hierbei ist der Einbezug mehrerer Forschungsperspektiven (PflegeberaterInnen, pflegende Angehörige, Menschen ohne Pflegeerfahrungen) essenziell, um einen multiperspektivischen Eindruck zu erhalten. Dennoch schränken die geringen Stichprobengrößen sowie die Rekrutierung in einem Bundesland die Übertragbarkeit der Ergebnisse stark ein. Des Weiteren war es im Rahmen dieser Forschungsarbeit besonders schwierig die Perspektive von pflegenden Männern zu erfassen, da trotz verstärkter Rekrutierungsversuche mehr pflegende Frauen an der Befragung teilgenommen haben. Bei der Rekrutierung und Durchführung der Interviews ist zudem aufgefallen, dass Pflege für viele ein schwieriges, komplexes und sensibles Thema ist. Die Verallgemeinerung von Ergebnissen ist bei qualitativen Studien somit kaum möglich, aber auch nicht das Ziel dieser Erhebungsmethode. Ein großer Kritikpunkt bei der Durchführung qualitativer Studien ist die Beurteilung der Qualität und Vergleichbarkeit mit anderen Studien. Aus diesem Grund wurden Checklisten wie bspw. die SRQR (*Standards for Reporting Qualitative Research*) Leitlinie erstellt, die bei der Darstellung und Beschreibung von qualitativen Studien für Transparenz sorgen. Eine detaillierte Erhebung von Herausforderungen, Bedürfnissen, Erfahrungen und Einschätzungen in den Interviews kann in die weitere Identifikation von Entscheidungskriterien im Rahmen von Präferenzerhebungen mittels DCE einfließen (Module 7, 8) oder Ansatzpunkte zur kritischen Überprüfung des deutschen Pflegesystems (Modul 4) liefern.

Bei der Auswahl von Attributen und Ausprägungen im Rahmen von DCE Erhebungen (Module 7, 8) existiert bisher kein Goldstandard, jedoch erhöht die Einbeziehung von systematischen Literaturrecherchen (Module 3, 6) sowie qualitativen Interviews (Module 4, 5) die Nachvollziehbarkeit der Kriterienfindung. Vor allem qualitative Interviews erlauben im Vergleich zu anderen qualitativen Methoden (bspw. Fokusgruppen) eine tiefergehende Erforschung entscheidungsrelevanter Attribute [29] und erhöhen das Verständnis von informeller Pflege und dessen Einflussfaktoren. Eine so aufwendige Vorstudie ist jedoch auch besonders zeit- und kostenintensiv und muss deshalb von Beginn an in das Studienvorhaben eingeplant werden. Bei der Auswahl der Attribute und Level sollte die Anzahl begrenzt werden, um eine Überforderung der TeilnehmerInnen zu vermeiden. Für die DCE-Erhebung der Pflegebereitschaft in Deutschland wurde ein symmetrisches Design ausgewählt mit fünf entscheidungsrelevanten Attributen mit jeweils drei Ausprägungen. Ein wichtiger Schritt ist die Prüfung der Verständlichkeit (der Beschreibungen) dieser Attribute und Level, welche im Rahmen von zwei mehrstufigen Pretests (Module 7, 8) überprüft wurde.

Um eine möglichst hohe Qualität der Präferenzerhebung mittels DCE zu gewährleisten, existieren auch hier Leitlinien und Checklisten, bspw. von der ISPOR (*International Society for Pharmacoeconomics and Outcomes*) oder Lancsar und Louviere [24]. Dabei ist neben der Auswahl der Attribute und Level sowie der Durchführung eines umfangreichen Pretests unter anderem auch das experimentelle Design, die Konstruktion der Entscheidungssets sowie die Datenerhebung und -auswertung besonders wichtig. Diese Checklisten wurden auch in dieser DCE Erhebung verwendet, um eine hohe Nachvollziehbarkeit des Studienvorgehens zu ermöglichen. Eine Präferenzerhebung mittels DCE ermöglicht in erster Linie Rückschlüsse auf die relative Bedeutung und den Wert, den die TeilnehmerInnen den unterschiedlichen Merkmalen der informellen Pflegesituation zuschreiben. Dies erfolgt aufgrund von Trade-offs, die von TeilnehmerInnen bei der Auswahl zwischen zwei Pflegesituationen getroffen werden müssen. Das Design der DCE-Erhebung verlangt jedoch eine Entscheidungsfindung basierend auf hypothetischen Pflegesituationen und kann daher nicht das tatsächliche Verhalten in der Zukunft vorhersehen.

Die Verwendung eines „forced choice"–Designs hat zudem TeilnehmerInnen gezwungen, sich mehrfach zwischen zwei Pflegesituationen zu entscheiden, auch wenn sie sich in der Realität gegen eine Übernahme der informellen Pflege mit den aufgeführten Rahmenbedingungen entscheiden könnten.

Die qualitativen Interviews (Modul 5) haben gezeigt, dass die Pflegebereitschaft von vielen Einflussfaktoren bestimmt wird und sich in Zukunft möglicherweise ändern kann. Eine Einbeziehung von allen Einflussfaktoren in das DCE Design ist jedoch nicht möglich ohne die Komplexität der Entscheidungssets wesentlich zu erhöhen. Zudem hat die geringe Rücklaufquote und der hohe Anteil an Fragebögen mit fehlenden Werten (Modul 7) bereits auf eine hohe Komplexität der DCE Methodik gedeutet und sollte zumindest in Anbetracht der Anzahl von Attributen nicht erhöht werden. Eine Weiterentwicklung des DCE (Modul 7) war in diesem Projekt mit der Integration der Art und des Schweregrads der Pflegebedürftigkeit in die Fallbeschreibung der Entscheidungssets möglich (Modul 8). Obwohl die Ergebnisse bei identischer Verwendung von Attributen und Leveln einen statistisch signifikanten Einfluss des Gesundheitszustands auf die Entscheidungen gezeigt haben, ist ein direkter Vergleich der Pflegebereitschaft zwischen den zwei Stichproben aufgrund der soziodemografischen Unterschiede nicht möglich. Zusätzlich wurde der Gesundheitszustand nur in Modul 8 genauer erläutert, was bereits zu Unterschieden in der Entscheidung zwischen den Pflegesituationen führen kann.

Die systematische Literaturrecherche (Modul 6) hat gezeigt, dass bei der Gestaltung von Langzeitpflegesystemen die Nachfrage nach Präferenzdaten vor allem in den letzten Jahren stark angestiegen ist. Insbesondere DCE werden zur Erhebung von Pflegepräferenzen gehäuft angewandt. Die Ergebnisse dieser DCE Erhebung konnten zum einem die Relevanz bestimmter Pflegemerkmale aufzeigen und zum anderen mit dem integrierten Attribut der Lohnersatzleistung die Berechnung von WTA-Werten für die unterschiedlichen Attribute ermöglichen. Eine Verallgemeinerung der Ergebnisse ist jedoch, aufgrund der geringeren Stichprobe und der ausschließlichen Rekrutierung in einem Bundesland (Niedersachsen), nur schwer möglich. Zudem nahm ein deutlich höherer Anteil an Frauen an der Studie teil. Ein Bias bei der Stichprobenauswahl ist somit möglich und sollte bei der Interpretation der Ergebnisse beachtet werden. Aufgrund der begrenzten Stichprobengröße war es nicht angemessen, konkrete politische Vorschläge und Empfehlungen abzuleiten. Außerdem wiesen aufgrund der Stichprobengröße mehrere unabhängige Variablen eine zu geringe Variation auf, was eine Schätzung eines Effekts dieser auf die Klassensegmentierung des LCM nicht ermöglichte. Eine größere Stichprobe könnte die Einbeziehung weiterer unabhängiger Variablen ermöglichen. Ein zentraler Kritikpunkt der durchgeführten Schritte der Präferenzerhebung (Module 4, 5, 7 – 9) ist die Erhebung zu einem einzigen Zeitpunkt. Somit ist die Untersuchung zeitlicher Veränderungen in den Präferenzen und der Pflegebereitschaft nicht möglich. Diese würde jedoch einen langen Beobachtungszeitraum benötigen.

Vor dem Hintergrund sich wandelnder gesellschaftlicher und kultureller Entwicklungen ist es trotz aufgeführter Limitationen besonders wichtig, dass Studien die Präferenzen und die Pflegebereitschaft von (potenziellen) pflegenden Angehörigen untersuchen. Da die informelle Pflege weiterhin eine wichtige Säule im deutschen Pflegesystem ausmacht, ist die Pflegebereitschaft ein wichtiger Indikator für das informelle Pflegepotenzial eines Landes. Im gesundheitsökonomischen Kontext können Präferenzen bei der Weiterentwicklung von bestehenden Versorgungsstrukturen und Leistungen dabei helfen, eine Vorhersage des informellen Pflegepotenzials zu leisten und den Einfluss von Faktoren wie einer Lohnersatzleistung auf die Pflegebereitschaft zu untersuchen.

3. *Unter welchen Bedingungen stellt eine Lohnersatzleistung für informell Pflegende ein geeignetes Instrument zur Erhöhung der Pflegebereitschaft in der Allgemeinbevölkerung dar?*

Die Vereinbarkeit von Pflege- und Berufstätigkeit stellt für viele (potenziell) Pflegende einen erheblichen Belastungsfaktor dar. Ein höherer Pflegeumfang pro Tag führt in vielen Fällen zu einer Reduktion oder einem Pausieren der Arbeitszeit. Bisherige politische Maßnahmen ermöglichen für die Erbringung von informeller Pflege eine Freistellung der Berufstätigkeit für einen Zeitraum von bis zu 6 Monaten [30] bzw. bis zu 24 Monaten [31]. Bei der finanziellen Überbrückung dieser Pflegezeit sollen zinslose Darlehen helfen, werden jedoch bisher kaum in Anspruch genommen. Die Reduktion bzw. das temporäre Pausieren der Arbeitszeit kann daher zum einen die finanzielle Stabilität informell Pflegender beeinflussen und zum anderen zu einer Reduktion der späteren Altersrente führen.

Für eine bessere Vereinbarkeit von Pflege und Berufstätigkeit und zur Vorbeugung dieser Art von Mehrfachbelastung, wurde von der Bundestagsfraktion Bündnis 90 / Die Grünen eine Lohnersatzleistung analog zum Elterngeld vorgeschlagen. Konkret sieht der Vorschlag der Partei einen Vollausstieg aus der Berufstätigkeit für bis zu 3 Monate und einen Teilausstieg für bis zu 36 Monate vor, sofern die pflegebedürftige Person mindestens einen Pflegegrad 2 aufweist. Eine Reduktion von mindestens 20% ist hier vorgesehen, wobei die Arbeitszeit immer mindestens 20 Stunden pro Woche betragen muss. Der Lohnersatz soll sich hierbei in der Regel auf 67% des entgangenen Nettoeinkommens belaufen [32]. So eine Form der Lohnersatzleistung für die informelle Pflege wurde in den Modulen 7, 8 und 9 untersucht und diskutiert. Der Einschluss dieses Attributs in der DCE Erhebung (Module 7, 8) hat die Relevanz einer Lohnersatzleistung in Abhängigkeit der anderen vier Attribute gezeigt und die Berechnung von WTA-Werten ermöglicht. Die Latent Class Analyse (Modul 7) konnte in Bezug auf die Lohnersatzleistung erhebliche Präferenzunterschiede aufzeigen. So hatte eine Lohnersatzleistung für eine Subgruppe (gekennzeichnet durch einen signifikant höheren Anteil an Frauen und TeilnehmerInnen ohne Pflegeerfahrungen sowie einer geringeren Wichtigkeit später von Angehörigen gepflegt zu werden) keinen signifikanten Einfluss auf die Pflegebereitschaft. Im Vergleich hatte eine Lohnersatzleistung von 12€ pro Stunde den größten positiven Einfluss auf die Pflegebereitschaft einer weiteren Subgruppe, welche durch einen höheren Anteil von Personen mit Pflegeerfahrungen und ein geringeres Haushaltseinkommen gekennzeichnet ist. Zusätzlich war diese Gruppe zu einem höheren Pflegeumfang und -dauer zu pflegen bereit und gab einen größeren Wunsch an, von Familienangehörigen in Zukunft ebenfalls gepflegt zu werden. Für die Erhöhung der Pflegebereitschaft war in dieser Gruppe der Erhalt einer Lohnersatzleistung besonders wichtig.

Ebenso hatte eine Lohnersatzleistung in der Onlinebefragung (Modul 8) einen signifikanten Einfluss auf die Pflegebereitschaft, jedoch insgesamt einen weniger starken als in der postalischen Befragung (Modul 7). Dies hat sich vor allem in den großen Unterschieden der WTA-Werte bemerkbar gemacht, insbesondere der hohen Mindestsätze pro informeller Pflegestunde, die TeilnehmerInnen der Onlinebefragung akzeptieren würden. Eine geringere Pflegebereitschaft der Online-Stichprobe könnte aufgrund des jungen Alters, einem höheren Anteil an TeilnehmerInnen ohne Pflegeerfahrungen und Vollzeitbeschäftigten erklärt werden. In der Fragebogenauswertung (Modul 9) konnte gezeigt werden, dass eine Lohnersatzleistung für TeilnehmerInnen, die nicht bereit waren ihre Arbeitszeit in Zukunft zu reduzieren, am wichtigsten war. Der Großteil gab hierfür finanzielle Gründe an. Ein vorübergehendes Pausieren der Arbeitszeit konnten sich vor allem TeilnehmerInnen mit Kindern und einem höheren Haushaltseinkommen vorstellen. TeilnehmerInnen mit einem höheren Einkommen waren insgesamt eher bereit, ihre Arbeitszeit zu reduzieren. Eine Lohnersatzleistung hat eine weniger wichtige Rolle für diese Entscheidung gespielt.

Die Ergebnisse der Module 7 bis 9 konnten zeigen, dass eine Lohnersatzleistung nicht für alle die Pflegebereitschaft erhöht. Ein finanzieller Ausgleich für die Erbringung informeller Pflege war in den befragten Stichproben vor allem für TeilnehmerInnen mit geringerem Haushaltseinkommen, schlechterem Gesundheitszustand, eigenen Pflegeerfahrungen und stärkerem Wunsch, später von Angehörigen gepflegt zu werden, relevant. Für diese Personen könnte eine Lohnersatzleistung zumindest für einen gewissen Zeitraum eine finanzielle Entlastung bieten und die Pflegebereitschaft erhöhen. Die Ergebnisse haben aber auch gezeigt, dass für Personen mit einem höheren Haushaltseinkommen andere Faktoren als wichtiger eingestuft wurden, wie bspw. der Pflegeumfang und die Häufigkeit professioneller Unterstützung. Um die Bereitschaft von Personen aus unterschiedlichen Lebensphasen zu erhöhen, bedarf es somit flexibler Ansätze, wie bspw. der frühzeitigen Einbindung ambulanter Pflegedienste und Entlastungsleistungen. Der Vorschlag einer Lohnersatzleistung der Bundestagsfraktion Bündnis 90 / Die Grünen könnte für einige Personen vorübergehend finanzielle Entlastung bieten. Ein Vergleich zu den Elterngeldregelungen ist jedoch schwierig, da sich der Vorschlag bereits in der Ausgestaltung des Vollausstiegs unterscheidet, anders als bei der Elternzeit die Dauer der Pflegesituation nur schwer vorhersehbar ist und der Pflegeumfang tendenziell zunimmt. Eine zeitliche Begrenzung der

Lohnersatzleistung könnte somit möglicherweise nicht die gesamte Dauer der informellen Pflegesituation abdecken, aber für die Organisation von Folgelösungen hilfreich sein.

3.2. Ausblick und weiterer Forschungsbedarf

Für eine präferenzbasierte Gestaltung und Weiterentwicklung von Pflegeleistungen und -strukturen ist das Wissen über Bedürfnisse, Wünsche und Prioritäten unerlässlich. Die eingeschlossenen Module können wichtige Einblicke in die Pflegepräferenzen, die erwartete Pflegebereitschaft und zentrale Determinanten der informellen Pflege aus unterschiedlichen Perspektiven liefern. Dabei konnten die neun Module alle in das theoretische Modell eingeordnet werden und die ausgewählten Dimensionen des Modells ebenfalls in empirischen Beiträgen in Deutschland nachgewiesen werden. Die Module zeigen einen Ausschnitt der komplexen Zusammenhänge im deutschen Pflegewesen auf. Somit wurde die Eigenverantwortung der BürgerInnen bei der Wahl des Wohnraums hervorgehoben, um altersbedingte Bedürfnisse und regionale Versorgungsstrukturen zu berücksichtigen. Die Pflegebereitschaft ist und bleibt zentraler Bestandteil des deutschen Pflegesystems aufgrund begrenzter finanzieller und personeller Ressourcen. Es konnte auch gezeigt werden, dass vor allem jüngere Befragte weniger bereit waren, ihre Angehörigen in Zukunft zu pflegen und die Voraussetzungen für die Übernahme der informellen Pflege sich verschlechtern. Dies sind wichtige Indikatoren für das informelle Pflegepotenzial in Deutschland. Die Ergebnisse dieser Arbeit haben zudem Präferenzheterogenitäten aufgezeigt. Während für einige TeilnehmerInnen eine Lohnersatzleistung als relevant eingestuft wurde und ein geeignetes Instrument zur Erhöhung der Pflegebereitschaft darstellt, wurde der Pflegeumfang und die Häufigkeit einer professionellen Unterstützung für andere als wichtiger eingestuft. Somit bedarf es flexibler Ansätze zur Erhöhung der Pflegebereitschaft. Außerdem wird eine Einschätzung der realistischen Kapazitäten informell Pflegender bezüglich Art, Umfang und Dauer der informellen Pflege sowie eine frühzeitige Einbindung von ambulanten Diensten und Beratungsmöglichkeiten benötigt, um eine Überlastung informell Pflegender zu vermeiden. Aktuell stellen die späte Inanspruchnahme von Hilfeleistungen informell Pflegender aufgrund fehlender Informationen sowie die negative Wahrnehmung professioneller Pflegedienste und stationärer Pflegeeinrichtungen aufgrund der Medienberichte große Herausforderungen dar.

Für die Ableitung konkreter politischer Empfehlungen ist der Einbezug einer deutlich größeren und möglichst deutschlandweiten Stichprobe entscheidend. Eine größere Stichprobe könnte zudem die Integration weiterer unabhängiger Variablen in die Untersuchung von Präferenzunterschieden ermöglichen. Da bereits Präferenzheterogenität in einer Stichprobe in Niedersachsen nachgewiesen wurde, sollte eine Übertragbarkeit der Ergebnisse mit einer deutschlandweiten Stichprobe überprüft werden.

Zudem könnte eine größere Stichprobe die Rolle einer Lohnersatzleistung als Hebel zur Erhöhung der Pflegebereitschaft in der deutschen Allgemeinbevölkerung näher untersuchen. Pflege stellt ein sehr komplexes und sensibles Thema für viele Menschen dar. Vor allem bei der Übernahme der informellen Pflege spielen auch häufig Pflicht– und Schuldgefühle eine Rolle, bspw. in Bezug auf die Inanspruchnahme frühzeitiger Unterstützung oder auf den Übergang zu einer ausschließlich formellen Pflege. Daher sollten zukünftige Forschungsarbeiten untersuchen, inwiefern sich Pflegepräferenzen und die Pflegebereitschaft im Laufe der Zeit ändern können. Dabei geht es um die Vorbeugung erheblicher Be- oder sogar Überlastungen informell Pflegender und somit die Vermeidung gesellschaftlicher Kosten aufgrund ausgeprägter gesundheitlicher Belastungen. Dies geschieht vor allem vor dem Hintergrund der Herausforderung einer notwendigen Reformierung der Finanzierung der Pflegeversicherung, insbesondere in Anbetracht der Tatsache, dass eine Verstärkung der vorhandenen Unterfinanzierung aufgrund des demografischen Wandels erwartet wird.

Literaturverzeichnis

1. United Nations, Department of Economic and Social Affairs, Population Division. World Population Ageing 2019: Highlights. 430th ed. New York, 2019. ISBN: 978-92-1-148325-3.
2. Statistisches Bundesamt (Destatis). Bevölkerung - Demographischer Wandel: Mehr Pflegebedürftige. 2022. https://www.destatis.de/DE/Themen/Querschnitt/Demografischer-Wandel/Hintergruende-Auswirkungen/demografie-pflege.html (letzter Zugriff: 02.02.2022).
3. Rothgang H. Schriftenreihe zur Gesundheitsanalyse–Band 32. BARMER Pflegereport 2021, Wirkungen der Pflegereformen und Zukunftstrends. Berlin, 2021. ISBN: 978-3-946199-68-7.
4. Matthews Z, Channon A, van Lerberghe W. Will there be enough people to care? Notes on workforce implications of demographic change 2005–2050. World Health Organization: Geneva, Switzerland. 2006.
5. Triantafillou J, Naiditch M, Repkova K, Stiehr K, Carretero S, Emilsson T, et al. Informal care in the long-term care system European overview paper. Athens/Vienna, 2010.
6. Zigante V. Informal care in Europe: Exploring formalisation, availability and quality. European Commission, London School of Economics and Political Science. Brussels, 2018. ISBN: 978-92-79-86583-1.
7. Bundesministerium der Justiz und für Verbraucherschutz. Sozialgesetzbuch (SGB) - Elftes Buch (XI) - Soziale Pflegeversicherung: § 3 Vorrang der häuslichen Pflege. https://www.sozialgesetzbuch-sgb.de/sgbxi/3.html (letzter Zugriff: 03.02.2022).
8. Arntz M, Sacchetto R, Spermann A, Steffes S, Widmaier S. The German social long-term care insurance-structure and reform options. IZA Discussion Paper No. 2625. Bonn, 2007.
9. Bundesministerium der Justiz und für Verbraucherschutz. Sozialgesetzbuch (SGB) - Elftes Buch (XI) - Soziale Pflegeversicherung: § 15 Ermittlung des Grades der Pflegebedürftigkeit, Begutachtungsinstrument. https://www.sozialgesetzbuch-sgb.de/sgbxi/15.html (letzter Zugriff: 03.02.2022).
10. Bundesministerium für Gesundheit. Zahlen und Fakten zur Pflegeversicherung. 2019. https://www.bundesgesundheitsministerium.de/fileadmin/Dateien/Downloads/Statistiken/Pflegeversicherung/Zahlen_und_Fakten/Zahlen-u-Fakten-zur-Pflegeversicherung_2019.pdf (letzter Zugriff: 17. 05. 2022).
11. Heuchert M, König H-H, Lehnert T. Die Rolle von Präferenzen für Langzeitpflege in der sozialen Pflegeversicherung - Ergebnisse von Experteninterviews. Gesundheitswesen. 2017; 79:1052–7. DOI:10.1055/s-0041-111839.
12. Lehnert T, Heuchert MA, Hussain K, Koenig H-H. Stated preferences for long-term care: A literature review. Ageing & Society. 2019; 39:1873–913. DOI: 10.1017/S0144686X18000314.
13. Die Techniker (TK). TK-Meinungspuls Gesundheit, So sieht Deutschland sein Gesundheitssystem, 2021. https://www.tk.de/resource/blob/2105222/5122ff972fe2eddd8f4ae1e73500bf62/booklet-tk-meinungspuls-2021-data.pdf (letzter Zugriff: 21.04.2022).
14. Hajek A, Lehnert T, Wegener A, Riedel-Heller SG, König H-H. Factors associated with preferences for long-term care settings in old age: evidence from a population-based survey in Germany. BMC Health Serv Res. 2017; 17:1–9. DOI:10.1186/s12913-017-2101-y.
15. Geyer J, Schulz E. Who cares? Die Bedeutung der informellen Pflege durch Erwerbstätige in Deutschland. Diw Wochenbericht. 2014; 81:294–301.
16. Ärzteblatt. Bereitschaft zur Pflege von Angehörigen sinkt. 2022. https://www.aerzteblatt.de/nachrichten/60070/Bereitschaft-zur-Pflege-von-Angehoerigen-sinkt (letzter Zugriff: 21.04.2022).

17. Blinkert B, Klie T. Die Versorgungssituation pflegebedürftiger Menschen vor dem Hintergrund von Bedarf und Chancen. In: Soziale Ungleichheit und Pflege. VS Verlag für Sozialwissenschaften, 2008: 238–255. DOI: 10.1007/978-3-531-91014-7_9.
18. Hajek A, Lehnert T, Wegener A, Riedel-Heller SG, König H-H. Potential for informal care of the elderly in Germany: Results of a representative population-based survey. Z Gerontol Geriatr. 2018; 51:612–9. DOI:10.1007/s00391-017-1181-y.
19. Hajek A, Brettschneider C, Ernst A, Posselt T, Wiese B, Prokein J, et al. Longitudinal predictors of informal and formal caregiving time in community-dwelling dementia patients. Social psychiatry and psychiatric epidemiology. 2016; 51:607–16. DOI: 10.1007/s00127-015-1138-7.
20. Geyer J. Informell Pflegende in der deutschen Erwerbsbevölkerung: Soziodemografie, Pflegesituation und Erwerbsverhalten. Zentrum für Qualität in der Pflege (Hrsg.) ZQP-Themenreport. Vereinbarkeit von Beruf und Pflege. 2016:24–43.
21. Keck W. Was kommt nach der Pflege? Die Pflege eines Angehörigen senkt Beschäftigungschancen von Pflegepersonen nachhaltig. Sozialer Fortschritt. 2016:112–9. DOI: 10.3790/sfo.65.5.112.
22. Schneider U. Informelle Pflege aus ökonomischer Sicht. Zeitschrift für Sozialreform. 2006; 52:493–520. DOI: 10.1515/zsr-2006-0407.
23. Hoefman RJ, van Exel J, Brouwer W. How to include informal care in economic evaluations. Pharmacoeconomics. 2013; 31:1105–19. DOI: 10.1007/s40273-013-0104-z.
24. Lancsar E, Louviere J. Conducting discrete choice experiments to inform healthcare decision making. Pharmacoeconomics. 2008; 26:661–77. DOI: 10.2165/00019053-200826080-00004.
25. Broese van Groenou, Marjolein I, Boer A de. Providing informal care in a changing society. European Journal of Ageing. 2016; 13:271–9. DOI: 10.1007/s10433-016-0370-7.
26. Zarzycki M, Morrison V. Getting back or giving back: understanding caregiver motivations and willingness to provide informal care. Health Psychology and Behavioral Medicine. 2021; 9:636–61. DOI: 10.1080/21642850.2021.1951737.
27. Dombestein H, Norheim A, Lunde Husebø AM. Understanding informal caregivers' motivation from the perspective of self-determination theory: An integrative review. Scandinavian journal of caring sciences. 2020; 34:267–79. DOI: 10.1111/scs.12735.
28. Knesebeck O von dem, Angermeyer MC, Lüdecke D, Kofahl C. Emotional reactions toward people with dementia–results of a population survey from Germany. International Psychogeriatrics. 2014; 26:435–41. DOI: 10.1017/S1041610213002056.
29. Coast J, Al-Janabi H, Sutton EJ, Horrocks SA, Vosper AJ, Swancutt DR, Flynn TN. Using qualitative methods for attribute development for discrete choice experiments: issues and recommendations. Health economics. 2012; 21:730–41. DOI: 10.1002/hec.1739.
30. Bundesministerium der Justiz und für Verbraucherschutz. Gesetz über die Pflegezeit (Pflegezeitgesetz - PflegeZG); 2008. https://www.gesetze-im-internet.de/pflegezg/ BJNR089600008.html (letzter Zugriff: 19.05.2022).
31. Bundesministerium der Justiz und für Verbraucherschutz. Gesetz über die Familienpflegezeit (Familienpflegezeitgesetz - FPfZG); 2011. https://www.gesetze-im-internet.de/fpfzg/ BJNR256410011.html. (letzter Zugriff: 19.05.2022).
32. Rothgang H. Stellungnahme zum Antrag der Fraktion Bündnis 90/Die Grünen „Pflege gerecht und stabil finanzieren–Die Pflege-Bürgerversicherung vollenden “. BT-Drucksache. 2019;19:8561.

Modulübersicht der kumulativen Dissertation

Modul 1:

de Jong L., Plöthner M., Stahmeyer J. T., Eberhard S., Zeidler J., Damm K.: Informal and formal care preferences and expected willingness of providing elderly care in Germany: protocol for a mixed-methods study. BMJ Open 2019; 9(1): e023253. DOI: 10.1136/bmjopen-2018-023253

Modul 2:

Herbst, F. A., Stiel, S., Damm, K., **de Jong, L**., Stahmeyer, J. T., & Schneider N.: Exploring the status of and demand for palliative day-care clinics and day hospices in Germany: a protocol for a mixed-methods study. BMC Palliative Care 2021; 20(1), 1-9. DOI: 10.1186/s12904-021-00792-5

Modul 3:

Plöthner M., Schmidt K., **de Jong L.**, Zeidler J., Damm K.: Needs and preferences of informal caregivers regarding outpatient care for the elderly: a systematic literature review. BMC Geriatrics 2019; 19(1):82, 1-22. DOI: 10.1186/s12877-019-1068-4

Modul 4:

de Jong L., Stahmeyer J. T., Eberhard S., Zeidler J., Damm K.: „Aber vielfach scheitert man dann an Besonderheiten“ – Pflegeberater über Gesetzesänderungen und die Herausforderungen ihrer Arbeit: Eine qualitative Untersuchung. Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen 2020; 150, 65-72. DOI: 10.1016/j.zefq.2020.03.008 1865-9217/

Modul 5:

de Jong, L., Stahmeyer, J. T., Eberhard, S., Zeidler, J., & Damm, K.: Willingness and preparedness to provide care: interviews with individuals of different ages and with different caregiving experiences. BMC geriatrics 2021; 21(1), 1-14. DOI: 1-14. 10.1186/s12877-021-02149-2

Modul 6:

de Jong L., Zeidler J., Damm K.: A systematic review to identify the use of stated preference research in the field of older adult care. Submitted to: European Journal of Ageing 2021.

Modul 7:

de Jong, L., Schmidt, T., Stahmeyer, J. T., Eberhard, S., Zeidler, J., & Damm, K.: Willingness to provide informal care to older adults in Germany: a discrete choice experiment. The European Journal of Health Economics 2022; 1-12. DOI: 10.1007/s10198-022-01483-5

Modul 8:

de Jong L., Schmidt, T., Carstens, A., Damm K.: The impact of different care dependencies on people's willingness to provide informal care: A discrete choice experiment in Germany. Submitted to: Health Economics Review 2022.

Modul 9:

de Jong L., Schmidt, T., Stahmeyer J. T., Eberhard S., Zeidler J., Damm K.: Pflegebereitschaft in Abhängigkeit von der beruflichen Situation. Submitted to: Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen 2022.

Modul 1

Informal and formal care preferences and expected willingness of providing elderly care in Germany: protocol for a mixed-methods study

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BMJ Open; 9(1): e023253

DOI: 10.1136/bmjopen-2018-023253

2019

Open access Protocol

BMJ Open

Informal and formal care preferences and expected willingness of providing elderly care in Germany: protocol for a mixed-methods study

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To cite: de Jong L, Plöthner M, Stahmeyer JT, *et al*. Informal and formal care preferences and expected willingness of providing elderly care in Germany: protocol for a mixed-methods study. *BMJ Open* 2019;**9**:e023253. doi:10.1136/bmjopen-2018-023253

► Prepublication history for this paper is available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2018-023253).

Received 28 March 2018
Revised 22 November 2018
Accepted 26 November 2018

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ABSTRACT

Introduction In Germany, the number of elderly people in need of care is expected to increase from 2.4 million in 2015 to 3.2 million in 2030. The subsequent rise in demand for long-term care facilities is unlikely to be met by the current care structures and available staff. Additionally, many Germans still prefer to be cared for at home for as long as possible. In light of recent changes, such as increasing employment rates of women and growing geographical distances of family members, informal caregiving becomes more challenging in the future. The aim of this study is to explore preferences for informal and formal care services in the German general population, as well as the expected willingness of providing elderly care.

Methods and analysis A mixed-methods approach will be used to explore care preferences and expected willingness of providing elderly care in the German general population. A systematic literature review will be performed to provide an overview of the current academic literature on the topic. Qualitative interviews will be conducted with informal caregivers, care consultants and people with no prior caregiving experiences. A labelled discrete choice experiment will be designed and conducted to quantitatively measure the preferences for informal and formal care in the German general population. People between 18 and 65 years of age will be recruited in cooperation with a (regional) statutory health insurance (AOK Lower Saxony). A mixed multinomial logit regression model and a latent class finite mixture model will be used to analyse the data and test for subgroup differences in care preferences.

Ethics and dissemination The study has been approved by the Committee for Clinical Ethics of the Medical School in Hannover. Data will be treated confidential to ensure the participants' anonymity. The results will be discussed and disseminated to relevant stakeholders in the field.

Trial registration number DRKS00012266.

Strengths and limitations of this study

- This is the first study based on a (labelled) discrete choice experiment design to elicit care preferences of the German general population, as well as the expected willingness of providing elderly care.
- This method enables an inferability to the relative importance and value people place on different care characteristics, as they need to make trade-offs between a number of attributes and their levels in deciding between two hypothetical care scenarios.
- Results can be used to better tailor existing care structures and payment systems in Germany.
- However, the study focuses on the German general population. Transferability of the results needs to be tested with transnational comparisons.
- The design of the discrete choice experiment demands participants to make decisions based on what they think and thus might not predict real behaviours.

INTRODUCTION

Demographic developments towards an increasingly ageing population place significant pressure on national health systems to adequately prepare for future challenges. More specifically, health systems will likely face growing healthcare costs due to rising numbers of chronic diseases and people in need of care, while reductions in revenues for long-term care insurance are expected as a consequence of lower birth rates.[1] The latest statistics for the year 2015 found that 2.4 million Germans aged 65 years and older were in need of care.[2 3] While a need for care can arise at any age, we will only focus on the growing dependency on care of the elderly in this study. Future projections estimate an increase of people in need of care to 3.2 million by 2030 and 4.4 million by 2060.[3–5]

Of the currently 2.4 million elderly people in need of care, the majority of Germans are being cared for at home through relatives or friends (informal care) and/or outpatient services.[2 6] To exemplify, 79% of the age group 60–69 and 57% of elderly aged 90+ are being cared for at home.[6] It is often reported that the majority of people in need of care prefer to stay in their familiar surroundings for as long as possible to maintain a high degree of autonomy and their social ties.[7 8] Home care is also encouraged by German health policy and political efforts, as it is less costly for the state and the social security system.[9] However, these political efforts do not necessarily coincide with the required support and incentives of providing care at home.

Different economic theories exist that aim to explain the decision to provide informal care. This needs to be seen against the background that several studies have stressed the extreme burden caregivers are under as a result of time-consuming and straining work.[10 11] Others have also found positive outcomes of providing informal care, such as increased self-esteem.[12] In a model of altruistic behaviour, the benefits or utility of caregiving (eg, increased self-esteem) need to outweigh the costs and burden to warrant the decision to provide informal care. Other behavioural models are based on strategic exchanges between parents and their children in the form of financial incentives for caregiving to explain the decision-making process.[13] Studies have found determining factors of making use of home care services to include having children, previous experience in providing informal care, as well as the proximity of family resources.[8 13–15]

In light of changing family dynamics, such as increasing employment rates of women and growing geographical distances of family members, while male labour participation and involvement as informal caregivers has remained nearly consistent, some experts expect the rates of informal caregiving to decrease in the future.[8 9] However, the subsequent increase in demand for long-term care facilities is unlikely to be met by the current number of facilities and qualified staff members.[9] Thus, as informal caregiving will likely become more challenging to provide and with the number of people in need of care continuously increasing, sustainable solutions are needed.

Aims

The objective of this study is to explore preferences for informal and formal (outpatient) care services in the German general population, as well as the expected willingness of providing elderly care. First, we would like to survey the general population's preferences for providing informal and formal care services for their relative(s) in need of care. Second, we seek to explore any differences in preferences between an own hypothetical dependency on care compared with their relatives' need for care. Lastly, we look to find and provide recommendations on ways to optimise care by considering people's preferences. We will place particular emphasis on the analysis of subgroup differences in care preferences, such as age, gender, previous caregiving experiences, migration background or occupation. This study will be the first to use a discrete choice experiment (DCE) as a validated stated preference method to measure the caregiving preferences of the German general population.[16 17] Analysing people's preferences presents an important source of information and indication towards better tailoring current care structures and payment systems.

METHODS AND ANALYSIS

A mixed-methods approach will be used to explore informal and formal care preferences and expected willingness of providing elderly care in Germany. In particular, a systematic literature review, face-to-face interviews and a DCE will be conducted to assess people's care preferences. Face-to-face interviews will be used to ascertain a range of experiences and explore challenges people face when it comes to caregiving. These insights will then be used to inform the design of the DCE. The International Society for Pharmacoeconomics and Outcomes Research (ISPOR) guidelines for good research practices for conjoint analysis in health will be followed for the DCE.[18]

Systematic literature review

To create a guideline for the qualitative interviews and design the DCE, we will perform a systematic literature review on published academic studies researching preferences for informal and formal care services. The review will be carried out in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.[19] The selection process will be based on predefined inclusion and exclusion criteria. The electronic databases PubMed, Scopus and Dimdi (German Institute of Medical Documentation and Information) will be used with a predefined search strategy. A list of search terms of the four main concepts 'informal and formal care', 'long term care', 'preferences' and 'age of interest' will be created and connected with the Boolean operators AND and OR. Truncations (*) will be used to find all forms of the word. English and German search terms will be employed in the database search. No specific time frame will be set for the database search. After removing duplicates, two independent reviewers will perform the selection process. The first selection of articles will be based on screening the titles and abstracts. If the inclusion criteria are met, the full text of the articles will be read and checked for final inclusion. In case of disagreement, a third reviewer will be consulted. The database search will additionally be complemented by handsearching the reference lists of the included literature. The quality of the systematic literature review will be tested with the PRISMA checklist.[19]

Face-to-face interviews

Semistructured, guideline-based face-to-face interviews will be conducted in the region of Hannover, Germany to explore people's views and caregiving preferences. Eligible interviewees will receive detailed information beforehand concerning the aim and scope of the study, as well as any data management issues. Interviews will only be conducted after a written informed consent was signed. For the interviews, informal caregivers, care consultants and people with no prior caregiving experiences will be recruited. For this purpose, primarily self-help groups, care consultancies and care support points will be identified in the region of Hannover and subsequently contacted. Maximum variation purposive sampling will be used to identify heterogeneous participants for the qualitative interviews.[20] The total sample size will be based on the principle of theoretical saturation, meaning no new views on the topic are expressed.[21]

One experienced researcher (LdJ) will conduct all interviews to ensure homogeneity. The researcher will make sure beforehand that each participant is familiar with the study's aims and the voluntary nature of participating in it. The guideline will be used for each interview and continually revised to incorporate new points of interest identified during the interviews. Each interview will be audio recorded and subsequently transcribed. In order to analyse the transcripts of the audio recording context-oriented, interviewees will be asked to fill out a questionnaire following the interview, disclosing essential sociodemographic factors such as age, gender, profession, previous and/or current caregiving experiences as well as the geographical distance to the person in need of care. The planned expenditure of time is set at 30 min, as the target audience of informal caregivers is unlikely to be able to spare too much time for participating in interviews.

The guideline interview questions will be based on information collected by means of the systematic literature review. To test the comprehensibility of the interview questions, a group of experts and randomly selected lay people will be consulted. During the interviews, we will ask participants about the current structure of care they provide and if this type of care reflects their wishes as well as the wishes of the person in need of care. We additionally seek to know the perceived challenges of providing care and any observed effects on their time and cost structure. One central question will be people's wishes and preferences for their own hypothetical care and any perceived differences to the provision of care for their relatives. An interesting subquestion at this point will be the responsibility for providing care, that is, if people perceive this to be a familial or societal obligation. In the execution of care, we seek to ask people's preferences for care provided by other people versus potential technical support. Furthermore, we will ask people for suggestions for improving the current care structure in Germany.

Interview analysis

With the informed consent of each participant, all interviews will be recorded, transcribed and subsequently analysed. All transcripts will be entered into MAXQDA V.11 and reviewed line by line. For the analysis of the transcripts, a qualitative content analysis will be performed by two independent researchers based on Mayring.[22] The content analysis will take on a directed approach, making use of deductive categories identified in the interview guide, while at the same time leaving room for further inductive categories generated during the analysis of the interview transcripts.[23] A codebook will additionally be created for the two researchers performing the analysis. Findings will be crucial in informing the design of the DCE, in particular, the generation of attributes for the DCE.

Discrete choice experiment

Description of the DCE

The DCE is a stated preference method, combining knowledge from random utility theory, experimental design theory, consumer theory and econometric analysis.[24] The method of DCE has been increasingly applied and deemed useful in the field of healthcare research to elicit people's preferences.[25 26] In a DCE, people are asked to choose between two or more alternative scenarios. The underlying assumptions of a DCE are that any intervention or service looked at can be described by its attributes or characteristics and that people value these attributes differently depending on their levels.[27] The attributes and its different levels are then comprised to several scenarios, of which people are asked to choose one based on their preference. This method enables an inferability to the relative importance and value people place on different attributes, as these need to make trade-offs between the several attributes and their levels in their decision-making process.[18]

Design of the DCE

We will conduct a DCE to measure the caregiving preferences in the German general population. In the process of constructing an optimal or nearly optimal experimental design, two statistical issues need to be examined. Namely, identification meaning the ability to obtain independent and unbiased parameter estimates and efficiency as the precision with which such effects are estimated.[17] Several authors argue that design identification should take priority, as efficiency can be improved later by, for instance, increasing the sample size. However, identification errors in the design cannot be altered retrospectively and are likely to produce biased and confounded results.[17 28 29] Statistical efficiency and response efficiency need to be balanced to maximise the precision of parameter estimates.[30] We will use the D-efficiency criterion as a measure of statistical efficiency, while blocking certain choice sets will be used to increase response efficiency by reducing the information load of participants. The D-efficiency criterion has been increasingly used to measure statistical efficiency when aiming to create optimal designs with an efficiency of 100%. Thus, we will create choice sets that minimise the D-error, which in turn maximises the D-efficiency.[26 28] A full factorial design is generally regarded as an optimal design to estimate all main effects as well as all interaction effects. However, a full factorial design is rarely feasible depending on the final number of attributes and levels. Thus, we might have to opt for the largest possible fractional factorial design with a high D-efficiency. We will use SAS V. 9.4 to construct the choice sets of the DCE. We chose to construct a labelled

DCE for our study, which uses specific labels or titles for the different alternatives, thus already conveying information to the study participants. For this study, the label 'type of care' will be used, categorised into 'only informal care', 'mix of informal and formal/outpatient care' and 'only formal/outpatient care'. While labelled DCEs are currently less frequently used in health economics, alternatives will be less abstract and more realistic for respondents, adding to the validity of the results.[31]

Results from the systematic literature review, as well as the interviews, will be used to establish the attributes for the DCE. In total, four to six attributes will be created on the basis of their relevance to the research question and decision context.[18] In the creation of the attributes, particular focus will be placed on the independence of attributes. We would like to respectively include at least one attribute connected to cost (or time). The willingness to pay for services will be integrated as an attribute in the DCE. Other potential attributes might be quality of care or retention of autonomy. With the selection of included attributes, the corresponding range of levels for each attribute will also be decided on and discussed with experts. No opt-out option will be included in the profiles to ensure the complete estimation of preference structures and trade-offs made between choice sets. Additionally, the option of not providing needed care is no realistic scenario in this case.

Data collection and sampling strategy

For the sample, people between 18 and 65 years of age will be recruited from the German general population with no own need for care. The aim of the age limit is the ascertainability of a group of people of working age with no own dependency on care. Occupational and familial obligations are expected to influence the individual willingness to provide care for relatives. Study participants will be recruited in cooperation with a statutory health insurance (AOK Lower Saxony) by random selection of insured Germans in the chosen age range. Particular attention will be placed on the population group 45–64 years of age, as they most likely have own informal caregiving experiences. The primary mode of administration will be a mail survey. Study participants will receive detailed information about the study and the data management plan beforehand. Data will only be used after written informed consent by all study participants. In accordance with the new European General Data Protection Regulation, the statutory health insurance will be in charge of recruitment and contacting potential study participants. We will only receive the filled out questionnaires of study participants after written informed consent has been obtained. All personal data, that is, sociodemographic characteristics, will be provided to us in a pseudonymised manner.[32] Based on the first estimations, the targeted sample size is approximately 250 per questionnaire version.[33] Calculating with two questionnaire versions and estimating with a response rate of 1/3, we would send out about 1500 questionnaires. To verify these first estimations, we will use the sample size calculations by de Bekker-Grob *et al*. This approach consists of five elements that are deemed necessary for calculating the required sample size of a DCE. Particularly, the significance level, the statistical power, the statistical model used in the DCE, initial beliefs about parameter values and the DCE design itself are needed.[24]

Once all the attributes, descriptions and levels, as well as the different choice sets have been established, we will perform a pretest (n=20) to make sure the questionnaire is understandable for study participants. Next to the understanding of attributes and their levels, we will also test the length and complexity of the DCE questionnaire. A rationality test will be included in the survey to make sure study participants understand the questions. After making any necessary adjustments to the questionnaire following the pretest, we will be able to send out the final survey. Next to the DCE choice sets, we will ask participants to disclose a number of important sociodemographic factors, as well as provide an assessment of their perceived quality of life. This data will then be used in the analysis of the questionnaires. To measure the health-related quality of life of study participants, we will use the standardised 5-level EQ-5D (EQ-5D-5L) instrument introduced by the EuroQol Group in 2009, consisting of the five dimensions mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Next to the descriptive system of the instrument, comprised of the five dimensions with five severity levels each, respondents will also be asked to judge their current health state on a Visual Analogue Scale from 0 to 100.[34]

Data analysis of DCE

Following data collection, we will analyse the data with descriptive statistics and conduct several logistic regression analyses to determine factors that influenced the choices made by the study participants. We will analyse and compare the distribution of mean age and sex between the included respondents of the DCE and the people who did not respond. The core of the statistical analysis rests on the random utility theory, in which choices can be divided into an explainable component and a random component and people's preferences are summarised by their utility function.[24] The random component can be due to different types of error, unobservable attributes or preference variation.[17] The assumption is that people choose the option with the highest utility. For the multivariate analyses, we will use a mixed multinomial logit regression model and a latent class finite mixture model. Both multivariate analyses are appropriate to compare subgroups and see if factors such as gender, age and previous caregiving experience influence the choices made. We chose to perform a multinomial logit model, as our dependent variable (type of care) has more than two levels. Additionally, we will conduct a latent class finite mixture model, which allows the identification of latent classes or subgroups within the sample with different preference weights.[35] With the statistical analyses, we aim to investigate if certain sociodemographic characteristics or previous caregiving experiences influence the choices made by the study participants with regard to care preferences. The statistical program R will be used to perform all statistical analyses.

Patient and public involvement

The development of the research question and outcome measures were informed by the current demographic changes and political efforts in Germany, as well as the lack of preference studies in the field of elderly care in Germany. No patients or members of the public were involved in the design of the study. The public will be involved during the design of the questionnaire, as well as the conduction of the DCE. The results of the face-to-face interviews will be sent and disseminated to the study participants. The results of the systematic literature review and the DCE will be published in open-access journals.

ETHICAL CONSIDERATIONS AND DISSEMINATION

The study has been registered at the German Registry of Clinical Trials (DRKS00012266) and is already visible on the WHO International Clinical Trials Registry Platform. A contact person will be provided for all participants in the event of questions or later withdrawal from the study. The results of the study will be discussed and disseminated to relevant stakeholders in the field. Important experts are for instance payers, care providers and lobbyists. Outcomes in the form of recommendations regarding a more efficient use of the limited resources available will also be made by taking into consideration the preferences of the German general population. We will subsequently publish the results in peer-reviewed scientific journals.

DISCUSSION

Elderly people in need of care are expected to increase from 2.4 million in 2015 to 4.4 million in 2060 due to changing demographics, rising numbers of multimorbidities and increasing life expectancy. Of the 4.4 million elderly Germans in need of care in 2060, the group aged 80+ is projected to make up 74% in total.[3] At the same time, current demographic and societal changes will likely make informal caregiving more challenging in the future and the subsequent demand for long-term care facilities is unlikely to be met. To reduce the growing expenses of the long-term care insurance in Germany, political efforts have previously encouraged informal caregiving and the use of outpatient services to prolong caregiving at home. In the most recent care support act of 2017, the state increased monetary support for caregiving at home and aimed to facilitate the agreement of caregiving and professional responsibilities for informal caregivers. However, insufficient research has been done in Germany to see if political efforts match the wishes and needs of informal caregivers and to representatively measure the preferences of (potential) informal caregivers.

The results from this study will provide an important source of information towards improving the German care structures and payment systems to accommodate future demographic and societal trends. Our analysis will address the aims of this study by providing estimates of the importance of each attribute/care characteristic for the overall preference of the type of care. Additionally, the study will provide an indication to which extent people are willing to trade-off between attributes. Several logistic regression models will be used to analyse subgroup differences in preferences, such as sociodemographic factors, previous informal caregiving experiences or migrant background. The outputs of the study will be critically discussed and disseminated to stakeholders in the field to spark political debate. Suggested solutions will be made to improve the current care structures and use available resources more efficiently. Available care services for informal caregivers can be improved preference based to further encourage and facilitate caregiving at home. Additionally, the surveyed willingness to provide care and willingness to pay for services of the German general population can be used to better tailor existing services. This study will be the first in Germany to use a (labelled) DCE to elicit people's caregiving preferences for care characteristics such as time and cost.

Contributors LdJ, KD, MP and JZ were involved in the design of the study. JTS and SE were responsible for the design of the recruitment process. LdJ was responsible for drafting the manuscript. All authors approved the final study design and were involved in revising the manuscript. All authors agree to be accountable for all aspects of the work.

Funding This work was supported by the Federal Ministry of Education and Research, grant number 01EH1603A. The publication of this article was funded by the Open Access Fund of the Leibniz University Hannover.

Competing interests None declared.

Patient consent for publication Not required.

Ethics approval The study has been approved by the Medizinische Hochschule Hannover (MHH)'s Committee for Clinical Ethics (Reference number 09.05.17/La).

Provenance and peer review Not commissioned; externally peer reviewed.

REFERENCES

1. Matthews Z, Channon A. *Will there be enough people to care? Notes on workforce implications of demographic change 2005 - 2050*. Geneva: Evidence and Information for Policy, Organisation Mondiale de la santé, 2006.
2. Destatis. *Pflegestatistik 2015: Pflege im Rahmen der Pflegeversicherung Deutschlandergebnisse*. Wiesbaden, 2017.
3. Bundesinstitut für Bevölkerungsforschung. Zahlen und Fakten: Anzahl der Pflegebedürftigen steigt vor allem bei den Hochbetagten: Pflegebedürftige nach Altersgruppen, 1999-2060. 2017 http://www.demografie-portal.de/SharedDocs/Informieren/DE/ZahlenFakten/Pflegebeduerftige_Anzahl.html (Accessed 23 Aug 2018).
4. Rothgang H, Müller R, Unger R, *et al*. *Themenreport Pflege 2030: Was ist zu erwarten - was ist zu tun?* Bertelsmann Stiftung, 2012.

5. Bundesministerium für Gesundheit. Sechster Bericht der Bundesregierung über die Entwicklung der Pflegeversicherung und den Stand der pflegerischen Versorgung in der Bundesrepublik Deutschland. https://www.bundesgesundheitsministerium.de/fileadmin/Dateien/5_Publikationen/Pflege/Berichte/6.Pflegebericht.pdf (Accessed 23 Aug 2018).
6. Bundesinstitut für Bevölkerungsforschung. Zahlen und Fakten: Pflegebedürftige werden meistens zu Hause versorgt. 2017 http://www.demografie-portal.de/SharedDocs/Informieren/DE/ZahlenFakten/Pflegebeduerftige_Versorgung.html (Accessed 23 Aug 2018).
7. Heuchert M, König HH, Lehnert T. The role of preferences in the German long-term care insurance - results from expert interviews. *Gesundheitswesen* 2017;79:1052–7.
8. Hajek A, Lehnert T, Wegener A, *et al*. Potential for informal care of the elderly in Germany: results of a representative population-based survey. *Z Gerontol Geriatr* 2018;51:612–9.
9. Hajek A, Lehnert T, Wegener A, *et al*. Factors associated with preferences for long-term care settings in old age: evidence from a population-based survey in Germany. *BMC Health Serv Res* 2017;17:1–9.
10. Hajek A, Brettschneider C, Ernst A, *et al*. Longitudinal predictors of informal and formal caregiving time in community-dwelling dementia patients. *Soc Psychiatry Psychiatr Epidemiol* 2016;51:607–16.
11. Geyer J, Schulz E. Who cares?: Die Bedeutung der informellen Pflege durch Erwerbstätige in Deutschland, DIW-Wochenbericht. 2014;81:294–301.
12. Haley WE. Family caregivers of elderly patients with cancer: understanding and minimizing the burden of care. *J Support Oncol* 2003;1(4 Suppl 2):25–9.
13. Schneider U. Informelle Pflege aus ökonomischer Sicht. *Zeitschrift für Sozialreform* 2006;52:493–520.
14. Kemper P. The use of formal and informal home care by the disabled elderly. *Health Serv Res* 1992;27:421–51.
15. Spangenberg L, Glaesmer H, Brähler E, *et al*. Use of family resources in future need of care. Care preferences and expected willingness of providing care among relatives: a population-based study. *Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz* 2012;55:954–60.
16. van den Berg B, Brouwer WB, Koopmanschap MA. Economic valuation of informal care. An overview of methods and applications. *Eur J Health Econ* 2004;5:36–45.
17. Lancsar E, Louviere J. Conducting discrete choice experiments to inform healthcare decision making: a user's guide. *Pharmacoeconomics* 2008;26:661–77.
18. Bridges JF, Hauber AB, Marshall D, *et al*. Conjoint analysis applications in health-a checklist: a report of the ISPOR Good Research Practices for Conjoint Analysis Task Force. *Value Health* 2011;14:403–13.
19. Moher D, Liberati A, Tetzlaff J, *et al*. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *J Clin Epidemiol* 2009;62:1006–12.
20. Palinkas LA, Horwitz SM, Green CA, *et al*. Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Adm Policy Ment Health* 2015;42:533–44.
21. Glaser BG, Strauss AL, Paul AT. *Grounded theory: Strategien qualitativer Forschung*. 1st edn. Bern: Huber, 2008.
22. Mayring P. Qualitative Inhaltsanalyse: Grundlagen und Techniken. s.l: Beltz Verlagsgruppe. 2010.
23. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005;15:1277–88.
24. de Bekker-Grob EW, Donkers B, Jonker MF, *et al*. Sample size requirements for discrete-choice experiments in healthcare: a practical guide. *Patient* 2015;8:373–84.
25. Ryan M, Bate A, Eastmond CJ, *et al*. Use of discrete choice experiments to elicit preferences. *Quality and Safety in Health Care* 2001;10(Supplement 1):i55–60.
26. de Bekker-Grob EW, Ryan M, Gerard K. Discrete choice experiments in health economics: a review of the literature. *Health Econ* 2012;21:145–72.
27. Coast J, Horrocks S. Developing attributes and levels for discrete choice experiments using qualitative methods. *J Health Serv Res Policy* 2007;12:25–30.
28. Street DJ, Burgess L, Louviere JJ. Quick and easy choice sets: constructing optimal and nearly optimal stated choice experiments. *Int J Res Mark* 2005;22:459–70.
29. Burgess L, Street DJ. Optimal designs for choice experiments with asymmetric attributes. *J Stat Plan Inference* 2005;134:288–301.
30. Reed Johnson F, Lancsar E, Marshall D, *et al*. Constructing experimental designs for discrete-choice experiments: report of the ISPOR Conjoint analysis experimental design good research practices task force. *Value Health* 2013;16:3–13.
31. de Bekker-Grob EW, Hol L, Donkers B, *et al*. Labeled versus unlabeled discrete choice experiments in health economics: an application to colorectal cancer screening. *Value Health* 2010;13:315–23.
32. EUR-Lex. Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation): CELEX no. 32016R0679. 2016.
33. Orme B. *Getting started with conjoint analysis: strategies for product design and pricing research*. Madison, Wis: Research Publishers LLC, 2010.
34. van Reenen M, Janssen B. EQ-5D-5L User guide: basic information on how to use the EQ-5D-5L instrument. 2015 (Accessed 23 Aug 2018).
35. Hauber AB, González JM, Groothuis-Oudshoorn CG, *et al*. Statistical methods for the analysis of discrete choice experiments: a report of the ispor conjoint analysis good research practices task force. *Value Health* 2016;19:300–15.

Modul 2

Exploring the status of and demand for palliative day-care clinics and day hospices in Germany: a protocol for a mixed-methods study

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BMC Palliative Care; 20(1), 1-9
DOI: 10.1186/s12904-021-00792-5

2021

Herbst *et al. BMC Palliative Care* (2021) 20:94
https://doi.org/10.1186/s12904-021-00792-5

BMC Palliative Care

STUDY PROTOCOL
Open Access

Exploring the status of and demand for palliative day-care clinics and day hospices in Germany: a protocol for a mixed-methods study

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Abstract

Background: To date, the establishment and development of palliative day-care clinics and day hospices in Germany have been completely unsystematic. Research is needed to gain insight into these services and to ensure their accessibility and quality. Accordingly, the ABPATITE research project aims at: (1) identifying the characteristics of palliative day-care clinics and day hospices in Germany, (2) determining demand and preferences for these services, and (3) proposing recommendations (with expert agreement) for the needs-based establishment and development of these services.

Methods: The research is a multi-perspective, prospective, observational study following a mixed-methods approach across three study phases. In phase 1a, qualitative expert interviews will be conducted to capture the facility-related characteristics of palliative day-care clinics and day hospices in Germany; the results will feed into a questionnaire sent to all such institutions identified nationwide. In phase 1b, a questionnaire will be sent to local statutory health insurance providers, to gain insight into their contracts and accounting and remuneration models. In phase 2a, a service preference survey will be conducted with patients and family caregivers. In phase 2b, semi-structured interviews with management staff will explore the factors that promote and hinder the provision of service. In phase 2c, the external perspective will be surveyed via focus groups with local actors involved in hospice and palliative care. In phase 3a, focus groups with representatives from relevant areas will be conducted to develop recommendations. Finally, in phase 3b, recommendations will be agreed upon through a Delphi survey.

Discussion: The empirically developed recommendations should enable the establishment and development of day hospices and palliative day-care clinics in Germany to be better managed, more oriented to actual demand, and more effectively integrated into wider health care services. Importantly, the findings are expected to optimize the overall development of hospice and palliative care services.

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Trial registration:: The study was prospectively registered in the German Clinical Trials Register (Deutsches Register Klinischer Studien) (Registration N° DRKS00021446; date of registration: April 20, 2020). The study is searchable under the International Clinical Trials Registry Platform Search Portal of the World Health Organization, under the German Clinical Trials Register number.

Keywords: palliative care, hospice care, day-care, medical, adult day-care centers, patient preference, end of life care, palliative day-care clinic, day hospice, health care planning

Background

In Germany, trans-sectoral inpatient and ambulatory hospice and palliative care services for people with incurable, progressive illnesses and limited lifespans have significantly advanced in recent years, in both specialized and general sectors. More than likely, this is due to the socio-political relevance of and support for end of life care in Germany, where inpatient hospices, palliative care units, ambulatory hospice services, and specialized palliative home care services are widely established.

The Hospice and Palliative Care Act 2015 has placed a greater focus on strengthening and expanding general palliative care in Germany [1]. Specifically, this dynamic law aims at establishing needs-oriented, comprehensive care services in both urban centers and economically weak and rural regions, as well as improving access to all hospice and palliative care services, particularly for immigrants and members of socially disadvantaged groups (e.g. prisoners). This promotion of a needs-based, patient-oriented approach to hospice and palliative care also applies to palliative day-care clinics and day hospices [2]. While these services are not necessarily defined by social law in Germany, they must still adhere to regulations in order to successfully claim costs back from statutory health insurance providers. Day-care services are often linked to institutions such as inpatient hospices and palliative care units or hospitals; however, they may also operate independently. The primary aims of these day-care institutions, in which patients spend up to five days per week, are maintaining patients' autonomy, improving patients' quality of life, and supporting family caregivers by granting them "respite care" [3].

To date, the establishment and development of palliative day-care clinics and day hospices in Germany have been completely unsystematic. Thus, existing institutions may have implemented—and may continue to implement—insular solutions that are not coordinated with other institutions or with regional health care services, or indeed with the general health care services covered by statutory health insurance providers. For this reason, patients at their end of life may find that these institutions are not sufficiently integrated into the German health care system. In Germany, structural standards and quality indices for palliative day-care do not exist, and the label of "day hospice" is applied to practices that are very heterogeneous, in terms of services offered. This can generate confusion among patients and family caregivers, making it difficult for them to choose an adequate and needs-oriented form of care. However, standards do exist for services financed by statutory health insurance providers, and these standards ensure a high quality of care [4].

Investigating the status of and demand for palliative day-care clinics and day hospices

In 2010, the European Association for Palliative Care estimated that one palliative day-care clinic or day hospice was needed for a catchment area of 150,000 residents [5]. More recent surveys of demand in Germany have investigated palliative day-care clinics and day hospices only marginally, or not at all [6–8]. Internationally, mostly qualitative interview studies and quantitative surveys and analyses of patient records show a high level of patient satisfaction with the quality of care received at palliative day-care clinics and day hospices, relating to the opportunities for social participation offered by these institutions and their maintenance of quality of life [9, 10]. However, systematic findings from controlled studies of high methodological quality are lacking, particularly in relation to the effectiveness of these end of life institutions in: improving symptoms, providing inter-sectoral continuity of care, preventing inpatient hospital admissions and nursing home or hospice admissions, and delivering cost savings across the course of a disease [11, 12]. Notwithstanding the scientific evidence for the need and effectiveness of day-care services in Germany, initiatives to establish palliative day-care clinics and day hospices are evolving [13–22].

Study aims

Scientific research is needed to provide an overview of current hospice and palliative day-care services in Germany; to increase the transparency of these services over the long term; and to ensure the accessibility and quality of these services. In response to this need, the ABPATITE consortium study aims at answering the following questions, across three phases:

Phase 1: What palliative day-care clinics and day hospices are operating or in development in Germany, and what are the characteristics of these facilities?

Phase 2: What is the demand for palliative day-care clinics and day hospices in Germany, as assessed by health care professionals, stakeholders, and representatives, and what are the service preferences of patients and family caregivers?

Phase 3: What recommendations can be determined and agreed upon for the needs-based establishment and development of day hospices and palliative day-care clinics in Germany?

Aims of the study protocol

The present research is a mixed-methods study involving qualitative and quantitative methods and participatory aspects. The project aims at making an original contribution to the palliative care literature by increasing the transparency of palliative day-care clinics and day hospices in Germany. Publication of the study protocol represents the first step in this process. In their previous Dy@EoL project [23], the authors experienced that recruitment partners and scientists studying similar topics were interested in consulting the study protocol to obtain an overview of the project. Furthermore, the processes of establishing and developing institutions and measuring status and demand in palliative day-care clinics and day hospices are not necessarily straightforward. The present study protocol is designed to shed light on these processes. In addition, the study protocol addresses ethical considerations, data security, and the dissemination and implementation of the study results. Finally, the study design for systematic research on palliative day-care clinics and day hospices is of relevance to the scientific community.

Methods and design

The present multi-perspective, prospective, observational study follows a mixed-methods approach, spread across three research phases. The study protocol adheres to STROBE guidelines [24].

In phase 1a, palliative day-care clinics and day hospices in Germany are being identified through national online databases of hospices and palliative care providers [25, 26] and general Internet searches. Exploratory, qualitative expert interviews are being conducted (currently underway) with facility managers to capture relevant facility-related characteristics. These results will be used to develop a standardized quantitative questionnaire that will be sent to all palliative day-care clinics and day-hospices identified nationwide.

In phase 1b, a quantitative, standardized instrument will be developed in cooperation with a local statutory health insurance provider (AOK Lower Saxony) to identify and record all day hospices and palliative day-care clinics that are contracts with the statutory health insurance funds. The instrument will not only record the contractual partners, but it will also capture contractual terms relating to remuneration and services provided, as well as the number of patients treated in these facilities. Further, the number of claims and approvals filed by the day hospices and palliative day-care clinics will be collected.

In phase 2a, a preference survey about hospice and palliative care will be administered to patients with a potentially palliative course of illness and their family caregivers. The aim of this quantitative step will be to determine the preferences of patients and their family caregivers regarding palliative care services they may draw on in the future. The questionnaire will contain a case description of a patient in palliative care, as well as a discrete choice experiment (DCE) [27, 28]. In the DCE, participants will be asked to choose between two alternative palliative care situations. From the DCE data, conclusions will be drawn about the perceived importance of individual care characteristics. The questionnaire will also capture patients' socio-demographic and medical data (related specifically to their disease), as well as data on family caregivers' willingness or capacity to provide care. A literature search and expert discussion with representatives of the German Association for Palliative Medicine and the German Hospice and Palliative Care Association will inform the design of the questionnaire and DCE. The validity, comprehensibility, and feasibility of the questionnaire will be tested in a pre-test with patients and family caregivers, using the verbal probing technique [29]. To minimize the risk of response bias, the questionnaire will be formulated in a way that is generally understandable and can be completed independently by patients and relatives.

In phase 2b, semi-structured (telephone) interviews with managers from three to five selected day hospices and palliative day-care clinics in Germany will be conducted as case studies ($N = 6–10$ persons; two persons in different functions per facility). The interview guide will comprise open, stimulating questions with the aim of highlighting thematic complexes such as local networking with hospice and palliative care providers. After each interview, the guide will be reviewed and adapted. The objective of this phase will be to explore the conditions under which the respective facilities have evolved, identify the factors that promote and hinder their service provision, and elicit information on their integration into regional hospice and palliative care networks from an internal perspective. The external perspective on day hospices and palliative day-care clinics in Germany will be surveyed in phase 2c by way of focus groups [30, 31] with local actors involved in hospice work and palliative care (e.g. actors affiliated with ambulatory palliative home care, specialized palliative home care, in-patient hospices, palliative care wards, long-term care support centers, and municipalities). The results of phase 2b will be used to identify potential participants.

Using a participatory action research methodology [32], in phase 3a, 2-hour focus groups with representatives from relevant areas (e.g. the German Association for Palliative Medicine, the German Hospice and Palliative Care Association, the German College of General Practitioners and Family Physicians, the German Home Care and Nursing Society, the German Association of Towns and Municipalities, the National Association of Statutory Health Insurance Physicians, regional Associations of Statutory Health Insurance Physicians, the German Medical Association, the Association of German Cities, the National Association of Statutory Health Insurance Funds, the Association of Private Health Insurance Companies, and social and health policy) will be conducted to develop recommendations for the needs-oriented establishment and development of day hospices and palliative day-care clinics in Germany.

Finally, in phase 3b, the empirically derived recommendations from phase 3a will be agreed upon via a Delphi survey [33] with experts, including participants from phase 3a.

Study population and data collection

Following a descriptive analysis of the initial search data from phase 1a, a heterogeneous group of palliative day-care clinic and day hospice managers (approx. $n = 6$) (from facilities of varying sizes, years of operation, urban vs. rural areas) will be recruited to participate in a qualitative telephone interview. The exact number of interviews will be determined during the course of study, on the basis of the minimum number needed to represent relevant institution-related criteria. Similarly, the final number of palliative day-care clinics and day hospices to be surveyed will be determined during this study phase. In phase 1b, the standardized written survey will be distributed to all 11 local statutory health insurance providers (AOK).

Patients ($N = 300$) and their family caregivers ($N = 300$) will be recruited in phase 2a, via six partnering internal medicine wards, acute care clinics, and rehabilitation hospitals in Lower Saxony. These participants will complete a DCE in which they will choose between hypothetical palliative care situations described by a set of attributes and corresponding levels. The underlying assumption of a DCE is that any intervention or service can be described using characteristics (attributes), and that participants will rate these differently according to the levels of each attribute provided by the relevant intervention or service (e.g. hours of care per week, activities offered). The DCE used in the present study will include eight sets, each with two alternatives. The sample size of 300 patients and 300 family caregivers is reasonable for this number of DCE choice sets, attributes, and levels. However, according to Johnson and Orme's conservative calculation method [27, 28], only a small sample size may be required to generate significant findings. Therefore, once 20 % of the originally calculated minimum sample ($n = 60$ patients, $n = 60$ family caregivers) complete the DCE, the sample calculation will be reviewed. Notwithstanding the results of this calculation, the aim will still be to include 600 participants, in order to increase statistical power, especially for the subgroup analyses. Study eligibility will be reviewed and approved by two project study nurses, in consultation with the recruitment partners. Potential participants (patients and their family caregivers) who meet the inclusion criteria (see section "Inclusion, exclusion, and termination criteria") will be approached by one of the project study nurses, who will personally invite them to participate, inform them of the study objectives and the relevance of the topic, and—if desired—be present when the participants complete the questionnaire, in order to answer any questions that may arise. The researchers will consult with the study nurses regularly about the recruitment process, in order to promptly identify and manage any challenges, as appropriate (i.e. by modifying the recruitment process). Six institutional partners have already agreed to assist in the recruitment process. If necessary, further recruitment partners will be integrated during the research.

In phase 2b, managers of palliative day-care clinics and day hospices ($N = 6$–10; two managers with differing responsibilities per facility) will be recruited and administered semi-structured interviews. If possible, members of the institutional founding team will be included, to enable the facility's history to be traced. All managers should be experienced with and knowledgeable of hospice and/or palliative care structures. For this phase, the recruitment technique of snowball sampling will be utilized, as good networking between management staff is expected.

In phase 2c, local actors involved in hospice work and palliative care ($n = 5$–8 participants per group) will be questioned in focus groups. Participants will be selected according to the principle of diversity, in order to adequately represent the views of inpatient, ambulatory, general, and specialist service providers. A drop-out rate of 10 % due to illness, other commitments, and personal reasons is expected. To reach the minimum number of five participants per focus group, a maximum of eight persons will be assigned to each group.

A heterogeneous sample of key actors ($N = 40$) with sufficient influence to nationally promote the project results and recommendations will be recruited in phases 3a and b. These actors will either hold responsibility for the development of end of life care or they will work in areas that intersect with hospice or palliative care. In phase 3a, participants will be divided into a maximum of eight homogeneous focus groups of up to five persons each, in order to discuss specific topics that correspond with their areas of expertise (e.g. representatives from health insurance providers may discuss recommendations for financing). As in phase 2c, a 10 % drop-out rate is expected. In phase 3b, Delphi survey data will be collected with the aid of an online tool. Participants will be asked to indicate their level of agreement with each individual recommendation on a 4-point Likert scale, with regard to criteria such as relevance, clarity, and feasibility. Free text fields will be included for participants to provide additional comments on the recommendations.

An overlap of participants in phases 1, 2b, 2c, 3a, and 3b will promote participants' long-term commitment to and identification with the project. The project team will enforce this through regular communication of the project status and preliminary results, as well as via individual and personal contact.

Inclusion, exclusion, and termination criteria

Phase 2a will include patients (aged 18 years or older) who are currently hospitalized with an illness that may become palliative, in addition to their family caregivers. Patients with both oncological and non-oncological diseases (e.g. organ dysfunction or a degenerative neurological disease) will be included, provided they have sufficient physical and mental capacity to participate. Patients should not have begun palliative or hospice care, so they are able to prospectively evaluate different scenarios regarding such care. After receiving detailed information about the type, content, and purpose of the study and their participation, each patient and family caregiver will provide written informed consent to participate. Patients and family caregivers of all genders (f/m/d) and ethnic backgrounds will be invited to participate in the study.

