Aus dem Institut für Medizinische Informationsverarbeitung, Biometrie und Epidemiologie (IBE) der
Ludwig-Maximilians-Universität München

Vorstand: Prof. Dr. Ulrich Mansmann

Der Einfluss von Gelenkkontrakturen auf die Funktionsfähigkeit und die soziale Teilhabe von älteren Menschen – Entwicklung eines Standard Sets auf Basis der Internationalen Klassifikation für Funktionsfähigkeit, Behinderung und Gesundheit (ICF) der WHO

Dissertation
zum Erwerb des Doktorgrades der Humanbiologie
an der Medizinischen Fakultät der
Ludwig-Maximilians-Universität zu München

vorgelegt von

Herrn Uli Fischer

aus Haag in Oberbayern
im Jahr 2015

Mit Genehmigung der Medizinischen Fakultät
der Universität München

Berichterstatter:	Prof. Dr. Eva Grill, MPH
Mitberichterstatter:	Priv. Doz. Dr. Susanne Mayer Prof. Dr. Ralf Zimmer
Mitbetreuung durch den promovierten Mitarbeiter:	Dr. Martin Müller, MPH
Dekan:	Prof. Dr. med. Dr. h.c. M. Reiser, FACR, FRCR
Tag der mündlichen Prüfung:	17.04.2015

1 Einleitung und Hintergrund

1.1 Gelenkkontrakturen als relevantes Symptom in der medizinisch-pflegerischen Versorgung

Die Epidemiologie von Gelenkkontrakturen

Die freie Beweglichkeit der Gelenke des menschlichen Körpers ist eine unbedingte Voraussetzung für Mobilität und stellt somit eine der wichtigsten Grundbedingungen für viele Alltagsaktivitäten dar. Körperliche und psychische Einschränkungen des vollen Bewegungsumfangs eines Gelenks, des sogenannten *range of motion (ROM)*, durch physische Deformationen von Gliedern oder Schmerzen bei der Bewegung sind bei älteren Menschen sehr häufig [1]. Derartige Einschränkungen in der Gelenkbeweglichkeit verschiedener Kausalitäten werden mangels präziserer Definitionen unter dem Begriff Gelenkkontrakturen subsumiert [2, 3]. Die wenigen vorhandenen epidemiologischen Studien geben Prävalenzen von Kontrakturen bei älteren Menschen von 25% [4] bis zu 80% [5-7] an. Diese breite Streuung an Prävalenzschätzungen ergibt sich aus der uneinheitlichen Definition des Kontrakturenbegriffs [3], aus den verschiedenen Ein- bzw. Ausschlusskriterien, aus den unterschiedlichen Methoden der Datenerhebung und letztlich auch aus den Charakteristika der Teilnehmerinnen und Teilnehmer der einzelnen Studien [8].

Insgesamt werden Gelenkkontrakturen in pflegeintensiven Kontexten, wie beispielsweise der ambulanten und stationären Altenpflege oder in geriatrischen Kliniken, stets als ein sehr umfassendes und hinsichtlich der ökonomischen Ressourcenfrage relevantes Problemfeld dargestellt, was durch aktuelle Studien bestätigt wird [9-11].

Risikofaktoren für Gelenkkontrakturen

Als Hauptrisikofaktor für die Entwicklung einer Gelenkkontraktur gelten Unbeweglichkeit oder fehlende Mobilität auf Grund einer akuten Erkrankung oder Verletzung [12]. Eine Verminderung der Muskelmasse oder der Muskelkraft, ein schlechter körperlicher Trainings- oder Allgemeinzustand, Schmerzen oder kognitive Einschränkungen wurden als weitere mögliche Hochrisikofaktoren identifiziert [7, 13].

Hinsichtlich der Auswirkungen wird häufig zwischen Kontrakturen der oberen und unteren Extremitäten unterschieden. Während Kontrakturen in den Gelenken der oberen Extremitäten, wie beispielsweise in Schulter, Ellenbogen, Handgelenk oder Fingern dazu führen, dass Aktivitäten des alltäglichen Lebens wie Essen, Trinken, sich Kleiden oder sich selbst pflegen nicht mehr selbstständig ausgeführt werden können, erhöhen Kontrakturen der unteren Extremitäten, zum Beispiel in Hüfte, Knie oder Sprunggelenk, das Risiko von Bewegungsarmut und Stürzen und führen somit zu einem insgesamt höheren Risiko für Schmerzen, Immobilität und Bettlägerigkeit. Letztlich können alle diese Aspekte zu einer Erhöhung des Pflegebedarfs der Betroffenen führen [8, 14].

Trotz dieser starken Relevanz sind Gelenkkontrakturen und vor allem deren Auswirkungen auf Aktivitäten und Teilhabe ein kaum erforschtes und kaum untersuchtes Problemfeld innerhalb der medizinischen und pflegerischen Wissenschaften. Eine mögliche Erklärung hierfür ist die facettenreiche, heterogene und keinesfalls immer eindeutige Ätiologie von Gelenkkontrakturen, welche durch eine Vielzahl von alterstypischen Begleiterkrankungen konfundiert wird und eine klare Zuordnung von Ursache zu Wirkung häufig schwierig oder unmöglich macht. Gerade bei älteren Menschen sind die Ursachen für Gelenkseinschränkungen oft sehr vielschichtig und deren Auswirkung eben nicht immer eindeutig zuordenbar.

Kontrakturenassessment

In den USA ist die Entwicklung von Gelenkkontrakturen in Pflegeheimen seit vielen Jahren ein etablierter Indikator für pflegerische Versorgungsqualität. Dieser wird routinemäßig in Einrichtungen der stationären Altenhilfe erhoben [1, 15]. Auch in Deutschland benutzt man verschiedene Beurteilungsinstrumente zur Bestimmung des individuellen Kontrakturenrisikos von Patientinnen und Patienten bzw. Bewohnerinnen und Bewohnern [16]. Der Gebrauch von verschiedenen, uneinheitlichen und nicht validierten Kontrakturenassessments muss in diesem Zusammenhang kritisch gesehen werden, da eine wissenschaftliche Beurteilung dieser Instrumente bislang fehlt, sich methodisch schwierig gestaltet und hinsichtlich der Zielgruppe auch anzunehmen ist, dass es unterschiedliche „Normalbewegungsumfänge“ geben müsste [3].

Neben dem Erwerb von Gelenkkontrakturen zählt die regelmäßige Durchführung verschiedener Kontrakturpräventionsmaßnahmen durch qualifiziertes Fachpersonal ebenfalls zu den standardmäßig erhobenen Qualitätsindikatoren im ambulanten und stationären Pflegebereich, obwohl über die Wirksamkeit von einigen dieser Maßnahmen kein Konsens besteht [10, 11, 13]. Im Bereich der stationären Altenhilfe sind Träger entsprechender Einrichtungen durch die §§114ff. SGB XI verpflichtet, bei Bewohnerinnen und Bewohnern regelmäßig eine Bewertung des Kontrakturenrisikos durchzuführen und Kontrakturpräventionsmaßnahmen anzubieten [17], welche durch den Medizinischen Dienst der Krankenkassen (MDK) oder die Fachstelle für Qualität in der Altenpflege (FQA), ehemals Heimaufsicht, überprüft werden.

Auf Grund des Fehlens eines einheitlichen Beurteilungsinstruments werden von den Pflegekräften Gelenkkontrakturen häufig lediglich nach der aktiven oder passiven Gelenksbeweglichkeit entsprechend dem ROM beurteilt und die Behandlungsstrategien gemäß dieser Assessments ausgewählt bzw. angepasst, obwohl, wie bereits oben berichtet, keine definierten „Normalbewegungsumfänge“ existieren und daher Normdeviationen nicht festgestellt werden können [3].

Aus Patienten- und Versorgungssicht ist es somit unklar, wieso eine ressourcenintensive, systematische Kontrakturenerfassung und –bewertung überhaupt stattfinden soll, solange einerseits der Zusammenhang zwischen Gelenkkontrakturen und deren Auswirkung auf die

Funktionsfähigkeit der betroffenen Patienten nicht umfassend erforscht wurde und andererseits die Beurteilung der Kontrakturerkrankungen kaum Konsequenzen für die Therapieauswahl hat. Die bislang eingesetzte, funktionsfokussierte Beurteilung von Gelenkkontrakturen kann somit nur anteilsmäßig dazu beitragen, umfassendere patientenorientierte Indikatoren zur Bewertung von Behandlungsergebnissen, wie beispielsweise die Steigerung oder der Erhalt der Lebensqualität, die Teilnahme am Alltagsleben oder soziale Partizipation zu explorieren und zu beurteilen.

Problemstellung

Auf welche Aspekte von Funktionsfähigkeit, Aktivität und Partizipation Gelenkkontrakturen bei betroffenen Patientinnen und Patienten bzw. bei betroffenen Bewohnerinnen und Bewohnern den größten Einfluss haben, darüber gibt die aktuelle wissenschaftliche Literatur keinen Aufschluss [3, 18]. Eine gute pflegerische und medizinische Versorgung zeichnet sich jedoch gerade durch eine patienten-orientierte Therapie aus. Um zukünftig gezielte Behandlungsstrategien auswählen bzw. entwickeln zu können, mussten daher im Rahmen dieser Arbeit zunächst verlässliche Daten über die spezifischen Krankheitsbelastungen von Patientinnen und Patienten bzw. Bewohnerinnen und Bewohnern mit Gelenkkontrakturen in den Dimensionen Funktionsfähigkeit, Aktivität und Partizipation, sowie diesbezüglich förderliche bzw. hemmende Umweltfaktoren klar identifiziert und auch quantifiziert werden.

Für die umfassende Beurteilung des Einflusses von Gelenkkontrakturen war es notwendig, die Perspektiven aller an der Behandlung beteiligten Gesundheitsprofessionen, wie auch die Perspektive der Betroffenen miteinzubeziehen [19]. Um diese komplexen Untersuchungen aus den verschiedenen Perspektiven durchführen zu können, benötigt man ein umfassendes und professionsübergreifendes theoretisches Modell. Durch die Einführung der *Internationalen Klassifikation für Funktionsfähigkeit, Behinderung und Gesundheit (ICF)* der *Word Health Organisation (WHO)* im Jahre 2001 ist ein Rahmenmodell geschaffen worden, um eine solche transprofessionelle Untersuchung durchführen zu können. Der Aufbau der ICF, das bio-psycho-soziale Funktionsfähigkeitsmodell als konzeptuelle und sinnstiftende Basis der ICF, sowie deren Taxonomie werden im nun folgenden Kapitel näher erläutert.

1.2 Die Internationale Klassifikation der Funktionsfähigkeit, Behinderung und Gesundheit (ICF) als Rahmenmodell

Die *Internationale Klassifikation der Funktionsfähigkeit, Behinderung und Gesundheit (ICF)* [20] ist neben der *Internationalen statistischen Klassifikation der Krankheiten und verwandter Gesundheitsprobleme (ICD)* die wohl bekannteste und meistverwendete Klassifikation der Weltgesundheitsorganisation (WHO). Beide Klassifikationen sind für verschiedene Anwendungen im Gesundheitsbereich konzipiert.

Während Gesundheitsprobleme, wie beispielsweise akute und chronische Krankheiten, Gesundheitsstörungen, Verletzungen oder Traumata in der ICD klassifiziert werden, beschreibt die ICF die mit dem jeweiligen Gesundheitsproblem assoziierte Funktionsfähigkeit bzw. Behinderung [20].

Das Ziel der ICF ist es, in einheitlicher und standardisierter Form eine universelle Sprache, eine einheitliche Taxonomie und damit einen für alle Professionen verbindlichen Rahmen zur Beschreibung und Beurteilung von Gesundheitszuständen zur Verfügung zu stellen, um die Kommunikation über die gesundheitliche Versorgung zwischen den Gesundheitsdisziplinen, den entsprechenden Wissenschaften und den Betroffenen zu verbessern.

Das bio-psycho-soziale Modell der ICF

Das bio-psycho-soziale Modell von Funktionsfähigkeit und Behinderung bildet die geistige Basis der ICF (siehe Abbildung 1). Es liefert den theoretischen Rahmen zur Anwendung dieser Klassifikation [20]. Das Modell integriert zwei unterschiedliche Modelle zur Beschreibung von Funktionsfähigkeit und Behinderung; das medizinische und das soziale Modell.

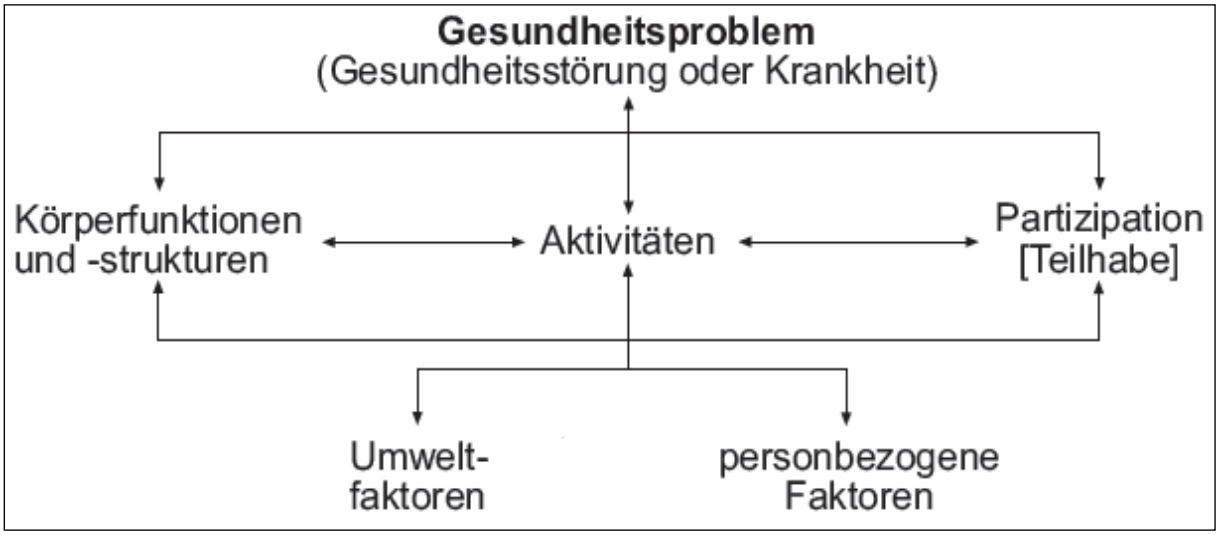


Abbildung 1 - Das bio-psycho-soziale Modell der ICF [20]

Das medizinische Modell betrachtet Behinderung im Sinne einer eingeschränkten Funktionsfähigkeit, die durch eine Erkrankung, einen Unfall oder ein Trauma verursacht wurde. Die Behinderung in Folge der zugrunde liegenden Erkrankung wird allein dem jeweiligen Individuum zugeschrieben. Die Behandlung einer Behinderung nach dem medizinischem Modell zielt auf spezielle medizinische, pflegerische oder therapeutische Versorgung oder auf eine Verhaltensänderung der betroffenen Person ab, welche für die Kuration, Rehabilitation oder den Erhalt des Status-quo notwendig ist.

Das soziale Modell sieht Behinderung als die Folge von gesellschaftlichen (Rahmen-) Bedingungen und somit nicht als immanent personenbezogenes Merkmal. Der Umfang einer Behinderung oder das Ausmaß von Beeinträchtigung ist abhängig von der Integration bzw. Inklusion der betroffenen Person in die Gesellschaft und der durch sie bereitgestellten Res-

sourcen. Der Umgang mit Behinderung und das Überwinden von Behinderung erfordert nach dem sozialen Modell gesamtgesellschaftliches Handeln. Es ist notwendig die gesellschaftlichen Bedingungen so zu gestalten, dass die soziale Integration der betroffenen Person gewährleistet wird. Bommes und Scherr [21] führen hierzu nicht nur die Schaffung positiver Inklusionsbedingungen, sondern auch Exklusionsvermeidung als originär gesellschaftliche Aufgabe an.

Bewertend kann festgestellt werden, dass die beiden Modelle singulär für sich jeweils einen sehr monodirektionalen Aspekt von Behinderung beschreiben und damit den ganzheitlichen Blickwinkel außer Acht lassen [22]. Die Synthese aus medizinischem und sozialem Modell in das bio-psycho-soziale Modell vereinigt die Vorteile der beiden Einzelmodelle und ermöglicht so einen umfassenderen Blick auf die Funktionsfähigkeit und Behinderung eines Menschen in seiner jeweiligen, individuellen Situation (siehe Abbildung 2).

Diese Integration der beiden Modelle führte zu einem Paradigmenwechsel in der Betrachtungsweise und der Beurteilung von Behinderung, da sich das neue Modell nicht mehr vorwiegend defizit-orientiert darstellt, sondern auch eine Adaption an die Ressourcen des betroffenen Menschen ermöglicht.

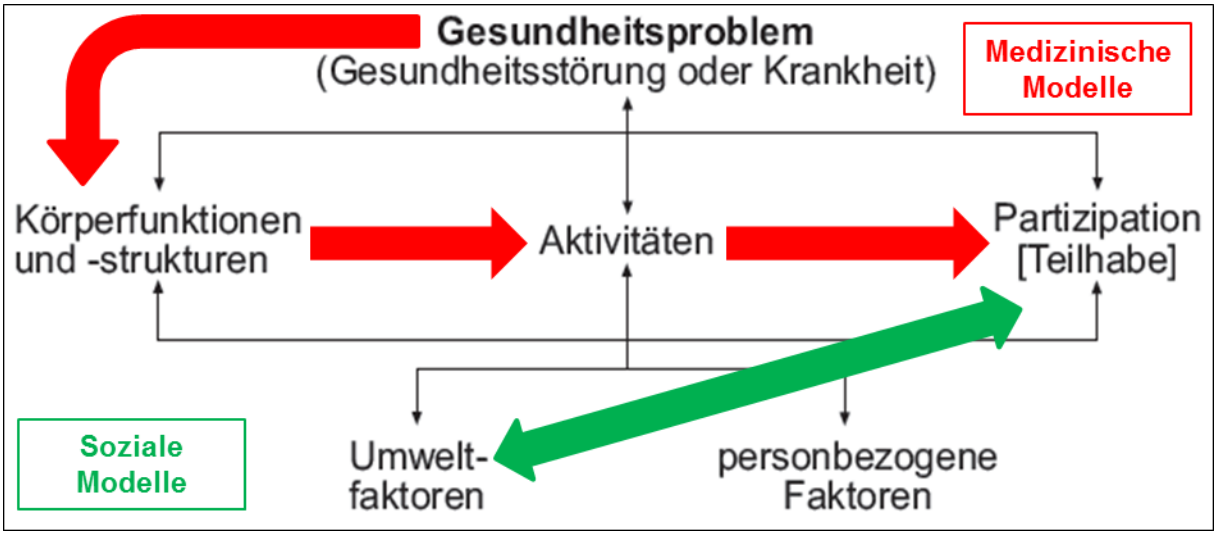


Abbildung 2 – Elemente des medizinischen und des sozialen Modells im bio-psycho-sozialen Modell der ICF

Die ICF ist damit weniger eine Klassifikation der *Folgen von Krankheit*, als vielmehr eine der *Komponenten von Gesundheit*, wie Körperfunktionen, Körperstrukturen, Aktivitäten und Partizipation (Teilhabe), sowie der Umweltfaktoren und ist daher als Modell auch auf gesunde Menschen bzw. Menschen ohne explizites Gesundheitsproblem anwendbar.

