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In Kooperation mit dem Deutschen Zentrum für Neurodegenerative Erkrankungen

ANWENDUNG NUTZERZENTRIERTER ANSÄTZE BEI DER ENTWICKLUNG SENSORBASIERTER ASSISTENZSYSTEME FÜR MENSCHEN MIT GEDÄCHTNISSTÖRUNGEN

Kumulative Inauguraldissertation zur Erlangung des akademischen Grades

Doktor der Medizinwissenschaften der Universitätsmedizin Rostock

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Jahr der Einreichung: 2024

Jahr der Verteidigung: 2025

Zusammenfassung

Als altersbedingte Erkrankung wird Demenz in den kommenden zehn Jahren stark zunehmen. In einer zunehmend technisierten Gesellschaft bieten digitale Technologien vielversprechende Hilfen für Menschen mit Demenz, sofern sie den Bedarfen und Bedürfnissen der Zielgruppe entsprechen. Nutzerzentrierte Ansätze, wie zum Beispiel das Wertesensitive Design erfassen die Wünsche, Bedarfe und Wertvorstellungen der zukünftigen Nutzer, sodass die technischen Systeme optimal an ihre Nutzer angepasst werden können.

Die vorliegende Arbeit identifizierte Designanforderungen und Wertvorstellungen im Zusammenhang mit unterstützenden, digitalen Technologien für Menschen mit Demenz. Dabei wurden in drei Studien insgesamt 57 Personen (26 Menschen mit Demenz, 11 pflegende Angehörigen und 20 Stakeholder) in halb-strukturierten Interviews oder Fokusgruppeninterviews befragt. Die Ergebnisse wurden mit Hilfe der thematischen Analyse, der logischen Analyse und der qualitativen Inhaltsanalyse nach Mayring ausgewertet.

Aus Studie 1 wurden Designanforderungen für die Entwicklung technischer Navigationsassistenten abgeleitet. Studie 2 identifizierte Wertvorstellungen im Zusammenhang mit digitalen technischen Assistenzsystemen. Aus ihr gingen Wertesensitivität und Anwendungsszenarien hervor. Die Studie beschrieb, wie Wertvorstellungen in unterstützende Technologien integriert werden können. Studie 3 diskutierte neben Designanforderungen und politischen Rahmenbedingungen ethische Bedenken im Zusammenhang mit unterstützenden Technologien.

Die Ergebnisse der Arbeit geben nicht nur Handlungsempfehlungen für die Entwicklung unterstützender digitaler Technologien, sondern heben auch die Machbarkeit des Einbezugs von Menschen mit Demenz bei der Anwendung nutzerzentrierter Ansätze für die Entwicklung solcher Technologien hervor.

Abstract

The prevalence of age-related diseases, such as dementia, will increase significantly in the next ten years. Novel digital technologies have the potential to help meeting the care needs of people with dementia and their caregivers. In an increasingly technological society, assistive technologies offer promising support for people with dementia if they meet the needs and requirements of this group. User-centred approaches, such as value-sensitive design, capture the wishes, needs and values of future users so that systems can be optimally adapted to their users.

The present study identified design requirements and values in the context of digital assistive technologies for people with dementia. In three studies, a total of 57 people (26 people living with dementia, 11 family caregivers and 20 stakeholders) were interviewed within semi-structured interviews or focus group discussions. The results were evaluated using thematic analysis, logical analysis and qualitative content analysis according to Mayring.

Design requirements for the development of technical navigation assistants were derived from Study 1. Study 2 identified value concepts in connection with digital assistance systems. It resulted in a value network and application scenarios. The study described how values can be integrated into assistive technologies. Study 3 discussed design requirements and political framework conditions as well as ethical concerns in connection with digital assistive technologies.

The results not only provide recommendations for the development of digital assistive technologies, but also highlight the feasibility of including people with dementia when applying user-centred approaches to the development of such technologies.

Abkürzungsverzeichnis

MMST	Mini-Mental-Status-Test
TAM	Technology Acceptance Model
UCD	User Centred Design
VSD	Value Sensitive Design

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Danksagung

An erster Stelle möchte ich mich bei meinem Doktorvater Herrn Prof. Dr. Teipel für sein Vertrauen in meine Fähigkeiten, seine zielführende Beratung und das Einbringen seiner wissenschaftlichen Expertise bedanken. Zudem gilt mein Dank unseren Studienteilnehmer*innen, die uns mit dem entgegengebrachten Vertrauen und den privaten Einblicken in ihr Leben nicht nur wissenschaftlich unterstützt, sondern uns auch beeindruckt und inspiriert haben. Weiterhin bedanke ich mich ganz herzlich bei meinen Kolleginnen und Kollegen für die anregenden Diskussionen und die mentale Unterstützung. Auch meiner Familie gebührt ein großer Dank dafür, dass sie mich während meines Studiums und meiner beruflichen Laufbahn bedingungslos unterstützt haben.

Gender-Disclaimer

Zur Vereinfachung der Lesbarkeit innerhalb der Befragung haben wir uns für die Nutzung des generischen Maskulinums entschieden. Selbstverständlich beziehen sich Personenbezeichnungen, sofern nicht anders gekennzeichnet, auf alle Geschlechter.

1. Einleitung

1.1 Epidemiologie und Symptomatik der Demenz

Bereits im Jahr 2030 wird etwa jeder dritte Deutsche älter als 60 Jahre alt sein (Statista, 2022). In Folge wird bis 2040 ein Anstieg der altersbedingten Demenzerkrankungen von derzeit rund 1,8 Millionen auf etwa 2,2 Millionen erwartet (Statista, 2024). Demenz ist ein Sammelbegriff für meist hirnganisch bedingte, progredient verlaufende Erkrankungen (Deutsches Institut für medizinische Dokumentation und Information, 2015; National Institute on Aging, 2017). Die häufigste Demenzform ist die Alzheimer Demenz (60-80%), gefolgt von der Frontotemporalen, der Lewy-Körperchen- und vaskulären der Demenz (je 5-10%) sowie anderen Demenzformen, wie zum Beispiel der Parkinson Demenz (Alzheimer's association, 2021).

Einschränkungen der Erinnerungs-, Lern- und Orientierungsfähigkeit, der sprachlichen Fähigkeiten, der Affektkontrolle sowie in der Durchführung von Aktivitäten des täglichen Lebens wie Körperpflege, Nahrungsaufnahme und Selbstversorgung sind Symptome von Demenzerkrankungen (Deutsches Institut für medizinische Dokumentation und Information, 2015; National Institute on Aging, 2017). Mit zunehmender Reduzierung der Erinnerungs-, Urteils- und Orientierungsfähigkeit steigt der Pflegebedarf der Erkrankten (Cahilla et al., 2007, 2007; Carpenter et al., 2006).

Räumliche Desorientierung tritt bereits im frühen Krankheitsstadium auf (Pai & Jacobs, 2004, S. 253). In der Follow-Up-Studie von Pai & Lee (Pai & Lee, 2016, S. 6) berichteten 67,6 Prozent der Teilnehmenden, dass sie schon mindestens einmal durch räumliche Desorientierung verloren gegangen sind (Pai & Lee, 2016, S. 10). Davon kamen 36,5 Prozent der Ereignisse während der zweieinhalb-jährigen Studie neu hinzu (Pai & Lee, 2016, S. 6). Verirrungsereignisse traten vor allem im häuslichen Umfeld (59%), in Pflegeheimen bzw. Krankenhäusern (29%) oder während eines Ausfluges (12%) auf (Bantry White & Montgomery, 2015). In fünf Prozent der Verirrungsereignissen kam es zu ernsthaften Schäden oder zum Tod (Bantry White & Montgomery, 2015). Zudem stellten die Verirrungsereignisse für alle Beteiligten eine hohe zeitliche und psychische Belastung dar (Bantry White & Montgomery, 2015; Digby et al., 2017; Seidel & Thyrian, 2019) und führten zur Abhängigkeit der Betroffenen von anderen Hilfspersonen (Cahilla et al., 2007). Daher sind geeignete Unterstützungsangebote zum Beispiel in Form digitaler technischer Assistenzsysteme zur Wegfindung für Menschen mit Demenz erforderlich.

Neben der psychischen Belastung durch Verirrungsereignisse kann die Pflege von Menschen mit Demenz zu körperlichen Beschwerden wie Kopf- und Rückenschmerzen sowie Schlafstörungen führen (Seidel & Thyrian, 2019, S. 658). Zudem besteht für informell Pflegenden ein erhöhtes Risiko an einer Depression zu erkranken (44%) oder gewalttätig gegenüber dem Pflegebedürftigen zu werden (64%) (Seidel & Thyrian, 2019, S. 659). Ebenso steigt im Laufe der Erkrankung der Bedarf an medizinischer Versorgung der Menschen mit Demenz in Krankenhäusern oder Pflegeheimen (Hoffmann et al., 2014; Miller et al., 2011; Motzek et al., 2017; Seidel & Thyrian, 2019; Sommerlad et al., 2019). Der zunehmende Fachkräftemangel in der medizinischen Versorgung (Brücher & Deufert, 2019, S. 1), das Altern der Bevölkerung (Statista, 2024) und der Wunsch der Betroffenen möglichst lange zu Hause von den Angehörigen (Storm et al., 2018, S. 64) versorgt zu werden, machen alternative Versorgungsformen und Unterstützungsangebote zur Deckung des steigenden Versorgungsbedarfes notwendig. Digitale technische Assistenzsysteme sind in der Lage, Menschen mit Demenz in verschiedenen Situationen zu unterstützen (Astell et al., 2019, S. 135) und deren Lebensqualität zu steigern (Pappadà et al., 2021, S. 15). Allerdings fehlt es derzeit an einer bedarfsgerechten Anpassung von marktüblichen Geräten an die Bedürfnisse, technischen Fähigkeiten und Wünsche der Menschen mit Demenz (Astell et al., 2019, S. 135) sowie einer ethischen Diskussion für den Einsatz digitaler technischer Assistenzsysteme (Diaz-Orueta et al., 2020), da 67 Prozent der Systeme ohne ethische Reflexion entwickelt werden (Ienca et al., 2018).

1.2 Einsatz von digitalen technischen Assistenzsystemen für Menschen mit Demenz

Die Zahl der digital abseitsstehenden Deutschen ist von 2018 bis 2024 um 20 Prozent auf 6 Prozent gesunken (Initiative D21 e.V., 2018 & 2024). Im gleichen Zeitraum ist ein Aufwärtstrend für die Nutzung portabler Endgeräte wie Tablet (von 36% auf 47%), Smartphone (von 70% auf 90%) und Wearables (von 5% auf 20%) erkennbar (Initiative D21 e.V., 2018 & 2024). An der Altersgruppe der Boomerjahrgänge (58 bis 67 Jahre) wird ein technischer Generationswechsel deutlich. Während Dienste der sozialen Medien wie WhatsApp bei den Menschen älter als 78 Jahre nur von 32 Prozent genutzt werden, nutzen sie bereits 79 Prozent der Boomerjahrgänge (Initiative D21 e.V., 2024). Auf Grundlage dieses Generationenwechsels ist eine sprunghafte Bedeutungszunahme digitaler technischer Assistenzsysteme zur Unterstützung von Menschen mit Demenz in den kommenden Jahren zu erwarten.

Vor allem sensorbasierte, selbstlernende Technologien, die ohne oder nur mit minimaler Eingabe der Nutzenden auskommen, scheinen besonders geeignet, um den kognitiven Defiziten der Zielgruppe gerecht zu werden (Boger et al., 2018, S. 3–4). Sensorbasierte Technologien können auf Basis künstlicher Intelligenz und unauffälliger Sensoren (Boger et al., 2018, S. 3)

eine situationsabhängige, also nur im Bedarfsfall initiierte, Assistenz bieten (Koldrack et al., 2015). Dies ermöglicht den Nutzenden maximale Selbstständigkeit bei gleichzeitiger Förderung ihrer kognitiven Fähigkeiten (Koldrack et al., 2015).

Voraussetzung für eine individuelle Unterstützung durch digitale technische Assistenzsysteme ist deren Abstimmung auf die Bedürfnisse, Werte und Fähigkeiten ihrer Nutzer (Astell et al., 2019, S. 135; Friedman et al., 2008). Diese Abstimmung erhöht den Mehrwert und die Eignung digitaler technischer Assistenzsysteme für die Zielgruppe (Suijkerbuijk et al., 2019, S. 1042). Laut des Technik-Akzeptanz-Modells (TAM) von Davis (Davis, 1985) hängt die spätere Techniknutzung maßgeblich von der wahrgenommenen Benutzerfreundlichkeit, dem wahrgenommenen Nutzen sowie der Einstellung zur Technologienutzung ab (siehe Abbildung 1).



Abbildung 1: Technik-Akzeptanz-Modell (eigene Abbildung nach Davis, 1985, S. 24)

Studien bestätigen die Bedeutung des TAM bei der Technologieentwicklung nicht nur im Bereich der Gesundheitsversorgung (Rahimi et al., 2018, S. 604) allgemein, sondern auch gezielt für ältere Menschen (Chen & Chan, 2013, S. 4651) und Menschen mit Demenz (Brookman et al., 2023; Evans et al., 2020). Aus dem TAM ergibt sich die Notwendigkeit der Nutzereinbindung, um die einzelnen Komponenten zielgruppenspezifisch auszugestalten.

1.3 User Centered Design und Wertesensitives Design in der Entwicklung digitaler technischer Assistenzsysteme

User Centered Design- (UCD) Ansätze bieten einen konzeptionellen Rahmen für die Implementierung der Nutzereinbindung in die Technologieentwicklung (Bevan, 2009). Ziel des UCD ist das Erzielen einer möglichst hohen Benutzerfreundlichkeit der Geräte durch das Erlangen eines tiefen Verständnisses für die Bedürfnisse und Wünsche der jeweilige Zielgruppe (Bevan, 2009; Weidekamp-Maicher, 2021, S. 112). Der UCD-Prozess besteht aus fünf Entwicklungsphasen mit iterativen Feedbackschleifen. Die Schleifen werden bis zur Erfüllung der

Anforderungen der Zielgruppe an die Technologie wiederholt (siehe Abbildung 2) (Bevan, 2009; Weidekamp-Maicher, 2021, S. 112).

- 1. Planung**
 - Planung des gesamten nutzerorientierten Design-Prozesses
- 2. Kontextklärung**
 - Klärung, Definition und Verstehen des Kontextes, in dem die Technik genutzt werden soll
- 3. Klärung Zielgruppe**
 - Klärung der Zielgruppe und deren Bedarfe hinsichtlich Benutzerzufriedenheit und Benutzeroberfläche
- 4. Geräteentwicklung**
 - Produktion eines Gerätes, welches den Anforderungen gerecht wird
- 5. Evaluation**
 - Bewertung des Erfolges der zielgruppengerechten Gerätegestaltung aus Sicht des Nutzenden & der Entwickelnden



Abbildung 2: UCD-Prozess (eigene Abbildung nach Bevan (2009) & Weidekamp-Maicher (2021))

In das UCD können andere Design-Ansätze, wie zum Beispiel das Wertesensitive Design (Value Sensitive Design, VSD), eingebettet werden (Weidekamp-Maicher, 2021, S. 109). Das VSD umfasst die Analyse von Wertvorstellungen, Bedarfen und Anforderungen an digitale technische Assistenzsysteme und bezieht dabei direkte sowie indirekte Stakeholder ein (Friedman et al., 2008). Durch die Einbindung des VSD wird das sehr gerätebezogene UCD um die Dimension der Wertvorstellungen, Einstellungen und Wertekonflikte der künftigen Nutzenden sowie um den Einbezug von deren Stakeholdern erweitert. In Abbildung 3 wird diese Einbettung dargestellt.

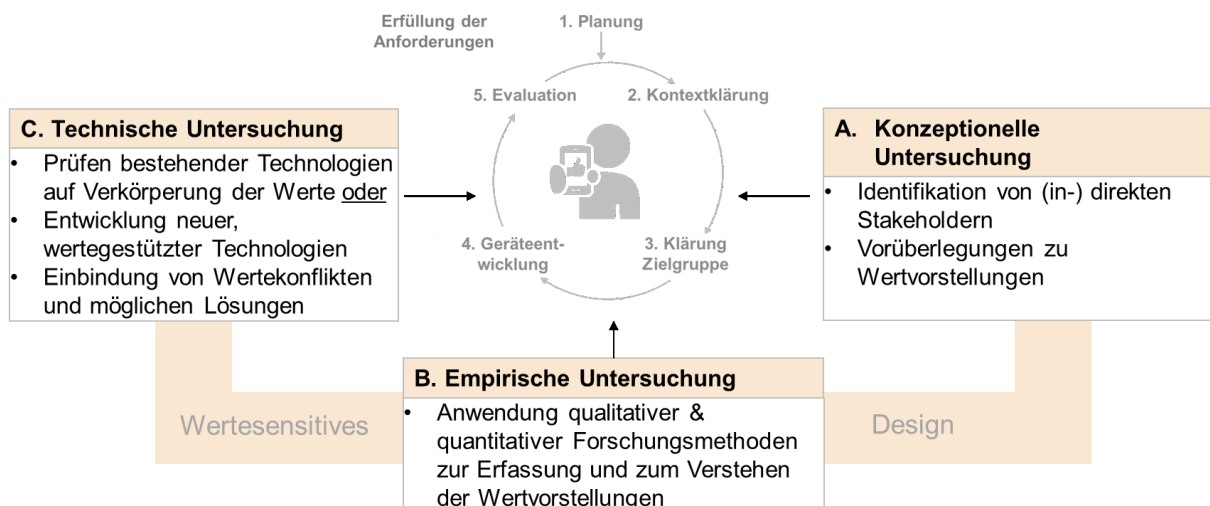


Abbildung 3: Phasen des Value Sensitive Design eingebettet in das User Centered Design (eigene Abbildung nach Bevan (2009) & Friedman et al. (2008))

Wissenschaftlich kann das VSD in Form von quantitativen Methoden wie Umfragen, aber auch mit Hilfe qualitativer Methoden wie Beobachtungen oder Interviews umgesetzt werden

(Friedman et al., 2008). Lediglich ein Drittel (33%) der intelligenten, technischen Assistenzsysteme für Menschen mit Demenz werden unter Einbezug der Wertevorstellung und ethischen Aspekten der Zielgruppen entwickelt (Ienca et al., 2018, S. 1047). Dieser fehlende Einbezug kann die Nutzbarkeit und Nützlichkeit für die Zielgruppe reduzieren und zur Nicht-Nutzung der Geräte führen (Ienca et al., 2018, S. 1047).

Der fehlende Einbezug von Werten und Wünschen von Menschen mit Demenz in die Technologieentwicklung kann eine Fehlausrichtung der Technologie zur Folge haben. Diese Fehlausrichtung äußert sich derzeit in der Fokussierung digitaler technischer Assistenzsysteme auf die Kompensation körperlicher Einschränkungen oder die Digitalisierung medizinischer Assessments unter Vernachlässigung der Kompensation kognitiver Defizite zur Unterstützung der Persönlichkeit der Betroffenen (Astell et al., 2019, S. 135; Kreps & Burmeister, 2019; World Intellectual Property Organization, 2021). Zudem fehlt es an Studien, in denen die Geräteentwicklung und -bewertung auf Grundlage eines theoretischen Modells basiert (Pappadà et al., 2021, S. 19). Diaz-Orueta et al. (2020, S. 3225) kritisierten die unzureichende ethische Betrachtung in der Entwicklung digitaler technischer Assistenzsysteme, insbesondere für vulnerable Gruppen. Diese Arbeit soll einen Beitrag zum Schließen dieser Forschungslücken leisten.

1.4 Die Bedeutung qualitativer Forschung in der Demenzforschung

Anhand von quantitativen Daten aus neuropsychologischen Test, MRT-Scans oder Biomarkeruntersuchungen kann eine Gedächtnisstörung diagnostiziert werden. Um zu verstehen, warum Menschen unterschiedlich mit Ihrer Erkrankung umgehen, wie die Gedächtnisstörung das Leben der Menschen beeinflusst, welche Gefühle sie damit verbinden, welchen Herausforderungen und Chancen sie gegenüberstehen, bedarf es qualitativer Methoden wie Interviews oder Beobachtungen (Patton, 2015, S. 13). Zwar ist die Generalisierbarkeit der Ergebnisse qualitativer Forschung aufgrund der kleinen Stichproben im Vergleich zu quantitativen Erhebungen reduziert, dafür ermöglicht qualitative Forschung durch das offene Fragen abseits von vorgefertigten Antworten einen tiefen Einblick in die Erfahrungswelt, Motivationen und Wertvorstellungen von Menschen (Aspers & Corte, 2019, S. 150–151; Patton, 2015, S. 7). Komplexe Zusammenhänge können aufgedeckt, Muster erkannt und erklärt werden. Qualitative Forschung dient daher nicht nur dem Wissenszuwachs, sondern dem Verstehen des Wissens und der Zusammenhänge in komplexen Systemen (Aspers & Corte, 2019, S. 150–151).

Anders als bei quantitativen Umfragen interagieren in der Interviewsituation Sender und Empfänger direkt miteinander. Dies ermöglicht Menschen mit Gedächtnisstörungen ein höheres Maß der Teilhabe, sofern die interviewende Person im Umgang mit Menschen mit Demenz geschult ist und direkt auf kognitive Herausforderungen, wie Wortfindungsstörungen, Konzentrationsproblemen, Gedächtnislücken oder affektive Störungen reagieren kann. So können

selbst Menschen mit starken kognitiven Einschränkungen an Forschung partizipieren (Beuser & Grando, 2009).

1.5 Untersuchungsziele

Die vorliegende Arbeit nutzte qualitative Methoden für die Entwicklung digitaler technischer Assistenzsysteme unter Anwendung des Technik-Akzeptanz-Modells, des User Centered Design sowie des Value Sensitive Design. Ziel war es, Design- und Funktionsanforderungen sowie wertebasierte Aspekte zu identifizieren, die in die Entwicklung von alltagsrelevanten Assistenzsystemen für Menschen mit Demenz einfließen sollten. Dafür wurden Bedarfssituationen für digitale technische Assistenzsysteme von Menschen mit Demenz und deren An- und Zugehörigen identifiziert. Zudem wurde erhoben, welche Designanforderungen für digitale technische Assistenzsysteme bestehen, welchen Wertvorstellungen die Technik entsprechen muss und welche ethischen Aspekte bei der Entwicklung bedacht werden sollten. Das Aufzeigen der Nutzerperspektive und deren Beachtung in der Technikentwicklung dienen der Akzeptanzsicherung für die Nutzung digitaler technischer Assistenzsysteme durch Menschen mit Demenz und ihren Stakeholdern.

Im Folgenden werden die Fragestellungen der einzelnen Studien aufgeführt:

Studie 1 „Navigationsassistenz“ (Köhler et al., 2020): Welchen Anforderungen müssen technische Navigationsassistenten gerecht werden, um Menschen mit Demenz bei der außerhäuslichen Wegfindung zu unterstützen?

Der erste Artikel untersuchte den Mobilitätswert, die Design-Anforderungen an einen Navigationsassistenten sowie die Technikaffinität von Menschen mit Demenz.

Studie 2 „Wertenetzwerk“ (Köhler et al., 2022): Welche Werte müssen digitale technische Assistenzsysteme für Menschen mit Demenz in stationären Einrichtungen verkörpern und wie stehen diese Werte in Verbindung zueinander? Wie können diese Werte in digitale technische Assistenzsysteme integriert werden?

Im medizinischen Kontext wurden Werte bisher einzeln oder paarweise gelistet (Al-Banna, 2017; Ienca et al., 2018; McNeese-Smith & Crook, 2003, S. 260; McWhinney, 1998; Rassin, 2008; Rider et al., 2014; Teipel et al., 2016; Toop, 1998; Zwetsloot et al., 2013). Der zweite Artikel beleuchtete das Zusammenspiel der Werte und veranschaulichte passende Anwendungsszenarien für digitale technische Assistenzsysteme, die diesen Werten gerecht werden.

Studie 3 „Ethik & Design“ (Köhler et al., 2024): Welche Bedarfe gibt es bei digitalen Lösungen für die Unterstützung und Versorgung von Menschen mit Demenz aus der Sicht verschiedener Stakeholder? Welche Anforderungen müssen technische Navigationsassistenten erfüllen, um die Wegfindung für Menschen mit Demenz zu ermöglichen?

Der dritte Artikel skizzierte Anwendungsbereiche digitaler technischer Assistenzsysteme im Bereich der Versorgung und Mobilität von Menschen mit Demenz und diskutierte ethische Aspekte in der Technikentwicklung und Gerätegestaltung.

Für die Beantwortung der Forschungsfragen im Sinne des UCD beziehungsweise VSD wurde ein qualitativer Ansatz gewählt. Mit Hilfe qualitativer Erhebungen erlangen Forschende einen tiefen Einblick in die Beweggründe, Zusammenhänge, Blickwinkel, Kontexte und Lebenswelten der befragten Personen (Patton, 2015, S. 13). Qualitative Forschung ermöglicht das Ableiten von Logiken und Mustern sowie das Verstehen der Perspektiven der Befragten (Patton, 2015, S. 13). Daher wurden für die Fragestellungen der Studie 1 und 2 halb-strukturierter Interviews untersucht. In Studie 3 wurden Fokusgruppeninterviews im Online-Format und in Form eines World-Cafés mit zwei Thementischen eingesetzt. Die Protokolle oder Transkripte wurden mit inhaltsanalytischen Methoden, zum Teil unter Ergänzung durch Methoden der gegenstandsbezogenen Theoriebildung, ausgewertet.

2 Methodik

2.1 Identifizierung der Stakeholder

Alle Studien haben Menschen mit Demenz als Experten für ihre Lebenssituation einbezogen (Gove et al., 2018, S. 726). Studie 1 war auf die Entwicklung eines Navigationsassistenten für die selbstständige, außerhäusliche Navigation ausgerichtet. Daher wurden in dieser Studie ausschließlich Menschen mit Demenz befragt. Studie 2 zielte auf die Entwicklung digitaler technischer Assistenzsysteme im Versorgungskontext der stationären Einrichtungen ab. Ergänzend zu den Menschen mit Demenz wurden anhand einer Literaturrecherche (Hughes et al., 2015; Richardson et al., 2019) kontextrelevante Stakeholder identifiziert und in die Studien 2 und 3 inkludiert. In Studie 2 wurden neben Menschen mit Demenz auch informell Pflegende sowie medizinisches Personal befragt. Studie 3 ergänzte die Befragtengruppe aus Studie 2 um Ethikexperten, Forschende, IT-Spezialisten, Mitglieder der Deutschen Alzheimer Gesellschaft und des lokalen Senioren-Beirates als Angehörigen- und Betroffenenvertretung.

2.2 Charakteristik der Befragten

Studie 1: Navigationsassistent für die außerhäusliche Navigation

Zur Erreichung der ersten Untersuchungsziele wurden 14 Menschen mit leichter bis mittelgradiger Demenz bei wahrscheinlicher Alzheimer-Erkrankung nach NIA-AA Kriterien (McKhann et al., 2011) befragt. Einschlusskriterien waren die Abwesenheit anderer kognitiver Störungen und ein Mini-Mental Status Test (MMST)-Wert (Folstein et al., 1975, S. 189) von größer gleich 15. Die 14 Probanden wurde über die Gedächtnissprechstunde und mit Hilfe der Deutschen

Alzheimer Gesellschaft, Landesverband Mecklenburg-Vorpommern e.V. auf die Studie angesprochen. Die Probandencharakteristik ist Tabelle 1 zu entnehmen. Sieben Befragte waren technisch vorgebildet, da sie einen technischen Beruf ausgeübt beziehungsweise gelernt hatten.

Studie 2: Wertesensitives Design

Die zweite Studie umfasst Interviews von insgesamt 30 Personen: je 10 Menschen mit Demenz, informell Pflegende und medizinisch ausgebildete Personen. Menschen mit einer dokumentierten leichten kognitiven Störung oder Demenz mit einem MMST zwischen 15 und 29 und einem Alter von mindestens 65 Jahren konnten an der Studie teilnehmen. Die Menschen mit kognitiven Beeinträchtigungen sollten in den vergangenen zwei Jahren vor dem Interview in einer stationären Einrichtung (Krankenhaus oder Pflegeheim) versorgt worden sein. Dies galt ebenfalls für die pflegebedürftige Person der informell Pflegenden. Als medizinisches Personal galten Personen, die in ihrem Arbeitsalltag als ärztliches, therapeutisches oder pflegerisches Personal in der medizinischen Versorgung von Menschen mit Demenz tätig sind. Die Probandencharakteristik wird in Tabelle 1 veranschaulicht. Insgesamt wurden je fünf Patienten und Pflegeheimbewohner befragt. Informell Pflegende waren die Ehepartner (n=7) oder Kinder der Betroffenen (n=3). Vom medizinischen Personal arbeiteten je fünf in einem Pflegeheim oder Krankenhaus. Je fünf gehörten den Heilberufen (Physiotherapie, Ergotherapie inkl. Assistenzen) und den Pflegeberufen (Krankenpflege inkl. Assistenzen) an.