Patients and family caregivers will be excluded from the study according to the following criteria: (1) patients are currently in a palliative or hospice care situation, (2) patients/family caregivers are not sufficiently proficient in the German language to complete the questionnaire (DCE), and/or (3) patients/family caregivers do no consent to participate in the study. Termination criteria will include: (1) significant emotional distress during participation in the study, (2) insufficient cognitive ability to complete the questionnaire (DCE), and/or (3) withdrawal of consent to participate in the study.

Data analysis

The data analysis will aim at describing the current situation and demand for palliative day-care clinics and day hospices in Germany, and determining agreed recommendations for the establishment and development of these services.

In phase 1a, quantitative data from the online searches (i.e. a national database and general Internet search) and the palliative day-care clinic and day hospice survey will be transferred to an electronic database using IBM SPSS Statistics 26 (SPSS Inc., Chicago, IL, USA) for Windows. The data will then be analyzed using descriptive and frequency statistics. Interviews will be recorded on tape, transcribed verbatim by an external party, and analyzed qualitatively in MaxQDA (VERBI Software Consult Sozialforschung GmbH, 1989–2020), using the methodological principles of qualitative content analysis [34, 35]. Characteristics that have already been determined for the institutions will comprise an a priori category system, which will be successively expanded with the interview data. The results will provide an extended overview of the defining characteristics of these institutions, based on primary information from facility managers.

In phase 1b, the collected data on insurance providers and their contractual partners will be integrated to produce an overview of day hospices and palliative day-care clinics. Quantitative data will be evaluated using descriptive and frequency statistics.

In phase 2a, participants' DCE data will be transferred into an electronic database. In the first step, the data will be effect coded, as follows: the binary coded care decision will represent the dependent variable; and DCE characteristics, socio-demographic data, and other personal data will be the independent variables. The data structures will be examined using descriptive analyses, and missing values will be identified. The statistical analysis will draw on random utility theory, assuming that participants will have selected the scenario (care situation) with the highest utility. Econometric methods (regression models) will be used to evaluate the data (e.g. mixed-effects models) [36]. Identification of the optimal model will be based on goodness of fit. Sociodemographic differences will be identified, as well as any relationships between preferences and illnesses (latent-class models), in order to identify potential sample subgroups with different preference weights. The results of the patient and family caregiver surveys will be compared. Statistical analyses will be carried out using R.

In phase 2b, the collected case study data will be evaluated using qualitative content analysis, according to Mayring [34, 35], as in phase 1a. The a priori topics, as defined for the interview guide, will be adopted as a category system and expanded and/or merged throughout the analysis.

In phase 2c, focus group data will be analyzed using qualitative content analysis, as in phase 2b. Coding of the collected material will be merged with the coding and a priori categories from phase 2b, to enable a systematic comparison of internal and external perspectives. The results will provide an overview of the health care services and limitations of palliative day-care clinics and day hospices. Moreover, the findings will enable an assessment of the extent to which such facilities are integrated into the local health care landscape, the challenges these facilities face, and the needs that these facilities can(not) meet.

In phase 3a, transcripts of the focus groups and notes from the feedback cards (from pin boards) will be subjected to merged qualitative content analysis, according to Mayring [37]. In advance, a priori categories will be developed on the basis of the topics addressed in the focus groups. Feedback card content will be assigned to the corresponding categories. Prior to analyzing the transcripts, relevant units of meaning and analysis will be determined. Irrelevant passages (e.g. questions and comments from the moderators and problem descriptions that do not contribute a recommendation) will not be coded. Recommendations will be paraphrased in the evaluation and summarized in the content analysis. Paraphrases with the same meaning will not be included in the category system and similar statements will be combined, in order to bundle ideas. Throughout the analysis—and on the basis of the data—the category system will be reviewed, revised, and ultimately translated into a system of higher-level categories. The final category system will be agreed upon by two scientists.

In phase 3b, recommendations from the first Delphi round that receive at least 80 % agreement from all respondents on the scale points "I rather agree" and "I fully agree" will be considered agreed. These results will be calculated by means of frequency analysis, using IBM SPSS Statistics 26 (SPSS Inc., Chicago, IL, USA). Recommendations that are lacking agreement will be revised on the basis of the free text comments from Delphi panelists and prepared for a second Delphi round. This interim analysis and adaptation of the recommendations will require approximately 2 to 3 weeks to complete. At this point, the modified recommendations will be sent to all participants who completed the first Delphi round. Again, an 80 % participation rate is expected. If necessary, depending on the data collection and analysis, a third Delphi round will be conducted. All agreed recommendations will be printed in a booklet.

Figure 1 provides an overview of the mixed-methods study design across the three phases. The figure illustrates the methods used to develop recommendations for the needs-based establishment and development of day hospices and palliative day-care clinics in Germany.

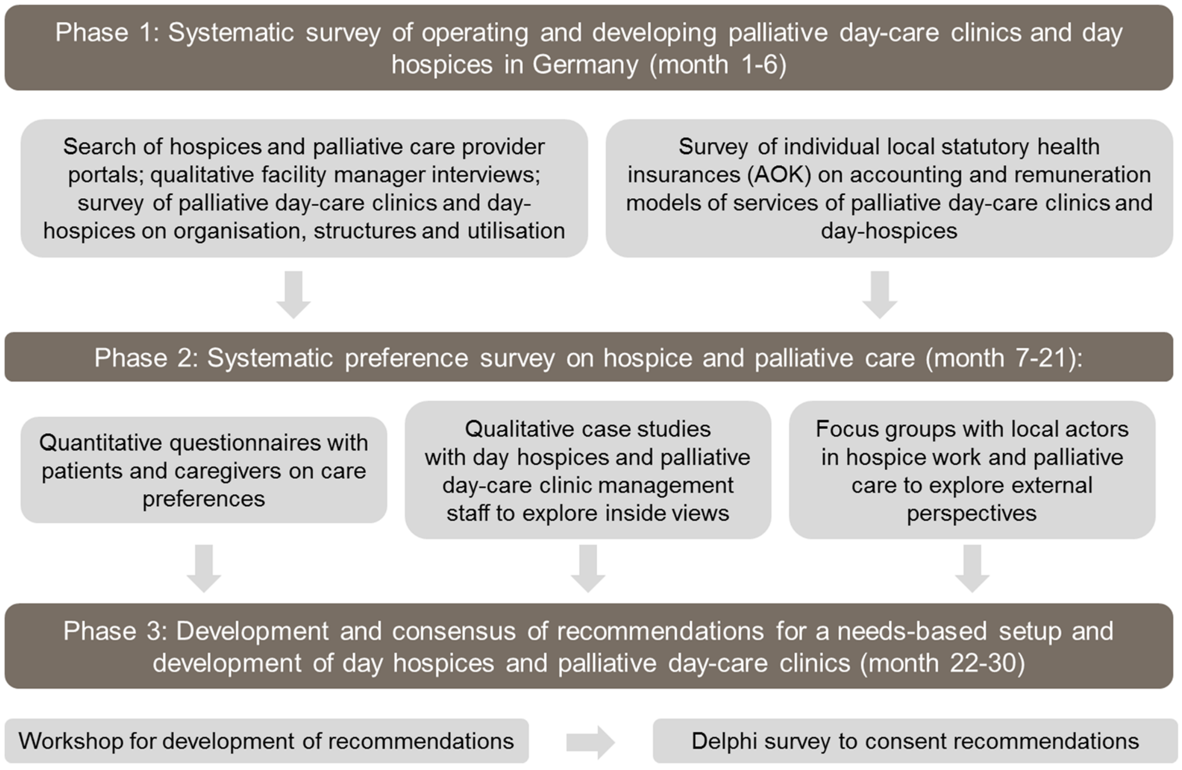

Fig. 1 Mixed-methods study design

Expected results

The main expected results are: (1) an overview of the defining characteristics of day hospices and palliative day-care clinics; (2) an understanding of patients' and family caregivers' preferences, with regards to health care services in palliative care; (3) insight into the establishment of new facilities, factors that promote and hinder their work, and integration into regional hospice and palliative care networks, from both internal and external perspectives; and (4) a group consensus on recommendations for the needs-based establishment and development of day hospices and palliative day-care clinics. These findings will contribute to the further development of end of life care services in Germany. Moreover, the results will facilitate the effective integration of day hospices and palliative day-care clinics into wider health care structures in Germany.

Discussion

Regarding the status of the current analysis in phase 1a, the research group is presently analyzing the search data on day hospices and palliative day-care clinics and integrating these data with feedback received from calls for feedback placed in the newsletters of the German Association for Palliative Medicine and the German Hospice and Palliative Care Association. Moreover, participant sampling criteria for the semi-structured interviews are being defined and the interview guide is being developed. At the same time, the standardized written survey for local statutory health insurance providers is being prepared.

Study risks

Access to patients, caregivers, professionals, and health care actors can be difficult, depending on their general attitudes towards and experiences with scientific research. Hence, it may be methodologically difficult to achieve the targeted number of participants. However, the proposed case numbers should be feasible, as the study is not seeking to recruit difficult-to-reach populations and the sample sizes have been calculated in accordance with the research methods applied in the respective study phases. To assist in fulfilling the target case number for the quantitative phase 2a (with patients and caregivers), partnerships with key facilities have already been initiated (prior to the start of the study). In the event of slow recruitment, further internal medicine wards, acute care clinics, and/or rehabilitation hospitals will be approached to assist in this process. With respect to the survey in phase 2a, selection effects may arise as a result of the choice of participating hospitals and departments.

Ethical considerations

All participating patients, caregivers, professionals, and health care actors will be informed orally and in writing about the purpose of the study, prior to their participation.

Regarding the participation of patients and family caregivers in phase 2a, no adverse events are expected, since the survey will not involve any changes in health care or interventions that may cause side effects. No further measurements and observations will be made, beyond this survey. The study nurse will personally explain the nature and purpose of the study and ask patients and family caregivers to participate. Prior to participation, the study nurse will address the methods by which confidentiality will be maintained and present the informed consent form. Participants will be asked if they understand the procedures to their full satisfaction, and they will be encouraged to ask any questions they may have. All questions will be answered by the study nurse. The survey will be administered only after the participant has signed the consent form. Each participant will receive a small token of appreciation, to a maximum value of 5.00€, in order to increase their motivation to participate. There will be no coercion, under any circumstance. Participants may experience discomfort when completing the survey, as it will ask them to reflect on hypothetical future health care options. In order to counteract this burden, the study nurses will be trained to recognize signs of distress and to provide crisis intervention, as needed.

Data security

All personal data will be treated in accordance with the German General Data Protection Regulation. Confidentiality will be maintained by assigning an identification number to all audio recordings and questionnaires. Identification numbers and their respective participant names will be combined into a list. This list will be kept in a locked filing cabinet, separate from the interview and questionnaire data, to ensure that no link is revealed between participants' personal data and their identification number. Consent forms will be stored separately from the interview and questionnaire data, in a locked cabinet.

For the purposes of data protection, a digital subfolder containing personal data will be assigned limited access rights. Files not kept in this folder but containing personal data will be stored in the project folder and provided with password protection. Access to the digital folders will be restricted to the researchers involved in the study. In order for the three project partners to jointly evaluate the results, the collected data will be anonymized.

The data will be exclusively analyzed with regard to the objectives stated in the project proposal. The same will hold true for any supplementary data analyses for project-related qualification. The quantitative survey data will be anonymized for the statistical analysis. The analysis of all qualitative data will be carried out in pseudonymized form (i.e. without the names of persons, institutions, or locations).

Dissemination and implementation

To promote the accessibility and longevity of the research data and results, the research team will report the project findings in a comprehensive and transparent manner. Regardless of the findings, national and international congress presentations and peer-reviewed publications will be produced, with open access, where possible. Data files with no personal identifying information will be kept after the study completion. In accordance with the American Psychological Association Code of Ethics, Sec. 8.14, "Sharing Research Data for Verification" [38], the project leader will not withhold any unidentifiable data from other researchers who wish to verify the conclusions of the author(s). Researchers who wish to use the project data to answer new research questions must obtain prior permission from the research group and author(s).

Conclusions

The present study protocol explains the purpose, significance, and scope of the mixed-methods ABPATITE study, as well as the study design. The empirically developed recommendations generated by this study are expected to optimize the establishment and development of day hospices and palliative day-care clinics in Germany, by ensuring they are better managed, more oriented to actual demand, and more effectively integrated into wider health care services. The results may also inform structural changes to the legal framework (e.g. to promote a framework agreement between the statutory health insurance umbrella association and health service providers). Finally, the empirically developed recommendations may be recast as a practice guide for the establishment and development of palliative day-care clinics and day hospices in Germany.

The authors' goal of publishing the present study protocol is to promote transparency by facilitating open access to comprehensive study details that extend beyond the summary publicized in the German Clinical Trials Register. Moreover, the study protocol may act as a point of reference for the scientific community and other parties interested in the scientific and ethical aspects of the study, and prevent unnecessary duplication.

Abbreviations

DCE: Discrete choice experiment.

Acknowledgements

The authors gratefully acknowledge the readiness of the German Association for Palliative Medicine and the German Hospice and Palliative Care Association to place calls for knowledge about established and developing palliative day-care clinics and day-hospices in their newsletters. Further thanks are due to the individuals who responded to this call. The authors also acknowledge Valerie Appleby's excellent editorial scrutiny of the language of the present study protocol.

Authors' contributions

SSt, NSch, JS, KD, and LdJ developed the original study plan, wrote the grant application, and obtained funding. FAH developed the manuscript on the basis of the original German grant application. SSt, NSch, JS, KD, and LdJ enhanced the quality of the draft manuscript by revising it critically. All authors read and approved the final manuscript.

Funding

The study "ABPATITE – Improving health care for patients with terminal, progressive illnesses: Status and demand analysis for palliative day-care clinics and day hospices and recommendations for health care planning" is funded (on the basis of peer review) by the Innovation Fund of the German Federal Joint Committee (G-BA) (Grant N° 01VSF19034). The funding body was not involved in the study design, the preparation of this paper, or the decision to submit the paper for publication. The funding body will not be involved in the collection, analysis, or interpretation of the study data. This study protocol has been reviewed by the funding body. Open Access funding enabled and organized by Projekt DEAL.

Availability of data and materials

Data sharing is not applicable to this article as no datasets have yet been generated or analyzed during the current study.

Declarations

Ethics approval and consent to participate

The study was approved on February 25, 2020, by the Ethics Committee of Hannover Medical School (N° 8892_BO_S_2020) and the appointed data protection officer of Hannover Medical School. Before distributing the questionnaires, the researchers will provide eligible participants with detailed information about the study type, content, purpose, and duration. Written informed consent will be sought from patients and family caregivers prior to data collection.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Received: 15 July 2020 Accepted: 9 June 2021

References

1. Bundesministerium der Justiz. Gesetz zur Verbesserung der Hospiz- und Palliativversorgung in Deutschland (Hospiz- und Palliativgesetz – HPG). Bundesgesetzblatt. 2015;48:2114–18.
2. Leitlinienprogramm Onkologie (Deutsche Krebsgesellschaft. Krebshilfe D, AWMF). Erweiterte S3-Leitlinie Palliativmedizin für Patienten mit einer nicht heilbaren Krebserkrankung. Langversion 2.1. 2020; https://www.leitlinienprogramm-onkologie.de/fileadmin/user_upload/Downloads/

Leitlinien/Palliativmedizin/Version_2/LL_Palliativmedizin_2.1_Langversion.pdf. Accessed 3 Jun 2020.

3. Kilonzo I, Lucey M, Twomey F. Implementing Outcome Measures Within an Enhanced Palliative Care Day Care Model. J Pain Symptom Manage. 2015; 50(3):419–23.
4. GKV-Spitzenverband B, Berlin ABundesverbandeV, Lenzkirch BKinderhospizeV, Freiburg DCaritasverbandeV. Deutscher Hospiz- und PalliativVerband e.V., Berlin, Deutscher Kinderhospizverein e.V., Olpe, Deutscher Paritätischer Wohlfahrtsverband – Gesamtverband e.V., Berlin, Deutsches Rotes Kreuz e.V., Berlin, Diakonie Deutschland – Evangelischer Bundesverband, Evangelisches Werk für Diakonie und Entwicklung e.V., Berlin. Rahmenvereinbarungnach § 39a Abs. 1 Satz 4SGB V über Art und Umfang sowie Sicherung der Qualität der stationären Hospizversorgung vom 13.03.1998, i. d. F. vom 31.03.2017; https://www.gkv-spitzenverband.de/media/dokumente/krankenversicherung_1/hospiz_palliativversorgung/20170331_Rahmenvereinbarung_nach__39a_Abs_1_Satz_4_stationaere_Hospize.pdf. Accessed 22 Jun 2021.
5. Radbruch L, Payne S. & the Board of Directors of the EAPC. White Paper on standards and norms for hospice and palliative care in Europe: part 2 – Recommendations from the European Association for Palliative Care. Eur J Palliat Care. 2010;17(1):22–33.
6. Bayerisches Staatsministerium für Umwelt und Gesundheit & Bayerisches Staatsministerium für Arbeit und Sozialordnung, Familie und Frauen. Begleitung und Versorgung Schwerstkranker und Sterbender sowie ihrer Angehörigen in Bayern: Rahmenkonzept zur Hospiz- und Palliativversorgung. 2011; https://www.bestellen.bayern.de/application/eshop_app000003?SID=240293221&ACTIONxSESSxSHOWPIC(BILDxKEY:%27stmug_kh_00008%27,BILDxCLASS:%27Artikel%27,BILDxTYPE:%27PDF%27). Accessed 22 Jun 2021.
7. Karmann A, Schneider M, Werblow A, Hofmann U, Wolf D. Fortschreibung der ‘Studie zu Standorten und demographischen Rahmenbedingungen von Hospizangeboten in Sachsen’ (Hospizstudie) –Endfassung. 2013.
8. Landesbeirat Palliativversorgung des Ministeriums für Arbeit und Sozialordnung, Familie, Frauen und Senioren Baden-Württemberg. Hospiz- und Palliativ-Versorgungskonzeption für Baden Württemberg – Zusammenfassung. 2014; https://sozialministerium.baden-wuerttemberg.de/fileadmin/redaktion/m-sm/intern/downloads/Downloads_Medizinische_Versorgung/Zusammenfassung_Konzeption_Hospiz-Palliativversorgung-BW.pdf. Accessed 3 Jun 2020.
9. Higginson IJ, Gao W, Amesbury B, Normand C. Does a social model of hospice day care affect advanced cancer patients’ use of other health and social services? A prospective quasi-experimental trial. Support Care Cancer. 2010;18(5):627–37.
10. Stevens E, Martin CR, White CA. The outcomes of palliative care day services: a systematic review. Palliat Med. 2011;25(2):153–69.
11. Davies E, Higginson IJ. Systematic review of specialist palliative day-care for adults with cancer. Support Care Cancer. 2005;13(8):607–27.
12. Goodwin DM, Higginson IJ, Myers K, Douglas H-R, Normand CE. Effectiveness of palliative day care in improving pain, symptom control, and quality of life. J Pain Symptom Manage. 2003;25(3):202–12.
13. Klinikum Aschaffenburg-Alzenau. Palliativmedizinische Tagesklinik. https://www.klinikum-ab-alz.de/medizin/kliniken-institute/palliativmedizin/ab-klinik-fuer-palliativmedizin/leistungen/palliativmedizinische-tagesklinik. Accessed 3 Jun 2020.
14. Bauch S. In Groß-Buchholz entsteht das erste Tageshospiz in Niedersachsen. 2019; https://www.haz.de/Hannover/Aus-der-Stadt/Hannover-Tageshospiz-ermoeglicht-Palliativversorgung-und-vertraute-Umgebung. Accessed 3 Jun 2020.
15. Beneker C. Kassen und Verbände warnen vor zu vielen Hospizen. Ärzte Zeitung Online. 2018; https://www.aerztezeitung.de/Politik/Kassen-und-Verbaende-warnen-vor-zu-vielen-Hospizen-231777.html. Accessed 3 Jun 2020.
16. dpa. Bayern. Hospiz- und Palliativversorgung wird 2020 ausgebaut. 2019; https://www.idowa.de/inhalt.bayern-hospiz-und-palliativversorgung-wird-2020-ausgebaut.ff2bfabe-000f-4f6f-a845-5704c0679dd9.html. Accessed 3 Jun 2020.
17. Ruppiner Hospiz e.V. Tageshospiz. https://www.ruppiner-hospiz.de/Tageshospiz_im_Haus_Wegwarte.41.htm. Accessed 3 Jun 2020.
18. Hospiz Aurich e.V. Tageshospiz "Strandkorb." https://www.hospiz-aurich.de/web/unser-angebot/begleitung-am-lebensende/tageshospiz/. Accessed 22 Jun 2021.
19. Fuchsbauer N. Hospizkonzept gewinnt Nürnberger Pflegepreis: MarktSpiegel. 2019; https://www.marktspiegel.de/nuernberg/c-lokales/hospizkonzept-gewinnt-nuernberger-pflegepreis_a53286. Accessed 3 Jun 2020.
20. Kastner B. Verein plant ambulantes Hospiz-Zentrum. Sueddeutsche Zeitung. 2020; https://www.sueddeutsche.de/muenchen/muenchen-hospiz-zentrum-sterben-1.4763905. Accessed 3 Jun 2020.
21. St. Anna Stiftung. Die teilstationäre Hospizversorgung im Hospiz St. Anna. http://www.st-anna-stiftung.de/2013/hospiz/teilstationaere-hilfe. Accessed 3 Jun 2020.
22. Tageblatt. Bremervörder Tageshospiz wächst in die Höhe. 2019; https://www.tageblatt.de/lokales/nachbarkreise_artikel,-Bremervoerder-Tageshospiz-waechst-in-die-Hoehe-_arid,1487097.html. Accessed 3 Jun 2020.
23. Stiel S, Stelzer E-M, Schneider N, Herbst FA. Exploring end-of-life interaction in dyads of parents and adult children: A protocol for a mixed-methods study. BMC Palliat Care. 2018;17(1):68.
24. von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: Guidelines for reporting observational studies. Lancet. 2007;370(9596):1453–7.
25. Deutsche Gesellschaft für Palliativmedizin. Wegweiser Hospiz- und Palliativversorgung Deutschland. https://www.wegweiser-hospiz-palliativmedizin.de/en. Accessed 3 Jun 2020.
26. Palliativ-Portal. Palliativ-Portal. https://www.palliativ-portal.de. Accessed 3 Jun 2020.
27. Lancsar E, Louviere J. Conducting discrete choice experiments to inform healthcare decision making – A user’s guide. Pharmacoeconomics. 2008; 26(8):661–7.
28. Orme B. Getting started with conjoint analysis: Strategies for product design and pricing research. 2nd ed. Madison: Research Publishers LLC; 2010.
29. Patrick DL, Burke LB, Gwaltney CJ, Leidy NK, Martin ML, Molsen E, et al. Content validity – Establishing and reporting the evidence in newly developed patient-reported outcomes (PRO) instruments for medical product evaluation: ISPOR PRO good research practices task force report: Part 1 – Eliciting concepts for a new PRO instrument. Value Health. 2011; 14(8):967–77.
30. Bortz J, Döring N. Forschungsmethoden und Evaluation in den Sozial- und Humanwissenschaften. Heidelberg: Springer; 2009.
31. Lamnek S, Krell C. Qualitative Sozialforschung: Lehrbuch. 5th rev. ed. Weinheim: Beltz; 2010.
32. Froggatt K, Hockley J. Action research in palliative care: Defining an evaluation methodology. Palliat Med. 2011;25(8):782–87.
33. Behmann M, Jünger S, Radbruch L, Schneider N. Public health actions to improve palliative care in Germany: Results of a three-round Delphi study. Health Policy. 2012;106(3):303–12.
34. Mayring P. Qualitative content analysis: Theoretical foundation, basic procedures and software solution. Klagenfurt; 2014.
35. Mayring P [Qualitative content analysis: Demarcation, varieties, developments]. Forum: Qualitative Sozialforschung Social Research. 2019; 20(3):Art 16.
36. Reed Johnson F, Lancsar E, Marshall D, Kilambi V, Mühlbacher A, Regier DA, et al. Constructing experimental designs for discrete-choice experiments: Report of the ISPOR Conjoint Analysis Experimental Design Good Research Practices Task Force. Value Health. 2013;16(1):3–13.
37. Mayring P. Qualitative Inhaltsanalyse. In: Flick U, von Kardoff E, Keupp H, von Rosenstiel L, Wolff S, editors. Handbuch qualitative Forschung: Grundlagen, Konzepte, Methoden und Anwendungen. München: Beltz – Psychologie Verl. Union; 1991. pp. 209–13.
38. American Psychological Association. Ethical principles of psychologists and code of conduct. In: Sharing Research Data for Verification. US; 2010. 8.14.

Publisher’s Note

Modul 3

Needs and preferences of informal caregivers regarding outpatient care for the elderly: a systematic literature review

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BMC Geriatrics; 19(1):82, 1-22

DOI: 10.1186/s12877-019-1068-4

2019

Plöthner *et al. BMC Geriatrics* (2019) 19:82
https://doi.org/10.1186/s12877-019-1068-4

BMC Geriatrics

RESEARCH ARTICLE **Open Access**

Needs and preferences of informal caregivers regarding outpatient care for the elderly: a systematic literature review

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Abstract

Background: Informal caregivers are an essential pillar for ensuring and maintaining the outpatient care of the frail elderly. Due to demographic changes, including an increase in the number of people in need of care as well as changing social structures (full-time employment of women, increasing number of single households, etc.) these informal care structures are fraught by considerable challenges. To support and facilitate informal caregivers in their role of nursing, it is important to identify their preferences, needs, and thus create a preference-oriented system.

Methods: A systematic review was conducted to identify preferences and needs regarding the organization of informal care. The database searches were performed by using EMBASE, Scopus and Dimdi.

Results: A total of 44 studies were included in the present review. Studies from 17 different countries provide broad international perspectives. Besides the preferences for long-term care structure, the following four principal topics were identified: (1) informational needs; (2) support needs; (3) organizational needs, and (4) needs for societal recognition.

Conclusion: To meet the current challenges in the outpatient or home-based care of elders, it is essential to strengthen the role of informal caregivers. Therefore, it is necessary to adopt and further develop informal care structures according to the needs of informal caregivers. However, demographic, financial and cultural aspects of each country need to be considered as these may influence the preferences and needs of informal caregivers.

Keywords: Informal caregivers, Information, Support, Organization, Preferences

Background

The number of people aged 60 and older is expected to grow from 962 million in 2017 to 21 billion in 2050 [1] in Europe. This global phenomenon affects most countries worldwide, whereas the speed of increase and hence the proportion of elderly differs between countries. The proportion of people aged 65 years and older is expected to grow to an average of 28% in the OECD countries in 2050, while in some countries (e.g. Japan, Spain, Portugal, Greece and Korea) a share of 40% is forecasted. China's proportion of older people will triple between 2015 and 2050 and also in the USA, Mexico and Israel these growing trends will be influenced by higher rates of fertility and migration. Higher age is associated with higher morbidity, which in turn affects care dependency [2, 3]. Prognosis regarding the number of people in need of care show an increase of 115% in the European Union between 2007 and 2060.The situation in countries outside of Europe is similar. For example the number of people in need of care in the US is expected to double from 13 million in 2000 to 27 million in 2050 [4] and in China, in the worst case scenario, an increase of 115% of individuals in need of long-term care (LTC) is expected between 2015 and 2030 [5]. Generally, elderly care can be organized in inpatient and outpatient care structures. However, in the European Union (EU), 60% of care is provided by informal caregivers [6]. Changing social and structural factors (more individualized household and family structures, increased women's employment rate, decreased family size, more geographically dispersed families, etc.) will reinforce this situation and will likely lead to a shift from informal

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to professional care [7]. These trends combined with the growing number of elderly and people in need of care as well as the shortage of formal and qualified caregivers pose a big challenge for the future regarding the structure and organization of long-term care for most countries.

The increasing number of care-dependent people leads to a high economic burden for most healthcare-systems. The principle "outpatient before inpatient" also applies to the nursing of older people in need of care. Institutional care is the primary cost driver in elderly long-term care and costs for long-term care in nursing homes exceed those of home-based care [8]. Hence, enabling care-dependent people to stay in a home-based care setting as long as possible is an efficient cost-cutting strategy for funding agencies.

The majority of the general population wishes to stay at home in old age and would prefer to receive informal care from children or formal care from home assistance services [9]. Informal caregivers are defined as individuals who provide some type of unpaid, ongoing assistance with activities of daily living (ADL), e.g., toileting, feeding, bathing, walking, clothing; or instrumental activities of daily living (IADL), e.g., shopping, meal preparation, housecleaning, and managing finances, for individuals with a chronic illness or disability [10, 11]. However, the decision of family members or relatives to take care of a dependent person, and thus fulfill their wish to age in a domestic environment, are influenced by a variety of factors. The degree of family relationship (children, children-in-law, spouse, etc.) has a significant influence on the willingness of family members to provide care as well as the scope of services [12]. Other aspects that affect the decision to provide outpatient care for a relative are the quality of relationship [13]. (e.g., harmonious or not [14], promises and pacts between the people in need of care and the (potential) caregiver, financial factors, perceptions and attitudes towards nursing homes, health of the caregiver [15], type of impairment of the people in need of care (physical (rates of comorbidity and medical complications) or mental [16], as well as the level of caregivers employment (full-time or part-time job) [17]). In addition, factors such as gender, assistance with elimination, and rearranging work hours affect the use of formal care services by informal caregivers [18]. In the EUROFAMCARE study additional influencing factors for informal care decisions were found. Emotional bonds (e.g., love and affection) (57%), sense of duty (15%) and a personal sense of obligation (13%) were the main reasons for engaging in informal care. Only 3% had taken over the role of caregiving due to the lack of alternatives [19].

Informal caregiving is often associated with negative effects. In the beginning, caregiving is not associated with negative effects [20]. However, several factors lead to an increase in caregivers' burden, including increased morbidities and higher levels of disability of the care-recipients, hours of care, more variation in caregiving tasks, care setting (care at home vs. institutional care), and gender and age of the caregiver [21]. Beyond demographic or care-specific aspects (type and stage of the disease), organizational aspects (e.g. received support), independence of the caregiver and demands of caring also influence the quality of life of informal caregivers [22]. The estimated nursing time of elderly relatives varies between two and eight years in Germany [23]. It may be a long time with unforeseeable consequences and burdens throughout. Independent of emotional motives such as a sense of responsibility, organizational and structural aspects may influence the decision to provide informal care. Hence, knowing the preferences as well as needs and wishes of informal caregivers enables decision makers to establish care structures meeting the living conditions of those involved and to integrate care into the living environment of the (potential) caregivers.

Facilitations (organizational and structural) in daily processes of caregiving as well as incentives must be established to support individuals' decision to provide informal care for a care-dependent person. An improvement of the current care arrangements according to the preferences (preferred organization of elderly care) and needs (requirements for organization of long-term care) of informal caregivers can strengthen outpatient care structures. The demographic changes in the society have led to a higher number of elderly and an increase in individuals living in frailty and having greater nursing care needs. This increasing frailty is accompanied by a comprehensive process of adapting to different life situations for both the elderly and their relatives. To meet the demand for the changed service utilization as well as the load limit or breaking point for caregivers, a proactive approach to care planning is necessary [24]. However, to take the load limit and the potential capacities of informal caregivers into account, it is important to understand their motives for providing care to a person in need. Therefore, we conducted a systematic review of literature on informal caregivers' needs and preferences. Moreover, this review is part of a comprehensive explorative investigation of care preferences and the expected willingness of providing elderly care in the German general population [25].

Methods

First, we clearly defined the elements of the review (objective/aim, inclusion and exclusion criteria, and outcomes) to focus the scientific issue (Table 1). In December 2016, we conducted a systematic literature search by using the PubMed and Scopus databases as well as the

Table 1 Review objective

Objective/ aim	To identify the preferences, needs, and wishes of informal caregivers regarding the organization of care for a care-dependent elderly relative.
Inclusion criteria	Only articles which directly state (explore) the needs/wishes/preferences of informal caregivers regarding the outpatient care of the elderly; articles were not restricted to a special methodology or according to the year of publication.
Exclusion criteria.	Studies focusing on illness-related care (care due to cancer, stroke, etc.; hospital discharge, terminally ill individuals); specific interventions (e.g., prostheses); preferences regarding nutrition, inpatient care, end-of-life care, and palliative care; and post-care studies as well as those focusing only on the quantitative assessment of needs or unmet needs (e.g., in activities of daily living and instrumental activities of daily living) were excluded. Studies focusing on specific types of illness, end-of-life care and palliative care were excluded due to the special care needs for medical and nursing interventions as these are different from elderly care in general.
Outcomes.	Need for information and support, preferences regarding organization of care (e.g., home care or institutional care).

meta-database of the German Institute for Medical Documentation and Information (DIMDI), which constitutes 16 different databases such as Medline, EMBASE, NHS, SciSearch, etc. The search strategy combined English terms for preferences, care, formal and informal care. Additional German terms were used for the systematic literature search in DIMDI. The following search strategy was utilized: [((care* OR geriatric* OR home nursing OR home-dwelling OR old age assistance) AND (elderly OR old* OR aged)) AND relatives OR formal OR informal OR kin OR family*)) AND (OR preferences OR wish OR needs)]. The operator "AND" combined different terms and the truncation "*" was used to achieve a greater coverage.

An additional search was conducted by hand. According to the PRISMA statement, the assessment was conducted by two independent researchers and disagreements were solved through discussion. Original studies published in full text were included in the assessment. Due to the high number of results, the present systematic review focused on articles pertaining to the perspective of informal caregivers. Results pertaining to care-recipients will be published in a separate overview. Figure 1 summarizes the search process. The contents of the included studies were examined to assign the comprehensive findings to superordinate categories and subcategories.

Results

The database search using the three databases identified 12,966 records. After removing 4790 duplicates, 8176 titles and abstracts were screened for eligibility, after which, 7859 records were excluded. The remaining 317 records were subsequently assessed for eligibility. Of these, 40 studies that fulfilled the inclusion criteria were included in the final assessment. The hand search resulted in the inclusion of four additional studies (Fig. 1).

Country, methods, and publication year

A broad international perspective could be achieved by the inclusion of studies conducted in 17 different countries. Thereby, studies from Asia [Malaysia ($n = 1$), Japan ($n = 2$), China (n = 2), Israel (n = 1)], Oceania [Australia ($n = 4$), and New Zealand (n = 1)], Europe [Sweden ($n = 3$), Netherlands (n = 1), UK (n = 3), Ireland (n = 2), Belgium (n = 1), Germany (n = 1), and France (n = 1)], and North America [US ($n = 12$) and Canada (n = 1)] enabled an overview of different cultural perspectives. Two studies conducted an analysis of three countries. Most of the included studies were from the US, whereas two of them analyzed the preferences of caregiving in the Hawaiian context [26, 27].

All included studies were published between 1988 and 2016. Most of the studies appeared in 2014 ($n = 8$), followed by 2016 ($n = 6$), 2012 (n = 6), 2010 ($n = 5$), and 2015 ($n = 4$). Qualitative research (interviews or focus groups) was the most prevalent methodology used.

Categorization of preferences and needs

The present systematic review identified preferences for the organization and structure of outpatient elderly care as well as various needs of informal caregivers regarding outpatient care within the organization of elderly care. Preferences refer to the organization of care for the elderly and needs to the requirements for the organization of long-term care of informal carers. These findings could be divided into five main topics: (1) preferences for the structure of care, (2) organizational needs, (3) informational needs, (4) support needs and (5) needs for societal recognition. Table 2 provides an overview of the created categories and sub-categories and Table 3 a detailed results overview.

Topic 1: Preferences regarding the structure of elderly care

Preferences for the organization of long-term care (LTC) was a recurring subject of interest in the literature. Regarding the choice of LTC-arrangements, Wang (2004) found that home care is the most preferred arrangement for caregivers as well as care-recipients. Home care, institutional care, and community-based care represent—in this order—the preferred organization of nursing. A study by McCann (1988) rated home-based care as the preferred caring option for spouses. Aspects for LTC or later life care (LLC) were evaluated by Denson et al.

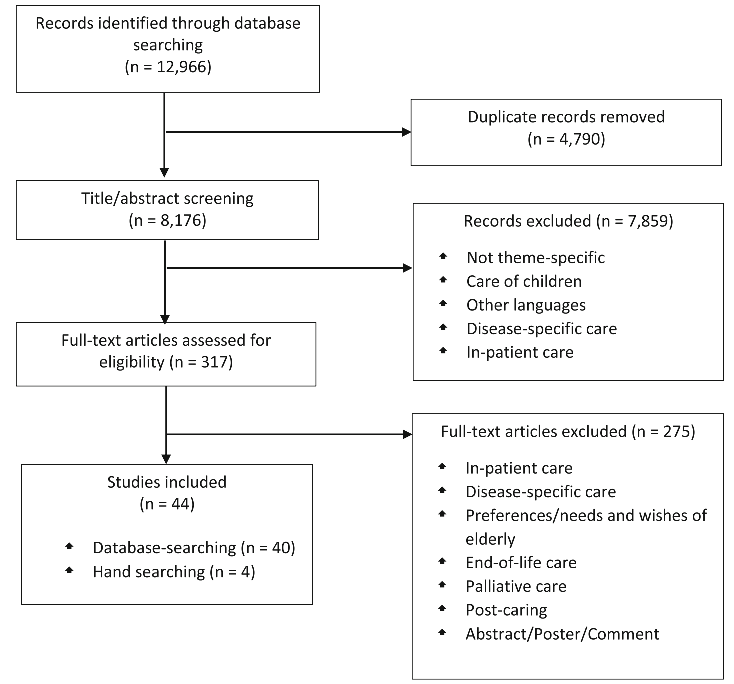

Fig. 1 Flow diagram of articles identified and evaluated based on inclusion criteria

(2013) and Stolee et al. (2014). Security, personal (psychological) value of living at home, finances, health, mental and physical abilities, psychological well-being, autonomy, caregiver burden, best interests of the elder, self-responsibility of the elder, and planning were some important factors that influenced caregivers' LTC decisions [28]. Stolee et al. (2014) identified the need for positive and respectful LLC conversations and for care decisions to be guided by concerns for the care-recipient's well-being [29].

Topic 2: Organizational needs

In the category of organizational needs, topics such as work-life-balance and respite were often mentioned. Providing informal care while being employed requires a balance between the needs of the care-dependent person and the workplace responsibilities of the caregiver. Eldh et al. (2011) and Mastel-Smith et al. (2012) found this to be achievable by sharing the care responsibility with others, frequent and regular dialogues between care managers and informal caregivers, and self-care or flexibility. The need for respite (time for self-care) [30] and a wish for a break [31] or specifically for short-time respite [15, 32] were identified. Mastel-Smith et al. (2010) defined respite to include, amongst others, professional care, family support, whereas participants stated that professional care was difficult to find. Furthermore, Feinberg et al. (1999) identified a preference for consumer-directed models via direct pay over agency-based in-home respite. Greenwood et al. (2012), Lund et al. (2014), and Stirling et al. (2014) assessed aspects for accepting respite. Trust in the care provider and individual care, the care provider's sensitivity to the care-recipient and his/her needs, and the care provider's ability to react to mood and condition changes of the care-dependent were identified as important aspects [33]. Moreover, participants wished for good care and an enjoyable experience for the care-recipient, as well as cost reductions of and longer opening times for respite services [34]. Weekly or bi-weekly visits were preferred intervention formats by caregivers [35].

Topic 3: Informational needs

Information was one of the major topics identified in this review. Informational needs, information sharing, and professional counselling/educational needs were defined as sub-categories. A broad range of informational needs were observed, including information about existing services [36] as well as information enabling the assessment of services and support [30]. We found a need for care-related information in general [37], for community aged care service structures and formal support services [38] in the included literature. Jorgensen et al. (2010) recommended the implementation of one national place for information in New Zealand. Wilde et al.

Table 2 Overview of the categories and sub-categories created

Preferences	Category	Sub-categories
	Structure of care	Long-Term-Care (LTC)
Needs	Organizational needs	Respite
	Informational needs	Informational needs
		Information sharing
		Professional counselling/advice/educational needs
	Support needs	Need for support
		Support systems
		Robots
	Needs for societal recognition.	Appreciation
		State responsibility

(2012) analyzed informational needs regarding reablement services. Mastel-Smith et al. (2012) found specific informational needs concerning caregiving essentials (safety issues in terms of mobility and fall prevention, etc.), information about diseases, death and dying. In the subcategory information sharing, themes such as wishes for medical information of the care-dependent parent for the coordination of care [39] and information sharing as a mutual effort between caregiver and provider were discussed. As a third aspect, caregiver counselling or education was recommended according to customer-related issues [40], as well as medical issues like wound care and symptom management [27]. Abu Bakar et al. (2014) identified a need for professional counselling and advice from others with similar problems in caregiving, while Van Houtven et al. (2010), who assessed different types of training for caregivers of frail US veterans, found that participants preferred phone-based training programs over training at the Veterans Affairs.

Topic 4: Support needs

Support emerged as a second major topic in connection to the organization of elderly care. Studies included here analyzed the need for support in general as well as for special types of support (such as social or financial assistance), special systems (like e-health), or support by robots.

The general need for support was assessed, for example, by Rodgers et al. (2015), Lane et al. (2004), and Zeng et al. (2014). Stockwell-Smith et al. (2010) identified concerns in terms of trust and quality of support regarding the acceptance of care support. Help in solving caregiving-related problems [41], help to access medication [27], as well as the desire for more frequent visits from health professionals [15] could be identified as specific wishes of informal caregivers. An evaluation of neighborhood caregiving, which is composed of social monitoring and emotional support, showed fears in terms of disadvantages and the preference to limit contact with the care-dependent neighbor [42]. Zabalegui et al. (2014) asked informal caregivers about their preferences regarding support resources. Family groups and networks were seen as the most helpful and available non-formal resource. Types of support mentioned in the focus groups included help for transport, home renovations, need for excessive workload, physical aids and adaptations, among others. Emotional/psychological and social support was classified as another subcategory in terms of support. In the study by Criel et al. (2014) the wish for emotional support due to emotional, psychological, and physical stress, as well as practical and organizational problems was stated. Furthermore, social support in caregiving to buffer the effects of stress [43] and the need for psychological services from counsellors and support groups [44] were pointed out.

Studies dealing with preferences for support systems for informal care were also identified. Participants in such studies were interviewed according to the design and requirements of support or web-based support systems. For instance, McCaffrey et al. (2015) analyzed the importance of service characteristics of support systems of Australian users. Information, choice and control, effective co-ordination and communication, responsiveness and flexibility, continuity and planning were mentioned in this context. Andersson et al. (2017) conducted semi-structured in-depth interviews to assess important features of a web-based family support network. A support hub for connecting peers, staff, and knowledge, links between accessibility, usability and flexibility in support as well as a personal firewall according to IT security were pointed out as requirements for the usage. E-health support constitutes a further possibility to facilitate caregivers in their role of caregiving. Blusi et al. (2014), Shah (2012), and Williamson et al. (2014) analyzed the preferences or needs of informal caregivers regarding e-health services, and flexibility and availability were identified as the essential properties of such assistive technologies [45]. Assistive technology services

Table 3 Detailed Overview of the studies included in the review

Categories	Author (Year)	Country	Aim	Data Collection Methods	Findings
Preferences regarding Long-Term-Care (LTC)					
Choice of LTC-Arrangements					
	Wang et al. (2004) [14]	Taiwan	Examination of the preferences of the elderly and their primary family caregivers regarding LTC arrangements.	Questionnaires	Home care is the most preferred LTC arrangement (Home care > institutional care > community based care).
	McCann (1988) [13]	USA	Understanding LTC from the perspective of elderly caregivers, comparison of this perspective with that of nurses and physicians who work with older caregivers and their patients, and learning how nurses and physicians can best address the needs of older caregivers.	Focus groups	Making decisions about home care, the nature of long term home care, and caregivers' concerns and needs. In general, most spouses want to provide home care for their partners but are often discouraged from doing so by their children and/or by health professionals. Caregivers receive little support in preparation for their roles, and most have little or no contact with the formal health care system.
Aspects for LTC/ Later life care (LLC) at home					
	Denson et al. (2013) [28]	Australia	Comparison of the opinions and values of frail elders living at home, younger relatives, and health professionals experienced in discharge-planning, prospectively: Before, not after, an LTC decision.	Interviews (semi-structured and open-ended questions)	Safety/ security; personal (psychological) value of living at home; finances, health; mental and physical abilities; psychological well-being; autonomy, caregiver burden; best interests of the elder; better functioning at home, self-responsibility of the elder, planning.
	Stolee et al. (2014) [29]	Canada	Understanding of views and experiences on later life care (LLC) planning conversations, in terms of (a) respective roles, and (b) barriers and facilitators that should be taken into account when having these conversations.	Interviews (semi-structured)	Effective LLC conversations need to be positive, respectful, and be guided by concerns for the older adult's well-being.
Characteristics of Community Directed Care (CDC)					
	McCaffrey et al. (2015) [78]	Australia	Determining features (attributes) of consumer-directed, home-based support services that are important to older individuals and their informal caregivers to inform the design of a discrete choice experiment (DCE).	Interviews (semi-structured)	The following were Important service characteristics for users: information, choice and control, effective co-ordination and communication, responsiveness and flexibility, and continuity and planning.
Needs within the organization of long term care					
Structural and organizational needs					
Work-life-Balance/ self-care/ Stress management					
	Eldh et al. (2011) [31]	Sweden	Elucidation of the experience of providing informal care to an ageing parent while managing the responsibilities of a working life.	Interviews (narrative)	Providing informal care while working implies seeking a balance between providing support to the parent's needs and one's responsibilities at work; possibility for balance by sharing responsibility with others; and the need for frequent and regular dialogue between the managers and the caregivers as employees, on what was currently the most effective arrangements for the workplace and as co-workers.
	Mastel-Smith et al. (2012) [79]	USA	Exploration of caregivers' educational needs and preferred methods of information delivery.	Focus groups	The need to learn how to balance caregiving and other responsibilities, and care for themselves; respite for time for themselves as a mean of self-care; and the need to be flexible.

Table 3 Detailed Overview of the studies included in the review *(Continued)*

Categories	Author (Year)	Country	Aim	Data Collection Methods	Findings
	Yedidia et al. (2008) [74]	USA	Elicitation of views of family caregivers regarding expected kinds of assistance from nurses and social workers.	Focus groups	Stress management and coping strategies regarding recognizing and addressing burnout, finding support groups, and accessing a crisis hotline.
Respite					
Need for respite					
	Jorgensen et al. (2010) [30]	New Zealand	Reporting the unmet needs.	Telephone interview (scales and open-ended questions)	Need for flexible and reliable respite provision.
	Mackenzie et al. (1996) [32]	China	Gaining personal accounts of experiences of primary caregivers caring for dependent family members.	Interviews (semi-structured)	Short-term respite in an acceptable and appropriate form.
	Feinberg et al. (1999)[50]	USA	Examination of the preferences for and characteristics of consumer-directed (i.e., direct pay) and professionally-managed care (i.e., agency-based) respite for family caregivers of adults with cognitive impairments.	Questionnaires (closed questions and one open-ended question)	Prefer consumer-directed mode (i.e., direct pay) over agency-based in-home respite.
	Eldh et al. (2011) [31]	Sweden	Elucidation of the experience of providing informal care to an ageing parent while managing the responsibilities of a working life.	Interviews (narrative)	Wish for a break from the task of providing support for the ageing parent due to the difficulties of being an informal caregiver and being employed; need for setting one's own limits.
	Mastel-Smith et al. (2012) [79]	USA	Exploration of caregivers' educational needs and preferred methods of information delivery.	Focus groups	Need for respite; respite included the need for professional care, family support and other issues; professional caregivers are difficult to find and unreliable.
	McCann (2002) [15]	Ireland	Identification of the views of individuals receiving care (informal caregivers were also interviewed).	Interviews[a]	Need for short-term respite care.
	Lane et al. (2003) [55]	Ireland	Exploration of the perceived health and social care needs of family caregivers of older individuals (including mentally infirm individuals) and exploration of their experience of home care.	Interviews (semi-structured)	Inadequacy of statutory respite services and other services.
Aspects affecting the acceptance of respite					
	Greenwood et al. (2012) [33]	UK	Investigation of caregivers' experiences with, or their perceptions of care workers with respite.	Interviews (semi-structured)	To accept or to use respite trust in the service provider and the individual care worker are very important. The care-recipient must be comfortable and able to communicate well with the care worker; the care worker's sensitivity to the caregiver's and care-recipient's needs and circumstances is an additional important element; they must also be able to respond to any changes in the care-recipient's condition or mood.
	Lund et al. (2014) [35]	USA	Examining the intervention *Time for Living and Caring (TLC)* in terms of feasibility and potential benefits, and how caregivers viewed their participation.	Survey[a] including scales and open-ended comments	(1) Weekly or bi-weekly intervention formats were accepted by caregivers. (2) Respite leads to a slight improvement with satisfaction with respite time-use and a slight reduction in burden levels, but no notable changes in satisfaction with caregiving; (3) The participating caregivers recognized the benefits of identifying, in advance, how they wanted to spend their respite time and setting specific goals, which helped empower them to

Table 3 Detailed Overview of the studies included in the review *(Continued)*

Categories	Author (Year)	Country	Aim	Data Collection Methods	Findings
					act on their preferences.
	Stirling et al. (2014) [34]	Australia	Assessment of caregiver's expectations and perceptions of adult day respite services and their commitment to using services.	Interview/survey including rating scales and open-ended questions	Respite decisions depends on the experience and benefits of the care-recipient: (1) want good care; (2) enjoyable experience for the care-recipient; other themes: "want a break." cost reduction of respite services, and longer opening times for respite services.
Information needs					
Need for information					
	Criel et al. (2014) [36]	Belgium	Identification of the specific needs of the informal caregiver.	Interviews (semi-structured)	Information about existing services
	Jorgensen et al. (2010) [30]	New Zealand	Reporting of the unmet needs	Telephone interview (scales and open-ended questions)	Need for accessible, up-to-date timely information to assess services and support; one national place for accessing information.
	Abu Bakar et al. (2014) [41]	Malaysia	Examination of Malaysian efforts in assisting informal caregivers, based on an analysis of the issues and concerns raised by the caregivers themselves.	Interviews (structured)	Information in solving specific care-giving concerns.
	Hirakawaa et al. (2011) [40]	Japan	Analyzing the priority information needs and sources of family caregivers of home elderly patients.	Questionnaires	Need for information on the public long-term care insurance service (home and institutional care services), and about food and nutrition.
	Mackenzie et al. (1996) [32]	China	Gaining personal accounts of experiences of primary caregivers caring for dependent family members.	Interviews (semi-structured)	Information about rehabilitation and health promoting activities related to emotional, psychological, and physical health; information about sources of community help.
	Zabalegui et al. (2008) [80]	Spain	Better understanding of informal caregivers' view, particularly about the resources that are available to them, or should be available to them.	Focus groups	Need for information and training (on the process of the illness, the care of the dependent person, and the care of the caregivers themselves, in connection to physical, psychological, and social tasks).
	Zeng et al. (2014) [37]	China	Exploration of the experience of seniors' family caregivers with regarding the responsibility, burden and support needs during caregiving in Shanghai, China.	Interviews (semi-structured)	Need for information due to the lack of clear information on support services.
	Stockwell-Smith et al. (2010) [38]	Australia	Exploration of the limiting and motivating factors that influence caregivers' use of respite services and the ability of currently available respite services to meet the needs of caregivers of frail older individuals.	Focus groups	Information need due to the lack of accurate information on community service structures for aged care and formal support services.
	Wilde et al. (2012) [73]	UK	Identification of experiences of home-care reablement service users and their caregivers.	Interviews (semi-structured)	Need for information regarding reablement services (initially and during the reablement).
	Mastel-Smith et al. (2012) [79]	USA	Exploration of caregivers' educational needs and preferred methods of information delivery.	Focus groups	Need for information on practical aspects of care or caregiving essentials (safety issues regarding the use of mobility aids and other equipment, safe transfer and positioning techniques, and fall prevention); need for disease-specific information; need for information about death and dying, and specifically the prolongation of life and the signs and symptoms of impending death.
	Nickel et al. (2011) [75]	Germany	Exploration of information needs of care-recipients as well as their relatives.	Questionnaire (semi-structured) to	Need for information on (1) the health care system, (2) individual access options

Table 3 Detailed Overview of the studies included in the review *(Continued)*

Categories	Author (Year)	Country	Aim	Data Collection Methods	Findings
				document consultation conversations	in the health care system, (3) regional service providers, (4) situation and disease-specific aspects.
	Stolee et al. (2014) [29]	Canada	Understanding of views and experiences on LLC planning conversations in terms of (a) respective roles, and (b) barriers and facilitators that should be taken into account when having these conversations.	Interviews (semi-structured)	Desire for information and comfortable mobilizing health care providers in LLC conversations with their care-recipients; information is necessary for making informed choices; useful information types for family members include legal advice, communication strategies, changing roles in their relationship with an older adult, community services and resources, helpful websites, and modifications. These allow their family member to live at home as long as possible.
	Lane et al. (2003) [55]	Ireland	Exploration of the perceived health and social care needs of family caregivers of older individuals (including mentally infirm individuals) and exploration of their experience of home care.	Interviews (semi-structured)	Frustration and hopelessness due to the lack of information
	Yedidia et al. (2008) [74]	USA	Elicitation of views of family caregivers regarding expected kinds of assistance from nurses and social workers.	Focus groups	Information about available services (daytime activities for care recipients, residential facilities, disease-specific services and care coordination); information about drugs.
Information sharing					
	Crotty et al. (2015) [39]	Israel	Identification of how patients older than 75 years and family caregivers of such patients approach sharing of health information, with the hope of applying the results to the development of collaborative patient portals.	Group discussions	Having information would decrease stress; need to acquire information that would help their parent; systems such as patient portals would help assuage some of the stress of caregiving; wish to have access to their elderly parents' medical records to be able to better coordinate care, appointments, and communication with the family; knowing the activities of the elders; coordinate care for their parents while respecting their preferences and preserving their sense of autonomy.
	LaVela et al. (2016) [81]	USA	Examination and comparison of caregiver perceptions of family centered care by age.	Questionnaire containing closed- and open-ended questions	Want to be informed at different points before, during, and after the patient's encounters, each representing times at which caregivers need to feel informed and need support; information sharing should be a mutual effort between the caregiver and care provider; younger caregivers require health providers to acknowledge and understand their level of involvement and commitment.
Professional counselling/advices /educational needs					
	Hirakawa et al. (2011) [40]	Japan	Analyzing the priority information needs and sources of family caregivers of home elderly patients.	Questionnaires	Educational need for customer-related issues (problems with customer products and contracts)
	Abu Bakar et al. (2014) [41]	Malaysia	Examination of Malaysian efforts in assisting informal caregivers, based on an analysis of the issues and concerns raised by the caregivers themselves.	Interviews (structured)	Professional counselling and advice from others with similar care-giving-problems
	Fernandes et al. (2013) [27]	Hawaii	Developing and testing a family caregiver training program for Palau in two phases: (1) assessing needs by interviewing key informants and surveying elders and (2)	Interviews (n/s)	Areas of priority include the need for patient education and training; future training topics include caregiver and family education, wound care, and pain

Table 3 Detailed Overview of the studies included in the review *(Continued)*

Categories	Author (Year)	Country	Aim	Data Collection Methods	Findings
			evaluating the caregiver training program that was designed based on findings from the assessment.		and symptom management
	Van Houtven et al. (2010) [72]	USA	Exploration of the preferences regarding home and community-based services or home-based primary care, (including: quantity and types of tasks provided and desired content for caregiver training programs)	Questionnaires	Interested in participation of caregiver training, especially through (1) phone-based programs (47%) and (2) training at Veterans Affairs.
	Lane et al. (2003) [55]	Ireland	Exploration of the perceived health and social care needs of family caregivers of older individuals (including mentally infirm individuals) and exploration of their experience of home care.	Interviews (semi-structured)	Lack of training for caregivers in relation to lifting and handling skills and a lack of monitoring and support caregivers (in cases of introduction of new or altered medication); the need for clearly systematic caregiver-oriented approaches to tracking, assessment, planning, intervention, and evaluation processes is integral to the strategic development of proactive service plans.
	Yedidia et al. (2008) [74]	USA	Elicitation of views of family caregivers regarding expected kinds of assistance from nurses and social workers.	Focus groups	Learning care tasks (training for bathing and moving, positioning diapers, inserting catheters, using medical equipment, and tailoring care procedures to particular situations); legal advices (negotiating resuscitation preferences and advance directives, and understanding laws applicable to guardianship).
Support needs					
Need for support					
Type of support					
	Rodger et al. (2015) [82]	Ireland	Exploration of the experiences of informal caregivers in Ireland and identification the required support in caring for older adults at home.	Interviews (unstructured)	The majority of informal caregiver have inconsistent or no support in caregiving; the following themes emerged: “time is not your own,” duty of care, burden of caring, and support for informal caregivers.
	Lane et al. (2003) [55]	Ireland	Exploration of the perceived health and social care needs of family caregivers of older individuals (including mentally infirm individuals) and exploration of their experience of home care.	Interviews (semi-structured)	Need to support the caregiver’s role.
	Zeng et al. (2014) [37]	China	Exploration of the experience of seniors’ family caregivers with regarding the responsibility, burden, and support needs during caregiving in Shanghai, China.	Interviews (semi-structured)	Caregivers stated that some support services are limited and/or not accessible; there are gaps in caregiver support service; feel sustained mental and emotional confusion and no freedom anymore.
	Stockewell-Smith et al. (2010) [38]	Australia	Exploration of the limiting and motivating factors that influence caregivers’ use of respite services and the ability of currently available respite services to meet the needs of caregivers of frail older individuals.	Focus groups	Selective accepting of assistance; majority of participants accepted the need for assistance but had concerns in terms of trust and quality of support; consistency of formal care services was valued highly.
	Van Dijk et al. (2013) [42]	Netherlands	Exploration of (i) types of informal neighbor support and (ii) experiences of neighbors, volunteers, and professionals providing support.	Interviews (narrative)	Need for professional support for neighbors: providing social monitoring and emotional support; fear of disadvantages and preferred to limit contact.
	Mackenzie et al. (1996)	China	Gaining personal accounts of experiences of primary caregivers caring for	Interviews (semi-structured)	Help in kind (help with tasks on a regular and acceptable basis); adopt of and

Table 3 Detailed Overview of the studies included in the review *(Continued)*

Categories	Author (Year)	Country	Aim	Data Collection Methods	Findings
	[32]		dependent family members.		providing equipment in home for the caring situation.
	Zabalegui et al. (2008) [80]	Spain	Better understanding of informal caregivers' view, particularly about the resources that are or should be available to them.	Focus groups	Preference of support resources: family group and informal networks are the most helpful and available non-formal resources; want the physician to play a greater role (dedicating more time, having greater tact, etc.), need help for excessive workload and the solitude they suffer as a caregiver; need for physical aids and adaptations; home renovations and help with transport.
	Abu Bakar et al. (2014) [41]	Malaysia	Examination of Malaysian efforts in assisting informal caregivers, based on an analysis of the issues and concerns raised by the caregivers themselves.	Interviews (structured)	Need of help in solving specific care-giving concerns
	Fernandes et al. (2013)[27]	Hawaii	Developing and test a family caregiver training program for Palau in two phases: (1) assessing needs by interviewing key informants and surveying elders and (2) evaluating the caregiver training program that was designed based on findings from the assessment.	Interviews[a]	Access to medication
	McCann et al. (2002) [15]	Ireland	Identification of the views of individuals receiving care (informal caregivers were also interviewed)	Interviews[a]	One-third of the participants expressed the need for more frequent visits from health professionals (e.g., public nurses).
	Browne et al. (2014) [26]	USA	Investigation of health and care preferences that offer the potential for improving well-being in later life for Native Hawaiian elders.	Focus groups	Preferred services: (1) use of community services (when one became familiar through a neighbor or friend); (2) agency personnel (who were culturally informed, professional staff who conducted home visits, services that were affordable and organizations whose policies and procedures were respectful and not intrusive, referred helpers were nurses or social workers, referred respite, family education and support and transportation, more health and prevention programs).
	Yedidia et al. (2008) [74]	USA	Elicitation of views of family caregivers regarding expected kinds of assistance from nurses and social workers.	Focus groups	Communication with professionals (coordination professional help across care sites, collaboration with professionals providing care and finding of compassionate providers); help in recruiting competent help (assistance with checking on qualifications and references and matching available expertise to the needs of the care recipient).
	McCann (1988) [13]	USA	Understanding long term caregiving from the perspective of elderly caregivers, comparison of this perspective with that of nurses and physicians who work with older caregivers and their patients, and learning how nurses and physicians can best address the needs of older caregivers.	Focus groups	Caregivers need more contact with health professionals, and opportunities to share concerns and needs with health professionals.
	Van Kempen et al. (2012) [83]	Netherlands	Exploration of the views and needs of community-dwelling frail older individuals concerning home visits.	Interviews (semi-structured)	Need for home visits of general practitioners; preferences in home visits are the psychosocial context, continuity in professionals, and the patient–professional relationship.

Table 3 Detailed Overview of the studies included in the review *(Continued)*

Categories	Author (Year)	Country	Aim	Data Collection Methods	Findings
Emotional/ psychological/social support					
	Long et al. (2009) [44]	Japan	Comparison of two groups regarding how they became the caregiver, their use of long-term care services and the difficulties, and positive outcomes of caregiving they have experienced.	Interviews	Need for psychological services (counsellors, support groups, etc.)
	Criel et al. (2014) [36]	Belgium	Establishment of a better picture of the various needs of the elderly in their home situation, and a better understanding of the way in which informal care is provided.	Interviews (semi-structured)	Emotional support regarding several problems (emotional, psychological and physically stress as well as practical and organizational problems).
	Milligan et al. (2016) [70]	UK	Gaining a clearer understanding of how (or if) gender plays a part in shaping the forms of formal care support extended to males.	Narrative correspondence: written stories	"Felt a real need and desire to have someone to talk to about the issues, but for this to be delivered through professional services (such as a mental health worker or counselling service)."
	Wailing et al. (1997) [43]	USA	Investigation of whether different dimensions of social support affect mental health via different mechanisms and whether the context in which the support is needed and received will temper its effects.	Interviews (structured questionnaires)	Need for social support in caregiving (to buffer the effects of stress).
	Yedidia et al. (2008) [74]	USA	Elicitation of views of family caregivers regarding expected kinds of assistance from nurses and social workers.	Focus groups	Addressing end-of-life issues, moving the recipient to a facility and dealing with the family.
Financial assistance					
	Jorgensen et al. (2010) [30]	New Zealand	Reporting the unmet needs.	Telephone interview (scales and open-ended questions)	Need for appropriate financial support.
	Abu Bakar et al. (2014) [41]	Malaysia	Examination of Malaysian efforts in assisting informal caregivers based on an analysis of the issues and concerns raised by the caregivers themselves.	Interviews (structured)	Financial help with medical costs.
	Mackenzie et al. (1996) [32]	China	Gaining personal accounts of experiences of primary caregivers caring for dependent family members.	Interviews (semi-structured)	Financial help to cover extra costs incurred owing to disability.
	Zabalegui et al. (2008) [80]	Spain	Better understanding of informal caregivers' view, particularly about the resources that are or should be available to them.	Focus groups	Need for economic support.
	Zeng et al. (2014) [37]	China	Exploration of the experience of seniors' family caregivers with regarding the responsibility, burden and support needs during caregiving in Shanghai, China.	Interviews (semi-structured)	Caregivers indicate high economic pressure.
	Yedidia et al. (2008) [74]	USA	Elicitation of views of family caregivers regarding expected kinds of assistance from nurses and social workers.	Focus groups	Assistance with financial issues and insurance coverage (locating sources of aid for various income groups, understanding eligibility rules, making health plan decisions, and long-term financing).
Support systems					
Design/features/requirements of (web-based) support systems/ web-based Apps					
	Andersson et al. (2017) [84]	Sweden	Exploration of the perceived benefits and challenges with web-based information and communication technologies as a means of supporting working caregivers to fulfill their caregiving role.	In-Depth interviews (semi-structured)	Features of an family-based support network: (1) Support hub for connecting with peers, personnel, and knowledge; emotional support, knowledge bank, and information sources; (2) Experiencing ICT

Table 3 Detailed Overview of the studies included in the review *(Continued)*

Categories	Author (Year)	Country	Aim	Data Collection Methods	Findings
					support as relevant in changing life circumstances: links between accessibility, usability and flexibility in support [availability according the caregiver's life situation (working life and caregiving)]; (3) Upholding one's personal firewall: utilization is connected to issues of IT security, keeping private matters private in protection of one's integrity, and ability to feel comfortable in using the system.
	Barbabella et al. (2016) [85]	Italy, Sweden, Germany	Caregivers' psychological well-being, perceived negative and positive aspects of caregiving, and social support received were assessed before and after the 3-month intervention.	Questionnaires and focus groups	Online social support, role awareness, caregiving activities, psychological well-being, and technical concerns. The analysis suggested that the intervention was useful and appropriate, and it improved self-efficacy and the reappraisal of the caregiver's role.
e-health support					
	Blusi et al. (2014) [45]	Sweden	Investigation of whether caregiver support provided as an e-health service could benefit older family caregivers in rural areas, as compared with conventional non-e-health based support.	Interviews (semi-structured)	Flexibility (choosing suitable information; deciding the time of support, matching support activities with current needs) and availability (always someone to ask, accessible at odd hours, on demand) of the systems are essential to meet the caregivers' needs.
	Shah et al. (2012) [46]	USA	Documentation of the experiences of patients, their caregivers, healthcare personnel, and staff members with a program that provides telemedicine-enhanced emergency care to older adults residing in senior living communities (SLCs) and to delineate perceived barriers and facilitators.	Interviews (semi-structured)	Telemedicine program eliminates the need to travel to the emergency departments; provision of care immediately.
	Williamson et al. (2014) [86]	USA	Assessing the information and technology needs of Long Distance Caregivers (LDC).	Interviews (semi-structured)	Requirements or design of an App for LDC: Information regarding medication regimens and adherence, calendaring, and cognitive health were most needed. Participants also described needs for video calling, activity data regarding sleep and physical exercise, asynchronous communication, photo sharing, journaling, access to online health resources, real-time monitoring, an overall summary of health, and feedback/suggestions to help them improve as caregivers. In addition, all respondents estimated their usage of a LDC health management website would be at least once per week, with half indicating a desire to access the website from a smartphone.
In-home-monitoring					
	Wild et al. (2008) [47]	USA	Identifying of monitoring needs and expectations of community-residing elderly and their family member.	Focus groups	Maintaining independence in the home (identifying and responding to immediate needs (e.g., falls); monitoring to detect cognitive decline over time; sharing information with the physician; trade-off between privacy and usefulness: usefulness regarding safety, maintaining independence and health was valued more as compared to privacy).
Robots					
Requirements					

Table 3 Detailed Overview of the studies included in the review *(Continued)*

Categories	Author (Year)	Country	Aim	Data Collection Methods	Findings
	Bedaf et al. (2016) [57]	Netherlands/ UK/ France	Assessment of the acceptability of robots of elderly individuals.	Focus groups	Autonomy (stay in control of the own life), Agreement (acceptability of a robot), Reminders (medication, motivation for physically activity), Behavior modification (promoting health-promoting behavior), Safety (should keep the user safe), Privacy (robots sharing data with the care team; seen as an extension of the care team), Independence (passive or obedient robot undermine the independence of the user in long term).
Tasks					
	Pigini et al. (2012) [87]	Spain	Aiming to generate user requirements and realistic usage scenarios maximizing the alignment with users' needs, perceptions, feelings and rights of service robots in elderly care at home.	Focus groups and questionnaire	Tasks: monitoring and managing emergency situations, helping with reaching, fetching and carrying objects; using robots in direct physical contact is not appreciated.
	Pino et al. (2015) [88]	France	Investigation of acceptance of socially assistive robots among older adults living in the community.	Questionnaire and focus groups	Services and functionalities were: (a) cognitive support applications to compensate cognitive impairment (e.g., locating lost items, reminding about tasks), (b) communication services to keep an active social life (e.g., video calls, email), (c) risk prevention and healthcare applications (e.g., fall detection, management of critical situations), and (d) applications for supporting everyday tasks (e.g., online grocery shopping, journey planning, simplified Internet access); other functionalities mentioned were entertainment (e.g., music, poetry, and reading) and information and news applications for keeping the user up to date with current events (e.g., broadcast news sources); "life memory albums" available via the robot to support autobiographic memory in persons with memory loss and encourage communication with caregivers and/or family members. Additionally, this application could include multimedia material, such as a genealogical tree, pictures and/or videos of significant moments of the life of the person.
Design					
	Pigini et al. (2012) [87]	Spain	Aiming to generate user requirements and realistic usage scenarios maximizing the alignment with users' needs, perceptions, feelings and rights of service robots in elderly care at home.	Focus groups and questionnaires	Preference of human-like appearance and the possibility of voice-command for controlling the robot.
	Pino et al. (2015) [88]	France	Investigation of acceptance of socially assistive robots among older adults living in the community.	Questionnaire and focus groups	Design: mechanical human-like robot integrating some anthropomorphic facial features within a global mechanical-looking design was preferred.
Needs for societal recognition					
Recognition					
	Jorgensen et al. (2010) [30]	New Zealand	Reporting the unmet needs.	Telephone interview (scales and open-ended questions)	Need for recognition for the caregiving role.

Table 3 Detailed Overview of the studies included in the review *(Continued)*

Categories	Author (Year)	Country	Aim	Data Collection Methods	Findings
	Abu Bakar et al. (2014) [41]	Malaysia	Examination of Malaysian efforts in assisting informal caregivers, based on an analysis of the issues and concerns raised by the caregivers themselves.	Interviews (structured)	Recognition and respect, support and encouragement, appreciation and understanding.
	Mackenzie et al. (1996) [32]	China	Gaining personal accounts of experiences of primary caregivers caring for dependent family members.	Interviews (semi-structured)	Acknowledgement of the importance of the caregiver's job.
	Eldh et al. (2011) [31]	Sweden	Elucidation of the experience of providing informal care to an ageing parent while managing the responsibilities of a working life.	Interviews (narrative)	Society should acknowledging caregivers better for providing support and care for their ageing parents.
State responsibility					
	Browne et al. (2014) [26]	USA	Investigation of health and care preferences that offer the potential for improving well-being in later life for Native Hawaiian elders.	Focus groups	Caregiving as a shared responsibility of the family and government; the government should have a role in taking care of elders and families (especially in making insurance and medications accessible and affordable); a few said that the government's care measures goes against the family's responsibility; receiving help from the family and friends (core Hawaiian value of family and extended networks). Barriers to government care include: (1) real or perceived costs of Services, (2) agency rules and regulations, (3) issues around respect and privacy, and (4) limited specific services.
	Eldh et al. (2011) [31]	Sweden	Elucidation of the experience of providing informal care to an ageing parent while managing the responsibilities of a working life.	Interviews (narrative)	Need for legislation for supporting employees' rights to provide care; need for such solutions.

[a]: No specific interview type was mentioned

reduce or eliminate the need to travel to emergency departments [46]. Williamson et al. (2014) addressed the requirements and features of APPs for long distance caregivers. Information regarding medication regimens and adherence, calendaring, and cognitive health were stated as most wanted. Furthermore, participants wished for video calling, recording of activity data regarding sleep and physical exercise, asynchronous communication, photo sharing, journaling, access to online health resources, real-time monitoring, and an overall summary of health. A need for feedback or suggestions to improve their role as caregivers was also mentioned. In-home monitoring was named a useful intervention to maintain independence at home. However, the trade-off between privacy and usefulness were discussed, while safety and maintaining independence achieved a higher value than privacy [47].