Die Taxonomie der ICF

Aufbauend auf dem bio-psycho-sozialen Modell wurde ein Klassifikationssystem entwickelt. Es besteht aus zwei grundlegenden Komponenten, die sich den beiden oben genannten Modellen zuordnen lassen. *Funktionsfähigkeit und Behinderung* haben ihren Ursprung im medizinischen Modell. Diese werden in der ICF durch *Körperfunktionen* und *Körperstruktu-*

ren, sowie *Aktivität und Partizipation (Teilhabe)* abgebildet. Das soziale Modell ist gedanklicher Ausgangspunkt für Kontextfaktoren, welche in der ICF durch *Umweltfaktoren* und *personenbezogene Faktoren* repräsentiert werden.
Unter *Körperfunktionen* versteht man physische und psychische Funktionen von Körpersystemen, wie beispielsweise die Hörfunktion. *Körperstrukturen* bezeichnen die anatomischen Bestandteile des Körpers, wie beispielsweise Organe, Organsysteme oder Gewebe, die eine bestimmte Körperfunktion ermöglichen. *Körperstrukturen* und *Körperfunktionen* sind unbedingte Voraussetzungen für die Durchführung einer Aufgabe oder einer Handlung und somit Basis jeder *Aktivität*. Dies expliziert das Einbezogensein in eine Lebenssituation und somit die Teilnahme und die Teilhabe am Alltagsleben.
Kontextfaktoren beschreiben generische Aspekte der Umwelt, die sowohl fördernd, als auch hemmend auf Funktionsfähigkeit eines Menschen Einfluss nehmen können. Hierbei bilden *Umweltfaktoren* die materielle, soziale und einstellungsbezogene Umwelt ab, in der Menschen leben und ihr Dasein entfalten. *Umweltfaktoren* sind extrinsisch und können die Leistung eines Menschen als Teil der ihn umgebenden Gesellschaft, seine Leistungsfähigkeit bei der Durchführung von Aufgaben und Handlungen, seine *Körperfunktionen* und auch *Körperstrukturen* positiv oder negativ beeinflussen. Die *personenbezogenen Faktoren* bilden den individuellen Lebenshintergrund bzw. die Lebensführung eines Menschen ab. Es handelt sich hierbei beispielsweise um Geschlecht, ethnische Zugehörigkeit, Alter, Lebensstil, sozioökonomischer Hintergrund, Erziehung oder individuelle Coping-Strategien. *Personenbezogene* Faktoren sind derzeit noch nicht in der ICF klassifiziert. Es existiert jedoch bereits ein Entwurf, um auch diese Faktoren in der ICF zu klassifizieren [23, 24].
Dem Modell der ICF ist eine hierarchisch organisierte und standardisierte Taxonomie zugeordnet, welche jeder Komponente einen Buchstaben zuweist und sich in verschiedene Domänen aufteilt. Auf Komponentenebene steht der Buchstabe „b“ für *Körperfunktionen*, „s“ für *Körperstrukturen*, „d“ für *Aktivität und Partizipation* und „e“ für *Umweltfaktoren*. Die Domänen gliedern sich zunächst in Kapitel mit entsprechendem einstelligen, arabischen Ziffernkode und in zweiter Ebene in Kategorien mit einem entsprechenden dreistelligen Ziffernkode, welche die Aspekte von Funktionsfähigkeit und Behinderung näher charakterisieren. Alle Kategorien sind jeweils untereinander unabhängig und disjunkt. In der dritten und vierten Ebene enthalten die Kategorien jeweils eine weitere Ziffer zur genaueren Bestimmung der jeweiligen Kategorie (siehe Tabelle 1).
Alle Kategorien der ICF sind so beschrieben, dass die übergeordneten Kategorien jeweils die detaillierten, untergeordneten Subkategorien mit einschließen. So kann mit Hilfe der Kategorien allen Aspekten von Funktionsfähigkeit und Behinderung, welche in der ICF klassifiziert sind, ein Ausprägungsmerkmal zugeteilt werden, um damit die Funktionsfähigkeit eines

Menschen charakterisieren und gesundheitsrelevante Kontextfaktoren identifizieren und beschreiben zu können [20].

Tabelle 1 – Die Taxonomie der ICF am Beispiel Schmerz

ICF Taxonomie	Label	Zuordnung
b	Körperfunktion	Komponente
b2	Sinnesfunktionen und Schmerz	Kapitel (erste Ebene)
b280	Schmerz	Kategorie (zweite Ebene)
b2801	Schmerz in einem Körperteil	Kategorie (dritte Ebene)
b28010	Nacken- und Kopfschmerz	Kategorie (vierte Ebene)

Die Anwendung der ICF im Rahmen dieser Arbeit

Basierend auf der ICF ist es möglich, für bestimmte Krankheitsbilder oder Symptome komplexe Listen von Standardkategorien, sogenannte ICF-Core-Sets [25, 26], aus der Gesamtklassifikation auszuwählen, die als Minimalstandard für die Erfassung der typischen Einschränkungen der Funktionsfähigkeit von Menschen mit der jeweiligen Erkrankung dienen können.

Die Entscheidung, die ICF als Rahmenmodell und Grundlage für die Instrumentenentwicklung zu wählen, begründet sich auf ihrer guten Anwendbarkeit, auf der Universalität hinsichtlich ihres Analyseportfolios und vor allem auf der Erfahrung, dass die ICF ein seit Jahren vielfach eingesetztes und validiertes Instrument zu Erhebung und Bewertung von Gesundheitszuständen bei verschiedenen Erkrankungen darstellt [25, 27, 28]. Sie ist somit das optimale Werkzeug zur Erstellung eines adaptierten Kategorienkatalogs, eines sog. Standard Sets, für die Beschreibung des Einflusses von Gelenkkontrakturen auf die Funktionsfähigkeit und die soziale Teilhabe älterer Menschen. Ein bereits etabliertes Standard-Set, das ICF-Core-Set für Patientinnen und Patienten in geriatrischen Rehabilitationseinrichtungen [29], diente bei der Entwicklung dieses neuen Standard-Sets für Kontrakturpatienten als Grundlage, da es einen großen Teil der relevanten Aspekte im Bezug auf Funktionsfähigkeit und Behinderung eben dieser Patientinnen und Patienten enthält. Methodisch orientiert sich die vorliegende Arbeit an einem etablierten Verfahren zur Entwicklung von ICF-Core-Sets, welches bereits im Rahmen vieler Studien eingesetzt und für die Anforderungen dieses Vorhabens entsprechend adaptiert wurde [25].

1.3 Motivation und Ziel der Arbeit

Die im ersten Kapitel dargestellte Relevanz von Gelenkkontrakturen für die medizinisch-pflegerische Versorgung alter Menschen bildet zusammen mit der bislang äußerst übersichtlichen Empirie in diesem Bereich die Grundlage und den Ausgangspunkt für die in dieser Dissertation vorgestellten Studien. Das übergeordnete Ziel der vorliegenden Arbeit war es, die wichtigsten Aspekte der Funktionsfähigkeit bei Menschen mit Kontrakturen zu identifizieren, um so die Basis für die Entwicklung eines Assessmentinstruments für die Auswirkungen von Kontrakturen zu schaffen. Die spezifischen Fragestellungen, die die einzelnen Manuskripte inhaltlich miteinander verbinden, lauten:

- → In welchen Bereichen der körperlichen Funktionsfähigkeit, in welchen Alltagsaktivitäten und in welchen Aspekten der sozialen Teilhabe sind ältere Menschen mit Gelenkkontrakturen eingeschränkt?
- → Wie häufig sind die jeweiligen Einschränkungen bei diesen älteren Menschen?
- → Welche Umweltfaktoren werden hinsichtlich der Unterstützungsbedarfe bei Gelenkkontrakturen als förderlich und/oder hinderlich beurteilt?

Diese Fragestellungen wurden durch die einzelnen Beiträge aus verschiedenen Perspektiven beleuchtet. Hierbei wurden durch drei einzelne Studien sowohl die Perspektive der Betroffenen, als auch die Perspektive von in der Behandlung von Gelenkkontrakturen langjährig erfahrenen Expertinnen und Experten untersucht und im Rahmen einer Querschnittstudie zusätzlich die Häufigkeit der Einschränkungen bzw. Schädigungen bei dieser speziellen Patientengruppe untersucht.
Das Leitmotiv aller Studien war die Erstellung einer verbindlichen Liste von ICF-Kategorien, welche betroffene Patientinnen und Patienten bzw. Bewohnerinnen und Bewohner, behandelnde Expertinnen und Experten, sowie auch Wissenschaftlerinnen und Wissenschaftler für die Funktionsfähigkeit und die Alltagsbewältigung von Gelenkkontrakturerkrankten als relevant erachten.
Die Notwendigkeit für die Erstellung dieser verbindlichen Kategorienliste ergibt sich einerseits aus der Erfahrung, dass die bislang bestehenden und weitverbreitet genutzten Instrumente unzulänglich sind, weil sie systemimmanent einen sehr reduktionistischen Behinderungsbegriff in sich tragen. Andererseits eröffnet dieses verbindliche Standard-Set die Möglichkeit, zukünftig ein patienten-orientiertes Instrument zur Beurteilung der Einschränkungen von Gelenkkontrakturen bei älteren Menschen hinsichtlich ihrer Alltagsfähigkeit und Teilhabe entwickeln und validieren zu können.

1.4 Vorstellung der Beiträge

Um den Einfluss von Gelenkkontrakturen auf die Funktionsfähigkeit und die Alltagsaktivitäten von betroffenen Patientinnen und Patienten beurteilen zu können, fehlte es bislang an Originaldaten, die aus verschiedenen Perspektiven beschreiben, welche Arten von Beeinträchtigungen und Einschränkungen für diese Patientinnen und Patienten überhaupt als relevant erachtet werden. Zur Untersuchung dieser verschiedenen Perspektiven wurden mehrere Studien in Form von qualitativen und quantitativen Primärdatenerhebungen durchgeführt, deren Ergebnisse als Artikel in internationalen Fachzeitschriften veröffentlicht worden sind. Im Folgenden werden die Inhalte der jeweiligen Publikationen kurz vorgestellt und die Beiträge des Doktoranden zu den verfassten Fachartikeln dargelegt.

1.4.1 Impact of joint contractures on functioning and social participation in older individuals – development of a standard set: study protocol

Dieser Artikel beinhaltet das Gesamtstudienprotokoll des vom deutschen Bundesministerium für Bildung und Forschung geförderten Projekts „JointConFunctionSet“ (Förderkennzeichen: 01GY1113B), zur Entwicklung eines Standard Sets, um den Einfluss von Gelenkkontrakturen auf die Funktionsfähigkeit und die Partizipation älterer Betroffener beurteilen zu können.
Der Doktorand beteiligte sich als Zweitautor maßgeblich an der Entwicklung des Manuskriptentwurfs und unterstützte den Erstautor bei Lektorat und Revision des Fachartikels.

1.4.2 Patients' view on health related aspects of functioning and disability of joint contractures: A qualitative interview study based on the International Classification of Functioning, Disability and Health (ICF)

Dieses Kapitel berichtet über die erste empirische Studie des Gesamtprojekts, in welcher leitfaden-gestützte face-to-face Interviews mit Patientinnen und Patienten in verschiedenen Versorgungssettings in zwei Regionen (Bayern, Nordrhein-Westfalen) durchgeführt, anschließend wörtlich transkribiert und qualitativ bzw. deskriptiv ausgewertet wurden. Die Ergebnisse dieser Studie geben Aufschluss darüber, welche Einschränkungen ältere, an Gelenkkontrakturen erkrankte Menschen hinsichtlich ihrer Funktions- und Alltagsfähigkeit erfahren und welche Umwelteinflüsse, diese als förderlich oder hinderlich erleben. Die Ergebnisse referenzieren die Sicht der Betroffenen.
Der Doktorand hat die Datenerhebung und die Transkription aller Interviews aus der Region Bayern durchgeführt, die Erhebung in Nordrhein-Westfalen koordiniert und anschließend die Analyse des Gesamtdatensatzes vollzogen. Als Erstautor war er verantwortlich für die Vorlage und Veröffentlichung des Manuskripts.

1.4.3 Examining functioning and contextual factors in individuals with joint contractures from the health professional perspective using the ICF: an international internet-based qualitative expert survey

Dieses Kapitel enthält die zweite empirische Studie des Gesamtprojekts, in der durch eine plattform-basierte Online-Befragung internationale und nationale Expertinnen und Experten aus den Gesundheitsfachberufen zu Einschränkungen und Hilfebedarfen von Patientinnen und Patienten mit Gelenkkontrakturen befragten wurden. Die Ergebnisse dieser Studie geben Aufschluss darüber, welche Einschränkungen ältere, an Gelenkkontrakturen erkrankte Menschen hinsichtlich ihrer körperlichen Funktionsfähigkeit, ihrer Aktivitäten und Teilhabe erfahren und welche Kontextfaktoren diese als förderlich oder hinderlich erleben. Die Ergebnisse dieser Studie referenzieren Einflüsse von Gelenkkontrakturen auf die Funktionsfähigkeit und Teilhabe von älteren Menschen aus der Sicht von behandelnden Berufsgruppen.
Der Doktorand hat die Programmierung der Online-Plattform, die Durchführung der Datenerhebung und die Analyse und Auswertung der Daten durchgeführt. Als Erstautor war er verantwortlich für die Vorlage und Veröffentlichung des Manuskripts.

1.4.4 Prevalence of functioning and disability in older patients with joint contractures: a cross-sectional study

Dieses Kapitel zeigt die Ergebnisse einer Querschnittsstudie im Rahmen des Gesamtprojekts, in welcher mittels eines standardisierten Fragebogens Patientinnen und Patienten in verschiedenen Versorgungssettings im Großraum München befragt worden sind. Die Ergebnisse dieser Studie geben Aufschluss darüber, wie häufig bestimmte Einschränkungen in Funktionsfähigkeit und Teilhabe bei älteren Menschen mit Gelenkkontrakturen vorkommen und welche Umwelteinflüsse, wie häufig als förderlich oder hinderlich erlebt werden.
Der Doktorand hat die Datenerhebung vorbereitet, teilweise selbst durchgeführt bzw. die Durchführung überwacht und die Auswertung der Daten vollzogen. Als Erstautor war er verantwortlich für die Vorlage und Veröffentlichung des Manuskripts.

1.5 Zusammenfassung

Gelenkkontrakturen sind ein relevantes und durchaus häufiges Symptom bei der medizinischen und pflegerischen Versorgung älterer Menschen. Durch die Einschränkung der vollen Gelenksbeweglichkeit oder durch eine physische Deformation des Gelenks begründen Kontrakturen eine erhebliche Krankheitslast und damit verbunden einen erhöhten Pflege- und /oder Unterstützungsbedarf der jeweils Betroffenen.
Bislang fehlen jedoch sowohl geeignete Instrumente, um die Auswirkungen von Gelenkkontrakturen auf die betroffenen Patientinnen und Patienten erheben zu können, als auch entsprechende Primärdaten, um eine derartiges Instrument überhaupt entwickeln zu können.
Das Ziel dieser Arbeit war es daher den Einfluss von Gelenkkontrakturen auf die Funktionsfähigkeit, auf Alltagsaktivitäten und auf die soziale Teilhabe von älteren Menschen aus verschiedenen Perspektiven zu untersuchen und mit Hilfe der Internationalen Klassifikation für Funktionsfähigkeit, Behinderung und Gesundheit (ICF) der WHO eine Kategorienliste zu identifizieren, welche für die Entwicklung eines patienten-relevanten Beurteilungsinstruments notwendig ist.
Die erste Publikation „Impact of joint contractures on functioning and social participation in older individuals – development of a standard set: study protocol“ beschreibt in Form eines Studienprotokolls das vom Bundesministerium für Bildung und Forschung finanzierte Gesamtprojekt inklusive aller Einzelstudien, welche geplant waren/sind, um ein ICF-Standard-Set für Gelenkkontrakturen zu entwickeln.
Das dritte Kapitel präsentiert die Ergebnisse einer qualitativen Interviewstudie, in der von Gelenkkontrakturen betroffenen Patienteninnen und Patienten ihre Einschränkungen hinsichtlich Funktionsfähigkeit, Aktivitäten und Teilhabe berichten. Es wurde gezeigt, dass Gelenkkontrakturen aus der Sicht von Betroffenen einen mannigfaltigen Einfluss auf verschiedene Aspekte von Funktionsfähigkeit und Partizipationsfähigkeit haben, und dass eine Vielzahl von persönlichen und umweltbezogenen Faktoren als unterstützend bzw. hinderlich erlebt wird. Die von den Patientinnen und Patienten berichteten Ergebnisse können einen wichtigen Beitrag zum besseren Verständnis des komplexen Zusammenwirkens von Gesundheitszustand und kontextualer Umwelt geben.
Die Publikation „Examining functioning and contextual factors in individuals with joint contractures from the health professional perspective using the ICF: an international internet-based qualitative expert survey“ im vierten Kapitel, berichtet von einer Studie, welche mittels einer Internetbefragung die Einschätzung von internationalen und nationalen Expertinnen und Experten zur Behinderung und Teilhabefähigkeit von älteren Menschen mit Gelenkkontrakturen exploriert hat. Hierbei wurden Mobilität und Unterstützung durch Angehörige oder Hilfspersonen als die für diese Personengruppe am meisten relevanten Kategorien identifiziert.