Tabelle 1: Charakteristik der interviewten Personen (*Angabe des Mittelwertes, Spannweite in Klammern)

Personengruppe	Merkmal	Studie 1 (N=14)	Studie 2 (N=30)
Menschen mit Demenz	n	14	10
	Alter*:	71 Jahre (58-71 Jahre)	84,4 Jahre (69-98 Jahre)
	Geschlecht:	8 männlich	2 männlich
	MMST*:	24,8 (17-28)	23,6 (15-29)
Informell Pflegende	n	-	10
	Alter*:		69,9 Jahre (55-84 Jahre)
	Geschlecht:		4 männlich
Medizinisches Personal	n	-	10
	Alter*:		38,8 Jahre (26-56 Jahre)
	Geschlecht:		2 männlich

Studie 3: Ethische Reflexionen und Designanforderungen

Für die Studie 3 wurden keine personenbezogenen Daten, außer dem Geschlecht und dem beruflichen Hintergrund beziehungsweise dem Bezug zu Demenzerkrankungen erhoben. Die Zusammensetzung der Teilnehmenden ist in Tabelle 2 dargestellt. Sie reicht von Menschen

mit Demenz und ihren Angehörigen über Ethik- und IT-Experten, (Qualitäts-)Managern, Pflegedienstleitungen, Patientenvertretungen bis hin zu Wissenschaftlern.

Tabelle 2: Sozio-demografische Angaben geteilt nach Teilnehmenden des World-Cafés sowie der Online-Fokusgruppendifkussion

Gruppen (n=13)	Geschlecht	Beruflicher Hintergrund/Bezug zur Demenz
World Café Tisch 1 (n=4)	weiblich	Expertin in der Gesundheitsversorgung & Mitglied der Deutschen Alzheimer Gesellschaft
	weiblich	Qualitätsmanagerin in einem Pflegeheim
	männlich	Ethikexperte
	männlich	Mitglied eines Seniorenbeirates
World Café Tisch 2 (n=3)	weiblich	Pflegedienstleitung eines Pflegeheims
	weiblich	Senior Strategy Manager für digital-assistierte medizinische Versorgung
	männlich	Pflegekraft und Pflegewissenschaftler
Online Fokusgruppe (n=6)	weiblich	Ehefrau eines Menschen mit Demenz
	weiblich	Mitarbeiterin eines Vereins zur Unterstützung von Menschen mit Demenz
	weiblich	Wissenschaftlerin in der Demenzforschung
	männlich	Mensch mit Demenz
	männlich	Mensch mit Demenz & Mitglied eines Beirates von Menschen mit Demenz
	männlich	Manager eines Pflegeheims

2.3 Datenerhebung

Für alle Befragungen wurde die schriftliche oder mündliche informierte Einwilligung der Interviewpartner beziehungsweise deren Bevollmächtigten eingeholt. Die Forschenden achteten während der Befragungen auf eine fortbestehende Einwilligung, insbesondere bei Menschen mit Demenz (Vgl. Gove et al., 2018, S. 725). Für alle Studien lag ein positives Ethikvotum der Ethikkommission der Universitätsmedizin Rostock vor (Studie 1: A 2013-0072, Studie 2: A 2018-0109, Studie 3: A 2022-0199).

Die nutzerzentrierten Ansätze aller drei Studien wurden durch halb-strukturierte Einzel-, Paar- oder Gruppeninterviews umgesetzt. Dabei konzentrierten sich die Untersuchungen auf Phase 1 bis 3 des UCD beziehungsweise Phase A und B des VSD. Für Studie 1 und 2 erfolgte zudem eine Prototypentestung. Die Ergebnisse der Prototypentestung für den Navigationsassistenten

sowie für ein digitales technisches Assistenzsystem in Form einer Smartwatch sind bei Koldrack et al. (2015) beziehungsweise Goerss et al. (2024) nachzulesen.

Die vorab entwickelten Interviewleitfäden basierten auf dem TAM (Davis, 1985, S. 24). Während Studie 1 unterschiedliche Nutzertypen und Anforderungen an einen außerhäuslichen Navigationsassistenten fokussierte, standen in Studie 2 die Wertvorstellungen der Teilnehmenden zu unterstützenden Technologien in der institutionellen Versorgung im Vordergrund. In Studie 3 wurden Ideen zu digitalen technischen Assistenzsystemen in der Versorgung von Menschen mit Demenz sowie zur Unterstützung ihrer Mobilität aus einer multiperspektivischen Sicht diskutiert. In Ergänzung zu den Vorarbeiten aus Studie 1 und 2 wurde das Hauptaugenmerk auf ethische Aspekte in der Entwicklung und Implementierung digitaler technischer Assistenzsysteme gelegt.

In Studie 1 wurden den Teilnehmenden Modellbeispiele für einen Navigationsassistenten und dessen Anzeigeformate zur leichteren Entscheidungsfindung vorgelegt.



Abbildung 4: Beispiele der Geräteformate für den Navigationsassistenten (Bildquelle: <https://pixabay.com/de> & <https://www.google.de/maps>)

Alle Einzelinterviews wurden aufgezeichnet, transkribiert und mit der qualitativen Inhaltsanalyse nach Mayring (Mayring, 2014, S. 32), zum Teil in Ergänzung mit der Logischen Analyse (Patton, 2015) aus dem Bereich der gegenstandsbezogenen Theoriebildung, ausgewertet.

Variante 1



Variante 2



Variante 3



Variante 4

Abbildung 5: Verschiedene Kartenansichten als Navigationshilfe für Menschen mit Demenz (<https://www.google.de/maps>)

Die Ergebnisse des World-Cafés und der Online Fokusgruppendifkussion wurden protokolliert. Zur Auswertung der Protokolle aus Studie 3 diente die thematische Inhaltsanalyse (Patton, 2015). Zur systematischen Auswertung aller Daten nutzten die Forschenden die Software MAXQDA (VERBI software, Consult. Sozialforschung GmbH, Berlin).

2.4 Datenauswertung

Die Datenauswertung erfolgte in den ersten beiden Studien mit der qualitativen Inhaltsanalyse nach Mayring (2014). Studie 1 nutzte zur Klassifikation der interviewten Personen zusätzlich die Affinity for Technology Interaction Scale (Franke et al., 2019). Dabei wurden alle genannten positiven Aspekte der Techniknutzungen (Nutzung von verschiedenen Endgeräten wie Festnetz- oder Mobiltelefon bzw. Smartphone, PC, Laptop, Tablet, Navigationsgerät in der Vergangenheit oder Gegenwart; persönlicher Nutzen der Techniknutzung sowie Problemlösungsstrategien und Ressourcen im Umgang mit Technik sowie technische Vorbildung) gegen die benannten negativen (Hürden und Probleme in der Techniknutzung) aufrechnet. Die Summe wurde mit der Einstellung zur modernen Technologie kombiniert.

In Studie 2 wurden, dem ersten Schritt des Wertesensitiven Designs folgend, die Stakeholder identifiziert. Dies geschah auf Basis einer Literaturrecherche. Im zweiten Schritt wurden Unterstützungsbedarfe und Wertvorstellungen aus Sicht der Befragten herausgearbeitet. Die

Werte wurden mit Hilfe der Logischen Analyse aus dem Bereich der gegenstandsbezogenen Theoriebildung (Patton, 2015) in einem Wertnetzwerk zusammengestellt, in dem förderliche und konfligierende Beziehungen zwischen den Werten dargestellt wurden. Im dritten Schritt wurden Anwendungsszenarien für eine unterstützende Technologie kreiert, die diese Werte integrieren.

Für Studie 3 wurden die Gesprächsprotokolle der Diskussionsrunden ausgewertet. Als Methodik wurde die thematische Inhaltsanalyse genutzt, da sie eine Strukturierung der Daten durch die Identifikation von Mustern und Themen in dem Material ermöglicht (Patton, 2015). Die Protokolle wurden neben Gestaltungskriterien und Anwendungsszenarien vor allem auf ethische Aspekte in der Nutzung und Entwicklung von digitalen technischen Assistenzsystemen für Menschen mit Demenz untersucht.

Studie 1 erfolgte ohne Reliabilitätsprüfung. Nach Reflexion der Studie 1 wurden die Ergebnisse der Studien 2 zur Steigerung der Ergebnisvalidität einer Intra- und Intercoder-Reliabilitätsprüfung unterzogen (Mayring, 2014). Die Reliabilitätsprüfung diente der Bestätigung der Auswertungsergebnisse. Berechnet wurde die Übereinstimmung des Vorhandenseins der gleichen Codes im Dokument. Dabei wurde zwischen der Intra- und Intercoder-Reliabilität unterschieden. Die Intracoder-Reliabilität beschreibt die Übereinstimmung der Codierungen innerhalb eines Codierenden (Mayring, 2014, S. 83). Sie dient der ersten Überprüfung der Sinnhaftigkeit und Nachvollziehbarkeit des Kategoriensystems. Anschließend erfolgt eine Prüfung der Kodierungen durch einen zweiten Prüfer (Intercoder-Reliabilität), der sich mit Hilfe des Kodierleitfadens in den Kodiermechanismus einliest und die Texte unvoreingenommen anhand des Kategoriensystems neu kodiert. Die Prüfung erfolgte anhand von 20 Prozent des Interviewmaterials (Mayring, 2014, S. 83). Da die Gesprächsprotokolle sowie deren Zusammenfassungen in Studie 3 im Umlaufverfahren unter den Teilnehmenden validiert wurden, wurde von einer weiteren Reliabilitätsprüfung abgesehen.

3 Ergebnisse

3.1 Technikaffinität von Menschen mit Demenz und deren Anforderungen an einen Assistenten für die außerhäusliche Navigation

3.1.1 Technikaffinität von Menschen mit Demenz und deren Einfluss auf das Nutzungsverhalten moderner Technologien

Während der Interviews wurden die Teilnehmenden zu ihrer Einstellung zu moderner Technologie und ihrem Nutzungsverhalten in der Vergangenheit (beruflich und privat) und aktuell be-

fragt. Aus Einstellung und Nutzungsverhalten wurde die Technikaffinität der Probanden abgeleitet. Vier Probanden wurden als nicht technikaffin eingestuft (X02, X06, X08 & X11). Die Technikaffinität sowie die Einstellung zur Technologie ließen keinen Rückschluss auf die derzeitige Techniknutzung zu. Die Techniknutzung war abhängig vom empfundenen persönlichen Nutzen der Technologie und von der Fähigkeit, Probleme im Umgang mit dem Gerät selbstständig zu lösen. Zudem waren die (frühere) berufliche Nutzung technischer Geräte wie Computer oder Mobiltelefon sowie ein hoher Bildungsgrad förderlich für die aktuelle Techniknutzung.

Hinsichtlich des Layouts präferierten eine interviewte Person Version 1, fünf Personen Version 2 und 3 und drei Personen Version 4 (für Versionen siehe Abbildung 5, S.11).

Die Befragten schilderten Hindernisse für die Nutzung technischer Geräte, wie Sehinderung, Scham, Angst vor Stigmatisierung und Verschlechterung ihrer Erkrankung, Überforderung durch neue, ungewohnte Geräte, das Fehlen eines persönlichen Nutzens sowie fehlende finanzielle Möglichkeiten:

*„Ach Gott, ich will mal so sagen, ich hab‘ mir vorgenommen, mich nicht mehr mit der neuesten Technik zu belasten. (.) Weil, das übersteigt jetzt auch meine Möglichkeiten.“
(Befragter X14, Z. 1432-1437)*

Gleichzeitig sprachen sich zwölf Teilnehmende für die Nutzung eines Navigationsassistenten aus. Dieser sollte durch eine einfache Handhabung, eine robuste Bauweise, ein großes Display sowie eine Sprachausgabe überzeugen.

3.1.2 Außerhäusliche Aktivitäten von Menschen mit Demenz und deren Stellenwert

Im Allgemeinen hatten Autonomie, Sicherheit und Selbstbestimmtheit einen hohen Stellenwert für die meisten Befragten. Sie nannten zahlreiche Aktivitäten, die sie eigenständig oder mit dem Partner durchführten (siehe Abbildung 6). Die Begleitung durch den Partner erhöhte dabei sowohl den Bewegungsradius als auch die Häufigkeit der Unternehmungen. In einem Fall schränkte eine Angehörige die Mobilität ihres Partners aus Sicherheitsgründen ein:

„Naja, Spazieren, da ist meine Frau schon nicht mehr erbaut von. Wir hatten nämlich auch schon mal// kam [ich, S.K.] nicht wieder zurück.“ (Befragter X13, Z. 381-382).

Sechs Teilnehmende berichteten Ereignisse von Desorientierung. Unbekannte Umgebungen, Dunkelheit, Unaufmerksamkeit, Unkonzentriertheit und hohe Fortbewegungsgeschwindigkeit, wie zum Beispiel im Auto, waren Auslöser für Desorientierung.



Abbildung 6: Aktivitäten außer Haus mit Grad der Überschneidung. Der Farbverlauf kennzeichnet die Aktivitäten, die sowohl selbstständig (blau) als auch mit dem Partner (grün) durchgeführt werden. Je weiter die Aktivitäten nach links verschoben sind, je häufiger werden sie selbstständig durchgeführt.

Einige Befragte hatten Schwierigkeiten, ihr Fahrrad oder Auto wiederzufinden, nachdem sie es abgestellt hatten. Im Fall der Orientierungslosigkeit fragten die Interviewten Passanten oder nutzten ihr Mobiltelefon. Um Desorientierung vorzubeugen, planten die Befragten ihre Routen sorgfältig, gingen in Begleitung und nutzten vor allem vertraute, eingeübte Wege.

3.1.3 Anforderungen an einen technischen Navigationsassistenten

Trotz der unterschiedlichen Einstellung zu modernen Technologien hatten alle Interviewten Ideen und Vorstellungen zu einem technischen Navigationsassistenten. Zwölf der vierzehn Befragten äußerten ihr Interesse, einen technischen Navigationsassistenten auszuprobieren:

„Joa, das denk` ich mal, dass man irgendwann wieder soweit ist. Es wird ja ständig an sowas gearbeitet, aber denn bin ich schon// wär` schon interessiert an sowas.“ (Befragter X02, Z. 807-809).

Neun Befragte wünschten sich einen Navigationsassistenten im Format eines Smartphones, sechs im Uhrenformat und einer im Format eines Tablets (Mehrfachnennung war möglich). Zwei Interviewte konnten sich den Anhänger einer Halskette als Endgerät vorstellen. Ein Drittel der Befragten (n=4) äußerte soziale Scham und Angst vor Stigmatisierung durch die Nutzung eines Navigationsassistenten. Den Befragten war daran gelegen, dass das Gerät möglichst unauffällig ist und ihr Hilfebedarf unerkant bleibt:

„Sie müssen Folgendes bedenken (..) dass wir, dass Demenzkranke bewusst sich ist, dass er überall auffällt. (.) Und wenn wir davon ausgehen, dann wird er nicht mit so=n Gerät// (...) //auf=er öffentliche Straße gehen.“ (Befragter X06, Z. 910-919)

Daher sprachen sich die Befragten für die Nutzung handelsüblicher Geräte aus und empfahlen die Nutzung von Kopfhörern.

Hinsichtlich des Anzeigeformates waren sich die Befragten sehr uneinig. Eine interviewte Person sprach sich für Version 1 aus, je fünf für Version 2 und 3 und drei für Version 4.

Zusammenfassend ließen sich die folgenden Empfehlungen für die Entwicklung und Implementierung technischer Navigationsassistenten ableiten:

Funktionale Anforderungen:

- Eingebaute Sicherheitsfunktionen wie einen Notrufknopf oder eine Ortungsfunktion
- Individuelle Programmierungsmöglichkeiten hinsichtlich der Funktionen, wie zum Beispiel eine App für den Öffentlichen Nahverkehr
- Ein gut leserliches, spiegelreies Display mit großen Buchstaben oder Symbolen

Designanforderungen:

- Unauffälliges Gerätedesign möglichst auf Basis handelsüblicher Geräte (zum Beispiel Smartwatch, Smartphone oder Halskette).
- Klar strukturierte Benutzerpfade (einfache Menüführung und eindeutige Symbole)

Empfehlungen für Schulungen und TechniksUPPORT

- Regelmäßige Überprüfung der technischen Geräte mit Bereitstellung eines festen technischen Ansprechpartners
 - Regelmäßige Schulungen unter Einbezug der Angehörigen und der individuellen Problemlösestrategien
-

3.2 Wertesensitives Design zur Entwicklung und Implementierung digitaler technischer Assistenzsysteme für Menschen mit Demenz in stationären Einrichtungen

Studie 2 untersuchte Wertvorstellungen und Anforderungen an ein digitales technisches Assistenzsystem zur Alltagsunterstützung in Pflegeheimen und Krankenhäusern. Neben den Menschen mit Demenz wurde der Befragtenkreis um Angehörige von Menschen mit Demenz und medizinisches Personal erweitert. Die Intracoder-Reliabilität erreichte einen Wert von 88,00 Prozent und die Intercoder-Reliabilität von 83,72 Prozent.

3.2.1 Unterstützungsbedarfe von Menschen mit Demenz aus eigener Sicht, aus Sicht pflegender Angehöriger und des medizinischen Personals

Anhand der Interviews konnten 36 Unterstützungsbedarfe von Menschen mit Demenz abgeleitet und unter vier Themenfeldern zusammengefasst werden: Beschäftigung, Betreuung, Organisation & Administration sowie pflegerische Versorgung. Dabei wurde gekennzeichnet, von welcher Gruppe welche Unterstützungsbedarfe genannt wurden. In den Bereich der Beschäftigung fielen zum Beispiel gemeinsames Singen, Spielen und gemeinsame Unternehmungen. Gespräche, permanente Begleitung und Unterstützung bei der Wegfindung wurden dem Bereich der Betreuung zugeordnet, wohingegen die Unterstützung der Körperhygiene, der Nahrungsaufnahme und der Medikamenteneinnahme unter dem Thema Pflege subsummiert wurde. Organisation und Administration umfasste unter anderem das Planen von (Arzt-)Terminen, Hausreinigung oder Behördengänge und Bankgeschäfte.

3.2.2 Werte im Zusammenhang mit der pflegerischen Versorgung von Menschen mit Demenz

Insgesamt wurden 44 Werte aus 167 Interviewaussagen extrahiert. Werte wurden als Glaubenssätze oder als moralische Grundsätze verstanden, die ausdrücken, was als richtig und falsch empfunden und welchen Dingen oder Personen eine persönliche Bedeutung beigemessen wird (Oxford English Dictionary, 2023). Die Werte wurden mit Hilfe des „analytic process for determining key values“ (Burmeister, 2016, S. 191) zu 17 Hauptwerten zusammengefasst. Nachdem die Hauptwerte bestimmt wurden, wurde die Beziehung der Werte zueinander untersucht. Im Ergebnis entstand ein Werternetzwerk (siehe Abbildung 7) mit förderlichen und konfligierenden Wertebeziehungen, wobei der Hauptwert Fürsorge und Empathie als Herzstück des Netzwerkes sichtbar wird.

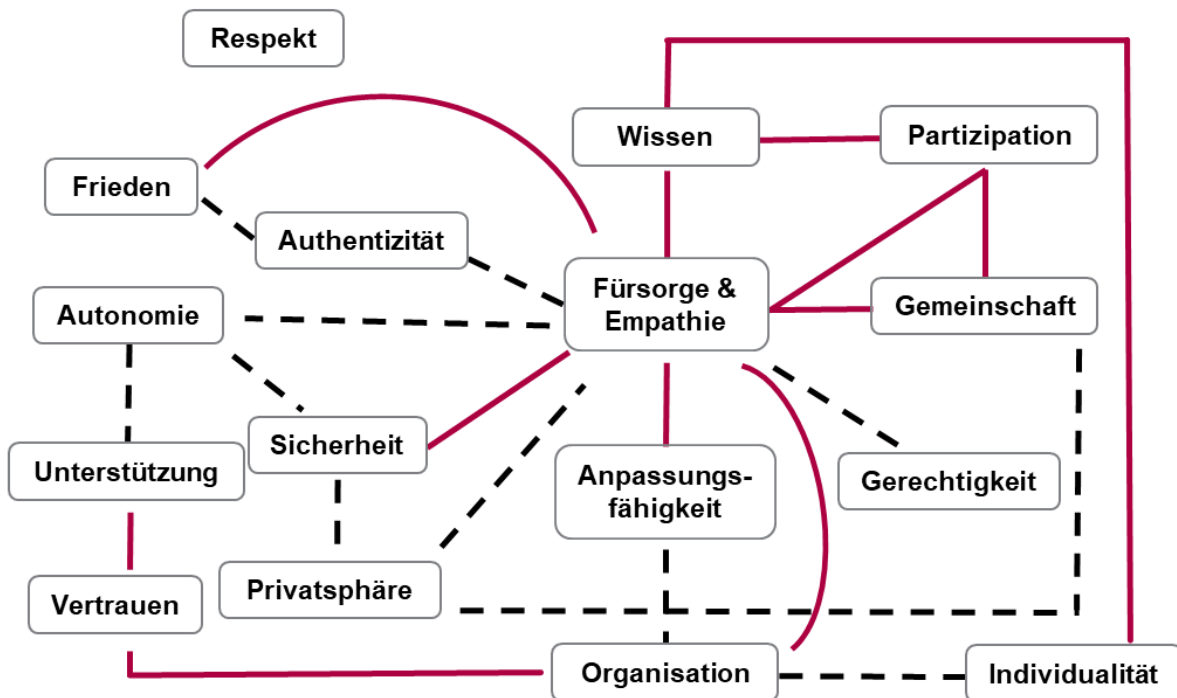


Abbildung 7: Werternetzwerk mit förderlichen (rote Linien) und konfligierenden (gestrichelte Linien) Beziehungen

Der Konflikt zwischen Autonomie und Sicherheit sowie die förderliche Beziehung zwischen Sicherheit und Fürsorge & Empathie wird beispielsweise in diesem Zitat einer Angehörigen deutlich:

„Die allerschlimmste (..) ist die Hinlauftendenz, weil sofern ich da jemanden hinterherlaufen muss außerhalb des Gebäudes, lasse ich meinen Wohnbereich zurück und habe keine zweite Kraft, die da ist und wacht. (...) Zum Beispiel stelle ich mir vor von einer Uhr, gerade so bei (Befragte nennt Namen), der ja auch gerne spazieren geht, dass ihm das nicht genommen wird, sondern dass die Uhr dann sagt: ‚Gehen Sie da und da und da lang‘ und er wieder nach Hause findet.“

(Pflegeassistentin, HcpNh05, Pos. 70 & 140)

3.2.3 Anwendungsszenarien für wertesensitive unterstützende Technologien in stationären Einrichtungen

Auf Grundlage der Unterstützungsbedarfe und des Werternetzwerkes konnten für jedes Themenfeld ein Anwendungsszenario für eine wertesensitive unterstützende Technologie entwickelt werden. Abbildung 8 zeigt wie eine Smartwatch einen Menschen mit Demenz nachts unterstützen kann. Eingebaute Bewegungs- und Beschleunigungssensoren, eingespeicherte Routinen des Nutzenden sowie integrierte Smart Home-Elemente ermöglichen eine individuelle und situationsgerechte Unterstützung. Die Remoteverbindung zur Pflegekraft gibt zusätzliche Sicherheit und eine bedarfsgerechte Hilfestellung.

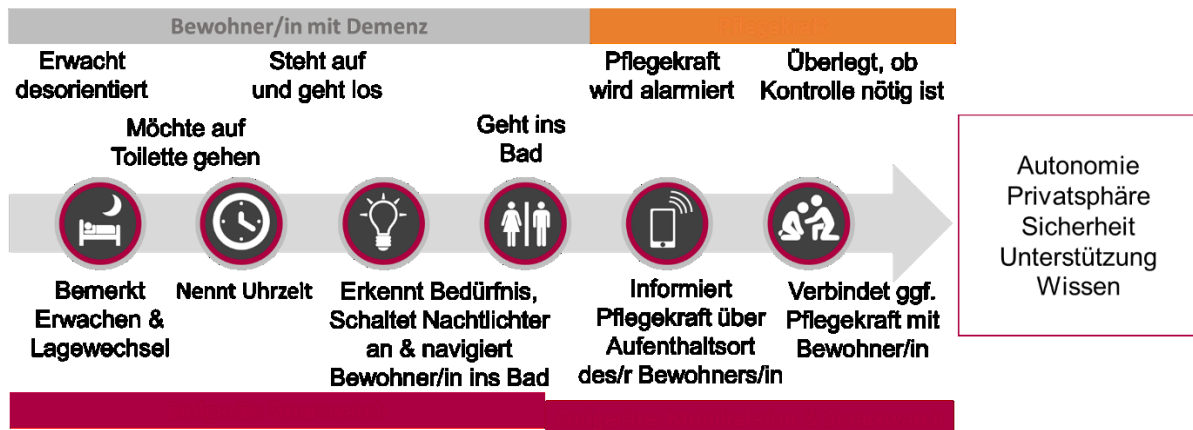


Abbildung 8: Beispiel eines Anwendungsszenarios für das Themenfeld "Pflege". Durch den Einsatz von digitalen technischen Assistenzsystemen können Autonomie, Privatsphäre, Wissen, Unterstützung und Sicherheit gefördert werden.

Weitere Anwendungsszenarien sind denkbar. Die Testung einer Smartwatch mit Aufforderungen zum Trinken (Pflege) und zum Erfüllen einer kognitiven Aufgabe (Beschäftigung) erfolgte in der Gedächtnissprechstunde (Goerss et al., 2024).

3.3 Ethische Reflexionen, Anwendungsbeispiele und Designvorschläge für digitale technische Assistenzsysteme für Menschen mit Demenz

Studie 3 diente der Identifikation von Förderfaktoren, Hindernissen und potentiellm Nutzen der Implementierung digitaler technischer Assistenzsysteme in der Versorgung von Menschen mit Demenz aus einer multiperspektivischen Sicht. Neben der Konzentration auf einen generellen Einsatz von digitalen technischen Assistenzsystemen lag ein Hauptaugenmerk auch auf der Unterstützung der Mobilität von Menschen mit Demenz in städtischen und ländlichen Regionen. Dazu wurden Fokusgruppensitzungen in Form eines World Cafés und einer Online-Fokusgruppe geführt. Da die außerhäusliche Mobilität während des World Cafés auf die Mobilität im eigenen Wohnraum beschränkt blieb, wurde diese Frage in der Online-Diskussionsrunde erneut aufgegriffen.

3.3.1 Ethische Aspekte des Einsatzes von digitalen technischen Assistenzsystemen für Menschen mit Demenz

Wie in Studie 1 und 2 wurde auch in dieser Studie die Bedeutung der Autonomie und Unabhängigkeit von Menschen mit Demenz betont sowie die damit verbundene Sorge um die Sicherheit von Menschen mit Demenz diskutiert. Vor allem bei der außerhäuslichen Mobilität bestand die Sorge vor dem Verlorengang des Betroffenen, insbesondere, wenn zum Beispiel Dunkelheit die Orientierung zusätzlich erschwert. Zudem wurden Aspekte der Privatsphäre,

des Datenschutzes und die Grenzen zwischen Assistenz und freiheitsentziehenden Maßnahmen besprochen. Ein Teilnehmender warf die Frage auf, wer im Falle einer Ablehnung der technischen Assistenz durch den Menschen mit Demenz die Befugnis haben sollte, das Gerät auszuschalten: der Nutzende oder das System? Auch wurde gefragt, ob ein Pflege-Roboter Menschen berühren dürfe und wenn ja, wann und wo?

Zudem wurden die Anwendung von Nudging¹, Incentives² und Gamification³ zur Erhöhung der Nutzerakzeptanz angesprochen. Hierbei warnten die Befragten vor Manipulation und Einschränkung der Wahlfreiheit durch diese Methoden.