The usage of robots in the outpatient care of elderly was another topic in the literature. In a study conducted by Bedaf et al. (2016), the requirements of robots in care were discussed in focus groups in the Netherlands, UK, and France. Thereby, autonomy (staying in control of one's own life), agreement (acceptance of a robot), reminders (medication and motivation for physical activity), behavior modification (promote a healthy behavior), safety, privacy (data sharing with the care team) and independence (passive or obedient robots) were identified as important features. Pigini et al. (2012) and Pino et al. (2015) explored caregivers' acceptance of types of tasks conducted by robots in care. Monitoring and managing emergency situations, assisting in reaching, fetching and carrying objects were preferred or accepted. However, robots with direct physical contact as a possible application area were not appreciated [48]. Furthermore, cognitive support applications (to compensate for cognitive impairment), communication services (to maintain an active social life), risk prevention and healthcare applications (e.g., fall detection), applications to support everyday tasks (e.g., online grocery shopping, journey planning), as well as information sources and applications that enable the user to stay up to date (e.g., broadcast news) and assist them with autobiographic memories, were identified as important functionalities. Additionally, Pigini et al. (2012) and Pino et al. (2015) identified a preference for a human-like appearance of the robots.

Topic 5: Needs for societal recognition

Appreciation for the role of a caregiver was a stated desire in four of the included studies (e.g., Jorgensen (2010)), as well as respect, support, encouragement, and understanding [31, 41]. Mackenzie et al. (1996) and Eldh et al. (2011) found the need for acknowledgement of the importance of the caregiver's job. The responsibility of the state was another subtopic in this category. Participants in the study conducted by Eldh et al. (2010) stated the need for legislation to support employees' rights to provide care.

Discussion

In this comprehensive systematic literature review, the needs and preferences of informal caregivers concerning the care of elderly relatives (family, neighbors and friends) were analyzed. We could identify preferences as well as essential needs regarding the organization of long-term care. All these identified needs could be categorized into the following four main categories: organizational needs informational needs, support needs, and needs for societal recognition.

In the current review, home care was the predominant preference regarding the organization of elderly care. Preferences regarding the organization and structure of long-term care for a care-dependent relative are highly dependent on various factors, such as the degree of family relationship (children, children-in-law, spouse etc.) [12]. In most cases, for example, spouses want to care for their partners [14]. However, financial factors, degree of care-dependence, employment etc. may be limiting factors, which obstruct home care and necessitate institutional care or community care [12, 14].

For the organization or design of informal care a few needs could be identified in the systematic review. In particular, factors related to community-based care or the design of long-term-care arrangements, as well as respite, were singled out in the literature. The need for respite services was identified. The need for support has to be clearly differentiated from the need for respite. While the need for support may arise due to dealing with the caregiving situation, such as support in daily care or mental help for caregivers to accept the situation, the need for respite is more complex. Respite serves the caring person for recreation. It constitutes a possibility for primary caregivers to obtain short-time discharge from their caregiving situation (from a few hours up to weeks) at home, at a healthcare facility, or at an adult day center [49]. During that time someone else is taking care of the person in need of care. Caregivers want safety as well as reliable and trustful help for their care-dependent relatives [50]. A few positive effects, e.g. reduction of depression, burden and stress, were associated with using respite interventions [51]. A lack of flexibility (e.g. long waiting times for beds or for respite at home) as well as poor quality were mentioned in studies as reasons for the non-use of respite services [48, 52]. A further barrier for the use of respite services was the lack of trust and confidence in the provider of such services [38]. An intense collaboration and coordination between informal caregivers and formal services may reduce such access barriers. Kaambwa (2015) conducted a discrete-choice experiment (DCE) to evaluate the preferences regarding the organization of community-directed care (CDC) [53]. In a preliminary study conducted by McCaffery et al. (2015), important service characteristics for users (information, choice and control, effective co-ordination and communication, responsiveness and flexibility, and continuity and planning) were identified via face-to-face interviews. These characteristics were used to define the attributes included in the DCE. Here, participants expressed a highly significant preference for individual budget managing, being able to choose some of the workers that provide their day-to-day services, and being able to have fully flexible support workers so that they could receive support for activities such as cleaning, shopping, meal preparation, and gardening [53].

The need for information was commonly found, but it varied from the need for information about existing services to information about sources of community help, to that about rehabilitation. Additionally, the need for information sharing on topics such as medical interventions of the care-recipient and organization of information sharing, as well as educational desires and preferences for professional counselling were identified. The European Charter for Family Carers, an initiative of the European Union, states that access to information and being informed about rights and duties are important for fulfilling the caregiver's role [19]. Furthermore, in a majority of studies support is a prevalent topic. However, the possibility as well the scope of support are defined by the countries' regulations and differ, like in China by geographic regions [54]. Hence, basic [55] or specific forms (psychological and emotional support) of support as well as financial assistance may influence the population needs. Only 16% of European family caregivers received or had used services or trainings to improve their skills and knowledge for a better care, whereas 10% of these were satisfied with this training [19]. In some European countries (Netherlands, Belgium, France and Luxembourg) various information sources such as formal information of the health insurances or social care professionals for support services were mentioned, which may influence the use of support services [54]. In addition to transnational differences, the use of formal and informal services can differ, for example from rural to urban environment [56] and across cultures

[41]. A majority of studies addressed needs regarding support systems, including web-based ones, e-health-related aspects as well as requirements, tasks, and the design of care robots. Several studies reported the wish of the elderly for home-based care or aging in place [57, 58]. The development of technologies in telecare leads to (new) possibilities of safety and security monitoring, monitoring of health parameters and vital signs, and support by information and communication applications [59]. On one side these technologies, for example ambient-assisted living-technologies (home sensors, alarm systems, etc. [60]), support care-recipients in daily living activities, and, on the other side, support caregivers by enabling them to leave the care-recipient alone at home for a short time. Robots for assisting in health tasks such as bathing and lifting reduce caregiver workload. However, no studies with regard to the usage of robots in home-based care could be identified. However, in 2015, approximately 4700 assistance robots were sold worldwide, and according to forecasts of the International Federation of Robotics in Frankfurt, the sales are expected to increase up to 37,500 by 2019 [61, 62]. This implies an existing demand for such devices.

The recognition of the caregiving role was also identified as a need of informal caregivers in the current review [30, 32, 41]. Recognition was a stated wish, need, or expectation from community members. More specifically, caregiving should be recognized as a time-consuming and stressful situation. The mentioned need for recognition of the caregiving role [30], appreciation, and understanding [32] reflect this. The lack of recognition by the state can lead to less support and cause dissatisfaction with the role of caring, social isolation, self-neglect, and concern for personal safety [63]. Recognition from state for informal caregiving can be derived from policy initiatives or defined benefits for informal care. The types and scopes of state responsibility differ internationally. Differences can be found in financial maintenance obligations, sharing of responsibilities between family and state, support measures, financial support measures (cash-for-care) and in-kind services (e.g. monitoring, home support devices) [64].

Organizational needs regarding LTC depend on the preferred type of care. For example, recognition of caregivers' burden may lead to an implementation of respite services. However, the use of these respite services depends on the information and trust of the caregivers and may in turn influence work-life balance and satisfaction. In a narrow sense, the work-care balance may influence the caregiver's work-life balance. Reducing working time or having flexible working hours is often essential to organize the long-term care for a care-dependent relative to equally fulfill the requirements at the workplace. Hence, the caregiver may be able to achieve a well-functioning work-care balance. A clear differentiation has to be made between a functioning work and care-life balance. Respite in this case enables a possibility to rest or to pursue the previous leisure activities.

Applying findings to the German case

Considering the German national context, about 2.9 million people were in need of care in 2015 according to the German Nursing Insurance Act (SGB XI), 83% of these were aged 65 years and above [65]. These demographic changes will likely lead to an increase in the number of care-dependent people to an estimated 3.4 million by 2030 [66]. The current nursing situation (e.g., staff shortage) is expected to deteriorate leading to a lack of approximately 500,000 caregivers by 2030 [67]. Presently, 73% of the care-dependent people are being cared for at home and in approximately two-thirds of the outpatient care cases, informal caregivers (including family, friends, relatives, and volunteers) take care of the care-dependent individuals alone or in combination with formal care services [68]. Care provided only by informal caregivers is the most common form (1.18 million), followed by caregiving provided only by formal care services (331,616) and a combination of formal and informal care (244,648) [69]. This shows that informal caregiving is an essential pillar in the German setting when it comes to providing care for the elderly, and therefore, it needs to be strengthened to tackle future challenges.

In recent years, as in many other Western countries, Germany has had a large number of policy initiatives and regulations focusing on the organization of long-term care in the outpatient care sector. Care by informal caregivers is with a total of 1.18 million cases in 2014 the most prevalent form of care in Germany [69]. Based on the socio-economic panel (SOEP) (2001–2012), the German Institute for Economic Research (DIW Berlin) found that 5–6% of adults provide informal care and 60% of these are at an employable age. In recent years, the proportion of the working population providing care under 65 years increased from 53 to 66%. This increase was higher in the group of full-time staff than in the group of part-time workers, whereas, generally, full-time employees combine informal care and career less often [69]. Similar to the OECD average, in Germany, unpaid care is often provided for parents (44.2%) and spouses (34.9%), followed by friends (21.5%) and relatives (13.0%). Further, caregivers are predominantly women (OECD, 2011); however, in recent years, an increase of male informal caregivers could be observed [70]. These findings show the relevance of strengthening the informal outpatient care sector.

According to a German statutory provision (SGB XI), the informal caregiver or care-dependent is entitled to several non-cash-benefits (contributions for personal hygiene, mobility, and nutrition), care allowance, services of care and discharge (§45b SGB XI), day and night care, short-time care, etc. Willemse et al. (2016) found existing support measures to be known and extensively used in Germany. In recent years, German legislation has enacted several laws regarding the organization of informal care to decrease the burden of caregiving and relief informal caregivers. The Long Term Care Strengthening Act was the first step to improve the situation for care-dependent individuals by expanding the insurance benefits in 2015 (The First Long Term Care Strengthening Act (PSG I). The second Long Term Care Strengthening Act (PSG II) focuses on self-reliance of individuals in need of care. An extension of the support in personal and daily care services for patients and a new categorization of care levels, including cognitive limitations as a factor to determine the need for care, was implemented in January 2017. Two further acts, strengthening the informal caregivers' compatibility of family, care, and profession, were also adopted in 2015. In the Home Care Leave Act (PflegeZG) regulations regarding the working time of employed caring relatives were defined. Employees can be exempted from work or have the opportunity to work part time for a limited time. Furthermore, informal caregivers are entitled to wage replacement. Moreover, major regulation contents of the PSG I and II were significant variations regarding informal care organization, including (1) improved home-care (free care courses and care consulting); (2) time-off (prevention care up to 6 weeks per year); (3) exemption from work (wage-replacement benefits up to ten days, financial compensation for care assistance and reduced working hours up to two years), and (4) better social security (unemployment and age insurance contributions). By means of these regulations the German legislature exercises its duty of care. Regulations to strengthen informal care and to compensate for the negative effects of caregiving meet the German conditions of the social security statute book to provide social justice and to avert or compensate particular burdens of life (§1 SGB I). Adjustments to informal care conditions contribute equally to the fulfillment of the aim of the Tallinn-Charta of the World Health Organization (WHO) stating that health systems have a duty to maintain health and prosperity [71].

Some of these political national measures initiated in recent years addressed the identified preferences and needs of informal caregivers. LTC at home was the most preferred type of care identified in the review, which is also reflected by the high number of informal caregivers in the current care setting. Therefore, a large number of support services were implemented in 2015 to disburden informal caregivers. Needs regarding the organization of LTC, in terms of work-life-balance or respite, were essential aspects for nursing relatives. The possibility of respite and reducing working time may influence self-care, stress and work-life-balance of informal caregivers. However, needs for accepting respite such as trust and satisfaction are difficult to achieve with legal guidelines. Trust in formal caregivers, for example, is very subjective and can therefore heavily influence the acceptance of respite. The need for information was also addressed by the FfZG in 2015. For instance, in an effort to provide information regarding solving specific caregiving concerns [72], reablement services [73], available services [74] or regional service providers [75], each care-dependent's health insurance covers the costs of care consulting and caregiving courses. Educational and professional counselling needs, such as learning care tasks (e.g. training for bathing and moving [74] or handling skills [Lane] were also covered by the implementation of care consulting. The need for support in general or specifically emotional, psychological and social support may also be an area of responsibility for professional counselling. Such consultations can be a central part of the training as well as the placement of other contact points such as self-help groups [Long]. Financial assistance were an additional need identified in the systematic review. In Germany, due to the introduction of a new classification system for the severity of care dependency, a wider access to financial support, e.g. for people with dementia, were created as the classification system not only assesses physical limitations in activities of daily living, but also cognitive impairments. However, with respect to support systems such as robots or in-home-monitoring, no concrete measures were defined by the legislation. Nonetheless, the scope of reimbursement of costs for support systems is made on a case-by-case decision depending on the healthcare insurance and the classified severity of care dependency. From the changes in recent years, the growing political will of the state to strengthen informal care can be deduced. However, needs of informal caregivers may differ by region (urban or rural) based on aspects such as availability and accessibility of formal home care services or inpatient LTC-arrangements.

Care, as a meaningful act in the context of life and family history [76], is a very sensitive and complex process demanding a lot from the ones involved, particularly family caregivers. Socio-demographic developments justify the demand for structures and services that allow for a combination of care and support activities, employment and private life, as well as the integration of familiar structures, including external familiar structures such as neighborhood and civil society resources [77].

In general, the preferences regarding structure and organization of long-term care as well as the needs for informal care vary from case to case. Germany is presented here as a case example. Of course, the relevance of the preferences and needs identified in this review also depend on country-specific circumstances. These include demographic aspects (e.g. average age of the population), financial and cultural aspects (e.g. care as family responsibility) as well as the current form of care in the country. In order to get a reliable picture of preferences and needs, each country or even region has to be considered individually. The previously mentioned influencing factors should, however, be taken into account when determining the needs and preferences of certain populations.

Limitations

The study has several limitations regarding the definition of the inclusion and exclusion criteria. Studies dealing with end-of-life (EOL) care and palliative care were excluded. These settings were assumed to have special care needs for medical and nursing interventions. However, these aspects are essential drivers for need and preferences regarding care. Our study focusses on elderly care in general, whereas EOL care often describes only the care needs at the end of life. The decision to provide care for an individual with a very limited life expectancy may result in other preferences compared to generally elderly care. Hence, also the willingness to provide care may be different. Moreover, some studies lacked a clear distinction between end-of-life care with regard to palliative care and "normal" nursing care for elders. Furthermore, studies with disabled care-recipients were excluded, whereas often a clear distinction of disability in the sense of people in need of care or a previous disability was also lacking. Different needs can be assumed. The included studies were all based on a qualitative survey design. Hence, a correlation between the preferences or needs and the socio-demographic properties of the participants cannot be shown. Caregiving contexts vary, but, due to the limited number of studies as well as their designs, the literature reviews did not enable a comparison between the qualitative studies on types of caregivers (partners vs. children, for example), or working and not-working caregivers, or males and females, or sole caregivers and those sharing caregiving responsibilities. However, further research projects could address these open questions, as they have a significant relevance to the design of informal care provision. Moreover, national regulations and country policies are further aspects, which should be taken into account when interpreting the needs and preferences of informal caregivers. However, due to the low representativeness of some countries in the systematic review, no conclusions can be drawn on the corresponding preferences and needs. These may have a direct impact on organization and structure of informal care and hence, influence preferences and needs of informal caregivers. Furthermore, the defined search strategy led to a large number of results, requiring the separate publication of the perspectives of informal caregivers and care-dependents.

Conclusion

The proportion of the elderly in the general population is increasing steadily in Germany and worldwide. The growing demand for nursing care and the lack of qualified caregivers requires further strengthening of outpatient care structures. Establishing an elderly outpatient care system, which supports families and friends in providing elderly care, while meeting the needs and wishes of informal caregivers, is of high relevance. A balanced arrangement of formal and informal care services, combined with an easy and comprehensive access to information, support services, and adequate financial compensations, as well as respect and encouragement for those who undertake informal care, could be an attractive model. Future research should measure the preferences regarding the organization of informal care as well as the usage of formal care services with appropriate techniques.

Abbreviations

CDC: community-directed care; DCE: discrete-choice experiment; LLC: later-life care; LTC: Long-term-care; US: United States

Acknowledgements
Not applicable.

Funding
This study was funded by the Federal Ministry of Education and Research, grant number 01EH1603A. The publication of the article was funded by the Open Access Fund of the Leibniz University Hannover.

Availability of data and materials

Not applicable.

Authors' contributions

MP, the lead author, created the study design and initial draft. KS, LDJ, JZ and KD contributed to the manuscript through a literature search, discussions on design and structure, writing, reviews and final approval.

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

Publisher's Note

Received: 6 July 2018 Accepted: 13 February 2019

References

1. United Nations. World Population Aging – Highlights. http://www.un.org/en/development/desa/population/publications/pdf/ageing/WPA2017_Highlights.pdf. Accessed 05 Dec 2018.
2. Koller D, Schön G, Schäfer I, Glaeske G, van den Bussche H, Hansen H. Multimorbidity and long-term care dependency—a five-year follow-up. BMC Geriatr. 2014. https://doi.org/10.1186/1471-2318-14-70.
3. Divo MJ, Martinez CH, Mannino DM. Aging and the epidemiology of multimorbidity. Eur Respir J. 2014. https://doi.org/10.1183/09031936.00059814.
4. U.S. Department of Health and Human Services, and U.S. Department of Labor. The future supply of long-term care workers in relation to the aging baby boom generation: Report to Congress. Washington, DC: Office of the Assistant Secretary for Planning and Evaluation; 2003. https://aspe.hhs.gov/basic-report/future-supply-long-term-care-workers-relation-aging-baby-boom-generation. Accessed 06 Dec 2018
5. Li F, Otani J. Financing elderly people's long-term care needs: evidence from China. Int J Health Plann Manag. 2018. https://doi.org/10.1002/hpm.2488.
6. Genet N, Boerma W, Kroneman M, Hutchinson A, Saltman RB. Home Care across Europe. Current structure and future challenges. http://www.euro.who.int/__data/assets/pdf_file/0008/181799/e96757.pdf. Accessed 06 Dec 2018.
7. Berufsgenossenschaft für Gesundheitsdienst und Wohlfahrtspflege. Auswirkungen des demografischen Wandels auf die Pflege. 2018. https://www.bgw-online.de/DE/Arbeitssicherheit-Gesundheitsschutz/Demografischer-Wandel/Auswirkungen-auf-die-Pflege/Auswirkungen_Pflege.html.
8. Kok L, Berden C, Sadiraj K. Costs and benefits of home care for the elderly versus residential care: a comparison using propensity scores. Eur J Health Econ. 2015. https://doi.org/10.1007/s10198-013-0557-1.
9. Karsch-Völk M, Landendörfer P, Linde K, Egermann A, Troeger-Weiß G, Schneider A. Medizinische und kommunale Herausforderungen einer alternden Gesellschaft im ländlichen Bereich. Gesundheitswesen. 2012. https://doi.org/10.1055/s-0031-1286272.
10. Roth DL, Fredman L, Haley WE. Informal caregiving and its impact on health: a reappraisal from population-based studies. Gerontol. 2015. https://doi.org/10.1093/geront/gnu177.
11. Better Health While Aging. What are activities of daily living (ADLs) & instrumental activities of daily living (IADLs)? 2018. https://betterhealthwhileaging.net/what-are-adls-and-iadls/. Accessed 26 Apr 2018.
12. Pinquart M, Sörensen S. Spouses, adult children, and children-in-law as caregivers of older adults: a meta-analytic comparison. Psychol Aging. 2011. https://doi.org/10.1037/a0021863.
13. McCann J. Long term home care for the elderly: perceptions of nurses, physicians, and primary caregivers. Qual Rev Bull. 1988;14(3):66–74.
14. Wang Y-C, Chung M-H, Lai K-L, Chou C-C, Kao S. Preferences of the elderly and their primary family caregivers in the arrangement of long-term care. J Formos Med Assoc. 2004;103:533–9.
15. McCann S, Evans DS. Informal care: the views of people receiving care. Health Soc Care Community. 2002;10(4):221–8.
16. Kim E-Y, Cho E, June KJ. Factors influencing use of home care and nursing homes. J Adv Nurs. 2006. https://doi.org/10.1111/j.1365-2648.2006.03839.x.
17. Doty P, Jackson ME, Crown W. The impact of female caregivers' employment status on patterns of formal and informal eldercare. Gerontol. 1998. https://doi.org/10.1093/geront/38.3.331.
18. Houde CS. Predictors of elders' and family caregivers' use of formal home services. Res Nurs Health. 1998. https://doi.org/10.1002/(SICI)1098-240X(199812)21:6<533::AID-NUR7>3.0.CO;2-I.
19. Birtha, M., Holm, K. COFACE families Europe - WHO CARES? Study on the challenges and needs of family carers in Europe. 2017. http://www.coface-eu.org/wp-content/uploads/2017/11/COFACE-Families-Europe_Study-Family-Carers.pdf. Accessed 11 May 2018.
20. Burton LC, Zdaniuk B, Schulz R, Jackson S, Hirsch C. Transitions in spousal caregiving. Gerontol. 2003. https://doi.org/10.1093/geront/43.2.230.
21. Metzelthin SF, Verbakel E, Veenstra MY, van Exel J, Ambergen AW, Kempen GIJM. Positive and negative outcomes of informal caregiving at home and in institutionalised long-term care: a cross-sectional study. BMC Geriatr. 2017. https://doi.org/10.1186/s12877-017-0620-3.
22. Farina N, Page TE, Daley S, Brown A, Bowling A, Basset T, et al. Factors associated with the quality of life of family carers of people with dementia: a systematic review. Alzheimers Dement. 2017. https://doi.org/10.1016/j.jalz.2016.12.010.
23. Emrich C, Rieger MA, Simoes E. Häusliche Pflegearrangements. Eine explorative Analyse auf Basis des Sozio-ökonomischen Panels, Wellen 2002-2009. Gesundheitswesen. 2012; doi:https://doi.org/10.1055/s-0032-1322013.
24. Klindtworth K, Geiger K, Pleschberger S, Bleidorn J, Schneider N, Müller-Mundt G. Leben und Sterben mit Gebrechlichkeit: Qualitative Interviews mit älteren Menschen im häuslichen Umfeld. Z Gerontol Geriatr. 2017. https://doi.org/10.1007/s00391-015-1011-z.
25. de Jong L, Plöthner M, Stahmeyer JT, Eberhard S, Zeidler J, Damm K. Informal and formal care preferences and expected willingness of providing elderly care in Germany: protocol for a mixed methods study. BMJ Open 2019;9:e023253. https://doi.org/10.1136/bmjopen-2018-023253.
26. Browne CV, Mokuau N, Ka'opua LS, Kim BJ, Higuchi P, Braun KL. Listening to the voices of native Hawaiian elders and 'ohana caregivers: discussions on aging, health, and care preferences. J Cross Cult Gerontol. 2014. https://doi.org/10.1007/s10823-014-9227-8.
27. Fernandes R, Osarch S, Bell CL, Flynn BW, Nguyen LV, Abad MJ, et al. Aging and caregiving in the Republic of Palau. J Cross Cult Gerontol. 2013. https://doi.org/10.1007/s10823-013-9192-7.
28. Denson LA, Winefield HR, Beilby JJ. Discharge-planning for long-term care needs: the values and priorities of older people, their younger relatives and health professionals. Scand J Caring Sci. 2013. https://doi.org/10.1111/j.1471-6712.2012.00987.x.
29. Stolee P, Zaza C, Sharratt MT. Later life care planning conversations for older adults and families. J Appl Gerontol. 2014. https://doi.org/10.1177/0733464813500712.
30. McCaffrey N, Gill L, Kaambwa B, Cameron ID, Patterson J, Crotty M, et al. Important features of home-based support services for older Australians and their informal carers. Health Soc Care Community. 2015. https://doi.org/10.1111/hsc.12185.
31. Eldh AC, Carlsson E. Seeking a balance between employment and the care of an ageing parent. Scand J Caring Sci. 2011. https://doi.org/10.1111/j.1471-6712.2010.00824.x.
32. Mastel-Smith B, Stanley-Hermanns M. "It's like we're grasping at anything": Caregivers' education needs and preferred learning methods. Qual Health Res. 2012. https://doi.org/10.1177/1049732312443739.
33. Yedidia MJ, Tiedemann A. How do family caregivers describe their needs for professional help? J Soc Work Educ. 2008. https://doi.org/10.5175/JSWE.2008.773247710.
34. Jorgensen D, Parsons M, Jacobs S, Arksey H. The New Zealand informal caregivers and their unmet needs. N Z Med J. 2010;123(1317):9–16.
35. Mackenzie AE, Holroyd EE. An exploration of the carers' perceptions of caregiving and caring responsibilities in Chinese families. Int J Nurs Stud. 1996. https://doi.org/10.1016/0020-7489(95)00066-6.
36. Feinberg LF, Whitlatch CJ. Family caregivers and in-home respite options. J Gerontol Soc Work. 1999. https://doi.org/10.1300/J083v30n03_03.
37. Lane P, McKenna H, Ryan A, Fleming P. The experience of the family caregivers' role: a qualitative study. Res Theory Nurs Pract. 2003;17:137–51.
38. Greenwood N, Habibi R, Mackenzie A. Respite: Carers' experiences and perceptions of respite at home. BMC Geriatr. 2012. https://doi.org/10.1186/1471-2318-12-42.
39. Lund DA, Utz RL, Caserta MS, Wright SD, Llanque SM, Lindfelt C, et al. Time for living and caring: an intervention to make respite more effective for caregivers. Int J Aging Hum Dev. 2014. https://doi.org/10.2190/AG.79.2.d.
40. Stirling CM, Dwan CA, McKenzie AR. Why carers use adult day respite: a mixed method case study. BMC Health Serv Res. 2014. https://doi.org/10.1186/1472-6963-14-245.
41. Criel B, Vanlerberghe V, de Koker B, Decraene B, Engels E, Waltens R. Informal home care for elderly in Belgium: A study on the features and challenges of informal care at local level. Community Ment Health J. 2014. https://doi.org/10.1007/s10597-014-9696-9.
42. Abu Bakar SH, Weatherley R, Omar N, Abdullah F, Mohamad Aun NS. Projecting social support needs of informal caregivers in Malaysia. Health Soc Care Community. 2014. https://doi.org/10.1111/hsc.12070.
43. Hirakawa Y, Kuzuya M, Enoki H, Uemura K. Information needs and sources of family caregivers of home elderly patients. Arch Gerontol Geriatr. 2011. https://doi.org/10.1016/j.archger.2010.03.019.

44. Zabalegui A, Bover A, Rodriquez E, Cabrera E, Diaz M, Gallart A, et al. Informal caregiving: perceived needs. Nurs Sci Q. 2008. https://doi.org/10.1177/0894318408314978.
45. Zeng L, Zhu X, Meng X, Mao Y, Wu Q, Shi Y, Zhou L. Responsibility and burden from the perspective of responsibility and burden from the perspective of seniors' family caregivers: a qualitative study in Shanghai. China Int J Clin Exp Med. 2014;7(7):1818–28.
46. Stockwell-Smith G, Kellett U, Moyle W. Why carers of frail older people are not using available respite services: an Australian study. J Clin Nurs. 2010. https://doi.org/10.1111/j.1365-2702.2009.03139.x.
47. Wilde A, Glendinning C. 'If they're helping me then how can I be independent?' The perceptions and experience of users of home-care re-ablement services. Health Soc Care Community. 2012. https://doi.org/10.1111/j.1365-2524.2012.01072.x.
48. Nickel W, Born A, Hanns S, Brähler E. Welche Informationsbedürfnisse haben pflegebedürftige ältere Menschen und pflegende Angehörige? Z Gerontol Geriatr. 2011. https://doi.org/10.1007/s00391-010-0146-1.
49. Crotty BH, Walker J, Dierks M, Lipsitz L, O'Brien J, Fischer S, et al. Information sharing preferences of older patients and their families. JAMA Intern Med. 2015. https://doi.org/10.1001/jamainternmed.2015.2903.
50. LaVela SL, Turcios S, Malhiot A, Etingen B, Hill JN, Miskevics S. Do perceptions of family-centered care differ in older and younger family/caregivers of U.S. veterans? Fam Syst Health. 2016. https://doi.org/10.1037/fsh0000173.
51. van Houtven CH, Oddone EZ, Weinberger M. Informal and formal care infrastructure and perceived need for caregiver training for frail US veterans referred to home and community-based services. Chronic Illn. 2010. https://doi.org/10.1177/1742395309352694.
52. Rodger D, Neill MO, Nugent L. Informal carers' experiences of caring for older adults at home: A phenomenological study. Br J Community Nurs. 2015. https://doi.org/10.12968/bjcn.2015.20.6.280.
53. van Dijk HM, Cramm JM, Nieboer AP. The experiences of neighbour, volunteer and professional support-givers in supporting community dwelling older people. Health Soc Care Community. 2013. https://doi.org/10.1111/hsc.12006.
54. van Kempen JAL, Robben SHM, Zuidema SU, Olde Rikkert MGM, Melis RJF, Schers HJ. Home visits for frail older people: a qualitative study on the needs and preferences of frail older people and their informal caregivers. Br J Gen Pract. 2012. https://doi.org/10.3399/bjgp12X653606.
55. Long SO, Campbell R, Nishimura C. Does it matter who cares?: a comparison of daughters versus daughters-in-law in Japanese elder care. Soc Sci Japan J. 2009. https://doi.org/10.1093/ssjj/jyn064.
56. Milligan C, Morbey H. Care, coping and identity: older men's experiences of spousal care-giving. J Aging Stud. 2016. https://doi.org/10.1016/j.jaging.2016.05.002.
57. Wailing LL, Seltzer MM, Greenberg JS. Social support and depressive symptoms: differential patterns in wife and daughter caregivers. J Gerontol. 1997;52B(4):S200–11.
58. Andersson S, Erlingsson C, Magnusson L, Hanson E. The experiences of working carers of older people regarding access to a web-based family care support network offered by a municipality. Scand J Caring Sci. 2017. https://doi.org/10.1111/scs.12361.
59. Barbabella F, Poli A, Andréasson F, Salzmann B, Papa R, Hanson E, et al. A web-based psychosocial intervention for family caregivers of older people: results from a mixed-methods study in three European countries. JMIR Res Protoc. 2016. https://doi.org/10.2196/resprot.5847.
60. Blusi M, Dalin R, Jong M. The benefits of e-health support for older family caregivers in rural areas. J Telemed Telecare. 2014. https://doi.org/10.1177/1357633X13519901.
61. Shah MN, Morris D, Jones CMC, Gillespie SM, Nelson DL, McConnochie KM, et al. A qualitative evaluation of a telemedicine-enhanced emergency care program for older adults. J Am Geriatr Soc. 2013. https://doi.org/10.1111/jgs.12157.
62. Williamson SS, Gorman PN, Jimison HB. A mobile/web app for long distance caregivers of older adults: functional requirements and design implications from a user centered design process. AMIA Annu Symp Proc. 2014;2014:1960–9.
63. Wild K, Boise L, Lundell J, Foucek A. Unobtrusive in-home monitoring of cognitive and physical health: reactions and perceptions of older adults. J Appl Gerontol. 2008. https://doi.org/10.1177/0733464807311435.
64. Bedaf S, Draper H, Gelderblom G-J, Sorell T, de Witte L. Can a service robot which supports independent living of older people disobey a command?: the views of older people, informal carers and professional caregivers on the acceptability of robots. Int J of Soc Robotics. 2016. https://doi.org/10.1007/s12369-016-0336-0.
65. Pigini L, Facal D, Blasi L, Andrich R. Service robots in elderly care at home: Users' needs and perceptions as a basis for concept development. Technol Disabil. 2012;24:303–11.
66. Pino M, Boulay M, Jouen F, Rigaud A-S. "Are we ready for robots that care for us?" Attitudes and opinions of older adults toward socially assistive robots. Front Aging Neurosci. 2015. https://doi.org/10.3389/fnagi.2015.00141.
67. National Institute on Age. What Is Respite Care? 2017. https://www.nia.nih.gov/health/what-respite-care. Accessed 22 May 2018.
68. Lopez Hartmann M, Wens J, Verhoeven V, Remmen R. The effect of caregiver support interventions for informal caregivers of community-dwelling frail elderly: a systematic review. Int J Integr Care. 2012. https://doi.org/10.5334/ijic.845.
69. Jeon Y-H, Brodaty H, Chesterson J. Respite care for caregivers and people with severe mental illness: literature review. J Adv Nurs. 2005. https://doi.org/10.1111/j.1365-2648.2004.03287.x.
70. Wiles J. Informal caregivers' experiences of formal support in a changing context. Health Soc Care Community. 2003. https://doi.org/10.1046/j.1365-2524.2003.00419.x.
71. Kaambwa B, Lancsar E, McCaffrey N, Chen G, Gill L, Cameron ID, et al. Investigating consumers' and informal carers' views and preferences for consumer directed care: a discrete choice experiment. Soc Sci Med. 2015. https://doi.org/10.1016/j.socscimed.2015.06.034.
72. Willemse E, Anthierens S, Farfan-Portet MI, Schmitz O, Macq J, Bastiaens H, et al. Do informal caregivers for elderly in the community use support measures? A qualitative study in five European countries. BMC Health Serv Res. 2016. https://doi.org/10.1186/s12913-016-1487-2.
73. Li M, Zhang Y, Zhang Z, Zhang Y, Zhou L, Chen K. Rural-urban differences in the long-term care of the disabled elderly in China. PLoS One. 2013. https://doi.org/10.1371/journal.pone.0079955.
74. Averill JB. Priorities for action in a rural older adults study. Fam Community Health. 2012. https://doi.org/10.1097/FCH.0b013e318266686e.
75. Barlow J, Singh D, Bayer S, Curry R. A systematic review of the benefits of home telecare for frail elderly people and those with long-term conditions. J Telemed Telecare. 2007. https://doi.org/10.1258/135763307780908058.
76. Blackman S, Matlo C, Bobrovitskiy C, Waldoch A, Fang ML, Jackson P, et al. Ambient assisted living technologies for aging well: a scoping review. J Intell Syst. 2016. https://doi.org/10.1515/jisys-2014-0136.
77. International Federation of Robotics. 31 million robots helping in households worldwide by 2019. 22.05.2018. https://ifr.org/ifr-press-releases/news/31-million-robots-helping-in-households-worldwide-by-2019. Accessed 22 May 2018.
78. Feuilherade P. Robots pick up the challenge of home care needs. 2017. http://robohub.org/robots-pick-up-the-challenge-of-home-care-needs/. Accessed 22 May 2018.
79. Scobi S. Unpaid carers: informal yet integral. Nuffieldtrust. Evidence for better health care. 2018. https://www.nuffieldtrust.org.uk/news-item/unpaid-carers-informal-yet-integral. Accessed 11 Dec 2018.
80. Triantafillou J, Naiditch M, Repkova K, Stiehr K, Carretero S, Emilsson T, Di Santo P et al. Informal care in the long-term care system European overview paper. 2010.
81. Statistisches Bundesamt. Pflegestatistik 2015 - Pflege im Rahmen der Pflegeversicherung Deutschlandergebnisse. 2017. https://www.destatis.de/DE/Publikationen/Thematisch/Gesundheit/Pflege/PflegeDeutschlandergebnisse5224001159004.pdf?__blob=publicationFile. Accessed 26 Apr 2018.
82. Statistisches Bundesamt. Pflegebedürftige heute und in Zukunft. 2010. https://www.destatis.de/GPStatistik/servlets/MCRFileNodeServlet/DEHeft_derivate_00012508/Demografischer_Wandel_Heft2.pdf. Accessed 04 Mar 2019.
83. Bertelsmann Stiftung. Pflegereport 2030 - Die Versorgungslücke in der Pflege wächst. 2018. https://www.bertelsmann-stiftung.de/de/unsere-projekte/pflege-vor-ort/projektthemen/pflegereport-2030/. Accessed 26 Apr 2018
84. Gerlinger T. Pflegebedarf und Pflegepotenziale in Deutschland. In: Böhme G, editor. Pflegenotstand: Der humane Rest. Bielefeld: Aisthesis Verlag; 2014. p. 15–29.
85. Geyer, J., Schulz, E. Who cares? Die Bedeutung der informellen Pflege durch Erwerbstätige in Deutschland. 2014. https://www.diw.de/documents/publikationen/73/diw_01.c.441657.de/14-14-2.pdf. Accessed 15 May 2018.

86. World Health Organization (WHO). Die Charta von Tallinn: Gesundheitssysteme für Gesundheit und Wohlstand. 2008. http://www.euro.who.int/__data/assets/pdf_file/0004/88609/E91438G.pdf. Accessed 22 May 2018.
87. Geister C. Die Belastungen der Angehörigen als Herausforderung für die professionelle Pflege. Public Health Forum. 2008. https://doi.org/10.1016/j.phf.2008.11.005.
88. Kehl K. Sozialinvestive Pflegepolitik in Deutschland. Wiesbaden: Springer Fachmedien Wiesbaden; 2016.

Modul 4

„Aber vielfach scheitert man dann an Besonderheiten“ - Pflegeberater über Gesetzesänderungen und die Herausforderungen ihrer Arbeit: Eine qualitative Untersuchung

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Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen; 150, 65–72

DOI: 10.1016/j.zefq.2020.03.008

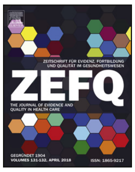
2020

Z. Evid. Fortbild. Qual. Gesundh. wesen (ZEFQ) 150–152 (2020) 65–72

Contents lists available at ScienceDirect

Z. Evid. Fortbild. Qual. Gesundh. wesen (ZEFQ)

journal homepage: http://www.elsevier.com/locate/zefq



Management der Gesundheitsversorgung / Health Care Management

„Aber vielfach scheitert man dann an Besonderheiten“ – Pflegeberater über Gesetzesänderungen und die Herausforderungen ihrer Arbeit: Eine qualitative Untersuchung

„But you often come unstuck on particularities” – Care consultants on legislation amendments and the challenges of their job: A qualitative investigation

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ARTIKEL INFO

Artikel-Historie:
Eingegangen: 3. September 2019
Revision eingegangen: 23. März 2020
Akzeptiert: 25. März 2020
Online gestellt: 17. May 2020

Schlüsselwörter:
Pflege
Berater
Pflegestärkungsgesetz
Interviews
Inhaltsanalyse

ZUSAMMENFASSUNG

Hintergrund: Um den strukturellen und finanziellen Bedürfnissen der steigenden Zahl an Pflegebedürftigen gerecht zu werden, haben seit der Einführung der Pflegeversicherung im Jahr 1995 diverse Reformen zur Weiterentwicklung des Pflegesystems beigetragen. Ziel dieser Studie ist es, eine Einschätzung der Reformansätze, Herausforderungen und Verbesserungsvorschläge aus Sicht von Pflegeberater*innen aufzuzeigen.
Methode: Grundlage der Analyse sind 14 semi-strukturierte, leitfadengestützte Einzelinterviews mit Pflegeberater*innen. Die Interviews wurden wörtlich transkribiert und nach der Methode der qualitativen Inhaltsanalyse ausgewertet.
Ergebnisse: Bei den gesetzlichen Änderungen nahmen die befragten Pflegeberater*innen spürbare positive Auswirkungen in Bezug auf den Leistungsumfang wahr, jedoch mit dem Verweis begrenzter Umsetzungsmöglichkeiten aufgrund fehlender Pflegeinfrastruktur. Herausforderungen wurden insbesondere in den häufigen Gesetzesänderungen, unklaren Zuständigkeiten und länderspezifischen Regelungen gesehen.
Diskussion und Schlussfolgerung: Insgesamt zeigten die Interviews komplexe Abhängigkeiten im deutschen Pflegesystem auf und die Notwendigkeit eines öffentlichen Diskurses zum Thema Eigenverantwortung, Gerechtigkeit und einer flächendeckenden Versorgung. Der Aufbau einer zentralen Informationsplattform wurde vorgeschlagen, um die Transparenz der Angebote auf kommunaler Ebene zu erhöhen.

ARTICLE INFO

Article History:
Received: 3 September 2019
Received in revised form: 23 March 2020
Accepted: 25 March 2020
Available online: 17 May 2020

Keywords:
Nursing care
Consultant
Long-term Care Strenghtening Act
Interviews
Content analysis

ABSTRACT

Introduction: Since the implementation of long-term care insurance in 1995, various reforms have contributed to the development of the German nursing care system in order to meet the structural and financial needs of the growing number of people in need of care. The aim of this paper is to present an assessment of care consultants on past legislation, challenges encountered during their work and suggestions to improve the current care system.
Methods: 14 semi-structured, face-to-face interviews were conducted with care consultants. All interviews were transcribed verbatim and a qualitative content analysis was performed.
Results: Care consultants perceived tangible improvements with regard to the scope of benefits as a direct result of recent legislation changes. The use of these benefits, however, is limited due to an insufficient growth of care infrastructure. Particularly frequent legislation changes, unclear responsibilities and dissimilar regulations between federal states were seen as challenges.

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https://doi.org/10.1016/j.zefq.2020.03.008
1865-9217/

Discussion and conclusion: Complex dependencies within the German nursing care system were identified and the necessity for a public discourse on themes such as self-responsibility, equity and a comprehensive (nationwide) care supply was underlined. A central information platform was proposed in order to concretely improve information about services available locally.

Einleitung

Ende 2017 lag der Anteil der pflegebedürftigen Menschen im Alter von 65 Jahren und älter bei etwa 2,8 Millionen in Deutschland [1]. Für das Jahr 2060 beläuft sich die aktuelle Prognose auf 4,5 Millionen Pflegebedürftige [2,3]. Von den oben genannten 2,8 Millionen Pflegebedürftigen wurden 73% zu Hause versorgt, entweder alleine durch Angehörige und/oder durch ambulante Pflegedienste [1]. Die meisten Älteren bevorzugen, so lange wie möglich zu Hause zu leben und versorgt zu werden, vor allem für den Erhalt ihrer Selbstständigkeit und sozialen Kontakte [4]. Angehörige, die eine entsprechende informelle Pflege übernehmen, äußern in Studien den Wunsch nach Entlastungsangeboten, professioneller Beratung und Schulung sowie einer stärkeren gesellschaftlichen Anerkennung ihrer Leistung [5]. Die häusliche Pflege wird auch von Seiten der Politik gestärkt. Im Sozialgesetzbuch (§3 SGB XI) ist der Vorrang der häuslichen Pflege fest verankert [6].

Gesetzlich ist die pflegerische Versorgung in Deutschland als gesamtgesellschaftliche Aufgabe definiert (§8 SGB XI) [7]. Die Bundesländer sind gemäß §9 SGB XI verantwortlich für die Vorhaltung einer angemessenen pflegerischen Versorgungsstruktur und können im Rahmen ihrer Kompetenzen länderspezifische Gesetze entwickeln [8]. Die Pflegekassen, als Träger der sozialen Pflegeversicherung, sind für die Sicherstellung der jeweiligen pflegerischen Versorgung verantwortlich (§12 SGB XI) [9]. Zur Stärkung der kommunalen Versorgung können Pflegestützpunkte nach §7c SGB XI eingerichtet werden, sofern die zuständige Landesbehörde dies bestimmt.

Seit der Einführung der Pflegeversicherung 1995 haben diverse Gesetzesänderungen zur Weiterentwicklung und Reformierung der sozialen Pflegeversicherung beigetragen. Das Pflegeleistungs-Ergänzungsgesetz (2002) und das Pflege-Neuausrichtungs-Gesetz (2013) haben insbesondere zur Erhöhung der Leistungen für Pflegebedürftige mit eingeschränkter Alltagskompetenz, wie zum Beispiel demenziell Erkrankte, geführt. Die drei Pflegestärkungsgesetze (PSG I, II, und III) bewirkten seit Januar 2015 unter anderem eine Umstellung der bisherigen drei Pflegestufen auf fünf Pflegegrade sowie die Einführung eines neuen Pflegebedürftigkeitsbegriffs und eines neuen Begutachtungsverfahrens [10]. Hierdurch ist die Zahl der Leistungsbezieher der sozialen und privaten Pflegeversicherung Ende 2018 auf knapp 3,9 Millionen gestiegen [11]. Im Fokus des PSG III stand die Stärkung der Rolle der Kommunen zur Ermöglichung einer bedarfszentrierten Versorgung, also einem der Nachfrage angepassten regionalen Pflegeangebot [12].

Seit Anfang 2009 hat jeder Pflegebedürftige in Deutschland einen Anspruch auf eine kostenlose Pflegeberatung durch die zuständige Pflegekasse (§7a SGB XI). Ziel dieser Pflegeberatung ist es, Pflegebedürftige und pflegende Angehörige individuell bei der Auswahl und Inanspruchnahme von bestehenden bundes- und landesspezifischen Sozialleistungen zu unterstützen, sowie weitere Unterstützungsangebote für die häusliche Pflege aufzuzeigen. Damit richtet sich die Pflegeberatung gemäß §7a SGB XI an alle Personen, die Leistungen nach dem SGB XI beziehen oder einen Antrag auf Leistungen gestellt haben [13]. Aufgabe der Pflegeberatung gemäß §7a SGB XI ist es insbesondere, den Hilfebedarf der anspruchsberechtigten Person (auf Wunsch auch in der eigenen Häuslichkeit) zu erfassen und zu analysieren und einen individuellen Versorgungsplan mit den im Einzelfall erforderlichen Sozialleistungen und gesundheitsfördernden medizinischen, pflegerischen und sozialen Hilfen zu erstellen. Weitere Aufgaben umfassen die für die Durchführung des Versorgungsplans erforderlichen Maßnahmen einschließlich deren Genehmigung durch den jeweiligen Leistungsträger einzuleiten, die Durchführung des Versorgungsplans zu überwachen und ggf. einer veränderten Bedarfslage anzupassen, bei besonders komplexen Fallgestaltungen den Hilfeprozess auszuwerten und zu dokumentieren sowie über Leistungen zur Entlastung der Pflegepersonen zu informieren [13]. Gemäß §7b SGB XI ist die Pflegekasse verpflichtet eine Pflegeberatung nach §7a SGB XI selbst innerhalb von zwei Wochen nach Antragsstellung durchzuführen oder einen Beratungsgutschein für alternative Beratungsstellen auszustellen [14]. Neben den gesetzlichen Kranken- und Pflegekassen beraten in Deutschland auch spezialisierte öffentliche und private Beratungsstellen, die knapp 450 Pflegestützpunkte, über 4.500 nicht-kommerzielle Organisationen und ein Großteil der über 14.000 ambulanten Pflegedienste [1,15–17].

In ihrer täglichen Arbeit erfahren die Pflegeberater*innen die Wünsche und Ansprüche der Pflegebedürftigen bzw. ihrer Angehörigen und unterstützen diese bei der Einforderung der durch die Gesetze und Richtlinien festgelegten Leistungen. Dieser Umstand verleiht ihnen die Möglichkeit, das aktuelle Pflegesystem inklusive der Reformansätze praxisnah zu beurteilen. Ziel dieser Arbeit ist es, diese Einschätzungen abzubilden und Herausforderungen bzw. Verbesserungsvorschläge aufzuzeigen.

Ethikvotum

Für diese Studie liegt ein positives Ethikvotum der Medizinischen Hochschule Hannover (MHH) vor (Nr. 09.05.17/La). Alle hier erhobenen Daten liegen in pseudonymisierter Form vor (mit einer Teilnehmernummer versehen). Eine schriftliche Einverständniserklärung aller Studienteilnehmer*innen wurde vorab eingeholt.

Methoden

Stichprobe und Durchführung

Im Rahmen dieser qualitativen Studie wurden von April bis September 2018 14 semi-strukturierte, leitfadengestützte Experteninterviews mit Pflegeberater*innen geführt. Die Gesamtstichprobe wurde bewusst heterogen ausgewählt nach theoretischen Vorüberlegungen hinsichtlich der Art und somit Perspektive der Berater [18]. Die Rekrutierung erfolgte primär in Niedersachsen über Pflegekassen, Pflegestützpunkte, Beratungs- und Interessenvertretungsstellen für pflegende Angehörige sowie kommerzielle Anbieter. Alle Interviews wurden von einer wissenschaftlichen Mitarbeiterin (de Jong) geführt und fanden in den jeweiligen Räumlichkeiten der Berater*innen statt.

Die Interviews wurden durch einen Leitfaden strukturiert, basierend auf einer vorab durchgeführten Literatursichtung über die Bedürfnisse pflegender Angehöriger sowie einer Literatursichtung bezüglich der Pflegeberatungslandschaft und -leistungen (Angebote) in Deutschland. Nach jedem Interview bzw. Erkenntnisgewinn wurden die Fragen erneut geprüft und teilweise angepasst. Die Themenblöcke waren: häufige thematische Anfragen von pflegenden Angehörigen bzw. die Herausforderungen für Angehörige, die häusliche Pflege zu organisieren und/oder selbst zu leisten; die Bewertung der Pflegereformen; die Arbeit der Pflegeberater*innen und Verbesserungsvorschläge für das deutsche Pflegesystem.

Datenauswertung

Alle Interviews wurden mit einem Tonbandgerät aufgezeichnet, wörtlich transkribiert und mithilfe des Verfahrens der inhaltlich strukturierten qualitativen Inhaltsanalyse nach Mayring ausgewertet [19]. Ziel dieser Art der Inhaltsanalyse ist es, bestimmte Themen aus den transkribierten Interviews herauszufiltern und mit Hilfe von Ober-bzw. Unterkategorien zu strukturieren und zusammenzufassen. Die Auswertung der Interviews erfolgte durch zwei unabhängige wissenschaftliche Mitarbeiterinnen (de Jong und Damm). Die Daten wurden mit dem Softwareprogramm MAXQDA Version 11 unabhängig voneinander kodiert und anschließend miteinander abgeglichen. Die Kategorienbildung erfolgte zunächst deduktiv anhand des Leitfadens und theoretischer Vorüberlegungen. Anschließend wurde das Kategoriensystem induktiv ergänzt und verfeinert. Jegliche Abweichungen wurden im Team diskutiert.

Ergebnisse

Von den insgesamt 14 Experteninterviews wurden drei mit Vertreter*innen von Pflegestützpunkten und weitere drei mit Vertreter*innen von Beratungszentren geführt. Diese sechs Befragten haben insgesamt gemein, dass sie sich um eine wohnortnahe Beratung in unterschiedlichen Gebieten in Niedersachsen bemühen. Weitere fünf Vertreter*innen von unterschiedlichen bundesweit tätigen Pflegekassen sowie zwei Vertreter*innen kommerzieller Anbieter wurden ebenfalls befragt. Zusätzlich wurde im Rahmen dieser Studie ein Interessenvertreter für pflegende Angehörige interviewt. Die Gruppe der Befragten bestand aus acht Frauen und sechs Männern. Das durchschnittliche Alter der Experten lag bei 52 Jahren. Alle bis auf eine Expertin hatten zusätzlich zu den beruflichen Erfahrungen auch persönliche Pflegeerfahrungen. Die durchschnittliche Interviewdauer lag bei 30 Minuten.

Das Kategoriensystem (mit Ober- und Unterkategorien) der Inhaltsanalyse ist in der folgenden Abbildung 1 dargestellt.

Kategorie 1: Häufige thematische Anfragen von pflegenden Angehörigen

Obwohl sich alle interviewten Expert*innen mit den Unterstützungsbedarfen pflegender Angehöriger beschäftigen, unterscheiden sich die thematischen Anfragen je nach Institution. Teilnehmer*innen von Pflegestützpunkten und Beratungszentren gingen, je nach Spezialisierung, spezifischer auf die Themen Entlastungsangebote, barrierefreier Wohnraum und Tagespflege ein.

Auf die Frage nach den häufigsten thematischen Anfragen von Ratsuchenden wurde vor allem auf das Thema wohnortnahe bzw. häusliche Leistungsinanspruchnahme verwiesen, insbesondere der barrierefreie Wohnraum, die Nutzung ambulanter Pflegedienste, hauswirtschaftliche Unterstützungsleistungen sowie Tagespflege. Des Weiteren nutzten die pflegenden Angehörigen die Beratungstermine auch zur Absicherung ihrer Entscheidungen.

In den Interviews mit Vertreter*innen der Pflegekassen wurde deutlich, dass ein Großteil der thematischen Anfragen innerhalb der hier geleisteten Beratung nach §7a SGB XI um die Antragsstellung, den Leistungsumfang und die Möglichkeiten der Leistungsinanspruchnahme im Rahmen der vorhandenen Pflegeinfrastruktur betrifft. Der Ablauf der Begutachtung durch den Medizinischen Dienst der Krankenkassen (MDK) wurde ebenfalls häufig in den Beratungsgesprächen erfragt.

Sofern eine Beratung durch die Pflegekasse innerhalb der ersten zwei Wochen nach einer Antragsstellung nicht möglich ist, wird die Beratung gemäß §7b SGB XI im Rahmen eines Beratungsgutscheins von externen Beratungsstellen und kommerziellen Anbietern durchgeführt. Die Aussagen der zwei Vertreter*innen kommerzieller Anbieter liegen somit thematisch nahe bei den Pflegekassen.

Der Interessenvertreter für pflegende Angehörige nannte als häufigste thematische Anfragen insbesondere den Entlastungsbetrag und die Möglichkeiten der Leistungsinanspruchnahme. Obwohl hier keine klassische / professionelle Beratung erfolgt, unterstützen die Interessenvertretungen im Rahmen von zahlreichen Informationsveranstaltungen.

Kategorie 2: Bewertungen der Pflegereformen

Alle interviewten Expert*innen wurden um eine Bewertung der vergangenen Pflegereformen sowie der aktuellen Reformvorschläge gebeten. Hier wurde vor allem auf die drei PSG eingegangen, insbesondere den Leistungsumfang und die Möglichkeiten der Leistungsinanspruchnahme, das neue Begutachtungsverfahren und gesondert den Pflegegrad 1. Im Hinblick auf aktuelle Reformvorschläge der 19. Legislaturperiode wurde das Entlastungsbudget diskutiert.

Leistungsumfang und Möglichkeiten der Leistungsinanspruchnahme

Die Einführung der PSG I, II und III strebte eine erhebliche Weiterentwicklung der Pflege in Deutschland an. Eine Ausweitung von Leistungen und mehr Individualität bei der Inanspruchnahme wurden vor allem mit der Einführung eines neuen Pflegebedürftigkeitsbegriffs und Begutachtungsverfahrens geschaffen. Insgesamt bewerten die Befragten die gesetzlichen Neuregelungen im Rahmen der PSG als positiv und nehmen spürbare Verbesserungen in Bezug auf den Leistungsumfang für die Pflegebedürftigen und pflegenden Angehörigen wahr. Unwissenheit bezüglich Art und Umfang der Leistungen sei jedoch eine große Herausforderung. Leistungen würden häufig zu spät oder gar nicht in Anspruch genommen.

> *„Also ich glaube, dass das gut ist, dieses Pflegestärkungsgesetz, weil es einfach wirklich wie es auch sagt die Angehörigen stärkt, die pflegenden Angehörigen stärkt in der häuslichen Versorgung. Das finde ich sehr gut. Allerdings hakt es natürlich auch da immer, wenn keiner weiß, was es denn so gibt und keiner gehört hat, dass es - was weiß ich - Tagespflege gibt. Wir hatten eine Angehörige, die sagt: „Hätte ich das vorher erfahren. Wir haben die Mutter - ich glaube ein paar Monate - betreut, dann ist sie verstorben". Und die Tochter war tot unglücklich, weil wir hätten das noch lange auffangen können, hätte sie es eher gewusst." (T18, Beratungszentrum)*

Problematisch sei auch die fehlende strukturelle Umsetzung der Neuerungen. Die tatsächlichen anerkannten Leistungsangebote entsprächen bislang noch nicht der Nachfrage und so gäbe es Gebiete, in denen eine Nutzung der Betreuungs-und Entlastungsleistungen nicht möglich sein.

> *„Ja. Ich finde, dass mehr Menschen Leistungen in Anspruch nehmen können. [. . .] Auf der anderen Seite, auf der Seite der Dienste, hat es nicht so große Auswirkungen gehabt. Die Damen, die gerade vorher zur Beratung da waren, die wohnen in einem Bereich wo es keine Betreuungs- und Entlastungsleistungen gibt. Also diese Strukturen sind noch nicht gewachsen. Das liegt nicht am Pflegestärkungsgesetz, sondern an den Richtlinien zur Anerkennung dieser Angebote." (T07, Pflegestützpunkt)*

Aufgrund von wohnortabhängigen Pflegeinfrastrukturen ist es einigen Pflegebedürftigen nicht möglich, die staatlichen

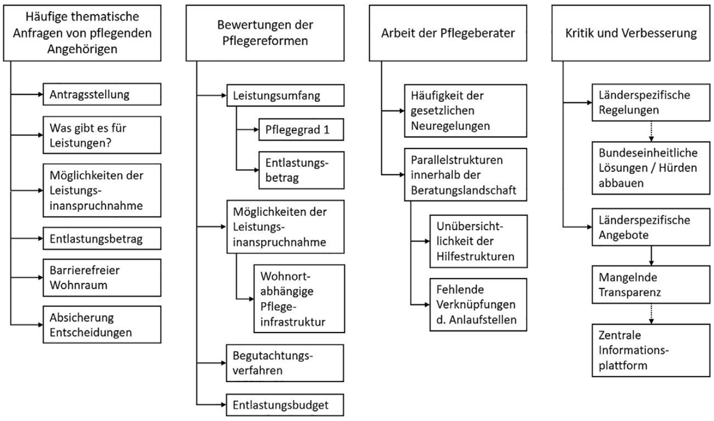

Abbildung 1. Kategoriensystem der qualitativen Inhaltsanalyse.

Leistungen der Pflegeversicherung auszugeben. Länderspezifische und regionale Unterschiede in den Möglichkeiten der Leistungsinanspruchnahme wurden an dieser Stelle als ungerecht hervorgehoben.

> *„Aber vielfach scheitert man dann an Besonderheiten. Nehmen wir jetzt diesen Entlastungsbetrag: Der steht allen Versicherten zur Verfügung. Ich habe aber Regionen, wo nichts angeboten wird. So, und einige Länder kümmern sich auch gar nicht so darum, also Bundesländer. So, also kann der Kunde dieses Geld nie ausgeben. [. . .].“ (T21, kommerzieller Anbieter)*

Pflegegrad 1

Der Leistungsumfang für Pflegegrad 1 wurde im Zusammenhang mit den PSG ebenfalls thematisiert. Bei einer Einstufung in Pflegegrad 1 besteht das Recht auf einen Betreuungs- und Entlastungsbetrag in Höhe von 125€, Pflegehilfsmittel zum Verbrauch von bis zu 40€ monatlich und Maßnahmen zur Verbesserung des Wohnumfeldes in Höhe von bis zu 4.000€ (§28a Leistungen bei Pflegegrad 1) [20]. Da es somit bei Pflegegrad 1 nur abrufbare Leistungen gibt, erhöhe dies den Beratungsbedarf, um frühzeitig Missverständnisse und Beschwerden auszuräumen.

Der Betreuungs- und Entlastungsbetrag in Höhe von 125€ dient der Förderung der Selbstständigkeit des Pflegebedürftigen im Alltag und kann einheitlich von allen Pflegegraden für unterschiedliche Leistungen von anerkannten Anbietern abgerufen werden. Verglichen mit dem alten System der Pflegestufen, in dem je nach Bedarf entweder ein Grundbetrag von 104€ oder ein erhöhter Betrag von 208€ gewährt wurde, könne der einheitliche Entlastungsbetrag nun zu Einschränkungen führen [21]. Hier wurde von einer Beraterin auf eine mögliche Fehldarstellung bzgl. des Umfangs der Leistung verwiesen. Insbesondere Pflegebedürftige, eingestuft in Pflegegrad 1, hätten häufig Schwierigkeiten einen ambulanten Pflegedienst zu finden und den Entlastungsbetrag von 125€ auszugeben.

> *„Also gut, es geht jetzt vielleicht ein bisschen in die Tiefe, aber es ist zum Beispiel so, dass diese Betreuungsleistungen früher so waren, dass demenziell erkrankte Menschen diese 104 Euro oder 208 Euro bekommen haben, wenn sie eine Demenz hatten. Mit diesem Geld konnte man verschiede Betreuungsleistungen, wie Tagespflege oder Betreuungsgruppen, in Anspruch nehmen. Jetzt ist es so, dass alle einen Einheitsbetrag von 125 Euro haben. Das heißt, da ist eine große Differenz zu 208 Euro.“ (T18, Beratungszentrum)*

Obwohl es nun im Bereich der Betreuungs-und Entlastungsleistungen zu Einschränkungen kommen kann, müssen diese jedoch mit der Ausweitung des gesamten Leistungsumfangs in Relation gebracht werden.

Das neue Begutachtungsverfahren

Zur Beurteilung der Pflegebedürftigkeit wurde im Rahmen des PSG II ein neues Begutachtungsverfahren eingeführt. Verglichen mit dem alten System der Pflegestufen, in dem eine Mindestpflegedauer von 90 Minuten pro Tag als Voraussetzung für das Erhalten einer Pflegestufe bestand, wird seit 2017 mit Hilfe von sechs Modulen (Lebensbereiche) der jeweilige Grad der Pflegebedürftigkeit ermittelt. Jedes der sechs Module besteht aus einzelnen Kriterien, für die Punktzahlen vergeben werden. Je höher der Summenwert des jeweiligen Moduls ist, desto höher ist auch die Beeinträchtigung der Selbstständigkeit. Für die Zuordnung der Pflegegrade werden die Summenwerte der Module als gewichtete Gesamtpunktzahl zusammengefasst [22]. Insgesamt bewerten die Berater*innen das neue Verfahren als gerechter, nachvollziehbarer und differenzierter.

Jedoch wurde die Gewichtung der Module zur Beurteilung einer Pflegebedürftigkeit mehrfach thematisiert. Das zweite PSG strebte explizit eine stärkere Berücksichtigung geistiger und psychischer Beeinträchtigungen, bspw. Demenz, an. Somit ist bei der Begutachtung vor allem auch die Selbstständigkeit und Bewältigung des Alltags jedes einzelnen Menschen von Bedeutung. Laut der Berater*innen sei dies gelungen, jedoch zu Lasten von Personen mit körperlicher Einschränkung. Diese hätten Schwierigkeiten in einen höheren Pflegegrad eingestuft zu werden. Langfristig bestünde bei der Gewichtung der sechs Module Nachbesserungsbedarf, damit Personen mit körperlichen Einschränkungen künftig nicht schlechter gestellt würden.

> *„Im Moment ist die Gewichtung der psychischen und kognitiven Bereiche einfach sehr, sehr hoch. Körperlich erkrankte Menschen haben aber eher das Problem meist mit der Mobilität und die wird im Moment sehr gering bewertet. [. . .] Zugunsten anderer, die auch wichtig sind, wo es tatsächlich eine deutliche Verbesserung gibt, gerade für psychisch erkrankte Menschen auch. Hier nochmal eine bessere Anerkennung zu kriegen, die vorher gar nicht möglich war. Also das ist grundsätzlich schon richtig, vielleicht müsste man langfristig über die Gewichtung einfach nochmal nachdenken.“ (T08, Pflegestützpunkt)*

Bewertung des Entlastungsbudgets

Im aktuellen Koalitionsvertrag der Bundesregierung wird u. a. ein jährliches Entlastungsbudget vorgeschlagen, welches die Kurzzeit- und Verhinderungs- sowie die Tages- und Nachtpflege zusammenfasst, um eine flexiblere Inanspruchnahme zu gewähren und somit zur Entbürokratisierung beizutragen [22]. Das Entlastungsbudget bzw. eine generelle Budgetierung von Leistungen wurde ebenfalls von den Interviewten thematisiert. Die Interessenvertretung für pflegende Angehörige sieht diesen Ansatz als sehr positiv, da dieser zu einer erhöhten Selbstständigkeit und Flexibilität in der Inanspruchnahme von Leistungen führe.

> *„[...] das Stichwort „mehr Selbständigkeit in der Entscheidung der Art der Entlastung, die ich in Anspruch nehmen möchte". Das ist wirklich und echt das Thema, was wir auch immer wieder als Spiegelbild von unseren Angehörigen hören. Ganz, ganz klar." (T31, Interessenvertreter)*

Ein Gesprächspartner verwies ebenfalls auf die Notwendigkeit mehr Flexibilität und Kreativität zuzulassen, um die gesetzlichen Möglichkeiten für den jeweiligen Pflegebedürftigen bestmöglich auszuschöpfen. So sollte es möglich sein, die vorhandenen Mittel bspw. für die Entlastung der Pflegenden bedarfsangepasst und unter Berücksichtigung des Angebots einzusetzen, indem ein gewisser Erstattungsspielraum zugelassen würde.

> *„Und da gibt es sicherlich auch Möglichkeiten, Varianten, wo man vielleicht auch Alternativen zulassen sollte. Oder aber auch mehr Variationsmöglichkeiten, mehr Kreativität, die Kassen auch nutzen könnten, um das Gesetz besser umsetzen zu können." (T21, kommerzieller Anbieter)*

Dagegen spricht sich ein Kassenvertreter aus, begründet durch die fehlenden, bzw. nur durch hohen bürokratischen Aufwand erreichbaren Möglichkeiten der Qualitätssicherung, welche wiederum einer Entbürokratisierung entgegenstünden.

> *„Budgets entziehen sich immer einer Qualitätssicherung. Und ansonsten müsste ich wieder den nächsten Bürokratie, Bürokratismus aufbauen. Deswegen sind wir zum Beispiel auch gegen diese Budgets und auch diese Verbindung zwischen Verhinderungspflege, Kurzzeitpflege UND Tages-Nacht-Pflege, das ist für uns ein ganz klares No-Go." (T30, Pflegekasse)*

Kategorie 3: Arbeit der Pflegeberater

Bei der Frage nach der Arbeit der Pflegeberater*innen wurden einige Herausforderungen im Rahmen der Beratungsgespräche identifiziert. Vor allem die Häufigkeit der gesetzlichen Reformen sowie die Vielzahl an Akteure innerhalb der Beratungslandschaft würden die Durchführung einer bereichsübergreifenden Beratung erschweren.

Häufigkeit der gesetzlichen Neuregelungen

Obwohl die vergangenen Gesetzesänderungen als wichtig dargestellt wurden, um das Pflegesystem zu verbessern, führten auch die häufigen Veränderungen beim Leistungsumfang zu Unsicherheiten auf Seiten der Berater, Pflegebedürftigen und pflegenden Angehörigen.

> *„Das Problem, das ich sehe, eigentlich ist, dass [...] fast jährlich neue Regelungen in der Pflegeversicherung kommen. [...] Und diese ständigen Veränderungen, die bringen natürlich in diese ganze Sache auch eine ziemlich große Unsicherheit für alle mithinein. Und darum ist der Beratungsbedarf auch nach wie vor relativ hoch, weil keiner, der einmal sich damit beschäftigt hat, eigentlich nachkommt in den ganzen Veränderungen, die es da gegeben hat." (T25, Pflegekasse)*

Aufgrund der ständigen Veränderungen und daraus resultierenden Unsicherheiten, würde das Potential der Leistungen häufig noch nicht genutzt wie intendiert.

> *„Ich meine, das ist ja so ein bisschen die Kritik, die teilweise in der Öffentlichkeit oder bei der Regierung auch ist, dass die Möglichkeiten, die im Moment da sind, eigentlich noch gar nicht so genutzt werden, wie sie eigentlich genutzt werden könnten." (T25, Pflegekasse)*

Zwar wurde von den Gesprächsteilnehmer*innen auf weiteren Reformbedarf im Bereich der Pflege verwiesen, kurzfristig jedoch auch eine Phase der Umsetzung und Stabilisierung der neu geschaffenen Regelungen angeregt.

> *„[...] Deswegen Reformen in dem Sinne...Ich würde mal sagen stabilisieren [...]." (T24, Pflegekasse)*

Parallelstrukturen innerhalb der Beratungslandschaft

Die heterogene Beratungslandschaft mit ihrer Vielzahl an Beratungsstellen sehen die Befragten als Herausforderung an. Durch die politische Entscheidung Pflegestützpunkte einzurichten, um eine wohnortnahe Beratung und Versorgung zu ermöglichen (§7c SGB XI), wurde laut Pflegekassenvertreter*innen Unsicherheit infolge von Parallelstrukturen geschaffen.

> *„Man müsste es vielmehr konzentrieren und dadurch, dass Krankenkassen überall auch ihre Beratungsbereiche haben, ist auch diese politische Entscheidung: „Ich mache Pflegestützpunkte", eine ganz interessante, die so ein bisschen Parallelstrukturen auch bewirkt hat." (T24, Pflegekasse)*

Die Beratung auf bundes-, länder- sowie kommunaler Ebene, durch alle beteiligten Institutionen, führe zu Unsicherheit und einer Unübersichtlichkeit von Zuständigkeiten. Eine Kassenvertreterin verwies hier explizit auf das Problem der unterschiedlichen Finanzierungsquellen, wodurch eine notwendige Konzentration nicht möglich sei. Die Parallelstrukturen erhöhten den Informationsaufwand sowohl für Berater*innen als auch für die Ratsuchenden.

> *„Früher hatte man eine Anlaufstelle. Und diese Anlaufstelle hat einem mitgeteilt: So und so und so ist das. Und dann wusste man, wo man dran war. Heute hat man viele Anlaufstellen und die widersprechen sich teilweise, [...]. Es liegt aber daran, dass es unterschiedliche Finanzierungsquellen gibt. Wenn man diese Finanzierung vereinheitlichen würde, dann wäre die Sache relativ klar." (T24, Pflegekasse)*

Deutlich wird diese Komplexität noch einmal mit dem Verweis auf die Individualität einer Pflegebedürftigkeit und den spezifischen Antragsstellungen auf ganz unterschiedliche Fördermittel.

> *„Genau. Und das ist schon komplex. Das merken wir selber, dass wir auch da sitzen und sagen: Okay, es gibt so viele unterschiedliche Abteilungen bei den Sozialämtern oder eine Eingliederungshilfe, Unterstützung über Schwerbehinderung." (T20, Pflegekasse)*

Eine Kassenvertreterin bemängelte die fehlenden Verknüpfungen der unterschiedlichen Anlaufstellen, die es erschwerten, eine gesamtheitliche Beratung durchzuführen und für jeden Versicherten alle möglichen Angebote aufzuzeigen.

Kategorie 4: Kritik und Verbesserung

Auf die Frage nach Verbesserungsvorschlägen für das jetzige Pflegesystem wurden nur selten konkrete Vorschläge von den Expert*innen genannt. Zwei Kritikpunkte inklusive Lösungsansätze konnten jedoch identifiziert werden. Zum einen wurde eine wohnortabhängige Ungleichbehandlung durch länderspezifische Regelungen und Angebote als ungerecht bemängelt. Diese Kritik bezieht sich auf Unterschiede in den Geldleistungen, Versorgungsregelungen und Infrastrukturen. Zum anderen wurde auf eine mangelnde Transparenz der Angebotsstrukturen verwiesen.

Wohnortabhängige Ungleichbehandlung durch länderspezifische Regelungen und Angebote

Auf Länderebene besteht das Recht die bundeseinheitlichen Leistungen der Pflegeversicherung durch zusätzliche Geldleistungen zu ergänzen. Daraus resultierende Unterschiede in den gewährten finanziellen Hilfen wurden kritisch beurteilt. Als konkretes Beispiel wurde hier auf das Landespflegegeld in Bayern verwiesen. Bayern ist das erste Bundesland, in dem seit 2018 jährlich 1.000€ zusätzlich zu den regulären Pflegeleistungen gezahlt wird für Pflegebedürftige ab Pflegegrad 2 mit einem Hauptwohnsitz im Freistaat [23].