Aus den Ergebnissen dieser beiden Vorstudien wurde ein standardisierter Fragebogen entwickelt, welcher im Rahmen einer Querschnittstudie zur Erhebung der Häufigkeit und Intensität bestimmter Einschränkungen verwendet wurde. Das fünfte Kapitel berichtet über diese Querschnittsstudie, in welcher 150 Patientinnen und Patienten mit Gelenkkontrakturen zum Ausmaß ihrer Einschränkungen befragt wurden. Mit Hilfe der Ergebnisse dieser Studie konnte gezeigt werden, dass auf die körperliche Beweglichkeit bezogene Faktoren, wie Muskeltonus oder Muskelkraft, aber auch die Gangfunktion die am häufigsten und auch am stärksten betroffenen Bereiche der körperlichen Funktionsfähigkeit darstellen.
Zusammenfassend zeigt sich, dass die Erfassung und die Beurteilung der Einschränkungen von Gelenkkontrakturen bei älteren Menschen eine komplexe Aufgabe ist, welche auf Grund ihrer starken Relevanznein standardisiertes Vorgehen bzw. möglichst ein standardisiertes Instrument erfordert. Aus den Ergebnissen dieser Arbeit kann nun ein patienten-orientiertes, standardisiertes Beurteilungsinstrument zur Erhebung des Einflusses von Gelenkkontrakturen auf die körperliche Funktionsfähigkeit, auf Alltagsaktivitäten und auf die soziale Teilhabe von betroffenen, älteren Menschen entwickelt werden.

1.6 Summary

Joint contractures are a relevant and quite common symptom in medical and nursing care of elderly people. By restricting the full joint mobility or because of a physical joint deformity contractures substantiate a considerable burden of disease and associate increased nursing care and/or increased assistance.

However, so far neither there are appropriate tools to explore the impact of joint contractures on affected patients nor corresponding primary data in order to develop an appropriate assessment-instrument.

Therefor the aim of this study was to investigate the influence of joint contractures on functioning, on activities of daily life and on social participation of older people from different perspectives using the International Classification of Functioning, Disability and Health (ICF) of the WHO to explore a list of categories to develop a new patient-relevant assessment instrument.

The first publication "Impact of joint contractures on functioning and social participation in older individuals - development of a standard set: study protocol" describes the overall project funded by the Federal Ministry for Education and Research including all single studies, which were/are planned to develop a ICF-standard set for joint contractures.

Chapter three presents the results of a qualitative interview study in which patients affected by joint contractures report their limitations on functioning, activities and participation. It has been shown that joint contractures from the perspective of those who are affected have a varied impact on different aspects of functioning and participation capability, and that a variety of personal and environmental factors is experienced as supportive or obstructive. The results reported by the patient results can give an important contribution to a better understanding of the complex interaction of health condition and contextual environment.

The publication of chapter four "Examining functioning and contextual factors in individuals with joint contractures from the health professional perspective using the ICF: an international internet-based qualitative expert survey" reports on a study, which surveyed the assessment of international and national experts regarding disability and participation capacity of older people with joint contractures using an internet-based tool. Mobility and support by family/support by health professionals were identified as the most relevant categories for this group.

From the results of these preliminary studies, a standardized questionnaire was developed, which was used as part of a cross-sectional study to survey the frequency and intensity of certain limitations. The fifth chapter reports on this cross-sectional study in which 150 patients with joint contractures were asked to the extent of their limitations. The results of this study showed that categories concerning mobility, such as muscle tone or muscle strength,

but also gait pattern function represent most common and also most affected physical functioning.

In conclusion the identification and the assessment of the entire limitations of joint contractures in older people is a complex task, which requires a standardized procedure and a standardized assessment-instrument because of its strong relevance. From the results of this thesis a patient-oriented, standardized assessment-instrument to survey the influence of joint contractures on functioning, activities and participation of older people can now be developed.

1.7 Referenzen

[1.] Harrington, C., *Nursing Facilities, Staffing, Residents and Facility Deficiencies, 2003 Through 2008*. 2009, Department of Social and Behavioral Sciences, University of California.

[2.] Sackley, C., et al., *The prevalence of joint contractures, pressure sores, painful shoulder, other pain, falls, and depression in the year after a severely disabling stroke.* Stroke, 2008. 39(12): p. 3329-34.

[3.] Gnass, I., et al., *Joint contractures in older age. A systematic literature review.* Z Gerontol Geriatr, 2010. 43(3): p. 147-57.

[4.] Resnick, B., *Functional performance and exercise of older adults in long-term care settings.* Journal of gerontological nursing, 2000. 26(3): p. 7-16.

[5.] Mollinger, L.A. and T.M. Steffen, *Knee flexion contractures in institutionalized elderly: prevalence, severity, stability, and related variables.* Physical therapy, 1993. 73(7): p. 437-44; discussion 444-6.

[6.] Souren, L.E., E.H. Franssen, and B. Reisberg, *Contractures and loss of function in patients with Alzheimer's disease.* Journal of the American Geriatrics Society, 1995. 43(6): p. 650-5.

[7.] Selikson, S., K. Damus, and D. Hamerman, *Risk factors associated with immobility.* J Am Geriatr Soc, 1988. 36(8): p. 707-12.

[8.] Fergusson, D., B. Hutton, and A. Drodge, *The epidemiology of major joint contractures: a systematic review of the literature.* Clinical orthopaedics and related research, 2007. 456: p. 22-9.

[9.] Clavet, H., et al., *Joint contractures in the intensive care unit: association with resource utilization and ambulatory status at discharge.* Disability & Rehabilitation, 2011. 33(2): p. 105-112.

[10.] Katalinic, O.M., et al., *Stretch for the treatment and prevention of contractures.* Cochrane Database Syst Rev, 2010(9): p. CD007455.

[11.] Fox, P., et al., *Effectiveness of a bed positioning program for treating older adults with knee contractures who are institutionalized.* Physical therapy, 2000. 80(4): p. 363-72.

[12.] Clavet, H., et al., *Joint contracture following prolonged stay in the intensive care unit.* CMAJ, 2008. 178(6): p. 691-7.

[13.] IQP, I.f.Q.i.d.P.-. *Kontrakturprävention in der Langzeitpflege Älterer. Stand der Forschung und Bedeutung für die Praxis*. 2011.

[14.] Rabiner, A., et al., *Characteristics of Nursing Home Residents with Contractures.* Physical & Occupational Therapy in Geriatrics, 1996. 13(4): p. 1-10.

[15.] Castle, N.G., H. Degenholtz, and J. Engberg, *State variability in indicators of quality of care in nursing facilities.* The journals of gerontology Series A, Biological sciences and medical sciences, 2005. 60(9): p. 1173-9.
[16.] Huhn, S., *Praxisheft Kontrakturprophylaxe: Aktueller Wissensstand pflegerischer Interventionen*. 2012: DBfK Nordost e.V.
[17.] Medizinischer Dienst des Spitzenverbandes Bund der Krankenkassen e.V. (MDS), *Grundlagen der MDK-Qualitätsprüfungen in der stationären Pflege*. 2010.
[18.] Offenbacher, M., et al., *Contractures with special reference in elderly: definition and risk factors - a systematic review with practical implications.* Disabil Rehabil, 2013.
[19.] White, M.J., et al., *A pilot for understanding interdisciplinary teams in rehabilitation practice.* Rehabil Nurs, 2013. 38(3): p. 142-52.
[20.] World Health Organisation, *International Classification of Functioning, Disability and Health: ICF*. 2001, Geneva: WHO.
[21.] Bommes, M. and A. Scherr, *Soziologie der sozialen Arbeit eine Einführung in Formen und Funktionen organisierter Hilfe*. 2000, Weinheim ; München: Juventa-Verl.
[22.] Hallier, E., *Medizinische und berufliche Rehabilitation Orientierungshilfe für Betrieb, Praxis und Klinik ; Schwerpunktthema Jahrestagung DGAUM 2012*. 2013, Heidelberg ; München ; Landsberg [u.a.]: Ecomed Medizin.
[23.] Grotkamp, S., et al., *[Personal factors of the ICF].* Gesundheitswesen, 2012. 74(7): p. 449-58.
[24.] Grotkamp, S., et al., *[Relevance of Personal Contextual Factors of the ICF for Use in Practical Social Medicine and Rehabilitation].* Gesundheitswesen, 2014. 76(3): p. 172-80.
[25.] Grill, E., et al., *ICF Core Sets development for the acute hospital and early post-acute rehabilitation facilities.* Disabil Rehabil, 2005. 27(7-8): p. 361-6.
[26.] Bickenbach, J.E., et al., eds. *ICF Core Sets - Manual for Clinical Practice*. 2012, Hogrefe Publishing.
[27.] Grill, E., et al., *ICF Core Sets for early post-acute rehabilitation facilities.* Journal of rehabilitation medicine : official journal of the UEMS European Board of Physical and Rehabilitation Medicine, 2011. 43(2): p. 131-8.
[28.] Cieza, A., et al., *Development of ICF Core Sets for patients with chronic conditions.* J Rehabil Med, 2004(44 Suppl): p. 9-11.
[29.] Stier-Jarmer, M., et al., *Validation of the comprehensive ICF Core Set for patients in geriatric post-acute rehabilitation facilities.* Journal of rehabilitation medicine : official journal of the UEMS European Board of Physical and Rehabilitation Medicine, 2011. 43(2): p. 102-12.

2 Impact of joint contractures on functioning and social participation in older individuals – development of a standard set: study protocol

Martin Müller[1], Uli Fischer[1], Gabriele Bartoszek[2], Eva Grill[1], Gabriele Meyer[2§]

[1] Institute for Medical Information Processing, Biometrics and Epidemiology, Ludwig-Maximilians-Universität München, Munich, Germany
[2] School of Nursing Science, Witten/Herdecke University, Witten, Germany

[§] Corresponding author

Email addresses:
MM: martin.mueller@med.uni-muenchen.de
UF: uli.fischer@med.uni-muenchen.de
GB: gabriele.bartoszek@uni-wh.de
EG: eva.grill@med.uni-muenchen.de
GM: gabriele.meyer@uni-wh.de

This chapter was published as:

BMC Geriatr. 2013 Feb 21;13:18. doi: 10.1186/1471-2318-13-18.
Impact of joint contractures on functioning and social participation in older individuals - development of a standard set (JointConFunctionSet): study protocol.
Müller M, Fischer U, Bartoszek G, Grill E, Meyer

2.1 Abstract

Background

Joint contractures are frequent in older individuals in geriatric care settings. Even though they are used as indicator of quality of care, there is neither a common standard to describe functioning and disability in patients nor an established standardized assessment to describe and quantify the impact of joint contractures on patients' functioning. Thus, the aim of our study is (1) to develop a standard set for the assessment of the impact of joint contractures on functioning and social participation in older individuals and (2) to develop and validate a standardized assessment instrument for describing and quantifying the impact of joint contractures on the individuals' functioning.

Methods

The standard set for joint contractures integrate the perspectives of all potentially relevant user groups, from the affected individuals to clinicians and researchers. The development of this set follows the methodology to develop an International Classification of Functioning Disability and Health (ICF) Core Set and involves a formal decision-making and consensus process. Evidence from four preparatory studies will be integrated including qualitative interviews with patients, a systematic review of the literature, a survey with health professionals, and a cross sectional study with patients affected by joint contractures. The assessment instrument will be developed using item-response-theory models. The instrument will be validated.

Discussion

The standard set for joint contractures will provide a list of aspects of functioning and health most relevant for older individuals in geriatric care settings with joint contractures. This list will describe body functions, body structures, activities and participation and related environmental factors. This standard set will define what aspects of functioning should be assessed in individuals with joint contractures and will be the basis of the new assessment instrument to evaluate the impact of joint contractures on functioning and social participation.

Keywords

Contracture (MeSH)
Aged (MeSH)
Disabled Persons (MeSH)
Outcome Assessment (Health care) (MeSH)
Geriatric rehabilitation
Home care (MeSH)
Nursing homes (MeSH)
Acute hospital care

2.2 Background

Free movement of the limbs is a prerequisite of mobility and autonomy in old age. Joint contractures, i.e. restrictions in full range of motion of any joint due to deformity, disuse or pain, are common problems of frail older people, particularly in nursing home residents [1]. Contractures are among the most unexplored and underreported syndromes in clinical and homecare settings. Epidemiological studies indicate a wide range of prevalence of joint contractures in older individuals between 20% and 80% [2-4]. This variation is due to different definitions of contracture and varying diagnostic criteria or data collection methods, different research settings, sample size and study participants' characteristics [5]. The aetiology of joint contractures is multifaceted. In older people contractures may be caused by a variety of health conditions and situations, but immobility due to an acute injury or disease seems to be the major risk factor [6].

Upper limb joint contractures may result in loss of ability to dress or eat independently while lower limb contractures may lead to instability and inability to walk independently and higher risk of bed confinement [5, 7]. Joint contractures further increase the risk of other adverse patient outcomes like pain, pressure ulcers and risk of falls [8]. Thus, joint contractures are a major cause for excess disability in older people with a significant impact on overall quality of life and functioning. Preventive and rehabilitation interventions targeting joint contractures may decrease morbidity, increase functioning and quality of life, and, ultimately, prevent long-term disability.

In the United States of America, presence of joint contractures is an established indicator of quality of care in nursing facilities [1, 9]. In Germany, joint contracture risk assessment and prevention have recently been defined as a quality indicator of nursing home care that should be regularly monitored by experts from the statutory health insurance system. Nursing homes are obliged to report whether they regularly assess the risk of joint contracture and administer relevant preventive measures [10, 11]. In clinical settings, joint contractures are assessed by measuring the range of motion. However, from a patient- and nursing-oriented perspective the relevance of a systematic registration of contractures in care-dependent older people is unclear unless their impact on functioning is understood. Contracture assessment is only an intermediate step in the evaluation of patient-relevant outcomes such as quality of life, functioning, and the ability to participate in everyday life and social participation.

Arguably, a clinical definition of joint contracture is difficult because the contracture's severity is determined by the consequences on activities of daily living, quality of life and social participation. In addition, there is no consensus on aspects most relevant to the affected individuals. A variety of functional measures is currently used for the assessment and evaluation of geriatric patients. To date, there is no consensus on common concepts for the choice of out-

come measures specifically for evaluating the impact of interventions targeted on joint contractures. Reliable data on individuals' (and families') burden due to joint contracture are a prerequisite for the development of tailored interventions targeted to vulnerable groups and specific situations.

Considering that interdisciplinary collaboration is a key aspect of rehabilitation quality, and that assessment is one of the basic features of this collaboration, a common conceptual basis needs to take into account the perspectives of different health professionals involved as well as the perspective of the affected individuals. The International Classification of Functioning, Disability and Health (ICF) is likely to be a suitable common framework. Based on the ICF it is possible to select sets of categories, the ICF Core Sets [12], out of the whole classification which can serve as minimal standards for the assessment of the consequences of contractures on functioning. One established ICF Core Set, the ICF Core Set for patients in geriatric post-acute rehabilitation facilities [13] – which may cover a large fraction of aspects of functioning and disability relevant to patients with joint contracture –, will have to be taken into account for this.

The aim of our study is (1) to develop a standard set for the assessment of the impact of joint contractures on functioning and social participation in older individuals and (2) to develop and validate a standardized assessment instrument for describing and quantifying the impact of joint contractures on the individuals' functioning.

2.3 Methods/ Design

The ICF classifies domains of functioning, along with their contextual factors, which are encountered in human life [14]. As such, the ICF will be the basis of our study. To address all potentially relevant risk factors for joint contractures, we will apply the well-established methodology of developing ICF Core Sets to the health care problem of joint contractures [12]. ICF Core Sets are selections of ICF categories from the entire classification which are relevant to specific health conditions or care situations. Specifically, the ICF Core Sets are developed in a formal decision-making and consensus approach, integrating evidence from four preliminary studies:

(1) Qualitative interviews with individuals with joint contractures and their caregivers will be carried out to explore aspects of functioning and health, which are important to the affected individuals and their significant others.

(2) An expert survey will be performed via an online platform to gather the opinion of international experts from different professions regarding the most relevant and typical areas of functioning and health to be considered in individuals with joint contractures.

(3) A multicentre cross-sectional study with individuals with joint contractures will be performed to describe the prevalence of limitations and restrictions in functioning and health in individuals with joint contractures in geriatric care settings.

(4) A recently performed systematic review [15] will be updated and re-analysed to extract categories of the ICF from the outcome measures used.

The information collected in the four preparatory studies will be presented at a consensus conference [12]. Experts in the field of joint contractures including nurses, physicians, physical therapists, occupational therapists (both researchers and clinicians) and patients' representatives will be invited to work actively together in order to arrive at a consensus on the most adequate categories of the ICF to be included in the standard set for joint contractures (see figure 1).

Based on this standard set, a standardized assessment instrument for describing and quantifying the impact of joint contractures on the individuals' functioning will be developed.

Study designs and samples

As there is no consensual definition for identifying joint contractures, we operationalize their presence as follows: Joint contractures will be defined as restricted active and passive range of motion in at least one major joint (shoulder, elbow, wrist, hip, knee, and ankle). The presence has to be indicated by 1) physicians' diagnosis or 2) physiotherapists' or trained nurses' assessment.