Die Befragten sprachen sich generell für den Einsatz von digitalen technischen Assistenzsystemen aus, wenn diese mehr Zeit und Ressourcen für zwischenmenschliche Interaktion ermöglichen.

3.3.2 Akzeptanzkriterien für digitale technische Assistenzsysteme

Digitale technische Assistenzsysteme sollten im frühen Krankheitsstadium eingeführt werden, um Gewöhnung und Routinen zu ermöglichen. Zudem müssen die Geräte an die spezielle Zielgruppe angepasst und deren Funktionsweise erklärt werden:

„Das ganze Zeug mit den Handys und Smartwatches. Das ist ja gang und gäbe. Das kann sich jeder Mensch kaufen. Für ein paar Euro, zehn oder einen Hunni. (...) Bloß ich habe festgestellt, (...) dass viele Betroffene jetzt für sich, dass die das gar nicht können. Die verstehen das gar nicht.“ (Teilnehmer mit Demenz)

Die Systeme sollten ganzheitlich sowie ressourcen- statt defizitorientiert programmiert sein. Statt als Hilfsmittel sollten sie als Life-Style-Produkt wahrgenommen werden. Die Befragten sprachen sich zudem für selbstlernende Systeme aus, die sich an den Krankheitsfortschritt des Nutzenden anpassen:

„Also, ich will damit sagen: es gibt einen Haufen Kram, bloß es ist eben das Problem, dass die Betroffenen eben unterschiedliche Krankheitsstadien haben (...), aber wenn das System antrainiert ist, dann funktioniert es.“ (Teilnehmer mit Demenz)

Unabhängig vom Gesundheitszustand benannten die Befragten die fehlende Digitalkompetenz aller Stakeholder als Grund für die Ablehnung digitaler technischer Assistenzsysteme.

¹ Nach Bendel (2024) wird unter Nudging eine subtile Beeinflussung des Nutzungs- oder Kaufverhaltens von Menschen verstanden, die zum Beispiel über Voreinstellung bei technischen Geräten oder gezielte Produktplatzierung erzielt wird.

² Nordgren (2018, S. 414) bezeichnet Incentives als zusätzliche Boni, die außerhalb der pflegerischen Versorgung liegen, wie zum Beispiel eine Massage oder dem Lieblingsessen.

³ Gamification bezeichnet spielerische Elemente zur Belohnung oder Motivation der Nutzenden, wie zum Beispiel Ranglisten oder virtuelle Bezahlsysteme zum Kauf zusätzlicher Boni (Oxford University Press, 2024).

3.3.3 Bedenken bezüglich digitaler technischer Assistenzsysteme

Drei Befragte äußerten Sorgen in Bezug auf den Einsatz von Pflegerobotern. Zum einen bezweifelten sie, dass Roboter auf die emotionalen Bedürfnisse der Pflegebedürftigen eingehen können. Zum anderen befürchteten sie, eine zu große Menschenähnlichkeit könnte Menschen mit Demenz verwirren oder ängstigen. Gleichzeitig nannten sie Probleme mit der Einhaltung der Hygieneverordnungen, wenn Roboter, wie die Robbe PARO, mit Fell überzogen sind, welches nicht waschbar ist.

3.3.4 Technische, politische und administrative Hürden bei der Implementierung von digitalen technischen Assistenzsystemen

Die Befragten kritisierten langwierige und kostspielige Zertifizierungsprozesse im Rahmen des Medizinproduktegesetzes (siehe DQS Medizinprodukte GmbH [MED], 2024) als Hürde für Innovationen und den Einsatz von digitalen technischen Assistenzsystemen. Zudem fehle es Pflegeheimen an finanziellen Mitteln zur Anschaffung digitaler Systeme. Fehlendes WLAN in den Einrichtungen und fehlende Schnittstellen zwischen den einzelnen Endgeräten wurden als weitere Hemmnisse für den Einsatz von internet- und sensorbasierten Systemen in der Patientenversorgung genannt.

3.3.5 Unterstützung der außerhäuslichen Mobilität in Stadt und Land

Die Befragten sprachen sich gegen „*Demenzdörfer, wo sich das ganze Umfeld dann quasi künstlich erzeugt*“ (Teilnehmender Gesundheitswesen), aber für eine demenzfreundliche Gesellschaft aus. Sie sahen die Mitmenschen in der Mitverantwortung, Menschen mit Demenz zum Beispiel bei der Navigation nach Hause zu unterstützen:

„(...) dass man [der Bäcker, S.K.] einfach sagt, hier sind die Brötchen und denken Sie daran, da vorne rechts abbiegen“ (Teilnehmender ohne Demenz)

Insgesamt wäre die Erreichbarkeit von Hilfsangeboten auf dem Land schlechter, dafür wären die Orte übersichtlicher und die Wege bekannter:

„Je kleiner die Strukturen sind, in einem Dorf, wo es nur einen Bäcker gibt, finde ich mich natürlich potentiell etwas leichter zurecht und brauche das [digitale technische Assistenzsystem, S.K.] vielleicht gar nicht.“ (Manager eines Pflegeheims)

Gleichzeitig hemmt in ländlichen Strukturen eine unzureichende Netzabdeckung die Nutzung von digitalen technischen Assistenzsystemen. Veraltete Fahrpläne erschweren laut der Befragten die Nutzung des öffentlichen Nahverkehrs auf dem Land.

In Innenstädten schlug ein Teilnehmer mit Demenz vor, freie Hot-Spots als Navigationshilfe zu nutzen. Insgesamt sprachen sich die Teilnehmenden für Ausflüge in Sportgruppen, mit anders Erkrankten oder mit Freunden und der Familie aus:

„Ich gehe als Gruppe beispielsweise raus. Also zwei, drei Behinderte laufen draußen rum. Die könnten sich auch gegenseitig helfen.“ (Teilnehmer mit Demenz)

In der Zusammenschau unterstrich die Studie die Bedeutung zwischenmenschlicher Interaktion und identifizierte administrative, politische und technische Hürden für die Implementierung von digitalen technischen Assistenzsystemen in der Versorgungspraxis von Menschen mit Demenz.

4 Diskussion

4.1 Empfehlungen für die Entwicklung digitaler technischer Assistenzsysteme für Menschen mit Gedächtnisstörungen

Obwohl die Anzahl der digitalen technischen Assistenzsysteme rapide zunimmt (World Intellectual Property Organization, 2021, S. 14), gilt die Forschung zu digitalen technischen Assistenzsystemen für Menschen mit Gedächtnisstörungen als unzureichend und wenig beachtet (Boot et al., 2017) (World Intellectual Property Organization, 2021, S. 16). Ein Review zu unterstützenden Technologien für Menschen mit Demenz bewertete den Fokus auf Nutzerzentriertes Design als ungenügend (Pappadà et al., 2021, S. 19). Hindernisse für die Nutzung unterstützender Technologien aus Sicht der Menschen mit Demenz werden als unzureichend untersucht eingestuft (Boot et al., 2017). Die vorliegende Arbeit nutzte Methoden des UCD, gekoppelt mit dem TAM, um Förderfaktoren, Hindernisse und Anforderungen an digitale technische Assistenzsysteme zur Unterstützung der Alltagsfähigkeiten und Orientierung umzusetzen. Im Ergebnis konnten zahlreiche Handlungsempfehlungen für die Gestaltung unterstützender Technologien publiziert werden.

In der Literatur sind unterstützende Technologien meist auf gezielte Unterstützungsbedarfe, wie zum Beispiel Erinnerung, Mobilität oder Überwachung ausgelegt (Astell et al., 2019, S. 131; Pappadà et al., 2021; World Intellectual Property Organization, 2021, S. 29). Die Ergebnisse dieser Arbeiten skizzieren unterstützende Technologien, die über eine Insellösung für einzelne Probleme hinausgeht. Die Studien dieser Arbeit verdeutlichen den Bedarf an komplexen, sensorbasierten, intelligenten Systemen, die sich an die sich verändernden Bedarfe, Fähigkeiten und Vorstellungen der Nutzenden anpassen. Diese Anpassung beginnt bei der Auswahl des Endgerätes. Konsens bestand in den vorliegenden Studien hinsichtlich der Tragbarkeit der Geräte, mit Ausnahme der institutionellen Pflege, wo auch Roboter vorgeschlagen wurden. Auch das Review von Pappadà benannte tragbare Geräte, wie ein Smartphone, einen

Gürtel oder Uhren als passende Endgeräte (Pappadà et al., 2021, S. 6). Daher sollten unterstützende Technologien nicht als Begriff für eine Hardware, sondern vielmehr als Fähigkeitsprofil der Software verstanden werden. Diese Software sollte auf unterschiedlichen Geräten installierbar und mit anderen Geräten (zum Beispiel Smarthome-Equipment) kompatibel sein. Die Art der Unterstützung und Bedienung des Gerätes sollte adaptiv und intuitiv sein. Die vorliegende Arbeit bestätigt die Ergebnisse von Burmeister (2016, S. 186), wonach eine Benutzung und Gewöhnung in frühen Stadien der Demenz durch den Betroffenen angestrebt werden soll und kann, wohingegen in einem späteren Stadium die Benutzung zunehmend über die Pflegenden erfolgt und mehr passive als aktive Assistenz bietet. Mit Fortschreiten der Erkrankung und zunehmendem Unterstützungsbedarf der Betroffenen skizzieren Pappadà et al. (2021, S. 19) einen Wechsel des Profiteurs der unterstützenden Technologie vom Betroffenen zu den Pflegenden. Auch dieser Ansatz wird in den Studien dieser Arbeit bestätigt. Der Zeitpunkt des Übergangs von einer aktiv in eine passiv geprägte Unterstützung bleibt unbeantwortet und bedarf Langzeituntersuchungen, insbesondere im Hinblick auf die Akzeptanz von unterstützenden Technologien im späten Krankheitsstadium als auch bezüglich der Reagibilität der Nutzenden mit Demenz auf zum Beispiel Aufforderung der unterstützenden Technologien. Hier bietet Studie 3 einen Ansatz, indem sie die Entscheidungs- und Einwilligungsfähigkeit der Nutzenden als möglichen Wendepunkt von der aktiven zur passiven Unterstützung identifiziert. Dieses Ergebnis deckt sich mit unseren Ergebnissen aus Goerss et al. (2024), die anhand einer Smartwatch-basierten Intervention zeigten, dass die empfundene Nutzerfreundlichkeit parallel zur kognitiven Leistungsfähigkeit abnimmt.

Das Beispiel der Robbe PARO zeigte, wie wichtig der Einbezug der Nutzenden in die Entwicklung digitaler technischer Assistenzsysteme für die spätere Nutzung ist. Trotz einer positiven Studienlage (Kelly et al., 2021, S. 37), kann die Roboter-Robbe vor dem Hintergrund der Hygienerichtlinien (Robert Koch-Institut [RKI], 2005, S. 1065) in deutschen Pflegeheimen und Krankenhäusern nicht eingesetzt werden. Durch den Einbezug zukünftiger Nutzenden hätte diese Hürde vermutlich rechtzeitig identifiziert und genommen werden können.

Studie 1 und 3 zeigen konkrete Empfehlungen für die Gestaltung eines technischen Navigationsassistenten für die außerhäusliche Mobilität auf. Da die erste Studie der dritten zeitlich deutlich vorgelagert war, spielten Ansätze wie selbstlernende Systeme und das Nutzen von Hot-Spots für die Navigation in Studie 1 noch keine Rolle. Eine mögliche Begrenzung der Ideen kann in Studie 1 auch durch die Vorauswahl der Endgeräte und Designs entstanden sein. Parallel zur Studie 1 wünschten sich die Befragten aus Studie 3 ebenfalls ein möglichst unauffälliges Design für die Navigation im Außenbereich, welches eher als Life-Style-Produkt anstatt als Hilfsmittel wahrgenommen wird. Dies zeigt die Sorge vor Stigmatisierung bei der Nutzung

von digitalen technischen Assistenzsystemen, welche zuvor auch in systematischen Übersichtsarbeiten identifiziert wurde (Holthe et al., 2018, S. 880; Yusif et al., 2016).

Durch die Erweiterung des Bewegungsradius durch gemeinsame Ausflüge mit Angehörigen in Studie 1 und der Forderung nach einer demenz-freundlichen Gesellschaft in Studie 3 betonten beide Studien die Relevanz von zwischenmenschlicher Interaktion für die Navigation.

4.2 Empfehlungen für die Anwendung des Wertesensitiven Designs in der Forschung

Studie 2 und 3 identifizierten Werte im Zusammenhang mit digitalen technischen Assistenzsystemen in der Versorgung von Menschen mit Demenz. Das Wertennetzwerk aus Studie 2 gibt einen umfangreichen Einblick in die Komplexität der Wertvorstellungen und deren Abwägung untereinander. Auch in Studie 3 wurden Werte wie Autonomie, Selbstbestimmtheit, Privatsphäre, Sicherheit und soziale Interaktion diskutiert. Dies betont die Bedeutung dieser Werte für Menschen mit Demenz und deren Stakeholdern und passt zu den Ergebnissen von Teipel et al. (2016), Ienca et al. (2018) oder Yusif et al. (2016), unterscheidet sich jedoch von unseren Ergebnissen von Kowe et al. (2020), in denen Menschen mit Demenz und deren Angehörige unabhängig voneinander gleiche Interviewpassagen auf darin enthaltene Werte untersuchten. Im Ergebnis identifizierten nur die Menschen mit Demenz, nicht die Angehörigen, die Werte Autonomie und Privatsphäre (Kowe et al., 2022, S. 2). Studie 3 erweiterte Studie 2 durch das Aufzeigen von Spannungsfeldern beim Einsatz digitaler technischer Assistenzsysteme und dem Einhalten der Wertvorstellungen. Teilnehmende der Studie 3 sorgten sich über den möglichen Einsatz manipulativer Marketingmethoden wie Nudging, Gamification oder Incentives (für eine Begriffsdefinition siehe S.19). Hierzu fehlt es an ethischer und methodischer Forschung zu Handlungsempfehlungen und Einsatzkriterien dieser Marketingmethoden bei Menschen mit Demenz.

Zudem wurden rechtliche Rahmenbedingungen und Grenzen für den Einsatz von digitalen technischen Assistenzsystemen, wie zum Beispiel beim geografischen Lokalisieren von desorientierten Menschen, erörtert. In allen Studien dieser Arbeit wurde die Bedeutung zwischenmenschlicher Interaktion hervorgehoben. Der Einsatz von digitalen technischen Assistenzsystemen sollte Fachkräfte zu Gunsten von „Qualitätszeit“ mit den Pflegebedürftigen entlasten, jedoch nicht den zwischenmenschlichen Kontakt ersetzen. Dieser Wunsch der Befragten aus Studie 2 und 3 deckt sich mit den Ergebnissen anderer Studien (Astell et al., 2019; Brookman et al., 2023).

4.3 Limitationen und Stärken dieser Arbeit

Die vorliegende Arbeit zielte auf die Anwendung nutzerzentrierter Ansätze bei der Entwicklung digitaler technischer Assistenzsysteme für Menschen mit kognitiven Beeinträchtigungen ab. Dabei wurden in jeder Studie Menschen mit Demenz direkt einbezogen, was als Stärke der Arbeit zu sehen ist, da Menschen mit Demenz häufig nur indirekt von ihren Angehörigen vertreten werden (Pappadà et al., 2021, S. 19). Die erste Studie inkludierte nur Menschen mit Demenz, wodurch eine Datentriangulation, die eine multiperspektivische Sicht auf das Forschungsfeld erlaubt, ausblieb (Baur & Blasius, 2014, S. 418). Die Datentriangulation wurde in den kommenden Studien stufenweise erweitert, zunächst durch Einbezug pflegender Angehöriger und medizinischen Personals, später zusätzlich durch die Befragung von Patientenvertretungen, Wissenschaftlern, Pflegeheimmitarbeitern sowie Ethik- und IT-Experten. Die Stichprobengröße entsprach dabei der vergleichbarer Studien zu digitalen technischen Assistenzsystemen für Menschen mit Demenz (Ienca et al., 2017, S. 1335; Øksnebjerg et al., 2020, S. 948).

Die Ergebnisse der Studie 1 wurden nicht durch einen zweiten Rater geprüft. Durch die Ähnlichkeit der Ergebnisse aus Studie 1 und 3 hinsichtlich der Anforderungen an ein digitales technisches Assistenzsystem kann dennoch auf eine hohe Gültigkeit der Ergebnisse aus Studie 1 geschlossen werden. Um die Gültigkeit der Ergebnisse zukünftig zu objektivieren, wurde die Studie 2 einer Prüfung der Intra- sowie Interraterreliabilität unterworfen. Die hohe Übereinstimmung in der Interpretation der Daten (siehe 3.2), gemessen mit Hilfe der Reliabilitätsprüfungen, sprechen für die hohe Objektivität der Forschungsergebnisse.

Die Divergenz in der Begriffsdefinition „Mobilität“ aus Studie 3 zeigt, wie wichtig eine klare Einigung auf ein einheitliches Begriffsverständnis in der qualitativen Forschung ist. Dies sollte bei zukünftigen Forschungen berücksichtigt werden. Schulungen von Forschenden und Studienteilnehmern sind ein geeignetes Instrument, um Missverständnissen vorzubeugen (Gove et al., 2018, S. 726).

5 Schlussbetrachtung

Die Nutzung digitaler Geräte steigt bei den älteren Menschen zunehmend an (Initiative D21 e.V., 2024). Dies spricht für einen hohen Nutzen digitaler technischer Assistenzsysteme in der medizinischen Versorgung der Zukunft. Wachsende Versorgungslücken, bedingt durch die Alterung der Bevölkerung (Statista, 2022), bei zeitgleich steigendem Fachkräftemangel (Brücher & Deufert, 2019, S. 1) prägen zunehmend die medizinische und pflegerische Versorgung. Eine gute medizinische Versorgung wird in der Zukunft vermutlich nur mit technischer Unterstützung möglich sein.

Die Studien dieser Arbeit geben Handlungsempfehlungen für die Entwicklung digitaler technischer Assistenzsysteme unter Einbeziehung der späteren Nutzenden. Die vorliegende Arbeit verdeutlicht zudem die Machbarkeit des Einbezugs von Menschen mit Demenz in die Entwicklung digitaler technischer Assistenzsysteme. Menschen mit Demenz werden bei der Entwicklung digitaler technischer Assistenzsysteme nach wie vor vernachlässigt, in dem sie gar nicht oder nur in einzelnen Studienphasen einbezogen werden (Ienca et al., 2017, S. 1335; Øksnebjerg et al., 2020, S. 949). Diese Arbeit zeigt verschiedene Möglichkeiten, qualitative Methoden in der Forschungspraxis mit Menschen mit Demenz umzusetzen.

Nutzerzentrierte Ansätze finden kaum Anwendung in der Entwicklung digitaler technischer Assistenzsysteme, obgleich sie eine sinnvolle methodische Grundlage für den Entwicklungsprozess bieten (Ienca et al., 2018, S. 1043). Ein Grund könnte in der fehlenden methodischen Ausgestaltung des nutzerzentrierten Ansatzes für Menschen mit Demenz liegen (Pappadà et al., 2021, S. 19). Øksnebjerg et al. weisen in ihrem Scoping Review darauf hin, dass es an konkreten Leitfäden und Methodiken fehlt, wie Menschen mit Demenz partizipativ und iterativ in die Entwicklung digitaler technischer Assistenzsysteme einbezogen werden können. Dies hat zur Folge, dass die Studien zur Entwicklung digitaler technischer Assistenzsysteme sehr heterogen und wenig vergleichbar sind (Øksnebjerg et al., 2020, S. 949; Pappadà et al., 2021, S. 19). Bei der Entwicklung von Leitfäden sollten die Progredienz der Erkrankung und die Vulnerabilität der Betroffenen und ihrer Angehörigen Beachtung finden. Eine Hilfestellung zur Erarbeitung eines Leitfadens bietet das Positionspapier von Gove et al. zur partizipativen Einbeziehung von Menschen mit Demenz (Gove et al., 2018, S. 725).

Die Autorin dieser Arbeit arbeitet gemeinsam mit anderen partizipativ forschenden Kollegen an der Erprobung und Dokumentation sinnvoller und machbarer wissenschaftlicher Formate für und mit Menschen mit Demenz zur Umsetzung nutzerzentrierter Ansätze.

Die Ergebnisse illustrieren den Wunsch von Menschen mit Demenz und deren An- und Zugehörigen nach individualisierbaren, selbstlernenden Systemen, die unabhängig vom Krankheitsfortschritt, dem Betriebssystem und Endgerät genutzt werden können. Der Einbezug der Wertvorstellungen ist neben den Anforderungen an eine einfache Handhabung und Bedienbarkeit eine Grundvoraussetzung zur Akzeptanzsicherung und Nutzung digitaler technischer Assistenzsysteme und sollte bei der Entwicklung zwingend Beachtung finden.

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Selbstständigkeitserklärung

Ich erkläre hiermit, dass ich die vorliegende Dissertation selbstständig und ohne unerlaubte Hilfe verfasst habe. Ich versichere, dass ich ausschließlich die angegebenen Quellen und Hilfsmittel verwendet habe. Die Regeln zur Sicherung guter wissenschaftlicher Praxis wurden beachtet. Die Arbeit wurde nie zuvor einer anderen Prüfungsbehörde vorgelegt.

Rostock, den 04.10.2024

Stefanie Köhler

Akademischer Lebenslauf

Stefanie Köhler (geb. Habermann), geboren am 07.05.1987 in Rostock

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Publikationen (inklusive der Publikationen dieser Arbeit):

Weschke, S., Zarm, K., Schwarz, S., Ruhkiewick, K., Zwingmann, I., **Köhler, S.** & Teipel, S. (2019). Was brauchen Angehörige in der Versorgung von Demenzkranken? *Pflegezeitschrift* 72, 55–57 (2019). <https://doi.org/10.1007/s41906-019-0103-6>

Kowe, A., **Köhler, S.**, Klein, O. A., Lühje, C., Kalzendorf, J., Weschke, S. & Teipel, S. (2020). Stakeholder involvement in dementia research- A qualitative approach with healthy senior citizens and providers of dementia care in Germany. *Health and Social Care in the Community* 00:1–10. <http://dx.doi.org/10.1111/hsc.13238>

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König, A., Linz, N., Baykara, E., Tröger, J., Ritchie, C., Saunders, S., Teipel, S., **Köhler, S.**, Sánchez-Benavides, G., Grau-Rivera, O., Gispert, J.D., Palmqvist, S., Tideman, P., Hansson, O. (2023). Screening over Speech in Unselected Populations for Clinical Trials in AD (PROSPECT-AD): Study Design and Protocol. *The Journal of Prevention of Alzheimer's Disease*. <http://dx.doi.org/10.14283/jpad.2023.11>

Scharf, A., Raedke, A., **Köhler, S.**, Heppner, M.M., Purwins, D., Roes, M., Teipel, S., Hoffmann, W., Michalowsky, B. (2023). Design and implementation of the participatory German network for translational dementia care research (TaNDem) – A Mixed-Method Study on the Perspectives of Healthcare Providers and Dementia Researchers in Dementia Care Research. *Health Expectations*. <https://doi.org/10.1111/hex.13748>

Goerss, D., **Köhler, S.**, Rong, E., Temp, A. G., Kilimann, I., Bieber, G., Teipel, S. (2024). Smartwatch-Based Interventions for People With Dementia: User-Centered Design Approach. *JMIR Aging* 7: e50107. <https://doi.org/10.2196/50107>

König, A., **Köhler, S.**, Tröger, J., Düzel, E., Glanz, W., Butryn, M., Mallick, E., Priller, J., Altenstein, S., Spottke, A., Kimmich, O., Falkenburger, B., Osterrath, A., Wiltfang, J., Bartels, C., Kilimann, I., Laske, C., Munk, M.H., Roeske, S., Frommann, I., Hoffmann, D.C., Jessen, F., Wagner, M. Linz, N. & Teipel, S. (2024). Automated remote speech based testing of individuals with cognitive decline –Bayesian agreement of transcription accuracy. *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*. <https://doi.org/10.1002/dad2.70011>. In Produktion

Köhler, S., Perry, J., Biernetzky, O. A., Kirste, T. & Teipel, S. J. (2024). Ethics, design, and implementation criteria of digital assistive technologies for people with dementia from a multiple stakeholder perspective: a qualitative study. *BMC Medical Ethics* 25:84. <https://doi.org/10.1186/s12910-024-01080-6>

Reviews für Fachzeitschriften:

Bae, M., Seo, M.G., Ko H., Ham H., Kim, K.Y. & Lee, J.Y. (2023). The efficacy of memory load on speech-based detection of Alzheimer's disease. *Frontiers in Aging Neuroscience* 15:1186786; <https://doi.org/10.3389/fnagi.2023.1186786>

Buchkapitel:

Teipel, S., Kowe, A., Drewelow, E., **Köhler, S.**, Wollny, A. & Weidekamp-Maicher, M. (2024). *Partizipative Forschung in der Geriatrie*. In: Jürgen M. Bauer, J.M., Becker, C., Denking, M., Wirth, R. (Hrsg.). *Geriatric - Das gesamte Spektrum der Altersmedizin für Klinik und Praxis*. S.896-903, ISBN-13: 978-3170417946

Kongressbeiträge:

Vorträge:

Köhler, S., Kowe A., Görß, D. & Teipel, S. (2020) „Use-cases and users' requirements for design of an individualized sensor-based assistive system for people with dementia in nursing home facilities-A user centered design approach using qualitative research”. Vortrag und Session Chair auf der Alzheimer's Association International Conference

Köhler, S. & Kowe, A. (2021). Die mehrstufige Einbindung verschiedener Stakeholder in das Projekt SAMi (Sensorbasierter persönlicher Aktivitätsmanagementassistent für die individualisierte stationäre Betreuung von Menschen mit Demenz). Vortrag während der 5. Berliner Werkstatt Partizipative Forschung

Köhler, S. (2022). Value Sensitive Design to design assistive technology for people with dementia. Vortrag auf der Konferenz Ethics by Design: Responsible Development of Technology

Köhler, S. & Teipel, S. (2023). Prospect-AD- prädiktive Sprachtestung für die Früherkennung der Alzheimer-Erkrankung. Vortrag auf dem DGPPN-Kongress in Berlin

Ausgewählte Posterpräsentationen:

Köhler, S., Koldrack, P., Zarm, K., Weschke, S., Kirste, T. & Teipel, S. (2019). Mobilität und Technikaffinität bei Menschen mit Demenz - Ein nutzerzentrierter Ansatz. Posterpräsentation auf dem DGPPN-Kongress in Berlin

Köhler, S., Scharf, A., Raedke, A., Heppner, M.M., Roes, M., Michalowsky, B., Hoffmann, W., Teipel, S (2022). Coexistence or cooperation? The perspective of people affected by dementia on participation and research. Posterpräsentation auf der Alzheimer's Association International Conference 2022

Köhler, S., König, A., Linz, N., Glanz, W., Altenstein, S., Jessen, F., Spottke, A. & Teipel, S.J. (2023). Digital biomarker co-design with people with preclinical or prodromal dementia. Posterpräsentation auf der Alzheimer's Association International Conference in Amsterdam

Köhler, S., König, A., Linz, N., Altenstein, S., Butryn, M., Glanz, W., Jessen, F., Munk, M. H., Osterrath, A., Schott, B.H., Spottke, A. & Teipel, S.J. (2024). Usability of phone-based cognitive assessments for developing a digital speech-based biomarker for early detection of Alzheimer's disease. Posterpräsentation auf dem AD/PD (Alzheimer's Dementia & Parkinson's disease) – Kongress in Lissabon

Köhler, S., König, A., Linz, N., Altenstein, S., Butryn, M., Glanz, W., Jessen, F., Munk, M. H., Osterrath, A., Schott, B.H., Spottke, A. & Teipel, S.J. (2024). Digital biomarker co-design with people with preclinical or prodromal dementia. Posterpräsentation auf der Alzheimer's Association International Conference 2024

Publikationen als Bestandteil dieser Dissertation

Die folgenden Publikationen sind Bestandteil der vorliegenden Dissertation und sind als Volltext der Arbeit angehängt.