> *„[. . .] die staatlichen Leistungen, ob die bundesweit sind oder ob die von den Ländern entschieden werden können, sind immer Glückssache. Je nachdem wie das Bundesland gerade so aufgestellt ist und die Wirtschaft funktioniert.“ (T24, Pflegekasse)*

Neben den landesspezifischen Geldleistungen wurden auch landesspezifische Versorgungsregelungen angesprochen. Ein Beispiel ist die Anerkennung von Angeboten zur Alltagsunterstützung im Rahmen der Nachbarschaftshilfe, die je nach Bundesland unterschiedlich möglich ist. Einige Berater*innen kritisierten diese Ungleichbehandlung bezüglich gesetzlicher Möglichkeiten der Leistungsinanspruchnahme.

> *„Bleibe ich nochmal beim Entlastungsbetrag: Zum Beispiel es gibt in Nordrheinwestfalen seit über 10 Jahren gibt es da einen Erlass-, einen Ministererlass, dass auch im Rahmen der Nachbarschaftshilfe. Also dass der Nachbar erbringen kann, wenn er zum Beispiel nachweist, dass er an einem Pflegekurs teilgenommen hat. Das hab ich in anderen Bundesländern nicht. Und das ist eine Ungleichbehandlung innerhalb des Systems [. . .]. Und das kann eigentlich vom Gesetzgeber nicht gewollt sein.“ (T30, Pflegekasse).*

Zur Reduktion der Versorgungsunterschiede zwischen den Ländern forderten insbesondere Vertreter*innen bundesweit tätiger Kassen bundeseinheitliche Lösungen, um gleiche Voraussetzungen für die Inanspruchnahme von Leistungen zu schaffen.

> *„Ja, [. . .] also mein Gedankengang ist auch noch, dass es wenn grundsätzlich Reformen auch angestrebt werden, das auf eine bundesweite Lösung halt abzielen. Im Moment haben wir sehr viele, [. . .] sehr viele Auswirkungen bei uns in Bundesländern, wo die Länder da Bestrebungen haben eben Dinge zu tun. [. . .] Ja, und das macht es natürlich als bundesweite Kasse auch sehr, sehr schwer im gesamten Bezirk da zu agieren.“ (T29, Pflegekasse).*

Mangelnde Transparenz

Landesspezifische Angebote seinen zudem nicht transparent für den Ratsuchenden sichtbar. Auch auf der Angebotsseite erschwere die zurzeit stark wohnortsabhängige Versorgungslage die Beratung und Unterstützung.

> *„Die Transparenz fehlt einfach, weil es auf Landesebene zu viele unterschiedliche Regelungen gibt.“ (T21, kommerzieller Anbieter)*

Als konkreter Verbesserungsvorschlag für die fehlende Angebotstransparenz wurde von einer Kassenvertreterin die Einrichtung einer zentralen Plattform vorgeschlagen, mit dem Ziel, Informationen zu bündeln. Diese sollte als Anlaufstelle für alle Bundesländer fungieren und von einer neutralen Instanz organisiert und aktualisiert werden.

> *„Es müsste eine zentrale Datenbank geben. Da kann der Versicherte, ich bin jetzt kreativ mit Ihnen zusammen, da könnte der Versicherte seine Postleitzahl eingeben und das ist eine Plattform, die muss staatlich finanziert sein. Und nicht von irgendeinem Privaten, der nebenbei seine ganzen schönen Produkte verkaufen möchte. Sondern wirklich eine neutrale Instanz, die vom Bund, - von mir aus - organsiert wird, wo man dann nach Postleitzahl eingeben kann, das sind meine ganzen Pflegedienste. Das sind meine ganzen Pflegekassen, die ich im Umfeld habe. Das sind meine staatlichen Ansprechpartner für Schwerbehindertenausweis, für keine Ahnung was.“ (T24, Pflegekasse)*

Diskussion

Vor dem Hintergrund der steigenden Zahl an Pflegebedürftigen haben seit der Einführung der Pflegeversicherung im Jahr 1995 unterschiedliche Gesetzesänderungen zur Weiterentwicklung des deutschen Pflegesystems beigetragen. Aufgrund der Aktualität des Themas in den Medien, der zentralen Pflegereformen seit Januar 2015 (PSG I, II, und III) sowie der aktuellen Reformvorschläge dieser Legislaturperiode, hatte diese qualitative Studie zum Ziel, eine Einschätzung der Auswirkungen vergangener Reformen, Herausforderungen im Rahmen der Pflegeberatung und Verbesserungsvorschläge bzw. den Bedarf an zukünftigen Reformen aus Sicht von Pflegeberater*innen abzubilden. Insgesamt zeigten die Interviews einen Ausschnitt der komplexen Abhängigkeiten im deutschen Pflegesystem, welche folglich auch durch inhaltliche Überschneidungen der hier analysierten Kategorien deutlich wurden.

Zur Anpassung des Pflegesystems an die aktuellen und künftigen Herausforderungen hoben die befragten Expert*innen die hohe Bedeutung von Gesetzesänderungen hervor. Vor allem die Einführung eines neuen Pflegebedürftigkeitsbegriffs und Begutachtungsverfahrens im Rahmen der PSG hätten zu einer spürbaren Ausweitung des Leistungsumfangs und mehr Individualität bei der Leistungsinanspruchnahme geführt. Das neue Begutachtungsverfahren, mit einem Fokus auf der Selbstständigkeit und Bewältigung des Alltags der pflegebedürftigen Person, wird als gerechter empfunden. Jedoch wurde auf eine notwendige Nachjustierung der Gewichtung von physischen und psychischen/kognitiven Einschränkungen innerhalb des Begutachtungsverfahrens von Pflegebedürftigkeit verwiesen, um eine Schlechterstellung körperlich eingeschränkter Personen zu vermeiden. Da eine solche Nachjustierung erneut zu Benachteiligungen Anderer führen kann, erfordert die Anpassung der Gewichtungen ein umsichtiges Vorgehen unter Einbezug interdisziplinärer Einschätzungen. Zwar sehen die Expert*innen auch weiteren Reformbedarf, betonten jedoch ebenfalls die Notwendigkeit einer Phase der Stabilisierung. Neuregelungen müssten zunächst ganzheitlich umgesetzt werden, um ihre Güte bewerten und weiteren Reformbedarf erfahrungsbasiert formulieren zu können. Die Reformunübersichtlichkeit aufgrund der Häufigkeit gesetzlicher Neuregelungen wurde als Herausforderung für die Beratung gesehen.

Der aktuelle Koalitionsvertrag, welcher im Zuge der 19. Legislaturperiode zu staatlichem Handeln führen soll [24], greift die Weiterentwicklung der Pflege erneut auf. In der sogenannten „Pflegeoffensive“ der Regierung wird vor allem eine Verbesserung der Ausbildung, Arbeitsbedingungen und Bezahlung der Pflegekräfte angestrebt mit dem Ziel der Erhöhung des Pflegeangebots. Um pflegende Angehörige zu unterstützen wird ein Entlastungsbudget vorgeschlagen, zur Bündelung von Kurzzeit- und Verhinderungspflege sowie Tages-und Nachtpflege [20]. In den geführten Interviews zeigte sich eine kontroverse Betrachtung einer Budgetierung dieser Leistungen. Während Interessenvertreter von pflegenden Angehörigen dies als wichtigen Schritt zur Entbürokratisierung und flexiblen Inanspruchnahme von Leistungen einstuften, verwiesen Kassenvertreter*innen auf die Probleme der Qualitätskontrolle durch Budgets. Auf der einen Seite könnte eine Budgetierung die Flexibilität erhöhen und insbesondere in Gebieten mit geringerem Angebot die fehlende Infrastruktur ein Stück weit ausgleichen bzw. auffangen. Auf der anderen Seite könnte dies zu fehlenden Kontrollmöglichkeiten der Qualität und zweifelhaften Angeboten auf dem Pflegemarkt führen. Diesbezügliche Abwägungen müssen daher die Unterschiede der jeweils vorhandenen (kommunalen) Versorgungsstrukturen und Bedürfnisse berücksichtigen.

Eine Ungleichbehandlung im System wurde von Vertreter*innen der Pflegekassen und kommerziellen Anbietern bemängelt. Dieser Kritikpunkt bezieht sich auf länderspezifische Regelungen und Infrastrukturen. Hierbei sollte die gesetzliche Regelung jedoch sehr deutlich von der Versorgung differenziert werden. Ziel der Pflegeberatung ist es zunächst, innerhalb der gesetzlichen Regelungen einen bestmöglichen und individuellen Versorgungsplan zu erstellen. In den Interviews wurde jedoch sehr deutlich die Überforderung der Berater*innen betont, eine spezifische, bereichsübergreifende Beratung zu leisten. Grund dafür seien u.a. länderspezifische Gesetzesregelungen [8]. Je nach Bundesland ergäben sich unterschiedliche gesetzliche und strukturelle Möglichkeiten, Leistungen in Anspruch zu nehmen (bspw. Nachbarschaftshilfe in NRW). Auch das Landespflegegeld in Bayern wurde hier angeführt, als Beispiel landespezifischer Geldleistungen. Da eine Gewährung dieser unterschiedlichen Leistungen „Glückssache“ sei, u.a. abhängig von der wirtschaftlichen Lage des jeweiligen Bundeslandes, wurden diese Spezifika als ungerecht bewertet. Einige Vertreter*innen der Pflegekassen haben in diesem Zuge die Notwendigkeit bundeseinheitlicher Regelungen für die Inanspruchnahme von Leistungen herausgestellt. Diese würden ebenfalls den Beratungsaufwand für die bundesweit tätigen Pflegekassen reduzieren und die Ungerechtigkeit infolge länderspezifischer Regelungen verringern. Jedoch stehen bundeseinheitliche Lösungen wieder dem Wunsch nach mehr Flexibilität und einer bedarfsbezogenen Inanspruchnahme der Leistungen entgegen und erfordern deshalb eine gründliche Abwägung. Neben den länderspezifischen Regelungen wurden auch die länderspezifischen Angebote als problematisch dargestellt. Die Befragten sprachen die zurzeit erheblichen Unterschiede in den Angebotsstrukturen der verschiedenen Bundesländer und Kommunen an, mit denen sie ebenfalls umgehen müssten. Die Unterversorgung in einigen Gebieten führe dazu, dass Pflegebedürftige ihre Pflegesachleistungen nicht ausgeben könnten. Verwiesen wurde jedoch auch auf die Eigenverantwortung der Individuen, bei der Wahl des Wohnraums infrastrukturelle Gegebenheiten einzubeziehen und keine gleichwertigen Verhältnisse der Regionen zu erwarten. Im öffentlichen Diskurs gilt es abzuwägen, wie hoch die Bedeutung eines flächendeckenden umfänglichen Pflegeangebots für die Gesellschaft ist bzw. in welchem Maße Flexibilität von den zu Pflegenden und ihren Angehörigen verlangt werden kann.

Eine weitere Herausforderung besteht laut Kassenvertreter*innen in der mangelnden Bereitstellung und Verfügbarkeit von Informationen über die Angebote in den Regionen. Dies könnte ein Grund dafür sein, dass laut der Befragten sowie dem aktuellen BARMER Pflegereport das Unterstützungspotenzial noch nicht ausgereizt und teils nicht genutzt wird [25,26]. Zur Verbesserung wird deshalb eine zentrale Informationsplattform vorgeschlagen. Dort könnten alle verfügbaren Angebote auf kommunaler, Landes- und Bundesebene gebündelt werden und online für jeden verfügbar sein. Die Zuständigkeit für diese Informationsplattform müsste eine neutrale Instanz übernehmen. Das Zentrum für Qualität in der Pflege (ZQP) setzt an diesem Punkt an und hat bereits die Datenbank „Beratung zur Pflege“ aufgebaut, welche regelmäßig aktualisiert Beratungsstellen im gesamten Bundesgebiet ausweist [27]. Die Vorstellung der Interviewten geht jedoch über dieses Angebot hinaus. Gewünscht wird eine Plattform, die jegliche Informationen bzgl. z. B. ambulanter Pflegediensten, Entlastungsmöglichkeiten für Angehörige, Selbsthilfegruppen oder relevante Behörden (z. B. für die Beantragung eines Schwerbehindertenausweises) bündelt und für jede Postleitzahl einen Überblick über Angebote und Zuständigkeiten schafft [28].

Für die Arbeit der Pflegeberater*innen wurden von Seiten der bundesweit tätigen Pflegekassen ebenfalls die unklaren Zuständigkeiten (inkl. Parallelstrukturen) als herausfordernd dargestellt, begründet durch unterschiedliche Finanzierungsquellen bzw. die Einrichtung der Pflegestützpunkte. Die Idee einer unabhängigen und umfassenden, kommunal tätigen und flächendeckenden Beratung der Pflegestützpunkte kann Informationsasymmetrien abbauen, steht jedoch auch dem Konzept der Beratung „aus einer Hand“ durch einen Ansprechpartner entgegen. Zu prüfen ist, inwiefern sich dieser Kurs zukünftig bewehrt. Die Vertreter*innen der Pflegestützpunkte haben in diesem Zusammenhang vor allem die Unübersichtlichkeit der Hilfestrukturen und Zuständigkeiten (bspw. Abteilungen der Sozialämter) angesprochen.

Stärken und Limitationen der Studie

Pflegeberater*innen sind die ersten und direkten Ansprechpartner für Pflegebedürftige und ihre Angehörigen. Von ihnen erfahren sie Wünsche, Ansprüche und Herausforderungen. Unterstützungsmöglichkeiten und Leistungsansprüche, die von den Berater*innen aufgezeigt werden, sind durch die bundes- und länderspezifischen Gesetzgebungen festgelegt. Entsprechend können die im Rahmen dieser Studie geführten Einzelinterviews mit Pflegeberater*innen Hinweise darauf geben, inwiefern die gesetzlichen Neuregelungen der letzten Jahre den Problemen im Pflegebereich begegnet sind und welche Herausforderungen aktuell bestehen. Aufgrund der fehlenden Repräsentativität dieser qualitativen Studie, können die Ergebnisse jedoch nicht verallgemeinert werden, zeigen aber Ansatzpunkte zur kritischen Überprüfung des Pflegesystems. Eine weitere Limitation besteht in der Auswahl der Forschungsperspektive mit einem alleinigen Fokus auf Pflegeberater*innen. Eine Gegenüberstellung der Aussagen von Pflegeberatern mit denen der Beratungssuchenden sollte in künftigen Forschungsarbeiten angestrebt werden.

Fazit

Insgesamt zeigten die Interviews einen Ausschnitt der komplexen Abhängigkeiten im deutschen Pflegesystem. Die in dieser Studie befragte - relativ homogene - Expertengruppe äußerte sowohl den Wunsch nach Flexibilität, um mit den vorhandenen finanziellen Mitteln gerade auch in unterversorgten Regionen Leistungen zu ermöglichen, verwies aber auch auf die Herausforderungen eines bundesweiten „Flickenteppichs“ landesspezifischer Regelungen. In diesem Zusammenhang wurden auch das Problem der Qualitätssicherung im Rahmen flexibilitätssteigernder Pflegebudgets sowie diverse Fragestellungen nach Gerechtigkeit, Gleichbehandlung und Eigenverantwortung angesprochen.

Förderung

Dieses Projekt wird gefördert vom Bundesministerium für Bildung und Forschung (BMBF), Förderkennzeichen 01EH1603A.

Interessenkonflikte

Die Autoren geben an, dass kein Interessenkonflikt besteht.

Die Studie wurde von der Ethikkommission der Medizinischen Hochschule Hannover (MHH) genehmigt (Nr. 09.05.17/La).

Autorenschaft

Lea de Jong: Konzeptualisierung, Methodik, Formale Analyse, Ermittlung, Manuskripterstellung, Manuskriptrevision. Jona Theodor Stahmeyer: Konzeptualisierung, Manuskripterstellung, Manuskriptrevision. Sveja Eberhard: Konzeptualisierung, Manuskripterstellung, Manuskriptrevision. Jan Zeidler: Konzeptualisierung, Manuskripterstellung, Manuskriptrevision. Kathrin Damm: Konzeptualisierung, Methodik, Formale Analyse, Manuskripterstellung, Manuskriptrevision, Supervision.

References

[1] Statistisches Bundesamt, Pflegestatistik: Pflege im Rahmen der Pflegeversicherung Ländervergleich - Pflegebedürftige, 2018.

[2] Bundesinstitut für Bevölkerungsforschung, Anzahl der Pflegebedürftigen steigt vor allem bei den Hochbetagten: Pflegebedürftige nach Altersgruppen, 1990-2060. https://www.demografie-portal.de/SharedDocs/Informieren/DE/ZahlenFakten/Pflegebeduerftige_Anzahl.html (accessed 17 May 2019).

[3] Rothgang H, Müller R, Runte R, Unger R, Kalwitzki T. BARMER Pflegereport 2015: Schriftenreihe zur Gesundheitsanalyse 1st ed. Asgard Verlagsservice Siegburg 2015.

[4] Heuchert M, König H-H, Lehnert T. Die Rolle von Präferenzen für Langzeitpflege in der sozialen Pflegeversicherung - Ergebnisse von Experteninterviews. Gesundheitswesen 2017;79:1052–7, http://dx.doi.org/10.1055/s-0041-111839.

[5] Plöthner M, Schmidt K, de Jong L, Zeidler J, Damm K. Needs and preferences of informal caregivers regarding outpatient care for the elderly: a systematic literature review. BMC Geriatrics 2019;19(1):82, http://dx.doi.org/10.1186/s12877-019-1068-4.

[6] Bundesministerium der Justiz und für Verbraucherschutz, Sozialgesetzbuch (SGB) - Elftes Buch (XI) - Soziale Pflegeversicherung: § 3 Vorrang der häuslichen Pflege.

[7] Bundesministerium der Justiz und für Verbraucherschutz, Sozialgesetzbuch (SGB) - Elftes Buch (XI) - Soziale Pflegeversicherung: § 8 SGB XI Gemeinsame Verantwortung.

[8] Bundesministerium der Justiz und für Verbraucherschutz, Sozialgesetzbuch (SGB) - Elftes Buch (XI) - Soziale Pflegeversicherung: § 9 Aufgaben der Länder.

[9] Bundesministerium der Justiz und für Verbraucherschutz, Sozialgesetzbuch (SGB) - Elftes Buch (XI) - Soziale Pflegeversicherung: § 12 Aufgaben der Pflegekassen.

[10] Bundesministerium für Gesundheit, Sechster Bericht der Bundesregierung über die Entwicklung der Pflegeversicherung und den Stand der pflegerischen Versorgung in der Bundesrepublik Deutschland. https://www.bundesgesundheitsministerium.de/fileadmin/Dateien/5_Publikationen/Pflege/Berichte/6.Pflegebericht.pdf (accessed 23 August 2018).

[11] Bundesministerium für Gesundheit, Zahlen und Fakten zur Pflegeversicherung, 2019. https://www.bundesgesundheitsministerium.de/fileadmin/Dateien/Downloads/Statistiken/Pflegeversicherung/Zahlen_und_Fakten/Zahlen-u-Fakten-zur-Pflegeversicherung_2019.pdf.(accessed 17 May 2019).

[12] Deutscher Bundestag, Drittes Gesetz zur Stärkung der pflegerischen Versorgung und zur Änderung weiterer Vorschriften (Drittes Pflegestärkungsgesetz - PSG III), 2016.

[13] Bundesministerium der Justiz und für Verbraucherschutz, Sozialgesetzbuch (SGB) - Elftes Buch (XI) - Soziale Pflegeversicherung: § 7a Pflegeberatung.

[14] Bundesministerium der Justiz und für Verbraucherschutz, Sozialgesetzbuch (SGB) - Elftes Buch (XI) - Soziale Pflegeversicherung: § 7b Beratungsgutscheine.

[15] Braeseke G, Pflug C, Beikirch E. Studie zur Erfüllung der Koordinierungs- und Vernetzungsaufgaben sowie der Qualitätssicherung in Pflegestützpunkten: Abschlussbericht für das Bundesministerium für Gesundheit. Berlin 2018.

[16] Spitzenverband GKV. Die gesetzlichen Krankenkassen 2019, https://www.gkv-spitzenverband.de/krankenversicherung/kv_grundprinzipien/alle_gesetzlichen_krankenkassen/alle_gesetzlichen_krankenkassen.jsp (accessed 17 May 2019).

[17] Dohmeyer H. Infografik: Pflegeberatung in Deutschland 2017: 8.11. Tag der Pflegeberatung 2017, https://tag-der-pflegeberatung.de/wp-content/uploads/2017/11/INFOGRAFIK-Pflegeberatung-in-Deutschland-2017-1.pdf (accessed 4 July 2019).

[18] Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, Hoagwood K. Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. Adm. Policy Ment. Health 2015;42:533–44, http://dx.doi.org/10.1007/s10488-013-0528-y.

[19] Mayring P. Qualitative Inhaltsanalyse: Grundlagen und Techniken 12th ed. Beltz, J, Weinheim. Bergstr 2015.

[20] Bundesministerium der Justiz und für Verbraucherschutz, Sozialgesetzbuch (SGB) - Elftes Buch (XI) - Soziale Pflegeversicherung (Artikel 1 des Gesetzes vom 26. Mai 1994, BGBl. I S. 1014): § 28a Leistungen bei Pflegegrad 1.

[21] Bundesministerium für Gesundheit, Pflegeleistungen ab 1. Januar 2015. https://www.bundesgesundheitsministerium.de/fileadmin/Dateien/Downloads/P/Pflegestaerkungsgesetze/Tabellen_Plegeleistungen_BRat_071114.pdf (accessed 5 December 2019).

[22] Barmer Pflegekasse, Vom Punktwert zum Pflegegrad: Die Bewertungssystematik der Pflegebegutachtung, 2017.

[23] Bayerische Staatskanzlei, Bayerisches Landespflegegeldgesetz: BayLPflGG, 2018.

[24] Georgii H. Aktueller Begriff: Koalitionsverhandlungen - Koalitionsvertrag 2009, https://www.bundestag.de/resource/blob/529210/2b950af0bd9fb1b1ee4c10c459ba3a5b/kw40_aktueller_begriff_koalitionsverhandlungen-data.pdf (accessed 23 May 2019).

[25] Rothgang H, Müller R. Pflegereport 2018: Schriftenreihe zur Gesundheitsanalyse 12th ed. Barmer 2018.

[26] Bundesministerium für Gesundheit, Empfehlungen der Bund-Länder-Arbeitsgruppe zur Stärkung der Rolle der Kommunen in der Pflege, 2015.

[27] Stiftung ZQP, Datenbank Beratung zur Pflege. https://www.zqp.de/beratung-pflege/.(accessed 12 December 2019).

[28] Bundesinstitut für Bevölkerungsforschung, Zahlen und Fakten: Vom demografischen Wandel besonders betroffene Regionen: Abgrenzung und Handlungsbedarf. http://www.demografie-portal.de/SharedDocs/Informieren/DE/ZahlenFakten/Betroffene_Regionen.html (accessed 27 May 2019).

Modul 5

Willingness and preparedness to provide care: interviews with individuals of different ages and with different caregiving experiences

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BMC Geriatrics; 21(1), 1-14
DOI: 10.1186/s12877-021-02149-2

2021

de Jong *et al. BMC Geriatrics* (2021) 21:207
https://doi.org/10.1186/s12877-021-02149-2

BMC Geriatrics

RESEARCH ARTICLE **Open Access**

Willingness and preparedness to provide care: interviews with individuals of different ages and with different caregiving experiences

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Abstract

Background: At present, the provision of informal care to older relatives is an essential pillar of the long-term care system in Germany. However, the impact of demographic and social changes on informal caregiving remains unclear.

Methods: Thirty-three semi-structured interviews were conducted with care consultants, informal caregivers and people without any caregiving experience to explore if people are willing to provide older adult care and how prepared these are with regard to the possibility of becoming care dependent themselves.

Results: In total, three main categories (willingness to provide care, willingness to receive care and information as preparation) with several sub-categories were identified during the content analysis. While almost all interviewees were willing to provide care for close family members, most were hesitant to receive informal care. Other factors such as the available housing space, flexible working hours and the proximity of relatives were essential indicators of a person's preparedness to provide informal care. It is, however, unclear if care preferences change over time and generations. Six out of 12 informal caregivers and nine out of 14 care consultants also reported an information gap. Because they do not possess adequate information, informal caregivers do not seek help until it is too late and they experience high physical and mental strain. Despite the increased efforts of care consultants in recent years, trying to inform caregivers earlier was seen as almost impossible.

Conclusions: The very negative perception of caregiving as a burden was a reoccurring theme throughout all interviews and influenced people's willingness to receive care as well as seeking timely information. Despite recent political efforts to strengthen home-based care in Germany, it remains unclear whether political efforts will be effective in changing individuals' perceptions of informal caregiving and their willingness to be better prepared for the highly likely scenario of having to care for a close relative or becoming care dependent at a later stage in life.

Keywords: Home care, Qualitative, Long-term care, Information, Older adult care, Content analysis, Willingness to care

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Background

Because of recent demographic and social developments, older adult care has emerged as an important and widely debated topic worldwide. Similarly, in Germany media coverage of and public awareness about older adult and long-term care as well as related issues has increased over the last few years. Particular focus is given to current demographic forecasts, a shortage of qualified personnel, and concerns about the quality and financing of care services and personnel [1]. In recent times, political efforts have been taken to address these concerns by introducing care reforms and pursuing other objectives to strengthen this sector. For instance, the new definition of care dependency, which was introduced in 2017, resulted in an increase in the number of individuals who were classified as long-term care beneficiaries, and long-term care centers have been established to provide local support and disseminate information [2].

As part of the social security system in Germany, long-term care insurance is mandatory since 1995 and covers the entire population. Long-term care insurance funds are either linked to a statutory or private health insurance and entitlement to insurance benefits is based on a calculated care dependency level [3]. To assess the long-term care insurance entitlements of individuals, five care grades were introduced in 2017 to replace the previously used three care levels. The new instrument uses six modules (e.g. mobility, cognitive and communicative capacity or self-sufficiency) to determine the need for care of each person. Each of the six modules is comprised of a series of criteria, for which points are allocated. To classify a care grade, the points of all modules are added to a sum score, adjusted for the respective weight of the module. A range from 0 to 100 points is used for this classification. A higher care grade translates to a more severe care dependency [4]. Of the 2.8 million long-term care insurance claimants aged 65 years and above in 2017, 73% received home care [5]. Home care is either supported by cash benefits, in-kind benefits or a combination of the two. Cash benefits are usually passed on to informal caregivers with no regulations on how to use such benefits (given that adequate caregiving is guaranteed). In-kind benefits may be used for different types of professional home-care services. Expenses are covered by the long-term care insurance until the benefit cap of the respective care grade [6].

In a majority of home-based care settings in Germany, one or more informal caregivers are actively involved in providing or organizing care for the person who requires it. When family members, relatives, and/or friends assume the role of a caregiver, they often witness major changes in their everyday lives. A study by Geyer (2016) has shown that caring for a person in need for more than 1 h a day reduces working hours by approximately 5 to 8 h per week [7]. Further, such individuals may not be able to reenter the workforce as full-time employees once the caregiving situation has ended [8]. In addition, several studies have highlighted the heavy burden that caregivers shoulder. More specifically, informal caregiving adversely affects their physical and mental health and can lead to financial hardship [9, 10]. However, caregiving can also confer positive effects such as increased self-esteem, resilience, and meaning in relation to care provision [11, 12].

It is often reported that most older adults prefer to stay in their own homes or familiar surroundings for as long as possible. Nevertheless, research has shown that changing family dynamics and structures, such as increasing employment rates of women, higher number of single households and growing geographical distances between family members, can make informal and home-based caregiving more difficult [13, 14]. The exact reasons for people to take on the often time-consuming role of caregiver are complex and still not well understood [15]. When trying to understand the provision of informal caregiving, studies have focused on different determinants and used varying concepts. In a study by Broese van Groenou and De Boer (2016) the informal care model was applied as a theoretical foundation, in which dispositional factors and external conditions are of particular importance. The individual disposition of caregivers is further described by the person's attitudes and affection, which incorporate individual's motivation, values and normative beliefs concerning informal caregiving. Competence, time or financial resources, can be perceived as barriers to the individual disposition of caregivers [16]. Research on motivation behind informal care provision is largely theory-driven, with individuals explaining their reasons to take on the role of informal caregiver by for instance altruistic behavior or strategic exchanges in the form of money transfers [17]. Other studies have found that some caregivers feel a strong sense of responsibility and obligation to take care of older family members, others motivate their decision with feelings of love and reciprocity [15, 18]. The concept "motivation" was also investigated by a recent literature review from the perspective of self-determination theory. According to the study, motivation is important for the way in which caregivers ultimately experience informal caregiving [19].

Another group of studies focused on people's willingness to provide informal care. In a report by the European Commission, the willingness of caregivers to provide care was singled out as a key determinant in terms of the availability of informal care. In addition, the extent of a person's willingness to provide care with regard to, amongst others, the amount of hours per week is essential to determine the availability of informal care

[20]. When it comes to people's willingness to provide and receive or accept informal care, studies in Germany and the Netherlands have found the proximity of children, having a partner (or not) and having few siblings to constitute decisive indictors [21, 22].

Older adults are likely to become care dependent or have a relative who requires care as they grow older. In most cases, the question is not if, but how and when, such a situation will arise. Nevertheless, when a family member or close friend/acquaintance becomes care dependent, the need for support, consultation, and information gains significance [23, 24]. In addition, research has shown that family members who felt ready and prepared to take on different caregiving tasks, were generally prone to lower levels of mental and physical strain. Feelings of preparedness or readiness to care may therefore protect informal caregivers from high levels of burden and stress [25–27].

Accordingly, the aim of this qualitative study was to explore if people are *willing* to provide informal care and how *prepared* they are to care for a care-dependent person in the German context. Depending on the age of the interviewee, this can either primarily refer to an own hypothetical care dependency or having to take care of a care-dependent relative. The overarching research questions were 1) "Are people willing to provide informal care and which motives and other influencing factors play a role in the consideration?", 2) "When providing or being willing to provide care, what are the expectations or wishes for receiving care?", 3) "How prepared are individuals to provide informal care and what value does "preparedness to care" have for people?"

Method

Design

A qualitative explorative study was performed to gain insight into individuals' perceptions of caregiving as well as reasons linked to their willingness and preparedness to provide informal care to older family members. Semi-structured face-to-face interviews were conducted with three different groups of individuals: (1) those with no prior caregiving experience, (2) informal caregivers, and (3) care consultants. Because of differences in their caregiving experiences, the perspectives of all the participants (i.e., all three groups) offered valuable insights into their willingness and preparedness to provide informal care. Parts of the results of this study have been reported elsewhere [28].

Participants

Purposive sampling was used to recruit participants from self-help groups, long-term care centers in the region, and long-term care insurances [29]. Those with no prior caregiving experience were approached via direct email recruitment (personal contacts) with the appeal to forward the email to potential participants. Additionally, referrals for further participants were made by those already in the sample, in line with snowball sampling [30]. Prior to each interview, the participant was provided with sufficient information about the aims of the study, structure of the interview, data management procedure, and that their participation was voluntary.

Those who were ≥ 18 years of age, fluent in German, and able to provide informed consent were eligible for inclusion. The only other eligibility criterion that had been stipulated in advance was caregiving (in)experience. Specifically, to be eligible for inclusion, informal caregivers were required to be providers of care and/or assistance (either currently or in the past) to a person who required care in a home-based setting. In contrast, care consultants needed to have first-hand experience in providing consultation services to informal caregivers and people who are in need of care. Some care consultants also had personal experience in providing care to a person in need. Those individuals without any caregiving experience were deemed eligible for inclusion if they had no personal experience of providing informal care or assistance to a person in need of care.

Those with no prior caregiving experience ($n = 7$), informal caregivers ($n = 12$), and care consultants ($n = 14$) were interviewed between April and September 2018. On average, the interviews lasted for approximately 35 min, but the interviews with informal caregivers took considerably longer (between 30 and 75 min). The sample consisted of 11 men and 22 women. A majority of those with no prior caregiving experience were between the ages of 20 and 39 years. The majority of the care consultants and informal caregivers were between the ages of 40 and 59 years and 50 and 69 years, respectively. Care consultants are usually the first points of contact whom informal caregivers approach to acquire pertinent information (e.g. assessment procedure to obtain a care dependency grade, financial benefits, type and access to services). Therefore, from their vantage point, they can offer a comprehensive overview of caregiver needs and challenges. Since 2009, every person in need of care is entitled to a free care consultancy session provided by their long-term care insurance. Next to the statutory and private long-term care insurances, approximately 450 long-term care centers, more than 4.500 charity organizations and the majority of the 14.000 ambulatory services offer care consultancy services in Germany [5, 31–33]. Because of the heterogeneity of care consultants in Germany, different types of consultants were interviewed for this study. Three representatives from long-term care centers and consultancy centers each had been providing local support to informal caregivers and those who require care within the federal state of Lower

Saxony. Five representatives from long-term care insurance companies and two commercial care consultants provided relevant inputs regarding the application, scope, and possibility of utilizing the existing care services within the German care infrastructure. Additionally, a lobbyist for informal caregivers was interviewed to gain insights into caregivers' needs, wishes, and challenges. The lobbyist is part of an advocacy group that tries to strengthen the voice of informal caregivers in different settings (research, politics, other social communities). All but three care consultants had personal experiences in caregiving. All of the informal caregivers were either currently caring for a relative or had cared for a relative in the past, and a few of them had also provided care to a relative of their partner or close friends. All five care grades according to the long-term care insurance entitlements in Germany [4] were represented, and the duration for which they provided care ranged from 5 months to 20 years. For further details, please see Table 1.

Procedure

Thirty-three semi-structured face-to-face interviews were conducted in the region of Lower Saxony, Northern Germany. To ensure homogeneity, one researcher (de Jong, M.Sc.) conducted all the interviews in German, and a native speaker translated the relevant excerpts into English for inclusion in this article (Translation Agency Perfect). All interviews were conducted in a neutral environment or, if preferred, in the home of the respondent. Based on literature reviews and expert discussions, an interview guide was developed for each group of participants (no caregiving experience, care consultants, informal caregivers). After each interview, the questions were revised based on newly emergent themes to incorporate the newly acquired knowledge. On average, six questions were posed to each interviewee, and several subquestions were posed when required.

Interview guide

With regard to those with no prior caregiving experience, the questions aimed to capture their notions about informal caregiving, willingness to provide informal care, and personal preferences regarding receiving care themselves, if they were to become care dependent. Informal caregivers were asked to describe their current or past caregiving experiences and delineate the factors that influenced their decision to take on the role of a caregiver, the challenges that they faced, and its effects on various aspects of their lives (e.g., occupation, finances, time for hobbies/family/friends). Informal caregivers were also asked to state (a) their personal preferences regarding care reception, if they were to become care dependent, and (b) any perceived differences in their preferences regarding care provision and reception. Care consultants were asked to describe the concerns that were most frequently shared by their clients and the challenges that informal caregivers commonly experience. The participants of all three groups were asked to indicate whether they considered care provision to be a familial or societal obligation.

Data analysis

With the informed consent of each participant, all the interviews were audio-recorded and transcribed verbatim. To increase rigor, the transcripts were checked and verified for accuracy. Two researchers (de Jong and Damm) independently coded each transcript using MAXQDA version 11 and conducted a qualitative content analysis or, more specifically, a structured content analysis, in accordance with the procedure that has been outlined by Mayring [34]. Both researchers used deductive main categories, which were derived from the interview guide, and further inductive sub-categories were generated during the coding process from the interview material (for more details, see Fig. 1). Several overarching themes were identified and discussed during the coding process. Once the two researchers finished coding the transcripts, the two documents were merged and compared. Discrepancies were discussed among the team members, and required amendments were made.

Ethical considerations and quality control

The Institutional Review Board of the Medical School in Hanover granted ethical approval to conduct this study (reference number: 09.05.17/La). A written informed consent form was signed by each participant prior to the interview. The quality of this study was checked with the COREQ (Consolidated criteria for reporting qualitative research) checklist, consisting of 32 items and aiming to improve the reporting of qualitative studies [35].

Results

In total, three main categories and several subcategories were identified using the content analysis. An overview of the categories is provided in Fig. 1, and a detailed description of each category is presented in the following sections. It needs to be noted here that the statements in the category "willingness to receive informal care" were not made by care-dependent people themselves that are currently receiving care but rather are opinions of respondents concerning their hypothetical willingness to receive informal care.

Willingness to provide informal care

Over the course of the interviews, each participant was asked to indicate his or her willingness or readiness to take on the role of a caregiver. Depending on their

Table 1 Description of included respondents ($n = 33$)

Perspective	**No caregiving experience**	**Informal caregiver**	**Care consultant**				
			Long-term care support centre	**Consultancy centre**	**Long-term care insurance**	**Commercial care consultant**	**Lobbyist for informal caregivers**
n	7	12	3	3	5	2	1
Sex, n							
Female	5	9	2	3	2	1	
Male	2	3	1		3	1	1
Age (years), n							
20–29	2						
30–39	4					1	
40–49			1		1		
50–59	1	2	1	3	4	1	
60–69		6	1				
≥ 75		4					1
Family status, n							
Single	2	1					
Married or in serious relationship	5	10					
Widowed		1					
Children, n							
Yes	5	11					
No	2	1					
Employment status, n							
Student	1						
Working, full-time	3	1					
Working, part-time	3	1					
Unemployed		2					
Retired		8					
Relationship to the person in need of care, n							
Relatives of mine		8	2	2	3		
Relatives of my partner						1	
Relatives of mine and relatives of my partner		3					
Relatives of mine and close friends		1			1		1
Relatives of mine, Relatives of my partner and close friends				1			
Care grades, n							
1		2					
2		2	1			1	
3		5	1	2	3		
4		3					1
5				1	1		
Total care duration, n							
Less than 1 year			1		1		
Between 1 and 2 years		3		1	1	1	
Between 3 and 4 years		1	1	1			
Between 4 and 5 years		2			1		

Table 1 Description of included respondents ($n = 33$) *(Continued)*

Perspective	No caregiving experience	Informal caregiver	Care consultant				
			Long-term care support centre	Consultancy centre	Long-term care insurance	Commercial care consultant	Lobbyist for informal caregivers
Between 5 and 6 years		2					
Between 8 and 9 years		2					
More than 10 years		2		1	1		1

Care consultants were only asked to provide information on their age, sex and the type of care consultancy they work at. Informal caregivers and people without any prior caregiving situation were additionally asked to provide information on their family status, whether they have children and employment status. Thus, for these three characteristics, information is only available for $n = 19$ interviewees. For the last three characteristics describing the respective caregiving experience of respondents, information is only available for $n = 23$ interviewees

caregiving experience, they provided responses based on hypothetical scenarios or current or past caregiving experiences. Being willing to care was contingent on several factors such as the nature of the relationship that they shared with the care-dependent person or the need to exclude other undesirable options (e.g., admission to nursing homes).

Depending on the person in need of care

When asked about their willingness to provide care, the responses of all the young interviewees (20 to 39 years of age) with no prior caregiving experience were brief but positive. The responses of those who belonged to the other two groups (informal caregivers and care consultants) tended to be more complex, and their willingness was contingent on the nature of the relationship that they shared with the care-dependent person, the extent and type of support that he or she would require (e.g., caregiving time, tasks, and duration), and living arrangements. It remains unclear if the willingness to provide care changes as a function of age and/or caregiving experience. Since informal caregiving is a time-consuming activity, several participants in all three groups reported that their willingness to provide care would depend on the person that was in need of care, specifically, the nature of the relationship that they share with the care-dependent person. Most were willing to provide informal care to not only their partners but also their parents (mother or father).

> "*Yes. For sure. Well, not for all of my relatives. But, for my own mother, I would definitely do that.*" (No caregiving experience 1)

They often attributed their willingness to care for their parents and closest relatives to love, reciprocity, and the desire to give something back to these individuals. However, this was observed only among those who shared close relationships with their parents and had positive childhood memories.

Exclusion criterion: nursing home

For several participants with no caregiving experience (20 to 39 years of age), their willingness to provide care was rooted in their unwillingness to admit their loved one to a nursing home and place the responsibility of caring for him or her in the hands of a stranger; thus out of one's own control and quality standards. These arguments were often attributable to the negative manner in which nursing homes have been portrayed by the media and perceived by society.

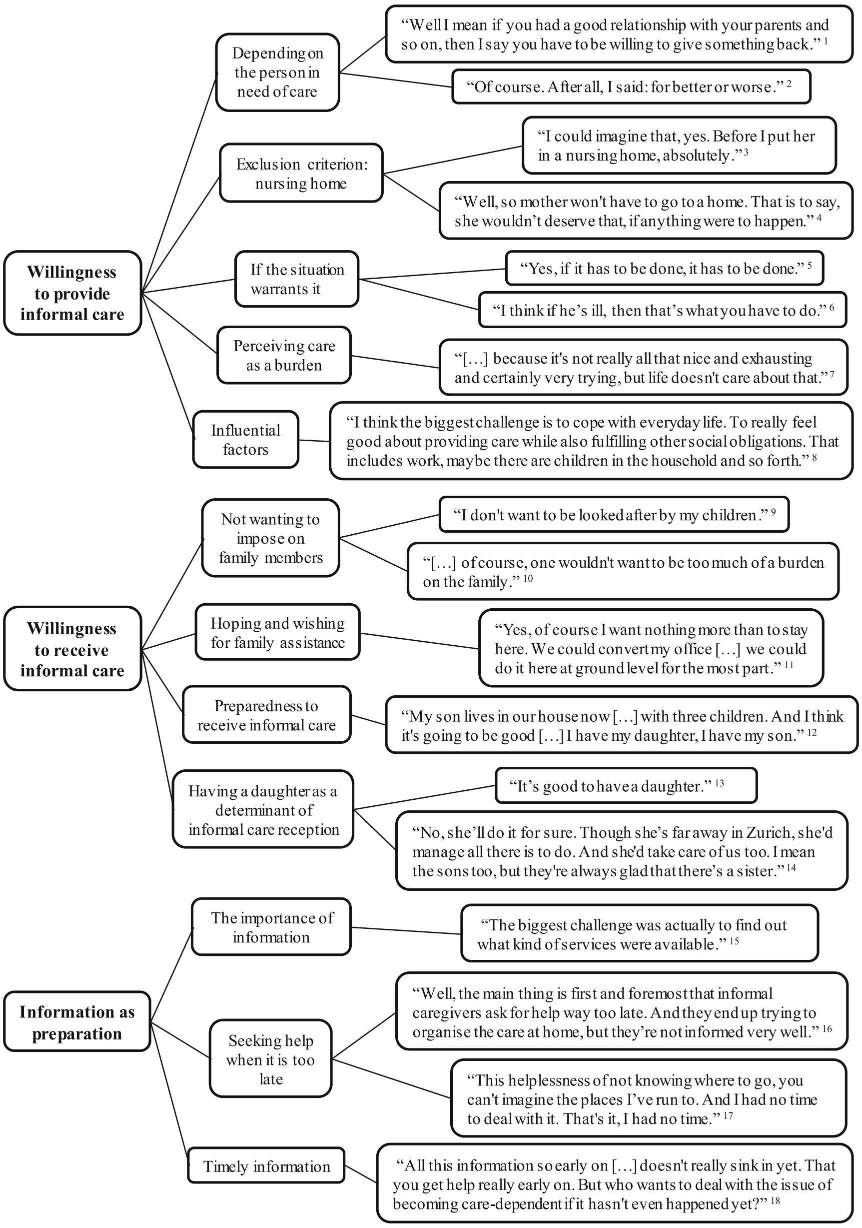
> "*Personally, I would find it difficult to just put her in a nursing home, into someone else's hands.*" (No caregiving experience 2)

Several informal caregivers (50 to 69 years of age) reported similar reasons. For some, it was an acute care dependency (often hospital stay), in which the possibility of a nursing home was excluded right away and it was decided to assume the role of an informal caregiver. For others, equating the life in a nursing home with poor quality of life led them to take on the informal caregiving role. In addition to the reasons reported by those with no prior caregiving experience, informal caregivers noted that their negative perceptions stemmed from their memories of seeing their older friends or neighbors in their nursing homes.

If the situation warrants it

In contradistinction to the motives of love and reciprocity, several interviewees with and without caregiving experience attributed their willingness to provide care to a sense of obligation. Instead of offering a positive rationale (i.e., love for the person who requires care), they provided a negative reason. Caregiving was perceived to be a burdensome task, and such situations were described as life events that no one wishes for but have to be dealt with.

> "*Of course. If it has to be done (laughs). But, I obviously wouldn't be crazy about the idea.*" (No caregiving experience 3)



"Well I mean if you had a good relationship with your parents and so on, then I say you have to be willing to give something back." [1]

"Of course. After all, I said: for better or worse." [2]

"I could imagine that, yes. Before I put her in a nursing home, absolutely." [3]

"Well, so mother won't have to go to a home. That is to say, she wouldn't deserve that, if anything were to happen." [4]

"Yes, if it has to be done, it has to be done." [5]

"I think if he's ill, then that's what you have to do." [6]

"[…] because it's not really all that nice and exhausting and certainly very trying, but life doesn't care about that." [7]

"I think the biggest challenge is to cope with everyday life. To really feel good about providing care while also fulfilling other social obligations. That includes work, maybe there are children in the household and so forth." [8]

"I don't want to be looked after by my children." [9]

"[…] of course, one wouldn't want to be too much of a burden on the family." [10]

"Yes, of course I want nothing more than to stay here. We could convert my office […] we could do it here at ground level for the most part." [11]

"My son lives in our house now […] with three children. And I think it's going to be good […] I have my daughter, I have my son." [12]

"It's good to have a daughter." [13]

"No, she'll do it for sure. Though she's far away in Zurich, she'd manage all there is to do. And she'd take care of us too. I mean the sons too, but they're always glad that there's a sister." [14]

"The biggest challenge was actually to find out what kind of services were available." [15]

"Well, the main thing is first and foremost that informal caregivers ask for help way too late. And they end up trying to organise the care at home, but they're not informed very well." [16]

"This helplessness of not knowing where to go, you can't imagine the places I've run to. And I had no time to deal with it. That's it, I had no time." [17]

"All this information so early on […] doesn't really sink in yet. That you get help really early on. But who wants to deal with the issue of becoming care-dependent if it hasn't even happened yet?" [18]

Fig. 1 An overview of identified categories, subcategories and examples of characteristic participant responses. Legend: 1 = Informal caregiver 5. 2 = Informal caregiver 6. 3 = No caregiving experience 6. 4 = Informal caregiver 5. 5 = No caregiving experience 3. 6 = Informal caregiver 6. 7 = No caregiving experience 3. 8 = Care consultant 6. 9 = Informal caregiver 6. 10 = No caregiving experience 6. 11 = Informal caregiver 7. 12 = Informal caregiver 1. 13 = Informal caregiver 8. 14 = Informal caregiver 8. 15 = Informal caregiver 3. 16 = Care consultant 3. 17 = Informal caregiver 1. 18 = Care consultant 3

When delineating her reasoning behind wanting to provide informal care, one participant elaborated upon her sense of obligation. She considered her family to be her first priority. Therefore, if the situation warranted it, she was willing to accept the consequences of taking on this responsibility on her working hours and free time.

"If it has to be done, then family comes first, and I would cut back in other areas of my life. I don't know if, once it is foreseeable, we can find other options or ways or at least help from older adult care services and the like." (No caregiving experience 4)

Moreover, more than half of the interviewed informal caregivers also felt obliged to provide informal care, especially to their partners.

Perceiving care as a burden

Across all the interviews, the perception of caregiving as a burden was a frequently recurring theme, and it was closely linked to their willingness to provide care. Almost all of the informal caregivers perceived caregiving to be a burden because of the high levels of mental and physical strain that they had experienced. Even those with no prior caregiving experience perceived or, more accurately, imagined informal caregiving as something that no one wishes for, and they described it as a strenuous, burdensome, and trying task.

> "*Not even necessarily, but I believe that* [providing informal care] *should not be underestimated. It is a burden, and you have to invest a lot, and I believe that this is also an environment where sorrow is quite evident.*" (No caregiving experience 5)

Their perceptions of caregiving were partly rooted in their own personal experiences (e.g., observing their parents care for their grandparent) or media portrayals.

Influential factors

The intrinsic desire to provide care may not necessarily translate into the actual provision of informal care. Accordingly, participants without caregiving experience (30 to 39 years of age) as well as informal caregivers underscored the different factors that are likely to influence their willingness to provide care. They did not consider their willingness to be an absolute state. Instead, they perceived it as one that is contingent on other personal responsibilities that can prevent them from being able to provide informal care. Examples of such responsibilities included the need to work to ensure financial stability, having young children at home, and large geographical distances between family members.

> "*There are several prerequisites. Family must live in the same city. That is not the case for us at all. That wouldn't work from here. I think there are professional and, as always, other factors that have an influence on that.*" (No caregiving experience 4)

Many informal caregivers also reported these personal responsibilities, especially when they explained why it was possible for them to provide informal care. For example, flexible working hours and the possibility of working from home were reported as factors that permitted them to provide informal care. Additionally, three informal caregivers reported that living in the same house or close to the relative who required care were the core foundational factors that made informal caregiving possible and a self-evident option.

> "*Thank God we had our mother-in-law in the house! That is why the foundation—the foundation was already there.*" (Informal caregiver 1)

According to representatives of different types of care consultancies (long-term care insurance, commercial care consultants, long-term care support centers) and informal caregivers, large geographical distances between family members (e.g., those living in other countries or federal states) make it difficult for relatives to actively take on the role of a caregiver, when moving is either not possible or desired. Some informal caregivers who were willing to provide care had set clear boundaries with regard to the location in which they would provide care (i.e., own house or apartment), the type of care that they would provide (e.g., personal hygiene), and the number of hours (per week) for which they could provide care.

Willingness to receive informal care

Not wanting to impose on family members

When asked about their preferences regarding care reception in a home-based setting, the participants, especially the younger ones who lacked prior caregiving experience (20 to 39 years of age), reported that they did not want to impose on their family members and concordantly perceived caregiving as a burdensome task. All of them were willing to provide informal care; however, they did not want to become a burden, especially to their own children or partner. The main reasons for such a preference were the toll that it takes on the caregiver and their unwillingness to restrict their lives to take on the role of a caregiver.

> "*Because you do hear from other people caring for relatives at home that it's a full-time job. Personally, I wouldn't want to put my kids or my partner or whomever through that.*" (No caregiving experience 4)

Informed by their personal experiences, several informal caregivers reported that they did not want to impose on their own children. More specifically, one informal caregiver mentioned that having a full-time job and small children at home makes it almost impossible for a person to care for a loved one who requires care. Although she wished to stay in her own home for as long as possible, she did not want to impose on her own children. She reported that she would voluntarily move into a nursing home to spare them the burden of caring for her.

> “*They all work. They won’t be able to do what I was able to do as a housewife. And, like I said, it’s hard as hell, and I’d go into a nursing home as well for the sake of the children. But, of course, it’s everyone’s wish to be properly cared for in their own homes, no question about that.”* (Informal caregiver 2)

In contradistinction to the relatively brief statements that were made by those with no prior caregiving experience, this response, which was provided by an informal caregiver, is an example of a more nuanced explanation. Informal caregivers mentioned that, in the future, it would be necessary to strike a balance between their wish to (a) live in a home-based setting rather than a nursing home for as long as possible and (b) not become a burden to their children and family members.

Hoping and wishing for family assistance

Most of the informal caregivers and care consultants wished or hoped to continue living in their own homes for as long as possible. The statements in this category were more cautious. They did not clearly describe their expectations about receiving informal care; instead, they articulated their wish to receive familial support in the future. For example, one care consultant offered a more nuanced explanation, wherein she differentiated between her expectations about receiving care from her children and her partner. Specifically, she stated that she would like her partner to play some role in ensuring that they continue living in their own home for as long as possible.

> “*I have children too. I wouldn’t expect them to care for me. I don’t know what would be going on in their lives then; no idea. I have a partner. So, I would want to and expect to be at home with him for as long as possible.*” (Care consultant 1)

Another care consultant believed that anyone with a good relationship with his or her family members and relatives would want them to play some type of caregiving role when they find out that he or she requires care.

> “[…] *but I think anybody who has any relatives or family would like to be supported and for them to take on some of it.*” (Care consultant 2)

None of the participants wanted any of their family members to be their sole caregiver. Instead, they wanted them to play a supportive role, but they differed in the extent to which they wanted them to play a supportive role.

Preparedness to receive informal care

A few informal caregivers articulated clearer expectations about receiving informal care from their family members in the future. Their houses were perceived as one of the key foundations that made independent home-based care possible. Accordingly, these informal caregivers had already made concrete plans to repurpose specific rooms and make the living space more accessible. Living in a ground-floor apartment and proximity to one’s child (e.g., living in the same house or close by) were considered to be indicators of preparedness for old age, because they facilitate the provision of home-based care, if and when necessary.

> “*Of course. Thank God we have the possibility! My son lives right above us. We’re on the ground floor; so, we’ve already pretty much set everything up.*” (Informal caregiver 1)

In very few cases, expectations about receiving informal care had been clearly communicated through strategic exchanges. One participant reported that her parents had promised her sister their house in exchange for taking care of them when they need her assistance. This may also be partially attributable to differences in expectations between those who live in urban and rural areas.

> “*For sure. I’m from the countryside, and I am one of four children—fortunately, at this point—and I live the farthest away from everyone. And* [my parents] *clearly expect that. They have a single-family house, which they have more or less gifted to my oldest sister, so to speak, with a promise that they will be taken care of. So yes, these are traditional expectations, as it were. They did it just like that with their parents.*” (Care consultant 1)

Having a daughter as a determinant of informal care reception

Although male interviewees were willing to provide care, several participants in all three groups considered daughters to be the person who is most likely to take on the role of a caregiver. Those who had a daughter often expressed a sense of relief because they knew that they would be taken care of, if such a need were to arise. Numerous informal caregivers had already spoken to their daughters about hypothetical situations in which they may be rendered care dependent and had shared their wishes with them. Therefore, they were able to rely on their support. In the case of several female informal caregivers the decision to take on a caregiving role was a self-evident option and not based on previous family discussions on responsibilities. In these situations, their brothers were also involved, but they tended to play a supportive role. However, in most cases, care-dependent mothers made this decision by first asking their daughters for help.

> "*Yes, and my mother was getting older and needed more help. And there was really no question about who would do it. That was me.*" (Informal caregiver 3)

One female informal caregiver further distinguished between having sons (whom she had) and being her mother's daughter and primary caregiver. For example, she described the composition of the support groups for relatives in the nursing home. Another informal caregiver, who was providing care to her partner, mentioned that her daughter had already assured them of her organizational support (if required), despite a large geographical distance between them. Further, she mentioned that, while her two sons would also support them, they were glad to have a sister on whom they could rely.

Information as preparation

Care dependency creates a substantial need for information. Thus, in all the interviews, information emerged as a relevant theme. Information here refers to information about available support services, insurance benefits as well as what informal caregiving might entail or what should be expected. In particular, information was considered to be an indicator of adequate preparedness to provide care to a care-dependent person. The possibility of informing people about available support services at an early stage was additionally discussed.

The importance of information

As the likelihood of becoming care dependent increases with old age, it is no surprise to find yourself in such a situation. Nevertheless, more often than not, the participating informal caregivers (50 to 69 years of age) had gradually grown into their caregiving roles without much preparation or planning.

> "*We never used to talk about that. It never crossed either of our minds, or let's just say at least not my mind.*" (Informal caregiver 4)

In retrospect, however, all the informal caregivers criticized the lack of information about available care services and financial support. Further, the care consultants observed that, sometimes, the available information on insurance benefits and services does not reach those who need it the most. For example, one care consultant recounted a conversation between her and an informal caregiver in which the importance of information in facilitating and prolonging informal caregiving at home (with support) was emphasized.

> "*We had a relative who said, 'If only I had known this before.' They took care of the mother for a couple of months, I think, and, then, she passed away. The daughter was so unhappy, because we could have prolonged this* [informal caregiving at home] *if she'd known sooner. That's kind of the problem, isn't it? There's not enough information.*" (Care consultant 3)

The caregivers stated that, if they had known what informal caregiving would entail, they would have prepared better, also with respect to accessing home-based support services sooner instead of coping with the given circumstances for too long. On the one hand, information was considered to be essential in helping one prepare for a situation in which he or she might have to take on the role of a caregiver. On the other hand, informal caregivers highlighted the uncertainty surrounding the extent to which their support would be needed, and this made it difficult for them to adequately plan and prepare in advance.

Seeking help when it is too late

Based on the responses of the care consultants and informal caregivers, the unmet need for information on services and the extend of insurance benefits was identified as a major issue. Rather than challenges in accessing services, informal caregivers and consultants highlighted an information gap about available services. This is regarded as the main prerequisite for actually seeking help and accessing assessment and support services. Those who are confronted with the task of providing informal care are often inadequately informed about and prepared for this task. Even when a family member gradually becomes more dependent on external sources of support, individuals tend to cope with their current circumstances without additional help for as long as possible.

> "*I think it's safe to say that one generally addresses the matter too late. I believe that to be the problem behind it all. Even if you have parents or someone else, when you realize that things aren't going too well, you look at them and say, 'Yes, that's still alright.'*" (Care consultant 4)

Therefore, informal caregivers often fail to recognize and cope with their high levels of mental and physical strain for a long time.

> "*First of all, my health. I just couldn't do it anymore. My nerves were at a breaking point and I was emotionally drained. I was really at the end of my strength.*" (Informal caregiver 6)

According to almost all care consultants, this is one of the reasons why many informal caregivers constitute the next generation of care-dependent individuals. More specifically, care consultants reported that informal caregivers find it difficult to let go of their own quality standards and strong sense of obligation to provide informal care and therefore fail to seek help early enough to avoid feeling overburdened.

Timely information

Although the likelihood of becoming care dependent or being required to care for a care-dependent relative increases with age, a majority of individuals prefer to not think about and prepare for such an event. Care consultants, therefore, try to provide timely information through different local information sessions or directly visit large firms and inform their employees. Half of the care consultants (long-term care support centers and insurance) underscored the need for early information, but they also noted that, if a person is not directly confronted with a situation in which he or she is required to provide care, he or she is unlikely to be receptive to the available information.

> "*Well, I think it's human nature to shun things and ignore things I don't want to have to deal with. And, yet, we still try to pass out information material and set up campaigns in such a way, so as to give out information at a very early stage.*" (Care consultant 5)

At the same time, all of the long-term care insurance consultants observed that information culture is already quite widespread in Germany. Nevertheless, until a person is confronted with such a situation, he or she is unlikely to pay adequate attention to such information and prepare for such an event. Thus, providing early information is not the main challenge; instead, informing them at an appropriate time to ensure that they seek help by accessing available services before it is too late (high physical and mental strain) is a major challenge.

Discussion

As it is often only a matter of how and when someone within one's own family becomes care dependent, the aim of this qualitative study was to explore firstly if people are willing to provide informal care and secondly how prepared they are to care for a care-dependent person. At present, the provision of informal care to older relatives is an essential pillar of the long-term care system in Germany and many other countries [20, 36]. However, the impact of demographic and social changes (e.g., changing family structures and labor market participation) on informal caregiving remains unclear.

The first research question of this study investigated people's willingness to provide care and its influencing factors. A vast majority of the interviewees were willing to provide informal care to close family members such as their partner and parents. Different motives were used by respondents to describe the reasons for their willingness to provide care. Whereas some participants attributed their willingness to provide care to motives of love and reciprocity, others attributed it to a sense of obligation and their desire to avoid admitting their loved ones to a nursing home. Age and experience of respondents tended to result in more complex statements with regard to their willingness to provide care. It remains, however, unclear if the willingness to provide care of our respondents changes as a function of age and/or caregiving experience as we did not follow our respondents over a period of time. Many participants stated that their future decisions to provide informal care were not certain and that their actual decisions would depend on other influential factors such as the available housing space, occupational demands, the geographical distance between family members, personal relationships, and having children at home. Some of the perceived barriers to caregiving found in our interviews were also reported in two recent studies, in which determinants of providing informal care were investigated. In particular, proximity of and having children and/or a partner at home [21] as well as having few siblings, a short geographical distance between relatives, and having a widowed parent without a new partner emerged as decisive factors [22].

In contrast, to answer our second research question, quite a few interviewees were less inclined to receive informal care. It needs to be reiterated that the opinions and wishes of the respondents were purely speculative, as none had personal experience of receiving informal care by family members. Such views can therefore change over time. In the interviews, the reasons of respondents for their reluctance in voicing their willingness to receive care ranged from not wanting to impose on family members to cautiously hoping to receive familial support and clearly expecting the support of their daughters. While individuals were generally willing to provide care, they did not expect the same in return. The desire to not impose on family members was most frequently reported by those who had no prior caregiving experience, and this preference was rooted in their negative perception of caregiving as a burden. It remains unclear whether this wish to not become a burden to one's family members is a recent generational aspiration or if earlier generations also espoused the same wish but changed their views and care preferences when they grew older. With regard to expecting the support of one's daughters, Sharma, Chakrabarti and Grover (2016) as well as Six, Musomi and Deschepper (2019) have reported similar results, still suggesting a traditional role for women to take care of their older relatives [37, 38]. It is noteworthy that it remains unclear whether one's willingness to provide or receive care changes over time. Additionally, those who live in rural and urban areas may differ in their expectations about family members providing care to each other, and these differences need to be investigated further. Longitudinal studies should be conducted to examine the stability and consistency of long-term care preferences across time and generations.

Our third research question investigated people's preparedness to care. Living in a ground-level apartment or in the proximity of children, especially daughters, were considered good indicators of preparedness for old age. At the same time, informal caregivers often reported not having prepared in advance, as it was difficult to plan for the intensity of care dependency and the future living arrangements of the care-dependent person and informal caregiver are often uncertain in advance. In addition, it is especially difficult for most individuals to think about and prepare for a situation in which they would be rendered care dependent. Nevertheless, recent statistics suggest that there has been an increase in the number of people who opt for supplementary insurance for long-term care. This trend may be attributable to the extensive supply of information in Germany, and it may be an indicator of improved foresight [39].

The possession of adequate information was considered to be a prerequisite for preparedness for caregiving and accessing available services. The (unmet) need for information was reported as a challenge by almost all of the informal caregivers and care consultants. Accordingly, in Germany, care consultants have tried to increase the dissemination of available information. However, informing people at an early stage (i.e., before a loved one becomes care dependent) was perceived to be almost impossible. Because informal caregiving is often perceived to be a burdensome task, most people try to not think about such a possibility, unless absolutely necessary. Additionally, preferences and available care options change over time, and the actual extent of care dependency remains uncertain. Thus, early information may become outdated by the time caregiving is warranted. However, because of the unmet need for information, many informal caregivers do not seek help until it is too late, and they experience a high level of mental and physical strain. Feelings of preparedness to care have been associated with decreased levels of burden and caregiver strain in previous studies [25]. Instead of trying to inform people earlier, it may be more prudent to ensure that new informal caregivers receive the requisite information at the right time. More specifically, it is very crucial that they know whom to contact to acquire the requisite information. According to the participating care consultants, the diversity of such care consultancies in Germany make it more difficult for new informal caregivers to correctly identify the service provider that they should approach to acquire the information that they need [28].

Beyond what was already said to the three research questions, we found that irrespective of the group to which they belonged, almost all the interviewees held negative perceptions of caregiving (i.e., when providing or receiving informal care) as a burdensome and demanding task. First, care consultants delineated the challenges that were faced by informal caregivers, and informal caregivers reported that they experienced mental overload and physical strain as a result of providing care. Second, most young participants with no prior caregiving experience perceived aging and informal caregiving very negatively. This perception was mainly rooted in negative media portrayals of older adult care (e.g., shortage of personnel and poor quality care provided in nursing homes) [1]. Although past findings suggest that caregiving does have positive effects, such as increased self-esteem [11], only one informal caregiver considered the task of caring for her care-dependent husband to be a positive experience. Positive perceptions of aging have been found to be positively associated with Singaporean teenagers' willingness to care for their parents in the future [40]. In addition to perceptions of caregiving, the recognition of informal caregiving as an important and difficult task is vital and has increased over the past few years.

Limitations

This study has several limitations, which need to be articulated. First, the sample was recruited from one federal state in Germany, namely, Lower Saxony. This limits the transferability of the findings. Although efforts were taken to maximize the heterogeneity of the participants, the findings cannot be generalized to the general population because the sample size was only 33. Moreover, despite our best efforts to recruit a higher number of male informal caregivers, a higher number of women participated in our study. Since our data were collected at a single point in time, temporal changes in preferences regarding care provision and preparedness to provide informal care could not be examined. Ideally, researchers should use longitudinal designs and large samples to examine the decision-making processes that underlie the process by which one's willingness to provide care translates into the actual provision of informal care until a point is reached when alternative solutions have to be sought.

Conclusion

In conclusion, this study provided insights into reasons for providing informal care, looking at people's willingness to provide and receive care, diverging expectations and notions of preparedness to care. A person's willingness to provide care was contingent on the (relationship to the) care-dependent person and explained by different motives. Willingness to provide care was not seen as an absolute state, but rather influenced by potential barriers such as distance between family members or time restrictions due to work or familial obligations. Willingness to provide care of our respondents was also highly influenced by the negative perception of caregiving as burdensome. While individuals were generally willing to provide care, the negative perception of caregiving and not wanting to impose on their own children often resulted in individuals being reluctant to receive care. The possession of adequate information emerged as an important indicator of one's preparedness to provide care to care-dependent individuals. To avoid caregivers experiencing high physical and mental strain caused by caregiving, the need to provide timely information to potential caregivers was underscored. Nevertheless, despite the best efforts of the care consultants, providing early information (i.e., before the need to care for a care-dependent person arises) was perceived to be almost impossible. This was attributable (at least in part) to the very negative perceptions of caregiving that were held by our participants. Further research is needed to examine how long-term care preferences change across time and generations as well as on the best timing for providing information to (potential) informal caregivers in order to reach individuals and avoid significant strain.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12877-021-02149-2.

Additional file 1. Interview Guide.

Acknowledgments
We thank all participants for agreeing to be interviewed for our study.

Authors' contributions

LDJ was responsible for study concept and design, the acquisition of data, analysis and interpretation of data and drafting the manuscript. KD contributed to the study concept and design, acquisition of data, analysis and interpretation of data and the drafting of the manuscript. JTS, SE and JZ contributed to the study concept and design, and the drafting of the manuscript. All authors revised and approved the final manuscript.

Funding
This work was supported by the Federal Ministry of Education and Research (grant number 01EH1603A). The funding body had no role in the design of the study, the collection, analysis, and interpretation of data or in the writing of the manuscript. Open Access funding enabled and organized by Projekt DEAL.

Availability of data and materials

The data generated during the current study are not publicly available due to data protection regulations but are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

The Institutional Review Board of the Medical School in Hanover granted ethical approval to conduct this study (reference number: 09.05.17/La). Each participant signed a written informed consent form.

Consent for publication

Not applicable, as demographics are presented as a group and quotations are not linked to a particular individual in order to not threaten anonymity.

Competing interests

The authors declare that there is no conflict of interest.

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Received: 14 June 2020 Accepted: 11 March 2021

References

1. Isfort. Pflege in den Medien. 2009.
2. Bundesministerium für Gesundheit. Zahlen und Fakten zur Pflegeversicherung. 2019. https://www.bundesgesundheitsministerium.de/fileadmin/Dateien/Downloads/Statistiken/Pflegeversicherung/Zahlen_und_Fakten/Zahlen-u-Fakten-zur-Pflegeversicherung_2019.pdf. Accessed 17 May 2019.
3. Arntz M, Sacchetto R, Spermann A, Steffes S, Widmaier S. The German social long-term care insurance-structure and reform options; 2007.
4. Bundesministerium der Justiz und für Verbraucherschutz. Sozialgesetzbuch (SGB) - Elftes Buch (XI) - Soziale Pflegeversicherung: § 15 Ermittlung des Grades der Pflegebedürftigkeit, Begutachtungsinstrument.
5. Statistisches Bundesamt (Destatis). Pflegestatistik: Pflege im Rahmen der Pflegeversicherung Ländervergleich - Pflegebedürftige; Dezember 2018.
6. Rothgang H. Social insurance for long-term care: an evaluation of the German model. Soc Policy Admin. 2010;44(4):436–60. https://doi.org/10.1111/j.1467-9515.2010.00722.x.
7. Geyer J. Informell Pflegende in der deutschen Erwerbsbevölkerung: Soziodemografie. Berlin: Pflegesituation und Erwerbsverhalten; 2016.
8. Keck. Was kommt nach der Pflege?: Die Pflege eines Angehörigen senkt Beschäftigungschancen von Pflegepersonen nachhaltig. Sozialer Fortschritt. 2016;65:112–9.
9. Hajek A, Brettschneider C, Ernst A, Posselt T, Wiese B, Prokein J, Weyerer S, Werle J, Fuchs A, Pentzek M, Stein J, Riedel-Heller SG, Bickel H, Mösch E, Heser K, Jessen F, Maier W, Scherer M, König HH. Longitudinal predictors of informal and formal caregiving time in community-dwelling dementia patients. Soc Psychiatry Psychiatr Epidemiol. 2016;51(4):607–16. https://doi.org/10.1007/s00127-015-1138-7.
10. Geyer J, Schulz E. Who cares?: Die Bedeutung der informellen Pflege durch Erwerbstätige in Deutschland. 14th ed; 2014.
11. Stansfeld S, Wenborn V-D, Moniz-Cook, Orrell. Positive psychology outcome measures for family caregivers of people living with dementia: a systematic review. Int Psychogeriatrics. 2017;29:1281–96. https://doi.org/10.1017/S1041610217000655.
12. Pendergrass M, Graessel Ö, Karg. Predictors of the personal benefits and positive aspects of informal caregiving. Aging Mental Health. 2019;23:1533–8.
13. Heuchert M, König HH, Lehnert T. The role of preferences in the German long-term care insurance-results from expert interviews. Gesundheitswesen (Bundesverband Der Arzte Des Offentlichen Gesundheitsdienstes Germany). 2016;79:1052–7.
14. Hajek A, Lehnert T, Wegener A, Riedel-Heller SG, König H-H. Potential for informal care of the elderly in Germany: results of a representative population-based survey. Z Gerontol Geriatr. 2018;51(6):612–9. https://doi.org/10.1007/s00391-017-1181-y.
15. Al-Janabi H, Carmichael F, Oyebode J. Informal care: choice or constraint? Scand J Caring Sci. 2018;32(1):157–67. https://doi.org/10.1111/scs.12441.
16. van Groenou MIB, de Boer A. Providing informal care in a changing society. Eur J Ageing. 2016;13(3):271–9. https://doi.org/10.1007/s10433-016-0370-7.