Qualitative interviews with affected individuals will be carried out separately for each study setting (home care, nursing home, geriatric acute wards, post-acute geriatric rehabilitation facilities) in order to be able to compare the findings between different situations of care. The sample size will be determined by saturation, i.e. the point at which an investigator has obtained sufficient information from the field. Experiences from our own earlier studies [16, 17] indicate a sample size of 10 to 15 persons per setting. The sampling strategy follows the idea of theoretical sampling adopted from the grounded theory methodology [18]. This strategy aims to assure maximum sensitivity in order to gather a maximum variety of experiences from the participants. Inclusion criteria will be fluency in the German language, age ≥65 years, presence of joint contractures as defined above, MMSE ≥24 points [19, 20] and written formal consent. Potential participants will be asked for willingness to participate by the staff of the cooperation partners. A short study summary and patient information will be provided. The expert survey via an online platform will involve health professionals from all relevant professions (nurses, physicians, physiotherapists, occupational therapists, social worker). Inclusion criteria are clinical expertise (work experience in patients with joint contractures >5 years in geriatric care settings, i.e. hospitals, rehabilitation facilities and nursing homes) or research expertise (relevant publication on joint contractures within the last 5 years). The fields of practice or research should be well-balanced between the experts and

according to the study population. Sample size calculation with a power of 0.8 and a level of significance of 0.05 revealed a sample size of 204 experts to determine frequencies of relevant aspects of functioning and health with a precision of 10%. Based on previous experiences from studies [21], inclusion and participation of about 200 international experts within six months is likely to be feasible. We will contact national and international professional organizations to nominate experts in the field of joint contractures. At the same time, first and senior authors of the papers identified in the systematic review will be contacted and asked to participate. In addition, all participating experts will be asked to nominate further experts. The recruitment procedure has been well proven in former own studies [21, 22]

For the cross-sectional survey, inclusion criteria will be age ≥65 years, presence of joint contracture as defined above and written informed consent. In order to get a representative sample of individuals with contractures data will be collected consecutively in three different settings and in two different German regions (Munich, Bavaria, and Witten, North Rhine-Westphalia). The involved facilities have large catchment areas predisposing a representative case-mix. Each of the coordinating sites will be responsible for 50% of the sample, i.e. for 100 participants. Eligible patients will be identified by the weekly team conferences held at the respective hospitals. The study nurses will then be informed. Additionally, they will participate in ward rounds of the respective hospitals and sites. Under the assumption of an equal effects model [23], a power of 0.8 and a level of significance of 0.05, a sample size of 194 individuals would be necessary in order to determine frequencies with a precision of 10%. For the instrument validation, participants will also be asked to consent to a follow-up. An overview of methods and designs is given in table 1.

Data collection

Data for the qualitative study will be gathered by face-to-face interviews based on an established interview guideline [17, 24]. The interviews will be audio-recorded and transcribed verbatim.

Data collection for the expert survey will be conducted via an online platform based on the Delphi Method [25]. The experts will be asked to list the impairments, limitations and restrictions in body functions and structures and activities and participation, as well as relevant environmental and personal factors of individuals with joint contractures.

In the cross-sectional study, data on functioning and health will be collected using the ICF check list [26] in structured interviews. In cases of individuals with communication impairments, data will be collected in a proxy interview with the affected relatives or nurses in charge. In addition, individuals and health professionals in charge are requested to evaluate health and functioning using a rating scale ranging from 10 (excellent/no problems) to 0 (poor/complete problems). This will serve as an outcome for multiple analyses. Socio-demographic and condition-specific data, such as marital status, main medical diagnosis or

duration of in hospital stay will also be recorded. In order to gain a comprehensive view on the consequences, data will be collected from individuals who are about to be discharged from acute geriatric wards, from individuals in post-acute rehabilitation facilities, from individuals in nursing homes and in home care situations. Items of the outcome measures used in the study retrieved by the recent systematic review by Gnass et al. (2010) will be identified using a standardized procedure [27].

The consensus conference follows an established procedure of formal decision making and consensus building integrating the results from the previous studies [12, 28]. According to extensive former experiences, it will involve about 30 expert experts in the field of joint contractures including clinicians and researchers from all relevant professions as well as consumer representatives.

The developed standardized assessment instrument will be tested at the study sites participating in the cross-sectional study. Participants will be asked to fill in the instrument and will be contacted again after discharge for a follow up assessment.

2.4 Analysis

Qualitative content analysis following a descriptive approach will be used to analyse the content of the qualitative interview [29]. The retrieved aspects of functioning and health will be translated into categories of the ICF [27]. The result of this analysis will be a list of ICF categories relevant for affected individuals and their caregivers.

The results of the expert survey will be translated into categories of the ICF using a standardized procedure [27]. Frequencies of ICF categories and their 95% confidence intervals will be calculated.

All items of the outcome measures extracted from the systematic review will be translated into categories of the ICF following a standardized approach [27]. Frequencies of ICF categories and their 95% confidence intervals will be calculated.

For cross-sectional analyses, absolute and relative frequencies (prevalence) of impairment, limitation or restriction alongside 95% confidence intervals will be calculated. To identify potential confounders, analyses will be stratified for age groups and sex. Based on previous experiences in ICF Core Set development and validation studies, only few subjects are expected to have missing values.

To develop an instrument for describing and quantifying the impact of joint contractures on the individuals' functioning, we will apply Item Response Theory-modelling to the data of the cross-sectional-study and the knowledge from the consented standard set. By using Item Response Theory methods [30] one can examine whether the selected categories cover a common underlying trait (such as disability following joint contractures), thus forming a scale, or which of the selected categories have a reasonable fit in relation to the assumed trait, or

whether the selected categories cover the spectrum of ability one is likely to encounter in typical affected individuals. The approach has been shown to result in valid scales [31]. We will test the inter-rater reliability of the resulting instrument in a validation sample with repeated measurements. The optimal sample size for reliability testing will be determined by feasibility and precision considerations. The experiences gathered from other reliability studies involving ICF Core Sets [32] have shown that this can be done, even given a very high or very low proportion of positive ratings, with a sample size of n=30 to detect a moderate kappa (0.5–0.6) with a power of 0.8. Internal consistency will be examined by Cronbach's alpha. Since there is no criterion measure available, criterion validity will be examined by means of predictive validity of the instrument. This predictive utility will be examined by investigating whether the new instrument is able to predict future participation restriction. Eligible participants from the sites of the cross-sectional study will be followed up after discharge by phone calls or home visits to examine participation restriction. We will use the Impact on Autonomy and Participation (IPA) questionnaire for validation. This is a generic questionnaire focusing on self-perceived restriction in participation associated with health condition or disability [33]. The IPA covers the main aspects of the component Activities and Participation as described by the ICF [34]. A German version of the IPA has recently been validated. The IPA consists of eight subscales with a total of 41 items: self-care and appearance, mobility, leisure, social relationships, work, education, family role, financial independence. Each item is scored on a five-point rating scale, ranging from 1 (excellent) to 5 (very poor). For each subscale, a standardised summary measure can be calculated based on the item scores weighed by the number of items, where a higher score indicates a greater perceived handicap. The score developed from the cross-sectional data will be investigated as to whether it is able to predict participation restriction in this sample of older persons. The predictive validity will be analysed by regression models where perceived participation serves as a dependent variable and the ICF measure as an independent variable.

2.5 Discussion

The standard set for joint contractures will provide a list of aspects of functioning and health most relevant for older individuals with joint contractures. This list will contain body functions, body structures, activities and participation and related environmental factors. This set will define what aspects of functioning should be assessed in individuals with joint contractures and will be the basis of a new instrument. This instrument should assess the consequences of joint contractures and will provide a clinical and scientific basis to study and therefore understand the impact of this condition in older individuals in geriatric care settings. In the clinical situation, the instrument will lead to better care of patients since it allows to assess the impact of the condition from a patient-centred perspective and therefore to choose the ade-

quate treatment. It will also allow evaluating treatment strategies and comparing them amongst each other in a meaningful way, or might be the basis for developing new treatment programmes based on the knowledge about aspects really relevant to the affected individuals.

2.6 Supplement

Competing interests

The authors declare that they are no competing interests.

Authors' contributions

MM, EG, GM and GB contributed to the conception of the study and applied for funding. MM and EG conceived the study design, GM and GB contributed to the study design. MM and EG drafted the manuscript. UF, GM and GB critically revised the drafts and contributed to the final writing of the paper. All authors read and approved the final manuscript.

Acknowledgements

The project is funded by the German Federal Ministry of Education and Research.

2.7 References

[1.] Harrington, C., Nursing Facilities, Staffing, Residents and Facility Deficiencies, 2003 Through 2008. 2009, Department of Social and Behavioral Sciences, University of California.

[2.] Resnick, B., Functional performance and exercise of older adults in long-term care settings. Journal of gerontological nursing, 2000. 26(3): p. 7-16.

[3.] Souren, L.E., E.H. Franssen, and B. Reisberg, Contractures and loss of function in patients with Alzheimer's disease. Journal of the American Geriatrics Society, 1995. 43(6): p. 650-5.

[4.] Mollinger, L.A. and T.M. Steffen, Knee flexion contractures in institutionalized elderly: prevalence, severity, stability, and related variables. Physical therapy, 1993. 73(7): p. 437-44; discussion 444-6.

[5.] Fergusson, D., B. Hutton, and A. Drodge, The epidemiology of major joint contractures: a systematic review of the literature. Clinical orthopaedics and related research, 2007. 456: p. 22-9.

[6.] Clavet, H., et al., Joint contracture following prolonged stay in the intensive care unit. CMAJ, 2008. 178(6): p. 691-7.

[7.] Rabiner, A., et al., Characteristics of Nursing Home Residents with Contractures. Physical & Occupational Therapy in Geriatrics, 1996. 13(4): p. 1-10.

[8.] Wagner, L.M., et al., Contractures in frail nursing home residents. Geriatric nursing (New York, N Y), 2008. 29(4): p. 259-66.

[9.] Castle, N.G., H. Degenholtz, and J. Engberg, State variability in indicators of quality of care in nursing facilities. The journals of gerontology Series A, Biological sciences and medical sciences, 2005. 60(9): p. 1173-9.

[10.] Medizinischer Dienst des Spitzenverbandes Bund der Krankenkassen e.V. (MDS), Vereinbarung nach § 115 Abs. 1a Satz 6 SGB XI über die Kriterien der Veröffentlichung sowie die Bewertungssystematik der Qualitätsprüfungen der Medizinischen Dienste der Krankenversicherung sowie gleichwertiger Prüfergebnisse in der stationären Pflege -Pflege-Transparenzvereinbarung stationär (PTVS)- vom 17. Dezember 2008. 2008.

[11.] Medizinischer Dienst des Spitzenverbandes Bund der Krankenkassen e.V. (MDS), Grundlagen der MDK-Qualitätsprüfungen in der stationären Pflege. 2010.

[12.] Grill, E., et al., ICF Core Sets development for the acute hospital and early post-acute rehabilitation facilities. Disabil Rehabil, 2005. 27(7-8): p. 361-6.

[13.] Stier-Jarmer, M., et al., Validation of the comprehensive ICF Core Set for patients in geriatric post-acute rehabilitation facilities. Journal of rehabilitation medicine : official journal of the UEMS European Board of Physical and Rehabilitation Medicine, 2011. 43(2): p. 102-12.

[14.] World Health Organisation, International Classification of Functioning, Disability and Health: ICF. 2001, Geneva: WHO.
[15.] Gnass, I., et al., Joint contractures in older age. A systematic literature review. Z Gerontol Geriatr, 2010. 43(3): p. 147-57.
[16.] Mueller, M., et al., Functioning and health in patients with cancer on home-parenteral nutrition: a qualitative study. Health Qual Life Outcomes, 2010. 8: p. 41.
[17.] Mueller, M., et al., Identification of aspects of functioning, disability and health relevant to patients experiencing vertigo: a qualitative study using the international classification of functioning, disability and health. Health Qual Life Outcomes, 2012. 10(1): p. 75.
[18.] Glaser, B.G. and A.L. Strauss, The Discovery of Grounded Theory. Strategies for Qualitative Research. 1967: Aldine Publishing Company.
[19.] Folstein, M.F., S.E. Folstein, and P.R. McHugh, “Mini-mental state”: A practical method for grading the cognitive state of patients for the clinician. Journal of Psychiatric Research, 1975. 12(3): p. 189-198.
[20.] Galasko, D., et al., An inventory to assess activities of daily living for clinical trials in Alzheimer's disease. The Alzheimer's Disease Cooperative Study. Alzheimer disease and associated disorders, 1997. 11 Suppl 2: p. S33-9.
[21.] Scheuringer, M., et al., Identification of problems in individuals with spinal cord injury from the health professional perspective using the ICF: a worldwide expert survey. Spinal Cord, 2010. 48(7): p. 529-36.
[22.] Herrmann, K.H., et al., The comprehensive ICF core sets for spinal cord injury from the perspective of occupational therapists: a worldwide validation study using the Delphi technique. Spinal Cord, 2011. 49(5): p. 600-13.
[23.] Laird, N.M. and F. Mosteller, Some statistical methods for combining experimental results. Int J Technol Assess Health Care, 1990. 6(1): p. 5-30.
[24.] Coenen, M., et al., Validation of the International Classification of Functioning, Disability and Health (ICF) Core Set for rheumatoid arthritis from the patient perspective using focus groups. Arthritis Res Ther, 2006. 8(4): p. R84.
[25.] Murphy, M.K., et al., Consensus development methods, and their use in clinical guideline development. Health Technol Assess, 1998. 2(3): p. i-iv, 1-88.
[26.] World Health Organization ICF Checklist. Version 2.1a. Clinician Form for International Classification of Functioning, Disability and Health. 2003.
[27.] Cieza, A., et al., ICF linking rules: an update based on lessons learned. Journal of rehabilitation medicine : official journal of the UEMS European Board of Physical and Rehabilitation Medicine, 2005. 37(4): p. 212-8.

[28.] Grill, E., et al., International Classification of Functioning, Disability and Health (ICF) Core Set for patients with vertigo, dizziness and balance disorders. Journal of Vestibular Research, 2012.
[29.] Sandelowski, M., Whatever happened to qualitative description? Research in nursing & health, 2000. 23(4): p. 334-40.
[30.] Tennant, A., Principles and practice of measuring outcome., in Advances in rehabilitation. Assessment in Physical Medicine and Rehabilitation. , Barat M and F. F, Editors. 2004.
[31.] Grill, E. and G. Stucki, Scales could be developed based on simple clinical ratings of International Classification of Functioning, Disability and Health Core Set categories. J Clin Epidemiol, 2009. 62(9): p. 891-8.
[32.] Grill, E. and G. Stucki, Criteria for validating comprehensive ICF Core Sets and developing brief ICF Core Set versions. Journal of rehabilitation medicine : official journal of the UEMS European Board of Physical and Rehabilitation Medicine, 2011. 43(2): p. 87-91.
[33.] Cardol, M., et al., The development of a handicap assessment questionnaire: the Impact on Participation and Autonomy (IPA). Clin Rehabil, 1999. 13(5): p. 411-9.
[34.] Noonan, V.K., et al., Comparing the content of participation instruments using the international classification of functioning, disability and health. Health Qual Life Outcomes, 2009. 7: p. 93.

2.8 Figures and tables

Figure 1 - Process of developing the standard set, instrument development and validation

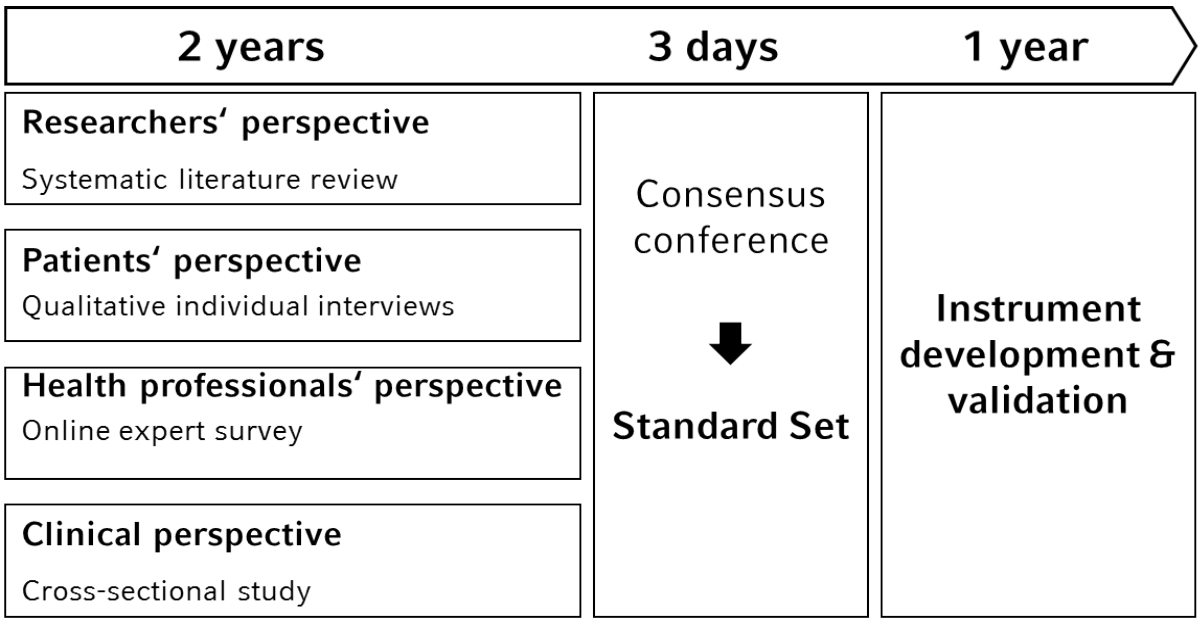


Table 1 - Overview of the study parts

	Aim	Design	Participants	Estimated sample size
Researchers' perspective	Identification of outcome measures used in studies focusing on contractures using the ICF as a reference framework	Systematic Review	Not applicable	
Patients' perspective	Identification of aspects of functioning and disability relevant to older individuals with contractures using the ICF as a reference framework	Qualitative individual interviews	Individuals in nursing homes, specialized geriatric rehabilitation facilities, geriatric wards in acute hospitals	Approx. 30 depending on data saturation
Health professionals' perspective	Identification of aspects of functioning and disability relevant in the management and treatment of individuals with contractures from the perspective of experienced professionals using the ICF as a reference framework	Online expert survey	Health professionals with >5 years experience (nurses, physicians, physiotherapists, occupational therapists)	Approx. 200
Clinical (epidemiological) perspective	To describe functioning and disability of individuals with vertigo and to identify the most common problems using the ICF	Cross-sectional study	Individuals in nursing homes, specialized geriatric rehabilitation facilities, geriatric wards in acute hospitals	Approx. 200
Instrument validation	To examine inter-rater-reliability and predictive validity of the developed instrument	Cross-sectional study	Individuals in nursing homes, specialized geriatric rehabilitation facilities, geriatric wards in acute hospitals	Approx. 30

3 Patients' view on health related aspects of functioning and disability of joint contractures: A qualitative interview study based on the International Classification of Functioning, Disability and Health (ICF)

Uli Fischer[1,†], Gabriele Bartoszek[2,†]
Martin Müller[1,3]
Ralf Strobl[1]
Gabriele Meyer[2,4]
Eva Grill[1,3]

[1]Institute for Medical Information Processing, Biometrics and Epidemiology, Ludwig-Maximilians-Universität München, Munich, Germany
[2]School of Nursing Science, Witten/Herdecke University, Witten, Germany
[3]German Center for Vertigo and Balance Disorders, Ludwig-Maximilians-Universität München, Munich, Germany
[4]Institute for Health and Nursing Sciences, Martin-Luther-University Halle-Wittenberg, Halle, Germany

[†]Both authors contributed equally to the presented project.