Studie 1:

Köhler, S., Koldrack, P., Zarm, K., Weschke, S., Kirste, T. & Teipel, S. (2021). Technology for mobility: A user-centered approach evaluating affinity for technology and requirements for a navigation assistant for people with cognitive impairment. *Gerontechnology* 20:1. <https://doi.org/10.4017/gt.2021.20.435.04> (Impact-Faktor: 0,66)

Studie 2:

Köhler, S., Görß, D., Kowe, A. & Teipel, S. (2022). Matching values to technology: a value sensitive design approach to identify values and use cases of an assistive system for people with dementia in institutional care. *Ethics and Information Technology* 24:27. <https://doi.org/10.1007/s10676-022-09656-9> (Impact-Faktor: 4,34)

Studie 3:

Köhler, S., Perry, J., Biernetzky, O. A., Kirste, T. & Teipel, S. J. (2024). Ethics, design, and implementation criteria of digital assistive technologies for people with dementia from a multiple stakeholder perspective: a qualitative study. *BMC Medical Ethics* 25:84. <https://doi.org/10.1186/s12910-024-01080-6> (Impact-Faktor: 3,1)

Studie 1:

Technology for mobility: A user-centered approach evaluating affinity for technology and requirements for a navigation assistant for people with cognitive impairment

Technology for mobility: A user-centered approach evaluating affinity for technology and requirements for a navigation assistant for people with cognitive impairment

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Abstract

Background: People with dementia experience problems to maintain autonomy and self-determined mobility. Assistive technology devices, if adapted to the specific needs of this user-group, may support people with dementia and help them maintaining daily functioning and independence.

Objective: This study aimed to examine the future users' perspective on function and design requirements for technical navigation assistants to support outdoor mobility in people with cognitive impairment.

Method: Within a user-centered design approach we conducted semi-structured interviews on mobility behaviour and technology affinity with 14 people with mild cognitive impairment or mild to moderate dementia. Qualitative content analysis as described by Mayring was used to analyse the data.

Results: Nearly all of the participants expressed the need for self-determined mobility and all participants used technical devices in their daily life. Five of 14 participants had experienced phases of disorientation outside their homes, resulting in discomfort and a reduction or avoidance of outdoor activities. The participants' requirements for a technical navigation assistant comprised the following features: Integration of safety services; customisable functions, a legible display, a small, unobtrusive design of the device (e.g., a smartphone or watch), and additional support for the selection of and adherence to compensation strategies. Despite previous experiences with navigation systems, participants did not use them. This indicates the need for innovations in this area.

Conclusion: People with dementia provide us with essential expert insights into dementia-related mobility constraints and requirements for the design of technical navigation assistants. These insights will help to improve usability and acceptance of such technologies by the intended users.

Keywords: Dementia, disorientation, assistive technology, spatial navigations, user participation

INTRODUCTION

People with dementia are at risk of loss of autonomy and need of care (McKhann et al., 2011). Physical activity is a resilience factor identified in dementia (Bherer, Erickson, & Liu-Ambrose, 2013 & Heyn, Abreu, & Ottenbacher, 2004). Independent mobility outside the home is important for maintaining the quality of life and preventing nursing home admission (Groessl et al., 2007). It is estimated that more than half of persons living with Alzheimer's disease experience orientation problems which may be alleviated with navigational assistance technology (Pai & Jacobs, 2004). Such assistance should be situation-adaptive so that it delivers interven-

tions only in instances of need. This would allow the users to continue to rely on their cognitive resources as long as they are not critically impaired (Teipel et al., 2016). User involvement ensures adaption of technological devices to users' needs (Yatawara, Lee, Lim, Zhou, & Kandiah, 2017, Kwan, Cheung, & Kor, 2018 & Span, Heting, Vernooij-Dassen, Eefsting, & Smits, 2013).

There are no intelligent and situation-adaptive assistance systems that are able to recognize needs and propose interventions for the outdoor sector (Kan, Huq, Hoey, Goetschalckx, & Mihailidis, 2011). Current systems are limited to geofencing (i.e., setting up digital motion zones), helping

Navigation assistant for people with cognitive impairment

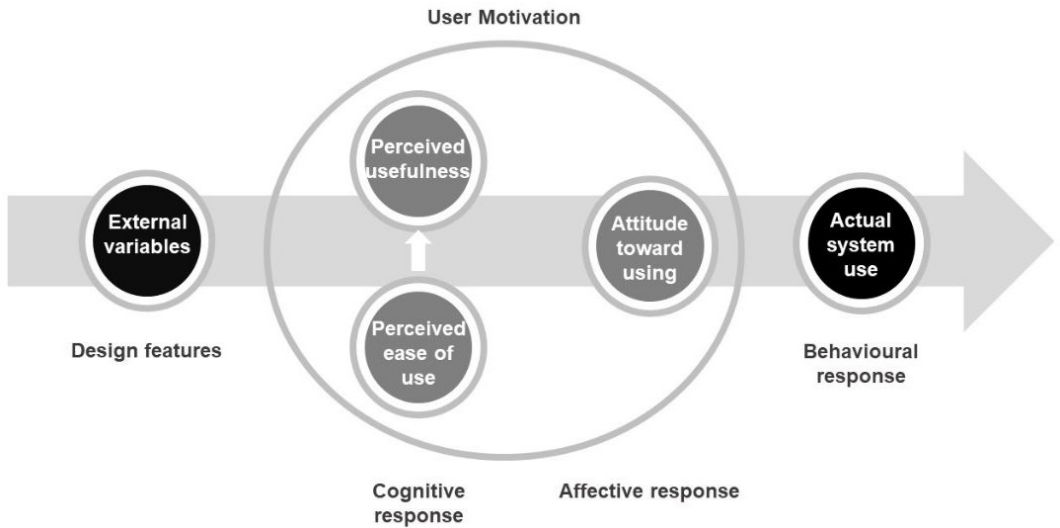


Figure 1. Technology Acceptance Model (original representation, based on Davis, 1985, p. 24).

people to find their way back home or alerting a caregiver (Dröes et al., 2009 & Huang, Lin, Yu, Liu, Kuo, 2015 & Megges, Freiesleben, Jankowski, Haas, & Peters, 2017). The discrepancy between the users' need for autonomy and current systems' abilities suggests that people with cognitive impairment, including people with dementia, should be actively involved in the design of such technologies to incorporate their values and needs. User-centered development approaches (e.g., Value Sensitive Design, VSD) systematically capture the values and needs of future users to develop responsive and marketable technologies that meet their needs (Friedman, Hendry, & Borning, 2017). Qualitative user surveys play a central role in understanding the users' perspective as they allow complex and context-sensitive insights into individual demands on assistive technology beyond predefined answers (Aspers & Corte, 2019). Approaches focusing on the assessment of the values and needs of people with dementia are established in many contexts

(Tsekleves, Bingley, Luján Escalante, & Gradinar, 2018), but have not been widely used with respect to an affinity for technology. The current work aimed to elicit necessary factors and design features for the development of a navigational assistive technology from people with cognitive impairment, including people with dementia, as the future users of such technologies. The catalogue of questions was based on Davis' Technology Acceptance Model (TAM), which specifies predisposition factors that are important to ensure user-acceptance (Davis, 1985): design features, sociodemographic characteristics, technological experience, the perceived ease of use, and the perceived usefulness (Figure 1) (Davis, 1985 & Venkatesh & Bala, 2008). To adapt future prototypes to the needs of people with dementia, information on their mobility behaviour and expectations of navigational assistive technology are required.

Accordingly, we examined the following questions:

- I. Which mobility needs do people with mild and moderate dementia have?
- II. How can these mobility needs of people with dementia be supported by navigational assistance technology?
- III. How technologically incline is the target group?
- IV. How must the device be designed to be accepted by the users?

METHODS

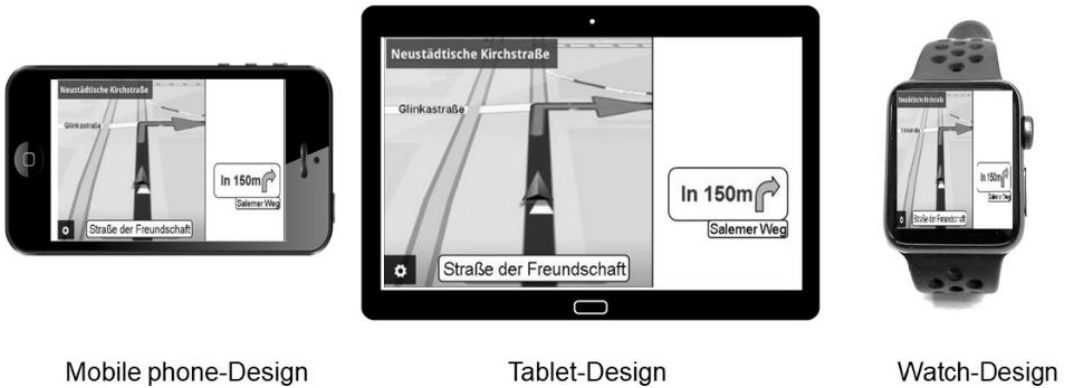
The user-centered approach was embedded within a qualitative research method using semi-structured interviews (see Procedure).

Table 1. Sample.

Interview ID	Age	Sex	MMSE*	Highest level of education	Technological education
X01	73	F	26	Vocational training	No
X02	73	M	27	Vocational training	Yes
X03	58	F	25	Higher Education	No
X04	59	M	17	Higher Education	Yes
X05	64	M	26	Higher Education	Yes
X06	82	M	28	Vocational training	Yes
X07	86	M	25	Higher Education	Yes
X08	58	F	26	Vocational training	No
X09	62	F	20	Vocational training	No
X10	76	F	25	Vocational training	No
X11	78	F	28	Vocational training	No
X12	73	M	27	Higher Education	Yes
X13	71	M	23	Higher Education	Yes
X14	81	M	24	Higher Education	No

*at time of interview

Navigation assistant for people with cognitive impairment



Mobile phone-Design

Tablet-Design

Watch-Design

Figure 2. Examples of possible devices for navigational assistance technology (Source: <https://pixabay.com/de> & <https://www.google.de/maps>).

Sample

We interviewed 14 people with mild cognitive impairment or mild to moderate dementia due to clinically probable Alzheimer's disease, according to NIA_AA criteria (Albert et al., 2011 & McKhann et al., 2011). The inclusion criterion was the absence of other clinical causes of cognitive impairment in clinical examination, routine blood examination, and MR imaging and cognitive decline not more pronounced than moderate dementia (operationalized as a value of ≥ 15 in the Mini-Mental-Status-Examination (MMSE) (Folstein, Folstein, & McHugh, 1975). The mean age of participants was 71 years (range: 58-81 years) and the mean MMSE test value was 24.8 (range: 17-28) (Table 1). Fifty percent had received vocational training, fifty percent had undergone higher education. Seven of fourteen were technologically educated.

Procedure

Participants were recruited through the Memory Clinic of the University Medical Center and the Research Outpatient Clinic in Rostock, Germany. The interviews took place at the Research Outpatient Clinic or the participant's home. All patients or their representatives provided written informed consent. The interviewers ensured ongoing consents. The study was approved by the ethics committees of the University Medical Center Rostock (A 2013-0072) and conducted in accord with the Declaration of Helsinki (1975).

Two different researchers conducted the interviews. All fourteen interviews were digitally recorded, anonymized, and transcribed verbatim. The interview guideline contained four main categories:

- A) Living conditions and socio-economic status.
- B) Use of digital technology.
- C) Need for help when navigating outside the home (need for support, purpose, significance, frequency, and range of mobility).
- D) Requirements for the usability of a device to support outdoor navigation.

The technological sections (B & D) were based on the TAM. A priori, we deduced a category system based on the guideline. This category system was inductively supplemented during the evaluation of the interview material (Mayring, 2000). To ensure a consistent coding procedure, an intercoder check was conducted (Mayring, 2014). Two coders contributed to the evaluation process.

Material

To increase participants' imagination of a future navigational assistive technology the following examples were shown to all participants (Figure 2). In addition, a sample of display layouts for navigation information was given to all participants (Figure 3).

Analysis

The data was evaluated using qualitative content analysis as described by Mayring (Mayring, 2014). We divided the data into the following units: evaluation unit (all transcripts), context



Figure 3. Different versions of Google street views used as navigation aid for people with dementia (Source: <https://www.google.de/maps>).

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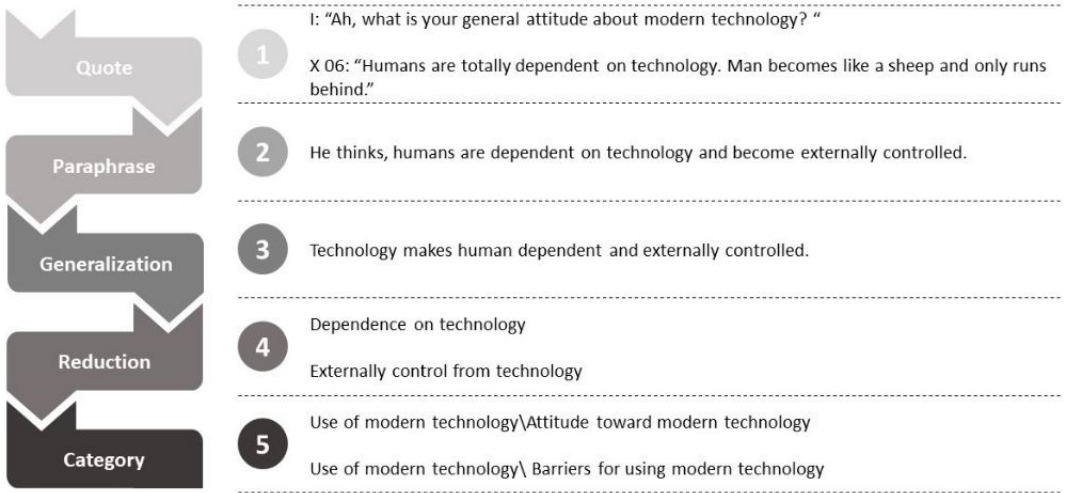


Figure 4. Process of reduction.

unit (sense sections), and coding unit (individual words/word groups) (Mayring, 2014). The coding unit was paraphrased, generalized, and reduced (Figure 4). The reduction was classified in the smallest existing (sub-)categories (deductive) or, if necessary, in newly built ones (inductive).

Besides, a coding guideline was developed to structure the coding process (coding rules) (Mayring, 2000). The coding guideline defined the meaning of subcategories and provided anchor examples for these definitions (Table 2). Further, the coding rules specified the content of answers and determined the manner how the answers should be coded in this category (i.e. values, yes/no, or reasons) (Mayring, 2014).

To structure, organize and summarize the data a qualitative data analysis software (MAXQDA 2018, release 18.2.4, VERBI software, Consult. Sozialforschung GmbH, Berlin, Germany) was used. After finishing all evaluations, the identical

reductions in each (sub-)category were added up to present the priorities of the statements.

The affinity for technology features personal resources, personality, and the willingness to interact with new technology (Franke, Attig, & Wessel, 2019). To derive affinity for technology for each participant, we applied the Affinity for Technology Interaction Scale (Franke et al., 2019). We took the sum of all positive factors towards technology use (past and present use of landline phone and mobile or smartphone, tablet, personal computer, notebook, device for navigation; technological education; resources; coping strategies and personal benefit) and subtracted all negative factors (obstacles; barriers and problems). The sum built the ability to use modern technology and was set in relation to the attitude.

RESULTS

In total, we extracted 1,432 codings in 115 subcategories. The amount of the codings per inter-

Table 2. Extract from the coding guideline.

Category 2: Use of modern technology (affinity for technology)	
Question:	Do you have any difficulties with electronic/technological devices that you use?
Subcategory 1	Difficulties during operation
Definition	All problems, obstacles and difficulties arising during the operation of technological equipment or constituting a barrier to operation.
Anchor example	"I: OK. And what electronic devices, would you say, //or technological devices, where you would say, "this is actually more difficult for me (.) to use"? X04: (...) But with the new devices, especially the one, the ones (...) uh, (..) the small computers//; (...) Tablets. Right. Uh, with these I had to work my way through, but once you've spent a bit of time with them and you understand how to use them better//
Coding rule	All answers to this question that indicate difficulties in operation were coded under this category, even if the interviewed person had strategies to overcome the difficulties.

Navigation assistant for people with cognitive impairment

Table 3. Different attitudes toward modern technology.

ID	Quotation	
X01	"Yes. (.) Indeed. I absolutely want to stick to that too, because I think it's an immense feeling of freedom"	positive
X02	"No. Not me. I'll get there // I won't get along with it. There I am // I'm not even interested in."	negative
X03	"Yes, yes, yes! So I want// And like I said, I've got it all figured out for the winter. So, I just realize that this is a different age group that can do it better. So it's easier for the younger ones."	positive
X04	"It's nice when something new comes."	positive
X05	"Yes, actually open. (...) Due to history."	positive
X06	"Humans are totally dependent on technology. Man becomes like a sheep and only runs behind."	negative
X07	"But otherwise, technological devices that // I'm not afraid of, let's say."	neutral
X08	"Not that good. No, this bells and whistles and if they have 1000 other things."	negative
X09	"Yes, great if you know how to do it. Yes, it is already, it is already beautiful." "Yes. And it will always go on. I don't need anything anymore. So what's new now."	positive
X10	"If that stays within limits. <i>Then it is OK?</i> Yes. But if all of life is based on technology, I don't think that's a good thing."	neutral
X11	"Well, if I can handle it, then it's fine// Yes. //but if I can't handle it, I'm avoiding it."	neutral
X12	"Positive, actually. And that then this general communication between people is indeed blocked by it."	positive
X13	"Well, I'm actually quite open-minded. Yes, you would also like to see how it goes on."	positive
X14	"Yes, I am amazed to see what the new times have in store. And when I'm gone, how it goes on. I'm making thoughts about that. And that's where I have ideas."	positive

view was independent from the MMSE-Score or age. The average interview duration was 30:55 minutes (range: 15:16 - 45:53 min) (Contact corresponding author to obtain supplementary materials written in German).

Living conditions and socio-economic status

Ten people lived with their partners, four lived alone. Eight of the 14 participants previously worked in the technological field, with nobody currently working (13 pensions/early retirement, one unemployed). Nine of the interviewees reported physical illnesses that might limit mobility behaviour: cardio-vascular diseases (n=1), visual impairment (n=4), degenerative changes in the musculoskeletal system (n=4), and balance disorders or faint (n=3).

Use of digital technology (affinity for technology)

Concerning the usage of technology, eleven participants had a mobile phone and eight used a car navigation device, in addition to the use of communication and kitchen appliances.

Obstacles and resources for technology use

Major obstacles for technology use arose from visual impairment, partially in combination with wrong prescription glasses, with fear of increas-

ing impairment, the confrontation with unusual, new technology as well as from lack of perceived benefit and financial resources. Complex device operation was also described as problematic because it frustrated and overwhelmed the user: "*Oh, God, let me put it this way, I've decided not to burden myself with the latest technology. (.) Because that's beyond my ability now.*" (X14, L.1432-1437). When participants faced problems using technological devices they relied on the following strategies: (i) they read the instructions to solve problems, (ii) they took time to calm down before they tried again, (iii) or they used a different device instead (e.g., their microwave instead of their stove). Additionally, asking the children or spouse for help was named: "*And the washing machine, if, if I can do it and if I can handle it, I'll do it myself and otherwise my daughter will do it*" (X11, L.200-202). At the same time, the spouses were a barrier for technology use relieving the operation of complex devices because the spouses did not think that the participants could manage these: "*(...) he always thinks he's doing something good for me if he helps me with everything. I don't want him to. I want to do as much as possible myself. (...) And it's all working out if he lets me.*" (X08, L. 537ff.). Some participants described inhibitions

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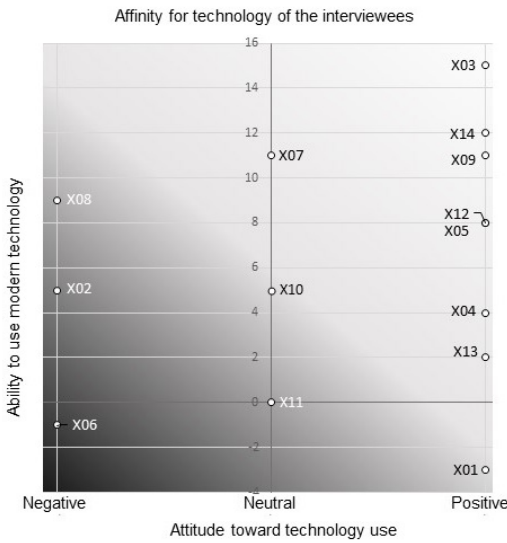


Figure 5. Affinity for technology of our interviewees derived by use of technology and attitude towards modern technology. Dark grey means not technologically inclined, light grey means neutral, and white means technologically inclined.

to ask their spouses for help; the participants felt ashamed or feared conflicts: "And then I say// it's too embarrassing for me to say, 'get me maps in there', that I don't even ask that anymore." (X01, L.675-676) and: "Yeah, I'll do it myself, I'll read it again, and I'll try it out and what I need. If he tries to explain it to me, it's gonna be a cramp." (X08, L. 332-334).

Besides the independent exploration of devices at one's own pace, interest in technology, as well as constant use, were important for the handling of technological devices. The perceived benefit at home and in professional settings was named as important factors for using technological devices, as underlined by this quote: "I: So, would you also say, that you are open to electronic devices, such as computers? X01: Yes. (.) Indeed. I absolutely want to stick to that too, because I think it's an immense feeling of freedom" (I1, l.177ff.).

Despite that technological education being named as an advantage when using technology by the technologically educated participants (n=8), they did not use more often or more modern technology and did not report fewer struggles with it. Even interviewees with technological backgrounds had no personal computers or mobile phones for work because they had worked as mechanics or welders. In most cases, the crucial point for using modern technology was the need to handle digital devices, like personal computers or mobile phones in their previous work and a high degree of education itself.

Attitude towards modern technology

The attitude towards modern technology can be divided into positive, neutral, and negative by interviewees' answers to the question: "What is your general attitude towards modern technology?" (Table 3). Most of the participants were open-minded towards modern technology (8 positive, 3 neutral, 3 negative). Positive attitudes included anticipation, fascination, and progress. In contrast, disinterest, the feeling of dependence on technology, and worries about decreasing social interaction were facets of negative attitudes.

The attitude towards modern technology itself was not sufficient to infer technology use. A more precise picture was obtained from evaluating the affinity for technology for each participant (Figure 5).

The absence of affinity in the four least technologically inclined participants (X02, X06, X08, X11) may be explained by their backgrounds (Figure 6).

For the technologically inclined participants, there was a strong tendency to use several different devices, but their ability to cope with problems in use was different. All participants who were currently using a personal computer were considered technologically inclined and had previously operated it in their work-life; they had a positive attitude towards modern technology. However, not all participants with a positive or neutral attitude who had previously used a computer in their work-life were still using it at the time of the study. Further, the use of a mobile or smartphone was independent of their affinity for technology. X02 used his mobile phone only for calls and recognized the benefit in cases of disorientation. X08 used her mobile phone out of habit, but only for calls, SMS, and in case of emergency (emergency button). X06 and X11 did not have mobile phones. X13 did not own a mobile phone, reported not leaving his property, and thus perceived his landline phone as sufficient.

In summary, the affinity for technology depended on various, individual experiences and abilities and could not be strictly classified.

Need for help when navigating outside the home

Outside activities

One of the interviewees no longer left the property on his own. Ten of the interviewed persons reported going out by themselves at least twice a week. Three did not respond directly to this question but from their other answers, we inferred that they went out alone as well. Being accompanied by other persons increased the frequency of mobility outside the home in two interviewees. For four participants, the radius of movement was increased by the presence of another person.

Navigation assistant for people with cognitive impairment

X08, Female, not affine

- 10 years of formal schooling
- Technical & Non-technical vocational training
- Computer (in the past) and mobile phone (for emergency) only in private life
- Negative attitude: feels overwhelmed by technology, hates the internet because of experience with deception
- Preference for analogue solutions (pen & paper)

X11, Female, undecided

- 8 years of formal schooling
- Non-technical vocational training
- No mobile phone, no computer neither at work nor in private life
- Neutral attitude: Doubts about herself by using technology (rejects technologies that she cannot handle)
- Inability to cope changes/new things
- Acceptance of operation by third parties
- No expected personal benefit
- Mistrust in general



X02, Male, not affine

- 8 years of formal schooling
- Technical vocational training
- No interest
- No computer or mobile phone for work
- Mobile phone only for calls with preset functions
- Acceptance of operation by third parties
- Negative attitude: Fear of worsening of the disease by using technology
- No expected personal benefit

X06, Male, not affine

- 8 years of formal schooling
- Technical & Non-technical vocational training
- Negative attitude: dependence & decreasing social interaction
- No mobile phone, no computer neither at work nor in private life
- No expected personal benefit

Figure 6. Characteristics of not technologically inclined interviewees.

About a third of participants (n=4) were still mobile by car and regional trains, six participants used bicycles and seven participants used the local public transport or were front-seat passengers. All participants were mobile by foot.

Figure 7 provides an overview of outdoor activities, divided into independent and accompanying activities. Participants reported engaging in certain types of activities either on their own, with their partners, or both. Tendencies to one side represent the degree to which each activity is done more frequently alone or accompanied.

Reasons for and importance of outdoor mobility
Reasons for leaving the house included the need for self-sufficiency, good weather conditions, interest in the living environment, or exercise. In addition, maintaining social relationships as well as having time for oneself were mentioned: "I'm always happy when I can get out on my own.

That I could be without his exaggerated vigilance." (X08, L. 612-613). Additionally, independent activities were crucial for the partnership because they provided new topics for conversation and reduced conflicts: "And I'm always really happy when I come out. (...) Before you get arguing at home." (X08, L. 655-659). Reported destinations varied from forests, neighbours, and locations in the city, like doctor's or therapist's office, flea markets, and shopping malls.

Independence and self-determination were of great importance to most participants: "I put great importance on it, that I decide all this myself" (X14, L. 831-832). Eleven participants felt that their independence was severely restricted by physical impairment, fear of crime, shame caused by a lack of affective control, dependence on local transport (with frequent changes), lack of leisure offers, accompaniment, and necessity. Sometimes, the partner played a role in this:

"I have a bike, but I haven't been riding for a while. My wife doesn't want to." (X13, L. 458-459) and "Well, going for a walk, my wife's not happy about it right now. Because we've also had times// I didn't come back." (X13, L. 381-382). This participant was the only one who had neither coping strategies in case of disorientation nor a mobile phone.



Figure 7. Independent or accompanied outside activities and degree of overlap.

Disorientation and coping strategies

In total, six participants reported situations of disorientation (Figure 8). The main factors for upcoming disori-

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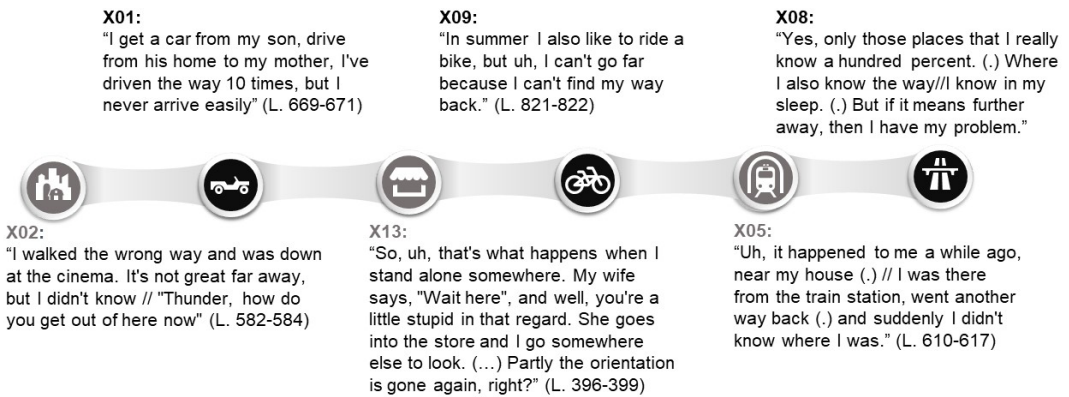


Figure 8. Reported situations of disorientation.

entation were unfamiliar, confusing surroundings, darkness, inattentiveness, lack of concentration, and high velocity i.e., by using the car. Disorientation was caused by struggling to relocate their bicycles or cars. Some participants described that their cognitive skills depended on their day-to-day psychological well-being.

To cope with disorientation, participants used different strategies, such as exact planning of the routes with the public transport departure times; using familiar, already learned routes; asking passers-by for direction; going accompanied and carrying a mobile phone as an emergency call possibility.

Requirements for the usability of a device

Mobile phone usage

There was high variability in how participants used their mobile phones. About three quarters of participants with mobile phones (9/11) used their phones to make calls, two of them limited the use to emergency calls. Out of the eleven, four used messaging services such as SMS, WhatsApp, E-mail, weather apps, Google Maps, the alarm clock, and the camera function.