17. Greenwood N, Smith R. Motivations for being informal carers of people living with dementia: a systematic review of qualitative literature. BMC Geriatr. 2019;19(1):169. https://doi.org/10.1186/s12877-019-1185-0.
18. Della Giusta M, Jewell S. Unpaid work and conformity: why care? Camb J Econ. 2015;39(3):689–710. https://doi.org/10.1093/cje/beu061.
19. Dombestein H, Norheim A, Lunde Husebø AM. Understanding informal caregivers' motivation from the perspective of self-determination theory: an integrative review. Scand J Caring Sci. 2020;34(2):267–79. https://doi.org/10.1111/scs.12735.
20. Zigante V. Informal care in Europe.: Exploring Formalisation, Availability and Quality. Brussels: European Commission; 2018.
21. Spangenberg L, Glaesmer H, Brähler E, Strauß B. Inanspruchnahme familiärer Ressourcen bei späterem Pflegebedarf. Bundesgesundheitsblatt-Gesundheitsforschung-Gesundheitsschutz. 2012;55(8):954–60. https://doi.org/10.1007/s00103-012-1512-5.
22. Stuifbergen MC, Van Delden JJ, Dykstra PA. The implications of today's family structures for support giving to older parents. Aging Soc. 2008;28(3):413–34. https://doi.org/10.1017/S0144686X07006666.
23. Plöthner S, de Jong Z, Damm. Needs and preferences of informal caregivers regarding outpatient care for the elderly: a systematic literature review. BMC Geriatrics. 2019;19:1–22. https://doi.org/10.1186/s12877-019-1068-4.
24. Wackerbarth & Johnson. Essential information and support needs of family caregivers. Patient Educ Counsel. 2002;47:95–100.
25. Henriksson A, Årestedt K. Exploring factors and caregiver outcomes associated with feelings of preparedness for caregiving in family caregivers in palliative care: a correlational, cross-sectional study. Palliat Med. 2013;27(7):639–46. https://doi.org/10.1177/0269216313486954.
26. Archbold PG, Stewart BJ, Greenlick MR, Harvath T. Mutuality and preparedness as predictors of caregiver role strain. Res Nurs Health. 1990;13(6):375–84. https://doi.org/10.1002/nur.4770130605.
27. Wang Y-N, Shyu Y-IL, Tsai W-C, Yang P-S, Yao G. Exploring conflict between caregiving and work for caregivers of elders with dementia: a cross-sectional, correlational study. J Adv Nurs. 2013;69(5):1051–62. https://doi.org/10.1111/j.1365-2648.2012.06092.x.
28. de Jong L, Stahmeyer JT, Eberhard S, Zeidler J, Damm K. „Aber vielfach scheitert man dann an Besonderheiten" – Pflegeberater über Gesetzesänderungen und die Herausforderungen ihrer Arbeit: Eine qualitative Untersuchung. ZEFQ;2020.
29. Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, Hoagwood K. Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. Admin Pol Ment Health. 2015;42(5):533–44. https://doi.org/10.1007/s10488-013-0528-y.
30. Mack N, Woodsong C, MacQueen KM, Guest G, Namey E. Qualitative Research Methods: A data collector's field guide. North Carolina: Family Health International; 2005.
31. Dohmeyer H. Infografik: Pflegeberatung in Deutschland 2017. 2017. https://tag-der-pflegeberatung.de/wp-content/uploads/2017/11/INFOGRAFIK-Pflegeberatung-in-Deutschland-2017-1.pdf. Accessed 4 Jul 2019.
32. Braeseke G, Pflug C, Beikirch E. Studie zur Erfüllung der Koordinierungs- und Vernetzungsaufgaben sowie der Qualitätssicherung in Pflegestützpunkten: Abschlussbericht für das Bundesministerium für Gesundheit. Berlin; Juni 2018.
33. GKV Spitzenverband. Die gesetzlichen Krankenkassen. 27.03.2019. https://www.gkv-spitzenverband.de/krankenversicherung/kv_grundprinzipien/alle_gesetzlichen_krankenkassen/alle_gesetzlichen_krankenkassen.jsp. Accessed 17 May 2019.
34. Mayring P. Qualitative Inhaltsanalyse: Grundlagen und Techniken. 12th ed. Weinheim, Bergstr: Beltz, J; 2015.
35. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(6):349–57. https://doi.org/10.1093/intqhc/mzm042.
36. Wetzstein, Rommel, Lange. Pflegende Angehörige – Deutschlands größter Pflegedienst. 2015.
37. Sharma, Chakrabarti, Grover. Gender differences in caregiving among family - caregivers of people with mental illnesses. World J Psychiatry. 2016;22:7–17.
38. Six, Musomi, Deschepper. Are the Elderly Perceived as a Burden to Society? The Perspective of Family Caregivers in Belgium and Kenya: A Comparative Study. J Transcult Nurs. 2019;30:124–31.
39. Verband der Privaten Krankenversicherung (PKV). Zahlenbericht 2018. 2018. https://www.pkv.de/service/zahlen-und-fakten/archiv-pkv-zahlenbericht/zahlenbericht-2018.pdf. Accessed 17 Feb 2020.
40. Cheong CY, Ha NH, Choo RW, Yap PL. Will teenagers today live with and care for their aged parents tomorrow? Geriatr Gerontol Int. 2018;18(6):957–64. https://doi.org/10.1111/ggi.13288.

Publisher's Note

Interview Guide	
Group: Individuals with no prior caregiving experience	
Main questions	**Follow-up questions or comments**
1. Have you ever thought about your wishes or preferences if you were to become care dependent when you grow older? a. What do you think your relatives wish for in case of a care dependency situation?	▪ Have you ever talked to your relatives (e.g. your parents) about these wishes?
2. Do you know what options are available for older adult care?	▪ Do you have a preference regarding these options if you were to become care dependent (alternative: for your relatives)?
3. Could you imagine providing informal care to your relatives? a. Would you be willing to provide informal care if this means that you have to 1) forgo part of your salary 2) reduce your working hours or 3) reduce your leisure time (time for hobbies, friends and family)? b. Are there certain areas where you would prefer formal nursing assistance?	▪ Could you elaborate a bit more on your motivations behind this (lack of) willingness?
4. Who do you think is responsible for providing or organizing care in the event of a care-dependency situation?	▪ Familial vs. societal responsibility
Group: Informal caregivers	
1. How do you currently care for your relative (or retrospectively cared for your relative)?	▪ Do you make use of any professional services?
2. Does your current care situation reflect your wishes? a. Do you have the feeling your (care-dependent) relative would like something different?	
3. What factors played a role in your decision to take on the role of informal caregiver for your relative in need of care?	▪ What was the most important reason for you to take on this role/responsibility?

4. What do you perceive to be major challenges in organizing and/or providing care to your relative? a. Can you estimate how your everyday life, in particular your time distribution with regard to 1) working hours 2) time for leisure (family, friends, hobbies) 3) time for the person in need of care, has changed? b. Does caring for your relative affect your financial situation? c. In which areas would you like formal nursing support?	
5. What are your wishes if you were to become care-dependent? a. Do your wishes differ in the case of an own care-dependency from those for your relative(s)? b. Who do you think is responsible for providing or organizing care in the event of a care-dependency situation?	▪ In which areas would you prefer professional nursing assistance? ▪ Have your wishes changed because of your caregiving experience? ▪ Familial vs. societal responsibility
6. If you think about the current long-term care system in Germany, do you have any concrete suggestions for improvement?	
Group: Care consultant	
1. What are the most common inquiries or concerns that are shared by informal caregivers?	
2. What are the most common challenges informal caregivers experience when organizing and/or providing care?	▪ Further sub-questions depending on the expertise of the care consultant.
3. What are your wishes if you were to become care-dependent? c. Do your wishes differ in the case of an own care-dependency from those for your relative(s)? d. Who do you think is responsible for providing or organizing care in the event of a care-dependency situation?	▪ Do you have informal caregiving experiences? ▪ In which areas would you personally prefer professional nursing assistance? ▪ Have your wishes changed because of your caregiving experience and knowledge? ▪ Familial vs. societal responsibility

4. If you think about the current long-term care system in Germany, do you have any concrete suggestions for improvement? a. Do you have any wishes regarding new reforms or changes to the law?	

Modul 6

A systematic review to identify the use of stated preference research in the field of older adult care

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Eingereicht in: European Journal of Ageing, 2021

Überarbeitet und angenommen: 17.10.2022

Online veröffentlicht: 07.11.2022 unter DOI: 10.1007/s10433-022-00738-7

2022

A systematic review to identify the use of stated preference research in the field of older adult care

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Journal: European Journal of Ageing

Declarations:

Trial registration number
Not applicable.

Funding
This work was supported by the Federal Ministry of Education and Research (grant number 01EH1603A). The funding body had no role in the design of the study, the collection, analysis, and interpretation of data or in the writing of the manuscript.

Conflicts of interest/Competing interests
The authors declare that there is no conflict of interest.

Availability of data and material
The data generated during the current study are all presented in the publication.

Code availability
Not applicable.

Authors' contributions
LDJ was responsible for study concept and design as well as implementation, analysis and interpretation of the literature research and for drafting a first manuscript version. KD contributed to the study concept and design, as well as implementation, analysis and interpretation of the literature search and drafting the manuscript. JZ contributed to the study concept and the drafting of the manuscript. All authors revised and approved the final manuscript.

Ethics approval
Not applicable.

Consent to participate
Not applicable.

Consent for publication
Not applicable.

Abstract

In the design of long-term care systems, preferences can serve as an essential indication to better tailor services to the needs, wishes and expectations of its consumers. The aim of this systematic review was to summarize and synthesize available evidence on long-term care preferences that have been elicited by quantitative stated-preference methods. The databases PubMed and Web of Science were searched for the period 2000 to 2020 with an extensive set of search terms. Two independent researchers judged the eligibility of studies. The final number of included studies was 68, conducted in 19 different countries. Studies were systematized according to their content focus as well as the survey method used. Irrespective of the heterogeneity of studies with respect to research focus, study population, sample size and study design, some consistent findings emerged. When presented with a set of long-term care options, the majority of study participants preferred to “age in place” and make use of informal or home-based care. With increasing severity of physical and cognitive impairments, preferences shifted towards the exclusive use of formal care. Next to the severity of care needs, the influence on preferences of a range of other independent variables were tested, however none showed consistent effects across all studies. Future research should investigate how preferences might change over time and generations as well as people’s willingness and realistic capabilities of providing care.

Keywords: Stated preference, Systematic review, Elderly care, Older adult care, Long-term care, Preferences

Introduction

Population ageing, especially in developed countries, has long been recognized as a global phenomenon, with varied magnitude and projections worldwide. With the increasing population of older adults, substantial pressures are placed on national health and social care systems to adequately prepare for future challenges. The population of older adults aged 80 years or above is predicted to rise globally from 137 million in 2017 to 425 million in 2050 (United Nations, Department of Economic and Social Affairs, Population Division 2017). As an increase in age often coincides with an increasing likelihood of becoming care dependent, one major challenge that emerges is the delivery and financing of long-term care (LTC). In Europe, expenditure on LTC is expected to increase by 80% from 2015 to 2060 (Global Coalition on Aging 2018). According to the latest calculations of 2019, population ageing will lead to an increase in the number of consumers of LTC services (United Nations, Department of Economic and Social Affairs, Population Division 2019).

When a person becomes care-dependent and requires support from others, that person can generally either receive care in a home-based, community, or institutional setting. In a home-based setting, in most instances, one or more informal caregivers are actively involved in providing care. Formal caregiving provided by a professional service often complements informal caregiving in a home-based setting, however, formal caregivers could also be the sole care-provider. The proportion of informal to formal caregiving varies internationally. This can be partly explained by the manner in which LTC systems are organized, which differ substantially across countries with regard to their funding sources, entitlements, service providers, access, LTC workforce, and quality control measures (Royal Commission into Aged Care Quality and Safety 2020). Additional influencing factors might be diverging views on the responsibility for providing care (family vs. government), different normative beliefs and perceived barriers to caregiving as well as individual willingness to provide care (Hoefman et al. 2017). Other societal changes, such as increasing employment rates of women, larger geographical distances between family members, and a growing number of single-person households, might also play an important role (van Groenou, Marjolein I Broese and Boer 2016). Such societal changes, alongside demographic developments and a rising demand for high-quality care, increase the pressure for national governments to act and establish sustainable and affordable LTC systems (Royal Commission into Aged Care Quality and Safety 2020).

In the designing of LTC systems, preferences can serve as an important indication to better tailor services to the needs and wishes of its consumers. Recently, there has been an increase in the involvement of patients and the general public in healthcare decision-making (Coulter 2012, Litva et al. 2002). In systems with limited resources, it is important to know which aspects of LTC are most and least important to people. Integrating people’s preferences in the design of services and products has also been linked to improved quality of care, quality of life, and overall well-being (Swift and Callahan 2009). Stated preference (SP) methods are used to ask participants directly about their preferences. Quantitative techniques can be used to infer people's preferences by measuring a change in their utility function. As people are asked to trade-off between different aspects of care, it is possible to generate a ranking of said preferences. Examples of SP methods are contingent valuation (CV), best-worst scaling (BWS), discrete choice experiment (DCE), and other ranking or rating techniques (Klose et al. 2016). In the field of older adult care, SP methods have been increasingly applied since the last 10 to 15 years.

Preferences in the field of older adult care are multifaceted. It depends on multiple factors such as the study population, country in question, and the study's perspective and focus. The broad thematic use of SP studies in the field of older adult care is mainly motivated by the complexity of LTC. Therefore, some studies have investigated preferences for specific LTC services (e.g., home-based care packages) in order to make preference-based suggestions for the improvement of LTC service designs (Lehnert et al. 2018, Chester et al. 2017, Kampanellou et al. 2019). Other studies used instruments to measure caregiver's outcomes or investigate the suitability of different forms of LTC, providing an indirect measure of what LTC should look like according to people's preferences (Al-Janabi et al. 2011, Milte et al. 2018a). In a recent scoping review by Lehnert et al. (2019), stated preferences for LTC were reviewed and summarized. It identified 12 qualitative, 40 quantitative, and seven mixed-methods studies in the field from a database search in February 2016. This systematic review builds up on the scoping review by additionally capturing the period from February 2016 to October 2020 and including preferences for nursing home as well as dementia care. The aim of this review is to summarize and synthesize available evidence on LTC preferences that have been elicited by quantitative SP methods.

Methods

A systematic literature review was performed to identify original SP studies in the field of older adult care. Amongst others, these studies measure people's willingness to provide care or their preferences for different LTC services (informal or formal). The systematic review was performed in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines (Moher et al. 2009).

Search strategy and information sources

The literature search was conducted in September 2019 and updated in October 2020 using the scientific databases, PubMed and Web of Science. The search strategy combined English terms for older adult care [*care OR nursing OR elderly care OR long-term care OR LTC OR home care OR older adult care*] in search block A with search terms for SP elicitation methods [*stated preference(s) OR time* *trade-off OR TTO OR standard gamble OR conjoint OR contingent valuation OR discrete choice OR DCE OR willingness-to-pay OR WTP OR analytic hierarchy process OR AHP OR choice model OR best-worst scaling OR BWS OR willingness-to-accept OR WTA OR multi-criteria decision analysis OR MCDA OR multi-attribute utility OR MAUT*] in search block B. Search terms for block B were selected with the help of the literature survey on methods to perform systematic reviews of patient preferences by Yu, Enkh-Amgalan, and Zorigt (2017). The Boolean operator "AND" combined the search terms of block A and B. Database-specific adjustments were made in block A in Web of Science by leaving out the search terms "care" and "nursing," as these yielded a very high number of unspecific search hits in the database. Only one database-specific search filter was used in PubMed, specifically limiting the species to only humans. The timeframe was set to exclude studies published prior to 2000.

Eligibility criteria and study selection

The selection process was based on a set of pre-defined inclusion and exclusion criteria. Studies were deemed eligible for inclusion if they 1) reported peer-reviewed, original quantitative data using SP methods such as DCE, BWS, CV, or other ranking or rating techniques, 2) were published in English or German, 3) were published in or after the year 2000, and 4) were focused specifically on LTC preferences of older adults in need of care. Studies were excluded if they 1) did not report original, peer-reviewed data (such as poster sessions, book chapters, reviews, reports and letter to the editors), 2) used qualitative or revealed preference methods to elicit preferences, 3) were published prior to 2000, or 4) focused on illness-related care, end-of-life care, or telecare. Studies focusing on specific illnesses or palliative care were excluded because of their tailored care needs and medical interventions that differ from general older adult care. Care for common cognitive and physical signs of old age such as incontinence, memory loss, and dementia were exempted from illness-related care and therefore included in this review. Based on these criteria, two independent researchers (de Jong, Damm) made a first selection by screening the titles and abstracts. Following the first selection, full texts of the remaining studies were screened and judged for inclusion. In case of disagreement, a third reviewer was consulted. Reference lists of included studies were hand-searched by the lead author.

Data extraction and quality appraisal

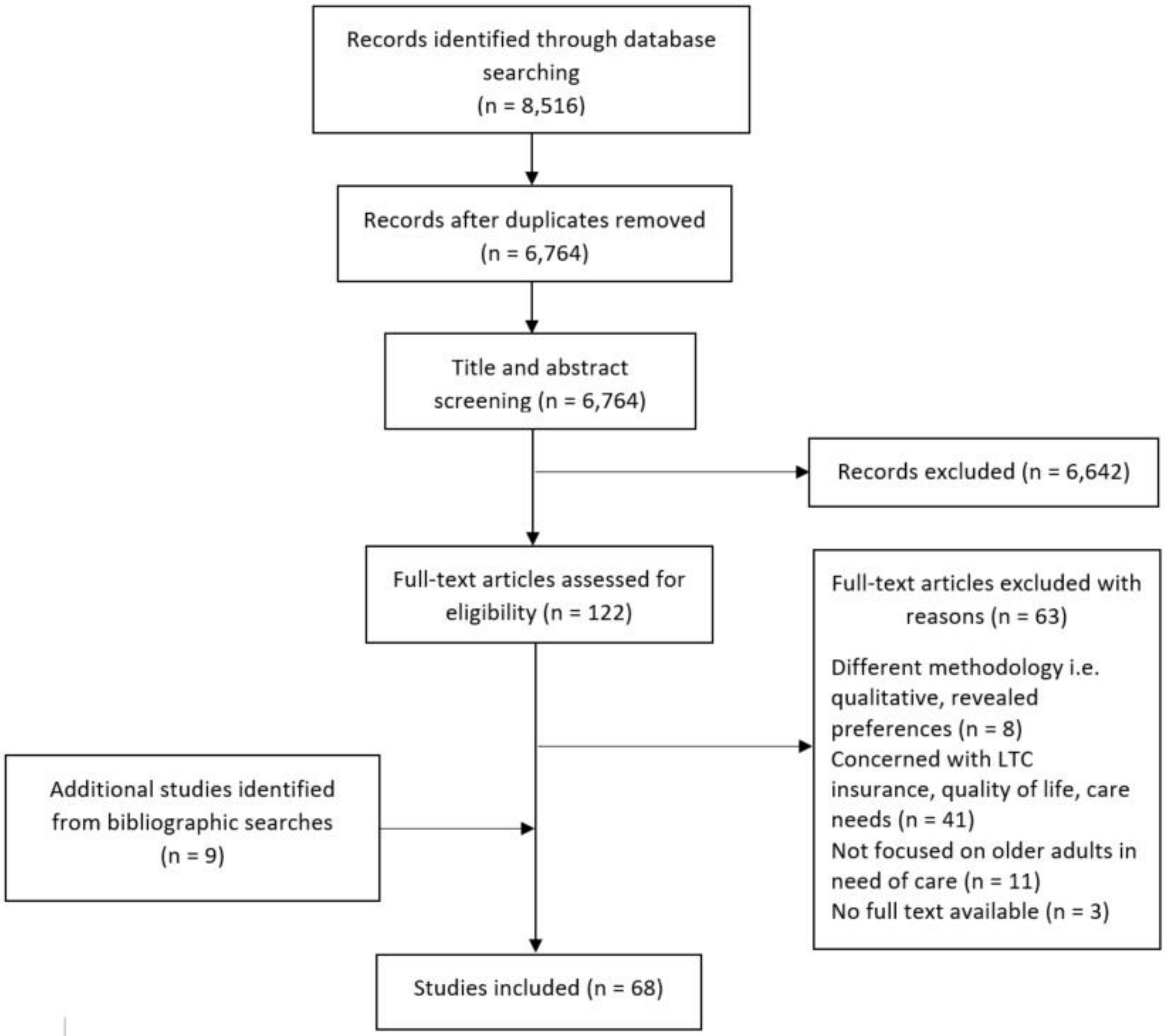
Key characteristics of each study were extracted and collected in an extensive Microsoft Excel file. The extracted characteristics included the year of publication, country, aim of the study, characteristics of the study participants, sample size, instrument design including the software used, attributes and levels if applicable, data analysis, and key findings. A summary of key characteristics is presented in Table 1 and a detailed overview of selected characteristics is presented in Tables 2, 3, and 4. The quality of this systematic review was ensured using the PRISMA 2009 Checklist (Moher et al. 2009).

The quality of the included studies was assessed using the PREFS (*Purpose, Respondents, Explanation, Findings, Significance*) checklist (Joy et al. 2013). According to the PREFS checklist, studies are ranked on a scale from zero to five, with five indicating the highest methodological quality. Two researchers (de Jong, Damm) independently judged the quality of the studies. Table 5 presents an overview of the quality scores of the included studies.

Results

In total, the search strategy yielded 8,516 articles to be screened for eligibility. After the removal of duplicates, two independent researchers screened and assessed 6,764 titles and abstracts with a set of predefined inclusion and exclusion criteria. As a result, 122 remaining full texts were assessed, of which 59 were ultimately included. Full texts with a different methodological or thematic focus, for instance, care needs or preferences for LTC insurance coverage were excluded. The reference lists of the included studies were additionally screened, which yielded another nine studies to be included. In total, 68 studies were included. The study selection process is shown in Figure 1.

Figure 1: Flow diagram



Description of included studies

The included studies were published between the year 2000 and 2020 and the majority were conducted in China (n = 17) and the United States of America (USA) (n = 18). Two studies collected data from multiple countries, particularly from the United Kingdom, Spain, USA, and Sweden (Gustavsson et al. 2010) and Germany and the USA (Pinquart and Sörensen 2002). In total, studies conducted in 19 different countries were included. An overview of study characteristics is shown in Table 1. Barring two studies that investigated preferences over time (Wolff et al. 2008, Abbott et al. 2018), the remaining used a cross-sectional design. The sample size ranged from 12 (Li and Wang 2016) to 244,718 respondents (Roberts and Saliba 2019). The share of women in the sample ranged from 38.2% (Qian et al. 2017) to 100% (Kasper et al. 2000, Wolff et al. 2008). The majority of the included studies (n = 39) surveyed a sample of the general population, mostly older adults aged 65 years and above. Eight studies included care-dependent older adults and eight informal caregivers or family members. Ten studies used multiple groups of study participants for their analysis, specifically, care-dependent older adults as well as their primary caregivers or family members as proxy. Most often (n = 45) the surveys were administered via telephone or face-to-face interviews to enable participants to ask questions. Next to descriptive statistics, most studies additionally used inferential statistics to analyze their findings. Multinomial logistic regression, conditional logistic regression, and mixed logit models were most frequently used.

- Insert table 1 here -

The included studies (n = 68) investigated different facets of LTC. For this systematic overview, studies were grouped into four main entities:

(1) Preferences for different LTC options and factors influencing these preferences: Twenty-nine studies exclusively focused on the preferred type of care in case the participants became care-dependent and its influencing factors (e.g., age, gender) that might explain respondent's preferences. Participants were asked to choose their preferred LTC option from a set of pre-specified categories or show their level of agreement to a set of statements concerning different LTC options (usually Likert scales). Binary-choice questions only investigated respondent's willingness to make use of only one type of LTC, e.g., nursing home care.

(2) Suitability of different types of care services and settings for hypothetical patient outcomes and factors influencing such preferences: In the majority of the studies (n = 11), hypothetical vignettes were used that depicted individuals in need of care, while the type and severity of impairment differed between studies. Physical and cognitive impairments were mostly com-

pared. Participants were then asked to put themselves in the position of the hypothetical person in need of care and state the appropriate LTC option. The influencing factors in most studies were then analyzed.

(3) Preferences for the design and structure of specific LTC services: Twenty-two studies focused on a singular type of LTC to make preference-based suggestions for the improvement of specific LTC service designs. Participants were mostly asked to make trade-offs between different attributes of the depicted LTC service, e.g., the cost and care time per day of two home-based care packages. DCE and conjoint analyses were most frequently used. When reported, the number of included attributes in the experimental designs ranged from four to ten. Studies either focused on informal care, home-based, and community-based care or LTC facilities.

(4) Impact of LTC services to value quality of life or quality of care instruments: Preference-based instruments typically incorporate a scoring algorithm that has been elicited by using various SP methods and can be used to measure caregiver's outcomes.

Block 1.1: Preferences for different LTC options

Twenty-nine studies exclusively asked respondents for their preferred LTC option in case of a care dependency situation and investigated the impact of a variety of independent variables on the choices of respondents. The majority of these studies were conducted in China (n = 12) and the USA (n = 7). The most preferred care option by almost all (60 to 85%) participants was home care, either provided by relatives or professionals (Chung et al. 2008, Costa-Font et al. 2009, Eckert et al. 2004, Fernandez-Carro 2016, Fu et al. 2017, Filipovič Hrast et al. 2019, Hajek et al. 2017, Imamoğlu and Imamoğlu 2006, Laditka et al. 2001, Liu et al. 2019, Rong et al. 2019, Spangenberg et al. 2012, Wei and Zhang 2020, Zeng et al. 2019, Zhang et al. 2017, Fisher 2003, Kim and Choi 2008, Wang et al. 2004, Iwasaki et al. 2016). Some studies further differentiated between receiving care and living in one's own home or the relative's home, of which the option of remaining in one's own home was preferred by all except in the study by Fernández-Carro (2016). Here living in the relative's home was preferred by 56% of respondents compared to 21% of respondents preferring to be cared for in their own home. Pinquart et al. (2002) found that older respondents preferred informal or mixed support for short-term care dependency and more formal assistance in the case of LTC needs. Seven studies investigated preferences for community-based care. On average, 5 to 10% of the respondents preferred to use community services in case of a care dependency (Chung et al. 2008, Liu et al. 2019, Wei and Zhang 2020, Zhang et al. 2017). In the remaining three studies, willingness to use community services was higher, documenting up to 38.7% (Laditka et al. 2001, Rong et al. 2019, Zeng et al. 2019).

The third LTC option most often investigated was institutional care, particularly, respondent's intention or willingness to enter a nursing home when in need of care. Acceptability of institutional care varied greatly between studies. In most studies, 2 to 20% of respondents expressed their willingness to enter a care home in the future (Chung et al. 2008, Costa-Font et al. 2009, Eckert et al. 2004, Fernandez-Carro 2016, Fu et al. 2019, Liu et al. 2019, Wei and Zhang 2020, Zeng et al. 2019, Huang et al. 2018, Kim and Kim 2004, Qian et al. 2017, Qian et al. 2018, Chou 2010, Wang et al. 2004, Iwasaki et al. 2016). The lowest acceptability rate was found in a Chinese survey with 14,373 participants aged 60 and above with a willingness of less than 3% to enter a nursing home (Zhang et al. 2017). Studies by Hrast et al. (2019) (72%) in Slovenia and Chan et al. (2000) (86%) recorded the highest acceptability rates.

Block 1.2: Factors influencing preferences for different LTC options

To evaluate the influence of different independent variables on the choice of the different LTC options, many of the included studies applied Anderson's model of health service utilization (n = 13). This model can be used to differentiate the influence of *predisposing* (e.g. age, sex, nationality, education level, living arrangement), *enabling* (e.g. income, number of children, family network, social support), *need* (e.g. self-rated health, cognitive function, number of chronic diseases) and *psychological* (e.g. attitudes, social norms, intergenerational ties) factors on the choices of respondents. In the German study by Hajek et al. (2017) preferences for home care were positively associated with lower self-rated care (OR: 1.3), no need of care (OR: 5.5), and providing care for family members or friends (OR: 1.6). Expectations of reciprocity and strong family bonds might explain such preferences. In the Chinese study by Liu et al. (2019), older adults living in rural areas preferred home-based services and receiving support from family members. Eckert, Morgan and Swamy (2004) found a higher education (OR: 1.78) and being female (OR: 1.55) increased preference for care by kin. Contrastingly, Fernandez-Carro (2016) found that factors like being widowed (Coeff: 0.09), a low educational (Coeff: 0.15), and financial profile (Coeff: 0.28), and already living at children's home (Coeff: 0.14) significantly increased the likelihood of choosing co-residence at a relative's home. Compared to home care, those respondents who preferred community-based care were in need of visiting a medical care team (OR: 2.12) and needed self-care information (OR: 4.39) (Chung et al. 2008). A study involving 169 older caregivers in the USA found a significant gender difference for being able to afford to pay for services. It found that almost 60% of male respondents and 33.9% of female respondents would rather use community services than ask family for help (Laditka et al. 2001).

Several studies found that poorer health status was positively associated with respondents' willingness to use institutional care services (Wei and Zhang 2020, Rong et al. 2019, Zhang et al. 2017, Jang et al. 2008, Kim and Kim 2004, Hajek et al. 2017). Marital status (unmarried or widowed) additionally positively influenced respondents' willingness to enter a care home (Wei and Zhang 2020, Zeng et al. 2019, Rong et al. 2019, Qian et al. 2018, Fernandez-Carro 2016). Income was found to have a statistically significant impact on respondents' choice to receive institutional care in several studies. Studies by Wei and Zhang (2020), Qian et al. (2018), and Dong et al. (2020) found that respondents with a higher income were more likely to prefer an institutional setting. However, Kim and Kim (2004) and Kim and Choi (2008) found that the opposite was true. A higher education was also found to positively influence respondents' willingness to enter a care home (Wei and Zhang 2020, Qian et al. 2018, Fernandez-Carro 2016, Chou 2010, Dong et al. 2020). Fewer children or a poor relationship with one's children increased respondents' willingness to move to a LTC facility in the future (Kim and Kim 2004, Qian et al. 2018). Having an acquaintance already living in a nursing home (OR: 2.80) additionally increased respondents' willingness to enter a nursing home (Jang et al. 2008). A Chinese study investigating age-cohort differences on the intention towards old age home placement found that middle-aged and older Chinese respondents tended to have more positive attitudes towards old age home and were willing to enter a nursing home than younger participants (Tang et al. 2009)

- Insert table 2 here -

Block 2.1: Suitability of different types of care services and settings for hypothetical patient outcomes

Nieboer et al. (2010) elicited the preferences of the general Dutch elderly population (n = 1,082) for LTC services by means of a DCE. In each choice set, respondents had to choose the most suitable care package (A vs. B) for a specific patient. Four patient profiles were presented: physically frail elderly, elderly with dementia, and then both groups either living alone or with a partner. Irrespective of the group, the greatest value was attached to a regular care provider and the availability of transportation services. For physically frail elderly, transportation services were deemed most important (*living alone* coeff: -0.572, WTP: €120; *living with a partner* coeff: -0.459, WTP: €76). For older patients with dementia who were *living alone*, the most important attribute was living in an apartment building in close proximity of the caregiver (Coeff: 0.498, WTP: €177). For patients with dementia who were *living with a partner*, the most important attribute was a regular care provider (Coeff: -0,493, WTP: €88). Generally, all services were deemed more important to care-dependent people living alone compared to those living with a partner. Living in a care or nursing home was the least preferred living situation, except for dementia patients living alone.

Additionally, 14 studies examined the suitability of LTC settings for different hypothetical patient outcomes. Of these studies, two applied the conjoint analysis method (Fahey et al. 2017, Robinson et al. 2015), one the time-trade off method (Guo et al. 2015), and the remaining 11 a vignette survey. Fahey et al. (2017) found that respondents placed the greatest weight on reducing strain on family members and wanting to stay at home with support for as long as possible. Robinson et al. (2015) found that the most important attribute of the respondents was going home with care support.

Half of the respondents were additionally willing to sacrifice one year or more of their life to be able to stay at home with support. Guo et al. (2015) found that home care was strongly preferred compared to nursing home for mild to moderate physical impairments. Such preferences were found to decrease by 0.04 quality of life weight for every additional ADL impairment. With increasing severity of impairment, especially of a cognitive nature, preferences tended to shift towards nursing home care.

In the remaining studies, vignettes depicting situations with hypothetical older adults in need of care were used. In most cases, the severity of the depicted care dependency was altered in the vignettes and respondents were asked to choose an appropriate LTC option for that person. The majority of the vignette surveys were conducted in the USA and differentiated the hypothetical care dependencies into physical and cognitive impairments (Bradley et al. 2004, McCormick et al. 2002, Min 2005, Min and Barrio 2009, Wolff et al. 2008). In case of IADL needs or a hypothetical hip fracture, respondents preferred to make use of informal or formal home-based care services (Wolff et al. 2008, McCormick et al. 2002, Min 2005, Min and Barrio 2009, Kasper et al. 2000, Kasper et al. 2019). While McCormick et al. (2002) found similar preferences between Japanese-Americans and Caucasian-Americans in case of a hip fracture, Min & Barrio (2009) found that 83.3% of non-Latino white older adults expressed a preference to rely on formal or paid help compared to 54.6% of Mexican-Americans. In terms of cultural values, 73.3% of Mexican-American respondents agreed that care should be provided by family members and not by outsiders as compared to 32.6% of non-Latino White respondents (Min and Barrio 2009). In a US study by Bradley et al. (2004), in the hypothetical case of cognitive and physical impairment, African-American respondents were more likely to use informal LTC (72.3%). In the hypothetical case of dementia or stroke, preferences shifted towards nursing home care or an exclusive use of formal care services (Min 2005, Wolff et al. 2008, Werner and Segel-Karpas 2016, Kasper et al. 2000). With increasing severity of impairment, preferences tended to also shift towards nursing home care (Carvalho et al. 2020, Santos-Eggimann and Meylan 2017). Adult children were more likely to recommend moving to a retirement facility than older adults (Caro et al. 2012).

Block 2.2: Factors influencing preferences for LTC settings for hypothetical patient outcomes

In case of a hip fracture, age (OR: 1.07) and being female (OR: 2.24) increased the likelihood of Japanese-American respondents choosing home healthcare (McCormick et al. 2002). In a sample of 144 Korean-Americans, being female (OR: 0.09), having a higher education (OR: 0.76), and having stronger traditional values (OR: 0.79) significantly increased the likelihood of choosing an informal instead of formal care arrangement for a possible hip fracture (Min 2005). With increasing severity of incontinence, the proportion of people choosing institutional care instead of home-based care increased significantly. Personal incontinence of respondents had no significant impact on their choice of LTC option (Carvalho et al. 2020). In three studies, race played a significant role in explaining preferences. Being African-American (OR: 2.41) and Mexican-American (OR: 4.6) increased the likelihood of turning to an informal caregiver in case of a care dependency situation (Bradley et al. 2004, Min and Barrio 2009). African-American respondents were less positive than white respondents about nursing home staff, trust, and quality (Bradley et al. 2004).

In case of dementia, age (OR: 0.96), being female (OR: 1.41), and marital status (OR: 0.53) significantly affected the intention of Japanese-Americans to use nursing home care (McCormick et al. 2002). In case of Alzheimer's disease, institutional care was preferred by respondents with a higher education, better cognitive status, greater number of illnesses, and not wanting to become a burden on family (Werner and Segel-Karpas 2016). For a hypothetical stroke, independent decision-making style (OR: 7.96) increased the likelihood of choosing a mixed care arrangement instead of informal care. An independent decision-making style (OR: 9.83), having health insurance coverage (OR: 12.72), and greater IADL limitation (OR: 3.53) increased the odds of relying on all formal care (Min 2005).

Block 3: Preferences for the design and structure of specific LTC services

Home-based and community-based care

Six studies investigated people's preferences for home-based services (package A vs. B) for care-dependent people by means of a DCE (Chester et al. 2017, Kaambwa et al. 2015, Kampanellou et al. 2019, Lehnert et al. 2018, Walsh et al. 2020, Chester et al. 2018). While Chester et al. (2017) and Kampanellou et al. (2019) asked British caregivers to people with dementia (PWD) for their appraisal, Kaambwa et al. (2015) and Chester et al. (2018) questioned care-dependent people as well as informal caregivers. Lehnert et al. (2018) and Walsh et al. (2020) surveyed a sample of the general population. Less rotation in the number of caregivers per month were valued as crucial by respondents in the DCE of Chester et al. (2017) and Lehnert et al. (2018). In the DCE by Lehnert et al., respondents were willing to pay up to 213.86€ per month for a regular caregiver. When it comes to dementia care, several studies have found specialized training and communication skills to be the most important attributes for respondents. In a second DCE by Chester et al. (2018), "support with personal feelings and concerns provided by a trained counsellor at home" (Coeff: 0.676, WTP: £31) and "information on coping with dementia provided by an experienced worker at home" (Coeff: 0.592, WTP: £27) were valued the highest. In the study by Walsh et al. (2020) "personalized communication with the person with dementia" (Coeff: 0.54, WTP: €135.45) was found to be one of the most important determinants of person-oriented home-care services for PWD. Guzman et al. (2019) investigated the type of communication skills. It found that non-verbal communication (eye contact, tone of voice, body language) has the greatest significance to the respondents. Especially implementing interventions or procedures promptly and completely (Coeff: 6.763) and listening attentively to verbalization of patients (Coeff: 4.732) was most important.

Loh and Shapiro (2013) assessed the willingness to pay for home- and community-based services (HCBS) was assessed. On average, respondents were willing to pay up to $933.32 for HCBS per months. WTP varied across different HCBS programs, with the highest WTP of $1776.61 documented for Alzheimer Disease Initiative program (Loh and Shapiro 2013). Lehnert et al. (2018) found, respondents of the German DCE by were willing to pay up to €233.71 per month and up to €429.10 per month for high quality care and very high quality of care, respectively. Walsh et al. (2019) found, respondents were willing to pay up to €154.18 for "20 hours per week of publicly funded care hours" and up to €139.64 for "high flexibility of service provision." Furthermore, Kampanellou et al. (2019) found that respondents ranked the attributes "respite care for you is available regularly to fit your needs" (Coeff: 1.292; WTP: £235) and "home care such as personal care and cleaning is provided regularly for as long as needed" (Coeff: 0.933; WTP: £170) to be the most important.

In the study by Kaambwa et al. (2015) the most preferred community aged care (CDC) package that was chosen across all subgroups with a probability of 0.124 was the one with multiple service providers as well as family members to provide day-to-day services. The individual (client) was responsible for managing funds. Li and Wang (2016) found that community- and home-based care services were broken down into five key criteria with a total of 25 indicator layer indexes. According to twelve experts, "living care," "medical and nursing care," and "social participation" were ranked as the most important. An evaluation index system was constructed to evaluate the quality of community home-care services. Another Chinese study by Xiang et al. (2019) found the provision of health care services the most important, of which regular health examination (mean priority: 1.51) and health counselling (mean priority: 2.46) were the most important. Culture-related activities were judged as the least important by the respondents, although it was deemed slightly crucial by the male respondents compared to the women. Respondents' education levels also influenced their answers. Respondents with a higher educational level placed greater importance on daily life assistance.

Long-term care facilities

Three studies examined people's preferences for LTC facilities or nursing homes by means of a DCE (Milte et al. 2018b, Sawamura et al. 2015, Song et al. 2020). In an Australian study by Milte et al. 2018b, residents of nursing homes as well as family members as proxies were surveyed; the study focused on food preferences. The most important attribute of respondents was the taste of the food, whereby it was judged that it is crucial for the food that is provided to have an excellent taste (Coeff: 0.558, WTP: $24 per week). In the Japanese DCE by Sawamura et al. (2015), respondents had to choose between facility A and B for two different patient profiles, one with dementia and the other one with a fracture. Respondents valued the facility where relocation was not required as the highest even when the health of the patient deteriorates (*dementia* coeff: 1.67, *fracture* coeff: 1.36). Respondents with personal caregiving experience showed significantly greater preference for the availability of individual choice of daily schedule and meals. In the Chinese study by Song et al. (2020), older adults with the intention or willingness to live in a nursing home were asked to choose either between nursing homes A and B or neither of the options. The most important attributes for respondents were “location” and “care service”. The respondents preferred inner suburbs and regarded good care service as important.

In a large study by Roberts and Saliba (2019), assessment data of nursing homes was used to rank 16 daily care and activity services on a Likert scale from one to five. The latent class model showed that preferences could be grouped into four classes, namely “important” (38.3%), “activity” (27.1%), “care” (24.1%), and “unimportant” (10.4%). Race, ethnicity, cognition, and depression were found to be predicting values to determine the group to which the respondents were most likely to belong. African-American race and Hispanic ethnicity were predictors of membership to the first group, which ranked almost all care and activity preferences as important. Cognitive impairment and depression were predictive factors of belonging to the fourth group, in which respondents ranked more than half of daily care and activity preferences as unimportant.

In a survey study by Abbott et al. (2018), changes in preferences of 255 nursing home residents were examined over a period of three months. Sixteen of 72 preferences were rated as very or somewhat important by 90% or more of the residents. These preferences fell predominantly into the domain of self-dominion (n = 9) and enlisting others in care (n = 4). A total of 96.50% of respondents preferred having staff show respect to nursing home residents. When asked again after three months, the average agreement rate was 59% although 68 of 72 preferences had 70% or higher stability over the time period. Results reveal that residents who report high levels of importance at baseline are likely to report the same high preferences after the time period of three months. In a study by Przybyla et al. (2019), 214 senior Polish citizens were surveyed regarding their housing preferences. Willingness to move to housing options better tailored towards limited mobility was found in respondents living in larger cities. Based on the answers of the respondents, the preferred facilities at a senior housing estate included a 24h medical care service (63%), a guarded estate (50%), having house cleaning services (48%), and a canteen (47%). A live-in caregiver was judged as important by less than 20% of respondents.

Informal care

Mentzakis et al. (2011) conducted a DCE in Scotland with 209 informal caregivers to estimate monetary valuations for various informal care tasks. Initially, respondents were asked to choose between two hypothetical informal care situations, with the opportunity to opt out in a second step and let a person of their choice take over. A three-class model was fitted and illustrated preference heterogeneity between these three groups. Monetary compensation to the caregiver was judged as more important by younger respondents than older adults. For the first class, the attribute "household tasks" was the most important, with the lower the number of hours of household tasks per week being preferred (Coeff: -0.0109). For the second and third class, "personal care" was the most important attribute, where a lower number of hours of personal care per week was preferred (Coeff: -0.0232 and -0.0704 respectively). Willingness to accept values were additionally calculated. For class 1, the only statistically significant value was for household tasks being valued £0.6 per hour. For class 2, a per hour value of £0.38 for personal care was estimated.

Several studies tried to explore the value of informal care by estimating the willingness-to-pay (WTP) for a reduction in informal caregiving time through contingent valuation method (Gervès et al. 2013, Gustavsson et al. 2010, Fu et al. 2019, Liu et al. 2020, König and Wettstein 2002). Three of these studies (Gustavsson et al. 2010, Gervès et al. 2013, König and Wettstein 2002) focused on informal care for Alzheimer's disease or other mental disorders. Gervès et al. (2013) surveyed French informal caregivers of elderly care recipients with cognitive impairments. The authors found that negative influences on caregiver's morale was associated with the ability of respondents to estimate a WTP value for a 1h reduction in care time. About 45% of the respondents were, however, unable to estimate a WTP value; 19% were willing to pay ≤ €13, 23% between > €13 and ≤ €18 and 13% were willing to pay more than €18 to be replaced for one hour. Gustavsson et al. (2010) surveyed a total of 517 informal caregivers of elderly care recipients in four countries. Mean WTP was calculated for a 1h reduction in care need per day. For the UK, Spain, Sweden, and the US, the estimated values were £105, £121, £59 and £144 per month, respectively. In a Swiss study by König and Wellstein (2002), 109 pairs of informal caregivers and PWD were interviewed. On average, informal caregivers of the sample were willing to pay 57,500 CHF (US$ 38,000) for the complete elimination of burden and around SRF 2,200 (US$ 1,500) per year for a reduction of self-rated burden from moderate to low. For a hypothetical cure, caregivers were willing to pay up to 29% of their wealth and up to 23% to prevent future worsening of the disease. In a Chinese study by Liu et al. (2020), WTP and WTA values for 1h reduction or increase of the least preferred care tasks of 371 informal caregivers were estimated. The average WTP of the respondents for a 1h reduction of the least-preferred care task per week was 25.31 CNY. The minimum WTA for having to provide another hour of their least-preferred care task per week was 38.66 CNY. In a study by Fu et al. (2019) the number of co-payment respondents were willing to pay for voucher schemes in Hong Kong was investigated. Older age, greater financial resources, and a positive attitude towards voucher schemes resulted in a higher WTP of respondents.

- Insert table 3 here -

Block 4: Impact of LTC services on care-related quality of life and caregiver's outcomes

Different instruments have been developed to measure care-related quality of life and caregiver's outcomes to be used in economic evaluations. This provides an indirect measure of what caregivers wish for their LTC situation to look like. One of these preference-based index instruments is the *Carer Experience Scale* that was designed to capture the caring experience and consists of six domains, each with three levels. Al-Janabi et al. (2011) conducted a BWS experiment to estimate index values for England. For the surveyed informal caregivers, being able to do most of the activities you want outside caring (Coeff: 4.41) and getting a lot of support from family and friends (Coeff: 4.08) were selected most often as best.

The *Consumer Choice Index – Six Dimension* (CCI-6D) instrument was developed in Australia to assess the quality of care in nursing homes. Milte et al. (2018) generated a scoring algorithm for the instrument by means of a DCE with 126 residents of nursing homes and 416 family member proxies. Always having the room set up to make the resident feel "at home" was the most important for residents (Coeff: 0.616). While this was equally important to family members (Coeff: 0.623), the most important item for family members was that care staff are always able to spend time with their care-dependent family member (Coeff: 0.648). The authors recommend using the resident scoring algorithm, as they have live experience and their preferences showed greater consistency across answers (Milte et al. 2018a).

- Insert table 4 here -

Results of the quality appraisal

The results of the quality assessment are presented in Table 5. According to the checklist, most studies were deemed to have a good or very good quality. Three studies adequately addressed all five elements of the PREFS Checklist, and a further 46 addressed four out of five elements. Most often, studies did not report any evidence on differences between responders and non-responders of the sample, thereby neglecting to adequately assess potential selection bias. As preference studies often do not possess information on non-responders, other reviews have decided to disregard this area of the checklist from the appraisals (Lepper et al. 2020). Seventeen additional studies adequately reported three out of five elements of the checklist. However, only two studies adequately reported on less than three elements.

- Insert table 5 here -

Discussion

The aim of this systematic review was to summarize and synthesize available evidence on LTC preferences of older adults in need of care. Sixty-eight international peer-reviewed studies applying SP methods to elicit preferences were included and relevant results were extracted. While this review focused exclusively on quantitative SP methods, the heterogeneous results of the included studies reflect the complexity of LTC. Even when the same methodology was applied, the studies differed with regard to their research focus, study population, sample size, analysis model, and study design. Studies conducted in 19 different countries were included, with a majority of studies conducted in Asia dealt with rapidly ageing populations. The overview of attributes and levels used in the choice-based elicitation techniques (DCE, BWS, CA) provide an important impression on how the studies operationalized LTC and measured related preferences, as the choice of attributes is usually substantiated by extensive literature reviews and/or qualitative interviews with the target population.

Irrespective of the heterogeneity of studies, some consistent findings emerged. When presented with a set of LTC options, the majority of study participants preferred to “age in place” and make use of home-based services or informal care by family members in case of becoming care-dependent. Especially for short-term or mild-to-moderate care needs (e.g. hip fracture), they generally preferred informal caregiving with some professional assistance if needed. Remaining in one’s own home was linked with maintaining independence, autonomy, control, and their social contacts. With increasing care-dependency needs, a shift in the preferences of study participants across all studies could be noticed towards the exclusive use of formal LTC services or nursing home care. For dementia patients, especially, nursing home care or a regular formal care provider at home was deemed important by respondents. Nevertheless, nursing home care was associated by many with a loss of freedom, independence, and dignity but preferred by some to not impose on family members in case of a greater care-dependency. Next to the severity of care needs, a few other independent variables were shown to influence LTC preferences, while none showed consistent effects across all studies. Being female, married with children, and already living with a partner or their children increased the likelihood of preferring informal or home-based care. A higher income, higher educational level, being unmarried or widowed, poorer health status, and having provided informal care in the past increased the likelihood of choosing nursing home care in the future.

The choice-based elicitation techniques showed that for home-based services, quality of care and less rotation in the number of caregivers per month were deemed to be crucial. In the selection of attributes, home-based packages tailored to informal caregivers to PWD placed a larger focus on the availability of respite and relaxation opportunities as well as sufficient support and coping strategies to deal with the disease. Specialized training and communication skills as well as support with personal feelings were very important to informal caregivers. For the design of LTC facilities, location, care services, individual choice of daily schedule, and excellent taste of served food were found to be the most important attributes for respondents. Even when focusing on one LTC service, attributes and levels differed greatly between studies. Nevertheless, the cost of services in terms of a co-payment played an important role and was integrated as an attribute in each of the 12 DCE studies. Additionally, several contingent valuation studies assessed the value of informal care by estimating the willingness-to-pay for a reduction in informal caregiving time.

Among all the choice-based elicitation techniques, DCE was mostly applied, enabling not only a ranking of the importance of attributes but also an assessment of which trade-offs respondents were willing to make for certain attributes. The use of conjoint analysis, AHP, DCE, and BWS to elicit LTC preferences is a relatively recent development as the vast majority of these studies have been published between 2015 and 2020. A major concern in the design and implementation of a DCE or conjoint analysis design is its complexity, comprehensibility, and feasibility. The fact that in more than 50% of these studies, older adults in need of care or older hospital patients were surveyed, sometimes in addition to informal caregivers, shows that these types of stated preference methods are not only suitable for targeting the general population. Preference elicitation techniques in the field of older adult care have largely been cross-sectional, measuring preferences at a single point in time. Thus, little is known about the changes in preferences across time and generations. The two studies in this review examining changes in preferences have done so in a period of three months or one year. Although extremely resource-intensive, further longitudinal studies could help understand changes in preferences.

Other reviews have tried to synthesize evidence on LTC preferences of dementia patients (Lepper et al. 2020), institutionalization factors for entering a nursing home for older adults (Luppa et al. 2010) or instruments for measuring outcomes within aged care (Bulamu et al. 2015). Such reviews underline the purpose of trying to reduce the complexity within the field of LTC by attempting to systematically reveal and condense the heterogeneity of results and studies. This systematic review builds upon the recent scoping review by Lehnert et al. (2019) by additionally capturing the period from February 2016 to October 2020 and including preferences for nursing home as well as dementia care. We included a total of 34 additional studies from 2016 to October 2020. The inclusion of these recent studies showcase the very dynamic research interest in LTC preferences. Additionally, two-thirds of the included DCE and conjoint analyses were conducted in this period. Such elicitation techniques have considerably increased in the last few years as a way to quantify preferences (Soekhai et al. 2019).

Limitations

Our study has several limitations. Our search strategy was limited to studies published in German or English after 2000. Furthermore, we exclusively searched in two major databases and focused on peer-reviewed studies. No grey literature was searched. Therefore, certain studies might have been missed.

Implications for research and policy

In the design of LTC systems, the demand for preference data has increased over the last few years as a way to integrate people’s priorities, needs and expectations. National governments need to establish sustainable and affordable LTC systems to evolve with the on-going demographic developments. The heterogeneous methods and LTC operationalizations used in the included studies mirror the national LTC systems and their confrontation with LTC in general. Thus, comparing preferences across countries is onerous. National preference data should be consulted especially for improving policies and LTC structures. Against the background of changing social developments, studies are needed that investigate LTC preferences and needs from the perspective of care-dependent older adults as well as (potential) informal caregivers. Further research is needed on people’s willingness to care as well as their realistic capabilities to ease the immense physical and psychological strain most informal caregivers experience. As informal caregiving is still considered as an essential pillar of most LTC systems, willingness to care as an indicator of the informal care potential of each country is vital. Nevertheless, to avoid caregivers becoming the next generation of care-dependent people due to immense burden, LTC services should ideally be available to supplement informal care right from the beginning. Therefore, preference-based data on how LTC services such as home-based or nursing home care should look like is needed.

Conclusion

Irrespective of the heterogeneity of the included studies, the majority of study participants preferred to “age in place” and make use of home-based services or informal care by family members in case of becoming care-dependent. With increasing severity of functional and especially cognitive impairment, preferences shifted towards an exclusive use of formal care services. Several influencing factors were investigated and reported that might explain such preferences; however, none showed consistent effects across all studies. The inclusion of preference data in the design of LTC systems can constitute an important part in finding sustainable and affordable LTC solutions that specifically support caregivers and mirror the needs and wishes of people in need of care. As shown by the rapid rise in published studies in recent years, the research interest in LTC preferences is consistently increasing. Future research should additionally investigate the changes in preferences across time and generations as well as research people’s willingness to care and their realistic capability to care next to other responsibilities such as occupation and children in the household.

Table 1: Summary of study characteristics (n = 68)

	n (%)	References
Published year		
2000 – 2002	6 (9)	(König and Wettstein 2002, Laditka et al. 2001, McCormick et al. 2002, Pinquart and Sörensen 2002, Kasper et al. 2000, Chan et al. 2000)
2003 – 2005	6 (9)	(Eckert et al. 2004, Kim and Kim 2004, Min 2005, Bradley et al. 2004, Fisher 2003, Wang et al. 2004)
2006 – 2008	5 (7)	(Imamoğlu and Imamoğlu 2006, Jang et al. 2008, Chung et al. 2008, Kim and Choi 2008, Wolff et al. 2008)
2009 – 2011	8 (12)	(Costa-Font et al. 2009, Min and Barrio 2009, Tang et al. 2009, Al-Janabi et al. 2011, Gustavsson et al. 2010, Mentzakis et al. 2011, Nieboer et al. 2010, Chou 2010)
2012 – 2014	4 (6)	(Gervès et al. 2013, Loh and Shapiro 2013, Spangenberg et al. 2012, Caro et al. 2012)
2015 – 2017	8 (12)	(Kaambwa et al. 2015, Robinson et al. 2015, Sawamura et al. 2015, Li and Wang 2016, Fernandez-Carro 2016, Werner and Segel-Karpas 2016, Iwasaki et al. 2016, Guo et al. 2015)
2017 – 2019	25 (38)	(Chester et al. 2017, Fahey et al. 2017, Guzman et al. 2019, Kampanellou et al. 2019, Lehnert et al. 2018, Milte et al. 2018a, Milte et al. 2018b, Fu et al. 2019, Liu et al. 2019, Rong et al. 2019, Zeng et al. 2019, Roberts and Saliba 2019, Filipovič Hrast et al. 2019, Przybyła et al. 2019, Chester et al. 2018, Abbott et al. 2018, Hajek et al. 2017, Santos-Eggimann and Meylan 2017, Qian et al. 2018, Qian et al. 2017, Zhang et al. 2017, Huang et al. 2018, Fu et al. 2017, Kasper et al. 2019, Xiang et al. 2019)
2020	6 (9)	(Liu et al. 2020, Song et al. 2020, Carvalho et al. 2020, Walsh et al. 2020, Wei and Zhang 2020, Dong et al. 2020)
Country		
Australia	4 (6)	(Kaambwa et al. 2015, Milte et al. 2018a, Milte et al. 2018b, Chan et al. 2000)
China	17 (26)	(Liu et al. 2020, Song et al. 2020, Fu et al. 2019, Liu et al. 2019, Rong et al. 2019, Zeng et al. 2019, Xiang et al. 2019, Li and Wang 2016, Qian et al. 2018, Tang et al. 2009, Wei and Zhang 2020, Qian et al. 2017, Zhang et al. 2017, Huang et al. 2018, Dong et al. 2020, Fu et al. 2017, Chou 2010)
France	1 (1)	(Gervès et al. 2013)
Germany	3 (4)	(Lehnert et al. 2018, Hajek et al. 2017, Spangenberg et al. 2012)
Ireland	1 (1)	(Walsh et al. 2020)
Israel	1 (1)	(Werner and Segel-Karpas 2016)
Korea	2 (3)	(Kim and Kim 2004, Kim and Choi 2008)
Netherlands	1 (1)	(Nieboer et al. 2010)
United Kingdom	7 (10)	(Al-Janabi et al. 2011, Chester et al. 2017, Kampanellou et al. 2019, Mentzakis et al. 2011, Robinson et al. 2015, Chester et al. 2018, Fahey et al. 2017)
United States of America	18 (26)	(Roberts and Saliba 2019, Abbott et al. 2018, Eckert et al. 2004, Imamoğlu and Imamoğlu 2006, Jang et al. 2008, McCormick et al. 2002, Min 2005, Min and Barrio 2009, Bradley et al. 2004, Laditka et al. 2001, Loh and Shapiro 2013, Wolff et al. 2008, Kasper et al. 2000, Kasper et al. 2019, Fisher 2003, Iwasaki et al. 2016, Caro et al. 2012, Guo et al. 2015)
Philippines	1 (1)	(Guzman et al. 2019)
Poland	1 (1)	(Przybyła et al. 2019)

Switzerland	3 (4)	(Carvalho et al. 2020, Santos-Eggimann and Meylan 2017, König and Wettstein 2002)
Slovenia	1 (1)	(Filipovič Hrast et al. 2019)
Spain	2 (3)	(Costa-Font et al. 2009, Fernandez-Carro 2016)
Taiwan	2 (3)	(Chung et al. 2008, Wang et al. 2004)
Japan	1 (1)	(Sawamura et al. 2015)
Multiple Countries	2 (3)	(Gustavsson et al. 2010, Pinquart and Sörensen 2002)
Study Population		
Care-dependent older adults	8 (12)	(Fu et al. 2019, Roberts and Saliba 2019, Abbott et al. 2018, Kim and Kim 2004, Wolff et al. 2008, Guzman et al. 2019, Kasper et al. 2000, Kasper et al. 2019)
Informal caregivers or family members as proxy	8 (12)	(Al-Janabi et al. 2011, Chester et al. 2017, Gervès et al. 2013, Gustavsson et al. 2010, Kampanellou et al. 2019, Mentzakis et al. 2011, Liu et al. 2020, Laditka et al. 2001)
Older hospital patients *(> 60 years of age)*	2 (3)	(Fahey et al. 2017, Robinson et al. 2015)
General population (*most often subpopulation: older adults > 65 years*)	39 (57)	(Lehnert et al. 2018, Nieboer et al. 2010, Rong et al. 2019, Walsh et al. 2020, Hajek et al. 2017, Carvalho et al. 2020, Filipovič Hrast et al. 2019, Liu et al. 2019, Song et al. 2020, Sawamura et al. 2015, Przybyła et al. 2019, Xiang et al. 2019, Zeng et al. 2019, Santos-Eggimann and Meylan 2017, Costa-Font et al. 2009, Eckert et al. 2004, Fernandez-Carro 2016, Imamoğlu and Imamoğlu 2006, Jang et al. 2008, McCormick et al. 2002, Min 2005, Min and Barrio 2009, Pinquart and Sörensen 2002, Qian et al. 2018, Wei and Zhang 2020, Werner and Segel-Karpas 2016, Bradley et al. 2004, Chung et al. 2008, Spangenberg et al. 2012, Qian et al. 2017, Zhang et al. 2017, Huang et al. 2018, Dong et al. 2020, Fu et al. 2017, Chan et al. 2000, Fisher 2003, Chou 2010, Iwasaki et al. 2016, Guo et al. 2015)
Experts	1 (1)	(Li and Wang 2016)
Multiple groups of study participants	10 (15)	(Chester et al. 2018, Kaambwa et al. 2015, Milte et al. 2018a, Milte et al. 2018b, König and Wettstein 2002, Tang et al. 2009, Kim and Choi 2008, Loh and Shapiro 2013, Wang et al. 2004, Caro et al. 2012)
Sample size		
< 100	6 (9)	(Chester et al. 2017, Robinson et al. 2015, Xiang et al. 2019, Li and Wang 2016, Imamoğlu and Imamoğlu 2006, Guo et al. 2015)
Between 100 and < 300	17 (25)	(Al-Janabi et al. 2011, Mentzakis et al. 2011, Fahey et al. 2017, Gervès et al. 2013, Guzman et al. 2019, Milte et al. 2018b, Song et al. 2020, Przybyła et al. 2019, Kaambwa et al. 2015, Chester et al. 2018, Abbott et al. 2018, Kampanellou et al. 2019, König and Wettstein 2002, Min 2005, Min and Barrio 2009, Laditka et al. 2001, Caro et al. 2012)
Between 300 and < 500	11 (16)	(Sawamura et al. 2015, Liu et al. 2020, Rong et al. 2019, Jang et al. 2008, Werner and Segel-Karpas 2016, Bradley et al. 2004, Loh and Shapiro 2013, Wolff et al. 2008, Chan et al. 2000, Fisher 2003, Iwasaki et al. 2016)
Between 500 and < 1000	11 (16)	(Filipovič Hrast et al. 2019, Walsh et al. 2020, Gustavsson et al. 2010, Fu et al. 2019, Liu et al. 2019, Milte et al. 2018a, Costa-Font et al. 2009, Tang et al. 2009, Chung et al. 2008, Qian et al. 2017, Huang et al. 2018)
Between 1000 and < 2000	14 (21)	(Lehnert et al. 2018, Nieboer et al. 2010, Zeng et al. 2019, Hajek et al. 2017, Eckert et al. 2004, Pinquart and Sörensen 2002, Spangenberg et al. 2012, Dong et al. 2020, Fu et al. 2017, Kasper et al. 2000, Kasper et al. 2019, Wang et al. 2004, Kim and Kim 2004, Kim and Choi 2008)
≥ 2000	9 (13)	(Carvalho et al. 2020, Roberts and Saliba 2019, Santos-Eggimann and Meylan 2017, Fernandez-Carro 2016, McCormick et al. 2002, Qian et al. 2018, Wei and Zhang 2020, Zhang et al. 2017, Chou 2010)

Method		
Analytic hierarchy process	1 (1)	(Li and Wang 2016)
Best-worst scaling	1 (1)	(Al-Janabi et al. 2011)
Contingent valuation	6 (9)	(Gervès et al. 2013, Gustavsson et al. 2010, Liu et al. 2020, Fu et al. 2019, König and Wettstein 2002, Loh and Shapiro 2013)
Conjoint analysis	3 (5)	(Fahey et al. 2017, Guzman et al. 2019, Robinson et al. 2015)
Discrete choice experiment	12 (18)	(Chester et al. 2017, Kaambwa et al. 2015, Kampanellou et al. 2019, Lehnert et al. 2018, Mentzakis et al. 2011, Milte et al. 2018a, Milte et al. 2018b, Nieboer et al. 2010, Sawamura et al. 2015, Song et al. 2020, Chester et al. 2018, Walsh et al. 2020)
Time-trade off	1 (1)	(Guo et al. 2015)
Vignette	11 (16)	(Bradley et al. 2004, Carvalho et al. 2020, Kasper et al. 2000, Kasper et al. 2019, McCormick et al. 2002, Min and Barrio 2009, Min 2005, Santos-Eggimann and Meylan 2017, Werner and Segel-Karpas 2016, Wolff et al. 2008, Caro et al. 2012)
Ranking	1 (1)	(Xiang et al. 2019)
Rating	10 (15)	(Abbott et al. 2018, Chan et al. 2000, Filipovič Hrast et al. 2019, Hajek et al. 2017, Imamoğlu and Imamoğlu 2006, Iwasaki et al. 2016, Laditka et al. 2001, Roberts and Saliba 2019, Tang et al. 2009, Eckert et al. 2004)
Questions with pre-specified categories (single choice, binary choice)	22 (32)	(Chou 2010, Dong et al. 2020, Huang et al. 2018, Jang et al. 2008, Kim and Kim 2004, Przybyła et al. 2019, Qian et al. 2017, Qian et al. 2018, Fisher 2003, Chung et al. 2008, Costa-Font et al. 2009, Fernandez-Carro 2016, Fu et al. 2017, Kim and Choi 2008, Liu et al. 2019, Pinquart and Sörensen 2002, Rong et al. 2019, Spangenberg et al. 2012, Wang et al. 2004, Wei and Zhang 2020, Zeng et al. 2019, Zhang et al. 2017)
Administration of survey		
Postal/Paper (*self-administered*)	15 (22)	(Al-Janabi et al. 2011, Mentzakis et al. 2011, Sawamura et al. 2015, Carvalho et al. 2020, Roberts and Saliba 2019, Santos-Eggimann and Meylan 2017, Imamoğlu and Imamoğlu 2006, Jang et al. 2008, Pinquart and Sörensen 2002, Tang et al. 2009, Laditka et al. 2001, Zhang et al. 2017, Chan et al. 2000, Iwasaki et al. 2016, Przybyła et al. 2019)
Online (*self-administered*)	3 (4)	(Nieboer et al. 2010, Walsh et al. 2020, Costa-Font et al. 2009)
Face-to-face or phone interviews (*participants were able to ask questions*)	45 (66)	(Chester et al. 2017, Fahey et al. 2017, Gervès et al. 2013, Gustavsson et al. 2010, Guzman et al. 2019, Kaambwa et al. 2015, Milte et al. 2018a, Milte et al. 2018b, Robinson et al. 2015, Liu et al. 2020, Rong et al. 2019, Zeng et al. 2019, Xiang et al. 2019, Filipovič Hrast et al. 2019, Li and Wang 2016, Liu et al. 2019, Abbott et al. 2018, Hajek et al. 2017, Eckert et al. 2004, Fernandez-Carro 2016, Kim and Kim 2004, König and Wettstein 2002, McCormick et al. 2002, Min 2005, Min and Barrio 2009, Qian et al. 2018, Wei and Zhang 2020, Werner and Segel-Karpas 2016, Bradley et al. 2004, Chung et al. 2008, Kim and Choi 2008, Loh and Shapiro 2013, Spangenberg et al. 2012, Wolff et al. 2008, Qian et al. 2017, Huang et al. 2018, Dong et al. 2020, Fu et al. 2017, Kasper et al. 2000, Kasper et al. 2019, Fisher 2003, Wang et al. 2004, Chou 2010, Fu et al. 2019, Guo et al. 2015)
Multiple techniques	5 (7)	(Chester et al. 2018, Kampanellou et al. 2019, Lehnert et al. 2018, Song et al. 2020, Caro et al. 2012)

Table 2: Included studies using other stated preference techniques (n = 33)

Author(s), year	Country	Population	Study objective	Method	Type of measurement	Main results
Abbott et al., 2018	United States	255 nursing home residents	To examine the change in nursing home residents' importance ratings of everyday living preferences over time.	Rating	72 preferences for everyday living from five domains: 1. *Self-dominion/autonomy in care* (e.g. taking care of personal belongings) 2. *Enlisting others in care* (e.g. be involved in discussions about your care) 3. *Leisure and diversionary activities* (e.g. watching TV, doing outdoor tasks) 4. *Social contact (*e.g. having regular contact with friends) 5. *Growth activities* (e.g. keeping up with the news)	Six most important preferences (%): 1) Have staff show you respect (96.50%) 2) Take care of your personal belongings or things (95.70%) 3) Have staff show they care about you (95.20%) 4) Have regular contact with family (93.30%) 5) Do what helps you feel better when you are upset (93.20%) 6) Choose who you would like involved in discussions about your care (92.90%)
Chan, Parsons & Piterman (2000)	Australia	431 randomly selected members of the Chung Wah Association, Western Australia.	To examine Chinese attitudes to institutional care of their aged and to identify the factors that influence these attitudes.	Rating	Dependent variable: Attitudes towards institutional care for the elderly Independent variables: age, gender, education, social/cultural values, migration to Australia, country of origin, length of residence, occupation	54% of respondents would not institutionalize their non-disabled elderly, 21% would, 24% remained neutral. 86% of respondents would place their disabled elderly in an institutional care setting. Disabled was defined as a person who cannot live independently without help. Likelihood of institutionalization increased for families with no other person to help and different health factors*(likelihood score): unable to dress (2.4), unable to walk (2.2), unable to bathe (2.2), unable to feed (2.1), urine incontinence (1.9), confused or wandering home (1.9), difficult or violent behavior (1.9), fecal incontinence (1.8)
Chapleski, Sobeck & Fisher (2003)	USA	252 elders age 55 and older and 74 middle generation children of Great Lakes American Indians	To explore differences in preferences between parent and middle generations for where and how LTC might be provided under conditions of dependency.	Single question with pre-specified categories	Dependent variable: LTC preferences "*If you (your parent) could no longer take care of yourself (himself or herself) without help, which housing option would you prefer*?" Options: 1) Stay in own home with paid helpers, 2) Stay in own home with family help,	Preferred LTC option (Parent generation): 1) Stay in own home with paid helpers (30.4%), 2) Stay in own home with family help (31.3%), 3) Move in with family (4.4%), 4) Assisted living/foster care/group home (22.5%), 5) Nursing home (8.0%) Preferred LTC option (Middle generation): 1) Stay in own home with paid helpers (13.4%), 2) Stay in

		living in 3 residential areas.			3) Move in with family, 4) Assisted living/foster care/group home, 5) Nursing home Independent variables: age, education, sex, place of residence, index of illnesses, traditional culture, behaviors and attitudes related to LTC planning, language fluency	own home with family help (46.3%), 3) Move in with family (31.3%), 4) Assisted living/foster care/group home (5.9%), 5) Nursing home (3.1%) Preference for home care, Elder cohort*: female (OR: 2.08), traditional culture (OR: 1.25)
Chung et al., 2008	Taiwan	562 elderly people aged ≥ 65 years from 7 counties/cities in northern Taiwan	To investigate the preferences of the elderly in northern Taiwan with regard to various types of LTC services.	Single question with pre-specified categories	Dependent variable: "*If you needed LTC services, taking every factor into practical consideration, which kind of LTC would you feel more inclined to accept*?" - 1) Institutional care, 2) Community-based care, 3) Home care Independent variables: *predisposing factors* (age, gender, ethnic origin, marital status, education level, religion, living arrangements, economic condition), *need factors* (health condition, access to medical services, perceived health status, chronic diseases, outpatient visits, emergency visits, hospitalization history, regular physical examinations, preferred medical and rehabilitation services), subject's understanding of and attitudes toward available LTC services	Preferred type of LTC: 1) Institutional care (16.72%), 2) Community-based care (9.61%), 3) Home care (73.67%) Home care vs. community-based care*: Visiting medical care team (OR: 2.12), Self-care information and others (OR: 4.39) Home care vs. institutional care*: Visiting medical care team (OR: 0.45)
Chou, 2010	China	20255 older adults	To examine the willingness among older Chinese to live in eldercare institutions and to investigate the social, cultural, health and economic factors associated with such willingness.	Binary choice (yes/no)	Dependent variable: "*Are you willing to live in an eldercare institution, such as an institution for respecting older adults, social welfare institution or senior apartment*?" Independent variables: *predisposing factors* (age, gender, education, marital status, having children, current living arrangement, willingness to live	19.7% of urban respondents were willing to enter a care home compared to 16.6% of rural older Chinese. Factors influencing willingness to enter a care home*: 1) Urban: age (OR: 0.98), female (OR: 1.44), junior high school (OR: 1.28), senior high/technical school (OR: 1.37), college or above (OR: 1.71), willingness to live with children (OR:

					with children, family relations, socio-cultural beliefs and practices, psychological factors, knowledge and opinions), *enabling factors* (presence or local availability of eldercare institutions, monthly pension, savings for old age, self-assessed economic status), *need factors* (ADL, IADL, number of bed-ridden days, self-rated health status)	0.85), family harmony (OR: 0.53), filial piety perceived (OR: 0.81), raising children to ensure eldercare (OR: 0.85), children unreliable for LTC (OR: 1.33), older adults are a family burden (OR: 1.11), feeling of loneliness (OR: 1.11), knowledge of eldercare institutions (OR: 1.87), opinions about eldercare institutions (OR: 2.82), amount of monthly pension (OR: 1.16), amount of savings for old age (OR: 1.13), self-assessed economic status (OR: 0.82); 2) Rural: female (OR: 0.80), married (OR: 1.21), family harmony (OR: 0.71), filial piety perceived (OR: 0.82), raising children to ensure eldercare (OR: 0.74), children unreliable for LTC (OR: 1.32), older adults are a family burden (OR: 0.91), knowledge of eldercare institutions (OR: 1.52), opinions about eldercare institutions (OR: 1.68), IADL score (OR: 0.95), eldercare institutions in the community (OR: 0.64), self-assessed economic status (OR: 0.82)
Costa-Font, Elvira & Mascarilla-Miró, 2009	Spain	729 older adults > 55 years old from a Spanish population sample	To examine ex-ante and current preferences for housing (in old age) and its suitability, given current and future needs and characteristics.	Single question (open ended)	Dependent variable: "*If in the future you were to suffer a restriction in some activities of daily living such as walking, bathing, taking medication or using the telephone, where would you prefer to live*?" Independent variables: Gender, age, housing price, size, income, saving, education, health and disability	Preferred type of residence in case of old-age dependency: 1) In my own home (men: 78.71%, women: 77.78%), 2) In a nursing home or similar (men: 17.67%, women: 15.6%), 3) In a relative's home (men: 3.61%, women: 6.62%) Willingness to move: housing suitability changes with age, women were less likely to prefer moving, 10% increase in housing asset reduced probability of moving by 1.5% Housing improvements: 51% of the 55-60 age-group were prepared to make structural improvements to their dwelling compared to only 18% in the over-80s group
Dong et al., 2020	China	1186 people over the age of 40	To describe willingness of urban and rural residents over the age of 40 to enter	Binary choice (yes/no)	Dependent variable: "*Would you be willing to reside in a care home in the future*?"	34.8% were willing to enter a care home (41.6% of urban participants and 25.8% of rural participants)

			care homes and to examine personal factors which impact willingness.		Independent variables: socio-demographics (age, gender, education, marital status, monthly income, occupation), physical health (chronic diseases), lifestyle and behavior (current residence, smoking, drinking, physical activity)	Willingness associated with*: Being employed (OR: 1.69), Education – high school (OR: 1.99), education – undergraduate or junior college (OR: 1.94), Higher monthly income (OR: 1.72)
Eckert, Morgan & Swamy, 2004	USA	1503 adults of the general population between ages 40 to 70	To disentangle the distribution of preferences for LTC along two dimensions: (1) care as home vs. a place other than home, (2) care provided by family vs. care by others.	Rating	Dependent variables: Preferences for care provided by 1) your family in your home, 2) your family in their home, 3) paid caregivers in your home or community, 4) a resident of an assisted living facility, 5) a resident of a nursing home Independent variables: self-rated health, educational attainment, age, self-reported race, marital status, household income, respondent's sex, additional questions to service familiarity	Preferred type of LTC: 1) your family in your home (63.5%), 2) your family in their home (32.8%), 3) paid caregivers in your home or community (46.6%), 4) a resident of an assisted living facility (30.1%), 5) a resident of a nursing home (10.0%) Preference for care at home: Female (OR: 1.39), very good health (0.39) Preference for care by kin: Education post high school (OR: 1.78), female (OR: 1.55), knowledge of services (OR: 0.86)
Fernández-Carro, 2016	Spain	2535 older adults aged 65 years and over living in private dwellings	To shed light on the preferred residential and care arrangements in later life.	Questions with pre-specified categories	Dependent variables: preferred setting in the case of not needing any kind of support/care and this setting in the case of suffering any disability which may impede the normal development of daily routines Independent variables: socio-demographic, income, health status, current living environment, psychological and attitudinal factors	Preferred residential solution in old age dependency: 1) In own home (21%), 2) Co-residence - relative's home (56%), 3) Co-residence – others (2%), 4) Institutionalization (21%) Preference for co-residence*: Widowed (Coeff: 0.09), living at children's home (Coeff: 0.14), primary school (Coeff: 0.15), savings and assets (Coeff: 0.28), health status (Coeff: 0.11), preference for informal care (Coeff: -0.07), older people need constant support (Coeff: -0.12), older people are active and enjoy life (Coeff: -0.19), older people support other family members (Coeff: -0.14), older people do not have the support of society (Coeff: -0.08) Preference for institutionalization*: Gender (Coeff: -0.06), age 65 (Coeff: 0.06), age 80 (Coeff: -