[*]Corresponding author
Uli Fischer M.A.
Institute for Medical Information Processing, Biometrics and Epidemiology,
Ludwig-Maximilians-Universität, Marchioninistraße 17, 81377 München, Germany
Email: uli.fischer@med.uni-muenchen.de
Phone: +49 (0)89 2180-72433

This chapter was published as:

Disabil Rehabil. 2014 Mar 13. [Epub ahead of print]
Patients' view on health-related aspects of functioning and disability of joint contractures: a qualitative interview study based on the International Classification of Functioning, Disability and Health (ICF).
Fischer U, Bartoszek G, Müller M, Strobl R, Meyer G, Grill E

3.1 Abstract

Purpose

The aim of this study was to identify health-relevant aspects of functioning and disability of persons aged 65 years or older with joint contractures, to link the findings to corresponding ICF categories and to describe the patients' perspective.

Methods

We conducted 43 qualitative, semi-structured, face-to-face interviews with affected persons in two different locations (Witten, Munich) and in three different settings. Data was analysed using the "meaning condensation procedure" and then linked to ICF categories.

Results

From all interviews a total of 2499 single meaning-concepts were extracted which were linked to 324 different ICF categories. The participants in all settings mainly reported problems related to "Mobility of a single joint (b710)", "sensation of pain (b280)" and problems related to "Walking (d450)". Almost all participants reported "Products and technology for personal indoor and outdoor mobility and transportation (e120)" as a relevant environmental factor.

Conclusions

From the patients' perspective, joint contractures have an impact on multifaceted aspects of functioning and disability, mainly body functions, environmental factors and activities and participation. The results of this study will contribute to the development of a standard instrument for measuring functioning, disability and health-relevant aspects for patients with joint contractures.

Keywords

Joint contracture (MeSH)
Geriatric (MeSH)
Outcome Assessment (Health Care) (MeSH)
Social participation (MeSH)
Qualitative research (MeSH)

3.2 Purpose

Joint contractures are restrictions in the full range of motion of any joint due to deformity, disuse or pain. They are common problems of frail older people, particularly in nursing home residents [1]. However, contractures are mostly underreported in clinical and homecare settings.

Upper limb joint contractures may result in loss of ability to dress or eat independently while lower limb contractures may lead to instability and inability to walk independently and higher risk of bed confinement [2, 3]. Contractures further increase the risk of pain, pressure ulcers and risk of falls [4]. Thus, contractures are a major cause of excess disability in older people, i.e. greater impairment than one would expect based on the underlying disease. Preventive and rehabilitation interventions targeting joint contractures may decrease morbidity, increase functioning, and, ultimately, prevent long-term disability.

In clinical settings, measuring the range of motion assesses joint contractures. However, from a patient- and nursing-oriented perspective the relevance of a systematic registration of contractures in care-dependent older people is unclear unless their impact on functioning is understood. Contracture assessment is only an intermediate step in the evaluation of patient-relevant outcomes such as quality of life, functioning, and the ability to participate in everyday life and social participation. Severity should be measured by the consequences on activities of daily living, quality of life and social participation.

However, until now there is no consensus on which aspects of functioning are most relevant to the affected individuals [5]. A variety of functional measures is currently used for the assessment and evaluation of geriatric patients [6]. Consensus on the most relevant concepts would make it easier to decide on appropriate measures and to collect reliable data. Information on individuals' burden of disability due to joint contractures is a prerequisite for the development of tailored rehabilitation interventions targeted to vulnerable groups and specific situations.

Considering all this a common conceptual consensus needs to take into account the perspectives of affected persons. The International Classification of Functioning, Disability and Health (ICF) is likely to be a suitable common framework for this [7]. Based on the ICF it is possible to select sets of categories, the ICF Core Sets [8], out of the whole classification which can serve as minimal standards for the assessment of the consequences of contractures on functioning.

The aim of our project [9] is (1) to develop a standard set for the assessment of the impact of joint contractures on functioning and social participation in older individuals and (2) to develop and validate a standardized assessment instrument for describing and quantifying the impact of joint contractures on the individuals' functioning.

The objective of this study was to investigate the perspectives of patients with joint contractures and their experience of functioning, social participation and health using the ICF. The specific aim was to identify relevant aspects of functioning and health for patients with joint contractures expressed by ICF categories in various clinical settings.

3.3 Methods

Study design

In autumn/winter 2012 we conducted a series of qualitative semi-structured face-to-face interviews using a descriptive approach [10]. All interviews were audio-recorded and transcribed verbatim. The interviews were initiated as narrative interviews. The interviewers were supported by an interview guideline that has been designed to address the components of the ICF: Body Functions, Body Structures, Activities and Participation, and the contextual Environmental and Personal Factors. The interview guide was developed using the experience from earlier individual interview studies, with the focus to explore relevant aspects of functioning and health in different populations [11]. The initial question and the optional questions for the ICF components are shown in table 1.

Participants

Interviews were carried out either in post-acute geriatric rehabilitation hospitals, in nursing homes, or in community nursing settings. Inpatients were recruited at three post-acute geriatric rehabilitation hospitals in Munich and in the Munich catchment area (Klinikum Neuperlach, Klinikum Schwabing, Klinikum Haag); nursing home and community nursing patients were recruited in several facilities both in Witten and in the Witten catchment area (GVS mobile Pflege Herdecke, St. Anna Stift Bochum, Seniorenstift Haus Berge). Physicians or nurses of the facilities initially contacted potential participants.

Participants were included if they were 65 years or older, had a diagnosed joint contracture of at least one major joint (wrist, elbow, shoulder, hip, knee, ankle), had a Mini-Mental-State Examination score [12] of at least 24 points or above, were able to understand and speak German, and had provided informed written consent. To ensure that the reported impairments, restrictions and limitations were referring to joint contractures, the interviewers asked the respondents to focus on the specific consequences of contractures. During the interview they repeated this definition. Positive votes of the ethics committee of the Medical Faculty of the Ludwig-Maximilians-Universität in Munich and of the German Association of Nursing Sciences in Witten were obtained prior to the start of the study.

The interviews were carried out by two investigators (UF, GB) who were trained and supervised by the senior researchers (EG, MM & GM). The interviewers were not part of the health-care team of the respective facilities.

Additionally collected data

To describe the study sample, socio-demographic and disease specific data (age, sex, living situation, medical diagnosis) were collected. The location of the joint contracture was determined using the medical or physical therapists' report. Self-rated "global health" was assessed on a 6-point Likert scale where 1 indicates the optimum. For description of the functional status of nursing home residents we used the nursing care level assessed by expert raters of the medical service of the German health insurance system (none; 1=considerable; 2=severe; 3=most severe) [13]. The Barthel Index [14] was filled in either by nurses or by the interviewer. Cognitive status was assessed by physicians, nurses or the interviewer using the Mini-Mental-State Examination [12].

Qualitative Data Analysis

The "meaning condensation procedure" [15] was used for the analysis of data content. In the first step, the interview transcripts were read through to get an overview of incorporated meaningful concepts. In the second step, the text was divided into meaning units, and the dominating theme for this unit was determined. A meaning unit was defined as a specific unit of text, either a few words or a few sentences with a common theme. In the third step, the specific concepts contained in the meaning units were identified. For quality assurance reasons, the qualitative data analysis was conducted independently by two trained researchers (UF, GB). The results were compared and discussed.

Linking the answers to the ICF

The identified concepts were linked to the categories of the ICF according to established linking rules. The linking was carried out by two independent researchers who had had the necessary training (UF, GB) [16]. The results of the linking procedure were discussed until consensus was reached. In the case of any disagreement, a third researcher (MM) was consulted, who was also experienced in linking. See table 2 for a scheme of qualitative data analysis and linking.

Sample size

The sample size was determined by saturation. Saturation refers to the point at which an investigator has obtained sufficient information from the field [17]. In this study we defined saturation as the point during data collection and analysis when two interviews consecutively revealed less than 5% additional ICF categories. The sampling strategy adopted the idea of theoretical sampling from the grounded theory methodology [18]. In the selection process, the researchers tried to balance relevant characteristics of the participants, such as gender, age and disease, to ensure maximum sensitivity and to gather a maximum variety of experiences from the participants. Saturation was analysed separately for each setting.

3.4 Results

We conducted 43 individual interviews from May 2012 until December 2012 until saturation was reached. Characteristics of the participants are shown in table 3.
Age range of participants was 68 to 101, 31 were women. The interviewed persons had joint contractures in the upper extremities (shoulder n=20, arm n=3 elbow n=6, hand n=3, carpus n=1, fingers n=12, thumb=2) and/or lower extremities (thigh n=1 hip n=17, knee n=16, foot n=1, ankle n=4, toes n=4, leg n=1).
We extracted 2499 single concepts from the interviews. The identified concepts were linked to 532 ICF categories; after removing duplicates 324 different single ICF categories remained. Ninety categories belonged to the component Body Functions (BF), 37 to the component Body Structures (BS), 144 to the component Activities and Participation (AP), and 53 to the component Environmental Factors (EF) (see table 4-7). Forty-five percent of all extracted concepts could not be linked to specific ICF categories. Most of them were related to health conditions such as specific surgery like total endoprosthesis and personal factors, such as special personal strategies of coping or emotional attitudes.
Most frequently, concepts were linked to categories of the component AP (n=661 of a total of n=1.386 linked concepts = 48 %). Twenty-three percent of concepts linked to categories of the component BF, 25% to categories of the component EF and 4% to categories of the component BS.
In the component BF, categories of the chapter Neuromusculoskeletal and movement-related functions (ICF code b710 – b789) were mentioned most frequently (n=90). In the component AP, categories of the chapter Walking and moving (d450 – d469) were mentioned most frequently (n=95).

> *"For five years I do not go out of the house because I cannot walk, since this [development of a knee contracture] happened." (d450 Walking - Pat. 015, female, aged 74, geriatric rehabilitation setting, knee contractures on both sides)*

> *"The main problem aren't the stairs, but I cannot hold on anywhere with this affected arm." (d4551 Climbing - Pat. 012, female, aged 73, geriatric rehabilitation setting, shoulder contractures on both sides)*

In the component EF, categories the chapter Support and relationships (e310 – e399) were mentioned most frequently (n=132). In the BS Structures related to movement (s710 – s799) were mentioned most frequently (n=40).
Besides the most prominent categories Sensation of pain (b280, n=39) and Mobility of joint functions (b710, n=36) of the component BF, which were reported by almost all participants,

many participants of all three settings reported problems related to emotional functions (b152, n=28).

> *“(…) I’m really burdened with that [shoulder contracture]. It makes me cry.” (b152 Emotional functions, b710 Mobility of joint function - Pat. 003, female, aged 74, post-acute setting, shoulder contracture on the right side)*

> *"(…) Well, I’m afraid of falling to the ground and that is something I cannot afford, because I’m insecure on my legs and my knees in general. (…) I do not have the normal strength.” (b152 Emotional functions - Pat. 009, female, aged 89, post-acute setting, shoulder and knee contractures on the right side)*

> *„(…) When I put something on the gas stove (…), then I have to think whether I can just go and get something from the bedroom (...).I know I’ve got enough time, but something in my head tells me, what if you fall on the way – there’s something on the stove, it might boil over and that would have serious consequences. So (…) I just have to stay there (…) because I’m afraid of falling.” (b152 Emotional functions - Pat. A05, female, aged 85, community-nursing setting, hip contracture on the right side, shoulder contracture on the left side, finger contractures on both sides)*

> *"(…) But I can’t manage the rollator any longer. It’s my arms. I can’t hold on. I’m always afraid of falling” (b152 Emotional functions - Pat. H07, female, nursing home setting, aged 77, knee and elbow contractures on both sides)*

In addition many participants reported problems with Walking (d450, n=33). Almost all participants reported support of Immediate family (e310, n=32) or Health professionals (e355, n=34) as relevant modifying environmental factors.

> *“(…) It is impossible that these two steps stop me from going out (…) take a taxi to the doctor; the taxi-driver helped me to go out and there I was, standing in front of the two steps. I wondered how I could go down those. That was one of those helpless moments. I couldn’t support myself. (…) but then they [the nurses] noticed and helped me down.” (e345 support of strangers, e355 support of health professionals - Pat. A01, male, aged 86, community-nursing setting, shoulder contracture on the right side, hip contracture on the left side)*

The next most frequent environmental factor was Health services, systems and policies (e580), which was mentioned by thirty-five participants. The results of the analysis of all interviews are shown in tables 4-7.

3.5 Discussion

This is one of the first studies to comprehensively examine consequences of joint contractures from the patients' perspective. We have demonstrated that persons with joint contractures report many different aspects of impairments in body functions and body structures, activity limitations and participation restrictions.

Categories from the component AP were most prominently captured, followed by categories covering the component BF. Various environmental and personal factors paint a multifaceted picture of functioning in persons with joint contractures. Our study showed that the ICF was a useful tool to code the various impairments and restrictions related to joint contractures and to describe disease-specific functioning.

With regard to the ICF component BF, participants reported that, apart from obvious aspects (e.g. pain in joints, mobility of joints), functions related to movement (e.g. muscle power, control of voluntary movement, gait pattern), emotional functions and motivation were relevant. It is commonly recognized in the literature that joint contractures have a considerable impact on movement-related functions [19-21]. However, these functions can be both the trigger and the cause of joint contractures and their immediate consequence [20, 22, 23]. It is not surprising that impairment associated with joint contractures had a strong impact on emotional functions like e.g. the fear of falling.

The large number of different categories of the ICF component AP that were mentioned as relevant in our study show how strongly the joint contractures affect daily life. The reported categories ranged from basic activities such as walking, climbing stairs, hand and arm use up to more complex procedures such as preparing meals, shopping, doing housework and maintaining one's health. This is supported by the literature [4, 24-26]. Participants also reported that there is a high dependency on aids and appliances and they need support from other people.

In our study most participants perceived social participation to be largely restricted; mobility and community life were affected most but also personal and formal relationships and domestic life. This result is also reflective of previous publications [19].

In addition to the fact that over 40% of all identified concepts were linked to personal factors, the statements of various participants and the current literature suggest that joint contractures have a strong connection to coping strategies, individual fears and specific response strategies to disability [27].

Several limitations of our study have to be mentioned: The defined inclusion criteria in this study probably do not reflect the typical population of older people who are affected by joint contractures. Especially very ill, old people, who have joint contractures, were excluded if they were not able to provide information. This is a common problem for studies that rely on the lived experience of a generally multimorbid population.
It was not intention of our study (and of qualitative studies in general) to draw generalizing conclusions on expectations and experiences, or to report representative outcomes in various subgroups. Rather, the results of our study should provide a pool of patient-relevant items to be investigated with respect to prevalence and change over time in future studies. The inherent selection bias has to be kept in mind when interpreting the results.

3.6 Conclusions

From the patients' perspective, joint contractures have impact on multifaceted aspects of functioning and disability, mainly body functions and activities and participation. Modifying contextual factors have to be taken into account to cover the complex interaction between health conditions and the individuals' daily life.

3.7 Supplement

Acknowledgements

We would like to express our gratitude to the participants for sharing their experiences in spite of the challenge of illness. We also thank the teams of the study centers, especially Stephan von Clarmann for recruiting the patients and support during field work.

Declaration of interest

The authors declare that they have no conflicts of interest. This project was supported by funds from the German Federal Ministry of Education and Research under the Grant codes: 01GY1113A and 01GY1113B. The authors bear full responsibility for the content of this publication.

Authors' contributions

MM, EG and GM designed the study and got the funding. UF and GB carried out the interviews and conducted the data collection and data processing. UF, GB and RS analysed the data. UF and GB interpreted the results and contributed in drafting the manuscript. UF revised the manuscript. All authors read and approved the final manuscript.

3.8 References

[1.] Harrington, C., Nursing Facilities, Staffing, Residents and Facility Deficiencies, 2003 Through 2008. 2009, Department of Social and Behavioral Sciences, University of California.

[2.] Rabiner, A., et al., Characteristics of Nursing Home Residents with Contractures. Physical & Occupational Therapy in Geriatrics, 1996. 13(4): p. 1-10.

[3.] Fergusson, D., B. Hutton, and A. Drodge, The epidemiology of major joint contractures: a systematic review of the literature. Clinical orthopaedics and related research, 2007. 456: p. 22-9.

[4.] Wagner, L.M., et al., Contractures in frail nursing home residents. Geriatric nursing (New York, N Y), 2008. 29(4): p. 259-66.

[5.] Fischer, U., M. Muller, and E. Grill, [Integrating the perspective of all involved. Development of an assessment instrument for measuring the effect of joint contractures on functional capacity and social participation]. Pflege Z, 2013. 66(1): p. 20-4.

[6.] Offenbacher, M., et al., Contractures with special reference in elderly: definition and risk factors - a systematic review with practical implications. Disabil Rehabil, 2013.

[7.] World Health Organisation, International Classification of Functioning, Disability and Health: ICF. 2001, Geneva: WHO.

[8.] Grill, E., et al., ICF Core Sets development for the acute hospital and early post-acute rehabilitation facilities. Disabil Rehabil, 2005. 27(7-8): p. 361-6.