Difficulties in operation arose from small touch screens, complicated menus, problems seeing the screen in sunlight and difficulties remembering the password/PIN to unlock the phone. Seven interviewees indicated that these problems prevented them from using mobile phones.

Readiness and design requirements for a navigational assistive technology

Despite the difference in affinity for technology, all participants provided ideas for the development of navigational assistive technology. Further, twelve of the interviewees were interested in using such a device: "Yoah, I think that at some point you will be ready again. They are always working on something like that, but I am already// would be interested in something like that." (X02,

L. 807-809). The two non-interested participants refused it due to a lack of necessity (X10, no disorientation experienced), mistrust, or a preference for non-technological assistance (X11). The interviewees reported that they would be interested in using assistance systems to support their health, well-being, and sense of security. In addition, independence, the maintenance of independence as well as mobility were highlighted.

Nine interviewees stated that they would prefer their navigational assistive technology to be on a smartphone, six preferred the format of a watch and one stated that the format of a tablet would be most convenient (participants named more than one device). The smartphone was chosen because of its size, the watch because it does not attract attention and can be worn at all times. Interestingly, two participants suggested that a device in form of a pendant on a necklace would be handy.

Nine interviewees stated that they would prefer using their assistance via a touch screen and three said they preferred a key panel. Two participants opted for voice control and one reported preferring pen control. One interviewee recommended adapting the display format based on the dementia stages and the associated cognitive problems. In addition to the design, interviewees listed further system functions they viewed as important: a reminder function, emergency calls, calendar, timetable for public transport and location display, watch, navigation, GPS, notes, and alarm function.

Clear functions, a large display, easy operation, robust construction, and audio support were also emphasized. The possibility to try out the device was important as the interviewees could not imagine its usability and benefit due to a lack of experience.

When presented with samples of display layouts there was some variation with respect to participants' preferences. One person opted for version 1 of the sample layouts, five persons each

Navigation assistant for people with cognitive impairment

Table 4. Quotations that express the feeling of shame and coping ideas.

Feeling of shame	Ideas to cope with shame
<p>"I mean, if someone knows that I have dementia, well, it's, uh, sometimes problematic, because then they think, I'm stupid and have to talk to me like a mental patient, but, uh, that's ignorance and I can't do anything about it, no." (X01, L. 891-894)</p>	<p>"That's, uh, uh, first of all, uh, the environment is interspersed with it, because people are all running, whether young, whether old//it's of course different things that they perceive and music or something like that//So, so that wouldn't bother me" (X07, L. 837-840)</p>
<p>"You have to keep in mind that we know (...) the dementia patient is aware that he is noticeable everywhere. And if we assume so, then he's not going out in the public road with a device like that." (X06, L. 910-919)</p>	<p>"They might think I'm a foreigner or something. (...) That's mine, my navigation system. I don't know my way around here, I'm not from here." (X09, L. 1746-1769)</p>
<p>"Well, I'm a little embarrassed then, right?" (X03, L. 1548-1549)</p>	
<p>"Nah, you can see that. Then the other people know" (X09, L. 1430)</p>	

for version 2 and 3, and three for version 4. A third of interviewees (n=4) addressed feelings of shame and fear of stigmatization when using navigational assistive technology (Table 4).

As a result, it was recommended to use commercially available navigation functions with audio support via headphones. This would facilitate the use of assistance systems by providing an important degree of discretion in public.

DISCUSSION

The results of this qualitative research show that people with dementia are in a position to voice their needs and preferences and that their experiences and perspectives contribute key aspects to the development of future navigational assistive technology. This highlights the value of qualitative approaches allowing researchers to examine questions outside the boundaries of predefined questionnaires, which is especially important for the development of new support systems. Our sample of participants represented a diverse group with respect to demographic and cognitive variables (e.g., age, cognitive impairment, gender). This allowed us to examine views from a diverse group of individuals with varied needs and preferences. Based on data saturation, a sample size of 14 was deemed sufficient in our study. Moreover, similar previous studies examining users' needs to assistance technology for dementia had a similar sample size (Span et al., 2013).

The results show the importance and value of self-determined mobility and independence in daily life. They provide important information with respect to preferred device designs, the

means of transport used, and the consideration of environmental factors, for example, darkness, that lead to disorientation.

The results of this qualitative research also support the findings of other studies and show that participants' statements are valid despite their cognitive impairment. Numerous inductively formed categories show the broad response spectrum of the participants and underline the added value of the qualitative research approach for device development.

Outdoors, our participants moved within the expected range for people with dementia (Tung et al., 2014). But two of them also went for regular walks in a forest. A sufficient strength of the GPS-signal to localize the persons in this special area must be ensured. The results of our study for participants' orientation difficulties support the findings by Pai & Jacobs (2004). Our interviewees were able to reliably report on situations of disorientation despite their cognitive problems. Although eight participants previously worked in a technological profession and most of those had experience with navigation systems (n=6), all interviewees stated that they did not use such systems to compensate for their orientation problems. This might point to deficits in the usability of currently available systems for people with cognitive impairments. Therefore, the following recommendations can be considered:

Increasing perceived benefit

We found that maintenance of self-determination, autonomy, and safety were crucial motives for people with dementia to use navigational as-

Navigation assistant for people with cognitive impairment

sistive technology. Against this background, an autonomy-focused system should respect the prioritized needs to ensure users' acceptance (Venkatesh & Bala, 2008). The functions need to be adaptable to serve individuals' needs, abilities, and circumstances.

The participants had difficulties identifying the benefits of using assistive technology devices. Furthermore, the ability to manage technological devices in daily life decreases for people with MCI or dementia (Malinowsky, Almkvist, Kottorp, & Nygård, 2010). In our interviews, the crucial factor for technology use was the affinity for technology, not MMSE or age. Therefore, to increase the habitual use of technological devices and a positive attitude, practical testing and training are necessary to examine and address barriers and incorporate facilitators. Our interviewees expressed their interest in such training programs. Also, Megges and colleagues, demonstrated the benefit of testing devices to examine the motivation to use an assistance prototype (Megges et al., 2017). For the future development of navigational assistive technology, we strongly recommend including people with dementia as co-designers to optimize outcomes and impact of such investigations (Tsekleves et al., 2018 & Teipel et al., 2016). Also, the interest in technology and its benefit should be promoted especially for people with a neutral attitude toward modern technology by offering public workshops or support courses. For the three non-technologically inclined participants, technological assistance may not be suitable. But the boundaries between technologically inclined and non-technologically inclined persons are fluid and the affinity might be changed by an individualized consultancy.

It cannot be determined if the negative attitude leads to a lack of using modern technology or the other way around. Future people living with dementia may experience a heightened inclination towards technology because of the increasing need to use it at work and leisure (Statista, 2019). Also, the relatives play a central role for using or avoiding technological devices. Thus, the relatives need to be included in the training and promotion efforts.

Increasing usability

Moreover, the technological navigation assistance should be usable and maintained independently by the person with dementia to increase motivation and confidence. Similar results were found by Megges and colleagues (2017). Increased training opportunities for individuals to use technological devices may reduce the barriers identified in this study, thereby increasing the use of assistance systems. Besides the implementation of training opportunities, individual com-

pensation strategies should be promoted. Consistent with the simplicity of the devices' control, interviewees commented that the display panel (10 interviewees selected versions 2 & 3) should be more abstract, i.e., contain fewer details.

Removing barriers

According to our results, and consistent with earlier reports, barriers for use were high costs, difficult and unsuccessful handling of the device, and the lack of perceived added benefit (Boger, Quraishi, Turcotte, & Dunal, 2014). In line with this, our results highlighted the need for low costs, ease of use, familiarity, and portability as well as opportunities to strengthen and ensure acceptance by a perceived benefit. The fear of stigmatization and the users' sense of shame also played a role in our and the previous study (Boger et al., 2014). Moreover, there were device aspects, such as sufficient size, which Span and colleagues had also reported before (Span et al., 2013). In summary, the aim should be a simple, intuitive operation with a focus on the needs of the users in mind.

Strengthening self-efficacy and confidence by mobility

Local transport is a crucial part of participants' mobility. Problems often arose by frequent changes of train or bus. A navigational assistive technology should regard this problem and secure the usage of the most direct connection and a smooth change-process.

Disorientation reduces the life space of people with dementia if they have no eligible coping strategies. Relatives increase participants' life space as well as their independent mobility i.e. by committing their loved one to use a mobile phone. Along the same lines, relatives' exaggerated surveillance and fear of their spouses getting lost may limit the independence and self-determination of the people with dementia. Therefore, also training for relatives which provide technological and non-technological coping strategies for their spouses getting lost are useful.

Their mentioned fears of unfamiliar routes and disorientation could be addressed with the help of the navigation assistant. The assistant should support the individual to maintain independence, promote mobility and, if necessary, inform the partner if help is needed.

Strengths and limitations

Qualitative approaches allow an in-depth examination of participants' daily mobility and reasons towards or against technology use which may apply to similarly characterized groups of people with dementia. Many challenges for modern technology use were pointed out which may be

overcome by individual training offers and long-term technological support.

Interviews offer the advantage of compensating for disease-specific symptoms by paraphrasing or clarifying specific questions. In qualitative research, the researcher is seen as an instrument (Patton, 2002). The quality of the interview guideline, depth of participants' answers, and valid interpretation of the data depend on the interviewers' experience.

The interview guideline was based on the TAM and mainly focused on technology use. In the future, the affinity for technology should be put more in the foreground, i.e. by using the recently published Affinity for Technology Interaction Scale (Franke et al., 2019). Since affinity for technology is not uniformly defined (Franke et al., 2019) a clarification of the term and an explanation to the interviewees is needed in future investigations.

To accommodate participants' special needs, interviews were conducted by dementia-educated interviewers, who strengthened the participants' self-confidence. The interview was adopted to the degree of participants' cognitive abilities. Showing participants options of a future device helped their understanding of the concept of a navigational assistance technology as well.

Social desirability bias can be increased through direct contact with researchers and the resulting temporary lack of anonymity. The interviewers tried to create a rapport during the interviews to ensure that participants feel comfortable answering honestly.

Triangulation by involving caregivers and other experts would be useful for further investigation and is already in progress. Also, an affinity for technology for people with dementia is poorly researched and should also be focused on in future investigations.

Acknowledgements

- First of all, the authors want to thank the participants, which were open to giving us a deep view of their private life, especially their mobility and use of technical devices. We also want to thank the professionals and the Memory Clinic for recruiting our interviewees.
- The research was funded by the German Federal Ministry of Education and Research (Project: SiNDeM-Situation-Aware Navigation Assistance for Dementia Patients using Causal Behavior Models, Funding reference number: 16SV7091) and in part by a grant from the European Union (EFRE) (Project: SAMi-Sensor-based individualized activity management system for people with dementia in nursing facilities, grant number: TBI-1-103-VBW-035).

IMPLICATIONS

On mobility behaviour

Despite participants' cognitive impairment, valuable results were obtained on mobility behaviour, on participants' experience with technology, and on their ideas regarding the equipment characteristics of a navigational assistive technology for external mobility in dementia. The interviewees named independent mobility as a basic need and felt that it was restricted by the disease.

On navigational assistive technology

Recommendations for navigational assistive technology for people with dementia, according to our participants:

Functional recommendations

- Built-in security features (e.g., emergency button or localization tools)
- Easy-to-read touch screen (large letters or symbols as well as sufficient brightness and antireflection coating)
- Individual programming of functions and displays (e.g., an app for public transport only for people who use bus/train/tram)

Design recommendations

- Inconspicuousness of the devices' design which is similar to mainstream devices (e.g., smartphone, a watch, or a necklace)
- Clearly structured display formats (e.g., clear symbols or easily structured menus)

Recommendations for training und technological support

- Intensive and regular examination of technological equipment (e.g., provide a permanent technological contact)
- Regular training with the integration of self-chosen compensation strategies
- Integration of the relatives in training and compensation strategies.

Research ethics and patient consent

- For this qualitative study, a positive ethics vote of the University Medical Centre Rostock (Nr.: A 2013-0072) had been obtained.

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Studie 2:

Matching values to technology: a value sensitive design approach to identify values and use cases of an assistive system for people with dementia in institutional care



Matching values to technology: a value sensitive design approach to identify values and use cases of an assistive system for people with dementia in institutional care

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Accepted: 22 June 2022
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Abstract

The number of people with dementia is increasing worldwide. At the same time, family and professional caregivers' resources are limited. A promising approach to relieve these carers' burden and assist people with dementia is assistive technology. In order to be useful and accepted, such technologies need to respect the values and needs of their intended users. We applied the value sensitive design approach to identify values and needs of patients with dementia and family and professional caregivers in respect to assistive technologies to assist people with dementia in institutionalized care. Based on semi-structured interviews of residents/patients with cognitive impairment, relatives, and healthcare professionals (10 each), we identified 44 values summarized by 18 core values. From these values, we created a values' network to demonstrate the interplay between the values. The core of this network was caring and empathy as most strongly interacting value. Furthermore, we found 36 needs for assistance belonging to the four action fields of activity, care, management/administration, and nursing. Based on these values and needs for assistance, we created possible use cases for assistive technologies in each of the identified four action fields. All these use cases already are technologically feasible today but are not currently being used in healthcare facilities. This underlines the need for development of value-based technologies to ensure not only technological feasibility but also acceptance and implementation of assistive technologies. Our results help balance conflicting values and provide concrete suggestions for how engineers and designers can incorporate values into assistive technologies.

Keywords Assistive technology · Delivery of health care · Self-help devices · User-centered design · Value sensitive design

Introduction

Dementia is a key risk factor for admission to nursing home facilities (Miller et al., 2011) and hospitals (Bickel et al., 2018; Sommerlad et al., 2019). In Germany, the shortage of medical staff increases as well as the number of medical treatments and patients with need for care (Brücher & Deufert, 2019). Consequently, unskilled workers or those with only a short training in nursing are working as nursing assistants in hospitals or nursing homes and take over basic nursing tasks such as dressing, body care, and cleaning up resident's or patient's room. In nursing home facilities, more than a half of the residents are living with dementia (Hoffmann et al., 2014). In hospitals, people with dementia are often challenged by an unfamiliar environment. People with dementia may exhibit challenging behaviors due to disorientation and confusion (Digby et al., 2017). This leads to high burden for patients and caregivers and increased demands on time for caregiving (Digby et al., 2017). Staff needs to

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provide surveillance and practical assistance and has to cope with challenging behaviors of patients with dementia (Lorenzo-López et al., 2017; Misplon et al., 2004). These increasing needs meet decreasing numbers of trained medical staff in many countries. Assistive technologies (ATs) have the potential to support people with dementia in their daily life and may be able to take over some routine care activities (e.g. food preparation and intake) from professional caregivers in nursing homes and hospitals (Astell et al., 2019; Hoening et al., 2003). Therefore, these technological solutions may help saving nursing care resources and maintaining person-centered care for people with dementia in institutionalized care.

“Zero effort technologies” (ZET) provide assistance with little need of active user input (Boger et al., 2018). They are particularly relevant for people with dementia who have limited ability to handle a technological device (Malinowsky et al., 2010). Additionally, ZET may be tuned towards delivering situation-aware assistance, i.e. only in automatically detected instances of need for help (Boger et al., 2018; Teipel et al., 2016). Thus, a situation-aware ZET device may help to maintain or even enhance the users’ autonomy and self-efficacy (Boger et al., 2018).

The process of technological development has to identify and integrate needs and values of future users in order to create useful and accepted technological solutions (Scherer & Craddock, 2002). User-centered development approaches such as value sensitive design (VSD) collect users’ needs and values systematically to integrate them into technology development (Friedman et al., 2008). Recently, research interest in values for the development of ATs for people with dementia has intensified (Dahl & Holbø, 2012; Ienca et al., 2018; Teipel et al., 2016). However, more proactive and patient-centered ATs for institutional care settings are needed (Koumakis et al., 2019). Our study aimed for collecting values and identifying use cases of an AT for and with people with cognitive impairment or dementia in institutionalized care using the VSD approach. The majority of studies listed values in the context of care as single items or pairs (Al-Banna, 2017; Ienca et al., 2018; McNeese-Smith & Crook, 2003; McWhinney, 1998; Rassin, 2008; Rider et al., 2014; Teipel et al., 2016; Toop, 1998; Zwetsloot et al.,

2013). Our study aimed at a comprehensive network of values as well as an in-depth investigation of their conflicting and reinforcing interplay. This interplay is important to balance possibly conflicting needs and values in regard to the development of AT (Ienca et al., 2018). From this network we created use cases for the integration of values into AT for people with dementia in institutional care (hospital or nursing home) in a user-centered way.

Method

Following the iterative VSD approach (Friedman et al., 2008), in the first phase, we identified the relevant stakeholders. In the second phase, we elicited values within a qualitative research approach. By semi-structured interviews with key stakeholders, we ascertained need for assistance, values, and potential use cases. In the third phase, we created technological use cases based on the results of the first and second phase. The implementation of a technological device covering these use cases will be part of subsequent research.

Identification of stakeholder groups

Following the first phase of the VSD approach, we identified the following three stakeholder groups based on the review of Richardson et al. (2019): people with cognitive impairment, their relatives, and healthcare professionals. Table 1 shows the inclusion criteria for each group.

Elicitation of stakeholders’ values and needs

Participants

We interviewed ten persons per group (in total 30 persons, see Table 2). All people with cognitive impairment received a mini mental status examination (MMSE) before the interview to check if they met the inclusion criteria. The majority of these people were in mild to moderate stages of dementia. The mean age of the people with

Table 1 Inclusion criteria for the three Stakeholder groups

People with cognitive impairment	Mini-mental-status-examination (15–29) and clinically documented diagnosis of mild cognitive impairment (MCI) or dementia Age \geq 65 years Resident in a nursing home and/or experiences with hospital admission within the past 2 years
Relatives	Related to a person living with dementia or MCI residing in a nursing home and/or experienced hospital admission within the past 2 years Degree of relation: spouse or son/daughter (in law)
Healthcare professionals	Experiences in the treatment of people with dementia in their work life Occupational groups working in medical care such as physicians, nurses, therapists, and related occupations

Table 2 Characterization of participants

Patients or residents living with dementia						
ID	Duration audi- ofile (hours)	Group of interviewees	Age (years)	Sex	Former occupation	MMSE
Inpat01	00:18:14	Inpatient	77	Female	No response	19
Inpa02	00:25:07	Inpatient	92	Female	No response	29
Inpa03	00:15:50	Inpatient	88	Female	No response	26
Res04	00:27:02	Resident	98	Female	Post office clerk	27
Res05	00:32:06	Resident	83	Female	Factory worker	15
Res06	00:14:31	Resident	98	Female	Foreign language correspondent	23
Res07	00:41:32	Resident	82	Female	Healthcare employees	22
Res08	00:42:46	Resident	78	Female	Sales woman and train conductor	26
Pat09	00:22:46	Former patient	69	Male	Engineer	27
Pat10	00:15:29	Former patient	79	Male	Bricklayer	22
Mean	00:25:32	5 residents/5 in-/former patients	84.4	2 male/8 female		23.6
Relatives						
ID	Duration audiofile (hours)	Group of interviewees	Age (years)	Sex	Former occupation	Employment status
Rel01	00:30:12	Child	64	Female	No response	employed
Rel 02	00:33:00	Spouse	76	Female	Physician	retired
Rel 03	00:33:08	Child	55	Male	Engineer	employed
Rel 04	00:38:14	Spouse	81	Female	Farmer (academic)	retired
Rel05	01:04:23	Spouse	84	Male	Medical professor	retired
Rel06	00:22:16	Child	56	Male	Managing director	employed
Rel07	01:16:18	Spouse	68	Female	Economist and rehabilitation manager	retired
Rel08	00:37:51	Spouse	71	Male	Engineer	retired
Rel09	01:13:51	Spouse	80	Female	Office clerk	retired
Rel10	01:05:52	Spouse	64	Female	Sales woman	retired
Mean:	00:47:30	7 spouses/3 children	69.9	4 male/6 female		7 retired/3 working
Healthcare professionals						
ID	Duration audiofile (hours)	Group of interviewees	Age (years)	Sex	Occupation	Work experience (years)
HcpHo01	00:21:55	Healthcare Hospital	26	Male	Nursing assistant	9
HcpHo02	00:18:06	Healthcare Hospital	39	Female	Nurse	19
HcpHo03	00:19:54	Healthcare Hospital	32	Female	Occupational therapist	12
HcpHo04	00:29:51	Healthcare Hospital	44	Female	Occupational therapist	19
HcpHo05	00:48:22	Healthcare Hospital	54	Female	Physiotherapist	24
HcpNh01	00:24:47	Healthcare Nursing Home	36	Female	Nurse	15
HcpNh02	00:12:43	Healthcare Nursing Home	33	Female	Nurse	17
HcpNh03	00:50:13	Healthcare Nursing Home	32	Male	Occupational therapist assistant	5
HcpNh04	00:46:35	Healthcare Nursing Home	56	Female	Occupational therapist	20
HcpNh05	00:35:52	Healthcare Nursing Home	36	Female	Nursing assistant	9
Mean	00:30:50	5 hospital/5 nursing home	38.8	2 male/8female	5 therapists/5 nurses (nursing assistants)	14.9

cognitive impairment was 84.4 years (range: 69–98) and the mean MMSE was 23.6 points (range: 15–29).

The relatives' group consists of seven spouses and three children with a mean age of 69.9 (range: 55–84) years. The healthcare professionals had on average 14.9 (range: 5–24) years of work experience and were 38.8 years (range: 26–56) old.

Creation of the interview guideline

Following the second phase of VSD, we created an interview guideline for each stakeholder group to focus on specific needs, perspectives, and roles.

Besides socio-demographic data, the interview guidelines covered three further categories (see Table 3).

Socio-demographic and personal data contained age, sex, recent or previous occupational activity, details of illness, and living or working situation.

Category 2 focused on daily routines, leisure activity, working routines, and need for help.

We asked the following questions to people with cognitive impairment:

1. How does your everyday life look like?
2. What do you like to do?
3. Do you need assistance in your everyday life?
 - (a) If yes, in which activities?
 - (b) If yes, who provides assistance?

Category 3 covered challenging behaviors (e.g., disorientation during hospitalization), coping strategies for these behaviors and their consequences. We asked people with cognitive impairment and their relatives about difficulties in unfamiliar environments during their stay in institutional care:

1. Where did you/your relative have to adjust the most?
2. What problems did the hospitalization/admission to the nursing home cause?

Category 4 concentrated on experiences with modern technologies, expectations from technologies as well as concrete situations of need, kind of assistance provided, and design ideas of a conceivable AT. The questions were based on the technology acceptance model (Davis, 1985) and technology usage inventory (Kothgassner et al., 2013) and aimed to identify predictors for technology use. We asked for previous experiences with novel technologies, resources, and obstacles during use and barriers to access for technology use as well as desired functions and design ideas for an AT. Due to the large amount of collected data in category 4, we concentrated on the evaluation of the categories *everyday living & need for assistance* and *behavior on inpatient admission*.

All questions were openly formulated and tried to avoid any suggestions. If applicable, questions were supplemented by further in-depth sub-questions.

Procedure

The recruitment took place in the memory clinic of the University Medical Center Rostock, in the geriatric ward of a regional hospital and in a nursing home. In addition, relatives were recruited by the network of the German Alzheimer's Association.

All participants or their legal representatives provided written informed consent. Interviewers ensured ongoing consent during questioning. The study was approved by the responsible ethics committee of the University Medical Center Rostock (A 2018–0109) and conducted in accordance with the Declaration of Helsinki (WMA, 2018).

Two female dementia-educated researchers (SK, DG) from the University Medical Center conducted the interviews in rooms of the institutions, in a patients' day care facility, or at relatives' home. All thirty interviews were audio taped, transcribed verbatim, and pseudonymized.

Analysis

The analysis was divided into two parts. First, we applied qualitative content analysis according to Mayring to analyze

Table 3 Main categories of the semi-structured interview guideline

Category	Domain	People with dementia	Relatives	Healthcare professionals
1	Socio-demographic data	Socio-demographic and personal data		
2	Daily activities	Daily living Need for assistance		Daily work
3	Behavior	Behavior on inpatient admission		Challenging behaviors
4	Characteristics of technology	Potential areas of application of technological assistance Design ideas Acceptance and adoption of technology		

the transcribed material in respect to the daily living/work, situations of need, and potential use cases for an AT (Mayring, 2000). Secondly, we identified values and their interplay in the categories of daily living/work of the stakeholders within a grounded theory approach. To achieve this, we interpreted the data following the logical analysis method (Patton, 2015).

In line with Mayring’s qualitative content analysis approach, we defined the evaluation units (all transcripts), context units (sense section/paragraph), and coding unit (individual words/word groups/sentences) (Mayring, 2014). After identifying the coding unit, we categorized and reduced it in three steps: paraphrasing the coding unit, generalizing the paraphrase and reducing the generalization (see Fig. 1 for an example) (Mayring, 2014).

The main categories were built from the interview guideline and deductively filled with coding units and their reduction, respectively. If necessary, coding units were assigned to multiple categories. Deductively built categories were supplemented stepwise during the evaluation process by inductively creating new sub-categories from the interview material (Mayring, 2000). A coding guideline served to ensure an unambiguous assignment to the categories (see Table 4).

Further, we conducted intra- and intercoder-reliability checks (Mayring, 2014). In sum, three researchers contributed to the research process: two drew up the interview guidelines and conducted the interviews (SK, DG). The same researchers analyzed the data together with a third researcher (AK) to perform the intercoder-check. Within a grounded theory approach, we inductively extracted values from the interviewees’ answers coded in the categories *everyday living & need for assistance*, *challenging behavior*, and *behavior on inpatient admission*. Further, we conducted an intercoder-check (DG) and compared our results to the literature.

In accord to the logical analysis method (Patton, 2015), we extracted the values’ relations to each other by crossing the quotations. Logical analysis is an interpretative method which visualizes patterns and cross-classification matrices (Patton, 2015). Therefore, the analyst moves iteratively through the material to find and validate his/her findings until he/she achieves meaningful patterns (Patton, 2015). Figure 2 illustrates the analysis process. Instead of a matrix, we created a values’ network from the derived relations.

We used the evaluation software MAXQDA 2018, release 18.2.4 (VERBI software, Consult. Sozialforschung GmbH,

Fig. 1 Process of reduction according to Mayring (2000, 2014), created with power user

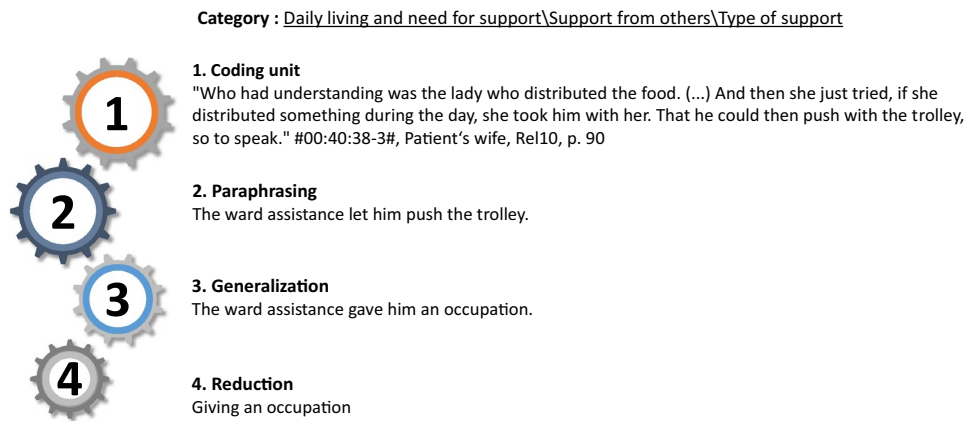
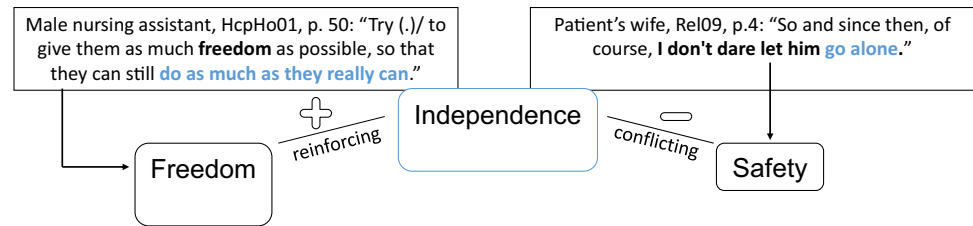


Table 4 Extract from the coding guideline

Main category: behavior during hospitalization/in nursing home
Sub-category 1
Behavior during stay\Problems with adaptation of people with cognitive impairment
Definition
Describes the adaptation to the unfamiliar environment from the perspective of the people with cognitive impairment or relatives
Anchor example
“Yeah, some things are different, for example it’s [the place] so small. It’s 2×4 m and I had a whole house.” Female participant, Res6 #00:04:07-4#
Coding rules
Barriers and difficulties due to admission as well as resources for a successful adaptation of people with cognitive impairment to unfamiliar environments are captured (e.g. multi-bedroom, day structure, lifestyle)

Fig. 2 Example for extracting reinforcing and conflicting connections between values using the logical analysis (Patton, 2015) approach



Berlin, Germany) and Microsoft Excel for data management and analysis (Please contact corresponding author to obtain supplementary materials, e.g. transcribed interviews or MAXQDA-data written in German).