						0.05), widowed (Coeff: -0.05), university (Coeff: 0.07), health status (-0.08), receiving formal care (Coeff: 0.09), loneliness (Coeff: 0.06), family satisfaction (Coeff: -0.09), preference for informal care (Coeff: -0.14), preference for paid care (Coeff: 0.07), older people need constant support (Coeff: 0.06), older people are a burden (Coeff: 0.09), older people do not have the support of society (Coeff: -0.08)
Fu et al., 2017	China	1090 participants from 4 Chinese cities	To explore and make theoretical sense of older people's LTC needs and to identify the factors influencing LTC needs.	Single question with pre-specified categories	Dependent variable: "*Which mode of LTC would you like to choose*?" – 1) family care, 2) Home- and community-based services (HCBS), 3) institutional care Independent variables: *predisposing characteristics* (age, gender, educational level, marital status, region), *enabling factors* (income, number of children, contact frequency with children), *need factors* (IADL, number of diseases), *psychosocial factors* (intergenerational relationships, unmet care service needs, self-image)	Preferred LTC option: 1) 75.3% family care, 2) 16.7% HCBS, 3) 8.0% institutional care Family care vs. HCBS*: Region – BJ (OR: 0.474), Region – GZ (OR: 0.265), Region – HB (OR: 0.382), Number of children (OR: 1.268), Unmet care needs (OR: 0.936), Self-image (OR: 1.027) Institutional care vs. HCBS*: Currently not married (OR: 2.362), Region – GZ (OR: 0.138), Intergenerational relationships (OR: 0.676), Unmet care service needs (OR: 0.912), Self-image (OR: 1.044)
Filipovic Hrast et al., 2019	Slovenia	930 people ≥ 50 years old	To test the willingness of the elderly to accept various housing options and the attitudes towards the different options.	Rating	Dependent variable: "*Have you considered moving in the future*?" - Attitudes towards living arrangements 1) Old people's home, 2) Sheltered housing, 3) Senior co-housing, 4) Living in a multigenerational residential building, 5) Household groups, 6) Living with another family or individual, 7) Living with a caregiving family for older people Independent variables: education, revenue, current health status, residence, age, type of settlement	Living arrangement (% acceptable): 1) Old people's home (71.7%), 2) Sheltered housing (55.6%), 3) Senior co-housing (25.8%), 4) Living in a multigenerational residential building (32.0%), 5) Household groups (30.6%), 6) Living with another family or individual (11.3%), 7) Living with a caregiving family for older people (7.5%) Associated with*: Education, revenue, current health status, age

Hajek et al., 2017	Germany	1006 older adults aged 65 and over	To investigate the factors associated with preferences for LTC settings in old age in Germany.	Rating	Dependent variable: *"When care is needed, I would like to be cared for…"* 1) at own home, 2) in relatives' homes, 3) in assisted living, 4) in nursing home/old age home, 5) in a foreign country Independent variables: age, sex, living situation, region, education, place of birth, having children, status of health insurance, providing informal care to family or friends	Preferred LTC settings: 1) Home care (n = 866, 87.2%), 2) Care in relatives' homes (n = 319, 32.3%), 3) Care in assisted living (n = 534, 55.6%), 4) Care in nursing home/old age home (n = 310, 32.0%), 5) Care in a foreign country (n = 54, 5.5%) Preference for home care*: provided care for family/friends (OR: 1.600), level of care (OR: 0.189), self-rated health (OR: 0.762) Preference for care in relatives' homes*: female (OR: 0.506), living situation (OR: 0.559), children (OR: 1.610), status of health insurance (OR: 1.566), provided care for family/friends (OR: 1.468), self-rated health (OR: 1.192) Preference for care in assisted living*: apprenticeship/full-time vocational school (OR: 2.984), professional school or trade and technical school (OR: 2.666), university/Fachhochschule/school of engineering (OR: 3.494), level of care (OR: 1.900) Preference for care in nursing home*: German-born (OR: 1.782), self-rated health (OR: 0.850) Preference for care in foreign country*: age (OR: 0.902), apprenticeship/full-time vocational school (OR: 0.246), German-born (OR: 0.184)
Huang et al., 2018	China	670 adults aged 60 and above in the Hezuo community in Chengdu, China	To describe Chinese older adults' willingness to enter LTC facilities and to examine individual factors associated with the willingness.	Binary choice (yes/no)	Dependent variable: "*Are you willing to enter into one of these LTC facilities that integrate medical and social services in the future*?" Independent variables: socio-demographics (age, gender, marital status, education, occupation, income, insurance, living condition, being sick in last two weeks, number and type of chronic diseases, hospitalization in prior year), general well-being index, social support	11.9% were willing to enter LTC facilities for meeting their medical and social service needs. Among those who were willing to enter LTC facilities, 81.2% would prefer going to a facility within 30-minute walking distance from their current residence, 82.5% indicated the need of nursing care, and 90.0% expected a partnership between the LTC facility and a large hospital. Willingness associated with*: Higher household income (OR: 4.55), insurance of urban resident basic medical insurance (OR: 4.80), unemployment (OR: 0.48)

Imamoglu & Imamoglu, 2006	USA	98 respondents with a mean age of 62	To explore attitudes toward and preferences for living in the newly emerging place type of assisted living facilities in comparison to nursing homes.	Rating	Dependent variables: “*In the future, how favorable or unfavorable would you feel about living in the places indicated below*?” (assisted living, nursing home, their own homes) Independent variables: age, gender, educational status, current living arrangements, occupation, current work status	Preferred LTC option: Living at home was most favorable/preferred (mean = 1.06, SD = 0.43), followed by assisted living facilities (mean = 2.43, SD = 1.02) and nursing homes (mean = 4.44, SD = 0.75)
Iwasaki et al., 2016	USA	499 “boomers” (age 51-71 years) in the state of Washington (Japanese-Americans compared to non-Japanese Americans)	To investigate perceptions about future LTC needs and preferences among the baby boomer generation of Japanese-American (JA) relative to non-JA older adults.	Rating	Dependent variables: LTC preferences, knowledge about LTC, LTC experience, expectation for LTC, LTC financial planning Independent variables: age, sex, race, marital status, education and household income, geographical distance to children	Preferred LTC option in old age for JA: remain in their own home (24.03%), move to retirement community (18.78%), move to continuing care retirement community (17.26%), move to a skilled nursing or assisted living (4.57%), live with family member or close friend (4.57%), unsure (38.58%) LTC knowledge: JA were more knowledgeable about the cost of a month’s stay at a NH, more aware that these services would have to be paid out of pocket and more knowledgeable about the prevalence of Alzheimer’s disease than non-JA Financial planning: JA participants were 3.15-fold more likely to have an IRA, 401-K account or an annuity and 2.55-fold more likely to have a LTC insurance policy than non-JA
Jang et al., 2008	USA	427 Korean-American adults aged 60 years or older	To explore predictors of willingness to use a nursing home in Korean American elders.	Binary choice (yes/no)	Dependent variable: Willingness to move to a nursing home Independent variables: *Predisposing factors* (age, gender, educational attainment, length of residence in the USA), *Potential health needs* (medical conditions, functional disability, self-perceived health), *Network-related enabling factors* (marital status, living arrangement, family network, relative living in a NH)	44.7% of the sample were willing to move to a nursing home in the future. Determinants of the willingness to use a nursing home*: poorer self-perceived health (OR: 1.46), having someone close living in a nursing home (OR: 2.80)

Kim & Choi, 2008	Korea	1168 older Korean adults aged 65 or older and their primary caregivers	To examine predictors of older adults' and primary caregivers' willingness to use LTC services.	Binary choice (yes/no)	Dependent variable: "*Who do you think should take care of older parents if they become frail and need care*?" 1) adult children only 2) both adult children and the government 3) the government only; Willingness to use LTC services - 1) home care services 2) nursing home care services Independent variables: *predisposing factors* (age, sex, marital status, education, employment, relationship to older adults, responsibility for care), *enabling factors* (number of children, monthly family income, geographic region), *need factors* (self-rated health, impairments in ADLs and IADLs, cognitive function, chronic conditions, care burden)	Willingness to use (*older adults*): home care (32.4%), nursing home care (16.6%) Willingness to use (*primary caregivers*): home care (40.5%), nursing home care (32.5%) Home care preference associated with*: 1) Older adults: elders saying care responsibility has children and government (ß = 0.76), caregivers saying care responsibility lies with children and government (ß = 0.55), 2) Primary caregivers: married (ß = 0.79), self-rated health as bad (ß = 0.58), care burden (ß = 0.02), caregivers saying care responsibility lies with children and government (ß = 1.53) Nursing home care preference associated with*: 1) Older adults: female (ß = -1.05), Number of children 5+ (ß = -1.30), monthly family income less than 1100 won (ß = 0.77), MMSE score 24-30 (ß = 1.01), Elders saying care responsibility lies with children and government (ß = 1.53), 2) Primary caregivers: middle school or more (ß = 1.06), Number of children 5+ (ß = -0.77), Elders saying care responsibility lies with children and government (ß = 0.62), care burden (0.03), primary caregivers saying care responsibility lies with children and government (ß = 0.96)
Kim & Kim, 2004	Korea	1850 people aged ≥ 65 years with > 1 limitation in ADLs or IADLs or scores <20 on the MMSE	To explore the factors influencing the intention of Korean elderly to use LTC facilities.	Binary choice (yes/no)	Dependent variable: Intention to use LTC facilities Independent variables: *Predisposing factors* (age, sex, marital status, education level, religion), *Enabling factors* (number of children, family structure, family income, place of residence), *Need factors* (self-rated health, ADLs, instrumental ADLs, cognitive level, comorbidity)	18.8% (347) respondents expressed the intention to use LTC facilities. Stronger intention associated with*: younger age (OR: 1), Cristian religion (OR: 1.44), fewer children (OR: 1), lower family income (OR: 1), more chronic comorbidity (OR: 1.59)

Laditka, Pappas-Rogich, Laditka, 2001	USA	169 well-educated, relatively affluent older caregivers	To examine gender differences in attitudes about home and community-based services, service use, interest in services, and barriers to service use.	Rating	Dependent variable: Interest in specific services, Attitudinal questions: preference for informal care, belief in caregiver independence, acceptance of government services Independent variables: age, sex, race, marital status, education, income, self-rated health, information about the care-recipient (age, sex, relationship to caregiver, ADLs, IADLs, frequency of help)	Service interest: Information about community and in-home support services (77.2%), Information about potential financial problems (78.9%), Support from other caregivers (61.1%), Respite care for family member (59.3%), Hospice Care (60.0%), Individual counselling (43.4%), Information about stress management (58.7%), Information about legal options (69.1%) Preferences for Informal care: I would rather use community services than ask for help from family (38.7%), I would rather ask family for help than use community services (56.7%) Belief in Caregiver Independence: I am proud of being able to care for my relative with little help from community services (63.1%), I think I should be able to care for my relative without help from community services (29.3%) Acceptance of Government Services: It is the government's responsibility to help me find ways to care for my relative (21.1%), I believe the government should support more community services to help families care for persons at home (78.1%)
Liu et al., 2019	China	517 elderly from three rural villages (60 years and above)	To explore the factors influencing the willingness of the elderly to receive institutional and community-based eldercare in rural communities in China.	Single question with pre-specified categories	Dependent variable: "*Which are you willing to choose?*" Options: 0) home-based care, 1) living in a nursing home, 2) living in a senior care unit of a hospital, 3) community-based care) Independent variables: socio-demographic information, physical disease, depression, anxiety, daily living activities, concerns toward eldercare in future	Preferred LTC options: 78.3% are willing to receive home-based eldercare, 10.8% institutional eldercare and 8.5% community-based eldercare. Major concerns toward 0: lack of care ability and loss of contact with family members Major concerns toward 1: unaffordable services and fear of being abandoned by children Major concerns toward 3: unaffordability and lack of necessary care
Pinquart & Sörensen, 2002	USA, Germany	558 American seniors and 772 German community-	To investigate preferences for future support by older adults	Questions with pre-specified categories	Dependent variable: Preferences for short- and long-term care: 1) getting help from relatives 2) getting help from friends and acquaintances 3)	Short-term care: 1. *Exclusive use of informal support*: USA (19.0%), GER (32.4), 2. *Exclusive use of formal support*: USA (17.5%), GER (13.7%), 3. *Use*

		dwelling older adults	who live an independent life in the community.		moving in with relatives, 4) getting home health care 5) moving to an assisted living facility 6) moving to a nursing home Independent variables: Deficits in everyday competence, socioeconomic status, informal network, previous receipt of personal care, age, gender, marital status, perceived availability of options	*of mixed support*: USA (59.5%), GER (51.7%), 4. *No support preferences:* USA (4.1%), GER (2.2%) Long-term care: 1. *Exclusive use of informal support*: USA (15.2%), GER (24.9%), 2. *Exclusive use of formal support:* USA (36.0%), GER (29.2%), 3. *Use of mixed support*: USA (43.2%), GER (39.6%), 4. *No support preferences:* USA (5.6%), GER (6.3%)
Pryzbyla, Heldak & Kurtyka-Marcak, 2019	Poland	214 senior citizens ≥ 55 years of age	To identify the willingness of pensioners to move from apartment/house to an apartment/house located in a housing estate.	Binary choice (yes/no)	Dependent variable: willingness to change housing adapted to the needs resulting from mobility limitations, preferences for facilities at senior housing estate Independent variables: gender, age, place of residence, family situation	Willingness to change place of residence: village (yes: 15.5%), city up to 50,000 residents (yes: 12.6%), city up to 100,000 residents (yes: 20.4%), city up to 250,000 residents (yes: 4.9%), city over 250,000 residents (yes: 46.6%) Most popular facilities were: 24h on-call medical care – button in the apartment (63%) and 24h medical care – on call duty at estate (60%)
Qian et al., 2017	China	505 rural single seniors from Shandong, China	To examine the gender difference towards utilization willingness of institutional care among rural single seniors.	Binary choice (yes/no)	Dependent variable: "*Which way of elder care are you willing for?"* – institutional care coded as yes, rest coded as no Independent variables: age, gender, education, number of children, relationship with children, residence, living arrangements, household income, family size, physical health status (self-rated health, non-communicable chronic diseases, ADL), psychological well-being (social support, psychological stress)	5.7% of rural single seniors were willing to use institutional care (9.3% of single male and 3.5% of single female seniors) Associated with*: female (OR: 0.19), living arrangement – with children or others (OR: 0.13), psychological stress (OR: 0.005)
Qian et al., 2018	China	3923 seniors in Shandong	To compare the willingness to use institutional care between empty-nest and non-	Binary choice (yes/no)	Dependent variable: "*Which endowment way are you willing for*?" - Seniors' willingness for institutional care (No = home-based care, community endowments or others)	8.5% of seniors indicate willingness for institutional care. Associated with*: Non-empty nester (OR: 1.0), Empty-nest single (OR: 5.301), Empty-nest couple (OR: 1.547), Junior school or above (OR: 1.617),

			empty-nest seniors in China.		Independent variables: gender, age, education, past occupation, marital status, number of children, relationship with children, residence, self-reported health status, psychological stress, ADL, non-communicable diseases, household income	Poor relationship with children (OR: 2.504), Rural Residence (OR: 0.546), ADL III (OR: 0.577), Household income Q3 (OR: 1.612), Household income Q4 (OR: 2.065)
Roberts & Saliba, 2019	USA	Data set with 244,718 residents ≥ 65 years	To group residents according to similarities in preferences and determine the factors that predict membership in these groups.	Rating	Dependent variable: nursing home preferences (The MDS preference assessment was used, which assesses the importance of 16 daily care and activity preferences using a 5-point Likert scale.) Independent variables: race, gender, cognition, ethnicity, depression	4 classes were determined: 1. “important” (38.3%), 2. “activity” (27.1%), 3. “care” (24.1%), 4. Unimportant (10.4%) Activity vs. care*: African American (OR: 1.6), Hispanic (OR: 2.1), Other (OR: 1.5), female (OR: 1.7), depressed (OR: 0.7), moderate cognitive impairment (OR: 1.5), severe cognitive impairment (OR: 3.1) Important vs. care*: African American (OR: 2.35), Hispanic (OR: 2.95), Other (OR: 1.5), female (OR: 1.6), depressed (OR: 0.65), severe cognitive impairment (OR: 2.0) Important vs. unimportant*: African American (OR: 2.15), Hispanic (OR: 2.1), female (OR: 2.05), depressed (OR: 0.5), severe cognitive impairment (OR: 0.6) Unimportant vs. care*: Other (OR: 1.8), moderate cognitive impairment (OR: 1.6), severe cognitive impairment (OR: 3.4) Activity vs. unimportant*: Hispanic (OR: 1.55), female (OR: 2.1), depressed (OR: 0.5) Activity vs. important*: African-American (OR: 0.7), severe cognitive impairment (OR: 1.5)
Rong et al., 2020	China	306 parents aged > 49 years who lost their only child in these communities:	To understand the elderly care needs of parents who lost their only child.	Questions with pre-specified categories	Dependent variables: “*Which mode of elderly care would you like to choose in the future?*” – 1) community or home care, 2) institutional, community or home care) and “*Whom do you want to look after you in the future?*”	Preferred LTC options: 1) 47.4% parents chose community or home care, 2) 52.6% chose institutional care. Preference associated with*: Higher GDS score (OR 1.179)

		Jinghu, Jiujiang, Yijiang and Sanshan			– 1) family, 2) nurse/nursing home, 3) volunteer) Independent variables: Sex, educational level, marital status, having grandchildren, number of chronic diseases, self-rated health status, monthly income, social support rating scale (SSRS), European Quality of Life-5 Dimensions (EQ-5D), Geriatric Depression scale (GDS)	
Spangenberg et al., 2012	Germany	1445 respondents ≥ 45 years from the general population	To assess wishes and expectations regarding family care.	Questions with pre-specified categories	Dependent variable: Willingness to make use of family resources in case of a care dependency Independent variables: sex, age, family status, education level, family income, living situation, care experience	In case of own need: 62.9% of participants would prefer care provided by relatives and 56.7% would prefer professional care Willingness to use family care associated with*: living together with a partner (OR: 3.65), having children (OR: 3.12), having personal care experiences (OR: 1.35), image of being a burden at old age (OR: 0.79) Perceived willingness of relatives to provide care was influenced by*: geographical distance >50km apart (OR: 0.30), spoken with child about wishes for old age (OR: 2.11), spoken with child about how care should be financed (OR: 1.90), being female (OR: 0.59), spoken with partner about wishes for old age (OR: 2.31)
Tang et al., 2009	China	186 young, 161 middle-aged and 185 older Chinese in Hong-Kong	To explore age-cohort differences on attitudes and intention toward old age home placement.	Rating	Dependent variable: Intention to enter/refer to old age home, attitudes toward old age homes and older people Independent variables: age, gender, marital status, educational attainment	Intention of referring to old age home: young adults (mean: 3.15), middle-aged (mean: 3.31) Intention of entering old age home: older Chinese (mean: 2.08) Intention of referring/entering old age home*: 1) Young adults: beliefs about independence (ß = 0.21), attitudes toward old people (ß = 0.18), attitudes toward old age home (ß = 0.42); 2) Middle-aged: attitudes toward old age home (ß = 0.30); 3) Old-aged Chinese: attitudes toward old age home (ß = 0.33)

Wang et al., 2004	Taiwan	593 elderly people aged ≥ 65 years and 587 caregivers	To examine the preferences of the elderly and their primary caregivers in LTC arrangements.	Single question with pre-specified categories	Dependent variable: “*If you (your elderly family member) needed LTC services, taking every factor into practical consideration, which kind of LTC would you feel more inclined to accept?*” Options: 1) Home care 2) Community care 3) Institutional care Independent variables: gender, age, educational level, marriage status, ethnic origin, religion, residency, monthly income, perceived health status, care resources, receipt of a monthly stipend from the government, care experience	Preferred LTC option (elderly): 1) Home care (73.7%) 2) Community care (9.6%) 3) Institutional care (16.7%) Preferred LTC option (primary caregiver): 1) Home care (68.1%) 2) Community care (12.2%) 3) Institutional care (19.7%) Factors influencing preference for institutional care*: 1) Elderly: ethnic origin - China (OR: 2.15), residential location – other areas (OR: 1.81), No government subsidy (OR: 1.78); 2) Primary caregiver: ethnic origin – China (OR: 2.24), elementary education (OR: 3.79), not harmonious relationship to elderly (OR: 1.66) Factors influencing preference for community-based care*: 1) Elderly: age 65-74 years (OR: 3.12); 2) Primary caregivers: ethnic origin – China (OR: 2.26), not harmonious relationship to elderly (OR: 1.84), no care difficulties (OR: 1.90)
Wei & Zhang, 2020	China	3260 elderly people aged ≥ 60 years	To provide a reference to enable policymakers to optimize resource arrangement and ensure the sustainability of China’s old-age security policy.	Questions with pre-specified categories	Dependent variable: Combination of medical care and Pension in LTC facilities (CMCP) - 1) “*Do you want to live in an LTC facility with CMCP?*”, 2) “*If you live in a CMCP facility, what kind of service would you like to receive?*” Independent variables: *predisposing variables* (age, gender, residence, current living arrangement, educational level), *enabling factors* (occupation, marital status, economic status, primary caregivers, number of children, medical insurance), *personal needs variables* (activities of daily living, feelings of loneliness, self-rated health status)	Preferred LTC options: 12.89% wanted to be admitted to a CMCP nursing facility, 82.01% preferred home-based care and 5.1% preferred community care. Significantly associated with*: Residence – Town (OR: 1.74), Residence – Rural (OR: 2.16), Not married (OR: 1.64), Economic status/expenditures are balanced (OR: 1.64), Economic status – income exceeded (OR: 2.28), Primary caregiver: spouse (OR: 0.32), Primary caregiver: others (OR: 1.77), ADL: relatively independent (OR: 2.13), ADL: Disability (OR: 3.69)

Xiang et al., 2019	China	82 senior citizens living in their original communities	To identify senior citizens' requirements related to 'embedded retirement facilities' (ERFs) – small-scale, multi-functional and community-based care facilities.	Ranking	Ranking of the four main aspects of services (in *cursive*), followed by ranking of 22 detailed services related to each main aspect.	1. *Health care* (1. Regular health examination, 2. Health counselling, 3. Going to the hospital with someone accompanied, 4. General practitioner, 5. Psychological counselling); 2. *Rehabilitation and entertainment* (1. Fitness exercises, 2. Chess and cards playing, 3. Singing and dancing, 4. Massage, 5. Post-operative nursing); 3. *Daily life assistance* (1. Canteens for senior citizens, 2. Room cleaning, 3. Meals on wheels, 4. Laundry, 5. Day care, 6. Purchasing, 7. Full-time nursery, 8. Legal assistance); 4. *Culture-related activities* (1. Reading, 2. Seminars, 3. Painting and calligraphy, 4. Hand-made activities)
Zeng et al., 2019	China	1308 elderly from Chengdu, Chongqing, Guizhou, and Hubei province	To explore the factors that affect LTC needs of the elderly.	Single question with pre-specified categories	Dependent variable: "*Which LTC way do you want to choose*?" – 1) home car, 2) community-based care, 3) institutional care Independent variables: *predisposing characteristics (*age, gender, education level, marital status, regions), *enabling factors* (income level, quantity of children, frequency of connection with children), *need factors* (IADL, quantity of chronic diseases) and *psychological factors* (intergenerational ties, unmet needs for LTC, self-image evaluation)	Preferred LTC option: 75.3% chose home care, 16.6% community-based care and 8.0% institutional care. Institutional care vs. community-based care*: unmarried (OR 2.4801), region – GZ (OR: 0.1449), intergenerational relationships (OR: 0.7098), unmet care service needs (OR: 0.9576), self-image evaluation (OR: 1.0962) Home care vs. community based care*: Region – CQ (OR: 0.4977), Region – GZ (OR: 1.2782), Region – HB (OR: 0.4011), number of children (OR: 1.3314), unmet care service needs (OR: 0.9828), self-image evaluation (OR: 1.0783)
Zhang, Zeng & Fang, 2017	China	14373 participants aged 60 and above	To assess the effects of health status and living arrangements on LTC models among the elderly of Xiamen, China.	Single question with pre-specified categories	Dependent variable: "*Where do you most want to receive LTC*?" – 1) family care, 2) community care, 3) institutional care) Independent variables: *predisposing factors* (age, gender, occupation, edu-	Preferred LTC options: 86.37% home care, 2.86% institutional care, 10.77% community-based care Associated with*: Health status – relatively independent (OR: 1.64), health status – disability (OR: 3.95), living arrangement with child (OR: 0.54), living arrangement –

				cation), *enabling variables* (living arrangements, residence location, marital status, medical insurance, family income, number of children), *need variables* (ADL, chronic diseases, self-rated health, life satisfaction, feelings of aloneness)	spouse and child (OR: 0.67), living arrangement – others (OR: 0.60),

Note: *only statistically significant results are presented* (*)

Table 3: Included studies using contingent valuation techniques (n = 6)

Author(s), year	Country	Population	Study objective	Type of measurement	Main results
Fu et al., 2019	China	536 older adults with different service needs living in Hong Kong	To explore the policy implications of introducing co-payments for LTC services in Hong Kong.	WTP: Payment scale format in questionnaire surveys for elderly respondents. The voucher was put as an alternative mode of service provision to the current provision-in-kind Other variables measured: Attitude toward the voucher scheme, financial condition, family support, sociodemographic characteristics, self-care ability	WTP in HK $ (%): 0 (4.1%), 1-100 (16.6%), 101-300 (9.0%), 301-500 (7.1%), 501-700 (7.6%), 701-900 (10.1%), 901-1100 (9.7%), 1101-1500 (12.1%), 1501-1700 (5.4%), 1701-2250 (10.3%), 2251 or more (8.0%) A positive perception of voucher schemes and a higher income contribute to a higher WTP. Family support plays a vital role and contributes to a higher WTP. Older people expressed a higher WTP for voucher scheme.
Gervés, Bellanger & Ankri, 2013	France	201 informal caregivers providing care to elderly care recipients with cognitive impairments	To explore the influence of intangible impacts of caring on both informal caregivers' ability to estimate their willingness to pay (WTP) to be replaced and their WTP value.	Derived payment card framework (Intangible impacts of caring is approximated by informal caregiver's WTP to be replaced for 1 hour of care)	WTP in € (% of respondents): 'I can't estimate it' (45%), ≤ €13 (19%), between > €13 and ≤ €18 (23%), > €18 (13%)
Gustavsson et al., 2010	United Kingdom, Spain, Sweden, United States	517 primary carers of patients with Alzheimer's disease	To explore the value of informal care using contingent valuation and more specifically to estimate the WTP of informal carers providing care	Hypothetical scenarios, in which caregivers would be given an opportunity to pay for a reduction in caregiving time	Mean WTP for a 1h reduction in care need per day was estimated to be £105, £121, £59 and £144 per month for UK, Spain, Sweden and US, respectively.

			to a person with Alzheimer’s disease, for reductions in patient care need.		
König & Wettstein, 2002	Switzerland	109 pairs of patients with dementia and their spouse or relative caregivers	To estimate the willingness-to-pay of informal caregivers for a reduction of their burden.	WTP for three hypothetical dementia treatments: (1) Prevent future worsening (2) Hypothetical cure (3) Reduction of burden Payment card format used, followed by an open question of the max. % of wealth participants were willing to pay	WTP in monetary amounts and % of wealth: 1) *Stabilization* (preventing future worsening): Median: 35000 CHF and 10% of wealth, Mean: 98119 CHF and 22.5% of wealth 2) *Hypothetical cure:* Median: 35000 CHF and 20% of wealth, Mean: 161682 CHF and 29.4% of wealth 3) *No burden:* Median: 15000 CHF and 10% of wealth, Mean: 57500 CHF and 17.0% of wealth
Liu et al., 2020	China	371 caregivers of dependent elderly people in Shanghai	To evaluate the economic value of informal caregiving in Shanghai and identify the associated factors of WTP and WTA of caregivers.	Maximum amount of money willing to pay for 1 hour of reduction in caregiving and minimum sum of money willing to accept for 1 extra hour of the least-preferred care task per week	Average maximum WTP for 1 hour decreasing in least-preferred care task was 25.31 CNY (SD = 18.10) and minimum WTA for 1 hour increasing in least-preferred care task was 38.66 CNY (SD = 22.95)
Loh & Shapiro, 2013	USA	409 clients of HCBS programs in Florida, including 109 proxy respondents	To assess the maximum dollar amount HCBS enrolees or eligible applicants are willing to pay as a measure of the value of the services to them.	Sequence of dichotomous choice or close-ended question formats followed by an open-ended follow-up question to elicit WTP. Bidding prices were randomly selected for each respondent from a range of values between $100 and $1200 with $50 increments.	Overall WTP for HCBS per month based on types of affordability: 1) Actual affordability: median WTP ($900.55), mean WTP ($933.32) 2) Hypothetical affordability: median WTP ($637.98), mean WTP ($707.13) 3) Self-reported WTP: mean WTP ($564.80)

Table 4: Included studies using choice-based (trade-off) techniques (n = 29)

Author(s), year	Country	Population	Study objective	Method	Choice Scenario	Attributes	Levels
Al-Janabi, Flynn & Coast, 2011	United Kingdom	162 unpaid carers for people over 65 years	To estimate preference-based index values for a profile measure of the caring experience (the	BWS	Informal caregiving scenarios	1. Activities outside caring 2. Support from family and friends 3. Assistance from organizations and the government 4. Fulfilment from caring 5. Control over caring	Most, Some, Few A lot of, Some, Little A lot of, Some, Little Mostly, Sometimes, Rarely Most, Some, Few

			Carer Experience Scale).			6. Getting on with person you care for	Mostly, Sometimes, Rarely
Bradley et al., 2004	USA	200 African-American and 200 White respondents ≥ 65 years, who had been hospitalised in the last year	To examine empirical difference in intended use of long-term care by African-American and white elderly and to assess how factors medicate the effect of race/ethnicity on intended use of informal LTC.	Vignette	Intended use of informal LTC in case of 2 hypothetical scenarios (patient outcomes)	1. Severity of disability	Cognitive (problems recalling events and recognizing familiar surroundings and people), physical and cognitive (unable to take a bath or use the toilet by yourself and cognitive impairment)
Caro et al. (2012)	USA	215 older adults with median age of 73 and 51 adult children	To contribute to an understanding of the basis upon which older people and their adult children make decisions about residential options.	Vignette	Suitability of LTC options for four hypothetical outcomes	1. Functional status	A visiting nurse has assessed name's physical and functional abilities. Name has no difficulty in climbing a flight of stairs. She can drive her car safely under any normal road and weather conditions. She does not have trouble doing light housework, A visiting nurse has assessed name's physical and functional abilities. Name is able to climb a flight of stairs but must use the handrail. She can drive her car safely but only within town and during daytime hours. She has some trouble doing light housework by herself, A visiting nurse has assessed name's physical and functional abilities. Name has difficulty in climbing one flight of stairs. She is not able to drive. She cannot do light housework by herself.
						2. Social network strength	Name has many good friends who live in her neighborhood, Name knows only a few people in the neighborhood; most of her friends have died or moved away,

							Name’s best friend lives in the retirement community that she is considering.
						3. Current housing characteristics	Name lives in a house that has many features that make it safe and attractive for an older person, Name lives in a house with features that make it challenging for an older person.
						4. Retirement community quality	Name is considering moving into a luxury retirement community in her area, Name is considering a move to a popular retirement community.
						5. Financial implications	Name’s financial planner has determined that her monthly spending money would increase by $194 if she moves to the retirement community. Name’s financial planner has determined that her monthly spending money would increase by $85 if she moves to the retirement community, Name’s financial planner has determined that her monthly spending money would decrease by $80 if she moves to the retirement community, Name’s financial planner has determined that her monthly spending money would decrease by $175 if she moves to the retirement community
						6. LTC arrangements	Stay at home, move to retirement community
Carvalho et al., 2020	Switzerland	3195 older adults living in Lausanne between 68 and 82 years old	To assess the impact of incontinence on LTC choices among community-dwelling older citizens.	Vignette	Suitability of LTC arrangements for hypothetical patient outcomes	1. Diverse needs for LTC ordered by type of severity (influencing factor: incontinence)	Urinary incontinence, fecal incontinence, mixed (urinary and fecal) incontinence
						2. Long-term care arrangements	Home, sheltered house, nursing home
Chester et al., 2017	England	28 carers of PWD		DCE		1. Home care workers use life story or memory wallets	Not at all, To some extent, Fully

			To test the applicability of the Discrete Choice Experiment method to assess carers' preferences for different attributes of home care for PWD.		Hypothetical home care packages (A vs. B)	2. There is a waiting list for this service	No waiting list, 5 weeks, 10 weeks
						3. Home care workers are available	Day time only Mon-Fri, Night time Mon-Fri also if required, Weekends also if required
						4. Respite opportunities for carers	Not provided, Limited respite services, Full respite service for weekends and longer periods
						5. The home care worker visiting	Can be a different person each time, Varies from time to time, Is the same person each time
						6. The cost of this service is	£140 per week, £170 per week, £200 per week
						7. Home care workers have additional training in dementia care	No training, Some training, Full training
Chester et al., 2018	England	44 PWD and 103 carers of PWD	To explore the relative value of attributes of home support in dementia from the perspective of both PWD and their carers in relation to the early stages of dementia using the DCE approach.	DCE	Hypothetical home care packages (A vs. B)	1. Advice on the use of memory aids (e.g. calendars, wall clocks) is	Not available, Available at a clinic, Provided by a trained worker at home
						2. Information on coping with dementia is	Available in writing only on request, Available over the phone or internet when needed, Provided by an experience worker at home
						3. Opportunities for social and recreational activities (e.g. walks) are	Not provided, Available through outside organizations, Provided by a dedicated worker at home
						4. Relaxation therapy is	Not available, Available at a clinic by appointment, Provided when needed at home
						5. Support with personal feelings and concerns is	Not provided, Available through a helpline, Provided by a trained counsellor at home
						6. Health promotion advice is	Not provided, Available at a clinic by appointment, Provided regularly at home
						7. The cost of the service, to you, is	£15 per week, £30 per week, £44 per week
de Guzman, Jaurigue &	Philippines	238 Filipino elderly patients from	To understand elderly patients' preferences on the type	Conjoint analysis	Type of nurse-patient interaction	1. Type of care provider	Staff nurse, Student nurse, Caregiver
						2. Gender	Male, Female

Jimenez, 2019		home health care and community settings	of nurse-patient interaction in home care and community settings.			3. Verbal communication	Nurse greets patient or returns greeting verbally, Nurse exchanges friendly/light comments or jokes showing ease with patient, Nurse makes clarifications/asks follow-up questions to further appraise for patient’s disease condition, Nurse gives adequate explanations patiently, Nurse volunteers needed information about procedures, meds, etc., Nurse provides verbal reassurance, Commands patient to do her instruction in a stern or irritated manner
						4. Nonverbal communication	Nurse ignores patient questions or comment, Nurse listens attentively to verbalisation of patients on feelings, health condition and personal/family info etc., Implements needed interventions/procedures promptly and competently, Nurse attends only to the IV and other routine procedure and ignores the patient
Fahey et al., 2017	Ireland	102 older hospital patients (65 – 80 years old) who do not suffer from dementia or delirium	To find out how people would balance and trade-off the different factors and outcomes that might arise if they developed significant dementia.	Conjoint analysis	Different hypothetical outcome scenarios for an 85 year-old with Alzheimer's disease (patient profile)	1. Place of residence	Home with support, nursing home
						2. Risk of harm	High (80% chance of a potentially harmful incident within a year), moderate (50% chance of a potentially harmful incident within a year), low (20% chance of a potentially harmful incident within a year)
						3. Burden ("difficulty and strain" on family	A lot, some, little
						4. Life expectancy	1 year, 2 years, 3 years

Guo et al. (2015)	USA	81 respondents at short-term risk of needing LTC, but not currently receiving LTC	To quantify LTC preferences between different delivery modes.	TTO	Choice for six health states of either 1) living a longer life (another 10 years) with a given disability health state or 2) living a shorter life (t years\ 10 years) without having the disability health state and not needing any LTC	1. Functional impairment (cannot do the following without assistance of at least 1 person) 2. Cognitive impairment 3. LTC arrangement	Different ADL needs: bathing, dressing, toileting, transferring, continence, feeding None, Mild to moderate dementia, Moderate to severe dementia Home care, Nursing home
Kaambwa et al., 2015	Australia	117 clients of community aged care services (CACS) delivered by 5 Australian providers (87 consumers and 30 informal caregivers)	To explore CACS clients' preferences for a variety of Consumer directed care (CDC) attributes and identified factors that may influence these preferences and potentially to inform improved design of future CDC models.	DCE	Hypothetical CDC packages (A vs. B)	1. Choice of service provider(s) 2. Budget management 3. Saving unused funds 4. Choice of support/care workers 5. Support worker flexibility 6. Level of contact with service coordinator	Single service provider, Multiple service provider, Multiple service providers and other individuals including family The individual (client), An informal carer, The service provider Save all unused funds, save half of unused funds, Not able to save unused funds All your support workers, Some of your support workers, None of your support workers Fully flexible, Partly flexible, Inflexible High contact (monthly), Medium contact (every three months), Low contact (every six months)
Kasper, Shore & Penninx, 2000	USA	1002 older women with moderate to severe disability in Baltimore	To describe caregiving arrangements and explore preferences for caregiving arrangements of older disabled women.	Vignette (Ranking)	Suitability of LTC arrangements (ranking from best to worst) for hypothetical patient outcomes	1. Severity of disability	Person who needs help with meals every day, and with shopping, housework and transportation, but can take care of basic needs like bathing and dressing; person who needs help with bathing, dressing, and moving around in their residence on a daily basis, in addition to

							meals and other chores; person who needs help with personal and household activities and also has Alzheimer’s Disease or dementia which will get worse as time goes by
						2. LTC arrangements	In their own home with help from family and friends, Living with an adult child, Living in an assisted facility or a continuing care residence, Living in a nursing home, Living in their own home with help from someone paid to come in
Kasper, Wolff & Skehan, 2019	USA	1783 Medicare beneficiaries aged 65 and older	To examine variations in care preferences and the extent to which preferences are congruent with or match current or future care arrangements.	Vignette	Suitability of LTC arrangements for hypothetical patient outcome	1. Severity of disability	“Imagine a person named Pat, who is 80 years old with health problems. Because of these problems, he/she needs someone to help with bathing, dressing and getting around inside. Please look at this card and tell me what would be best for Pat?”
						2. LTC arrangements	Living in their own home with help from friends and family, Living in their own home with help from someone paid to come in, Living with an adult child, Living in an assisted living facility or continuing care residence, Living in a nursing home.
Kampanellou et al., 2017	England	100 carers of people in later stage dementia	To examine the relative importance of different home support attributes from the perspective of carers of people with later-stage dementia.	DCE	Hypothetical home support packages (A vs. B) with a budget of £230 per week to pay for care	1. General home care such as personal care and cleaning is	Available irregularly, Available regularly but for short periods, Provided regularly for as long as needed
						2. Information on coping with dementia is	Available in writing only on request, Available over the phone or internet when needed, Provided by an experiences worker at home
						3. Respite care for you is	Not available, Available only for emergencies/special events, Available regularly to fit your needs
						4. Aids and adaptations in the home (e.g. light timers) are	Not available, Available if requested, Available regularly to fit your needs

						5. Training on how to manage behaviour and difficulties is	Not provided, Provided in a support group, Provided by a dedicated worker at home
						6. Emotional support to you is	Not provided, Available through a ‘helpline’, Provided regularly at home
						7. The cost of service, to you, is	£75 per week, £115 per week, £150 per week
Lehnert et al., (2018)	Germany	1.209 randomly selected participants from the general population aged 45 – 64 years	To investigate preferences for home- and community-based long-term care services packages (HCBS).	DCE	Hypothetical HCBS packages (A vs. B) for 1 patient profile (elderly person with health problems, functional limitations, in need of LTC)	1. Care time (per day)	30 min/day, 60 min/day, 90 min/day, 120 min/day
						2. Service level (range of services offered by the HCBS provider)	Standard, Extended
						3. Quality of care	Very high, high, satisfactory, sufficient
						4. Caregiver (per month)	1-2, 3-5, 6-8
						5. Co-Payment (per month)	€0, €300, €600, €900
Li & Wang, 2016	China	12 experts and scholars of questionnaire survey	To establish an aged care service quality evaluation mode.	AHP and FCE	Evaluation of 5 criteria layer indexes and 25 index layers on a 1-9 scale	1. Living care	Full-time housekeeper services, Aged nursery services, Hourly worker services, Milk delivery service, Laundry services, Elderly meal services, Indoor cleaning services
						2. Medical and nursing care	Home sick-bed services, Daily professional nursing services, Postoperative rehabilitation nursing service, Rational use of drugs and home safety guidance services, Acute disease nursing services
						3. Safety and security guarantee	Home appliance repair services, Liquefied gas replacement services, Drains dredging services, Hydropower maintenance and repair services, Elderly special equipment services
						4. Spiritual consolation	Chatting services, Reading services, Escort services, Social meeting for single senior citizens services

						5. Social participation	Tour and sight-seeing services, Senior citizen college service, Senior citizen association services, Voluntary labour organization services
McCormick et al., 2002	USA	1244 older Japanese Americans and 1354 Caucasian Americans	To compare attitudes toward the use of LTC between older Japanese Americans and older Caucasian Americans.	Vignette	Suitability of LTC arrangements for hypothetical patient outcomes	1. Severity of disability 2. LTC arrangements	Permanently disabled by dementia, temporarily disabled by hip fracture Move to a nursing home, receive paid home health care, be cared for at home by a loved one
Mentzakis, Ryan & McNamee, 2011	Scotland	209 carers	To value informal care tasks (personal care, supervising and household tasks) and model the relationship between time spent on formal and informal care.	DCE	Hypothetical informal caregiving situations (A vs. B) in a first step, opportunity to opt-out in a second step	1. Personal care (hours per week) 2. Supervising (hours per week) 3. Household tasks (hours per week) 4. Formal care (hours per week) 5. Monetary compensation (per hour compensation to the caregiver)	0, 15, 30, 50 0, 15, 30, 50 0, 15, 30, 50 0, 15, 30, 50 £0, £4, £10, £17
Milte et al, 2018a	Australia	126 residents of nursing homes and 416 family member proxies	To generate a scoring algorithm weighted on the preferences of consumers for assessing the quality of care in nursing homes in sex key domains (CCI-6D).	DCE	Alternative nursing home scenarios (Aged care home 1 vs. Aged care home 2)	1. How much time are care staff able to spend with me/my family member? 2. Do the shared spaces of the aged care home as a whole make you/your family member feel 'at home'? 3. Does your own room her make you/your family member feel 'at home'? 4. Is there access to outside and gardens in this aged care home?	Always able to, Sometimes able to, Rarely able to Very, Sometimes, Rarely Very, Sometimes, Rarely Always easily able to, Sometimes able to, Unable to easily

						5. How often does the facility offer me/my family member things to do that make me feel valued? 6. How flexible is the aged care home with the care routines (e.g. when you/your family member gets out of bed, shower, eat your meals)?	Often able to, Sometimes able to, Rarely or occasionally able to Very flexible, Sometimes flexible, Not much flexibility
Milte et al., 2018b	Australia	43 residents of aged care homes and 78 family member proxies	The aim of the study was to undertake a detailed analysis of the preferences for how food and the dining experience are provided within aged care homes and to elicit consumer preferences and their willingness to pay for food service in aged care homes.	DCE	Two kitchens that provide food differently in the residential aged care home (kitchen 1 vs. kitchen 2)	1. How good is the taste of the food provided? 2. How much choice do I have over serving size? 3. When do I choose what I would like to eat? 4. When do I eat my meal? 5. How visually appealing is the food? 6. How much extra money would I need to pay?	Not very, Satisfactory, Excellent No choice, A little, A lot of choice No choice, The day before the meal, At the time of serving Anytime I like, Within a 1-2h range, At a set time Not very, Satisfactory, Excellent $0 per week, $10 per week
Min, 2005	USA	144 older Korean Americans	To examine preferences for long-term care arrangements by Korean Americans.	Vignette	Suitability of LTC arrangements for hypothetical patient outcomes	1. Severity of disability 2. LTC arrangements	Hip fracture, stroke Informal caregiver at informal care location, paid helper at informal care location, paid helper at formal care facilities
Min & Barrio, 2009	USA	89 Mexican-American and 30 non-Latino White elders	To examine caregiver preferences in the event of hip fracture between Mexican-American	Vignette	Suitability of LTC arrangements for hypothetical patient outcome	1. Type of disability 2. LTC arrangements	Hip fracture Formal/professional helper, informal helper/caregiver

			(MA) and non-Latino White (NLW) elders.				
Nieboer, Koolman & Stolk, 2010	Netherlands	1082 participants from a subsample of the Dutch Survey Sampling International Panel (general population, 50 – 65 years old)	To elicit preferences in the general elderly population for long-term care services for varying types of patients.	DCE	Long-Term Care scenarios (packages) for 4 groups of hypothetical patients (frail and demented elderly, with and without partner)	1. Number of hours of care per week	4h, 8h, 12h, 16h
						2. Organized social activities	Not available, 1 Half day per week, 2 Half days per week, 3 Half days per week
						3. Transportation service	Available, Not available
						4. Living situation	Living independently at home, Apartment building in the proximity of care, Sheltered accommodation, Elderly or nursing home
						5. Who provides care	Regular care provider, Varying care providers
						6. Individual preferences	Standardized care, The content of care is determined individually
						7. Coordinated care services delivery	Have to arrange little, Have to arrange a lot
						8. Punctuality	Max. 15min waiting time, Max. 1h waiting time, Max. 2h waiting time, Max. 3h waiting time
						9. Waiting list in months	Directly available, 4 Months, 8 Months, 12 Months
						10. Co-payment per week	No co-payment, 50 Euro, 100 Euro, 150 Euro

Robinson et al., 2015	Ireland	97 hospital patients with a history of falls, fracture or osteoporosis (aged 70 years or older)	To investigate how older people at risk for hip fracture would balance and trade-off between the different factors and outcomes that might arise after a hip fracture with a poor functional outcome.	Conjoint analysis	Outcome scenarios for a patient with poor functional recovery after a hip fracture	1. Discharge location 2. Likely falls risk 3. Predicted life expectancy 4. Views of family	Home with support, Nursing home Yearly, Three per year, One per month 4 years, 2 years, 1 year Agree with discharge location, Disagree with discharge location
Santos-Eggimann & Meylan, 2017	Switzerland	2985 community-dwelling persons aged 68 years or older residing in a Swiss region	To collect the opinions of community-dwelling persons regarding LTC arrangements for a diversity of disability profiles.	Vignette	Suitability of LTC arrangements for hypothetical patient outcomes	1. Severity of disability 2. Living situation of hypothetical person 3. LTC arrangements	No ADL disability, mild disability (IADL only), moderate ADL disability, severe ADL disability, urinary incontinence, urinary and fecal incontinence, no cognitive impairment, moderate cognitive impairment, severe cognitive impairment Living with or without able-bodied spouse Usual home, sheltered home, nursing home
Sawamura, Sano & Nakanishi, 2015	Japan	371 adults aged 50-65 years old in 8 cities in Japan	To optimize resource allocation, we aim to clarify the priorities of the functions of long-term care facilities from the viewpoint of future beneficiaries.	DCE	Hypothetical long-term care facilities (facility 1 vs. facility 2)	1. Availability of individual choice of daily schedule and meals 2. Regular care staff 3. Room 4. Main daily interaction 5. Relocation because of medical deterioration 6. Waiting time 7. Distance from present residence 8. Monthly fee	Not available, Partially available, Entirely available Not available, Available Shared (2-4) room, Personal Room Mostly alone, Mostly with staff and other residents, Mostly with family and friends Necessary, Unnecessary Over 1 year, Within 1 year, Immediate occupancy Forty minutes by car, Twenty minutes by car, Within walking distance 100,000 yen, 250,000 yen, 400,000 yen

Song et al., 2020	China	293 Shanghai residents who have the intention or willingness to live in a nursing home but have not yet entered into one	To reveal the elderly people's preferences for the nursing homes, in order to clarify the reason for utilisation imbalance and put forward the efficient strategies for planning practice.	DCE	Nursing home A vs. B (with option to opt-out)	1. Location 2. Distance to home 3. Air quality 4. Comprehensive hospital 5. Metro station 6. Care service 7. Monthly fee	Downtown, Inner suburbs, Outer suburbs 10 min, 20 min, 40 min, 60 min Good, General 5 min, 15 min, 30 min, 45 min Yes, No Good, General CNY 1500, CNY 2000, CNY 2500, CNY 3000
Walsh et al., 2020	Ireland	551 individuals over 18 years of age	To understand public preferences for personhood in home-care services for people with moderate dementia.	DCE	Home-care packages (A vs. B vs. Status quo)	1. Communication 2. Flexibility 3. Number of care hours 4. Co-payment 5. Additional taxation per year	Standardized, Personalized Low, High 10 hours per week, 15 hours per week, 20 hours per week No co-payment, Means-test co-payment, Compulsory co-payment €50, €100, €150, €200, €250
Werner & Segel-Karpas, 2014	Israel	484 Jewish community-dwelling adults aged 45 and over	To study the willingness to use institutional care vs. home care in hypothetical situations of permanent disability and Alzheimer's disease.	Vignette	Suitability of LTC arrangements for hypothetical patient outcomes	1. Severity of disability 2. LTC arrangements	Permanently physically disabled, diagnosed with Alzheimer's diseases Being care for at home by family members, being cared for at home by paid caregivers, being cared for in sheltered housing by caregivers in a nursing ward, being cared for in a nursing home by professional caregivers
Wolff, Kasper, Shore (2008)	USA	420 disabled older women receiving informal care	To investigate LTC preferences across 3 hypothetical scenarios and over one year of time.	Vignette	Suitability of LTC arrangements for hypothetical patient outcomes	1. Severity of disability 2. LTC arrangements	IADLs needs, ADL needs, dementia In their own home with help from friends and family, in their own home with help from someone paid to come in, living with an adult child, in an assisted living facility or a continuing care residence, in a nursing home

Table 5: Results of the quality appraisal using the PREFS Checklist (n = 68)

Study	Purpose	Respondents	Explanation	Findings	Significance	Sum score
Abbott et al. (2018)	✓		✓	✓	✓	4/5
Al-Janabi, Flynn & Coast (2011)	✓		✓		✓	3/5
Bradley et al. (2004)			✓	✓	✓	3/5
Caro et al. (2012)			✓	✓	✓	3/5
Carvalho et al. (2020)	✓		✓	✓	✓	4/5
Chan, Parsons & Piterman (2000)				✓	✓	2/5
Chester et al. (2018)	✓		✓	✓	✓	4/5
Chester et al. (2017)	✓		✓	✓	✓	4/5
Chou (2010)	✓		✓	✓	✓	4/5
Chung et al. (2008)	✓		✓		✓	3/5
Costa-Font, Elvira & Mascarilla-Miró (2009)	✓		✓	✓	✓	4/5
Dong et al. (2020)	✓		✓	✓	✓	4/5
Eckert, Morgan & Swarmy (2004)	✓		✓	✓	✓	4/5
Fahey et al. (2017)	✓	✓	✓	✓		4/5
Fernandez-Carro (2016)	✓	✓	✓	✓	✓	5/5
Fisher (2003)	✓		✓	✓	✓	4/5
Fu et al. (2017)	✓		✓	✓	✓	4/5
Fu et al. (2019)	✓		✓	✓	✓	4/5
Gerves, Bellanger & Ankri (2013)	✓		✓	✓	✓	4/5
Gustavsson et al. (2010)	✓		✓	✓	✓	4/5
Guo et al. (2015)	✓		✓	✓	✓	4/5
Guzman, Jaurigue & Jimenez (2019)	✓		✓		✓	3/5
Hajek et al. (2017)	✓		✓		✓	3/5
Hrast et al. (2019)	✓		✓		✓	3/5
Huang et al. (2018)	✓		✓	✓	✓	4/5
Imamoğlu & Imamoğlu (2006)	✓		✓	✓	✓	4/5
Iwasaki et al. (2016)	✓		✓	✓	✓	4/5
Jang et al. (2008)	✓		✓	✓	✓	4/5
Kaambwa et al. (2015)	✓		✓	✓	✓	4/5
Kampanellou et al. (2017)	✓		✓	✓	✓	4/5
Kasper, Shore & Penninx (2000)	✓		✓	✓	✓	4/5

Kasper, Wolff & Skehan (2019)	✓		✓	✓	✓	4/5
Kim & Kim (2004)			✓	✓	✓	3/5
Kim & Choi (2008)	✓		✓	✓	✓	4/5
König & Wettstein (2002)	✓		✓	✓	✓	4/5
Laditka, Pappas-Rogich & Ladtika (2001)	✓		✓	✓	✓	4/5
Lehnert et al. (2018)	✓		✓	✓	✓	4/5
Li & Wang (2016)				✓		1/5
Liu et al. (2020)	✓		✓	✓	✓	4/5
Liu et al. (2019)	✓		✓	✓	✓	4/5
Loh & Shapiro (2013)	✓		✓	✓	✓	4/5
McCormick et al. (2002)	✓		✓	✓	✓	4/5
Mentzakis, Ryan & McNamee (2011)	✓		✓	✓	✓	4/5
Milte et al. (2018a)	✓		✓	✓	✓	4/5
Milte et al. (2018b)	✓		✓	✓	✓	4/5
Min (2005)	✓		✓	✓	✓	4/5
Min & Barrio (2009)	✓		✓	✓	✓	4/5
Nieboer, Koolman & Stolk (2010)	✓		✓	✓	✓	4/5
Pinquart & Sörensen (2002)	✓		✓	✓	✓	4/5
Przybyla, Heldak & Kurtyka-Marcak (2019)	✓		✓	✓	✓	4/5
Qian et al. (2018)	✓		✓	✓	✓	4/5
Qian et al. (2017)	✓		✓	✓	✓	4/5
Roberts & Saliba (2019)	✓		✓	✓		3/5
Robinson et al. (2015)	✓	✓	✓	✓	✓	5/5
Rong et al. (2020)	✓		✓		✓	3/5
Santos-Eggiman & Meylan (2017)	✓	✓	✓	✓	✓	5/5
Sawamura, Sano & Nakanishi (2015)	✓		✓	✓	✓	4/5
Song et al. (2020)	✓		✓		✓	3/5
Spangenberg et al. (2012)	✓		✓	✓	✓	4/5
Tang et al. (2009)			✓	✓	✓	3/5
Walsh et al. (2020)	✓		✓	✓	✓	4/5
Wang et al. (2004)	✓		✓	✓	✓	4/5
Wei & Zhang (2020)	✓			✓	✓	3/5
Werner & Segel-Karpas (2016)	✓		✓	✓	✓	4/5
Wolff, Kasper & Shore (2008)	✓		✓		✓	3/5

Xiang et al. (2019)	✓	✓	✓	3/5
Zeng et al. (2019)	✓	✓	✓	3/5
Zhang, Zeng & Fang (2017)	✓	✓	✓	3/5

References

Abbott KM, Heid AR, Kleban M, Rovine MJ, van Haitsma K (2018) The change in nursing home residents' preferences over time. Journal of the American Medical Directors Association 19(12):1092–1098

Al-Janabi H, Flynn TN, Coast J (2011) Estimation of a preference-based carer experience scale. Medical Decision Making 31(3):458–468

Bradley EH, Curry LA, Mcgraw SA, Webster TR, Kasl SV, Andersen R (2004) Intended use of informal long-term care: the role of race and ethnicity. Ethnicity & health 9(1):37–54

Bulamu NB, Kaambwa B, Ratcliffe J (2015) A systematic review of instruments for measuring outcomes in economic evaluation within aged care. Health and quality of life outcomes 13(1):1–23

Caro FG, Yee C, Levien S, Gottlieb AS, Winter J, McFadden DL, Ho TH (2012) Choosing among residential options: Results of a vignette experiment. Research on Aging 34(1):3–33

Carvalho N, Fustinoni S, Abolhassani N, Blanco JM, Meylan L, Santos-Eggimann B (2020) Impact of urine and mixed incontinence on long-term care preference: a vignette-survey study of community-dwelling older adults. BMC geriatrics 20(1):1–12

Chan YF, Parsons RW, Piterman L (2000) Chinese attitudes to institutional care of their aged. A study of members from the Chung Wah Association, Western Australia. Australian family physician 29(9):894–899

Chester H, Clarkson P, Davies L, Sutcliffe C, Davies S, Feast A, Hughes J, Challis D, HOST-D (Home Support in Dementia) Programme Management Group. (2018) People with dementia and carer preferences for home support services in early-stage dementia. Aging & mental health 22(2):270–279

Chester H, Clarkson P, Davies L, Sutcliffe C, Roe B, Hughes J, Challis D (2017) A discrete choice experiment to explore carer preferences. Quality in Ageing and Older Adults

Chou RJ-A (2010) Willingness to live in eldercare institutions among older adults in urban and rural China: a nationwide study. Ageing and Society 30(4):583

Chung M-H, Hsu N, Wang Y-C, Lin H-C, Huang Y-L, Amidon RL, Kao S (2008) Factors affecting the long-term care preferences of the elderly in Taiwan. Geriatric Nursing 29(5):293–301

Costa-Font J, Elvira D, Mascarilla-Miró O (2009) Ageing in place'? Exploring elderly people's housing preferences in Spain. Urban studies 46(2):295–316

Coulter A (2012) Patient engagement—what works? The Journal of ambulatory care management 35(2):80–89

Dong X, Wong BO, Yang C, Zhang F, Xu F, Zhao L, Liu Y (2020) Factors associated with willingness to enter care homes for the elderly and pre-elderly in west of China. Medicine 99(47)

Eckert JK, Morgan LA, Swamy N (2004) Preferences for receipt of care among community-dwelling adults. Journal of aging & social policy 16(2):49–65

Fahey A, Ní Chaoimh D, Mulkerrin GR, Mulkerrin EC, O'Keeffe ST (2017) Deciding about nursing home care in dementia: a conjoint analysis of how older people balance competing goals. Geriatrics & gerontology international 17(12):2435–2440

Fernandez-Carro C (2016) Ageing at home, co-residence or institutionalisation? Preferred care and residential arrangements of older adults in Spain. Ageing and Society 36(3):586

Filipovič Hrast M, Sendi R, Hlebec V, Kerbler B (2019) Moving house and housing preferences in older age in Slovenia. Housing, Theory and Society 36(1):76–91

Fisher C (2003) Long-term care preferences and attitudes among Great Lakes American Indian families: Cultural context matters. Care Management Journals 4(2):94

Fu YY, Chui EW, Law CK, Zhao X, Lou VWQ (2019) An exploration of older Hong Kong residents' willingness to make copayments toward vouchers for community care. Journal of aging & social policy 31(4):358–377

Fu YY, Guo Y, Bai X, Chui EWT (2017) Factors associated with older people's long-term care needs: a case study adopting the expanded version of the Anderson Model in China. BMC geriatrics 17(1):1–13

Gervès C, Bellanger MM, Ankri J (2013) Economic analysis of the intangible impacts of informal care for people with Alzheimer's disease and other mental disorders. Value in Health 16(5):745–754

Global Coalition on Aging (2018) Relationship-based Home Care: A Sustainable Solution For Europe's Elder Care Crisis

Guo J, Konetzka RT, Magett E, Dale W (2015) Quantifying long-term care preferences. Medical Decision Making 35(1):106–113

Gustavsson A, Jönsson L, McShane R, Boada M, Wimo A, Zbrozek AS (2010) Willingness-to-pay for reductions in care need: estimating the value of informal care in Alzheimer's disease. International Journal of Geriatric Psychiatry: A journal of the psychiatry of late life and allied sciences 25(6):622–632

Guzman AB de, Jaurigue KAM, Jimenez AAB (2019) A comparison of the nurse–patient interaction criteria among geriatric clients in home health care and community settings: a trade-off analysis. Educational Gerontology 45(3):176–190

Hajek A, Lehnert T, Wegener A, Riedel-Heller SG, König H-H (2017) Factors associated with preferences for long-term care settings in old age: evidence from a population-based survey in Germany. BMC health services research 17(1):1–9

Hoefman RJ, Meulenkamp TM, Jong JD de (2017) Who is responsible for providing care? Investigating the role of care tasks and past experiences in a cross-sectional survey in the Netherlands. BMC health services research 17(1):477

Huang Z, Liu Q, Meng H, Liu D, Dobbs D, Hyer K, Conner KO (2018) Factors associated with willingness to enter long-term care facilities among older adults in Chengdu, China. PloS one 13(8):e0202225

Imamoğlu Ç, Imamoğlu EO (2006) Relationship between familiarity, attitudes and preferences: Assisted living facilities as compared to nursing homes. Social indicators research 79(2):235–254

Iwasaki M, Pierson ME, Madison D, McCurry SM (2016) Long-term care planning and preferences among J apanese A merican baby boomers: Comparison with non-J apanese A mericans. Geriatrics & gerontology international 16(9):1074–1084

Jang Y, Kim G, Chiriboga DA, Cho S (2008) Willingness to use a nursing home: A study of Korean American elders. Journal of Applied Gerontology 27(1):110–117

Joy SM, Little E, Maruthur NM, Purnell TS, Bridges JFP (2013) Patient preferences for the treatment of type 2 diabetes: a scoping review. PharmacoEconomics 31(10):877–892

Kaambwa B, Lancsar E, McCaffrey N, Chen G, Gill L, Cameron ID, Crotty M, Ratcliffe J (2015) Investigating consumers' and informal carers' views and preferences for consumer directed care: A discrete choice experiment. Social Science & Medicine 140:81–94

Kampanellou E, Chester H, Davies L, Davies S, Giebel C, Hughes J, Challis D, Clarkson P, HOST-D (Home Support in Dementia) Programme Management Group (2019) Carer preferences for home support services in later stage dementia. Aging & mental health 23(1):60–68

Kasper JD, Shore A, Penninx B (2000) Caregiving arrangements of older disabled women, caregiving preferences, and views on adequacy of care. Aging Clinical and Experimental Research 12(2):141–153

Kasper JD, Wolff JL, Skehan M (2019) Care arrangements of older adults: What they prefer, what they have, and implications for quality of life. The Gerontologist 59(5):845–855

Kim E-Y, Kim C (2004) Who wants to enter a long-term care facility in a rapidly aging non-western society? Attitudes of older Koreans toward long-term care facilities. Journal of the American Geriatrics Society 52(12):2114–2119

Kim H, Choi W-Y (2008) Willingness to use formal long-term care services by Korean elders and their primary caregivers. Journal of aging & social policy 20(4):474–492

Klose K, Kreimeier S, Tangermann U, Aumann I, Damm K, RHO Group (2016) Patient-and person-reports on healthcare: preferences, outcomes, experiences, and satisfaction–an essay. Health economics review 6(1):18

König M, Wettstein A (2002) Caring for relatives with dementia: willingness-to-pay for a reduction in caregiver’s burden. Expert review of pharmacoeconomics & outcomes research 2(6):535–547

Laditka SB, Pappas-Rogich M, Laditka JN (2001) Home and community-based services for well educated older caregivers: gender differences in attitudes, barriers, and use. Home Health Care Services Quarterly 19(3):1–17

Lehnert T, Günther OH, Hajek A, Riedel-Heller SG, König HH (2018) Preferences for home-and community-based long-term care services in Germany: a discrete choice experiment. The European Journal of Health Economics 19(9):1213–1223

Lehnert T, Heuchert MA, Hussain K, Koenig H-H (2019) Stated preferences for long-term care: A literature review. Ageing and Society 39(9):1873–1913

Lepper S, Rädke A, Wehrmann H, Michalowsky B, Hoffmann W (2020) Preferences of Cognitively Impaired Patients and Patients Living with Dementia: A Systematic Review of Quantitative Patient Preference Studies. Journal of Alzheimer's Disease(Preprint):1–17

Li X, Wang J (2016) Fuzzy Comprehensive Evaluation of Aged Community Home-Care Service Quality Based on AHP

Litva A, Coast J, Donovan J, Eyles J, Shepherd M, Tacchi J, Abelson J, Morgan K (2002) 'The public is too subjective': public involvement at different levels of health-care decision making. Social Science & Medicine 54(12):1825–1837

Liu W, Lyu T, Zhang X, Yuan S, Zhang H (2020) Willingness-to-pay and willingness-to-accept of informal caregivers of dependent elderly people in Shanghai, China. BMC health services research 20(1):1–11

Liu Z-W, Yu Y, Fang L, Hu M, Zhou L, Xiao S-Y (2019) Willingness to receive institutional and community-based eldercare among the rural elderly in China. PloS one 14(11):e0225314

Loh C-P, Shapiro A (2013) Willingness to pay for home-and community-based services for seniors in Florida. Home Health Care Services Quarterly 32(1):17–34

Luppa M, Luck T, Weyerer S, König H-H, Brähler E, Riedel-Heller SG (2010) Prediction of institutionalization in the elderly. A systematic review. Age and ageing 39(1):31–38

McCormick WC, Ohata CY, Uomoto J, Young HM, Graves AB, Kukull W, Teri L, Vitaliano P, Mortimer JA, McCurry SM (2002) Similarities and differences in attitudes toward long-term care between Japanese Americans and Caucasian Americans. Journal of the American Geriatrics Society 50(6):1149–1155

Mentzakis E, Ryan M, McNamee P (2011) Using discrete choice experiments to value informal care tasks: exploring preference heterogeneity. Health economics 20(8):930–944

Milte R, Ratcliffe J, Chen G, Crotty M (2018a) What characteristics of nursing homes are most valued by consumers? A discrete choice experiment with residents and family members. Value in Health 21(7):843–849

Milte R, Ratcliffe J, Chen G, Miller M, Crotty M (2018b) Taste, choice and timing: Investigating resident and carer preferences for meals in aged care homes. Nursing & health sciences 20(1):116–124

Min JW (2005) Preference for long-term care arrangement and its correlates for older Korean Americans. Journal of Aging and Health 17(3):363–395

Min JW, Barrio C (2009) Cultural values and caregiver preference for Mexican-American and non-Latino White elders. Journal of cross-cultural gerontology 24(3):225

Moher D, Liberati A, Tetzlaff J, Altman DG, PRISMA Group (2009) Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. J Clin Epidemiol 62(10):1006–1012

Nieboer AP, Koolman X, Stolk EA (2010) Preferences for long-term care services: Willingness to pay estimates derived from a discrete choice experiment. Social Science & Medicine 70(9):1317–1325

Pinquart M, Sörensen S (2002) Older adults' preferences for informal, formal, and mixed support for future care needs: a comparison of Germany and the United States. The International Journal of Aging and Human Development 54(4):291–314

Przybyła K, Hełdak M, Kurtyka-Marcak I (2019) Demand for a housing offer addressed to senior citizens in Poland. International journal of environmental research and public health 16(22):4573

Qian Y, Chu J, Ge D, Zhang L, Sun L, Zhou C (2017) Gender difference in utilization willingness of institutional care among the single seniors: evidence from rural Shandong, China. International journal for equity in health 16(1):1–9

Qian Y, Qin W, Zhou C, Ge D, Zhang L, Sun L (2018) Utilisation willingness for institutional care by the elderly: a comparative study of empty nesters and non-empty nesters in Shandong, China. BMJ open 8(8):e022324

Roberts TJ, Saliba D (2019) Exploring Patterns in Preferences for Daily Care and Activities Among Nursing Home Residents. Journal of gerontological nursing 45(8):7–13

Robinson SM, Ní Bhuachalla B, Ní Mhaille B, Cotter PE, O'Connor M, O'Keeffe ST (2015) Home, please: a conjoint analysis of patient preferences after a bad hip fracture. Geriatrics & gerontology international 15(10):1165–1170

Rong C, Wan D, Xu C-M, Xiao L-W, Shen S-H, Lin J-M (2019) Factors associated with preferences for elderly care mode and choice of caregivers among parents who lost their only child in a central China city. Geriatrics & gerontology international 20(2):112–117

Royal Commission into Aged Care Quality and Safety (2020) Review of international systems for long-term care of older people. Research paper 2

Santos-Eggimann B, Meylan L (2017) Older Citizens' opinions on long-term care options: a vignette survey. Journal of the American Medical Directors Association 18(4):326–334

Sawamura K, Sano H, Nakanishi M (2015) Japanese public long-term care insured: Preferences for future long-term care facilities, including relocation, waiting times, and individualized care. Journal of the American Medical Directors Association 16(4):350. e9-350. e20

Soekhai V, Bekker-Grob EW de, Ellis AR, Vass CM (2019) Discrete choice experiments in health economics: past, present and future. PharmacoEconomics 37(2):201–226

Song S, de Wang, Zhu W, Wang C (2020) Study on the spatial configuration of nursing homes for the elderly people in Shanghai: Based on their choice preference. Technological Forecasting and Social Change 152:119859

Spangenberg L, Glaesmer H, Brähler E, Strauß B (2012) Use of family resources in future need of care. Care preferences and expected willingness of providing care among relatives: a population-based study. Bundesgesundheitsblatt, Gesundheitsforschung, Gesundheitsschutz 55(8):954–960

Swift JK, Callahan JL (2009) The impact of client treatment preferences on outcome: A meta-analysis. Journal of clinical psychology 65(4):368–381

Tang CS, Wu AMS, Yeung D, Yan E (2009) Attitudes and intention toward old age home placement: A study of young adult, middle-aged, and older Chinese. Ageing International 34(4):237–251

van Groenou, Marjolein I Broese, Boer A de (2016) Providing informal care in a changing society. European Journal of Ageing 13(3):271–279

Walsh S, O'Shea E, Pierse T, Kennelly B, Keogh F, Doherty E (2020) Public preferences for home care services for people with dementia: A discrete choice experiment on personhood. Social Science & Medicine 245:112675

Wang YC, Chung M-H, Lai KL, Chou CC, Kao S (2004) Preferences of the elderly and their primary family caregivers in the arrangement of long-term care. Journal of the Formosan Medical Association 103(7):533–539

Wei Y, Zhang L (2020) Analysis of the Influencing Factors on the Preferences of the Elderly for the Combination of Medical Care and Pension in Long-Term Care Facilities Based on the Andersen Model. International journal of environmental research and public health 17(15):5436

Werner P, Segel-Karpas D (2016) Factors associated with preferences for institutionalized care in elderly persons: Comparing hypothetical conditions of permanent disability and Alzheimer’s disease. Journal of Applied Gerontology 35(4):444–464

Wolff JL, Kasper JD, Shore AD (2008) Long-term care preferences among older adults: a moving target? Journal of aging & social policy 20(2):182–200

(2017) World Population Ageing 2017. Highlights, ST/ESA/SER.A/397, New York

(2019) World Population Ageing 2019. Highlights, ST/ESA/SER.A/430, New York

Xiang L, Ann TW, Tan Y, Shan X, Shen Q (2019) Senior citizens’ requirements of services provided by community-based care facilities: a China study. Facilities

Yu T, Enkh-Amgalan N, Zorigt G (2017) Methods to perform systematic reviews of patient preferences: a literature survey. BMC medical research methodology 17(1):166

Zeng L, Xu X, Zhang C, Chen L (2019) Factors influencing long-term care service needs among the elderly based on the latest anderson model: a case study from the middle and upper reaches of the yangtze river 4

Zhang L, Zeng Y, Fang Y (2017) The effect of health status and living arrangements on long term care models among older Chinese: A cross-sectional study. PloS one 12(9):e0182219

Modul 7

Willingness to provide informal care to older adults in Germany: a discrete choice experiment

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The European Journal of Health Economics; 1-12
DOI: 10.1007/s10198-022-01483-5

2022

The European Journal of Health Economics
https://doi.org/10.1007/s10198-022-01483-5

ORIGINAL PAPER

Willingness to provide informal care to older adults in Germany: a discrete choice experiment

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Received: 11 January 2022 / Accepted: 12 May 2022

Abstract

As the German population is continually aging and the majority of older adults still wish to 'age in place', the need for informal care provided by family and friends will correspondingly continue to increase. In addition, while the need for formal (professional) care services is also likely to increase, the supply already does not meet the demand in Germany today. The aim of our study is the elicitation of people's willingness to provide informal care by means of a discrete choice experiment. The self-complete postal survey was disseminated to a random sample of the German general population in Lower Saxony. Data cleansing resulted in a final sample size of 280 participants. A conditional logit and a latent class model were estimated. All attributes were judged as highly relevant by the respondents. The results revealed that an increase in the care hours per day had the greatest negative impact overall on the willingness to provide informal care in our sample. The marginal willingness-to-accept for 1 h of informal care was €14.54 when having to provide informal care for 8 h in reference to 2 h per day. This value is considerably higher than the national minimum wage of €9.82. A three-class latent class model revealed preference heterogeneity. While a monetary compensation is often discussed to increase the willingness and availability of informal care in a country, our results show that this statement could not be generalized within our entire sample.