[9.] Muller, M., et al., Impact of joint contractures on functioning and social participation in older individuals -- development of a standard set (JointConFunctionSet): study protocol. BMC Geriatr, 2013. 13(1): p. 18.

[10.] Sandelowski, M., Whatever happened to qualitative description? Res Nurs Health, 2000. 23(4): p. 334-40.

[11.] Mueller, M., et al., Identification of aspects of functioning, disability and health relevant to patients experiencing vertigo: a qualitative study using the international classification of functioning, disability and health. Health Qual Life Outcomes, 2012. 10: p. 75.

[12.] Folstein, M.F., S.E. Folstein, and P.R. McHugh, “Mini-mental state”: A practical method for grading the cognitive state of patients for the clinician. Journal of Psychiatric Research, 1975. 12(3): p. 189-198.

[13.] Dalichau, G., H. Grüner, and L. Müller-Alten, Pflegeversicherung, Sozialgesetzbuch (SGB), Elftes Buch. (XI), Kommentar. 2002.

[14.] Mahoney, F.I. and D.W. Barthel, Functional Evaluation: The Barthel Index. Md State Med J, 1965. 14: p. 61-5.

[15.] Kvale, S., Interviews - An Introduction to Qualitative Research Interviewing. 1996: Sage Publications.

[16.] Cieza, A., et al., ICF linking rules: an update based on lessons learned. J Rehabil Med, 2005. 37(4): p. 212.
[17.] Karlsson, G., Psychological Qualitative Research from a Phenomenological Perspective. 1995, Stockholm: Almquist & Wiskell International.
[18.] Barney G. Glaser and Anselm L. Strauss, The Discovery of Grounded Theory. Strategies for Qualitative Research. 1967: Aldine Transaction.
[19.] Clavet, H., et al., Joint contractures in the intensive care unit: association with resource utilization and ambulatory status at discharge. Disability & Rehabilitation, 2011. 33(2): p. 105-112.
[20.] Clavet, H., et al., Joint contracture following prolonged stay in the intensive care unit. CMAJ, 2008. 178(6): p. 691-7.
[21.] Singer, B.J., et al., Non-surgical management of ankle contracture following acquired brain injury. Disability & Rehabilitation, 2004. 26(6): p. 335-345.
[22.] IQP, I.f.Q.i.d.P.-. Kontrakturprävention in der Langzeitpflege Älterer. Stand der Forschung und Bedeutung für die Praxis. 2011.
[23.] Scheffel, S. and V. Hantikainen, [Preventive measures for the prophylaxis of contractures in geriatric nursing. A systematic review]. Pflege, 2011. 24(3): p. 183-94.
[24.] Mollinger, L.A. and T.M. Steffen, Knee flexion contractures in institutionalized elderly: prevalence, severity, stability, and related variables. Physical therapy, 1993. 73(7): p. 437-44; discussion 444-6.
[25.] Fox, P., et al., Effectiveness of a bed positioning program for treating older adults with knee contractures who are institutionalized. Physical therapy, 2000. 80(4): p. 363-72.
[26.] Fox, P., et al., Bed Positioning Programs for Older Adults in a Chronic Care Hospital-A Survey. Physical & Occupational Therapy in Geriatrics, 1997. 15(1): p. 75-89.
[27.] De, S.D., A.-M. Vranceanu, and D.C. Ring, Contribution of Kinesophobia and Catastrophic Thinking to Upper-Extremity-Specific Disability. The Journal of Bone & Joint Surgery, 2013. 95(1): p. 76-81.

3.9 Figures and tables

Table 1 – Interview scheme

Initial question	When did the joint contracture occur for the first time? How many years ago?
Body Functions	If you think about the functions of your body, your mind and your soul, what does not work the way it is supposed to?
Body Structures	If you think about your body, which parts cause problems?
Activities and Participation	If you think about your daily life, what are your problems? If you compare your life before the joint contracture occurred with your life now, what has changed?
Environmental Factors	If you think about your environment and your living conditions, what do you find helpful or supportive? What barriers do you experience?
Personal Factors	If you think about yourself, what is crucial when handling your current situation?

Table 2 - Scheme of qualitative data analysis and linking

Interview text	Meaning unit	ICF category
„I used to go swimming every week, but I can`t swim anymore (…)."	Unable to swim	d4554 Swimming
„My daughter helps me with (…)."	The patient gets help from the daughter	e310 Immediate family

Table 3 Characteristics of the study population (n=43)

		Mean	SD	Median	Range
Age, years		80.44	7.73	80	68-101
Barthel Index[1]		54.30	21.34	55	10-100
MMSE[2]		26.19	2.03	26	22-30
		N	**%**		
Sex	female	31	72.1		
Living situation	alone	14	32.6		
	with family	16	37.2		
	nursing home	13	30.2		
Nursing care level[3]	none	17	39.5		
	1	16	37.2		
	2	7	16.3		
	3	3	7.0		
Location of contracture[4]	upper extremity	47	---		
	lower extremity	44	---		
Setting	post-acute geriatric rehabilitation	18	41.9		
	home care	12	27.9		
	nursing home	13	30.2		
Study centre	Munich	18	41.9		
	Witten/Herdecke	25	58.2		

[1] Barthel Index: 1-100, indicating 100 = no impairment in activities of daily life

[2] Mini-Mental-Status-Examination: 0-30, indicating 30= no cognitive impairment

[3] Nursing care level: none, 1-3, indicating 1 means up to 90 minutes care requirement per day, 2 means up to 180 minutes/d, 3 up to 300 minutes/d

[4] We counted every single joint contracture.

Table 4 – ICF categories relevant in study population with joint contractures (ICF component body functions)

ICF code	ICF label	Frequency post-acute geriatric rehabilitation setting (Munich)	Frequency community nursing setting (Witten)	Frequency Nursing homes setting (Witten)	Frequency Overall
b114	Orientation functions			1	1
b126	Temperament and personality functions	3	1		4
b130	Energy and drive functions	3	3	5	11
b144	Memory functions		2	2	4
b152	Emotional functions	12	5	11	28
b156	Perceptual functions			1	1
b160	Thought functions			2	2
b164	Higher-level cognitive functions			1	1
b167	Mental functions of language			1	1
b176	Mental function of sequencing complex movements			1	1
b180	Experience of self and time functions	2			2
b210	Seeing functions	1		2	3
b230	Hearing functions		1		1
b235	Vestibular functions			1	1
b240	Sensations associated with hearing and vestibular function	1			1
b260	Proprioceptive function			1	1
b265	Touch function		4	4	8
b270	Sensory functions related to temperature and other stimuli		1	1	2
b280	Sensation of pain	15	12	12	39
b289	Sensation of pain, other specified and unspecified		1	1	2
b310	Voice functions			1	1
b340	Alternative vocalization functions		1	1	2
b430	Haematological system functions	2			2
b435	Immunological system functions	2		2	4
b450	Additional respiratory functions		1		1
b515	Digestive functions			1	1
b525	Defecation functions		1	1	2
b530	Weight maintenance functions		1		1
b550	Thermoregulatory functions			1	1
b620	Urination functions			2	2
b7	Neuromusculoskeletal and Movement-Related Functions	3			3
b710	Mobility of joint functions	12	12	12	36
b720	Mobility of bone functions		1	2	3

b729	Functions of the joints and bones, other specified and unspecified			2	2
b730	Muscle power functions	3	3	8	14
b735	Muscle tone functions	2	1	1	4
b740	Muscle endurance functions			1	1
b750	Motor reflex functions		1		1
b760	Control of voluntary movement functions	2	1	7	10
b765	Involuntary movement functions			2	2
b770	Gait pattern functions	5		3	8
b780	Sensations related to muscles and movement functions	1	1	4	6
b810	Protective functions of the skin		1	1	2
b820	Repair functions of the skin	1	1	1	3
b840	Sensation related to the skin			1	1

Table 5 - ICF categories relevant in patients with joint contractures (ICF component activities and participation)

ICF code	ICF label	Frequency post-acute geriatric rehabilita-tion setting (Munich)	Frequency community nursing setting (Witten)	Frequency Nursing homes setting (Witten)	Frequency Overall
d	Activities and Participation	1			1
d110	Watching	1			1
d115	Listening			1	1
d155	Acquiring skills	1		3	4
d159	Basic learning, other specified and unspeci-fied			1	1
d160	Focusing attention			1	1
d163	Thinking	1			1
d166	Reading	2		1	3
d170	Writing	3	2	3	8
d175	Solving problems		7	3	10
d177	Making decisions			1	1
d210	Undertaking a single task		1	2	3
d230	Carrying out daily routine		2	5	7
d240	Handling stress and other psychological demands			1	1
d350	Conversation	1			1
d360	Using communication devices and tech-niques	1		1	2
d4	Mobility	2			2
d410	Changing basic body position	6	11	10	27
d415	Maintaining a body position	7	6	3	16
d420	Transferring oneself			6	6
d430	Lifting and carrying objects	1	2	2	5
d435	Moving objects with lower extremities			2	2
d440	Fine hand use	2	4	8	14
d445	Hand and arm use	7	4	9	20
d449	Carrying, moving and handling objects, other specified and unspecified		1		1
d450	Walking	16	10	7	33
d455	Moving around	6	7	7	20
d460	Moving around in different locations	5	8	9	22
d465	Moving around using equipment	1	9	10	20
d470	Using transportation	4	7		11
d475	Driving	7	5		12
d5	Self-care	1			1
d510	Washing oneself	7	8	7	22

d520	Caring for body parts		3	3	6
d530	Toileting		6	9	15
d540	Dressing	4	7	9	20
d550	Eating	2	3	8	13
d560	Drinking	1	3	2	6
d570	Looking after one's health	10	1	3	14
d598	Self-care, other specified		1	1	2
d610	Acquiring a place to live	1			1
d620	Acquisition of goods and services	11	2	1	14
d630	Preparing meals	12	5	5	22
d640	Doing housework	13	3	2	18
d650	Caring for household objects	10	1	2	13
d660	Assisting others	4			4
d720	Complex interpersonal interactions	1			1
d740	Formal relationships	1	1		2
d750	Informal social relationships	2	5		7
d760	Family relationships	1	7	6	14
d770	Intimate relationships			1	1
d845	Acquiring, keeping and terminating a job	6	1		7
d850	Remunerative employment		1		1
d865	Complex economic transactions	1	1		2
d870	Economic self-sufficiency	2		1	3
d910	Community life	1	1	3	5
d920	Recreation and leisure	7	7	8	22
d930	Religion and spirituality		3	1	4

Table 6 - ICF categories relevant in patients with joint contractures (ICF component environmental factors)

ICF code	ICF label	Frequency post-acute geriatric rehabilitation setting (Munich)	Frequency community nursing setting (Witten)	Frequency Nursing homes setting (Witten	Frequency Overall
e110	Products or substances for personal consumption	7	9	5	21
e115	Products and technology for personal use in daily living	4	10	9	23
e120	Products and technology for personal indoor and outdoor mobility and transportation	14	8	12	34
e125	Products and technology for communication		4	1	5
e135	Products and technology for employment	1			1
e140	Products and technology for culture, recreation and sport		2		2
e145	Products and technology for the practice of religion and spirituality			1	1
e150	Design, construction and building products and technology of buildings for public use			1	1
e155	Design, construction and building products and technology of buildings for private use	5		1	6
e165	Assets			1	1
e225	Climate	4	3	2	9
e245	Time-related changes		3	1	4
e255	Vibration	1			1
e3	Support and relationships	5			5
e310	Immediate family	15	9	8	32
e315	Extended family	4	2		6
e320	Friends	3	1		4
e325	Acquaintances, peers, colleagues, neighbours and community members	11	4	1	16
e340	Personal care providers and personal assistants	9	7	10	26
e345	Strangers	1	1	1	3
e350	Domesticated animals	1			1
e355	Health professionals	15	10	9	34
e360	Other professionals	1	3		4
e399	Support and relationships, unspecified		1		1
e410	Individual attitudes of immediate family members	2		1	3
e425	Individual attitudes of acquaintances, peers, colleagues, neighbours and community members	1			1
e450	Individual attitudes of health professionals	2			2
e5	Services, systems and policies	1			1
e520	Open space planning services, systems and policies	1			1
e530	Utilities services, systems and policies		1		1
e540	Transportation services, systems and policies	2		1	3

e555	Associations and organizational services, systems and policies			1	1
e570	Social security services, systems and policies	3	2	1	6
e575	General social support services, systems and policies	2	1		3
e580	Health services, systems and policies	15	9	11	35
e590	Labour and employment services, systems and policies	1			1

Table 7 - ICF categories relevant in patients with joint contractures (ICF component body structures)

ICF code	ICF label	Frequency post-acute geriatric rehabilitation setting (Munich)	Frequency community nursing setting (Witten)	Frequency Nursing homes setting (Witten	Frequency Overall
s120	Spinal cord and related structures	1			1
s410	Structure of cardiovascular system	1			1
s550	Structure of pancreas		1		1
s710	Structure of head and neck region	1			1
s720	Structure of shoulder region	3	3		6
s730	Structure of upper extremity	2	4	4	10
s740	Structure of pelvic region	1	1	3	5
s750	Structure of lower extremity	5	4	4	13
s760	Structure of trunk	1	2		3
s770	Additional musculoskeletal structures related to movement		1	1	2
s810	Structure of areas of skin			2	2
s830	Structure of nails		1		1

3.10 Ethical appraisal

LMU LUDWIG-MAXIMILIANS-UNIVERSITÄT MÜNCHEN

ETHIKKOMMISSION BEI DER LMU MÜNCHEN

Ethikkommission ·Pettenkoferstr. 8 · 80336 München

Frau
Prof. Dr. E. Grill
Institut für IBE
Marchioninistr. 17
81377 München

Vorsitzender:
Prof. Dr. W. Eisenmenger
Telefon+49 (0)89 5160 - 5191
Telefax+49 (0)89 5160 - 5192
Ethikkommission@
med.uni-muenchen.de

www.ethikkommission.med.uni-muenchen.de

Postanschrift:
Pettenkoferstr. 8a
D-80336 München

Hausanschrift:
Pettenkoferstr. 8
D-80336 München

München, 26.03.2012 Hb/ cp

Titel:	**Einfluss von Gelenkkontrakturen auf die Funktionsfähigkeit und die soziale Teilhabe bei älteren Menschen - Entwicklung eines standardisierten Assessmentinstruments**
Antragsteller:	**Prof. Dr. Eva Grill, U. Fischer**
Projekt- Nr.	**087-12**

Sehr geehrte Frau Kollegin Grill,

besten Dank für Ihr Schreiben vom 19.03.2012 mit der Beantwortung unserer Fragen bzw. Erfüllung der Auflagen und den noch ausstehenden bzw. überarbeiteten Unterlagen (Studienprotokoll, Information und Einwilligungserklärung, Fragebögen).

Die Ethikkommission (EK) kann Ihrer Studie nun die ethisch-rechtliche Unbedenklichkeit zuerkennen.
Die EK geht davon aus, dass mit dem Vorhaben erst begonnen wird, wenn die Zustimmungen der Leiter der beteiligten Kliniken vorliegen; bitte dann nachreichen.

Vorsorglich möchte ich darauf hinweisen, dass auch bei einer positiven Beurteilung des Vorhabens durch die EK die ärztliche und juristische Verantwortung für die Durchführung des Projektes uneingeschränkt bei Ihnen und Ihren Mitarbeitern verbleibt.

Änderungen des Studienprotokolls sind der EK mitzuteilen.
Für Ihre Studie wünsche ich Ihnen viel Erfolg.

Mit freundlichen Grüßen

Prof. Dr. W. Eisenmenger
Vorsitzender der Ethikkommission

Dr. Beate Henrikus
Geschäftsstelle

N/ Mitglieder der Ethikkommission

P.S.: Bitte beachten Sie die aktuellen Richtlinien für Anträge an die Ethikkommission. Internetadresse: www.ethikkommission.med.uni-muenchen.de

4 Examining functioning and contextual factors in individuals with joint contractures from the health professional perspective using the ICF: an international internet-based qualitative expert survey

Uli Fischer, MA, RN[1,*]
Martin Müller, PhD, MPH, RN[1,2]
Ralf Strobl, PhD[1,2]
Gabriele Bartoszek, MScN, RN[3]
Gabriele Meyer, PhD, RN[3,4]
Eva Grill, PhD, MPH[1,2]

[1] Institute for Medical Information Processing, Biometrics and Epidemiology, Ludwig-Maximilians-Universität München, Munich, Germany
[2] German Center for Vertigo and Balance Disorders (DSGZ), Ludwig-Maximilians-Universität München, Munich, Germany
[3] School of Nursing Science, Witten/Herdecke University, Witten, Germany
[4] Institute of Health and Nursing Science, Martin-Luther-University Halle-Wittenberg, Halle, Germany

[*]Corresponding author
Uli Fischer M.A.
Institute for Medical Information Processing, Biometrics and Epidemiology,
Ludwig-Maximilians-Universität, Marchioninistraße 17, 81377 Munich, Germany
Email: uli.fischer@med.uni-muenchen.de
Phone: +49 (0) 89 2180-72433

This chapter is accepted for publication in:

Rehabilitation Nursing – Manuscript ID RNJ-13-11-000324.R2

4.1 Abstract

Purpose

The aim of this study was to identify disease-related aspects of functioning and disability in people with joint contractures from a health-professionals' perspective and to describe the findings, using categories of the International Classification of Functioning, Disability and Health (ICF).

Methods

We asked international health professionals for typical problems in functioning and important contextual factors of individuals with joint contractures using an internet-based open-ended questionnaire. All answers were linked to the ICF according to established rules. Absolute and relative frequencies of the linked ICF categories were reported.

Results

Eighty experts named 1785 meaning units which could be linked to 256 ICF categories. 24.2% of the categories belonged to the component Body Functions, 20.7% to Body Structures, 36.3% to Activities and Participation and 18.8% to Environmental Factors.

Conclusion

Health professionals addressed a large variety of functional problems and multifaceted aspects due to the symptom joint contractures.

Keywords

Contracture (MeSH)
Geriatric assessment (MeSH)
Activities of Daily Living (MeSH)
Social participation (MeSH)
Expert opinion (MeSH)

Key Practice Points

- Joint contractures are major causes for excess disability in older people.
- International health professionals address a large variety of aspects of functioning and health related to joint contractures.
- Mobility and support by others were frequently mentioned as aspects relevant for persons with joint contractures.
- The International Classification of Functioning, Disability and Health (ICF) provided a useful framework to capture the perspective of health care professionals.