Results

General data

In total we collected 17:19 h audio-material, ranging from 13 to 76 min for each participant.

In sum 4.228 codes were found in text material and assigned to 232 categories. The intracoder-reliability yielded 88.00 percent, the intercoder-reliability 83.72 percent for presence of the same codes in the document (evaluate unassigned codes as a match). We checked 23.30 percent of the interview material (7 Interviews).

Everyday living and need for assistance and potential action fields for an AT

In case of need, the persons living with dementia received assistance by a range of different caregivers. In the interviews, spouses, children, grandchildren, nieces, neighbors, colleagues, roommates, nursing service personnel, legal guardians, facility managers, ward assistance, and nurses were named as caregivers. Subsequently, we asked the participants, for which activities they needed assistance. The answers were summarized in four inductively built action fields: activity, management/administration, care, and nursing. These action fields were further divided according to the stakeholder groups (see Table 5). Table 5 broke down the widespread field of using AT in dementia care which was often only illustrated by few examples or generally as ADLs (Burmeister, 2016; Cahilla et al., 2007; Hoenig et al., 2003; Ienca et al., 2017).

Values associated with caring for people with dementia

In total we extracted 44 values from 167 extracts with an interpretative grounded theory approach. The quotes were screened by a second researcher (DG) and reached

concordance of 90.74 percent for identifying the same 44 values in the selected extracts. The interrater-team (SK, DG, AK) discussed values' translation from German (SK) into English and compared them to dementia and healthcare literature to ensure best possible translation. In result, we renamed some values, e.g. "charity" into "altruism", "openness" into "broadminded", and "integration" into "social inclusion". The literature check also pointed out that ten of our 44 values had not been reported before.

We structured the values according to the "analytic process for determining key design values" (Burmeister, 2016; Burmeister et al., 2011). In line with this process we searched for value categories and reduced them to themes. Finally, we defined key values within each theme (Burmeister, 2016; Burmeister et al., 2011). We identified key values by summarizing values which positively influenced each other or were semantically related with each other (see Table 6). After collecting the key values (further named as value/s), we analyzed their relationship. The majority of values was interacting, while some of them were not strongly related with others.

Figure 3 proposes a concept of a network of values derived from the interviewees' answers.

Caring & empathy was the most frequently connected value and built the core of the network. Besides many reinforcing connections, *caring & empathy* can contradict *autonomy* due to overprotection or admission to nursing home without consent in the context of *care* and *responsibility*. Also, *authenticity* can conflict with *caring & empathy* or *peace* because relatives lied to their relative living with dementia for example about the real circumstances [rehab instead of nursing home, (resident's wife, Rel07), p. 98] or they disguised their feelings [pretending to be happy to show strength, (resident's daughter, Rel01), p. 40] to avoid conflicts with their loved ones. The following extract shows how *justice* and *caring & empathy* are competing. The interviewee told us that she had many residents to care for but few residents demanded the majority of her time. If she wants to take care of these residents as they demand it, she would not be able to do justice to the other residents. This brings her into conflict with herself:

"So, it [the work] is always very focused on this one resident or on these two residents. That is often diffi-

Table 5 Need for assistance of people with dementia extracted from the interviews. Items named by all stakeholder groups are written in bold. Items in normal font were reported by only one or two stakeholders additionally labeled with Pwd (=people with dementia), Rel (relative), or Hcp (Healthcare professional)

Action field	Need for assistance
Activity	Activation/sports (Rel, Hcp) Assisting /initializing activity (puzzles, gaming, handcraft, music, celebrating, singing, dancing, and reading out) Bringing patient/resident visitors or things to the hospital/nursing home (such as visitors, the patient’s dog, or favorite things) (Rel) Practicing ways together (Rel) Conversation (including in low German)
Care	(Permanent) Accompaniment (meal, activity, toilet, or bed) (Rel, Hcp) Being a contact person Pushing someone with a wheelchair (Rel) Excursion/go for a walk (city, fair, dancing, café, group meetings for people with dementia) Interrupting wandering tendencies, searching for residents (Hcp) Mediating between nursing home and residents (Rel, Pwd) Picking up dropped things (Pwd) Promoting residents’/patients’ independence (Rel, Hcp) Supplying individualized or group-based interventions (Hcp) Keep company (incl. assistance settling in and explaining the new living-situation) (Rel, Pwd) Wayfinding outdoor (Rel)
Management/administration	Banking/dealing with authorities (Rel, Pwd) Cleaning up operations (reporting cleaning needs, house cleaning) (Hcp, Pwd) Dissolution or furnishing of the apartment (Rel, Pwd) Driving service (to emergency room, group care, physiotherapy, game afternoon) (Rel) Organization (appointments, treatments, nursing home places/moves/aids) (Rel, Hcp) Reminder (appointments, dates, drinking, washing) (Hcp) Shopping (Rel, Pwd) Taking over the correspondence (including making or assisting calls) (Rel, Pwd) Visiting a doctor (discussion of findings and medical treatments) (Rel, Pwd)
Nursing	At night: putting on fresh bed linen, dressing, waking up someone to getting him to toilet (Rel) Checking on residents (Hcp) Doing laundry Dressing (shoes, compression stockings) Food intake/processing (Rel, Pwd) Guiding at ADLs (verbal instruction) (Rel, Hcp) Help with medication intake (Rel, Hcp) Patient positioning and mobilization (Hcp) Personal hygiene Prepare items for clothing (Rel) Assisting healthcare professionals (Rel)

cult (...) to find a middle ground.” (female occupational therapist, HcpNh04, p. 30)

Privacy in institutional care can contradict *community*, especially due to roommates (resident’s wife, Rel04, p. 78) and disorientation of other residents (resident’s daughter, Rel01, p. 10). But also *caring & empathy* as well as *safety* encroaches on *privacy* due to nursing activities (female nurse, HcpNh01, p. 46) or *surveillance* (core value *safety*) (patient’s wife, Rel10, p. 50 & 66). *Adaptability* and *individuality* are limited through fixed *management* structures

(female occupational therapist, HcpNh04, p. 40 & female nursing assistant, HcpNh05 p. 48).

But *individuality* is also reinforced by *knowledge* as the following extract underlines:

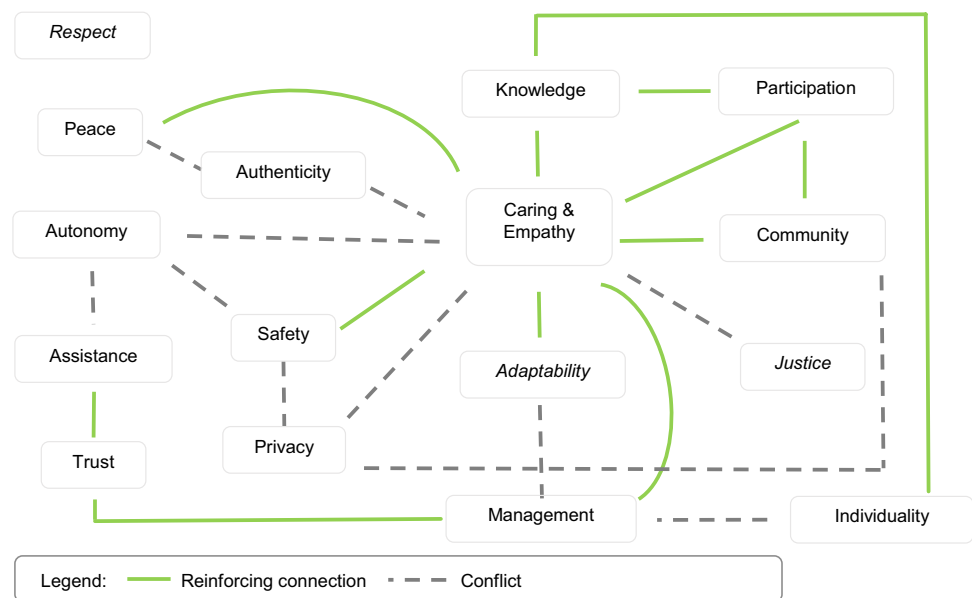
“Because every personality is different, you have to get to know people for a day or two to know how to deal with them.” (male nursing assistant, HcpHo01, p. 12).

Acting in accordance with these values is endangered by dementia symptoms, shortage of staff and time, and the infrastructure of institutional care. Challenging behavior (aggression, affective disorders), cognitive impairment

Table 6 Extracted values from all interviews and their assignment to core values. Values written in italics were not found in the literature (developed for these study)

<p>Adaptability Adaptability (Zwetsloot et al., 2013, p. 191)</p>	<p>Authenticity Authenticity and Honesty (Rassin, 2008, p. 619; Rider et al., 2014; Starr, 2008, p. 56)</p>
<p>Autonomy Autonomy, freedom, independence, autonomy in decision-making, and being useful/giving meaning to life (Al-Banna, 2017; Rider et al., 2014; Rassin, 2008, p. 619; Teipel et al., 2016, p. 697; van der Roest et al. 2007, p. 577; Zwetsloot et al., 2013, p. 191)</p>	<p>Caring and empathy Broadmindedness, empathy, tolerance/acceptance, <i>familiarity</i>, altruism, responsibility, patience/calm, <i>solicitude, and devotion</i> (Al-Banna, 2017; McNeese-Smith & Crook, 2003, p. 262; Rassin, 2008, p. 619–620; Rider et al., 2014; Toop, 1998; Zwetsloot et al., 2013, p. 192)</p>
<p>Community Community (Zwetsloot et al., 2013, p. 189)</p>	<p>Individuality Individuality, adapted care, and <i>tradition</i> (Al-Banna, 2017; Toop, 1998)</p>
<p>Justice/fairness Justice/fairness (Al-Banna, 2017; Bolmsjö et al., 2006, p. 345; Rider et al., 2014; Zwetsloot et al., 2013, p. 187)</p>	<p>Knowledge Knowledge, expertise/reflective practice, <i>understanding, and</i> personal development (Bolmsjö et al., 2006, p. 345; Rassin, 2008, p. 620; Toop, 1998; Zwetsloot et al., 2013, p. 193)</p>
<p>Management <i>Structure and continuity</i> (McNeese-Smith & Crook, 2003, p. 262)</p>	<p>Participation Social inclusion, integration, and participation (Ienca et al., 2018, p. 1047; Teipel et al., 2016, p. 697; Zwetsloot et al., 2013, p. 192)</p>
<p>Peace <i>Harmony, companionship, and contentment</i> (Rassin, 2008, p. 619)</p>	<p>Privacy Mature love and privacy (Ienca et al., 2018, p. 1041; Rassin, 2008, p. 620; Rider et al., 2014; Teipel et al., 2016, p. 697)</p>
<p>Respect Respect, <i>credibility, and</i> human dignity (Al-Banna, 2017; Rassin, 2008, p. 620; Zwetsloot et al., 2013, p. 192)</p>	<p>Safety Safety and surveillance (Rassin, 2008, p. 620; Teipel et al., 2016, p. 697; Zwetsloot et al., 2013, p. 187)</p>
<p>Assistance Assistance and cleanness (Rassin, 2008, p. 619; Zwetsloot et al., 2013, p. 193)</p>	<p>Trust Trust (Al-Banna, 2017; Rassin, 2008, p. 620; Rider et al., 2014; Toop, 1998; Teipel et al., 2016, p. 697)</p>

Fig. 3 Reinforcing and competing connections between the values derived from the interviews (developed for these study)



(disorientation, reduced sense for reality, memory decline), or neuropsychiatric symptoms (hallucination) lead to conflicts with *responsibility* (core value *caring & empathy*) and *self-efficacy* (core value *autonomy*):

“And then you think “yes”, you can do it. You can do it, as a doctor you have to manage to look after your own husband until the end of life, no matter when/. That is/the theory and in practice, it is completely different.” (resident’s wife, Rel02, p. 12).

Shortage of time and staff was named as challenging for practicing the values *continuity, trust, knowledge, responsibility, and self-efficacy*:

“(…) and now we get a lot of unskilled workers, always only assistants, so that tomorrow we don't even know who is responsible (.) for us or who is coming, that we sometimes have to wait a long time until someone comes.” (female resident, Res08, p. 76) or
 “We also have our workload, the other patients also want to be looked after, other things also have to be done. And we only have a certain amount of time available. And that then puts us under pressure.” (female physiotherapist, HcpHo05, p. 36).

Knowledge and *social inclusion* were endangered due to missing access to informative media in institutional care for inpatients or residents:

“We don't even know what's going on in the world. Every now and then we steal a newspaper so that we know whether the Federal Chancellor still exists.” (female resident, Res06, p. 113).

Additionally, *community* and *integration* are reduced due to “*coercive community*” (male occupational therapist assistant, HcpNh03, p. 30) and lack of *understanding* or *acceptance*:

“The integration of demented residents with non-demented residents, cognitively clear residents. I also find creating acceptance very difficult.” (female nurse, HcpNh02, p. 4).

Especially, *familiarity* gets lost due to admission to hospital or institutional care:

“I: Was that also a change factor? Female resident: Yes, at first yes. First of all, having meals, with strangers” (female resident, Res08, p. 86)
 “Yes, but they are in a completely new environment and if you imagine being torn out of, at home they could (...). These were processes that are stored in memory and everything is new in the hospital, whether it's the noises (...) And that scares them and then they become aggressive, not always, but they are scared.” (female physiotherapist, HcpHo05, p. 20)

These extracts show the vulnerability of values and how they are affected by dementia symptoms, shortage of staff, or/and admission to institutional care. Our results agree with the findings of an integrative review of (Digby et al., 2017) which point out the threat to values due to the conflict between time-consuming care of people with dementia and the need to finish caring tasks in time. The authors also show the stigmatization of people with dementia in institutional care expressed by less empathy, attention, and value-guided

care (Digby et al., 2017). Our interviewees reflected this stigma and showed empathy and understanding, but were bound by institutional guidelines and workload.

Derivation of use cases

In conclusion of the analysis of needs, of ideas from the stakeholders and the underlying values, we conceptualized four use cases for technological assistance. Due to the large amount of data, we created one use case for each of the four inductively found action fields expanding on everyday living and need for assistance (see Table 5).

In the first step, we created realistic use cases by filtering the situations and personal conditions that were described by the participants. Subsequently, we assigned the use cases to AT. In the third step, we identified the values that were touched by the use cases and the related AT. Hence, the following use cases represent a fusion of all stakeholder views, based on all analyzed categories.

From the stakeholders' perspective, the AT should mainly take the values *respect, adaptability, individuality, trust, and assistance* into account. *Respect* was understood as polite and calm communication which is adapted to the degree of impairment. *Adaptability* was understood as flexibility in interacting with the person concerned and adapting the assistance to the users' needs. This is strongly related to *individuality* which includes preferences, rituals, and daily structure. *Trust* should be realized by devices' reliability such as giving assistance if needed, being pervasive and always ready to use. *Assistance* was understood as giving useful and tailored assistance to the person of need. The following four figures show use cases derived from the interviewees' answers independently from feasibility and practicability criteria.

The first example covers sleep-disturbances at night (see Fig. 4). The resident or patient wakes up desoriented at night. The smartwatch on his/her wrist recognizes his/her awakening and his/her standing up. The smartwatch tells him/her the time and that it is time to sleep. Instead of lying down, the user starts walking so that the smartwatch infers -based on daily routines- that he/she needs to go to the toilet. It switches on nightlights and navigates him/her to the bathroom. Simultaneously, it informs the nurse who communicates by intercom with the patient/resident. Depending on the success of the communication he/she decides whether to check on him/her personally or not. In that way AT promotes *autonomy* and *safety* and support *privacy* to a large degree.

The second use case focusses on getting lost behavior (see Fig. 5).

The AT in this use case would promote the values *autonomy, participation, and safety*.

Example 3 illustrates the need for instructing ADLs due to impaired planning skills (see Fig. 6). Integrated fall

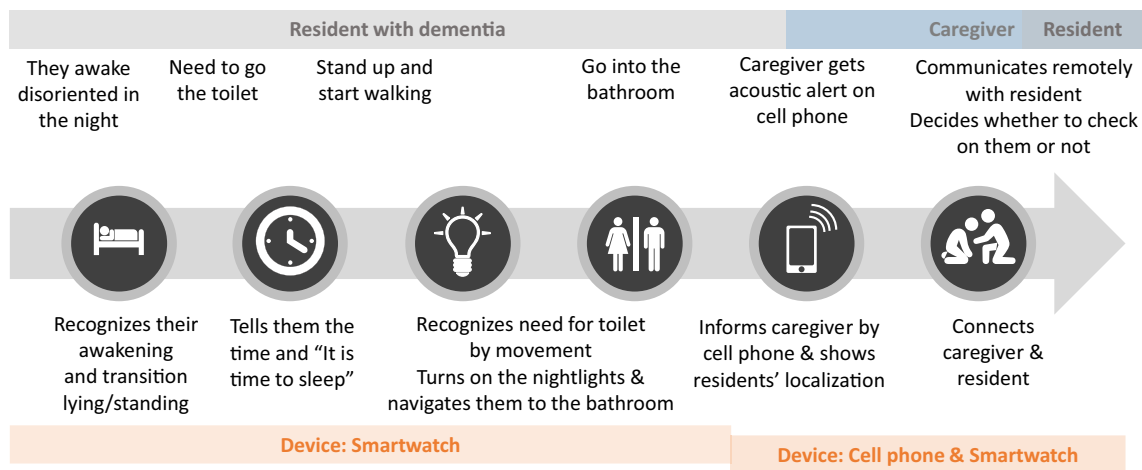


Fig. 4 Action field "Care": Flow diagram of an AT intervention providing accompaniment in case of sleep-disturbances (developed for these study with power user)

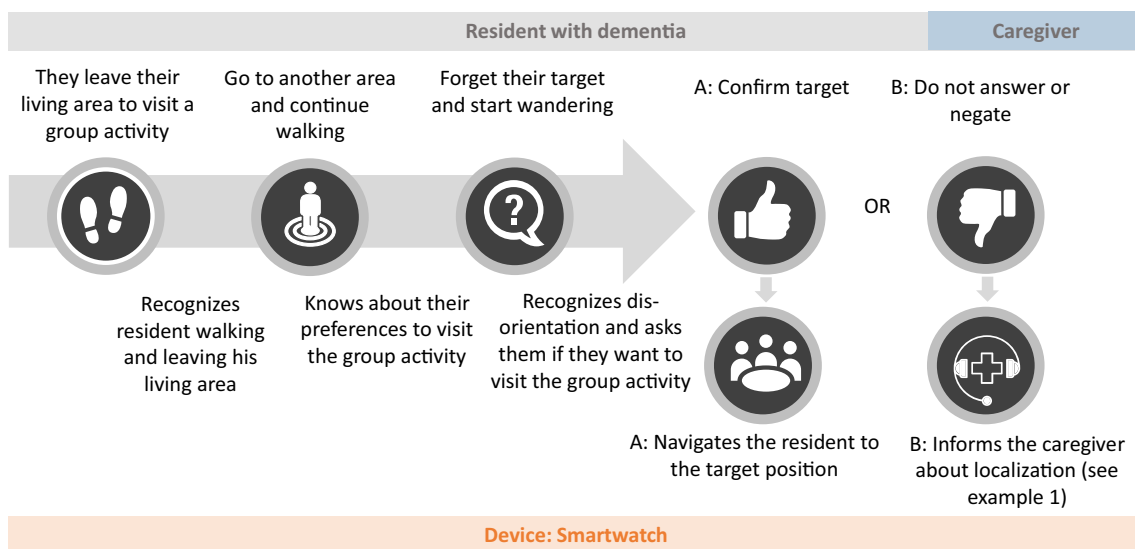


Fig. 5 Action field "Management": Flow diagram of an AT intervention in case of wandering tendencies and getting lost (developed for these study with power user)

detection would enhance *safety*. Other values promoted by this AT are *autonomy* and *privacy*.

The fourth example (see Fig. 7) takes the desire for activity and knowledge into account. This AT promotes *autonomy*, *community*, *participation*, *management*, and *knowledge*.

These examples of use cases show the widespread field of possible applications for AT. 14 of the 18 identified values were supported by or integrated in the presented AT. The values *peace*, *authenticity*, *caring & empathy* as well as *justice* are missing in our examples. Other use cases can be imagined that may address these values as

well. Although, values are context-sensitive (Burmeister, 2016; van Wynsberghe, 2013), our interviewees define the values *respect*, *adaptability*, *individuality*, *trust*, and *assistance* as fundamental for using ATs. Furthermore, our use cases underline the need for individuality and adoption to the user's current situation, which were also found in other studies (Boger et al., 2018; Cahilla et al., 2007). As different devices interact in our use cases, interoperability of technological solutions to deliver context sensitive and individual assistance needs to be ensured (Boger et al., 2018; Thorpe et al., 2016).

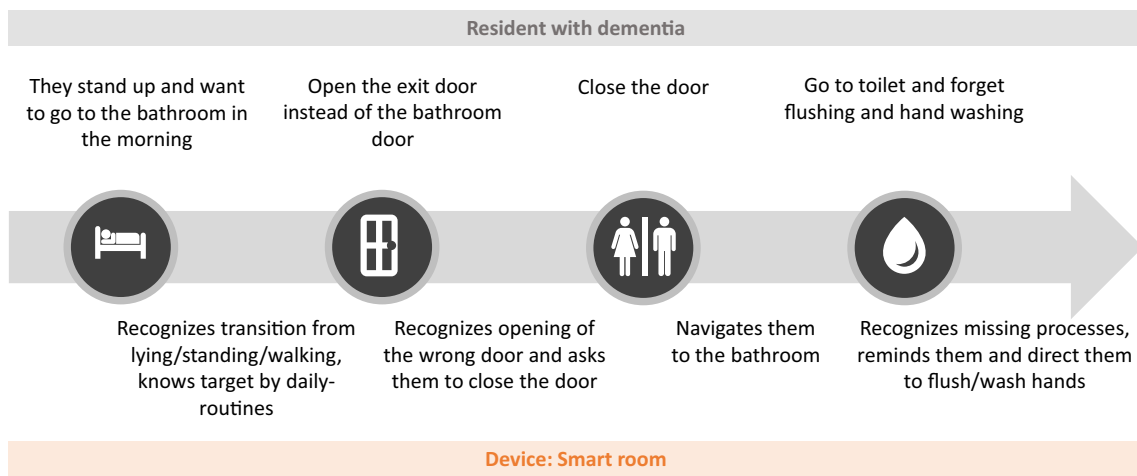


Fig. 6 Action field “Nursing”: Flow diagram of an AT intervention in case of impaired planning of ADLs (developed for these study with power user)

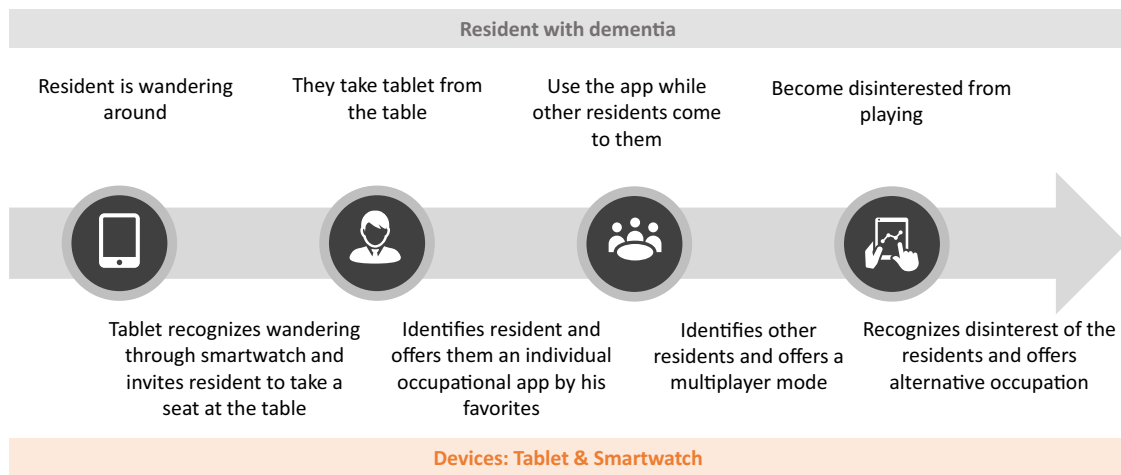


Fig. 7 Action field “Activity”: Flow diagram of an AT intervention to provide activity and knowledge (developed for these study with power user)

Discussion

Here, we identified values and needs of people with dementia, their family, and professional caregivers in institutionalized care. We constructed a value network from the reported values that allowed identifying both reinforcing and conflicting value interactions. On this basis, we constructed four use cases from the material provided by the stakeholders that illustrated how digital

ZET may promote values and contribute to resolving value conflicts.

Need for assistance

The stakeholders’ responses on need for assistance identified four action fields, including activity, care, management/administration, and nursing. The mentioned items in the action fields management/administration and nursing

agreed with the domains of the I-ADLs of Lawton and Brody which covered ability to use telephone, shopping, food preparation, housekeeping, laundry, mode of transportation, responsibility for own medication, and ability to handle finances (Lawton & Brody, 1969). Additionally, we identified caregiver needs concerning activity and care, such as conversation, being a contact person, assisting or initializing activities (e.g. puzzles, singing, handcraft), conflict mediation, and interrupting wandering tendencies or searching for residents. These results from the caregivers' perspective match the findings of a systematic review (Cadieux et al., 2013) and a cross-sectional survey (Miranda-Castillo et al., 2013) which identified from the patient perspective that daytime activities and company are the most frequently unmet needs of people with dementia. Current AT are mostly concentrated on assisting ADLs and house maintenance (Ienca et al., 2017; Lawton & Brody, 1969). If these technologies are well adapted to the needs of people with dementia, healthcare professionals and family caregivers could be relieved from routine tasks to provide socially salient support such as accompaniment, and social activities and interaction.

Values' network

We found a large range of values ($n = 44$) embedded in a complex system of interaction. Values play a guiding role in human interaction, health care, decision making, and in being authentic (Al-Banna, 2017; Rassin, 2008; Rider et al., 2014; Starr, 2008). According to our interviewees, conflicts between the identified values mostly emerged due to a lack of medical staff and its shortage of time, challenging behavior, and missing information.

Curse and blessing of management

Few conflicts were mapped in the values' network by the value *management*. On the one hand, *management* (*continuity* and *structure*) endangers *adaptability* and *individuality*. Our findings agree with findings in a previous study which reflected ethical problems in dementia care (Bolmsjö et al., 2006). This study identified organizational structures as obstacles for integrating values if routines prevail over individualized care (Bolmsjö et al., 2006). On the other hand, *management* leads to *trust*. As trust in nursing arises if someone behaves as expected (Hupcey et al., 2001), structure can give a framework for expectations. Further, continuity is necessary to build and maintain trust because trust in nursing is not transferable from one person to another (Hupcey et al., 2001). Regarding the development of an AT, *trust* and *management* should be incorporated by devices' reliability of functioning and well-structured procedures. Subsequently, adaptive assistance (*adaptability*) for the individual

needs (*individuality*) of the target group should be provided. Therefore, *knowledge* about daily routines, biography, and preferences of the person at need is necessary (Toop, 1998). Consequently, future AT in health care should be context sensitive and adaptive (Alirezaie et al., 2017).