Keywords Discrete choice experiment · Elderly care · Older adult care · Long-term care · Preferences · Willingness

JEL Classification C35 · I18 · J10 · J14

Introduction

Long-term care (LTC) encompasses a variety of services that aim to manage and further delay the functional decline of people with a care dependency by, among others, alleviating pain, assisting with activities of daily living, and ensuring independent living [1]. In Germany, a mandatory LTC insurance was introduced in 1995 to ensure access to LTC services for the entire population. Entitlement to LTC insurance benefits is based on a calculated care dependency grade. For this purpose, a new instrument was introduced in 2017 that uses six modules to determine the need for care of each person on a scale from 0 to 100. The modules and corresponding weights are as follows: 1. Mobility (10%), 2. Cognitive and communicative abilities or 3. Behaviour and psychiatric problems (15%), 4. Self-care (40%), 5. Dealing with requirements due to illness or therapy (20%), and 6. Organisation of everyday life and social contacts (15%). Each module consists of different items for which points are given. In the end, item points are added within each module and incorporated in the final score depending upon the mentioned module weights. The final score is then translated to one of the five care grades. A higher care grade translates to a more severe care dependency and therefore also a higher available budget [2, 3]. Recent statistics show that of the 4.1 million care-dependent Germans in 2019, 80% were cared for at home. Of these, 2.33 million (56%) were cared for exclusively by family members, neighbors, or friends. This type of care is also referred to as informal care and constitutes an important pillar of the LTC system in Germany and many other countries around the world [4].

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As the German population is continually aging and the majority of older adults still wish to ‘age in place’, the need for informal care will correspondingly continue to increase. In addition, while the need for home- and community-based services (HCBS) is also likely to increase, the supply already does not meet the demand in Germany today, due to a lack of qualified professionals and care infrastructure [5]. Therefore, recent care reforms have explicitly tried to strengthen home-based care and support informal caregivers, while many still criticize its implementation and reach. Nevertheless, current care systems rely on people’s willingness to provide informal care, as the professional care structures and workforce in place are not able to provide care to the increasing number of care-dependent older adults. When it comes to understanding the reasons for people to take on the role of an informal caregiver, arguments are complex and still not well understood [6]. On the one hand, many studies have highlighted the immense burden informal caregivers’ face in many life settings. First, studies have stressed the toll caregiving can have on a caregiver’s physical and mental health, including back pain, sleep deprivation, and depression [7]. Second, a study by Geyer (2016) has found out that caregivers that provided care for more than 1 h a day needed to reduce their working hours by 5–8 h per week [8]. In addition, re-entering the workforce as full-time employees following the informal caregiving situation is made more difficult [9]. Therefore, informal caregiving can lead to financial hardship [10]. Thirdly, many informal caregivers report that caregiving places increased pressure on their relationships to friends and family. This in turn adds pressure on the informal caregiver, and can lead to self-isolation in some cases and may influence quality of life [11]. On the other hand, studies have also shown that informal caregiving can confer positive psychological effects, which in turn can protect caregivers from experiencing high levels of stress. More specifically, studies report increased levels of resilience, self-confidence, and a sense of meaning [12, 13].

From an economic perspective, the decision to provide informal care is only rational if the utility or value outweighs its costs or burden. Costs or burden can be measured with different methods such as out-of-pocket expenses, time input, or instruments measuring the subjective burden or (health-related) quality of life. Quality of life and well-being instruments can also be used to measure the value of informal care [14]. Several theories try to explain the decision-making process. In an altruistic model, the hypothesis is that the selfless (informal) caregiver draws utility from the well-being of the person in need of care [15]. Cox and Stark (1996) have proposed a different theory, known as the demonstration effect. In this theory, adults with own children are incentivised to provide informal care to their older parents in hopes that their own children internalize the behavior and in turn care for them in the future. Other economic models try to explain informal caregiving using strategic exchanges between the two parties involved. Such exchanges can be in the form of financial incentives or money transfers (e.g., inheritance) between parents and children [16]. To be able to include informal care in economic evaluations, informal care needs to be valued either in terms of costs or carer effects. Monetary valuations of informal care can be done by for instance the opportunity cost method, proxy good method, contingent valuation, conjoint analysis, or discrete choice experiment (DCE), as has been applied in this study [14].

The study on LTC preferences in the field of older adult care has seen an increase over the last few years, especially by means of quantitative stated preference methods, such as DCE, contingent valuation, or best–worst scaling [17]. In the field of LTC, such methods have been used to elicit preferences for different LTC options, the suitability of different LTC settings for hypothetical patient outcomes, as well as the design and structure of specific LTC services such as home-based and community-based services or LTC facilities. Preferences can serve as an important indication to better tailor services to the needs, expectations, and wishes of its consumers. Among choice-based techniques in the field of older adult care, DCE were most often applied and enabled a ranking of the importance of the chosen attributes as well as an assessment on trade-offs respondents were willing to make. Specifically, in the field of informal care, most often contingent valuation methods were applied to explore the value of informal care by estimating the willingness-to-pay (WTP) for a reduction of 1 h in informal caregiving time [18–21]. In one of these studies, willingness-to-accept (WTA) values for having to provide one additional hour of informal care were additionally estimated by informal caregivers in China [21]. In a study by Mentzakis et al. (2011), a DCE was used to value various informal care tasks by informal caregivers in Scotland [22].

To date, one other DCE has been conducted in Germany in the field of LTC, however, focusing on investigating people’s preferences for home- and community-based services [23]. The aim of our study is the elicitation of people’s willingness to provide informal care in Germany by means of a DCE. The use of this methodology not only enables an inquiry into people’s willingness to care but also an assessment of what people value as most important and would be willing to trade-off. As national governments need to establish sustainable and affordable LTC systems, knowledge on people’s willingness to care as well as their trade-offs can add an important puzzle piece for the planning of services as well as support needed to enable more people to take on the role of caregiver.

Methods

DCEs are increasingly applied in health economics to elicit and quantify people's preferences. DCEs involve asking respondents to choose between two or more attribute-based alternatives. The underlying assumption of any DCE is that healthcare interventions and products can be decomposed and described by a set of characteristics (attributes) and that people value these differently depending on the levels of each attribute. The discrete choices made by respondents are then analyzed with different regression models and allow the estimation of the relative importance (utility) of each attribute [24, 25].

Attributes and levels

Results from a systematic literature review of the scientific databases PubMed, Scopus, and Dimdi [26] and 33 semi-structured qualitative interviews [6, 27] were used to identify the most relevant attributes and corresponding levels. While the type and severity of a care dependency as well as the (relationship to) the care-dependent person are important determinants for a person's willingness to provide care [6], we decided to solely focus on relevant attributes that describe informal caregiving situations in the DCE. Five quantitative attributes with three levels each were identified. A sufficiently wide-level range was classified as is recommended by the literature [28]. The chosen attributes, levels, and the description of each attribute can be found in Table 1. When choosing attributes and levels, compiled choice sets needed to be realistic but also force respondents to trade-off between the levels of each alternative and choose one of the two options. Therefore, 8 h per day in care time was for example chosen as an equivalent to a full-time working day. 0€ per hour of informal care, meaning no financial compensation, was chosen to exemplify the intrinsic willingness to provide care without any monetary compensation. In these scenarios it can be assumed that motivation exists on its own, for instance motivated by love or a sense of obligation for taking care of the relative in need.

The understanding of the attributes and levels as well as the entire questionnaire was piloted in a random sample of the general population ($n = 30$) in a step-wise procedure, meaning that the questionnaire was altered following participant comments and then tested again. The responses led to a series of wording alterations to simplify the questionnaire; however, no attributes or levels had to be changed.

Experimental design

A two-alternative forced-choice design was created with the software SAS [29]. As the full factorial design would result in 243 (Level Attribute = 3^5) possible attribute-level combinations, a fractional factorial design with 54 choice sets was created and blocked into six questionnaire versions with nine choice sets each to reduce respondents' burden. All of these choice sets were checked for plausibility, assigned to the blocks at random and it was ensured that there were no correlated attributes within versions. Generic alternatives (situation A vs. B) were chosen. The fractional factorial design was constructed using the %MktEx macro to make a candidate set of alternatives, followed by the %ChoicEff macro to create an efficient experimental design. The %ChoicEff macro uses a modified Fedorov algorithm, in which all design possibilities are considered and swapped out if the swap improves the D-efficiency [29]. A detailed explanation of all macros can be found in the book by Kuhfeld [29]. A

Table 1 DCE attributes and levels

Attribute	Attribute description	Levels
Expected period of caregiving (duration of care)	The period of time the caregiver would care for and/or look after the person in need of care	6 months 2 years 5 years
Care time (hours per day)	The amount of time (hours per day) the caregiver would provide care and/or supervise the person in need of care at home (e.g., personal care, household tasks, doctor visits etc.)	2 h per day 5 h per day 8 h per day
Formal care services (frequency per week)	The frequency of professional support that is additionally available to the caregiver (e.g., outpatient care services can assist with personal care or counselors can help with any open questions) A visit lasts about 30 min	None 3–4 times a week Daily
Respite (weeks per year)	The number of weeks a year that are available to the caregiver for a variety of respite options. During this time period, professionals care for the individual in need (e.g., during vacation)	None 3 weeks per year 6 weeks per year
Monetary compensation (€ per hour)	A wage replacement benefit (net) at the personal disposal of the caregiver. Paid as a financial compensation per hour for the care provided (in addition to the existing cash benefits by the LTC insurance in Germany)	€0 per hour €6 per hour €12 per hour

priori attribute coefficients were set to zero in the design. The design with 54 choice sets allowed for the clean estimation of main effects and all two-way interaction effects. In the design construction, the criteria ‘identification’ and ‘efficiency’ were explicitly considered as is recommended by the literature [28]. Identification, meaning that effects can be estimated independently, was determined by the structure of the inverse of the variance–covariance matrix of the parameter estimates. Efficiency, meaning the precision by which effects are estimated, was determined by improving the D-efficiency. The D-efficiency is a standard measure of goodness that can be used to compare the specific experimental designs that are created with the software SAS [29].

Study population and sample size

The mode of the data collection was a self-complete postal survey. The DCE questionnaire was disseminated to a stratified random sample of 4000 individuals of the German general population via a statutory health insurance (AOK Lower Saxony). The AOK Lower Saxony is the largest health insurance company in its region with a representative structure of insured compared to the entire German population in terms of socio-demographics such as age and sex. Differences were only observed in terms of education and occupation; in particular, the proportion of people with a university degree and higher job complexity was lower among AOK insured compared to the entire Lower Saxony population [30]. A reminder postcard was not sent. The population data from the end of 2017 were used as the data basis to draw a representative sample of the general population by the respective age and gender proportions between 18 and 65 years [31]. We used the equation by Johnson and Orme (2003) to determine the minimum required sample size of 250 respondents [32]. The formula is shown below, where t is the number of choice tasks, a is the number of alternatives, and c is the largest number of levels for any of the attributes or the largest product of levels of any two attributes [32]

$$N > \frac{500c}{(t * a)}$$

The questionnaire

The questionnaire was printed in a book format to enable easier readability and was a total of ten pages long. Respondents were given the contact information of the lead author to be able to ask questions. The first page contained a concise participant information including the necessary data protection clarifications. The following two pages enclosed instructions on how to complete the questionnaire, including a table of the attributes and levels as well as an example choice set (see Fig. 1). Respondents were asked to imagine a close relative in need of care. This person was able to be cared for at home and medical or nursing tasks (e.g., wound care) would be cared for professionally. The respondents were then shown an example choice task with two care situations (A vs. B) and it was underlined that no wrong answers were possible, as this was a subjective opinion. The main research question asked to the respondents was: “Under what conditions are you willing to provide care to a close relative? What is important to you personally?”. Subsequently, respondents were asked to choose the preferred care situation in the following nine choice tasks. The questionnaire blocks, meaning the respective DCE choice tasks, were presented to respondents in a random order to ensure that order bias was not systematic across the sample. After the DCE tasks, 19 additional questions were posed regarding age, gender, current health status, living and family situation, income, education, previous caregiving experience, and a number of attitudinal questions regarding the person’s willingness to care (e.g., willingness to reduce working hours). At the end of the questionnaire, a blank space was provided for further comments of the respondents.

Fig. 1 Example of a DCE choice set

Attributes (characteristics)	Situation A	Situation B
Expected period of caregiving (duration of care)	2 years	5 years
Care time (hours per day)	2 hours per day	5 hours per day
Formal care services (frequency per week)	Daily	None
Respite (weeks per year)	6 weeks per year	3 weeks per year
Monetary compensation (€ per hour)	12 € per hour	6 € per hour
In which situation would you prefer to provide care?	**Situation A:** ☐	**Situation B:** ☐

Data analysis and interpretation

Socio-demographic data were analyzed using descriptive methods following data cleansing. Except for mean age, all other variables were depicted as the absolute number of cases and respective percentages in reference to the total sample. The analysis of the collected choice data is theoretically based on Lancaster's characteristics theory of demand [33] and random utility theory [34]. More specifically, choice data are analyzed on the premise that each individual will choose the alternative (here: care situation) that provides the highest utility to the individual. The utility U of individual q choosing alternative i can be decomposed into a deterministic part V and a non-explainable or random component ε and written as [28]

$$U_{iq} = V_{iq} + \varepsilon_{iq}$$

For the multivariate analyses, a conditional logit model (CLM) and a latent class model (LCM) were used. For the CLM, we assumed that error terms are independently distributed with a type 1 extreme value (Gumbel) distribution. Models were estimated without and with two-way interaction effects. The probability of choosing one alternative i over the other is given by

$$P_{iq} = \frac{\exp(V_{iq})}{\sum_{j=1}^{J} \exp(V_{jq})}$$

All attribute levels were dummy-variable coded, except for the cost attribute in the CLM. Therefore, coefficients were interpreted as deviations from the reference level that was defined beforehand (except for the cost attribute). Positive coefficients > 0 indicate a preference for that attribute level, while negative coefficients < 0 indicate a non-preference for that attribute level. The coefficients were assumed to be statistically significant at a p value of ≤ 0.05. Since the DCE included the cost attribute "monetary compensation", we additionally calculated the marginal WTA (MWTA) for attribute levels in comparison to the reference levels using

$$\text{MWTA}_{\text{attribute}} = -\left(\frac{\beta_{\text{attribute}}}{\beta_{\text{costattribute}}}\right)$$

Further information on the theoretical foundation of DCE can be found elsewhere [22, 28]. In the LCM, we were able to include determining factors (e.g., sex or age) that influenced the choices made in the DCE between care situation A and B (dependent variable). Thus, the LCM allowed an estimation of the importance of DCE attributes for each class as well as the variables that determined class membership to estimate preference heterogeneity. The probability of individual q choosing alternative i in the depicted situation t depending on falling within the class c is written as follows:

$$P_{iqt|c} = \frac{\exp(x_{iqt}\beta_c)}{\sum_{j=1}^{J} \exp(x_{jqt}\beta_c)}$$

Models were tested with altering number of classes and different independent variables. Correlations between independent variables were tested using Spearman rank, polychoric, and Cramer's V correlation measures. As highly correlated independent variables weaken the statistical and explanatory power of our LCM, these were removed. Study population characteristics were included in the segmentation models from the beginning and not analyzed post-classification. For all multivariate analyses, Akaike (AIC) and Bayesian information criteria (BIC), log-likelihood as well as pseudo-R-squared values were used to determine the final model. In particular, when comparing models, the values AIC and BIC should be minimized, while the pseudo-R-squared value should be maximized. All analyses were conducted with R statistics 4.0.4, using the package "survival" for the CLM and the package "lcmm" for the LCM [35].

Results

Descriptive statistics

A total of 324 questionnaires were returned (response rate: 8.1%). Of the 324 questionnaires, 44 had missing values with regard to the DCE choice tasks as well as socio-demographic data and were therefore excluded from the analysis. The distribution of age and sex did not significantly differ between the included and the excluded participants, and the missing data were not specific to any one task or socio-demographic question. Socio-demographic data were analyzed descriptively and are shown in Table 2. A considerably higher proportion of women participated in our study (71%). On average, respondents were around 45 years old. The majority of included participants were married or in a permanent relationship (66%) and had children (68%). Around two-thirds of the sample had a high education (at least a completed vocational training or university entrance qualification) and approximately 80% were full- or part-time employed. Almost 60% of the participants had a household income of 1500€ and higher at their disposal. The majority of respondents reported a very good or good health status (65%). Having siblings and the fact whether or not the respondent's parents were still alive were additionally reported as two factors potentially influencing the reported willingness to provide informal care. 59% of the sample had personal care experiences. This refers to experiences either in organizing informal and/or home-based care services or providing informal care themselves (either alone or with support).

Table 2 Characteristics of included participants ($n = 280$)

	$N = 280$
Sex	
Male	81 (29%)
Female	199 (71%)
Mean age (median)	45.2 (49.00)
Marital status	
Single	67 (24%)
Married or in serious relationship	184 (66%)
Widowed	7 (3%)
Divorced or separated	22 (8%)
Having children	
Yes	189 (68%)
No	91 (33%)
Having siblings	
Yes	259 (93%)
No	21 (8%)
Education	
Low	103 (37%)
High	177 (63%)
Current employment status	
Part-time employment	80 (29%)
Full-time employment	133 (48%)
Unemployed	45 (16%)
Retired	22 (8%)
Household income	
Prefer not to say	26 (9%)
Below 500€ up to 1500€	92 (33%)
1500€ up to 3000€	107 (38%)
3000€ to 5000€ and above	55 (20%)
Are your parents still alive?	
Yes, both	134 (48%)
One parent is deceased	84 (30%)
No	62 (22%)
Health status	
Very good	49 (18%)
Good	132 (47%)
Satisfactory	65 (23%)
Less good	27 (10%)
Bad	7 (3%)
Care experience	
Yes	165 (59%)
None	115 (41%)

Multivariate analyses

Conditional logit model

Table 3 shows the main effect coefficients for the CLM and all five attributes were statistically significant to the entire sample. An increase in the expected period of caregiving (duration) as well as the care time per day had a negative impact on respondents' willingness to care, while the remaining three attributes had a positive impact. The largest negative coefficient was found for having to provide care for 8 h a day in reference to 2 h a day. This indicates that for the entire sample, an increase in the care hours per day reduced willingness to provide informal care. The largest positive coefficient was found for having formal services provide care three to four times a week to the person in need. This indicates that having formal care assistance was very important to the entire sample and increased their willingness to provide care. An increase in the formal care services correspondingly increased the odds of respondents being willing to provide care by the factor of 3.3. The MWTA for 1 h of informal care was €8.77 when having to provide care for 5 h a day and €14.54 when having to provide 8 h of care a day, always in reference to providing care for 2 h a day. For an increase in the expected duration of caregiving, respondents were willing to care for an expected period of 2 years when receiving a minimum of €3.34 of monetary compensation per hour and a minimum of €9.41 for an expected period of 5 years. Negative WTA values indicate that for our entire sample, these attributes or characteristics (formal care services and respite) would result in respondents being willing to forego a monetary compensation or theoretically even additionally pay for these services.

While interaction models are not often applied in the literature due to its complexity, we additionally calculated a CLM with main effects as well as all two-way interaction effects. Results are shown in Table 1 in the supplementary material. Similar to the findings of Nicolet et al. (2018), we found that including all two-way interaction effects slightly improved model fit [36]. In the interaction model, it is important to refrain from interpreting isolated main effects from interaction effects, as such interpretations can be misleading. Additionally, only statistically significant effects can be interpreted. While the main effects for daily formal care services and respite are no longer statistically significant on their own, the interaction effects indicate a very high (positive) impact on peoples' willingness to provide informal care when care situations included daily formal assistance and respite.

Latent class model

Models are estimated with different number of classes (2–5) and compared with reference to three goodness-of-fit measures (log-likelihood, AIC, and BIC). A particular emphasis is placed on the BIC when comparing LCMs, as is recommended in the literature [37]. Preference heterogeneity was investigated in reference to seven independent variables by means of the LCM. Based on BIC, a three-class LCM was selected. Class 1 comprised 40% of our sample, class 2

Table 3 Conditional logit model (main effects only)

Attributes/levels	Coefficient	OR	95% CI	SE	*P* value	MWTA (€)
Duration (Ref: 6 months)						
2 years	–0.37	0.69	(–0.53; –0.22)	0.08	0.00*	3.34
5 years	–1.06	0.35	(–1.21; –0.90)	0.08	0.00*	9.41
Care time (Ref: 2 h/day)						
5 h/day	–0.99	0.37	(–1.14; –0.83)	0.08	0.00*	8.77
8 h/day	–1.63	0.20	(–1.79; –1.48)	0.08	0.00*	14.54
Formal care services (Ref: none)						
3–4 times/week	1.20	3.31	(1.05; 1.35)	0.08	0.00*	–10.67
Daily	1.14	3.12	(0.98; 1.30)	0.08	0.00*	–10.14
Respite (Ref: none)						
3 weeks/year	0.58	1.78	(0.42; 0.73)	0.08	0.00*	–5.13
6 weeks/year	0.50	1.65	(0.35; 0.66)	0.08	0.00*	–4.48
Monetary compensation (€/h)	0.11	1.12	(0.60; 0.75)	0.01	0.00*	
Log likelihood	–2406.9					
Pseudo-R^2	0.19873					
AIC	4831.8					
BIC	4884.2					
No of observations	5030					
No of coefficients	9					

OR odds ratio; *AIC* akaike information criteria; *BIC* bayesian information criteria; *SE* standard error; *MWTA* marginal willingness to accept (€/h)

*$p < 0.05$

roughly 24%, and class 3 approximately 36%. Table 4 presents an overview of the preference data separated for the three classes.

Class 1 ($n = 112$) showed a strong dislike for an increase in the care time per day compared to the remaining two classes. Having to provide care for 8 h compared to 2 h a day had the greatest impact on respondents' willingness to care (*ß* = –1.82714, $p < 0.001$) in class 1. An increase in the expected period of caregiving (duration) was also valued negatively, while formal care services, respite and 12€ of monetary compensation per hour had a positive impact on the willingness to care of respondents in class 1. In comparison, for class 2 ($n = 66$), an increase in the expected period of caregiving had the greatest (negative) impact on their willingness to provide informal care, in particular 5 years in comparison to 6 months (*ß* = −1.30519, $p < 0.001$). A care time of 5 h in comparison to 2 h a day was valued positively by the respondents of class 2, along with formal care services and respite. Daily formal care services had the greatest positive impact on their willingness to care (*ß* = 0.96246, $p < 0.001$). Monetary compensation had no significant impact on respondents' decision-making in class 2. Class 3 ($n = 102$) was the only group that valued an expected period of caregiving of 5 years positively (ß = 0.13638, $p < 0.05$). Having to provide care for 8 h a day had a negative impact on the group's willingness to provide care (*ß* = –0.37385, $p < 0.001$). The most important attribute for class 3 was the monetary compensation. Receiving 12€ per hour of informal care had the greatest positive impact on their willingness to care (*ß* = 1.66179, $p < 0.001$).

As we included several independent variables in the segmentation process of the LCM, class membership effects could additionally be estimated. The differences between class 1 and 2 in reference to the included seven independent variables are shown in Table 5 (referenced against class 3).

Respondents in class 1 and 2 did not significantly differ in terms of age and health status in comparison to participants in class 3. Class 2 is comprised of a significantly greater proportion of women (*ß* = –1.37013, $p < 0.05$) and fewer people with care experience compared to class 3 (*ß* = –0.92833, $p < 0.05$). Both classes had a lower proportion of individuals that found it very important (Likert scale: 5) for family members to take care of themselves in case of a care dependency compared to class 3 (class 1: *ß* = –1.24867, $p < 0.05$, class 2: *ß* = –1.99153, $p < 0.05$). Class 2 additionally had a significantly higher proportion of respondents with a high household income in comparison to class 3 (*ß* = 1.23153, $p < 0.05$). The precise socio-demographic structure of all three classes is shown in Table 2 in the supplementary material with the absolute numbers as well as the probabilities per class.

Table 4 Latent class model (attribute preferences)

Attribute/level	Class 1 ($n = 112$, 40%)			Class 2 ($n = 66$, 23.57%)			Class 3 ($n = 102$, 36.43%)		
	Coefficient	SE	*P* value	Coefficient	SE	*P* value	Coefficient	SE	*P* value
Intercept	Not estimated			−1.03	0.18	0.00*	–2.27	0.12	0.00*
Duration (Ref: 6 months)									
2 years	–0.20	0.06	0.00*	–0.59	0.09	0.00*	0.10	0.07	0.12
5 years	–0.68	0.06	0.00*	−1.31	0.10	0.00*	0.14	0.06	0.03*
Care time (Ref: 2 h/day)									
5 h/day	−1.21	0.06	0.00*	0.23	0.10	0.02*	–0.25	0.06	0.00*
8 h/day	−1.83	0.07	0.00*	−0.13	0.09	0.12	–0.37	0.07	0.00*
Formal care services (Ref: none)									
3–4 times/week	0.58	0.06	0.00*	0.68	0.10	0.00*	0.71	0.07	0.00*
Daily	0.20	0.06	0.00*	0.96	0.10	0.00*	0.72	0.07	0.00*
Respite (Ref: none)									
3 weeks/year	0.19	0.06	0.00*	0.30	0.10	0.00*	0.27	0.07	0.00*
6 weeks/year	0.20	0.06	0.00*	0.21	0.09	0.02*	0.41	0.06	0.00*
Monetary compensation (Ref: 0€/h)									
6€/h	0.08	0.06	0.19	0.16	0.09	0.08	0.93	0.07	0.00*
12€/h	0.23	0.06	0.00*	0.10	0.09	0.28	1.66	0.08	0.00*
Log-likelihood	–2617.07								
AIC	5376.14								
BIC	5634.21								
Number of parameters	71								

*$p < 0.05$

Table 5 Class membership effects for the latent class model (fixed effects)

	Class 1 ($n = 112$, 40%)			Class 2 ($n = 66$, 23.57%)		
	Coefficient	SE	*P* value	Coefficient	SE	*P* value
Intercept	0.20	0.66	0.77	0.36	0.80	0.65
Sex (Ref: female)	–0.03	0.37	0.95	−1.37	0.55	0.01*
Age group 1 < 35 years (Ref: age group 3 > 50 years)	0.61	0.52	0.24	0.38	0.67	0.58
Age group 2 ≥ 35 and < 50 years (ref: age group 3 > 50 years)	0.59	0.46	0.20	0.87	0.60	0.15
Health status: very good (Ref: satisfactory)	0.47	0.88	0.59	–6.05	33.29	0.86
Health status: good (Ref: satisfactory)	–0.07	0.69	0.92	1.28	0.78	0.10
Health status: less good (Ref: satisfactory)	0.54	0.44	0.22	0.70	0.58	0.23
Health status: bad (Ref: satisfactory)	0.73	0.56	0.20	0.45	0.72	0.54
Having children (Ref: None)	0.04	0.45	0.93	–0.30	0.58	0.61
Household income: prefer not to say (Ref: 1500 up to 3000€)	–0.32	0.58	0.58	−1.01	0.82	0.22
Household income: < 500€ up to < 1500€ (Ref: 1500 up to 3000€)	–0.57	0.41	0.16	–0.53	0.52	0.30
Household income: 3000 to 5000€ and above (Ref: 1500 up to 3000€)	1.23	0.54	0.02*	1.23	0.64	0.05
Wishes[a] for having family provide informal care 1 (Ref: 3)	0.38	0.74	0.61	0.04	0.96	0.97
Wishes[a] for having family provide informal care 2 (Ref: 3)	0.32	0.75	0.67	1.45	0.80	0.07
Wishes[a] for having family provide informal care 4 (Ref: 3)	–0.45	0.48	0.35	–0.27	0.56	0.63
Wishes[a] for having family provide informal care 5 (Ref: 3)	−1.25	0.44	0.00*	−1.99	0.66	0.00*
Care experience (Ref: none)	–0.32	0.36	0.38	–0.93	0.46	0.04*

$^{*}p < 0.05$

[a] Wishes were ranked on a 5-point Likert scale, 1 not important and 5 very important

Discussion

This study investigated the willingness to provide informal care to older adults among 280 participants of the German general population by means of a DCE. With the help of qualitative interviews as well as a systematic literature review, five distinct aspects (attributes) were defined that influence a person's willingness to provide informal care. All of the included attributes were found to be statistically significant and thus relevant to the respondents when choosing between two hypothetical care situations. Almost all LTC systems around the world rely heavily on the support of informal caregivers and thus indirectly on the continuing willingness of people to provide informal care to their older or sicker relatives in need [4, 38]. Thus, the availability of informal caregivers is predominately determined by people's willingness to provide care and the support in place to enable informal caregiving [4]. Against the background of changing family structures, growing geographical distances between family members or the increasing employment rates of women, experts expect the rate of informal care to decrease in the future [39]. However, as many Germans still wish to 'age in place' and home-based care is considerably less costly for the state and the social security system, informal care remains an important pillar and research topic of interest. As the funding of the German LTC system is based on mandatory contributions, we chose to survey a sample of the general population. This study perspective as well as methodology used is an important distinction to other studies in the field that have predominately investigated the value of informal care by means of the contingent valuation method and surveying informal caregivers [18, 19, 21, 40].

When looking at the results of the CLM, the attribute care time constituted the most important attribute for the entire study population. As expected, needing to provide more hours of informal care per day was valued negatively. For the availability of informal caregivers in a country, a key determinant is the willingness of individuals to provide the number of care hours required for the care-dependent person [4]. Even though the needed care time per day or the expected duration of caregiving is difficult to plan ahead [6], it is important to know what people can imagine in terms of providing informal care. Studies show that with increasing care dependency, the necessary care time per day is often higher than our maximum level of 8 h care time per day [41, 42]. Nevertheless, the chosen level of 8 h was specifically intended to represent an equivalent to a full working day in Germany to additionally survey a willingness to reduce working hours if necessary. Other studies have also found that an increase in care hours per day often results in the reduction or temporary pause of working hours [8, 10].

One major challenge that is often described is the necessary reconciliation of informal care with other personal responsibilities, such as needing to work to ensure financial stability or having younger children at home to take care of. The heavy burden informal caregivers shoulder as a result of conflicting responsibilities often in turn lead to high physical and mental strain [7, 10]. One economic incentive for informal care provision that is discussed in politics is a monetary compensation paid to informal caregivers to increase peoples' willingness to care [43]. In Germany, the idea of such a monetary compensation would be paid in addition to the existing insurance benefits available to the care-dependent person, similar to other legal entitlements such as parental leave. Such a monetary compensation might ensure financial stability for the informal caregiver for a period of time by enabling a reduction of working hours [43]. As we included such a financial compensation as one attribute in our DCE, we were able to calculate WTA values for the different attribute levels. The highest WTA value of €14.54 per hour was found when being willing to provide 8 h of care in reference to 2 h of care per day, followed by €9.41 per hour when having to provide care for an estimated period of 5 years instead of six months. The current minimum wage in Germany is €9.82, which is considerably lower than the accepted value of €14.54 per hour of informal caregiving [44]. A similar approach was taken in the DCE by Mentzakis et al. (2011), however, to estimate monetary values for specific informal care tasks such as personal care or household tasks [22]. While several studies have found significant differences between WTA and WTP values [21, 45], a Dutch study by van den Berg et al. (2005) found only minor differences between WTP and WTA when it comes to informal care valuations [46].

Preference heterogeneity was additionally investigated in this study with a three-class LCM. Especially when it comes to the above-mentioned monetary compensation, a higher financial compensation had in fact the highest positive impact on the willingness to provide care of respondents in class 3 ($n=102$). This could in part be explained by class 3 having a significantly lower household income at their disposal in reference to class 1. Class 1 ($n=112$) placed the greatest negative weight by far on increasing care hours per day. For class 2 ($n=66$), instead of care hours, an increase in the expected duration of caregiving had the greatest negative value and the greatest positive impact was found for daily formal care services. Monetary compensation had no significant impact on respondent's willingness to provide care in class 2. Class 2 had a significantly higher proportion of women and respondents without care experiences compared to class 3. Moreover, wishes in terms of people's willingness to receive informal care in the future had a significant impact in both classes 1 and 2 in reference to class 3. Both classes had a significantly lower proportion of study participants that found it very important for their relatives to take care of them in the event of a care dependency. Thus, respondents of class 3 seemed to be very willing to provide informal care and in turn would wish for the same willingness by their relatives. While not statistically significant in our study, others have found determining factors for peoples' willingness to make use of informal care to include having children and living together with a partner [47].

To the best of our knowledge, our study is the first to investigate the willingness to provide informal care of the German general population by means of a DCE. While, in total, studies on LTC preferences in the field of older adult care have seen an increase over the past years, a direct comparison of our results to other studies in the field of informal care is challenging. However, as we included the attribute formal care services, one particular study of interest is the DCE conducted by Lehnert et al. (2018) in Germany. In this DCE, the authors also surveyed a sample of the general population to investigate preferences for home- and community-based formal care services. Two hypothetical care packages were distinguished in reference to five attributes: care time per day, service level, quality of care, number of caregivers per month, and a co-payment per month [23]. The results of the CLM can provide some indications towards the possible preferences or design of the attribute formal care services that was integrated in our DCE. Results of the study by Lehnert et al. (2018) show that very high quality of care and smaller groups of formal caregivers (less rotation) were preferred. The calculated WTP for one extra hour of formal care was €8.98 for the surveyed sample [23].

Limitations

This study has several limitations that need to be addressed. The sample was only recruited in one federal state of Germany (Lower Saxony), which means that transferability of study findings is limited. In addition, the response rate of 8.1% is considerably lower compared to other studies in the field of informal care (20%, [22]) or home-based care (23.4%, [23]). Unfortunately, a relatively high proportion of questionnaires also had to be excluded due to missing values (44 out of 324). This might be due to the complexity of the chosen method DCE combined with the research topic and postal survey. Due to the limited sample size, it was not appropriate to derive concrete policy suggestions or recommendations. For this reason, future studies should attempt to include a considerably larger and optimally German-wide sample to increase representativeness. Additionally, no reminder was sent in our study, as we believed that this topic of interest either sparked interest in participants or not. As previous qualitative work has shown that willingness to provide informal care is difficult for some to actively deal with until such a situation arises in the family, we believed that a reminder would not significantly increase participation [6]. Moreover, a considerably higher proportion of women participated in our study, which might also be explained by the research topic. We had similar challenges in our qualitative work in the field [6]. A sample selection bias is therefore possible and means interpretation of study results need to be done cautiously.

In the design of the DCE, we were unfortunately not able to integrate changes in the type and severity of the care dependency such as cognitive compared to physical impairments. As we expect this to have an impact on people's willingness to provide care, this should be integrated in future studies. It needs to be noted that willingness to provide care is additionally influenced by many other factors, such the relationship to the person in need of care, cultural and normative beliefs, as well as surrounding circumstances such as the geographical distance between family members or the available housing space [6]. The interpretation of these influencing factors were consciously left open to each study participant in the DCE as only the five attributes and the context of the care situation were provided. Moreover, the availability, quality, and affordability of near-by formal alternatives such as nursing homes might also impact willingness to provide informal care. This, however, is regionally very different in Germany and difficult to integrate in a DCE without substantially increasing the complexity of the choice sets. The use of a forced-choice design forced respondents to always choose between the two alternatives, even if in reality people might opt out and choose not to provide informal care.

Since our DCE data were only collected at one point in time, no temporal changes in people's willingness to care could be measured. As qualitative studies have shown that willingness to care is usually influenced by a number of complex contextual factors and can change over time with, for instance, altering personal responsibilities or changes in people's health status. Future studies should further investigate changes in people's willingness compared to the actual provision of informal care over time. Nevertheless, as some studies suggest that informal care will likely continue to decrease in the future, while the need for this type of care remains high, it remains important to investigate people's perceptions and general willingness to provide care. More specifically, it is vital to investigate which factors have a considerable impact on people's willingness to provide care, such as the included monetary compensation. Unfortunately, several independent variables had too little variation in our sample, which increased correlations between variables and made it impossible to estimate an effect of these variables on the class segmentation of the LCM. A bigger sample might enable the inclusion of further independent variables, such as the employment status in future studies.

Conclusion

The present study is the first that investigated people's willingness to provide informal care by means of a DCE. Willingness to provide care was decomposed into five distinct aspects (attributes). With the help of regression models, the relative importance and trade-offs between attributes could be inferred. Under the premise that informal care remains a vital pillar of the German LTC system, results can provide insights into structural aspects that need to be improved to ensure that people are willing to provide informal care without too much mental and physical strain, as this in turn often leads to higher health costs and work absenteeism. The results of our LCM showed that compared to preferences of our entire sample, preferences could be segmented into three distinct groups that placed a different focus on attributes. Care time per day and expected duration of caregiving were valued negatively, however, in the three groups to a significantly different extend. Class 1 placed by far the greatest negative weight on an increase in the care time by day. Class 2 had a lower proportion of people with caregiving experiences and placed the highest value on reducing the expected time period of caregiving as well as having daily formal care services for support. While a monetary compensation is discussed to increase the willingness and availability of informal care in a country, our results show that this statement could not be generalized to our entire sample. More specifically, a monetary compensation might therefore only reach and motivate a sample of the population (here class 3), in particular as our results show people with a lower household income at their disposal.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s10198-022-01483-5.

Funding Open Access funding enabled and organized by Projekt DEAL. This work was supported by the Federal Ministry of Education and Research (Grant Number 01EH1603A). The funding body had no role in the design of the study, the collection, analysis, and interpretation of data or in the writing of the manuscript.

Declarations

Conflict of interest The authors declare that there is no conflict of interest.

Ethical approval The study has been approved by the Committee for Clinical Ethics of the Medical School in Hannover, Germany (Reference number 09.05.17/La). The respondents provided their implicit consent by sending the completed questionnaire back to the contact person (lead author).

References

1. OECD/European Commission: OECD health policy studies: a good life in old age? Monitoring and improving quality in long-term care. OECD Publishing (2013). https://doi.org/10.1787/2074319x
2. Arntz, M., Sacchetto, R., Spermann, A., Steffes, S., Widmaier, S.: The German social long-term care insurance-structure and reform options. SSRN J (2007). https://doi.org/10.2139/ssrn.944780
3. Bundesministerium der Justiz und für Verbraucherschutz. Sozialgesetzbuch: Soziale Pflegeversicherung: § 15 Ermittlung des Grades der Pflegebedürftigkeit, Begutachtungsinstrument. https://www.sozialgesetzbuch-sgb.de/sgbxi/15.html. Accessed March 2
4. Zigante, V.: Informal care in Europe: exploring formalisation, availability and quality. European Commission, London School of Economics and Political Science (2018). https://data.europa.eu/doi/10.2767/78836. Accessed 25 Feb 2022
5. Völz, S., Schnecke, J.H.: Beruf und Pflege besser vereinbaren: Individuelle und betriebliche Perspektiven als regionaler Gestaltungsansatz. Forschung Aktuell 03/2021, 1–23 (2021)
6. de Jong, L., Stahmeyer, J.T., Eberhard, S., Zeidler, J., Damm, K.: Willingness and preparedness to provide care: interviews with individuals of different ages and with different caregiving experiences. BMC Geriatr **21**, 1–14 (2021)
7. Hajek, A., Brettschneider, C., Ernst, A., Posselt, T., Wiese, B., Prokein, J., Weyerer, S., Werle, J., Fuchs, A., Pentzek, M.: Longitudinal predictors of informal and formal caregiving time in community-dwelling dementia patients. Soc Psychiatry Psychiatr Epidemiol **51**, 607–616 (2016)
8. Geyer, J.: Informell Pflegende in der deutschen Erwerbsbevölkerung: Soziodemografie, Pflegesituation und Erwerbsverhalten. Zentrum für Qualität in der Pflege (eds.) ZQP-Themenreport. Vereinbarkeit von Beruf und Pflege, pp. 24–43. ZQP, Berlin (2016)
9. Keck, W.: Was kommt nach der Pflege? Die Pflege eines Angehörigen senkt Beschäftigungschancen von Pflegepersonen nachhaltig. Sozialer Fortschr **65**(5), 112–119 (2016)
10. Geyer, J., Schulz, E.: Who cares? Die Bedeutung der informellen Pflege durch Erwerbstätige in Deutschland. Diw Wochenber **81**, 294–301 (2014)
11. Rothgang, H., Müller, R., Runte, R., Unger, R.: Pflegereport 2018 Schriftenreihe zur Gesundheitsanalyse. Barmer, Berlin (2018)
12. Stansfeld, J., Stoner, C.R., Wenborn, J., Vernooij-Dassen, M.: Positive psychology outcome measures for family caregivers of people living with dementia: a systematic review. Int Psychogeriatr (2017). https://doi.org/10.1017/S1041610217000655
13. Pendergrass, A., Mittelman, M., Graessel, E., Özbe, D., Karg, N.: Predictors of the personal benefits and positive aspects of informal caregiving. Aging Ment Health **23**, 1533–1538 (2019)
14. Hoefman, R.J., van Exel, J., Brouwer, W.: How to include informal care in economic evaluations. Pharmacoeconomics **31**, 1105–1119 (2013)
15. Schneider, U.: Informelle Pflege aus ökonomischer Sicht. Zeitschr Sozialreform **52**, 493–520 (2006)
16. Jiménez-Martín, S., Vilaplana Prieto, C.: Informal care motivations and intergenerational transfers in European countries. Health Econ **24**, 89–103 (2015)

17. Lehnert, T., Heuchert, M.A., Hussain, K., Koenig, H.-H.: Stated preferences for long-term care: a literature review. Ageing Soc **39**, 1873–1913 (2019)
18. Gervès, C., Bellanger, M.M., Ankri, J.: Economic analysis of the intangible impacts of informal care for people with Alzheimer's disease and other mental disorders. Value Health **16**, 745–754 (2013)
19. Gustavsson, A., Jönsson, L., McShane, R., Boada, M., Wimo, A., Zbrozek, A.S.: Willingness-to-pay for reductions in care need: estimating the value of informal care in Alzheimer's disease. Int J Geriatr Psychiatry **25**, 622–632 (2010)
20. König, M., Wettstein, A.: Caring for relatives with dementia: willingness-to-pay for a reduction in caregiver's burden. Expert Rev Pharm Outcomes Res **2**, 535–547 (2002)
21. Liu, W., Lyu, T., Zhang, X., Yuan, S., Zhang, H.: Willingness-to-pay and willingness-to-accept of informal caregivers of dependent elderly people in Shanghai, China. BMC Health Serv Res **20**, 1–11 (2020)
22. Mentzakis, E., Ryan, M., McNamee, P.: Using discrete choice experiments to value informal care tasks: exploring preference heterogeneity. Health Econ **20**, 930–944 (2011)
23. Lehnert, T., Günther, O.H., Hajek, A., Riedel-Heller, S.G., König, H.H.: Preferences for home-and community-based long-term care services in Germany: a discrete choice experiment. Eur J Health Econ **19**, 1213–1223 (2018)
24. Johnson, F.R., Lancsar, E., Marshall, D., Kilambi, V., Mühlbacher, A., Regier, D.A., Bresnahan, B.W., Kanninen, B., Bridges, J.F.P.: Constructing experimental designs for discrete-choice experiments: report of the ISPOR conjoint analysis experimental design good research practices task force. Value Health **16**, 3–13 (2013)
25. Mühlbacher, A.C., Bethge, S., Tockhorn, A.: Präferenzmessung im gesundheitswesen: grundlagen von discrete-choice-experimenten. Gesundheitsökon Qualitätsmanage **18**, 159–172 (2013)
26. Plöthner, M., Schmidt, K., de Jong, L., Zeidler, J., Damm, K.: Needs and preferences of informal caregivers regarding outpatient care for the elderly: a systematic literature review. BMC Geriatr (2019). https://doi.org/10.1186/s12877-019-1068-4
27. de Jong, L., Stahmeyer, J.T., Eberhard, S., Zeidler, J., Damm, K.: „Aber vielfach scheitert man dann an Besonderheiten "–Pflegeberater über Gesetzesänderungen und die Herausforderungen ihrer Arbeit: Eine qualitative Untersuchung. Z Evid Fortbild Qual Gesundhwes **150**, 65–72 (2020)
28. Lancsar, E., Louviere, J.: Conducting discrete choice experiments to inform healthcare decision making. Pharmacoeconomics **26**, 661–677 (2008)
29. SAS Institute Inc. (ed.): Marketing research methods in SAS: experimental design, choice, conjoint, and graphical techniques. SAS Document TS-694.http://support.sas.com/techsup/technote/ts694.pdf. Accessed on March 2. Citeseer (2007)
30. Epping, J., Geyer, S., Eberhard, S., Tetzlaff, J.: Völlig unterschiedlich oder doch recht ähnlich? Die soziodemografische Struktur der AOK Niedersachsen im Vergleich zur niedersächsischen und bundesweiten Allgemein-und Erwerbsbevölkerung. Das Gesundheitswesen **83**, S77–S86 (2021)
31. Destatis—Statistisches Bundesamt: Bevölkerungsstand—Bevölkerung nach Altersgruppen. https://www.destatis.de/DE/Themen/Gesellschaft-Umwelt/Bevoelkerung/Bevoelkerungsstand/Tabellen/bevoelkerung-altersgruppen-deutschland.html. Accessed 8 October 2021
32. Johnson, R., Orme, B.: Getting the most from CBC. Sawtooth Software Research Paper Series, Sequim, Sawtooth Software (2003)
33. Lancaster, K.J.: A new approach to consumer theory. J Polit Econ **74**, 132–157 (1966)
34. Manski, C.F.: The structure of random utility models. Theor Decis **8**, 229 (1977)
35. The R Foundation for Statistical Computing: The R Foundation. https://www.r-project.org/foundation/. Accessed 19 October 2021
36. Nicolet, A., Groothuis-Oudshoorn, C.G.M., Krabbe, P.F.M.: Does inclusion of interactions result in higher precision of estimated health state values? Value health **21**, 1437–1444 (2018)
37. Nylund, K.L., Asparouhov, T., Muthén, B.O.: Deciding on the number of classes in latent class analysis and growth mixture modeling: a Monte Carlo simulation study. Struct Equ Model **14**, 535–569 (2007)
38. Spasova, S., Baeten, R., Vanhercke, B.: Challenges in long-term care in Europe. Eurohealth **24**, 7–12 (2018)
39. Hajek, A., Lehnert, T., Wegener, A., Riedel-Heller, S.G., König, H.-H.: Potential for informal care of the elderly in Germany results of a representative population-based survey (potential for informal care of the elderly in Germany: results of a representative population-based survey). Zeitschr Gerontol Geriatr **51**(6), 612–619 (2018)
40. Fu, Y.Y., Chui, E.W., Law, C.K., Zhao, X., Lou, V.W.Q.: An exploration of older Hong Kong residents' willingness to make copayments toward vouchers for community care. J Aging Soc Policy **31**, 358–377 (2019)
41. Wetzstein, M., Rommel, A., Lange, C.: Pflegende Angehörige-Deutschlands größter Pflegedienst. GBE kompakt **6**(3), 1–12 (2015). https://doi.org/10.17886/RKI-GBE-2016-018
42. Hielscher, V., Kirchen-Peters, S., Nock, L., Ischebeck, M.: Pflege in den eigenen vier Wänden: Zeitaufwand und Kosten. Pflegebedürftige und ihre Angehörigen geben Auskunft. (eds.) Hans-Böckler-Stiftung, No. 263. Hans-Böckler-Stiftung, Düsseldorf (2017)
43. Rothgang, H.: Stellungnahme zum Antrag der Fraktion Bündnis 90/Die Grünen „Pflege gerecht und stabil finanzieren–Die Pflege-Bürgerversicherung vollenden". BT-Drucksache **19**, 8561 (2019)
44. Destatis—Statistisches Bundesamt: Verdienste—Mindestlohn. https://www.destatis.de/DE/Themen/Arbeit/Verdienste/Mindestloehne/_inhalt.html (2022). Accessed 11 January 2022
45. Horowitz, J.K., McConnell, K.E.: A review of WTA/WTP studies. J Environ Econ Manage **44**, 426–447 (2002)
46. van den Berg, B., Bleichrodt, H., Eeckhoudt, L.: The economic value of informal care: a study of informal caregivers' and patients' willingness to pay and willingness to accept for informal care. Health Econ **14**, 363–376 (2005)
47. Spangenberg, L., Glaesmer, H., Brähler, E., Strauß, B.: Use of family resources in future need of care preferences and expected willingness of providing care among relatives: a population-based study. Bundesgesundheitsbl **55**(8), 954–960 (2012)

Supplementary material

Table 1: Conditional logit model (*main effects + all two-way interaction effects*)

Attribute/Level	**Coefficient**	**OR**	**95% CI**	**SE**	***p*-value**
Duration (*Ref: 6 months*)					
2 years	1.44	4.23	(0.75; 2.13)	0.35	0.00*
5 years	–0.46	0.63	(–0.92; –0.01)	0.23	0.04*
Care time (*Ref: 2 hours/day*)					
5 hours/day	–1.12	0.33	(–1.64; –0.59)	0.27	0.00*
8 hours/day	–2.02	0.13	(–2.63; –1.41)	0.31	0.00*
Formal care services (*Ref: None*)					
3–4 times/week	1.43	4.19	(0.93; 1.94)	0.26	0.00*
Daily	–0.48	0.62	(–1.06; 0.11)	0.30	0.11
Respite (*Ref: None*)					
3 weeks/year	0.06	1.06	(–0.47; 0.59)	0.27	0.83
6 weeks/year	0.05	1.05	(–0.55; 0.65)	0.31	0.88
Monetary compensation (€/hour)	1.05	2.87	(0.77; 1.33)	0.14	0.00*
Interaction effects					
2 years x 5 hours/day	–0.39	0.68	(–0.91; 0.13)	0.27	0.14
2 years x 8 hours/day	–1.41	0.24	(–2.03; –0.78)	0.32	0.00*
2 years x 3–4 times/week	–1.00	0.37	(–1.54; –0.45)	0.28	0.00*
2 years x Daily	–0.45	0.63	(–1.05; 0.14)	0.30	0.14
2 years x 3 weeks/year	–1.09	0.34	(–1.79; –0.38)	0.36	0.00*
2 years x 6 weeks/year	–0.87	0.42	(–1.47; –0.28)	0.30	0.00*
2 years x Monetary compensation	–0.49	0.61	(–0.75; –0.22)	0.13	0.00*
5 years x 5 hours/day	–0.53	0.59	(–1.02; –0.04)	0.25	0.04*
5 years x 8 hours/day	–1.01	0.36	(–1.55; –0.48)	0.27	0.00*
5 years x 3–4 times/week	–0.71	0.49	(–1.27; –0.15)	0.29	0.01*
5 years x Daily	0.55	1.73	(0.06; 1.04)	0.25	0.03*
5 years x 3 weeks/year	–0.20	0.82	(–0.74; 0.33)	0.27	0.45
5 years x 6 weeks/year	0.20	1.23	(–0.36; 0.77)	0.29	0.48
5 years x Monetary compensation	–0.39	0.67	(–0.62; –0.17)	0.12	0.00*
5 hours/day x 3–4 times/week	0.62	1.87	(0.18; 1.07)	0.23	0.01*
5 hours/day x Daily	0.75	2.11	(0.14; 1.36)	0.31	0.02*
5 hours/day x 3 weeks/year	0.28	1.32	(–0.25; 0.80)	0.27	0.30
5 hours/day x 6 weeks/year	0.16	1.18	(–0.36; 0.69)	0.27	0.54
5 hours/day x Monetary compensation	–0.23	0.79	(–0.49; 0.02)	0.13	0.08
8 hours/day x 3–4 times/week	0.78	2.19	(0.14; 1.43)	0.33	0.02*
8 hours/day x Daily	–0.74	0.48	(–1.46; –0.02)	0.37	0.04*
8 hours/day x 3 weeks/year	0.99	2.70	(0.42; 1.57)	0.29	0.00*
8 hours/day x 6 weeks/year	1.19	3.30	(0.60; 1.79)	0.30	0.00*
8 hours/day x Monetary compensation	–0.26	0.77	(–0.56; 0.05)	0.16	0.10
3–4 times/week x 3 weeks/year	0.21	1.24	(–0.36; 0.78)	0.29	0.46
3–4 times/week x 6 weeks/year	–0.32	0.73	(–0.82; 0.18)	0.25	0.20
3–4 times/week x Monetary compensation	–0.03	0.97	(–0.29; 0.22)	0.13	0.80
Daily x 3 weeks/year	2.41	11.18	(1.82; 3.01)	0.30	0.00*
Daily x 6 weeks/year	1.55	4.70	(0.99; 2.11)	0.29	0.00*
Daily x Monetary compensation	0.21	1.23	(–0.06; 0.48)	0.14	0.13
3 weeks/year x Monetary compensation	–0.07	0.93	(–0.31; 0.16)	0.12	0.55
6 weeks/year x Monetary compensation	–0.16	0.85	(–0.42; 0.11)	0.13	0.24
Log likelihood	–2296.7				
Pseudo R^2	0.22467				
AIC	4675.4				
BIC	4914.4				
No. of observations	5030				
No. of coefficients	41				

**significant at p<0.05, Monetary compensation is standardized*

Table 2: Socio-demographic structure of the classes within the LCM

	Class 1 (n = 122)	**Class 2 (n = 66)**	**Class 3 (n = 102)**
Sex			
Male	38 (33.93)	9 (13.64)	34 (33.33)
Female	74 (66.07)	57 (86.36)	68 (66.67)
Age group			
<35 years	37 (33.06)	16 (24.24)	23 (22.55)
≥35 & <50 years	29 (25.89)	22 (33.33)	18 (17.65)
>50 years	46 (41.07)	28 (42.42)	61 (59.80)
Health status			
Very good	26 (23.21)	10 (15.15)	13 (12.75)
Good	55 (49.11)	34 (51.51)	43 (42.16)
Satisfactory	23 (20.54)	12 (18.18)	30 (29.41)
Less good	5 (4.46)	10 (15.15)	12 (11.76)
Bad	3 (2.68)	0 (0.00)	4 (3.92)
Having children			
Yes	73 65.18)	44 (66.67)	72 (70.59)
No	39 (34.82)	22 (33.33)	30 (29.41)
Household income			
Prefer not to say	10 (8.93)	4 (6.06)	12 (11.76)
<500€ – 1500€	27 (24.11)	20 (30.30)	45 (44.12)
1500€ – 3000€	45 (40.18)	24 (36.36)	38 (37.25)
3000€ – 5000€ and more	30 (26.79)	18 (27.27)	7 (6.86)
Wishes			
1 (not important)	9 (8.04)	3 (4.55)	5 (4.90)
2	8 (7.14)	12 (18.18)	4 (3.92)
3	37 (33.04)	22 (33.33)	19 (18.63)
4	29 (25.89)	19 (28.79)	20 (19.61)
5 (very important)	29 (25.89)	10 (15.15)	54 (52.94)
Care experiences			
Yes	71 (63.39)	31 (46.97)	63 (61.76)
No	41 (36.61)	35 (53.03)	39 (38.24)

Note: The absolute and relative numbers per class are shown.

Modul 8

The impact of different care dependencies on people’s willingness to provide informal care: A discrete choice experiment in Germany

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Eingereicht in: Health Economics Review

2022

The impact of different care dependencies on people's willingness to provide informal care: A discrete choice experiment in Germany

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Journal: Health Economics Review

Abstract

Background: Informal care provided by family members, friends, or neighbors is a major pillar in the German long-term care system. As the number of care-dependent older adults grow, ensuring their future care still relies on the willingness of family members, friends, or neighbors to assume the role of an informal caregiver. This study aimed to investigate the impact on people's willingness to provide informal care to a close relative with predominately cognitive compared to physical impairments via a discrete choice experiment.

Methods: An online survey was distributed to the general population in Germany, which resulted in 260 participants. A conditional logit model was used to investigate the preferences.

Results: Increased care time per day (hours) and expected duration of caregiving were negatively valued by the participants and reduced willingness to care. Descriptions of the two health statuses had a significant impact on participants' decisions. Having to provide care to a close relative with cognitive impairments was slightly preferred over caring for a relative with physical impairments.

Conclusions: A possible explanation for the preferences as well as high willingness-to-accept values for an hour of caregiving might be the young age and sociodemographic structure of our cohort. Participants slightly preferring to care for a relative with cognitive impairments compared to physical impairments might be explained by the discomfort of providing personal care to a physically impaired relative or feelings of sympathy and pity toward people with dementia.

Keywords: Willingness to care; Older adult care; Discrete Choice Experiment; Long-term care

Introduction

When imagining how people would like to receive care when they get older, many aging adults prefer to remain in their familiar surroundings to maintain social ties and retain autonomy.[1,2] Of a representative German sample, 87% stated that they would like to stay in their own homes when care-dependent in the future.[3] When family members, friends, or neighbors assume the role of a caregiver, they usually do not receive monetary compensation or payment. This so-called informal care is an essential pillar in long-term care systems worldwide and varies regarding type and intensity of help provided, location, and duration.[4–6] In 2019 in Germany, 80% of the 4.1 million care-dependent people were cared for in a home-based setting, either by family members, neighbors, or friends (56%) and/or by outpatient services (24%).[7] Since the number of care-dependent older adults is expected to increase to six million by 2030,[7,8] need for informal care is also expected to increase. Therefore, ensuring future care still relies on individuals' willingness to assume the role of informal caregivers.[4,9] However, surveys showed that younger respondents felt a lesser familial belonging and sense of responsibility toward caring for older relatives.[10] Additionally, close relatives' ability to assume the role of informal caregivers has changed. Social changes, such as increased female labor force participation impact traditional caregiving. Moreover, the effects of globalization and increased job mobility often result in geographical distance between family members. Thus, the potential for informal care might decrease in the future, while demand grows.[2]

Assuming the role of an informal caregiver potentially impacts the caregivers' health, quality of life, occupation, and financial stability, among others.[8,11] Against the background that informal caregivers often experience high physical and mental strain, studies investigated the reasons or motivations for people to assume this time-consuming role.[12,13] Zarzycki and Morrison (2021) understood willingness to care as a consequence of the underlying motivations for caregiving,[14] such as feelings of love and affection, reciprocity, and a sense of obligation or feeling of indebtedness to the care receiver.[12,13,15,16] Willingness to provide care is influenced by the potential caregiver's socio-demographic factors (e.g. age, gender, family status, and place of residence), family structures and dynamics (e.g. number of siblings and proximity to children), religious affiliations, normative beliefs and values, and financial situation.[14,17,18] In addition, the type and severity of care dependency as well as the illness characteristics of the care receiver might influence a person's willingness to provide care.[14] It enables certain predictions regarding the types of caregiving tasks required, duration of the caregiving situation, and potential intensity of changes as the illness progress.[14,19] Although the actual duration and intensity of an informal caregiving situation are difficult to plan,[13] certain factors that might influence a person's willingness to provide care can be identified. However, these are understudied.[14] As an approximation, von dem Knesebeck et al. (2014) explored the emotional reactions and attitudes of the German general population toward people with dementia[20] and found that the majority expressed so-called pro-social reactions, they felt sympathy, pity, and wanted to help people with dementia. However, approximately 25% indicated that patients with dementia induced fear, and 46% felt uncomfortable in their presence. Furthermore, willingness to provide care was negatively associated with feelings of fear toward people with dementia, younger age, and lower socioeconomic status. Therefore, attitudes play a major role in a person's willingness to provide care.

In informal care research, contingent valuation methods have been applied to explore the value of informal caregiving. Willingness-to-pay (WTP) values for a reduction of one hour of caregiving or willingness-to-accept (WTA) values for providing an additional hour of caregiving were estimated.[21,22] Mentzakis et al. (2011) used a discrete choice experiment (DCE) to value informal care tasks, such as supervising, personal care, and household tasks.[23] Monetary compensation per informal care hour was also included to value informal care tasks.[23] To elicit people's willingness to provide informal care in Germany, we conducted a postal survey of 280 participants in the general population using a DCE.[24] Data analysis revealed that increased hours of caregiving per day had the greatest negative impact on willingness to care. Monetary compensation could significantly increase willingness to provide care among individuals with a lower household income. From the postal survey and as a central point of feedback, the type and severity of care dependency was found to be particularly relevant to know in advance and influenced people's willingness to provide care. Therefore, it should be included in the DCE choice sets. To investigate the relevance of the health status of a care receiver, this study further pursued the elicitation of the willingness to provide informal care among the German general population by adding two health descriptions of a hypothetical care receiver to the DCE with identical attributes and levels. Hence, the impact on participants' willingness to care for a close relative with predominately cognitive compared to physical impairments was investigated.

Methods

DCE design

To quantify and elicit people's preferences, a DCE was chosen as the central component of the survey. The research object was decomposed into a set of characteristics (attributes) and different levels. Hypothetical scenarios (choice sets) were designed with attributes and varied levels in each choice set. We created a symmetric experimental design with five quantitative attributes and three levels. The attributes and levels were chosen with the help of a systematic review [25] and semi-structured qualitative interviews[13,26]. An overview of the identified attributes and levels, including their descriptions, is presented in Table 1.

Table 1: Overview of DCE attributes and levels

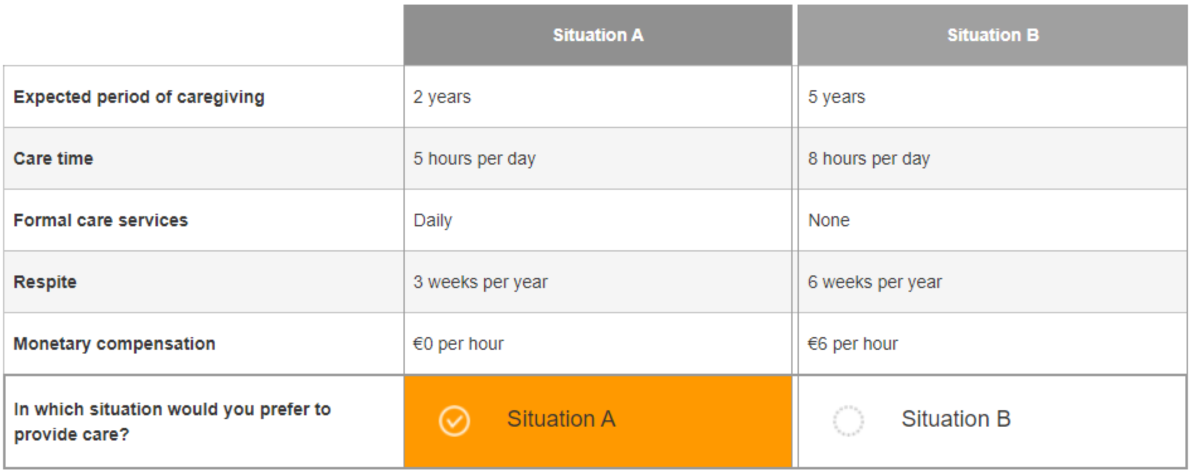
Attribute	Attribute description	Levels
Expected period of caregiving *(duration of care)*	The period of time the caregiver would care for and/or look after the person in need of care.	6 months 2 years 5 years
Care time *(hours per day)*	The amount of time (hours per day) the caregiver would provide care and/or supervise the person in need of care at home (e.g. personal care, household tasks, doctor visits etc.)	2 hours per day 5 hours per day 8 hours per day
Formal care services *(frequency per week)*	The frequency of professional support that is additionally available to the caregiver (e.g. outpatient care services can assist with personal care or counsellors can help with any open questions). A visit lasts about 30 minutes.	None 3 to 4 times a week Daily
Respite *(weeks per year)*	The number of weeks a year that are available to the caregiver for a variety of respite options. During this time period, professionals care for the individual in need (e.g. during vacation).	None 3 weeks per year 6 weeks per year
Monetary compensation *(€ per hour)*	A wage replacement benefit (net) at the personal disposal of the caregiver. Paid as a financial compensation per hour for the care provided (in addition to the existing cash benefits by the LTC insurance in Germany).	€0 per hour €6 per hour €12 per hour

SAS software was used to create a D-efficient experimental design. D-efficiency is a standard measure of the goodness-of-fit that indicates how well the main effects can be estimated.[27] The final experimental design was a fractional factorial design with 18 choice sets, blocked into three survey versions of six choice sets each to reduce respondents' burden. The choice sets were checked for plausibility and randomly assigned to respondents. The design allowed for a clean estimation of all the main effects. Understandability of the attributes, levels, and description of health states and functionality of the online survey on different devices was piloted in a sample of the general population (n = 15).

The survey

An online survey was conducted using SurveyEngine.[28] Potential participants were informed that their answers would be collected anonymously and treated confidentially. No IP addresses were saved and collected data were only analyzed at Leibniz University and not transmitted to any third party. Following participants' informed consent, the next two pages included instructions on how to complete the DCE-choice tasks. A detailed description of the attributes and levels, as well as an example choice set, is provided (see Figure 1).

Figure 1: Example of a DCE choice set



	Situation A	Situation B
Expected period of caregiving	2 years	5 years
Care time	5 hours per day	8 hours per day
Formal care services	Daily	None
Respite	3 weeks per year	6 weeks per year
Monetary compensation	€0 per hour	€6 per hour
In which situation would you prefer to provide care?	✓ Situation A	○ Situation B

Identical to the previously performed postal study, the main research question in the online survey was "*Under what conditions are you willing to provide care to a close relative? What is important to you personally*?". Respondents chose the preferred care situation (A or B) from the six choice sets depicted. For the choice sets, they were asked to imagine a close relative who could still be cared for in a home-based setting, while medical tasks would be cared for by professionals. To investigate the impact of elaborating on the type and severity of care-dependency of the hypothetical person, respondents were shown a first health status (*predominately physically impaired*) for the first three choice sets and a second health status (*predominately cognitively impaired*) for the others. Exact descriptions of the two health statuses can be found in the Supplementary Material. The DCE choice sets were randomly assigned to the respondents, while ensuring that all choice sets were shown the same amount. Following the six DCE choice tasks, sociodemographic questions were posed (e.g., age, gender, family situation, and previous caregiving experience). Additionally, questions regarding the factors that influenced participant's willingness to provide care were enquired. At the end, additional comments could be submitted to the research team.

Participants

The piloted survey was distributed to the general population in Germany through social media and flyers in public spaces as well as doctors' practices. Snowball sampling was used to increase the study population by asking the participants to share the survey link with other interested individuals. Individuals aged 18 to 65 years with no care dependency were eligible. We used Johnson and Orme's formula (2003) and determined that the minimum required sample size was 125 respondents.[29]

Data analysis

Since the participants were forced to select survey responses, only fully completed surveys were included. Sociodemographic data and attitudinal questions were analyzed descriptively. For the choice data, participants' discrete choices were analyzed using regression analysis to estimate the relative importance of each attribute. A conditional logit model (CLM) was used, and we assumed that the error terms were independently distributed with a Type 1 extreme value distribution.[23,30] To determine the final CLM and assess the model fit, the Akaike (AIC) and Bayesian information criteria (BIC), log likelihood, and pseudo R-squared values were used. All analyses were conducted with R statistics version 4.0.4, using the package "survival" for CLM. For the multivariate analysis, all attribute levels were dummy coded and interpreted compared to the reference category, except for monetary compensation. Only statistically significant coefficients with a p-value of ≤0.05 could be interpreted. Since we included a cost attribute in the DCE choice tasks, we also calculated the marginal willingness-to-accept (MWTA) for attribute levels using the following equation:

$$MWTA_{attribute} = -\left(\frac{\beta_{attribute}}{\beta_{cost\ attribute}}\right)$$

Ethical considerations

This study was approved by the Committee for Clinical Ethics of the Medical School in Hannover, Germany (*Reference number 09.05.17/La*). Respondents provided informed consent on the SurveyEngine platform before they commenced with the study questions.