4.2 Purpose

Functional limitations of joints are a common problem which often occurs in frail older people, particularly in nursing home residents [1]. In clinical and homecare settings, only few studies on joint contractures can be found, although the prevalence ranges from 24% up to 75% [2-4].

The impact and the cause of joint contractures are multifaceted. Joint contractures are accompanied by limitations in range of motion, deformity and disuse of affected joints. A person with upper limb joint contractures may be unable to drink or dress without aid, while lower limb contractures may cause unsteadiness of gait or confine the person to bed [4, 5]. Joint contractures are associated with nursing-relevant phenomena like pain, pressure ulcers and increased risk of falling [6]. Joint contractures may also represent a major cause of disability in frail older people. So prevention and treatment of joint contractures may possibly increase functioning, prevent long-term disability and decrease the overall burden of disease.

Recent literature reviews indicate that in patient care and research joint contractures are predominately assessed by determining the range of motion (ROM) [7, 8]. As opposed to ROM, which pursues a rather mechanistic approach, the assessment of the severity of joint contractures should be measured rather in terms of patient-relevant outcomes like the effects on activities and participation. From the patient and nursing perspective, a systematic assessment of contractures in care-dependent older people is only meaningful if the impact of contractures on activity and participation can be depicted.

Up to now, little is known about the consequences that are most relevant to the affected individuals [9]. With the exception of the use of a ROM measurement there is also no consensus about common concepts for the choice of outcome measures [2, 10]. The International Classification of Functioning, Disability and Health (ICF) is a framework to describe multifaceted consequences of a disease. It has been used to classify functioning for a large number of health-related problems. Thus it can be a basis for disease-specific nursing care plans and for identifying patient-specific targets for corresponding therapeutic treatments [11, 12].

The objective of this study is to explore the problems of older persons with joint contractures from the point of view of international experts. The specific aims of the study are (1) to identify relevant problems with functioning in patients with joint contractures from the perspective of health professionals involved in care or management of those patients and (2) to summarize the findings using the ICF.

4.3 Methods

Study design

This cross-sectional internet-based online survey was conducted between December 2012 and February 2013.

Participants for the online survey were included if they were recommended by national and international professional organizations, if they were authors of publications on joint contractures, or if already recruited participants recommended them.

Further inclusion criteria were (1) working as a health professional (physician, nurse, physical therapist, occupational therapist, psychologist, social worker), (2) a minimum of 5 years of experience in treatment of patients with joint contractures and (3) fluency in English. Experts were informed that the ICF would be used to analyse the responses but they were not asked if they had any expertise regarding the ICF terminology. Eligible participants were contacted by e-mail and provided with detailed information about the purpose of the study. Experts who consented to participate were provided with personalized login details for the survey website. We sent two email-reminders at intervals of two weeks, if there had been no participant-related activity on the survey website.

Recruitment

The initial database of experts comprised 573 health professionals from all five continents. After a first request, 95 out of 573 eligible experts (view rate: 16.6 %) agreed to participate in the survey, 25 refused participation and 421 did not answer our requests and reminders. Among the experts who initially agreed to participate eighty-four (88.4%) completed the questionnaire. Four experts had to be excluded because they did not fulfill the inclusion criteria. Response rate was 84.2%.

Questionnaire

The questionnaire consisted of two parts. The first part asked for demographic and professional characteristics: Age, sex, profession, special field of expertise and length of professional expertise. The second part consisted of five open questions that asked for specification of the problems in functioning as well as relevant environmental and personal factors of patients suffering from joint contractures (see table 1).

Survey development and data collection procedure

The survey was programmed based on the questionnaire, showing one question per webpage and using open-source software. All screens had a review button and a non-response option. Completeness was checked automatically before submission. We tested the survey in terms of usability, technical functionality and data security.

All experts who agreed to participate got a personalized email with a single access-link to the website of the internet survey in order to protect any unauthorized access. This email also included detailed information about the estimated length of the survey, data protection and

data analysis. In case the experts experienced any technical problems when entering data on this website, we offered technical support or sent them an equivalent case record form per mail. The answers were kept anonymous by using an irreversible numeric encryption method. We used the provided automatic method for feeding the responses into the database.

Linking to ICF

The ICF includes more than 1.400 disjunctive categories, which are structured in hierarchical manner. The letters b, s, d, and e refer to the components Body Functions, Body Structures, Activities and Participation, and Environmental Factors. They are followed by a numeric code starting with the chapter number (1 digit), for example b7 Neuromusculoskeletal and movement-related functions, followed by the second level (2 digits), for example b710 Mobility of joint functions.

All answers we retrieved from the experts were divided into meaning units that were translated ('linked') to the ICF using established linking rules [13].

In the context of this analysis, a meaning unit was defined as a distinct, manageable unit containing a node word and other words within its context that were needed to disambiguate this word. To give an example, the sentence "patients have problems with gait disturbance" contains the meaning unit "gait disturbance".

A sentence would be split into one or more meaning units which could then be linked to the respective ICF category. If an answer was too general to allow a decision on the linkage to a specific ICF category - for example, 'good living conditions' - the concept was regarded as 'not defined'. The most frequent concepts which have been regarded as 'not defined' were "disability (n=3)", "quality of life (n=2)" and "many aspects of living are affected (n=2)".

If an answer pertained to personal factors, which are not coded within the ICF system, the code 'personal factor' was attributed, e.g. 'acceptance of condition' or 'coping strategies'.

Quality assurance procedures

Two researchers carried out the linking procedure independently. The researchers involved in this process participated in a formal two-day hands-on training about extracting meaning units and linking them to the ICF. This training is an external formalized program supervised and conducted by the ICF Research Branch. In case of disagreement, the results were discussed. If consensus could not be reached, a third experienced researcher (MM) was consulted who supervised the whole process. After linking all the answers, the results were checked by RS and UF with regard to irregularities and implausibility. To assure the quality of data reporting we used the guidelines from the CHERRIES protocol [14].

Data analysis

We calculated absolute and relative frequencies of the linked ICF categories. ICF categories are presented at all levels of the ICF. Data analyses were carried out using R [15].

4.4 Results

Participants

The characteristics of the participants are shown in table 3. Most of the participants were physical therapists (35%), followed by nurses (27.5%), physicians (17.5%) and occupational therapists (6.3%). The remaining participants came from other professions like epidemiology, bioengineering, sports sciences and education. The mean number of years of general professional experience was 24.7 years (SD 9.5). The mean number of years of professional experience with patients with joint contractures was 19.1 years (SD 8.2).

Expert Survey

In total, 1.785 meaning units were identified from the experts' answers. From those we extracted 2280 single concepts. Two thousand and forty (89.5%) of them could be linked to ICF categories. 5% of the concepts were regarded as 'not defined', 3.6% were regarded as 'personal factors' and 1.9% were general statements about 'activities and participation' which could not be linked to a specific ICF category. Five hundred and six nominations were from the component "Body Functions", 619 nominations from the component "Activities and Participation", 521 nominations from the component "Environmental factors", and 394 nominations from the component "Body Structures". After removing duplicates, 256 different unique ICF categories were identified as relevant from the experts' perspective. Sixty-two belonged to the component "Body Functions" (BF), 93 to the component "Activities and Participations" (AP), 48 to the component "Environmental Factors" (EF) and 53 to the component "Body Structures" (BS).

In the component BF, categories from the chapter 'Neuromusculoskeletal and movement-related functions (ICF code b710 – b789)' were mentioned most frequently (n=100) followed by 'Pain (b280-b289)' (n=54). In the component AP, the majority of categories mentioned were from the chapter 'Mobility (d410-d499)' (n=180).

In the component EF, categories from the chapter 'Products and technology (e110 – e199)' were mentioned most frequently (n=131). In the BS 'Structures related to movement (s710 – s799)' were those most often mentioned (n=300).

'Sensation of pain (b280, n=46)', Mobility of joint functions (b710, n=42) and 'walking (d450, n=24)' were linked most frequently. Support of 'health professionals (e310, n=34)', 'health services, systems and policies (e580, n=33)' and support of 'immediate (e310)' and 'extended family (e315)'were mentioned as most relevant environmental factors. The detailed results are shown in table 4.

4.5 Discussion

To the best of our knowledge, this is the first internet survey examining the problems of individuals with joint contractures from a worldwide multi-professional healthcare perspective. We used the ICF as a reference that provides a neutral framework and language. The experts addressed a large variety of aspects in functioning and health.

The majority of the retrieved ICF categories referred to limitations in the component 'Activities and Participation' followed by impairments in 'Body Functions'.

This is in line with studies which conclude that the health- and social-relevant impact of joint contractures is multifaceted and influences the activities of daily life and social participation of affected people [5, 16, 17]. The chapter 'Mobility (d4)' in the ICF component "Activities and participation", specifically the category 'walking (d450)', was mentioned by several experts. This finding is confirmed by studies that report a high correlation between joint contractures and impaired mobility [3, 10, 18-20]. Categories from the chapter 'self-care (d5)' like 'washing (d510)', 'dressing (d540)' and 'eating (d550)' are also frequently mentioned. In contrast to recent literature, in our study the category 'Acquiring, keeping and terminating a job (d845)' was named by many experts and allows us to conclude that this category seems to be strongly associated by healthcare professionals, who are specialized in treatment of joint contractures. The impact of joint contractures on activities of daily life is shown by the large number of different categories of the ICF component Activities and Participation, as is reported in previous studies [2, 21].

With regard to the ICF component Body Functions, the experts report that, in addition to well-known aspects like 'pain (b280)' and functions related to 'movement (b7)', the categories 'psychic stability (b1263)', 'body image (b1801)' and 'optimism (b1265)' are particularly relevant. It is commonly recognized in literature that joint contractures have a considerable impact on emotional and psychological condition of affected persons [22, 23].

It is not surprising that 76.1% of all derived categories from the component Body Structures are categories from chapter 7 'structures related to movement'. The frequent mention of the category 'Structure of areas of skin (s810)' reflects the danger of pressure sores in these patients [19].

In general, an internet-based open-ended survey seems to be a suitable method to explore the perspective of international experts on problems of older persons with joint contractures. The participation rate was as high as in comparable studies [24, 25]. Inclusion of different professions and areas of expertise across several continents guaranteed a wide range of expert opinions.

Some limitations of our study have to be mentioned. The procedure of linking the patients' problems reported by health professionals to the appropriate ICF categories is very complex and depends on several factors, among those the exercise and the routine use of the ICF.

Earlier linking exercises, however, have demonstrated that it is possible to examine and compare the content of qualitative statements based on the ICF framework and predefined linking rules [26, 27].

4.6 Conclusion

In our survey international health professionals, especially nurses and physical therapists, reported a large variety of aspects of functioning and health, which are related to joint contractures. Mobility and support by others came up as the most relevant aspects.

4.7 Supplement

Acknowledgements

We would like to express our gratitude to the participants of the survey. We also thank the administration team of “https://www.soscisurvey.de” for their support. Our special thanks go to the research assistants Stefanie Schmid, Anne Frank and Alicja Ludyga for their commitment and support.

Authors' contributions

MM, EG and GM designed the study and got the funding. UF designed, programmed and conducted the survey. MM and UF supervised data collection and data processing. RS and UF analyzed the data. UF interpreted the results and contributed in drafting the manuscript. All authors read and approved the final manuscript.

Declaration of interest

The authors declare that they have no conflicts of interest. This project was supported by funds from the German Federal Ministry of Education and Research under the Grant codes: 01GY1113A and 01GY1113B. The authors bear full responsibility for the content of this publication.

4.8 References

[1.] Harrington, C., Nursing Facilities, Staffing, Residents and Facility Deficiencies, 2003 Through 2008. 2009, Department of Social and Behavioral Sciences, University of California.

[2.] Mollinger, L.A. and T.M. Steffen, Knee flexion contractures in institutionalized elderly: prevalence, severity, stability, and related variables. Physical therapy, 1993. 73(7): p. 437-44; discussion 444-6.

[3.] Souren, L.E., E.H. Franssen, and B. Reisberg, Contractures and loss of function in patients with Alzheimer's disease. Journal of the American Geriatrics Society, 1995. 43(6): p. 650-5.

[4.] Rabiner, A., et al., Characteristics of Nursing Home Residents with Contractures. Physical & Occupational Therapy in Geriatrics, 1996. 13(4): p. 1-10.

[5.] Fergusson, D., B. Hutton, and A. Drodge, The epidemiology of major joint contractures: a systematic review of the literature. Clinical orthopaedics and related research, 2007. 456: p. 22-9.

[6.] Wagner, L.M., et al., Contractures in frail nursing home residents. Geriatric nursing (New York, N Y), 2008. 29(4): p. 259-66.

[7.] Offenbacher, M., et al., Contractures with special reference in elderly: definition and risk factors - a systematic review with practical implications. Disabil Rehabil, 2013.

[8.] Gnass, I., et al., Joint contractures in older age. A systematic literature review. Z Gerontol Geriatr, 2010. 43(3): p. 147-57.

[9.] Fischer, U., M. Muller, and E. Grill, [Integrating the perspective of all involved. Development of an assessment instrument for measuring the effect of joint contractures on functional capacity and social participation]. Pflege Z, 2013. 66(1): p. 20-4.

[10.] Katalinic, O.M., L.A. Harvey, and R.D. Herbert, Effectiveness of stretch for the treatment and prevention of contractures in people with neurological conditions: a systematic review. Physical therapy, 2011. 91(1): p. 11-24.

[11.] Lohmann, S., et al., The ICF forms a useful framework for classifying individual patient goals in post-acute rehabilitation. Journal of rehabilitation medicine : official journal of the UEMS European Board of Physical and Rehabilitation Medicine, 2011. 43(2): p. 151-5.

[12.] Mueller, M., et al., Identification of ICF categories relevant for nursing in the situation of acute and early post-acute rehabilitation. BMC Nurs, 2008. 7: p. 3.

[13.] Cieza, A., et al., ICF linking rules: an update based on lessons learned. Journal of rehabilitation medicine : official journal of the UEMS European Board of Physical and Rehabilitation Medicine, 2005. 37(4): p. 212-8.

[14.] Eysenbach, G., Improving the quality of Web surveys: the Checklist for Reporting Results of Internet E-Surveys (CHERRIES). J Med Internet Res, 2004. 6(3): p. e34.

[15.] R Core Team, R: A Language and Environment for Statistical Computing. 2012, R Foundation for Statistical Computing: Vienna, Austria.
[16.] Resnick, B., Functional performance and exercise of older adults in long-term care settings. Journal of gerontological nursing, 2000. 26(3): p. 7-16.
[17.] Trudel, G., H.K. Uhthoff, and M. Brown, Extent and direction of joint motion limitation after prolonged immobility: an experimental study in the rat. Arch Phys Med Rehabil, 1999. 80(12): p. 1542-7.
[18.] Selikson, S., K. Damus, and D. Hamerman, Risk factors associated with immobility. J Am Geriatr Soc, 1988. 36(8): p. 707-12.
[19.] Clavet, H., et al., Joint contracture following prolonged stay in the intensive care unit. CMAJ, 2008. 178(6): p. 691-7.
[20.] Clavet, H., et al., Joint contractures in the intensive care unit: association with resource utilization and ambulatory status at discharge. Disability & Rehabilitation, 2011. 33(2): p. 105-112.
[21.] Fox, P., et al., Effectiveness of a bed positioning program for treating older adults with knee contractures who are institutionalized. Physical therapy, 2000. 80(4): p. 363-72.
[22.] Akkaya, N., et al., Impact of body image on quality of life and mood in mastectomized patients and amputees in Turkey. Asian Pac J Cancer Prev, 2011. 12(10): p. 2669-73.
[23.] Jolly, M., Body image issues in rheumatology, in Body image: A handbook of science, practice, and prevention (2nd ed.). T.F. Cash and L. Smolak, Editors. 2011, Guilford Press: New York, NY US. p. 350-357.
[24.] Weigl, M., et al., Identification of relevant ICF categories in patients with chronic health conditions: a Delphi exercise. J Rehabil Med, 2004(44 Suppl): p. 12-21.
[25.] Scheuringer, M., et al., Identification of problems in individuals with spinal cord injury from the health professional perspective using the ICF: a worldwide expert survey. Spinal Cord, 2010. 48(7): p. 529-36.
[26.] Schaffler, F., et al., Consequences of visual height intolerance for quality of life: a qualitative study. Qual Life Res, 2013.
[27.] Mueller, M., et al., Identification of aspects of functioning, disability and health relevant to patients experiencing vertigo: a qualitative study using the international classification of functioning, disability and health. Health Qual Life Outcomes, 2012. 10(1): p. 75.