Hazards for privacy, autonomy, and authenticity

Our values' network showed *privacy* (*privacy* and *mature love*), *autonomy* (*autonomy*, *freedom*, *independence*, *autonomy in decision-making*, and *being useful/giving meaning to life*), and *authenticity* (*authenticity* and *honesty*) as most endangered values. This endangerment arises from many conflicts, for instance with *caring & empathy* or *safety*, and a lack of supporting values. *Privacy*, *autonomy*, and *honesty* are central values in caregiving (Rassin, 2008; Rider et al., 2014) as reflected in the International Charta For Human Values In Healthcare (Rider et al., 2014). Nevertheless, our interviewees complained about difficulties in respecting these values in healthcare. Reasons were multi-bedrooms, challenging behavior and disorientation, nursing activities, prevention of conflicts, overprotecting, surveillance, or lack of consent of the people with dementia. In a previous study (Scerri et al., 2020), people with dementia in hospital were asked about their perceived needs. They also identified privacy as often unmet. Another need was being involved in decision making. An integrative review (Digby et al., 2017) which focused on the experiences of people with dementia and nurses in hospitals found that risk management by physical or chemical restraints was preferred to patients' dignity. Our data showed conflicts between *autonomy* and *safety* as well. Besides aspects of challenging behavior, our interviewees named infrastructural prerequisites and lack of staff as obstacles for acting in accordance with values. These results are similar to previous studies (Bolmsjö et al., 2006; Digby et al., 2017). Consequently, AT may be usefully employed if they leverage time and staff resources (Hoening et al., 2003) and free time for value oriented instead of routine-oriented care (Digby et al., 2017).

Bringing justice into care

Our interviewees reported problems in justice in care due to the different demands of residents with and without cognitive impairments. This leads to conflicts as other residents feel or are disadvantaged. An integrative review also described such conflicts of allocation based on time-consuming care and challenging behavior of people with dementia (Digby et al., 2017). However, cooperative people with dementia are endangered to receive less attention (Digby et al., 2017). In times of staff shortage, justice can be realised if basic needs of all residents/patients receive priority over less basic ones of individual residents/patients (Bolmsjö et al., 2006). But

this prioritisation endangers individual and need-oriented care (Digby et al., 2017). AT can undertake basic care tasks as assisting food preparation and delivery, leisure activities, in- and outdoor-mobility, toileting, and bathing (Astell et al., 2019; Hoenig et al., 2003; Ienca et al., 2017). Consequently, the use of AT reduces or solves conflicts of justice in care and lead to more need-oriented care and well-being of all parties involved.

In summary, our values' network underlined the complex relationships between values. Current literature on ethics and AT in healthcare presented values separately with little regard on conflicts or reinforcing connections (Al-Banna, 2017; Ienca et al., 2018; McNeese-Smith & Crook, 2003; Rassin, 2008; Rider et al., 2014; Teipel et al., 2016; Zwetsloot et al., 2013). Being aware of possible value conflicts and synergies will help in the creation of AT that avoid supporting one value at the cost of another. It also underscores that an individual user's values should drive the decision if a given AT should be used or not. Further, values' connection can be used for strengthening many values at the same time. For instance, if *knowledge* about preferences in daily activities will be increased, *participation* and in line with this *community* will also be promoted. These interplays can be used for enhancing benefit of AT.

Use cases

Technological feasibility

Our use cases showed scenarios for the application of AT addressing sleep-disturbances, getting lost behavior, instructions of ADLs, and activity. In the interviewees' opinions, AT should be aligned to give information, reduce possible value conflicts, and enhance self-efficacy by simple communication, localization, and individual assistance. In principle, all the use cases can be realized with currently available technologies such as detection of movements and body position by accelerometry (Fanchamps et al., 2018; Ge & Xu, 2014), ambient sensors like door-sensors or remote light switches (Alirezaie et al., 2017; Pirzada et al., 2018), indoor localization (van Haute et al., 2016), and remote communication. However, these technologies have not yet been implemented in institutional care facilities although they are technologically and in parts financially accessible (van Haute et al., 2016) and evaluated to be helpful by our interviewees. This points to a lack of specific adaptation of current technologies to the needs of the users. Currently, still an estimated 60 percent of AT are developed without an user-centered design approach (Ienca et al., 2018). Our data support the implementation of methods for participatory technology development following the VSD approach (Friedman et al., 2008).

Consideration of values

We identified privacy and autonomy as the most vulnerable values. Our use cases were based on personal data such as daily routines, localization, sensor data, personal preferences, and biography. A systematic review (Yusif et al., 2016) as well as several studies on values and AT reported concerns about privacy (Brewster & Dunlop, 2004; Dahl & Holbø, 2012; Ienca et al., 2018; Teipel et al., 2016). Privacy can be divided into personal privacy (being alone and unobserved) and data privacy (possibility to control own data) (Yusif et al., 2016). Providing adaptive and individual assistance requires access to data worth protecting. Therefore, the principle of data parsimony must be respected, i.e., collect only the minimally necessary data.

Autonomy is a driving value in our and previous studies (Ienca et al., 2018; Teipel et al., 2016) and people are even willing to exchange privacy for autonomy (Townsend et al., 2011). In contrast, autonomy is often restricted by safety (Scerri et al., 2020; Teipel et al., 2016). Consequently, providing autonomy should be an overarching goal of AT to justify restrictions of privacy. Automatic detection of endangering situations or need for personal assistance as shown in the first and second use case should be integrated in AT for ensuring safety and autonomy simultaneously. Additionally, little is known about the limits of the willingness to exchange privacy for autonomy. Future investigations should aim to identify user types and their individuality in need for privacy.

We found *peace* (*harmony, companionship, and contentment*), *authenticity, caring & empathy* (*broadminded, empathy, tolerance/acceptance, familiarity, altruism, responsibility, patience/calm, solicitude, and devotion*), and *justice* not covered by our use cases. *Authenticity* and *justice* were already discussed in the paragraph "**Bringing justice into care**". Furthermore, our results showed *caring & empathy* as most important value for our interviewees. Therefore, AT should be programmed on acting empathically and with care.

Strengths and limitations

Qualitative user surveys allow eliciting the users' perspective beyond limited predefined answer possibilities (Aspers & Corte, 2019; Patton, 2015). Qualitative surveys if conducted with an open mind have the potential not only to confirm already predefined answer options, but eventually to find different views on a topic (Patton, 2015). Here, we wanted to give the patients and caregivers a voice in how future technologies for assisting people with dementia should look like.

Our results demonstrated the ability of people with dementia to make valuable contributions to scientific research and underlined their expertise in expressing

their values, needs, and daily challenges. We linked their responses with those of healthcare professionals and relatives to validate the answers given by participants with dementia (Nygård, 2006). Although we consulted people with dementia in our project, involvement with decision power (Arnstein, 1969) of these people is missing. In future projects, we aim for a closer collaboration oriented on the needs and abilities of our target group.

The intercoder-reliability was high at different stages of the evaluation process. We applied a rule-guided, transparent evaluation method which we discussed and developed during the process of evaluation. Inductively built categories allowed us to gain further information across given categories. However, Mayring's content analysis is focused on the spoken words and neglects words' emphasis and non-verbal expression (Mayring, 2014). This may lead to incompleteness and different understanding during the reduction process although the intercoder-reliability was high. As the meaning of values differ between German and English, the translation could be improved by translating for- and backwards.

We showed a wide range of different values and emerging conflicts in nursing practice. Also, we proposed a concept of interactions of values. Due to the fact that values are very individual and depend on culture, society, and demographic data (Al-Banna, 2017; Rassin, 2008), our results must be understood as benchmark for other studies. Further, values in nursing are mostly investigated from the healthcare professionals view (Al-Banna, 2017; McNeese-Smith & Crook, 2003; McWhinney, 1998; Rassin, 2008; Rider et al., 2014; Toop, 1998; Zwetsloot et al., 2013). We presented a multi-perspective view on values without distinguishing between the stakeholder groups. Future investigations on values should aim on the values' prioritization for each stakeholder group to better understand which values are most important and to identify intersections. At least, these intersections should be integrated in technology.

Our results are mainly focused on the situation in hospitals and nursing homes. Therefore, transferability of our results to other care concepts (e.g., rehabilitation, daily care facilities or care at home) is unclear and requires further investigations.

Conclusion

Little is known about the interaction between values in the context of care. Our results provide a deeper understanding of values and use cases for AT from different stakeholders' views. Ienca et al. (2018) demand balancing conflicting values in the design of AT. Our network shows value chains in the literal sense which provides ideas on how negative impacts on values can be balanced. For example,

trust fosters management whereas *management* strengthens *caring and empathy*. *Caring and empathy* can balance the negative impact of *safety* on *privacy* and *autonomy*.

Our use cases, the values network and the needs for assistance in particular may help designers and engineers to tailor ATs to the users' needs and to enhance users' acceptance, perceived usefulness, and motivation to use (Boger et al., 2018; Cahilla et al., 2007; Ienca et al., 2018). Of course, this is just one example for such an approach that needs to be replicated and extended by future studies. Furthermore, we demonstrated a practical implementation of the value sensitive design in the context of institutional care. Our use cases demonstrated the need for interaction between different devices and sensors (for example, tablet, smartwatch, and/or smartphone each with integrated move and/or face recognition sensors) and access to multi-dimensional data (daily routines, sensor data, and biographic data). The need for interoperable devices emphasizes data security as well as the importance of compatibility between different (medical) devices and (medical) software (Iroju et al., 2013).

As existing technology seems unsuitable for the people with dementia in institutional care, researchers and engineers should continuously involve people with dementia and their caregivers in technology development. Thereby, VSD is a beneficial and realizable approach for iterative involvement of people with dementia and their stakeholders in technology development.

Acknowledgements First of all, the authors want to thank all participants for their open answers and for providing insight in their daily lives and personal values. We also want to thank our cooperating partners, especially the nursing home "Haus am Petersberg" of Diakoniewer Neues Ufer gGmbH and the SANA hospital Bad Doberan for recruiting our interviewees. Last but not least we thank Anna Gesine Temp for revising the English of the manuscript.

Author contributions All authors contributed to the study conception and design. Material preparation, data collection, and analysis were performed by SK, DG and AK. The first draft of the manuscript was written by SK and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Funding Open Access funding enabled and organized by Projekt DEAL. This work was supported by grants from the European Union (EFRE) [Grant Number: TBI-1-103-VBW-035]; the Federal Ministry of Education and Research (BMBF) [Grant Number: 01GP1901C]; and the European Union (ESF) [Grant Number: ESF/14-BM-A55-0021/19].

Data availability All transcribed interviews, MAXQDA-files, and the interview guidelines are available in German. Please contact corresponding author to obtain materials written in German.

Declarations

Conflict of interest Stefanie Köhler is a lecturer at the Europäischen Fachhochschule Rostock, Germany and for the German Alzheimer's Association, regional group Mecklenburg-Western Pomerania. An-

tonia Kowe is fellow of the program “Freies Wissen” by Wikimedia Deutschland. Doreen Görß declares to have no conflict of interest. Stefan Teipel has done the listed works below (all in Germany): MSD Sharp & Dohme GmbH, Lindenplatz 1, 85540 Haar: 11/09/2018—Quality circle for physicians in Kühlungsborn, Talk: “Dementia and Diabetes—current report”; 14/11/2018—MSD Expert-forum: NAB Alzheimer in Munich, participator as consultant & 13/08/2019—Event “Diabetes and Dementia” in Rostock, Talk: “Dementia and Diabetes—current report.” ROCHE Pharma AG, Emil-Barell-Str. 1, 79639 Grenzach-Wyhlen: 12/09/2019—3. Nationales Advisory-Board in Frankfurt am Main, participator as consultant & 27/09/2019—ROCHE Symposium at the DGN Congress in Stuttgart, Talk: “Amyloid as target for diagnosis and treatment in Alzheimer’s disease”. Biogen GmbH, Riederburger Straße 7, 81677 München: 23/04/2020—Biogen Advisory Board Session.

Ethical approval The study was approved by the responsible ethics committee of the University Medical Center Rostock (A 2018–0109) and conducted in accordance with the Declaration of Helsinki (WMA, 2018). All participants or their legal representatives provided written informed consent. Interviewers ensured ongoing consent during questioning.

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

Studie 3:

Ethics, design, and implementation criteria of digital assistive technologies for people with dementia from a multiple stakeholder perspective: a qualitative study

RESEARCH

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Ethics, design, and implementation criteria of digital assistive technologies for people with dementia from a multiple stakeholder perspective: a qualitative study

Stefanie Köhler^{1*} , Julia Perry⁴ , Olga A. Biernetzky¹, Thomas Kirste³ and Stefan J. Teipel^{1,2} 

Abstract

Background Dementia impairs the ability of people with dementia to be autonomous and independent. They need support from third parties, who should ideally respect their autonomy and independence as much as possible. Supporting people with dementia can be very burdensome for caregivers and numbers of patients increase while numbers of potential caregivers decline. Digital assistive technologies (DATs) that directly support patients or their caregivers may help bridging the increasing gap between need of support and available resources. DATs have the potential to preserve the autonomy and independence of people with dementia and promote their abilities, if they are properly designed in close interaction with future users. In our study, we focused on ethical concerns, technological requirements, and implementation criteria for DAT in general and specifically to support outdoor mobility of people with dementia.

Methods We applied a qualitative approach and conducted a World Café (2 tables, $n = 7$) and an online focus group ($n = 6$) with people with dementia, relatives, healthcare professionals, scientists, ethics experts, and experts for digitally-assisted medical care. We descriptively analyzed the data using a content analysis approach.

Results The participants reported technological (e.g., lack of Wi-Fi), financial (e.g., expensive devices or lack of budget for DATs), political (e.g., legal hurdles such as the European Medical Device Law or data protection regulations) as well as user-related hurdles (e.g., lack of digital competence) for the implementation of DAT in dementia care. Among the issues discussed were the importance of autonomy, independence, safety, privacy, and questions of decision making capacity in DAT's use. Participants identified opportunities and benefits in self-learning, situation-aware DATs and wished for dementia-friendly communities. They emphasized the value of personal interaction that should not be replaced, but rather supported by DAT.

Conclusion The results revealed multiple hurdles and ethical concerns for DAT use and provided recommendations for designing and implementing DATs. Further investigations are needed on the impact of DAT on personal interactions in caregiving and the role of DAT in dementia-friendly communities.

Keywords Dementia, Assistive technology, Ethics, Caregiving

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Introduction

Caring for people with dementia is not only emotionally and physically challenging, but also time consuming [1–4]. Worldwide, family caregivers of people with dementia spent about five hours a day providing domestic care [5]. People with dementia rely more often on institutional care compared to people of similar age who do not have dementia [6, 7], but shortage of medical staff increasingly hampers high quality and dementia-specific care [2, 8, 9]. Despite their need of care, people with dementia wish to maintain their independence and autonomy [10–12]. The dementia-related increase in dependence on support from others [9] stands in opposition to the wish for autonomy [12]. Coping with everyday life, such as shopping, visiting friends or a doctor, and participating in sports or cultural activities, is very important for the autonomy of people with dementia [11]. Furthermore, mobility is crucial for identity, well-being, and social connectedness [13]. As people with dementia often experience disorientation even in the early stage of the disease [14], the lived space decreases [13] while getting-lost events increase [15]. Furthermore, people with dementia reported to feel vulnerable and embarrassed in public spaces [13].

Digital assistive technology (DAT), such as smart home technologies, robots, smartphones e.g., with navigation app and GPS tracking, or digital games [16] could relieve formal and family caregivers and support people with dementia to maintain their autonomy and independence in general and mobility in particular [17]. We provided a definition of assistive technology (AT) in Text Box 1.

Text Box 1: Definition of Assistive Technologies and Ambient Assisted Living

The World Health Organization’s (WHO’s) Global Cooperation on Assistive Technology (GATE) defined assistive technology (AT) as “(.) the application of organized knowledge and skills related to assistive products, including systems and services” [18]. The WHO described “assistive products as devices, equipment, instruments or software from 6 functional domains: mobility, vision, hearing, communication, cognition and self-care. Examples of assistive products are physical products such as wheelchairs, spectacles and hearing aids, and digital products such as software and apps.” [19]. In our study, we focused on AT in the sense of digital assistive technologies. Ambient Assisted Living (AAL) encompasses the interaction of digital devices and includes activity recognition or the Internet of Things [20]. AAL aims to support people to live in their familiar environment by enhancing their independence, mobility, self-confidence, and autonomy by compensating or preventing cognitive or physical disabilities [21]. Hereby, social connectivity is an important part of AAL to prevent social isolation, increase safety, and involve healthcare providers and family caregivers in the care of (older) people with declining health [21]. Therefore, AT could play a crucial role in the aging-in-place paradigm, which allows people with dementia to live at home for longer rather than in institutional care. Although people with dementia often are the primary and direct users of DATs, they are often ignored in the development of AAL technologies and replaced by the involvement of secondary users such as relatives or healthcare professionals [20].

Technological support of people with dementia requires that DAT respects and supports the primary users’ needs and requirements [11, 22]. People with dementia and caregiving relatives perceived different values to be important for the use of DAT [23] which motivates the inclusion of people with dementia and their stakeholders into the design of DATs.

The user-centered design (UCD) enables to capture the needs and values of different users. UCD integrates the future users in designing DAT to enhance acceptance and usage of DAT [24]. The UCD process (see Fig. 1) includes identifying the context in which the technology will be

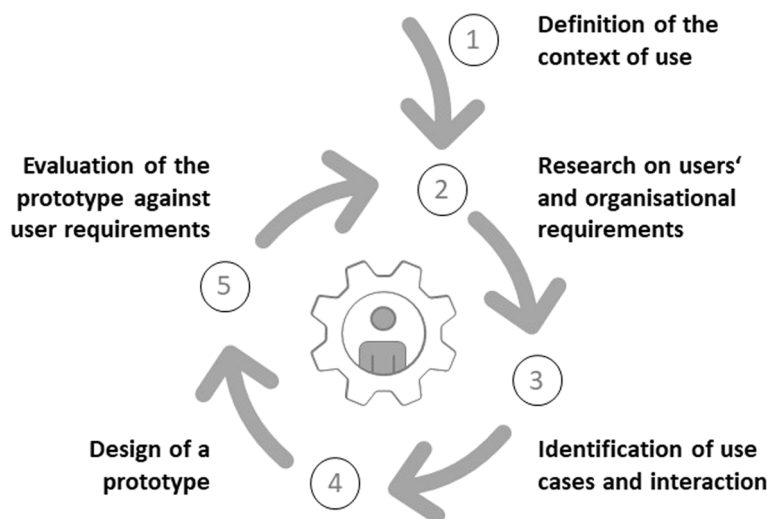


Fig. 1 User-centered design process (based on Bevan, [25] and Lubis et al., [26])

used, researching users' and organizational requirements, defining of use cases and the interaction between user and device, designing a prototype, and evaluating the prototype with future users [25, 26].

Besides technological requirements, such as design and functions, DAT should incorporate users' values [27] and undergo ethical reflections, especially in the context of medical care for people with dementia [28–30]. However, Diaz-Orueta, Hopper, and Konstantinidis [31] identified a lack of ethical consideration of researchers in working with people with dementia in the design process of DAT. Ethical recommendation for the use of AT exist e.g., from the Alzheimer's Societies of Canada and UK, from the Nuffield Council on Bioethics, and from the EU-funded research and development technology project "Assisting family Carers through the use of Telematics Interventions to meet Older persons' Needs (ACTION)" [32]. Still, the majority of AT (67%) have been developed without paying attention to ethical considerations [33]. The gap between theoretical discussion and actual involvement in technology development may indicate a greater need for interdisciplinary research projects to develop AT for people with dementia. The research questions developed for this study are based on our previous work [11]. We had investigated the affinity for technology and the needs of people with dementia regarding DAT to support outdoor mobility. In addition to needs and requirements for DAT, the study also revealed differences in mobility of people with dementia between rural and urban areas. Here, we present the discussion on DAT from a broader perspective due to the inclusion of dementia-, healthcare-, IT-, and ethics-experts following the first three steps of the UCD process.

Objectives

Our study explored the preferences and concerns of people with dementia and other stakeholders about the use and application of DAT in dementia care within a multidisciplinary approach. Additionally, we aimed to identify the participants' views on risks and chances associated with DAT. Participants discussed the following questions:

1. Which needs should DAT address to support people with dementia and healthcare in dementia?
2. Which application fields, needs, and benefits exist regarding DAT supporting mobility? What are limitations and hurdles?
3. How can DAT support outdoor mobility of people with dementia?
4. Which differences exist regarding outdoor mobility needs between urban and rural areas? Which chances and risks exist? Which general conditions must be fulfilled?

Methods

Recruitment

We recruited participants from previous research projects such as TaNDeM - German network for translational dementia care research [34], previous investigations as part of the EIDEC project-Ethical and Social Issues of Co-intelligent Sensory Dementia Care (EIDEC), and from the German Alzheimer's Association. Participants working at a university were recruited from the researchers' network. Our inclusion criteria included experts in dementia care, support, or research, either experts by experience or experts by profession. We invited in total 18 persons to join the World Café: persons from the regional Alzheimer's Association, experts in digital health applications, caregiving relatives of people with dementia, persons working in a nursing home, members of the State Senior Citizen Advisory Board (two each), three professors of health/nursing science or medical ethics, five scientists in dementia research or nursing science. Furthermore, we asked nine persons for participation in our online focus group: one person from the regional Alzheimer's Association, one employee of an institution for dementia support, one representative of a health insurance company, one caregiving relative, one scientist in dementia research, one consultant in the department of ageing, care and disability, one manager of a nursing home, and two people with dementia. We informed participants about the opportunity to participate by telephone or email. Participants rejected participation due to a lack of time (8) or acute illness (3). Three candidates did not respond to the invitation. In total, 13 participants joined the discussions (see Table 1). We planned the discussions for two different appointments with different stakeholders. We held one in-person discussion as a World Café and one focus group as a zoom online meeting. Our goal was to ensure diversity in terms of sex and (occupational) background when determining the composition of each group.

Procedure

Focus group discussions such as World Cafés or online discussions can give an overview about relevant themes from different perspectives [35]. The interaction and discussion between participants improves data quality [35]. Furthermore, focus group discussions enable to collect the perspective of many people in a time-effective way [35]. Therefore, we decided to implement these method in our study.

World Café

During the World Café, participants discussed questions 1 and 2 on needs, application fields, and benefits regarding DAT in healthcare and DAT in supporting mobility.

Table 1 Characterization of participants

Group (n = 13)	Sex	Background/Occupation
World Café table 1 (n = 4)	female	Expert in healthcare, Member of a regional Alzheimer's Association
	female	Quality manager at a nursing home
	male	Expert in ethics
	male	Member of the State Senior Citizen Advisory Board
World Café table 2 (n = 3)	female	Nursing manager at a nursing home
	female	Senior Strategy Manager for digitally-assisted medical care
	male	Male nurse and scientist for nursing science
Online focus group (n = 6)	female	Spouse of a person with dementia
	female	Employee in an institution for dementia support
	female	Scientist in dementia research
	male	Person with dementia
	male	Person with dementia, Member of an advisory board of people with dementia
	male	Manager of a nursing home

We prepared two different tables with a tablecloth made from flipchart paper. The questions to be discussed were visualized on the paper tablecloth to ease understanding and staying on topic. Furthermore, we invited our participants to independently document their ideas and arguments on paper. Two project members kept one protocol per table to document the results. Each table took 30 to 40 min for discussion and was moderated by one female researcher (O.A.B. & S.K.) with experience in participatory research. The moderators structured the discussion into the following points: greeting, introduction of the participants, presenting the question to be discussed, and if possible summarizing the results of the first discussion round. During discussion, moderators asked in-depth questions or clarified the correct understanding of participants' arguments and ideas. Furthermore, they ensured that everyone had the opportunity to contribute to the discussion. After a short break, participants but not the moderators changed tables.

Focus group

Due to the COVID-19-pandemic, we decided to keep the risk of infection for people with dementia low by offering an online focus group interview. In addition, our goal was to deepen and expand the results of the World Café in the online focus group. During the online focus group discussion, we concentrated on outdoor mobility (question 3 and 4) as this had not been discussed sufficiently before. One week before the discussion, we sent the results of the World Café to the participants of the online focus group. Providing the results in advance enabled participants to get used to the previous results and promoted in-depth discussion. Therefore, we summarized the results of the

World Café in an anonymized and easy to understand way. We planned 60 min for the online-meeting including 30 min for discussion. We structured the online focus group interview as follows: greeting, introduction of the participants, warm-up-question, discussion, summary of the discussion, and acknowledgement. Two project members wrote a protocol of the discussion. After obtaining consent, a video call recording completed the log. The moderator (S.K.) from the World Café led the focus group discussion.

Analysis

After discussions, participants and project members received the structured protocols. We asked them to validate the protocols and to give feedback if they had additions or disagreed with the content. They got two weeks to provide their feedback. In total, one participant and three project members gave feedback. One participant asked for deleting their quotations and for paraphrasing their comments. One participant of the online focus group communicated their interest in the topic after receiving the structured protocols for preparation. We analyzed, structured, and visualized the data from the protocols using a content analysis [35]. Content analysis enables a reduction of the volume of qualitative data by identifying patterns and themes in the material [35]. Patterns can be seen as umbrella term of categories or topics [35]. In our study, we inductively built patterns from paragraphs, word groups, or sentences in the protocols. After generating patterns, we deductively sorted themes to matching patterns. Themes describe the patterns in more detail and give context [35]. For example, the sentence: "Our participants worry when their loved ones

go outside alone in the dark.” leads to the theme “going out alone in the dark” which belongs to the pattern “concerns”. Here, we combined all responses from participants related to this pattern.

Results

We identified nine themes from the material: ethical values and DAT; acceptance of DAT; concerns regarding DAT; technological, administrative, and political hurdles in the usage of DAT; desires regarding DAT; user-related hurdles in the usage of DAT; use cases for DAT; facilitators for outdoor mobility; and differences in mobility and DAT between urban and rural areas. As only the online focus group discussion was recorded, we only cite quotations from the online focus group participants.

Ethical values and DAT

Participants discussed how the use of DAT impacts the values of autonomy, safety, social interaction, and privacy. They desired DAT that promoted autonomy and safety, associating autonomy with the independent management of daily life. Safety was mainly associated with physical integrity which is threatened by wandering tendencies, falls, and the inability to live at home. Participants feared a reduced autonomy if DATs took too many tasks away from people with dementia, resulting in a more rapid increase of cognitive impairment and dependence. They highlighted the need for a situation-aware assistance which only supports in cases of need and promotes abilities and activities. Situation-aware DAT should be ability- instead of deficit-oriented. However, users should be able to refuse DAT's support to prioritize autonomy over safety. In case of refusal of the support of DAT, participants raised the question as to who would turn off the DAT: The user with dementia or the DAT itself?

Participants further asked for whom safety should be provided by DAT: people with dementia or caregivers? One participant saw difficulties in using DAT to impede wandering tendencies as locating and door locking systems constitute deprivation of liberty and require a judicial decision. Further, participants raised the question of privacy and personal boundaries: Should DATs such as robots be programmed to touch people and if yes, how often, in which context, and on which part of the body?

DAT should support caregivers and “save time, which can be used for personal interaction”. Participants rejected the idea that DAT could substitute personal interaction. Participants emphasized that personally accompanying people with dementia to an appointment brings more ethical value than just ensuring that they arrive at the right place at the right time. Accompanying a person has a social and a medical value as caregivers can talk to the person in need and evaluate their health

condition. Therefore, they agreed to the use of DAT only if it saves time for additional personal interaction with the person in need.

For choosing a DAT for people with dementia, decision making strategies as nudging should be avoided as this would lead to an ethical dilemma. They defined nudging as discrete manipulation in decision-making such as positioning healthy food in the range of people's vision. Our participants feared manipulation and violation of autonomy and free choice of people with dementia due to nudging.

Acceptance of DAT

Participants of the World Café suggested to include people with dementia, caregiving relatives, and healthcare professionals in the development of DAT to increase the benefits and acceptance of DAT. For implementation of DAT, they also wished for integrating (nursing home) managers, IT managers of the institution, physical and occupational therapists, physicians, and product designers of digital devices. They suggested a collaboration among all professional groups from the beginning as prerequisite for a successful and need-oriented implementation of DAT. Participants of the online focus group preferred DAT as a common device which adapts automatically to the needs and resources of people with dementia:

“Well, what I want to say is: there's a bunch of stuff, the only problem is that those affected have different stages of the disease (...), but if the system is trained, then it works.” (Participant with dementia from the online focus group).

Gamification elements and incentives such as a massage, purring of an animal robot, or a visual feedback (e.g., interactive therapy balls) should be used to maintain motivation and acceptance and to leverage the reduced concentration span of people with dementia. At the same time, participants warned of technology being too human-like because people could be scared by that similarity. Participants felt that humanizing robots was problematic because people with dementia would not be able to distinguish between humans and robots.