Results

Participant characteristics

In total, 260 individuals were included. An overview of the respondents' characteristics is presented in Table 2. A considerably higher proportion were women (67%) and younger individuals (60%). Majority were unmarried (56%) and had no children (60%), which could be explained by the age structure. Of these, 64% had a household income of €1,500 or higher at their disposal. Half of the participants completed a university degree. Furthermore, 84% worked full-time, and the vast majority (90%) reported having a (very) good health status. Till date, 70% did not have any personal experience in organizing or providing informal care.

Table 2: Characteristics of included participants (n = 260)

	N = 260	
Sex		
Male	87	(33%)
Female	173	(67%)
Age group		
< 35 years	156	(60%)
>= 35 & <50 years	62	(24%)
> 50 years	42	(16%)
Marital status		
Single	146	(56%)
Married or in serious relationship	96	(37%)
Widowed	3	(1%)
Divorced or separated	15	(6%)
Having children		
Yes	103	(40%)
No	157	(60%)
Having siblings		
Yes	201	(77%)
No	59	(23%)
Education		
Completed primary education	69	(27%)
Completed vocational training	57	(22%)
Completed university degree	134	(52%)
Current employment status		
Part-time employment	28	(11%)
Full-time employment	219	(84%)
Unemployed	7	(3%)
Retired	6	(2%)
Household income		
Prefer not to say	16	(6%)
Below 500€ up to 1,500€	78	(30%)
1,500€ up to 3,000€	67	(26%)
3,000€ to 5,000€ and above	99	(38%)
Are your parents still alive?		
Yes, both	212	(82%)
One parent is deceased	29	(11%)
No	19	(7%)
Health status		
Very good	142	(55%)
Good	92	(35%)
Satisfactory	20	(8%)
Less good or bad	6	(2%)
Care experience		
Yes	79	(30%)
None	181	(70%)

Results of the conditional logit model

Table 3 shows the preference weights for the CLM. All attributes were statistically significant, except for respite. Increased expected duration of caregiving and care time per day was negatively valued and therefore reduced willingness to provide care. The largest negative coefficient was found regarding providing eight compared to two hours of informal care per day. The MWTA for one hour of caregiving was €56.18 when providing care for eight compared to two hours per day. For an increased expected period of caregiving (duration), participants were willing to accept a MWTA of €9.26 and €37.98 per hour when caring for an expected period of two or five years compared to six months, respectively. The largest positive coefficient was found for daily formal care services supporting informal caregiving. Increased frequency of formal care services increased the odds of participants being willing to provide care by a factor of 2.8. Negative MWTA values indicated that participants were willing to waive monetary compensation or potentially pay for increased formal care services. Explanation of health status before the DCE choice sets had a statistically significant impact on the respondents' decisions. Providing care to a close relative with cognitive impairments was slightly preferred to caring for those with physical impairments.

Table 3: Conditional logit model (*main effects only*)

Attributes / levels	**Coeff**	**OR**	**95% CI**	**SE**	***p*-value**	**MWTA**
Duration (*Ref: 6 months*)						
2 years	–0.332	0.718	(–0.577; –0.086)	0.125	0.008*	9.26
5 years	–1.360	0.257	(–1.642; –1.077)	0.144	0.000*	37.98
Care time (*Ref: 2 hours/day*)						
5 hours/day	–1.108	0.330	(–1.328; –0.886)	0.113	0.000*	30.94
8 hours/day	–2.011	0.134	(–2.239; –1.783)	0.123	0.000*	56.18
Formal care services (*Ref: None*)						
3–4 times/week	0.358	1.430	(0.117; 0.599)	0.122	0.000*	–9.99
Daily	1.021	2.775	(0.782; 1.260)	0.122	0.000*	–28.51
Respite (*Ref: None*)						
3 weeks/year	–0.082	0.921	(–0.283; 0.119)	0.103	0.424	2.29
6 weeks/year	0.029	1.030	(–0.201; 0.260)	0.118	0.803	–0.82
Health status (*Ref: physical*)	0.220	1.246	(0.061; 0.378)	0.081	0.007*	6.14
Monetary compensation (*€/hour)*	0.036	1.037	(0.015; 0.057)	0.011	0.001*	
Log likelihood	– 1375.2					
Pseudo R^2	0.21983					
AIC	2770.3					
BIC	2823.9					
No. of observations	3,120					
No. of coefficients	10					

*Legend: Coeff = Coefficient, OR = Odds ratio, *significant at p<0.05, AIC = Akaike information criteria, BIC = Bayesian information criteria, SE = standard error, MWTA = marginal willingness to accept (€/hour), Ref = Reference category, Ref: physical = physically impaired*

To further investigate the impact of explaining the two health statuses beforehand, particularly the extent of preference heterogeneity, two additional CLMs were estimated and can be found in the Supplementary Material. Overall, the coefficients remained largely robust for all three CLMs. The main effect coefficients for the expected caregiving duration were similar. Specifically, increased duration of caregiving was valued negatively. However, providing care for five years instead of six months was valued as slightly worse when caring for a relative with cognitive impairments. The largest difference in coefficients was seen for providing care for five compared to two hours per day. Particularly, providing care for five hours to a relative with cognitive impairments was not valued as negatively, for which respondents were willing to accept €26.50 per hour compared to €43.77 per hour for a close relative with physical impairments. Another difference was the importance of formal care. For relatives with cognitive impairments, “formal care services” had a significant impact on respondents’ willingness to provide care, while for relatives with physical impairments, only daily formal care services had a significant impact.

Discussion

This study aimed to build upon the previously performed DCE by de Jong et al. (2022) by investigating how an explicit depiction of a hypothetical type and severity of care dependency of a close relative impacted willingness to provide informal care. To ensure comparability, five identical attributes were used, previously shown to influence and establish relevance to a person’s willingness to provide care in a sample of the German general population. While all five attributes were found to be statistically significant and relevant in the postal sample, in our online sample, “respite” did not play a statistically significant role in respondent’s decision-making. Compared to the results of the CLM, “care time” constituted the most important aspect of caregiving for both samples and had a negative impact on people’s willingness. However, for the online sample, the need to provide more hours of informal care per day had a greater negative impact than the postal sample. In addition, differences in the importance of “formal care services” were identified. For the postal sample, both levels increased the odds of participants willing to care by approximately threefold. For the online sample, only daily formal care services compared to no services increased the odds of respondents being willing to care by a factor of 2.8. The MWTA values of both samples varied greatly, whereas the algebraic signs and directions were the same. The greatest difference was seen in the need to provide eight compared to two hours of care per day. While the postal sample would accept an hourly monetary compensation of €14.54 when providing eight hours of care, the online sample would accept a minimum of €56.18 per hour. In comparison, the current minimum wage in Germany is €9.82.[31] In the postal survey, monetary compensation increased willingness to provide care among people with lower household income. In the online sample, significantly higher MWTA values were estimated, as monetary compensation did not have an important overall effect on participants’ willingness to provide care.

We suspect that the major differences in MWTA values and preference weights might be explained by differences in the sociodemographic structures of the two samples. While a similar percentage of women participated in both samples, the age structures differed greatly. The largest proportion of participants (60%) were younger than 35 years in the online sample compared to the largest proportion (48%) of 50 years and older in the postal sample. The age structure of the two samples also influenced the remaining sociodemographic variables. While majority of the postal sample were married (66%) and had children (68%), majority of the online sample were single (56%) and had no children (60%). Of the online sample, 84% were employed full-time during the survey compared to 48% of the postal sample. The majority of both the samples had a household income of €1,500 and above at their disposal; 38% of the online sample had a very high household income of €3,000 to €5,000 and above at their disposal compared to 20% of the postal sample. Furthermore, 90% of the online sample reported having a (very) good self-reported health status, compared to 65% of the postal sample. Only 30% of the online sample had personal experience in either organizing or providing informal care compared to nearly 60% of the postal sample. Younger age was found to be negatively associated with willingness to provide care in a previously conducted German survey,[20] and younger respondents felt a lesser sense of responsibility toward caring for their older relatives.[10] In a previous qualitative study in Germany, younger respondents without any personal caregiving experience perceived aging and informal caregiving negatively, which influenced their willingness and motivation to provide informal care.[13] This negative perception of aging was also found in a comparative survey of young Germans and Americans. German participants generally viewed aging more negatively than the American respondents, and the results showed that cultural factors influenced the perceptions of aging, which included anxiety and fear associated with it.[32] Additionally, respite might not have played a statistically significant role in participants' decisions in the online sample due to a higher proportion of individuals without caregiving experiences. Studies found that informal caregivers often identified respite services as an essential type of support.[33,34]

Depicting the type and severity of care dependency in advance had a statistically significant impact on participants' willingness to provide informal care in the online sample. Taking care of relatives with cognitive impairments was slightly preferred over providing care to relatives with physical impairments. Two differences were observed when comparing the effects of describing the two health statuses. First, formal care services were valued differently. When caring for a person with cognitive impairments, all forms of formal care support had a significant positive impact on participants' willingness to care, which increased the odds by up to three times. When caring for a person with physical impairments, only daily formal care services had a significant impact, which increased the odds by 2.4. Second, providing care for five compared to two hours per day was not valued as negatively when caring for a person with cognitive impairments (Coeff: –0.784) compared to those with physical impairments (Coeff: –1.392). Providing care for eight hours instead of two had a similar impact on both health statuses.

This was the first study to compare respondents' willingness to provide care to a close relative either cognitively or physically impaired. Thus, a direct comparison with similar studies was difficult. Providing care to a relative with cognitive impairments was slightly preferred in our sample; one possible explanation might be discomfort of providing personal care to a relative who was physically impaired. For our sample, having formal care services assisted by personal care was the most important (mean: 3.68, median: 4.00) compared to household tasks (mean: 2.01, median: 2.00) or assistance with organizing everyday life (mean: 2.07, median: 2.00). In Mentzakis et al.'s study (2011), informal care tasks were valued, and personal care was the most influential (negatively valued) attribute.[23] In contrast, as von dem Knesebeck et al.'s study (2014) showed, majority of German respondents felt sympathy or pity for people with cognitive impairments, such as dementia, and felt the need to help them.[20]

Limitations

Since this survey was conducted online, a very young cohort of respondents participated. Therefore, the results should be interpreted cautiously and cannot be generalized to the entire German general population. While we compared our online results with the postal survey regarding the overall impact of the five attributes, the effect of including a description of the type and severity of care dependency was tested only in the online survey. Furthermore, temporal changes could not be investigated since two different samples participated in the surveys. In an ideal research scenario, an identical sample or a sample similar in socio-demographic variables to the postal survey would have been given the online choice sets, which included the two descriptions of the health statuses. Thus, the sole impact of describing either a cognitively or physically impaired relative could be estimated. In addition, we do not know what respondents specifically associated with the depicted health states, meaning which motivations and feelings a cognitive versus physically impaired person were brought out. Future qualitative research designs can help understand these motivations.

Conclusion

This study investigated people's willingness to provide informal care in the German general population using a DCE. The impact of participants' willingness to care for a relative with cognitive versus physical impairments was investigated. Participants slightly preferred caring for a close relative with cognitive impairments, which might be explained by fear or discomfort with providing personal care to a relative with physical impairments or feelings of sympathy and pity towards people with dementia. Increased care time per day had the greatest negative impact on participants' willingness to provide care, for which respondents were willing to accept a minimum of €56.18 per hour of caregiving when providing care for eight compared to two hours per day. Younger age and lack of personal experience in caregiving might explain the preference weights and high MWTA values in this survey, as younger age was found to be negatively associated with willingness to provide care in other studies.

Funding: No funding was available for this study.

Acknowledgments: We would like to thank all participants for taking part in our study.

Conflicts of interest: The authors declare that there are no conflicts of interest.

Key-points:

- This study is the first to compare respondents’ willingness to provide care to a close relative either cognitively or physically impaired in Germany.
- The use of the DCE methodology enabled an estimation of the relative importance of five care characteristics, as people needed to weigh and trade-off between several caregiving situations.
- The integration of a monetary compensation per informal care hour enabled the estimation of marginal willingness-to-accept values for the study sample.
- Participants slightly preferred caring for a relative with cognitive compared to physical impairments.

References

1 Hajek A, Lehnert T, Wegener A, Riedel-Heller SG, König H-H. Factors associated with preferences for long-term care settings in old age: evidence from a population-based survey in Germany. BMC health services research 2017;17(156):1–9.

2 Hajek A, Lehnert T, Wegener A, Riedel-Heller SG, König H-H. Potential for informal care of the elderly in Germany: Results of a representative population-based survey (Potential for informal care of the elderly in Germany Results of a representative population-based survey). Zeitschrift fur Gerontologie und Geriatrie 2018;51(6):612–19.

3 Die Techniker (TK). TK-Meinungspuls Gesundheit 2021: https://www.tk.de/resource/blob/2105222/5122ff972fe2eddd8f4ae1e73500bf62/booklet-tk-meinungspuls-2021-data.pdf Accessed Apr 21, 2022.

4 Zigante V. Informal care in Europe: Exploring formalisation, availability and quality. European Commission, London School of Economics and Political Science 2018.

5 Triantafillou J, Naiditch M, Repkova K et al. Informal care in the long-term care system European overview paper 2010.

6 Broese van Groenou, Marjolein I, Boer A de. Providing informal care in a changing society. European Journal of Ageing 2016;13(3):271–79.

7 Statistisches Bundesamt (Destatis). Bevölkerung - Demographischer Wandel: Mehr Pflegebedürftige: https://www.destatis.de/DE/Themen/Querschnitt/Demografischer-Wandel/Hintergruende-Auswirkungen/demografie-pflege.html Accessed Feb 2, 2022.

8 Rothgang H, Müller R, Runte R, Unger R. Pflegereport 2018 Schriftenreihe zur Gesundheitsanalyse. Barmer, Berlin 2018.

9 Spasova S, Baeten R, Vanhercke B. Challenges in long-term care in Europe. Eurohealth 2018;24(4):7–12.

10 Ärzteblatt. Bereitschaft zur Pflege von Angehörigen sinkt: https://www.aerzteblatt.de/nachrichten/60070/Bereitschaft-zur-Pflege-von-Angehoerigen-sinkt Accessed Apr 21, 2022.

11 Hajek A, Brettschneider C, Ernst A et al. Longitudinal predictors of informal and formal caregiving time in community-dwelling dementia patients. Social psychiatry and psychiatric epidemiology 2016;51(4):607–16.

12 Al-Janabi H, Carmichael F, Oyebode J. Informal care: choice or constraint? Scandinavian journal of caring sciences 2018;32(1):157–67.

13 de Jong L, Stahmeyer JT, Eberhard S, Zeidler J, Damm K. Willingness and preparedness to provide care: interviews with individuals of different ages and with different caregiving experiences. BMC geriatrics 2021;21(1):1–14.

14 Zarzycki M, Morrison V. Getting back or giving back: understanding caregiver motivations and willingness to provide informal care. Health Psychology and Behavioral Medicine 2021;9(1):636–61.

15 Della Giusta M, Jewell S. Unpaid work and conformity: why care? Cambridge Journal of Economics 2015;39(3):689–710.

16 Dombestein H, Norheim A, Lunde Husebø AM. Understanding informal caregivers' motivation from the perspective of self-determination theory: An integrative review. Scandinavian journal of caring sciences 2020;34(2):267–79.

17 Spangenberg L, Glaesmer H, Brähler E, Strauß B. Use of family resources in future need of care. Care preferences and expected willingness of providing care among relatives: a population-based study. Bundesgesundheitsblatt, Gesundheitsforschung, Gesundheitsschutz 2012;55(8):954–60.

18 Stuifbergen, M. C., Van Delden, J. J., & Dykstra, P. A. The implications of today's family structures for support giving to older parents. Aging & Society 2008;28(3):413–34.

19 Williams KL, Morrison V, Robinson CA. Exploring caregiving experiences: Caregiver coping and making sense of illness. Aging & Mental Health 2014;18(5):600–09.

20 Knesebeck O von dem, Angermeyer MC, Lüdecke D, Kofahl C. Emotional reactions toward people with dementia–results of a population survey from Germany. International Psychogeriatrics 2014;26(3):435–41.

21 Liu W, Lyu T, Zhang X, Yuan S, Zhang H. Willingness-to-pay and willingness-to-accept of informal caregivers of dependent elderly people in Shanghai, China. BMC health services research 2020;20(1):1–11.

22 Gervès C, Bellanger MM, Ankri J. Economic analysis of the intangible impacts of informal care for people with Alzheimer's disease and other mental disorders. Value in health 2013;16(5):745–54.

23 Mentzakis E, Ryan M, McNamee P. Using discrete choice experiments to value informal care tasks: exploring preference heterogeneity. Health economics 2011;20(8):930–44.

24 de Jong L, Schmidt T, Stahmeyer JT, Eberhard S, Zeidler J, Damm K. Willingness to provide informal care to older adults in Germany: a discrete choice experiment. The European Journal of Health Economics 2022:1–12.

25 Plöthner, M., Schmidt, K., de Jong, L., Zeidler, J., & Damm, K. Needs and preferences of informal caregivers regarding outpatient care for the elderly: a systematic literature review. BMC geriatrics;19(82):1–22.

26 de Jong L, Stahmeyer JT, Eberhard S, Zeidler J, Damm K. „Aber vielfach scheitert man dann an Besonderheiten "–Pflegeberater über Gesetzesänderungen und die Herausforderungen ihrer Arbeit: Eine qualitative Untersuchung. Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen 2020;150:65–72.

27 SAS Institute Inc., editor. Marketing research methods in SAS: experimental design, choice, conjoint, and graphical techniques: Citeseer, 2007.

28 SurveyEngine GmBH. Respondents, Technology & Support: https://surveyengine.com/.

29 Johnson R, Orme B. Getting the most from CBC. Sequim: Sawtooth Software Research Paper Series, Sawtooth Software 2003.

30 Lancsar E, Louviere J. Conducting discrete choice experiments to inform healthcare decision making. Pharmacoeconomics 2008;26(8):661–77.

31 Destatis - Statistisches Bundesamt. Verdienste - Mindestlohn: https://www.destatis.de/DE/Themen/Arbeit/Verdienste/Mindestloehne/_inhalt.html Accessed Jan 11, 2022.

32 McConatha JT, Schnell F, Volkwein K, Riley L, Leach E. Attitudes toward aging: A comparative analysis of young adults from the United States and Germany. The International Journal of Aging and Human Development 2003;57(3):203–15.

33 McCaffrey N, Gill L, Kaambwa B et al. Important features of home-based support services for older A ustralians and their informal carers. Health & Social Care in the Community 2015;23(6):654–64.

34 Eldh AC, Carlsson E. Seeking a balance between employment and the care of an ageing parent. Scandinavian journal of caring sciences 2011;25(2):285–93.

Supplementary material

Table 1: Description of the person in need of care (health status)

Health status of the care-dependent person #1

An older close relative of yours is in need of care. This person is severely physically impaired and needs assistance with personal hygiene, climbing stairs and walking. With assistive devices, the person can move around independently to a limited extent. Cognitively, the person is not impaired (no dementia). At times, night-time assistance is needed, as well as being accompanied to doctor's visits and administering medication.

Health status of the care-dependent person #2

An older close relative of yours is in need of care. This person is barely limited in mobility and can still walk and climb stairs independently. However, he or she is becoming increasingly forgetful (dementia) and needs to be reminded about eating/drinking, personal hygiene and supported in the household. At times, you would have to help with personal hygiene or getting dressed. Partly, he/she is also very restless at night and confuses the day and night rhythm. Furthermore, he/she needs assistance with doctor's visits and administering medication. Orientation outside his/her own home is difficult for him/her.

Table 2: Conditional logit model (*main effects only, health status: physical impairment*)

Attributes / levels	**Coeff**	**OR**	**95% CI**	**SE**	***p*-value**	**MWTA**
Duration (*Ref: 6 months*)						
2 years	–0.375	0.688	(–0.744; –0.005)	0.188	0.047*	11.78
5 years	–1.385	0.250	(–1.815; –0.954)	0.220	0.000*	43.54
Care time (*Ref: 2 hours/day*)						
5 hours/day	–1.392	0.249	(–1.696; –1.088)	0.155	0.000*	43.77
8 hours/day	–1.969	0.140	(–2.282; –1.656)	0.160	0.000*	61.90
Formal care services (*Ref: None*)						
3–4 times/week	0.235	1.265	(–0.099; 0.569)	0.170	0.168	–7.38
Daily	0.872	2.391	(0.556; 1.187)	0.161	0.000*	–27.41
Respite (*Ref: None*)						
3 weeks/year	–0.043	0.958	(–0.316; 0.231)	0.140	0.759	1.35
6 weeks/year	0.181	1.199	(–0.124; 0.485)	0.155	0.245	–5.69
Monetary compensation (*€/hour)*	0.032	1.032	(–0.001; 0.064)	0.017	0.054	
Log likelihood	–591.88					
Pseudo R^2	0.22854					
AIC	1201.8					
BIC	1243.7					
No. of observations	1560					
No. of coefficients	9					

*Legend: OR = Odds ratio, *significant at p<0.05, AIC = Akaike information criteria, BIC = Bayesian information criteria, SE = standard error, MWTA = marginal willingness to accept (€/hour), Ref = Reference category*

Table 3: Conditional logit model (*main effects only, health status: cognitive impairment*)

Attributes / levels	**Coeff**	**OR**	**95% CI**	**SE**	***p*-value**	**MWTA**
Duration (*Ref: 6 months*)						
2 years	–0.440	0.644	(–0.822; –0.057)	0.195	0.024*	14.86
5 years	–1.488	0.226	(–1.897; –1.078)	0.209	0.000*	50.26
Care time (*Ref: 2 hours/day*)						
5 hours/day	–0.784	0.456	(–1.106; –0.463)	0.164	0.000*	26.50
8 hours/day	–1.990	0.137	(–2.349; –1.632)	0.183	0.000*	67.24
Formal care services (*Ref: None*)						
3–4 times/week	0.490	1.633	(0.122; 0.859)	0.188	0.009*	–16.57
Daily	1.126	3.083	(0.761; 1.491)	0.186	0.000*	–38.04
Respite (*Ref: None*)						
3 weeks/year	0.036	1.037	(–0.281; 0.353)	0.162	0.824	–1.21
6 weeks/year	0.127	1.135	(–0.228; 0.482)	0.181	0.483	–4.29
Monetary compensation (*€/hour)*	0.030	1.030	(–0.000; 0.059)	0.015	0.053	
Log likelihood	–557.5					
Pseudo R^2	0.27268					
AIC	1133					
BIC	1174.9					
No. of observations	1560					
No. of coefficients	9					

*Legend: OR = Odds ratio, *significant at p<0.05, AIC = Akaike information criteria, BIC = Bayesian information criteria, SE = standard error, MWTA = marginal willingness to accept (€/hour), Ref = Reference category*

Modul 9

Pflegebereitschaft in Abhängigkeit von der beruflichen Situation

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Eingereicht in: Zeitschrift für Evidenz, Fortbildung und Quallität im Gesundheitswesen

2022

Pflegebereitschaft in Abhängigkeit von der beruflichen Situation

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Journal: Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen

Zusammenfassung

Hintergrund: Der Anteil pflegebedürftiger Personen in Deutschland wird weiter steigen. Ein Großteil der Pflegebedürftigen wurde 2019 zu Hause versorgt. Für viele Pflegende führt die Vereinbarkeit von Pflege und Berufstätigkeit zu einer erheblichen Belastung. Politisch wird deshalb eine Lohnersatzleistung für die Pflege diskutiert, um die Vereinbarkeit zu erleichtern. Ziel der Studie ist die Untersuchung, ob und unter welchen Umständen die deutsche Bevölkerung bereit ist, einen nahen Angehörigen zu pflegen. Ein besonderer Fokus wird hierbei auf die Bereitschaft, die Arbeitszeit zu reduzieren und die Wichtigkeit der Dauer der Pflegesituation und einer Lohnersatzleistung gelegt.

Methode: Es wurde eine zweistufige Primärdatenerhebung (Stichprobe der Allgemeinbevölkerung sowie zufälliges Online-Sample) mittels Fragebogen durchgeführt. Zunächst wurde eine schriftliche Einzelbefragung über die AOK Niedersachsen versendet und durch eine Online-Befragung ergänzt. Die Daten wurden deskriptiv und mittels logistischer Regressionen ausgewertet.

Ergebnisse: 543 Teilnehmer*innen wurden eingeschlossen. 90% der Stichprobe war bereit einen Angehörigen zu pflegen, wobei die Mehrheit angab, dass ihre Bereitschaft von unterschiedlichen Einflussfaktoren abhängig sei. Der Gesundheitszustand der zu pflegenden Person sowie die zu pflegende Person selbst hatten den größten Einfluss. 34% der Erwerbstätigen waren nicht bereit ihre Arbeitszeit zu reduzieren, meist aus finanziellen Gründen.

Diskussion und Schlussfolgerung: Viele ältere Menschen wünschen sich so lange wie möglich zu Hause gepflegt zu werden. Somit ist und bleibt die Bereitschaft und Übernahme der informellen Pflege zentraler Bestandteil des deutschen Pflegesystems. Das Zusammenspiel von informeller Pflege und Berufstätigkeit kann oftmals zu einer erheblichen Belastung führen. Eine Lohnersatzleistung könnte für Personen mit geringerem Haushaltseinkommen die Pflegebereitschaft erhöhen. Um die Bereitschaft von Personen aus unterschiedlichen Lebensphasen zu erhöhen, bedarf es flexibler Ansätze, die über eine Lohnersatzleistung hinausgehen.

Schlüsselwörter: Pflege, Bereitschaft, Vereinbarkeit, Berufstätigkeit

Willingness to provide care dependent on the occupational situation

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Abstract

Introduction: The proportion of people in need of care will continue to rise in Germany. A majority of people in need of care were cared for at home in 2019. For many caregivers, reconciling caregiving and work leads to a considerable burden. Therefore, a monetary compensation for care is being discussed politically in order to facilitate the reconciliation. The aim of this study is to investigate whether and under what circumstances the German population is willing to care for a close relative. A particular focus is placed on the willingness to reduce working hours and the importance of the expected period of caregiving and a monetary compensation.

Methods: A two-stage primary data collection (sample of the general population and random online sample) was conducted using a survey. First, a self-complete postal survey was sent out via the AOK Lower Saxony and complemented with an online survey. The data was analysed descriptively and using logistic regression.

Results: 543 participants were included. 90% of the surveyed sample was willing to care for a close relative, with the majority stating that their willingness depended on various influencing factors. The health status of the person being cared for and the person being cared for themselves had the greatest influence. 34% of the employed respondents were not willing to reduce their working hours, mostly for financial reasons.

Discussion and conclusion: Many older adults wish to remain in their homes for as long as possible. Thus, the willingness to provide and take over the role of informal caregiver is and will remain a central pillar of the German care system. The interaction between providing informal care and occupation often leads to a considerable burden. A monetary compensation might increase the willingness to provide care for people with lower household incomes at their disposal. However, in order to increase the willingness to provide care of people from different backgrounds and life stages, flexible approaches are needed that go beyond a monetary compensation.

Keywords: Caregiving, willingness to care, compatibility, employment

1. Einleitung

Der Anteil der pflegebedürftigen Personen in Deutschland wird im Zuge des demographischen Wandels und der damit einhergehenden Zunahme der Multimorbidität weiter steigen. Schätzungen zufolge lag dieser Ende 2019 bei 4,1 Millionen in Deutschland. 80% der Pflegebedürftigen sind 65 Jahre und älter und die Mehrheit sind Frauen (62%) [1]. Für das Jahr 2030 beläuft sich die aktuelle Prognose auf 6 Millionen Pflegebedürftige und ist somit deutlich höher als bisher angenommen [1,2]. Diese Entwicklungen verstärken den Druck auf die Sozialsysteme, den strukturellen und finanziellen Bedürfnissen der ansteigenden Zahl an Pflegebedürftigen gerecht zu werden. Die Kosten für Pflege werden ebenfalls weiter steigen. Aktuelle Prognosen erwarten bei einem konstanten Leistungsspektrum jährliche Ausgaben der Pflegeversicherung in Höhe von 59 Milliarden Euro bis zum Jahr 2030 [2]. Neben einer nachhaltigen Finanzierung ist der bestehende Mangel an professionellen Pflegekräften in Deutschland eine große Herausforderung, um eine angemessene Versorgung der Pflegebedürftigen langfristig gewährleisten zu können. Aufgrund struktureller und finanzieller Herausforderungen sind die aktuellen Pflegesysteme somit auf die Bereitschaft von Angehörigen zu pflegen angewiesen.

Als Teil des Sozialversicherungssystems wurde 1995 eine verpflichtende Pflegeversicherung für die gesamte deutsche Bevölkerung eingeführt. Diese ist entweder an eine gesetzliche oder eine private Krankenversicherung gekoppelt. Aktuell basiert der Anspruch auf Leistungen auf einem im Jahr 2017 überarbeiteten und eingeführtem Pflegegradkonzept. Die Einstufung in einen von fünf Pflegegrade erfolgt auf Basis von sechs Modulen (Mobilität, kognitive und kommunikative Fähigkeiten, Verhaltensweisen und psychische Problemlagen, Selbstversorgung, Umgang mit krankheitsspezifischen/therapiebedingten Anforderungen, Gestaltung des Alltagslebens und sozialer Kontakte) auf einer Skala von 0 bis 100 Punkten. Ein höherer Pflegegrad bedeutet eine höhere Pflegebedürftigkeit und somit ein höheres verfügbares Budget an Geld- und/oder Pflegesachleistungen in Abhängigkeit der Pflegeform [3,4].

3,3 Millionen (80%) der 4,1 Millionen Pflegebedürftigen wurden 2019 zu Hause versorgt, entweder alleine durch Angehörige (56%) und/oder durch ambulante Pflege- und Betreuungsdienste (24%). 20% der Pflegebedürftigen wurden 2019 vollstationär in Pflegeheimen betreut [1]. Die erbrachte Pflege und Versorgung alleine durch Angehörige wird auch als informelle Pflege bezeichnet und ist eine wichtige Säule in der deutschen Pflegeversorgung, die auch von Seiten der Politik gestärkt wird [5]. Die häusliche Versorgung ist mit deutlichen Kostenvorteilen für die Pflegeversicherung verbunden und entspricht laut Umfragen ebenfalls den Wünschen und Präferenzen der meisten Älteren [6]. Viele wünschen sich so lange wie möglich zu Hause versorgt zu werden, um einen hohen Grad an

Selbstständigkeit und Unabhängigkeit zu erhalten. Eine Versorgung im Pflegeheim wird von vielen Betroffenen mit einem Verlust an Kontrolle, Freiheit, Unabhängigkeit und Würde in Verbindung gebracht [7].

Die Übernahme von informeller Pflegeverantwortung bedeutet häufig große Veränderungen für die pflegende Person. Studien berichten vor allem von Beeinträchtigungen der psychischen und physischen Gesundheit informell Pflegender sowie Lohneinbußen aufgrund reduzierter Berufstätigkeit [8]. Laut einer Studie von Geyer (2016) haben informell Pflegende bei einer Pflegetätigkeit von mehr als 1 Stunde pro Tag ihre Arbeitszeit um ca. 5 bis 8 Stunden pro Woche reduziert [9]. Des Weiteren kann die Pflegetätigkeit die Beschäftigungschancen der informell Pflegende als Vollzeitbeschäftigte nachhaltig senken [10]. Die Vereinbarkeit von Pflege und Beruf ist somit häufig eine große Herausforderung für informell Pflegende. Politische Maßnahmen zielen daher darauf ab, eine Freistellung der Arbeit für informell Pflegende für einen Zeitraum von bis zu 6 Monaten (Pflegezeitgesetz) [11] bzw. bis zu 24 Monaten (Familienpflegezeitgesetz) [12] zu ermöglichen. Zinslose Darlehen sollen bei der Überbrückung dieser Zeit finanziell helfen, werden jedoch kaum in Anspruch genommen. Für eine bessere Vereinbarkeit von Pflege und Beruf wurde eine Lohnersatzleistung für informell Pflegende von der Fraktion Bündnis 90 / Die Grünen vorgeschlagen. Diese Leistung würde ähnlich zum Elterngeld für einen bestimmten Zeitraum der informellen Pflege ausgezahlt werden und könnte potentiell ebenfalls die Pflegebereitschaft in Deutschland erhöhen [13].

Im Rahmen der vorliegenden Studie wurde untersucht ob und unter welchen Bedingungen eine Stichprobe der Allgemeinbevölkerung bereit ist, einen älteren nahen Angehörigen von ihnen zu pflegen. Da die Vereinbarkeit von Pflege und beruflicher Tätigkeit für viele (potentiell) informell Pflegende ein großer Belastungsfaktor ist, wird ein besonderer Fokus auf die Bereitschaft die Arbeitszeit zu reduzieren sowie der Wichtigkeit der Dauer der Pflegesituation und einer Lohnersatzleistung für die informelle Pflege gelegt.

2. Methoden

2.1 Stichprobe und Datenerhebung

Im Rahmen dieser Studie wurde eine zweistufige Primärdatenerhebung mittels Fragebogen durchgeführt. Eine zufällig ausgewählte Stichprobe der Allgemeinbevölkerung zwischen 18 und 65 Jahren wurde zunächst über die AOK Niedersachsen angeschrieben (n = 4.000), um an einer postalischen Einmalbefragung teilzunehmen. In einem zweiten Schritt wurde der schriftliche Fragebogen mit Hilfe der Befragungssoftware SurveyEngine [14] in ein Online-Format mit identischen Fragen umgewandelt und über soziale Netzwerke sowie mit Hilfe von Flyern an weitere Personen aus der Allgemeinbevölkerung zwischen 18 und 65 Jahren verteilt. Der Link zur Befragung wurde per Schneeballprinzip an weitere potentielle Teilnehmer*innen weitergeleitet. Teilnehmer*innen erhielten die Kontaktinformationen des Erstautors, um Fragen stellen zu können und wurden zu Beginn über die Ziele der Befragung sowie datenschutzrechtliche Aspekte aufgeklärt. In der schriftlichen Befragung haben die Teilnehmer*innen mit der Rücksendung ihres ausgefüllten Fragebogens der Datenverarbeitung zugestimmt; in der Online-Befragung mussten die Teilnehmer*innen vor der Umfrage der Datenverarbeitung zustimmen. Ein positives Ethikvotum der Medizinischen Hochschule Hannover (MHH) liegt vor (Nr. 09.05.17/La).

Ergebnisse einer vorab durchgeführten qualitativen Vorstudie mit 33 semi-strukturieren Einzelinterviews wurden für die Erstellung des Fragebogens verwendet [15] und dieser wurde in einem Pretest mit insgesamt 30 Personen geprüft und verbessert. Der Fragebogen umfasst insgesamt 10 Seiten und besteht sowohl aus standardisierten Fragen mit Antwortskalen als auch einem experimentellen Teil. Für den gesamten Fragebogen wurden die Teilnehmer*innen gebeten, sich einen pflegebedürftigen älteren nahen Angehörigen vorzustellen, der Unterstützung benötigt. Diese hypothetische Person könnte aber noch gut zu Hause versorgt werden und medizinische oder pflegerische Aufgaben (z. B. Wundversorgung) würden durch eine professionelle Unterstützungskraft erledigt werden. Zusätzlich wurden Fragen über ihre Pflegebereitschaft in Abhängigkeit bestimmter Einflussfaktoren wie dem Gesundheitszustand der zu pflegenden Person sowie ihre Bereitschaft, die Arbeitszeit zu reduzieren oder in ihrer Freizeit zu pflegen gestellt. Ergänzt wurden diese Inhalte um Fragen zu Wünschen bei Eintreten einer hypothetischen eigenen Pflegebedürftigkeit, sozioökonomischer Angaben sowie eigene Pflegeerfahrungen. Wünsche wurden auf einer 5-Punkt Likert Skala erfragt (1 = ganz unwichtig, 5 = sehr wichtig). Mehrfachantworten waren möglich. Ergebnisse des experimentellen Teils des Fragebogens sind an anderer Stelle publiziert (*Quelle EJHE-D-22-00018*).

2.2 Datenauswertung und Software

Fragebogenantworten wurden zunächst auf fehlende Werte geprüft und deskriptiv ausgewertet. Eine vergleichende Untersuchung der eingeschlossenen Stichprobe mit Personen, die nicht an der Befragung teilgenommen haben, war nicht möglich, da diese von Seiten der AOK Niedersachsen nicht erfasst wurden. Mittels logistischer Regressionen wurden Einflussfaktoren auf die Bereitschaft zu pflegen und die Bereitschaft die Arbeitszeit zu reduzieren untersucht. Als mögliche Einflussfaktoren wurden alle Merkmale der Teilnehmer*innen aus Tabelle 1 sowie die Wünsche bzgl. eines späteren Pflegebedarfs geprüft. Zur Identifikation signifikanter Einflussfaktoren wurde ein schrittweiser Selektionsalgorithmus basierend auf dem BIC Kriterium und unter Verwendung des 5% Signifikanzniveaus durchgeführt. Alle Analysen erfolgten mit R (Version 4.1.2) [16].

3. Ergebnisse

3.1 Beschreibung der Stichprobe

Von der schriftlichen Befragung über die AOK Niedersachsen wurden insgesamt 324 Fragebögen zurückgeschickt (Rücklaufquote: 8,1%). 35 Fragebögen mussten aufgrund fehlender Angaben ausgeschlossen werden. Zusammen mit den 254 vollständig über die Online-Plattform SurveyEngine ausgefüllten Fragebögen ergibt sich somit eine Gesamtstichprobe von 543 Teilnehmer*innen. Im Sinne eines komplementären Ansatzes wurden die beiden Datensätze zusammengefügt. An der Befragung nahm ein deutlich höherer Anteil an Frauen teil (69%) und 43% der Stichprobe war zwischen 18 und 34 Jahren alt. Die Mehrheit der Teilnehmer*innen war entweder verheiratet oder in fester Partnerschaft (51%) und hatte Kinder (54%). Der Großteil der Teilnehmer*innen (66%) war Vollzeit berufstätig. Die Hälfte der Teilnehmer*innen hatte einen (sehr) guten subjektiv beurteilten Gesundheitszustand und etwas mehr als die Hälfte (55%) hatte keine persönlichen Pflegeerfahrungen. 242 Personen aus der Stichprobe haben entweder die Pflege und Betreuung eines Angehörigen selbst geleistet oder die Organisation hierfür bereits übernommen. Eine deskriptive Übersicht der Merkmale ist in Tabelle 1 zu finden.

Tabelle 1: Merkmale der Teilnehmer*innen

	***N* = 543**
Geschlecht	
Männlich	167 (31%)
Weiblich	376 (69%)
Altersgruppe	
< 35 Jahre	234 (43%)
≥ 35 Jahre und < 50 Jahre	132 (24%)
≥ 50 Jahre	177 (33%)
Familienstand	
Ledig	217 (40%)
Verheiratet oder in fester Partnerschaft	279 (51%)
Geschieden oder getrennt lebend	37 (7%)
Verwitwet	10 (2%)
Kinder	
Ja	292 (54%)
Nein	251 (46%)
Höchster Bildungsabschluss	
Ohne/Haupt-/Volks-/Realschulabschluss	114 (21%)
Abitur/Abgeschlossene Berufsausbildung	244 (45%)
Fachhochschulabschluss/abgeschlossenes Studium	185 (34%)
Jetzige berufliche Situation	
Berufstätig, Teilzeit	103 (19%)
Berufstätig, Vollzeit	358 (66%)
Nicht erwerbstätig	54 (10%)
Im Ruhestand	28 (5%)
Haushaltseinkommen	
Keine Angabe	45 (8%)
Unter 500€ bis unter 1.500€	168 (31%)
1.500€ bis unter 3.000€	175 (32%)

3.000€ bis unter 5.000€ und mehr	155 (29%)
Gesundheitszustand	
Sehr gut	151 (28%)
Gut	120 (22%)
Zufriedenstellend	88 (16%)
Weniger gut	133 (24%)
Schlecht	51 (9%)
Pflegeerfahrung	
Ja	242 (45%)
Nein	301 (55%)

3.2 Wünsche bei späterem Pflegebedarf

Die 543 Befragten wurden zu ihren Wünschen im Falle einer eigenen hypothetischen Pflegebedürftigkeit befragt. 149 (27%) war es wichtig und weiteren 151 (28%) sehr wichtig, von ihren Familienangehörigen im Falle einer eigenen Pflegebedürftigkeit versorgt zu werden. 142 (26%) standen der Frage neutral gegenüber. Insgesamt 92 (17%) war es (sehr) unwichtig von der Familie gepflegt zu werden.

3.3 Bereitschaft informell zu pflegen

53 (10%) der Befragten waren gar nicht bereit zu pflegen und würden die Pflege lieber an einen anderen Angehörigen oder professionellen Institution abgeben (s. Tabelle 2). 46 (8%) der Befragten war hingegen immer gerne bereit selbst zu pflegen. Der Großteil der Gesamtstichprobe (82%) war bereit zu pflegen, jedoch unter bestimmten Umständen. Die Bereitschaft zu pflegen wurde somit nicht als absolut angesehen, sondern hing am häufigsten vom Gesundheitszustand (Art und Schweregrad der Pflegebedürftigkeit) der pflegebedürftigen Person (89%) und der zu pflegenden Person selbst (83%) ab. Die verbleibende Lebenszeit der pflegebedürftigen Person hatte den geringsten Einfluss auf die Pflegebereitschaft mit 21%. Bei der Frage wen die Teilnehmer*innen bereit wären zu pflegen, waren 93% bereit ihren Partner zu pflegen und 91% ihre Eltern. 56% der Befragten waren bereit ihre Großeltern zu pflegen und 39% ihre Schwiegereltern.

Tabelle 2: Einstellung der Teilnehmer*innen (Bereitschaft)

	***N* = 543**
Ich bin gar nicht bereit zu pflegen. Ich gebe die Pflege komplett ab.	53 (10%)
Ich würde immer gerne selbst pflegen.	46 (8%)
Ich wäre bereit zu pflegen. Meine Bereitschaft hängt aber ab von:	444 (82%)
der zu pflegenden Person	367 (83%)
dem Gesundheitszustand der pflegebedürftigen Person (Schweregrad und Art der Pflegebedürftigkeit)	395 (89%)
den Wünschen der pflegebedürftigen Person	232 (52%)
der verbleibenden Lebenszeit der pflegebedürftigen Person	93 (21%)
der erwarteten Dauer der Pflegesituation	222 (50%)
einem finanziellen Ausgleich/Lohnersatz während der Pflegezeit	221 (50%)

3.3.1 Einflussfaktoren auf die Bereitschaft zu pflegen

Nähere Analysen zu den Einflussfaktoren (s. Tabelle 3) sowie Merkmalen der Befragten haben gezeigt, dass der Großteil der 53 Befragten, die nicht bereit waren zu pflegen, ledig (62%), ohne Kinder (70%), Vollzeit berufstätig (81%) und ohne Pflegeerfahrung (60%) waren. Die Wahrscheinlichkeit, dass Befragte aus der Gesamtstichprobe nicht bereit waren zu pflegen, hat sich signifikant erhöht mit einem jüngeren Alter (OR: 5,61 und OR: 5,10) sowie der Auffassung bei eigenem Pflegebedarf später nicht unbedingt von Familienangehörigen selbst gepflegt werden zu wollen (OR: 12,28). Bei den 46 Befragten, die immer bereit wären selbst zu pflegen, ist auffallend, dass 83% dieser Gruppe weiblich waren und die Mehrheit verheiratet oder in fester Partnerschaft (57%) mit Kindern (59%). Signifikanter Einflussfaktor war der Wunsch später selbst von Familienangehörigen gepflegt zu werden (OR: 3,71).

57% der Gruppe, die bereit waren unter bestimmten Umständen zu pflegen, war es selbst (sehr) wichtig im Falle einer Pflegebedürftigkeit von Familienangehörigen gepflegt zu werden (OR: 0,26). Verwitwet zu sein sowie ein jüngeres Alter zu haben, haben ebenfalls die Zugehörigkeitswahrscheinlichkeit in dieser Subgruppe signifikant gesenkt. Jeweils 50% der 444 Befragten, die unter bestimmten Umständen bereit waren zu pflegen, war die erwartete Dauer und der finanzielle Ausgleich (Lohnersatzleistung) sehr wichtig. Die Bereitschaft zu pflegen hing weniger an der erwarteten Dauer der Pflege bei nicht erwerbstätigen Personen im Vergleich zu Vollzeit Berufstätigen (OR: 0,43). Signifikante negative Prädiktoren für eine Lohnersatzleistung waren ein (sehr) guter Gesundheitszustand (OR: 0,46), ein hohes Haushaltseinkommen (OR: 0,58) und eine geringe Wichtigkeit von Familienangehörigen gepflegt zu werden (OR: 0,38). Eine Lohnersatzleistung hat somit die Bereitschaft zu pflegen bei Befragten mit einem niedrigeren Haushaltseinkommen und einem schlechteren Gesundheitszustand erhöht. Die Ergebnisse sind in Tabelle 3 dargestellt.

Tabelle 3: Einflussfaktoren auf die Bereitschaft der Teilnehmer*innen: Signifikante Ergebnisse der logistischen Regressionen

	Koeff	OR	KI
Ich bin gar nicht bereit zu pflegen. Ich gebe die Pflege komplett ab (n = 53).			
Altersgruppe: <35 Jahre (*Ref: >50 Jahre*)	1,73***	5,61	2,22–17,28
Altersgruppe: ≥35 Jahre und <50 Jahre (*Ref: >50 Jahre*)	1,63**	5,10	1,80–16,83
Wünsche: ganz unwichtig/unwichtig (*Ref: neutral*)	2,51***	12,28	6,56–23,59
	Nagelkerke R^2 = 0,288		
Ich würde immer gerne selbst pflegen (n = 46).			
Familienstand: verwitwet (*Ref: ledig*)	2,11**	8,23	1,95–32,10
Wünsche: sehr wichtig/wichtig (*Ref: neutral*)	1,31***	3,71	2,54–8,99
	Nagelkerke R^2 = 0,088		
Ich wäre bereit zu pflegen. Meine Bereitschaft hängt aber ab von unterschiedlichen Faktoren (n = 444).			
Altersgruppe: <35 Jahre (*Ref: >50 Jahre*)	–0,93**	0,40	0,21–0,72
Altersgruppe: ≥35 Jahre und <50 Jahre (*Ref: >50 Jahre*)	–1,06**	0,35	0,17–0,67

Familienstand: verwitwet (*Ref: ledig*)	–2,00**	0,14	0,03–0,58
Wünsche: ganz unwichtig/unwichtig (*Ref: neutral*)	–1,35***	0,26	0,16–0,44
	Nagelkerke R^2 = 0,129		
Meine Bereitschaft hängt aber ab von der erwarteten Dauer der Pflegesituation (n = 222).			
Berufliche Situation: Nicht erwerbstätig (*Ref: Vollzeit berufstätig*)	–0,86**	0,43	0,21–0,79
	Nagelkerke R^2 = 0,018		
Meine Bereitschaft hängt aber ab von einem finanziellen Ausgleich / Lohnersatz während der Pflegezeit (n = 221).			
Gesundheitszustand: sehr gut/gut (*Ref: zufriedenstellend*)	–0,79***	0,46	0,32–0,65
Haushaltseinkommen: 3.000€ bis unter 5.000€ und mehr (*Ref: 1.500€ bis unter 3.000€*)	–0,55**	0,58	0,38–0,87
Wünsche: ganz unwichtig/unwichtig (*Ref: neutral*)	–0,97***	0,38	0,22–0,63
	Nagelkerke R^2 = 0,104		
Nicht in den Modellen: Geschlecht, Kinder, Bildungsabschluss, Pflegeerfahrung			

***p<0,001, **p<0,01, *p<0,05, Koeff = Koeffizienten, OR = Odds Ratio, KI = Konfidenzintervall, Ref = Referenzkategorie

3.4 Bereitschaft zur Arbeitszeitreduktion

Die 490 Personen, die bereit waren zu pflegen, wurden zudem zu ihrer Bereitschaft in ihrer Freizeit zu pflegen und ihre Arbeitszeit zu reduzieren befragt. Eine große Mehrheit der Befragten (89%) war bereit, in ihrer Freizeit einen nahen Angehörigen zu pflegen. Bei der Frage nach der Bereitschaft ihre Arbeitszeit zu reduzieren, konnten 100 Teilnehmer*innen diese Frage nicht beantworten, da sie zum Zeitpunkt der Befragung nicht berufstätig waren. Von den übrigen 390 Personen haben 134 (34%) angegeben, dass sie nicht bereit wären ihre Arbeitszeit zu reduzieren aus unterschiedlichen Gründen. Am häufigsten (21%) haben die Befragten angegeben, dies sei aus finanziellen Gründen nicht möglich. 201 Befragte (52%) waren hingegen bereit ihre Arbeitszeit zu reduzieren, wollten aber zumindest 10 bis 30 Stunden pro Woche arbeiten. Weitere 55 Befragte (14%) waren bereit ihre Arbeitszeit komplett zu pausieren für einen Zeitraum von bis zu 6 Monaten bzw. bis zu 2 Jahren (s. Tabelle 4).

Tabelle 4: Einstellung der Teilnehmer*innen: Bereitschaft Arbeitszeit zu reduzieren

	***N* = 490**
Nicht zutreffend (weil nicht berufstätig)	100 (20%)
Nein, ich würde meine Arbeitszeit nicht reduzieren	
aus finanziellen Gründen (Einkommen)	104 (21%)
aus beruflichen Gründen (z.B. Karriere)	19 (4%)
aus anderen Gründen	11 (2%)
Ja, ich würde meine Arbeitszeit reduzieren, aber ich möchte zumindest	
10h/Woche arbeiten	35 (7%)
20h/Woche arbeiten	85 (17%)
30h/Woche arbeiten	81 (17%)
Ja, ich würde meine Arbeitszeit komplett pausieren für einen Zeitraum	
von bis zu 6 Monaten	25 (5%)
von bis zu 2 Jahre	30 (6%)

3.4.1 Einflussfaktoren auf die Bereitschaft zur Arbeitszeitreduktion

Die 390 Befragten wurden zur Untersuchung von Einflussfaktoren in drei Gruppen unterteilt, um mittels logistischer Regressionsmodelle potentielle Einflussfaktoren zu überprüfen. Die Ergebnisse sind in Tabelle 5 dargestellt. Bei den Personen, die nicht bereit waren ihre Arbeitszeit zu reduzieren, waren signifikante Einflussfaktoren ein (sehr) guter Gesundheitszustand im Vergleich zu einem zufriedenstellenden Gesundheitszustand (OR: 0,55) und der Familienstand geschieden oder getrennt lebend im Vergleich zu ledig (OR: 3,12).

Tabelle 5: Einflussfaktoren auf die Bereitschaft der Teilnehmer*innen die Arbeitszeit zu reduzieren: Signifikante Ergebnisse der logistischen Regressionen

	Koeff	OR	KI
Nein, ich würde meine Arbeitszeit nicht aus unterschiedlichen Gründen reduzieren (n = 134).			
Gesundheitszustand: sehr gut/gut (*Ref: zufriedenstellend*)	–0,61**	0,55	0,36–0,83
Familienstand: geschieden oder getrennt lebend (*Ref: ledig*)	1,14**	3,12	1,44–6,80
	Nagelkerke R^2 = 0,049		
Ja, ich würde meine Arbeitszeit reduzieren, aber möchte noch 10–30 Stunden/Woche arbeiten (n = 201).			
Familienstand: Verheiratet oder in fester Partnerschaft (*Ref: ledig*)	0,54**	1,72	1,15–2,58
Haushaltseinkommen: Unter 500€ bis unter 1.500€ (*Ref: 1.500 bis unter 3.000€*)	–0,85***	0,43	0,26–0,68
Wünsche: ganz unwichtig/unwichtig (*Ref: neutral*)	–0,96***	0,38	0,21–0,66
	Nagelkerke R^2 = 0,12		
Ja, ich würde meine Arbeitszeit komplett pausieren für einen gewissen Zeitraum (n = 55).			
Kinder: ja (*Ref: keine*)	1,28***	3,61	1,83–7,64
	Nagelkerke R^2 = 0,066		
Nicht in den Modellen: Geschlecht, Alter, Bildungsabschluss, Jetzige berufliche Situation, Pflegeerfahrung			

***p<0,001, **p<0,01, *p<0,05, Koeff = Koeffizienten, OR = Odds Ratio, KI = Konfidenzintervall, Ref = Referenzkategorie

Bei den 201 Befragten, die bereit waren ihre Arbeitszeit zu reduzieren, konnten drei signifikante Einflussfaktoren ermittelt werden: der Familienstand verheiratet oder in fester Partnerschaft (OR: 1,72), ein geringes Haushaltseinkommen (OR: 0,43) und eine geringe Wichtigkeit von Familienangehörigen gepflegt zu werden (OR: 0,38). Mit einem geringeren Haushaltseinkommen sowie geringeren Wichtigkeit von Angehörigen gepflegt zu werden sinkt somit die Wahrscheinlichkeit in der Zukunft bereit zu sein, die Arbeitszeit zu reduzieren. Aus den deskriptiven Analysen geht deutlich hervor, dass Personen mit einem höheren Haushaltseinkommen eher bereit waren ihre Arbeitszeit zu reduzieren oder komplett zu pausieren. 9,35% der Einkommensgruppe mit 3.000€ und mehr war nicht bereit ihre Arbeitszeit zu reduzieren im Vergleich zu 40,63% der Gruppe mit einem verfügbaren Einkommen von unter 500€ bis unter 1.500€. Bei den 55 Befragten, die bereit waren ihre Arbeitszeit komplett zu pausieren, konnte ein einziger signifikanter Einflussfaktor ermittelt werden: das Vorhandensein von Kindern (OR: 3,61). Ein höherer Anteil mit Kindern (76%) war in dieser Subgruppe bereit, die Berufstätigkeit für einen gewissen Zeitraum komplett zu pausieren.

Zusätzliche Analysen wurden durchgeführt, um zu überprüfen wie wichtig den drei Arbeitszeit-Gruppen eine Lohnersatzleistung sowie die Dauer der Pflegesituation wäre. Die größte Wichtigkeit mit 56% bzw. 58% hat die Gruppe, die nicht bereit war ihre Arbeitszeit zu reduzieren, einer Lohnersatzleistung bzw. der Dauer der Situation zugesprochen. Knapp 41% der 201 Befragten, die bereit waren ihre Arbeitszeit zu reduzieren und 35% der 55 Befragten, die bereit waren ihre Arbeitszeit komplett zu pausieren, haben angegeben, dass ihre Bereitschaft von einer Lohnersatzleistung und der Dauer der Pflegesituation abhängig sei.

4. Diskussion

Fast jedes Pflegesystem auf der Welt ist in hohem Maße auf die Unterstützung durch informelle Pflegepersonen angewiesen und somit indirekt auf die anhaltende Bereitschaft der Menschen, ihre älteren und pflegebedürftigen Angehörigen zu betreuen und zu pflegen [17,18]. Die Verfügbarkeit von informellen Pflegepersonen wird somit in erster Linie durch die individuelle Pflegebereitschaft der Menschen sowie der vorhandenen finanziellen und strukturellen Unterstützungsmöglichkeiten des Landes bestimmt [17,18]. 2019 wurden in Deutschland 80% der Pflegebedürftigen im häuslichen Umfeld versorgt, der Großteil davon alleine durch Angehörige und Bekannte. Vor dem Hintergrund sich verändernder Familienstrukturen, wachsender räumlicher Distanzen zwischen Angehörigen oder der zunehmenden Erwerbstätigkeit von Frauen erwarten Experten, dass der Anteil der pflegenden Angehörigen in Zukunft weiter abnehmen wird [6,19]. Viele ältere Deutsche wünschen sich jedoch weiterhin so lange wie möglich zu Hause versorgt zu werden [19], wofür die Bereitschaft zur und die tatsächliche Übernahme der informellen Pflege weiterhin essenziell bleiben wird. Somit hatte diese Studie zum Ziel zu untersuchen, ob und unter welchen Bedingungen, eine Stichprobe der Allgemeinbevölkerung bereit wäre informell zu pflegen. Da die Vereinbarkeit von Pflege und Beruf in vielen Fällen zu einer deutlichen Mehrfachbelastung führt [20,21], wurde ein besonderer Fokus in dieser Studie auf die Bereitschaft die Arbeitszeit zu reduzieren sowie die Wichtigkeit der Dauer der Pflegesituation sowie einer Lohnersatzleistung während der Pflegezeit gelegt.

Der Großteil der Befragten (90%) war bereit einen nahen Angehörigen zu pflegen, wobei die Mehrheit (82%) angab, dass ihre Bereitschaft nicht absolut, sondern von unterschiedlichen Einflussfaktoren abhängig sei. Diese Einflussfaktoren spiegeln häufig einen Großteil der Gegebenheiten wider, die für eine tatsächliche Übernahme der informellen Pflege maßgeblich sind. In der befragten Population hing ihre Pflegebereitschaft vor allem von dem Gesundheitszustand der pflegebedürftigen Person sowie der zu pflegenden Person selbst ab. Der Gesundheitszustand der zu pflegenden Person gibt Auskunft über die Art und den Schweregrad der Pflegebedürftigkeit und somit indirekt über den notwendigen Pflegeumfang und die Art der Pflegeaufgaben. Mit zunehmendem Schweregrad der Pflegebedürftigkeit steigt auch die zeitliche und damit häufig auch finanzielle Belastung (z.B. durch Reduktion der Arbeitszeit) der pflegenden Angehörigen. Studien berichten deshalb oftmals von gesundheitlichen und psychischen Beeinträchtigungen der pflegenden Angehörigen [22,23]. Somit kann der Gesundheitszustand Auskunft über den Pflegeumfang geben, den man sich persönlich zumuten würde. Die Art der Beziehung zur pflegenden Person war für die Mehrheit der Stichprobe ausschlaggebend für ihre Pflegebereitschaft. Die Wichtigkeit der persönlichen Beziehung zu der zu pflegenden Person wurde auch bereits in anderen Studien gezeigt [15]. Motive der Liebe, Zuneigung oder Verpflichtung wurden oftmals zur Begründung der Pflegebereitschaft für die zu pflegenden Person verwendet und sind ausschlaggebend für die Übernahme und den Erhalt der informellen Pflege [15,24,25].

Neben unterschiedlichen Motiven zur Übernahme der Pflegetätigkeit haben Studien gezeigt, dass ein großer Belastungsfaktor die Vereinbarkeit von Pflege und Beruf ist und die berufliche Situation die Aufnahme der Pflegetätigkeit beeinflusst [26]. In unserer Befragungsstudie haben 134 Personen angegeben, sie wären nicht bereit ihre Arbeitszeit zu reduzieren, der Großteil gab hierfür finanzielle Gründe an. Die erwartete Dauer der Pflegesituation sowie ein finanzieller Ausgleich (Lohnersatzleistung) während der Pflegezeit waren für diese Gruppe ausschlaggebende Einflussfaktoren für ihre Bereitschaft. Die Wahrscheinlichkeit, dass Personen nicht bereit waren ihre Arbeitszeit zu reduzieren war signifikant höher bei Personen mit dem Familienstand geschieden oder getrennt lebend im Vergleich zu ledig (OR: 3,12). Bei dieser Interpretation müssen jedoch die großen Unterschiede in der Anzahl der beiden Gruppen berücksichtigt werden. Der Familienstand und das Vorhandensein von Kindern war ebenfalls in den zwei Gruppen, die bereit waren ihre Arbeitszeit zu reduzieren oder zu pausieren, signifikante Einflussfaktoren. Beide Variablen hatten auch einen signifikanten Einfluss auf die Bereitschaft, familiäre Pflege in Anspruch zu nehmen, in der Studie von Spangenberg (2012) [27].

In zahlreichen Studien konnte gezeigt werden, dass eine Mehrfachbelastung von Pflege und Beruf zu einem Anstieg der Arbeitsunfähigkeitszeiten, dem kompletten Ausscheiden aus dem Berufsleben oder einer dauerhaften Reduktion der Arbeitszeit in Folge einer erhöhten Krankheitslast bei pflegenden Angehörigen führen kann [9,10,20,28]. Um dieser Art der Mehrfachbelastung frühzeitig vorzubeugen, wurde von der Politik eine Lohnersatzleistung vorgeschlagen und könnte während der Pflegezeit zumindest vorübergehend für eine gewisse finanzielle Stabilität sorgen [13]. Jedoch scheint so eine Form des finanziellen Ausgleichs nur für bestimmte Gruppen von Relevanz zu sein, vor allem bei Personen mit geringerem Haushaltseinkommen, schlechterem Gesundheitszustand und einem stärkeren Wunsch von Familienangehörigen gepflegt zu werden. Ein stärkerer Wunsch und die Erwartung von der Familie später selbst gepflegt zu werden, war auch in qualitativen Studien ein wesentlicher Einflussfaktor für die eigene Pflegebereitschaft [15]. Die Wirkung des Elterngelds auf das Haushaltseinkommen wurde bereits in einigen Studien untersucht [29], kann jedoch nur sehr eigeschränkt auf eine informelle Pflegezeit übertragen werden. Anders als bei der Elternzeit, ist es in der Altenpflege meist nicht möglich, die Dauer der Pflegesituation vorherzusehen und der Umfang nimmt tendenziell mit der Zeit zu. Durch eine zeitlich begrenzte Lohnersatzleistung wird somit ggf. nicht die gesamte Dauer der Pflegesituation abgedeckt, sie kann jedoch während der Organisation von langfristigen Folgelösungen unterstützend wirken. Zudem befinden sich pflegende Angehörige meist in einem höheren Alter, wodurch eigene gesundheitliche Beeinträchtigungen eine stärkere Rolle spielen. Der aktuell vorliegende Vorschlag der Fraktion Bündnis 90 / Die Grünen - ein vollständiges Pausieren der Arbeitszeit für 3 Monate und einen Teilausstieg für bis zu 3 Jahre - unterscheidet sich zudem in seiner Ausgestaltung von aktuellen Elterngeldregelungen [30]. Dennoch könnte zumindest für einige Menschen eine Lohnersatzleistung für eine bestimmte Zeit Entlastung bieten und die Pflegebereitschaft erhöhen.

4.1 Limitationen

Diese Studie hat einige Limitationen, die adressiert und bei der Interpretation der Ergebnisse berücksichtigt werden sollten. Da unsere Teilnehmer*innen nur zu einem einzigen Zeitpunkt befragt wurden, können zeitliche Veränderungen über die Jahre in Bezug auf die Pflegebereitschaft nicht untersucht werden. Des Weiteren ist zu berücksichtigen, dass eine Pflegebereitschaft nicht bedeuten muss, dass es tatsächlich zu der Übernahme der informellen Pflege kommt. Einflussfaktoren wie bspw. die berufliche, finanzielle oder Wohnsituation können allesamt die Übernahme der Pflege beeinflussen. Trotz allem ist die Bereitschaft zu pflegen ein zentrales Indiz für das informelle Pflegepotential in Deutschland. Zur Erhöhung der Teilnehmerzahl wurde eine postalische Befragung um eine Online-Befragung ergänzt. Die kombinierten Stichproben unterscheiden sich bzgl. der Rekrutierungsform. Bei der Rekrutierung der schriftlichen Befragung konnte eine Repräsentativität der Allgemeinbevölkerung per Zufallsstichprobe angestrebt werden, bei der zusätzlichen Online-Befragung war dies jedoch nicht möglich, da die Rekrutierung per Schneeballprinzip erfolgte.

5. Fazit

Vor dem Hintergrund des demographischen Wandels wird sich die Zahl der Pflegebedürftigen in Zukunft deutlich erhöhen und somit bedarf es nachhaltiger Lösungen für das deutsche Pflegesystem. Bereits heute besteht aufgrund des Fachkräftemangels und fehlender Infrastruktur ein Defizit an professioneller Pflege. Gleichzeitig wünschen sich viele Ältere so lange wie möglich zu Hause versorgt zu werden, wofür die informelle Pflege essentiell ist und wahrscheinlich auch bleiben wird. Die Beweggründe zur Übernahme der Pflege sind vielseitig, wobei eine bestehende Bereitschaft und Auseinandersetzung mit der Thematik die tatsächliche Übernahme der Pflegetätigkeit erhöht. Das Zusammenspiel von informeller Pflege und Berufstätigkeit kann oftmals zu einer erheblichen Be- oder sogar Überlastung führen, so dass eine Vereinbarkeit schwierig ist und deshalb ein zentraler Bestandteil von Optimierungsvorschlägen für die häusliche Versorgung sein sollte. Ein diskutierter Ansatz ist eine Lohnersatzleistung analog zum Elterngeld, um es informell pflegenden Angehörigen zu ermöglichen für einen gewissen Zeitraum ihre Arbeitszeit zu pausieren bzw. zu reduzieren. Für Personen mit geringerem Haushaltseinkommen konnte gezeigt werden, dass eine Lohnersatzleistung die Pflegebereitschaft erhöhen könnte und als wichtig eingestuft wird. Um jedoch die Bereitschaft von Personen aus unterschiedlichen Lebensphasen und Hintergründen zu erhöhen, bedarf es flexibler Ansätze, die über eine Lohnersatzleistung hinausgehen. Diese müssen sowohl beruflichen Einschnitten als auch negativen gesundheitlichen Auswirkungen entgegenwirken.

Einhaltung ethischer Richtlinien

Die Autoren geben an, dass kein Interessenkonflikt besteht.

Die Studie wurde von der Ethikkommission der Medizinischen Hochschule Hannover (MHH) genehmigt (Nr. 09.05.17/La).

Förderung

Dieses Projekt wird gefördert vom Bundesministerium für Bildung und Forschung (BMBF), Förderkennzeichen 01EH1603A.

Quellen

[1] Statistisches Bundesamt, Bevölkerung - Demographischer Wandel: Mehr Pflegebedürftige, 2022. https://www.destatis.de/DE/Themen/Querschnitt/Demografischer-Wandel/Hintergruende-Auswirkungen/demografie-pflege.html (accessed 2 February 2022).

[2] H. Rothgang, Schriftenreihe zur Gesundheitsanalyse–Band 32.

[3] Bundesministerium der Justiz und für Verbraucherschutz, Sozialgesetzbuch (SGB) - Elftes Buch (XI) - Soziale Pflegeversicherung: § 15 Ermittlung des Grades der Pflegebedürftigkeit, Begutachtungsinstrument.

[4] Bundesministerium für Gesundheit, Zahlen und Fakten zur Pflegeversicherung, 2019. https://www.bundesgesundheitsministerium.de/fileadmin/Dateien/Downloads/Statistiken/Pflegeversicherung/Zahlen_und_Fakten/Zahlen-u-Fakten-zur-Pflegeversicherung_2019.pdf (accessed 17 May 2019).

[5] Bundesministerium der Justiz und für Verbraucherschutz, Sozialgesetzbuch (SGB) - Elftes Buch (XI) - Soziale Pflegeversicherung: § 3 Vorrang der häuslichen Pflege.

[6] M. Heuchert, H.-H. König, T. Lehnert, Die Rolle von Präferenzen für Langzeitpflege in der sozialen Pflegeversicherung - Ergebnisse von Experteninterviews, Gesundheitswesen 79 (2017) 1052–1057. https://doi.org/10.1055/s-0041-111839.

[7] T. Lehnert, M.A. Heuchert, K. Hussain, H.-H. Koenig, Stated preferences for long-term care: A literature review, Ageing & Society 39 (2019) 1873–1913.

[8] K. Jacobs, A. Kuhlmey, S. Greß, J. Klauber, A. Schwinger, Pflege-Report 2020: Neuausrichtung von Versorgung und Finanzierung, Springer Nature, 2020.

[9] J. Geyer, Informell Pflegende in der deutschen Erwerbsbevölkerung: Soziodemografie, Pflegesituation und Erwerbsverhalten, Zentrum für Qualität in der Pflege (Hrsg.) ZQP-Themenreport. Vereinbarkeit von Beruf und Pflege (2016) 24–43.

[10] W. Keck, Was kommt nach der Pflege? Die Pflege eines Angehörigen senkt Beschäftigungschancen von Pflegepersonen nachhaltig, Sozialer Fortschritt (2016) 112–119.

[11] Bundesministerium der Justiz und für Verbraucherschutz, Gesetz über die Pflegezeit (Pflegezeitgesetz - PflegeZG), 2008.

[12] Bundesministerium der Justiz und für Verbraucherschutz, Gesetz über die Familienpflegezeit (Familienpflegezeitgesetz - FPfZG), 2011.

[13] H. Rothgang, Stellungnahme zum Antrag der Fraktion Bündnis 90/Die Grünen „Pflege gerecht und stabil finanzieren–Die Pflege-Bürgerversicherung vollenden “, BT-Drucksache 19 (2019) 8561.

[14] SurveyEngine GmBH, Respondents, Technology & Support, 2022. https://surveyengine.com/ (accessed 7 February 2022).

[15] L. de Jong, J.T. Stahmeyer, S. Eberhard, J. Zeidler, K. Damm, Willingness and preparedness to provide care: interviews with individuals of different ages and with different caregiving experiences, BMC geriatrics 21 (2021) 1–14.

[16] The R Foundation for Statistical Computing, The R Foundation. https://www.r-project.org/foundation/ (accessed 19 October 2021).

[17] V. Zigante, Informal care in Europe: Exploring formalisation, availability and quality, European Commission, London School of Economics and Political Science (2018).

[18] S. Spasova, R. Baeten, B. Vanhercke, Challenges in long-term care in Europe, Eurohealth 24 (2018) 7–12.

[19] A. Hajek, T. Lehnert, A. Wegener, S.G. Riedel-Heller, H.-H. König, Potential for informal care of the elderly in Germany: results of a representative population-based survey, Z. Gerontol. Geriatr. 51 (2018) 612.

[20] S. Völz, J.H. Schnecke, Beruf und Pflege besser vereinbaren: Individuelle und betriebliche Perspektiven als regionaler Gestaltungsansatz, 2021.

[21] Wetzstein, Rommel, Lange, Pflegende Angehörige – Deutschlands größter Pflegedienst., 2015.

[22] N.R. Chumbler, A.M. Pienta, J.W. Dwyer, The depressive symptomatology of parent care among the near elderly, Research on aging an international bimonthly journal 26 (2004) 330–351.

[23] H. Schmitz, M.A. Stroka, Health and the double burden of full-time work and informal care provision: Evidence from administrative data, Labour economics official journal of the European Association of Labour Economists 24 (2013) (2013) 305–322.

[24] H. Al-Janabi, F. Carmichael, J. Oyebode, Informal care: choice or constraint?, Scandinavian journal of caring sciences 32 (2018) 157–167.

[25] M. Della Giusta, S. Jewell, Unpaid work and conformity: why care?, Cambridge Journal of Economics 39 (2015) 689–710.

[26] Zentrum für Qualität in der Pflege, ZQP-Themenreport. Vereinbarkeit von Beruf und Pflege, Zentrum für Qualität in der Pflege Berlin, 2016.

[27] Spangenberg, L., Glaesmer, H., Brähler, E., & Strauß, B., Inanspruchnahme familiärer Ressourcen bei späterem Pflegebedarf, Bundesgesundheitsblatt-Gesundheitsforschung-Gesundheitsschutz 55 (2012) 954–960.

[28] J. Geyer, E. Schulz, Who cares? Die Bedeutung der informellen Pflege durch Erwerbstätige in Deutschland, Diw Wochenbericht 81 (2014) 294–301.

[29] M. Bujard, Wie wirkt das Elterngeld?, Konrad-Adenauer-Stiftung, 2013.

[30] Bündnis 90 Die Grünen, Wir sorgen für gute Pflege. https://www.gruene.de/themen/pflege (accessed 17 March 2022).