People with dementia should get familiar with DATs in an early stage of their impairment to ensure DATs' acceptance in a later stage. To ensure acceptance, participants demanded an early analysis of users' needs within a home-based screening. The screening should take the diversity of dementia symptoms into account. In addition, DATs should take gender-specific preferences into account. The voice output of DAT should integrate female as well as male voices to allow for user preferences.

Participants perceived a higher acceptance of medical aids such as walkers in a nursing home than in public

because many patients use medical aids which leads to a kind of group membership. The personal and public view of medical aids should evolve from “medical devices to status symbols”. DATs would have the potential to be lifestyle-products which can be used confidently instead of stressing need for help.

Participants mentioned that dementia-specific DATs are needful and user-friendly, but also “insanely expensive” (participant from the online focus group). Further, they recommended adapting ordinary existing devices to the need of people with dementia instead of developing expensive specialized devices. Features, such as fall detection and sensors to measure vital signs, would enhance the benefit and implementation of DATs in institutional care. A connection to the institutional network and access to Wi-Fi or Bluetooth should realize data transmission.

Participants pointed out that apps and smart home systems are easily accessible, but would miss the reality of life of people with dementia:

“All that mobile phone and smartwatch stuff. That’s common practice. Anyone can buy that. For a few euros, ten or a hundred. (...) I’ve just noticed (...) that many of those affected now can’t do it for themselves. They don’t understand that at all.” (participant with dementia from the online focus group).

Missing the reality of people with dementia would lead to non-use or would overwhelm users.

Participants summarized that DAT should follow a holistic and need-oriented approach to be accepted and useful. DATs should support each person integrated in healthcare and provide the optimal benefit.

Concerns regarding DAT

Three participants worried about the use of robots in dementia care. They emphasized the importance of emotions in dealing and communicating with people with dementia which robots could not express or react on adequately. Participants noted that especially robots are perceived as strange or repulsive and are seen mostly as a toy than as an assistance.

Participants further expressed concerns regarding hygiene standards. One participant reported to not use the robot seal Paro [36] in her nursing home because its fur cannot be cleaned sufficiently or machine-washed.

Technological, administrative, and political hurdles in the usage of DAT

Participants discussed the lack of basic technological infrastructure in healthcare. A lack of Wi-Fi would impede the use of cloud-based DAT and online applications. Participants emphasized the importance of

interoperability between different DATs, including sensor-based DAT. They named “isolated solutions” as a problem in using DAT and asked for integrated solutions, such as having a scale automatically transfer the patient’s weight into the patient record. For data transmission fulfilling the national data security regulations, data security concepts are missing.

Besides technological hurdles, they named a lack of time to introduce new technologies in their daily work as a hurdle for using DAT.

Participants questioned if the German funding system is able to adopt novel technologies for the benefit of patients and caregivers. Questions of liability in the use of DAT in healthcare remain unclear. Funding of DATs is possible if they have an approval as medical device by law. The approval is expensive and time-consuming due to high administrative hurdles and need of proof of effectiveness. Companies would avoid approval and focus on other application fields which hampers technological innovations in healthcare. Participants criticized the limited budget for medical aids in institutional care and the missing financial resources for purchasing DATs. Participants hoped for facilitated approval of applications and reimbursement of medical devices by healthcare insurances due to changes in legislation such as the new regulation for digital nursing applications.

Needs regarding DAT

Participants identified a lack of transfer of technologies into healthcare practice. They wished for a better, immediate transfer and implementation of useful DAT into healthcare. A seemingly simple example was an intercom system. This would help prioritizing residents’ needs and saving caregivers’ time. Although such systems have been available for decades, they have rarely been used in nursing homes or other facilities.

Additionally, participants asked for an overview of existing and user-friendly DATs. Designers and scientists should focus on usability testing including the target group of the DAT. Furthermore, research should focus more on existing DATs regarding acceptance and usefulness rather than on developing further DATs which may not be used in the end. They discussed if a central institution is needed to evaluate and collect existing, digital health and care applications and make them available and visible for the public. They preferred a data bank to evaluate and collect applications. Additionally, they spoke out for interoperability between devices starting with uniform charging cables.

User-related hurdles in the usage of DAT

In general, participants stated a poor digital competence of people with dementia, relatives, and healthcare

professionals as a hurdle for the use of DAT. Some people might be overwhelmed by technology. They expected a generational change which will lead to more digital competency in (older) people. Participants identified their lack of knowledge about existing, useful technologies as a hurdle for usage of DAT.

In addition, impairment of hearing (for understanding audio instructions) and eyesight could hinder the use of DAT especially in older people.

Use cases for DAT

Participants had many different ideas of use cases and designs for DAT. Tablets should provide entertainment for people with dementia such as singing, dancing, and playing. Although participants were concerned about the use of robots, they discussed use cases for robots in dementia care. If robots were used, they should support activities of daily life and reduce or handle aggressive behavior due to emotion recognition. The participants discussed the use of robots in the context of institutional care. In institutional care, personalized, electronic keys with iris scan should help with saving privacy by enabling people with dementia only to enter common or their own rooms.

Furthermore, DAT should help with stabilizing the day-night-rhythm and should provide assistance in case of disorientation. Participants evaluated GPS-trackers in a smartwatch-design as useful to locate people with dementia if they get lost. The smartwatch should navigate people with dementia and support people with dementia in case of disorientation by calling contact persons and transmitting their location. One man with dementia stated a smart home system to be helpful outdoors for navigation and at home for checking the weather and reminding on appointments for instance. Besides navigational aid, one participant named an app as inexpensive substitute for home emergency call systems.

Support for outdoor mobility

Regarding outdoor mobility, participants agreed that preserving autonomy of people with dementia and keeping “what you have, for example living in a residential area, for as long as possible” (participant from the online focus group) were priorities. Participants spoke out against “dementia-villages” which are designed specifically for people with dementia, but would exclude them from society.

Increasing disorientation in a person with dementia could lead to getting lost and they might become confused by traffic. Therefore, participants wished for involving people from the environment of people with dementia and informing them about the need to support wayfinding: “that you [the baker, S.K.] simply say, here are

the rolls and remember, turn right over there” (participant from the online focus group).

Participants named reaching destinations within walking distance, implementing dementia-friendly architecture, e.g. providing urban guidance systems for people with dementia, or a good connection to public transport as supportive for mobility. In case of disorientation, people would prefer to ask passersby for directions or call a relative rather than use a technological device. Multiple persons could act as contact persons to ensure accessibility for people with dementia. Participants emphasized social interaction, especially communication, as essential for outdoor mobility of people with dementia. Rural areas have the advantage of short, familiar, and clear routes. Participants questioned the need of DAT supporting mobility in rural areas:

“The smaller the structures are, in a village where there is only one bakery, it is of course potentially easier for me to find my way around and I may not need the [DAT, S.K.] at all” (participant from the online focus group).

In case of disorientation, participants mentioned that DATs are not part of the coping strategy of people with dementia. Some participants questioned if DAT can support mobility of people with dementia. They felt that social interaction can better promote mobility than a DAT e.g., by accompaniment by relatives and friends, outdoor sports groups, or groups including people with different impairments:

“For example, I go out as a group. So two or three disabled people are walking around outside. They could also help each other.” (participant with dementia from the online focus group).

Differences in mobility and DAT between urban and rural areas

Participants noted major differences between urban and rural areas in terms of public transport and technological infrastructure. Internet connection and mobile data are often poor in rural areas so that DATs for outdoor mobility would have to fall back on GPS alone. Participants mentioned differences within rural areas and cities itself and recommended an individual consideration of each area or city. One participant with dementia named free Wi-Fi hotspots in the city as a useful guidance system to navigate from hotspot to hotspot. The hotspots’ names would help people to orientate and to navigate through the city.

In rural areas, participants described the use of public transport as difficult because of poor accessibility and outdated schedules. However, older people may not have

devices that have a mobile Wi-Fi option which hampers use of public transport. Participants explained that in some villages the bus schedule is not up to date. Without internet access, people would be unable to find out about current departure times. They proposed to identify real-world hurdles of technology use for people with dementia and solve them individually.

Discussion

In our study, different stakeholders, including people with dementia, their relatives, healthcare professionals, scientists, and IT specialists, discussed ideas of DAT; the needs, benefits as well as the hurdles for implementation of DAT in healthcare practice and support of people with dementia. We focused on DAT in general as well as on DAT to support outdoor mobility of people with dementia. Participants discussed values and preferences affected by the use of DAT, structural hurdles for implementing DAT, and requirements for DAT supporting people with dementia.

Ethical implications

Both discussion groups, the World Café and the online focus group, emphasized the importance of autonomy for people with dementia and the usefulness of DAT to maintain autonomy. Participants reported conflicts between privacy and safety. A systematic review showed that people are willing to trade privacy for autonomy [37]. Our participants recommended a situation-aware assistance to promote users' abilities when needed. This would also reduce the negative impact of safety on privacy. A systematic review [38] and a qualitative study [9] emphasized the importance of privacy for people with dementia. Unobtrusive sensors, such as GPS or fall sensors, may enable both promoting safety and saving privacy if they only transmit data in case of need to pre-selected persons. In addition, privacy is also a question of protection of personal and medical data. In particular, sensor data could facilitate the establishment of a long-term, location-independent data recording system that extends beyond the confines of scheduled medical appointments [39]. Therefore, we agree with the call of Schicktanz and Schweda [39] for developing practicable data protection concepts that also ensure the privacy of personal, relational, and topological data. The development of these concepts may require a rethinking of aspects of privacy [30].

With respect to autonomy, participants of the World Café (table 2) raised the question of who should be able to turn off the DAT if a person with dementia refuses it. A previous study showed that people with dementia prioritized the value of autonomy, whereas relatives focused on safety [23]. However, relatives mentioned 'surveillance'

as crucial, but it was not found in the quotes of people with dementia. In line with this, the scoping review of Sundgren, Stolt, and Suhonen [40] reported that relatives would prefer to coerce people with dementia to use an AT in favor of safety. Our participants from all discussion groups emphasized the importance of autonomy for people with dementia which is in contrast with the findings of Kowe et al. [23] and Sundren et al. [40]. Our participants from the World Café raised this question in regard to decision-making capacity and self-determination. Self-determination is a civil right in the United Nations Charter, Article 1 and 55 [41] and the International Covenant on Civil and Political Rights, Article 1 [42] of the United Nations. Both Alzheimer Europe and Kim et al. have synthesized ethical decision-making approaches to AT use, for example from the Nuffield Council on Bioethics, Bjerneby et al., and the American Speech-Language-Hearing Association flowchart [32, 43]. These approaches focus on a joint discussion of ethical dilemmas with each person effected by the use of AT. However, decision-making capacity is context- and situation-specific and fluctuates with the cognitive abilities of people with dementia. It is impaired at the latest stages of the disease [44]. Therefore, in cases of advanced dementia, decision-making capacity can become fluid and tied to specific situations [44]. For example, in case of disorientation, people with dementia experience anxiety and confusion [45] that may affect their ability to make decisions. Given the fluctuating decision-making capacity and disease progression, advance care planning is recommended [44, 46] even in regard to the use of DAT [47]. Advance care planning could also be applied to the use of DAT and help answering the question when to and who can turn off a DAT, also in moments of fear or confusion. However, advance planning assumes people know about the functionality of DAT and their own future situation [48]. Therefore, care advisors should be trained in specification and functionality of DATs to support decision-making and planning the use of DAT. Additionally, it remains unclear whether people would reject a need-oriented, situation-aware DAT if it is unobtrusive and activates only in the situation of need.

Again focusing on autonomy, our participants were critical of the use of technological door locking systems, as these were seen as methods of physical restraint. According to the German Civil Code (BGB), the use of physical restraints requires sufficient justification and a legal decision by the guardianship court [49].

Another discussion point focused on the concept of using gamification and providing incentives (for a definition of gamification and incentives see Text Box 2) or nudging to influence people's decision making in using DAT. Incentives are benefits that are independent from

the care process, such as promising patients to get their favourite food or sweets [50]. Elements of gamification are e.g., high score lists, social competition, unlockable content, and quests or goals [51]. Following the systematic review on gamification for older adults [51], gamification helps improving health related wellbeing, social interaction, motivation, and engagement. In line with this, a systematic review and meta-analysis [52] found that the use of incentives enhanced the adherence of people with dementia or MCI to exercise interventions. Both gamification and incentives might be useful to increase motivation and adherence in people with dementia and dementia care. Nudging is used in healthcare for instance to improve healthy behaviour (e.g. nutrition scores on food). According to Cohen, nudging in healthcare is a form of libertarian paternalism which facilitates an informed consent, preserving patient's autonomy [53]. As DATs often are complex and their functions difficult to understand, it remains unclear if informed consent can be obtained from people with dementia and their relatives [54]. In contrast to Cohen, our participants feared manipulation and violation of autonomy and free choice of people with dementia through incentives or nudging. These concerns are understandable as marketing interests, personal hardships, or organizational shortcomings of a care facility may lead to the deployment of such a technology without considering the need and well-being of the person with dementia [55]. Nudging and incentives influence decision-making in subtle ways [50, 55], which could help to increase acceptance of DAT by people with advanced dementia. But, the effectiveness of nudging for people with dementia who may have impaired abilities in decision-making remains doubtful [50]. In conclusion, the challenge of incentives or nudging to encourage the use of DAT lies in preserving free choice and avoiding manipulation. Regarding the use of DAT, nudging and incentives could be seen as soft aid in decision-making if default points have been clarified: Who decides which DAT is best for people with dementia? How can we ensure that the decision to use nudging is made in the patient's best interest and not for personal or economic reasons? Which incentives are effective and desirable for people with dementia? These questions should be addressed in future studies.

Text Box 2: Definition of Gamification and Incentive

The Oxford dictionary defines gamification as "the use of elements of game-playing in another activity, usually in order to make that activity more interesting" [56].

An incentive is a reward, an additional benefit which is independent of the primary caring goal e.g., a massage or a pleasing reaction of the DAT (purring, flashing, applause) [50, 57].

Design requirements and image change

As a result of the World Café discussion, we found that participants were undecided about how the DAT should be designed. In order to make the discussion about DATs more concrete and tangible, we focused on outdoor mobility advices for the online discussion. Here, participants seemed to prefer DATs integrated in familiar and portable devices such as a smartwatch for supporting outdoor mobility. Non-wearable devices like robots should only be applied in institutional care to avoid stigmatization. Our participants stated that a gender specific adaptation of the voice of the DAT to the different users would be helpful. This is in agreement with a previous interview study with 20 participants, ten caregiving relatives, and ten healthcare professionals where a socially assistive robot was tested [58]. Our participants highlighted the need for adapting the DAT to the demands of different target groups (people with dementia, family caregiver, or nurse). Also Wu et al. [58] described different needs of nurses and family caregivers regarding DAT. According to Wu and colleagues [58], family caregivers focused more on social aspects of the robot such as accompaniment whereas healthcare professionals emphasized assistive aspects to relief them from workload. Additionally, our participants from all discussion groups discussed different hardware devices for a DAT. While the World Café participants discussed DAT, such as robots, fall detection mats, intercoms, and belts, the focus group participants focused mainly on wearables, such as smartphones or smartwatches. This need for flexibility and variability of features and design underlines the findings of previous studies arguing for highly customizable, personalized DATs to increase the uptake of DATs in healthcare [11, 58, 59]. As a result of our study, we suggest a modular system of different supporting and monitoring opportunities which can be selected in accordance to the user's needs. This system should run on different devices and be compatible with the usual operating systems such as Android or IOS.

Our participants felt that the image of assisting or supporting devices should change in the future. Currently, from their perspective, assisting devices indicate the need for help. This result stands in line with a systematic review [60] focusing on acceptability and usability of technology in people with cognitive impairment. The authors identified fear of stigmatization as a reason for people with cognitive impairment to not use assistive technology [60]. The authors suggested devices which reflect the user's identity [60]. In contrast, our participants preferred a mainstream market approach to an individualistic one. They wished that the image of DAT should change so that they are seen more as a life-style-product than as help for the helpless. This suggestion

might be comparable to the use of prescription glasses. Some years ago, prescription glasses were unstylish, pragmatically designed visual aids which transformed to fashion accessories even for people without visual impairment. DAT has the potential to be a medical aid with life-style-product character if design, healthcare, and technology experts design DAT collaboratively and integrate future users.

Structural hurdles for DATs' implementation

The panels identified hurdles to implementing DAT in healthcare practice due to restrictive laws and lack of funding or technological infrastructure. A position paper on assistive technology policy also stated rigid legislative requirements can hamper innovations and investigations due to time and cost intensive processes. [61]. Astell and colleagues [16] raised questions of funding since common devices (e.g., smartphones) miss the classification as medical device and reimbursement by the public healthcare system. In Europe, in particular in Germany, strict regulations of the national German and European Medical Device Law [62] and General Data Protection Regulations [63] are relevant for DAT systems in healthcare. Medical device law aims to protect users from harm, but it also leads to high cost for certification [64]. In addition, companies need to provide detailed information about their technology and go through a time-consuming process which could be a barrier to certification, especially for start-ups. For more details on the certification process see Text Box 3. Our participants reflected this double role of legislation and regulatory requirements both as protection and hurdle for technology use which agrees with the results of Mac Lachlan and colleagues [61]. It was beyond the scope of the panels to discuss concrete changes in legislation or novel technologies that would meet regulatory requirements at affordable costs.

Text Box 3: Additional information on the medical device certification process

In the European Economic Area, a medical device must be CE certified by the DQS med institute in order to be placed on the market [64]. Therefore, the DQS med institute requires a comprehensive application form with a detailed description on the technical documentation, the intended proposal, the risk classification, and the quality management system of the medical device [64]. Once the application has passed the initial review process, the DQS med will provide a cost estimate. Costs vary depending on, for example, the size of the company, the number of unannounced or announced audits or travel activities, with hourly rates for certification staff ranging from €300 to €600 per hour [64]. The certification process can take up to five years [64]. After successful certification, annual unannounced audits take place to ensure the quality of the medical device [64].

Participants identified the fact that the financing system for long-term care neglects investments in digitalization as a major hurdle. In nursing homes, investment

costs that exceed the state subsidy are covered by contributions of the residents [65]. In Germany, the contribution amounts to 2,610 Euros on average [66]. On average, old-age pensioners receive 1,168 Euros [67] which is insufficient to cover the contribution in nursing homes. Therefore, nursing home managers may try to keep investment costs low at the expense of digitalization. As a result, even long standing technologies such as intercoms are missing in nursing homes, although participants identified them as very useful. A qualitative study from Sweden, focusing on digital healthcare communication revealed an improvement of care due to digital communication [68]. The participants recommended a mix of physical and digital communication to realize sufficient interaction with the patient [68].

Our participants regretted that the robotic seal PARO was not used in their nursing home. PARO's fur is only antibacterial, but cannot be machine washed [36, 69]. As a result, the robot seal does not meet German hygiene standards for nursing homes [70]. Reviews found significant positive effects of PARO use on quality of life, affect, and social interaction [71, 72]. No studies from Germany could be found which supports the participant's statement that PARO cannot be used in German nursing homes. This dilemma between possible benefits of PARO versus the potential risk of infection, highlights the value and need to involve users in the development of technologies to design marketable products.

In rural areas, the technological infrastructure is insufficient to support the use of web-based DATs. Our findings agree with the position papers from the first global research, innovation, and education on assistive technology (GREAT) on assistive technology policy and assistive technology products which identified rural areas as problem areas for access to DAT [18, 61]. Consistently, the position paper promotes different digital solutions not only for different users, but also for geographical locations [18]. In our view, a digitalization initiative by politicians, municipalities, future users, computer engineers, and healthcare managers is needed to bring healthcare up to the state of the art and provide patient-centered healthcare. In line with this, strengthening the digital competency of healthcare professionals and family caregivers should be taken into account from managers and politicians as well as the expansion of the technological infrastructure. Furthermore, interoperability between different systems and devices should be ensured in favor of devices' compatibility and ease of use.

Dementia-friendly communities instead of DAT

Besides DATs' support, our participants saw wayfinding of people with dementia as general task for the society. They suggested that society as a whole (e.g., the

baker) should be aware of disoriented people and be a contact person in case of need for help. Social responsibility, social inclusion and participation, remaining in one's own living environment, sufficient technological infrastructure, and easy access to public transportation are conditions of dementia-friendly communities [73]. Dementia-friendly communities enable people with dementia to remain in their living environment by integrating, supporting, and promoting them [73]. In dementia-friendly communities, people with dementia, their families, organizations, and politicians cooperate to make the community aware of the social and occupational needs and rights of people with dementia by providing education, guidelines, and common activities [73]. However, in the literature of shaping dementia-friendly communities DATs play no or only a negative part [10, 73–76]. For instance, Shannon, Bail, and Neville [75] argue that online-based service applications such as self-checkout systems in libraries can confuse older people and prevent them from participating. For our participants, there seemed to be only one either-or perspective regarding the use of DAT as a navigational aid. In general, they were in favor of social interaction and dementia-friendly architecture and against the use of DAT. Our study revealed that the participants did not consider the possibility of combining both dimensions of support, technological and personal. However, combining physical and technological support might be useful as several reviews showed the benefit of DAT for people with dementia and their relatives [16, 77]. One illustrative example was provided by a participant with dementia from the online focus group. He proposed the use of Wi-Fi hotspots as an indicator of the life space zone. A DAT could assist the users by informing them when they leave a zone. In the event of disorientation, the DAT could provide a navigation aid with augmented reality, such as the live view in the Google Maps app. During navigation through the smartphone display, preset, well-known landmarks could be highlighted to assist the users in regaining their orientation. Dementia-friendly architecture and technical infrastructure could provide the hotspots as well as prominent landmarks. Therefore, we strongly recommend the integration of DAT as beneficial contributor to dementia-friendly communities.

Strengths and limitations

A strength of our study lies in the multi-perspective view on ethical considerations and requirements for DAT for people with dementia. As people with dementia are often overlooked as stakeholders in AT [61], we provided a framework for discussion in which people with dementia and their relatives could participate on an equal footing and without stigma.

Another strength of our study is the transparent and participatory feedback process. By immediately taking notes of what was said, either on the paper tablecloth or on a digital whiteboard, we ensured congruence between what was said and what was documented. We sent the transcripts to the participants so they had the opportunity to comment. We received feedback from one participant. In the future, we will encourage our participants more intensively and collect feedback more actively, for example by telephone.

The results may be limited because the concept of mobility was very narrowly defined by our World Café participants (mobility as ability to walk independently). We have learned that for broad topics, the terms should be defined at the beginning and the moderator should more actively direct the discussion to other aspects, e.g. outdoor mobility. Although the World Café mainly covered the walking ability and indoor mobility, the results are transferable to other applications as well e.g., regarding the design of DAT and concrete use cases. To minimize this limitation, we discussed outdoor mobility separately in the online focus group as it is also an important aspect of mobility.

Participants discussed hurdles and problems regarding the implementation of DAT, but did not suggest opportunities and solutions. Typical limitations of focus group discussions arise due to insufficient speaking time per participant [35]. Focus groups can give an overview about relevant themes, but lack an in-depth or micro discussion [35]. The identified hurdles may be discussed in workshops to reveal solutions. Some discussed points, for example, political hurdles, focused on national law, are only applicable to the European Union.

In qualitative research, the moderator plays a central role in engaging interviewees to share their perspectives and feelings [35, 78]. It is inevitable that the moderator will influence the interview by bringing his or her character, skills, knowledge, and expectations into the moderation [78]. As we needed two moderators for the World Café discussion, moderator effects may have occurred [35]. In order to minimize this bias, both moderators discussed about difficulties and good practices in moderating a group discussion prior to the event.

Our results may also be limited by the time allowed for discussion. Our discussion took 30 to 40 min, but the participants could have gone beyond that. Following Patton [35], we recommend an extension to at least 60 min since this can lead to a deeper discussion and increase the space for follow-up questions. The time extension should be adapted to the concentration capacity of people with dementia.

Another limitation was the low recruitment rate. Unfortunately, three potential participants of the World

Café discussion fell ill with COVID-19 at short notice, so we were unable to recruit additional participants. We also had to keep the number of participants low in order to reduce the risk of COVID-19 infection during the pandemic. Nevertheless, our number of participants is in line with Patton's [35] recommendations regarding focus group discussions. Patton [35] recommends six to ten participants per group. In addition, other studies involving stakeholders and people with dementia have reported similar numbers of participants [79, 80]. Qualitative research does not claim to be representative. The added value of qualitative research lies in uncovering opinions, understanding processes and contexts, and in comparing and discussing different points of view [35]. Our study was able to achieve these aims despite the small number of participants.

Conclusions

Our investigation gave in-depth insights into ethical concerns and requirements for DAT supporting people with dementia from multiple perspectives. Participants discussed autonomy, independence, decision making capacity, and decision-making strategies, such as nudging or incentives, as well as structural, political, and financial hurdles in implementing DAT in healthcare and supporting mobility. The design requirements were individual, but all participants agreed that DAT must adapt to the user not the user to the DAT. In summary, our study provides concrete ethical and technological requirements for the development of DAT.

Our participants valued interpersonal interaction and social responsibility very highly. They highlighted the importance of interpersonal interaction and worried that DAT could reduce human interaction. Therefore, future studies should examine how the implementation of AT influences the interaction of people with dementia, their caregivers, and their environment. Identifying and talking about these concerns with the future users is necessary to gain acceptance for DAT. Designers and researchers in the field of DAT should implement participatory design methods such as user-centered design to develop marketable and beneficial DATs incorporating users' needs and values. In the same line, concepts for dementia-friendly communities integrating DAT solutions must be developed.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12910-024-01080-6>.

Supplementary Material 1- Moderation table 1.

Supplementary Material 2- Moderation table 2.

Supplementary Material 3- Online focus group guideline.

Acknowledgements

The authors thank all participants for their time and the vivid discussion. We also want to thank our cooperating partners, the Faculty of Informatics and Electrical Engineering, for providing the rooms for the stakeholder conference. The World Café discussion was embedded in a stakeholder conference. Therefore, we thank our team from the EIDEC-project and all guests for participating and playing active parts at the stakeholder conference. Last but not least, our thanks goes to the German Alzheimer's Association for supporting recruitment of our participants.

Authors' contributions

S.K. and J.P. organized the stakeholder conference and the online focus group. S.K., J.P., O.A.B., T.K., and S.J.T. took part at the stakeholder conference. O.A.B. moderated one table of the World Café. S.K. moderated one table of the World Café and the online focus group while J.P. documented the results of both events. S.K. analyzed the protocols and wrote the manuscript. J.P., O.A.B., T.K., and S.J.T. reviewed the paper and gave substantial input on content and speech. S.J.T. supervised the study. All authors read and approved the final manuscript.

Funding

Open Access funding enabled and organized by Projekt DEAL. This work was supported by grants from the Federal Ministry of Education and Research (BMBF) [EIDEC, Grant Number: 01GP1901C, and TesiComp, Grant Number: 01GP2216A] and the European Union (EFRE) [SAMi, Grant Number: TBI-1-103-VBW-035]. The funding body played no role in the design of the study and collection, analysis, interpretation of data, and in writing the manuscript.

Availability of data and materials

The protocols generated during and/or analyzed during the current study are available in English language from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

All methods were performed in accordance with the Declaration of Helsinki [81] and the recommendation of Alzheimer Europe on involving people with dementia in research [82]. Furthermore, we received ethical approval from the local Ethics Committee of the University Medical Center Rostock (A 2022 – 0199). In agreement with the recommendation of Alzheimer Europe [82], all participants gave their informed consent independently in an oral or written way. Besides the informed consent, we ensured ongoing consent before and during the discussion. We informed the participants that participation was voluntary and written data would be pseudonymised. Additionally, we made data inaccessible to third parties. The participation was free of risk, all participants were able to consent independently and only few sociodemographic data (background, occupation, sex) were collected. Therefore, we obtained informed, oral consent from our participants. In agreement with the Declaration of Helsinki [81], we ensured ongoing consent of our participants during the discussion.

Consent for publication

Not applicable.

Competing interests

Stefan J. Teipel received advisory board fees from Roche, Eisai, Biogen, Grifols, and Biogen outside the submitted work. The other authors declare to not have conflicts of interest directly or indirectly related to the content of the work. Financial or non-financial interests. The authors have no relevant financial or non-financial interests to disclose.

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Received: 25 May 2023 Accepted: 4 July 2024
Published online: 27 July 2024

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