4.9 Figures and tables

Figure 1 – Eligible and responders

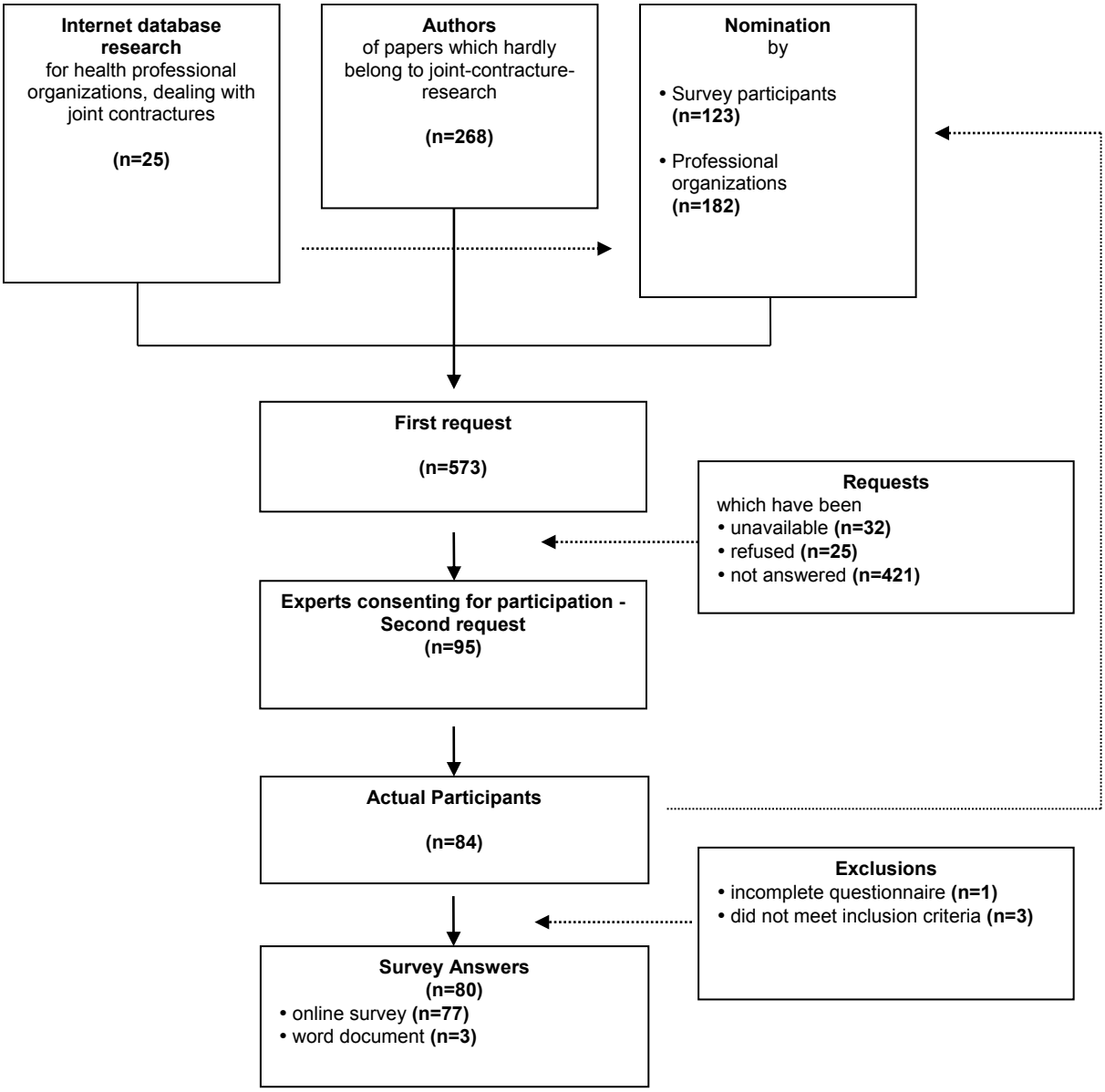


Table 1 – Second part of the online questionnaire

Body Functions	If you think about the body and mind of individuals with contractures, what does not work the way it is supposed to?
Body Structures	If you think about the body of individuals with contractures, in which parts are their problems?
Activities and Participation	If you think about the daily life of individuals with contractures, what are their problems?
Environmental Factors	If you think about the environment and the living conditions of individuals with contractures, what is supportive and / or what is hindering for them?
Personal Factors	If you think about individuals with contractures, what is important about them and the way they handle their condition?

Table 2 - Example of the linking procedure

Experts' answers	**Meaning unit**	**ICF category**
„difficulties in body care"	Limitation in caring for one self's body	d510 Washing oneself d520 Caring for body parts
„limited function of the limb with contracture"	Limitation of joint mobility	b710 Mobility of joint functions

Table 3 Characteristics of the experts (n=80)

Values are numbers (percentage) unless stated otherwise.

		Mean ± SD (range)	
Age, years		49.25 ± 8.93 (28-76)	
time of prof. expertise		24.68 ± 9.48 (6-50)	
contracture expertise		19.14 ± 8.15 (5-50)	
		N	**%**
Sex	female	46	57.5
	male	33	41.3
	missing	1	1.2
Continent	Europe	61	76.3
	Asia	1	1.2
	North/South America	6	7.5
	Australia	12	15.0
	Africa	0	
Profession	physician	14	17.5
	nurse	22	27.5
	physical therapy	28	35.0
	occupational therapy	5	6.3
	representative of professional organisation	1	1.2
	other	10	12.5
Area of expertise	neurology	19	23.8
single choice	orthopaedics	13	16.3
	geriatrics	12	15.0
	rehabilitation	11	13.7
	other	25	31.2
Main working field – location	hospital	48	60.0
Multiple choice possible	nursing home	13	16.3
	outpatient service	12	15.0
	home care	6	7.5
Main working field – role	education	33	41.3
Multiple choice possible	research	22	27.5
	management	6	7.5
	others	11	13.7

Table 4 - ICF categories (aggregated on 2nd level)

ICF	Label	Frequency
	BODY FUNCTIONS	
b110	Consciousness functions	1
b114	Orientation functions	1
b117	Intellectual functions	4
b126	Temperament and personality functions	29
b130	Energy and drive functions	15
b134	Sleep functions	3
b147	Psychomotor functions	1
b152	Emotional functions	9
b156	Perceptual functions	12
b164	Higher-level cognitive functions	12
b176	Mental function of sequencing complex movements	1
b180	Experience of self and time functions	18
b235	Vestibular functions	3
b260	Proprioceptive function	3
b265	Touch function	1
b280	Sensation of pain	50
b410	Heart functions	1
b420	Blood pressure functions	2
b440	Respiration functions	6
b445	Respiratory muscle functions	4
b455	Exercise tolerance functions	11
b510	Ingestion functions	1
b515	Digestive functions	2
b525	Defecation functions	2
b530	Weight maintenance functions	1
b540	General metabolic functions	1
b610	Urinary excretory functions	1
b620	Urination functions	2
b640	Sexual functions	3
b710	Mobility of joint functions	44
b715	Stability of joint functions	1
b720	Mobility of bone functions	1
b730	Muscle power functions	13
b735	Muscle tone functions	14
b740	Muscle endurance functions	4
b755	Involuntary movement reaction functions	4
b760	Control of voluntary movement functions	9
b765	Involuntary movement functions	1
b770	Gait pattern functions	2
b780	Sensations related to muscles and movement functions	4
b810	Protective functions of the skin	9
b820	Repair functions of the skin	9

b830	Other functions of the skin	1
	ACTIVITIES AND PARTICIPATION	
d155	Acquiring skills	2
d170	Writing	1
d175	Solving problems	1
d210	Undertaking a single task	12
d220	Undertaking multiple tasks	12
d230	Carrying out daily routine	3
d240	Handling stress and other psychological demands	6
d310	Communicating with - receiving - spoken messages	1
d315	Communicating with - receiving - nonverbal messages	3
d330	Speaking	2
d335	Producing nonverbal messages	1
d360	Using communication devices and techniques	1
d410	Changing basic body position	21
d415	Maintaining a body position	22
d420	Transferring oneself	11
d430	Lifting and carrying objects	3
d435	Moving objects with lower extremities	2
d440	Fine hand use	15
d445	Hand and arm use	13
d450	Walking	24
d455	Moving around	6
d465	Moving around using equipment	1
d470	Using transportation	1
d475	Driving	2
d510	Washing oneself	15
d520	Caring for body parts	3
d530	Toileting	4
d540	Dressing	13
d550	Eating	11
d560	Drinking	2
d570	Looking after one’s health	32
d630	Preparing meals	3
d640	Doing housework	4
d650	Caring for household objects	1
d660	Assisting others	3
d710	Basic interpersonal interactions	2
d760	Family relationships	1
d770	Intimate relationships	6
d810	Informal education	1
d820	School education	1
d845	Acquiring, keeping and terminating a job	22
d860	Basic economic transactions	2
d870	Economic self-sufficiency	2

d910	Community life	7
d920	Recreation and leisure	20
	ENVIRONMENTAL FACTORS	
e110	Products or substances for personal consumption	5
e115	Products and technology for personal use in daily living	28
e120	Products and technology for personal indoor and outdoor mobility and transportation	19
e125	Products and technology for communication	1
e135	Products and technology for employment	4
e140	Products and technology for culture, recreation and sport	1
e150	Design, construction and building products and technology of buildings for public use	13
e155	Design, construction and building products and technology of buildings for private use	16
e165	Assets	7
e225	Climate	4
e240	Light	1
e310	Immediate family	25
e315	Extended family	24
e320	Friends	8
e325	Acquaintances, peers, colleagues, neighbours and community members	4
e340	Personal care providers and personal assistants	12
e355	Health professionals	34
e360	Other professionals	2
e410	Individual attitudes of immediate family members	2
e415	Individual attitudes of extended family members	2
e420	Individual attitudes of friends	1
e430	Individual attitudes of people in positions of authority	1
e440	Individual attitudes of personal care providers and personal assistants	1
e450	Individual attitudes of health professionals	4
e520	Open space planning services, systems and policies	1
e540	Transportation services, systems and policies	4
e545	Civil protection services, systems and policies	1
e550	Legal services, systems and policies	1
e565	Economic services, systems and policies	1
e570	Social security services, systems and policies	3
e575	General social support services, systems and policies	3
e580	Health services, systems and policies	33
	BODY STRUCTURES	
s110	Structure of brain	1
s210	Structure of eye socket	1
s220	Structure of eyeball	1
s230	Structures around eye	1
s240	Structure of external ear	1
s250	Structure of middle ear	1
s260	Structure of inner ear	1
s310	Structure of nose	1
s320	Structure of mouth	2

s410	Structure of cardiovascular system	1
s420	Structure of immune system	1
s540	Structure of intestine	1
s710	Structure of head and neck region	11
s720	Structure of shoulder region	22
s730	Structure of upper extremity	39
s740	Structure of pelvic region	3
s750	Structure of lower extremity	35
s760	Structure of trunk	17
s770	Additional musculoskeletal structures related to movement	31
s810	Structure of areas of skin	17

4.10 Declaration of acceptance

Von: onbehalfof+Elaine.Miller+uc.edu@manuscriptcentral.com im Auftrag von Elaine.Miller@uc.edu
An: Fischer, Uli
Cc: gpannozzo@connect2amc.com
Thema: Rehabilitation Nursing - Decision on Manuscript ID RNJ-13-11-000324.R2
Datum: Mittwoch, 23. Juli 2014 02:32:36

22-Jul-2014

Dear Mr. Fischer:

It is a pleasure to inform you that your manuscript titled, "Examining functioning and contextual factors in individuals with joint contractures from the health professional perspective using the ICF: an international internet-based qualitative expert survey," has been accepted for publication in Rehabilitation Nursing.

AUTHOR SERVICES
Production Status Tracking - You can now track the production of your article using Wiley-Blackwell Publishing's Author Services. With Author Services, you can check the status of your article online, choose to receive automated emails at key stages of production, and receive free access to your article. When your article has been submitted to Wiley-Blackwell Publishing, you will receive an email with a unique code that automatically adds your article to the system when you register. In addition to providing article tracking alerts, Author Services is also the only way to receive a PDF offprint of your article. This PDF will automatically be uploaded to your author profile upon publication. For more information on this service, please visit authorservices.wiley.com.

Thank you for submitting this fine manuscript to Rehabilitation Nursing. We look forward to your continued contributions to the Journal.

Sincerely,
Dr. Elaine Miller
Editor-in-Chief, Rehabilitation Nursing
Elaine.Miller@uc.edu

Gail Pannozzo
Editorial Assistant
gpannozzo@connect2amc.com
Fax # 847/375.6441

5 Prevalence of functioning and disability in older patients with joint contractures: a cross-sectional study

U. Fischer[1], M. Müller[1,2], R. Strobl[1,2], G. Bartoszek[3], G. Meyer[3,4], E. Grill[1,2]

[1] Institute for Medical Information Processing, Biometrics and Epidemiology, Ludwig-Maximilians-Universität München, Munich, Germany
[2] German Center for Vertigo and Balance Disorders (DSGZ), Ludwig-Maximilians-Universität München, Munich, Germany
[3] School of Nursing Science, Witten/Herdecke University, Witten, Germany
[4] Institute of Health and Nursing Science, Martin-Luther-University Halle-Wittenberg, Halle, Germany

This chapter is accepted for publication in:

European Journal of Physical and Rehabilitation Medicine – Manuscript No.3525

and will be published as:

Eur J Phys Rehabil Med. 2014 Sep 5. [Epub ahead of print]
Prevalence of functioning and disability in older patients with joint contractures: a cross-sectional study.
Fischer U, Müller M, Strobl R, Bartoszek G, Meyer G, Grill E

5.1 Abstract

Background

Joint contractures are a common problem for older, frail people, particularly in rehabilitation, nursing home and homecare settings. Joint contractures are underreported and sparsely empirically investigated despite their high prevalence.

Aim

The objective of this study was to examine the prevalence of functional impairments, activity limitations and participation restrictions of patients with joint contractures using the International Classification of Functioning, Disability and Health (ICF) as a framework. We also examined contextual factors as potential mediators for functioning and disability.

Design

Cross-sectional study

Setting

Three acute-geriatric hospitals in and around Munich (Germany)

Population

Patients aged 65 and over with confirmed joint contractures requiring rehabilitation care

Methods

The patients were asked to answer a questionnaire that comprised 124 categories of the ICF. Patients' problems in functioning were registered separately for each category. Data were collected through face-to-face interviews with patients and health professionals and from patients' medical records.

Results

One hundred and fifty patients were eligible and agreed to participate. Mean age was 82.5 years (SD: 7.4), 64.8% of the patients were female.

Problems in 'muscle power functions' (95,9%) and 'driving human-powered transportation' (89,6%) were those most frequently identified. 'Health services, systems and policies' (98,6%) was the most frequent environmental facilitator.

Conclusion

Aged persons with joint contractures experience high levels of disability. Specifically, mobility, participation restrictions and interactions with the environment emerged as important issues of our study.

Clinical Rehabilitation Impact

Mobility and support by others were frequently mentioned as aspects relevant for persons with joint contractures. These aspects have to be considered when assessing the impact of joint contractures.

5.2 Introduction

Joint contractures cause functional restrictions and limitations of joint movement. They are a common problem for older, frail people, particularly in nursing home and homecare settings [1]. Joint contractures are underreported and hardly investigated despite their high prevalence [2-4].

Joint contractures limit the full range of motion and may therefore result in deformity and disuse of the affected joints. Upper limb joint contractures may be associated with the inability to dress or drink independently, while lower limb contractures may impair walking, consequently leading to a higher risk of bed confinement [4, 5]. In addition to an increased risk for pain and pressure ulcers, joint contractures increase the tendency of falls and may therefore be a relevant factor for further deterioration of functioning and ultimately for death[6]. There are a variety of therapeutic measures to prevent joint contractures; until today there is no empirical proof of their effectiveness [7].

As an increasing range of motion of the affected joint is hardly effective in older people[8], therapeutic, preventive and rehabilitative strategies should primarily focus on the various aspects of daily life and participation that are most important to the individual [9, 10]. However, there is no consensus on which aspects are most relevant for people suffering from joint contractures and should be assessed as part of routine care or to monitor the effect of interventions [2, 11, 12].

Nevertheless, range of motion (ROM) is still the most frequently reported outcome measure in clinical research on joint contractures [13, 14]. From the nursing and rehabilitation perspective, assessment should address patient-relevant outcomes, such as activity limitations and participation restrictions [15]. In addition, contextual factors that contribute to the impact of a certain condition on functioning and disability should be examined [16].

A detailed in-depth understanding of the burden of joint contractures on the affected individuals is a main prerequisite for the development of meaningful interventions. Considering that assessment is one of the basic preconditions of rehabilitation, a common conceptual basis and a common language must be taken into account.

The International Classification of Functioning, Disability and Health (ICF) is a suitable common framework for classifying functioning. Based on the ICF it is possible to select sets of categories, out of the whole classification, which can then serve as the minimal standard for the assessment of the consequences of contractures on functioning.

The objective of this study is to examine the prevalence of functional impairments, activity limitations and participation restrictions of patients with joint contractures using the ICF as a common framework. We also examined contextual factors as potential mediators for functioning and disability. We hypothesized that joint contractures restrict a broad range of body

functions, activities of daily life and social participation, and that the amount of restriction varies according to contracture localization.

5.3 Materials and methods

Study design and participants

The study was designed as a cross-sectional study in acute geriatric hospitals. Patients were recruited from three acute geriatric wards of hospitals in and around Munich between February and October 2013. Localization of joint contractures was extracted from the patients' medical records. Participants were included if they were 65 years of age or older, had a confirmed joint contracture in at least one major joint (wrist, elbow, shoulder, hip, knee, ankle, neck), and had provided informed written consent. In accordance with the Declaration of Helsinki, a positive vote from the ethics committee of the Medical Faculty of the Ludwig-Maximilians-Universität in Munich was obtained prior to starting. Informed consent was obtained from patients or, if a patient was unable to make an informed decision, from the patient's legal guardian. Under the assumption of an equal effects model [17], a power of 0.8 and a significance level of 0.05, a sample size of 144 individuals was necessary in order to determine frequencies with a precision of 10%.

Measures and questionnaire

The ICF is divided into two parts, each containing two separate components. Part 1 covers functioning and disability and includes the components Body Functions (b), Body Structures (s), and Activities and Participation (d). Part 2 covers contextual factors and includes the components Environmental Factors (e) and Personal Factors. In the ICF classification, the letters b, s, d and e, which refer to the components of the classification, are followed by a numeric code starting with the chapter number (one digit) followed by the second level (two digits), and the third and fourth level (one digit each). The ICF also provides a generic qualifier scale for the categories, where 0 stands for "no problem" (0-4% limitation/ impairment), 1 for "mild problem" (5-24% limitation/impairment), 2 for "moderate problem" (25-49% limitation/impairment), 3 for "severe problem" (50-95% limitation/impairment), and 4 for "complete problem" (96-100% limitation/ impairment) [18]. Following a previously established approach, we combined the qualifiers 1, 2 and 3 into one category because for most participants it is difficult to differentiate mild, moderate or severe problems in contrast to complete problems [19-22]. The categories of the component Environmental Factors were graded with 'B' for 'barrier' or 'No B' for 'no 'barrier' and 'F' for 'facilitator' or 'No F' for 'no facilitator'. The interviewers were trained and advised to report only limitations and impairment due to joint contractures and not to any comorbidity. If a patient had a limitation of a specific category due to a comorbidity that was not associated with the acute condition, this limitation was graded with 'C' and did not contribute to the prevalence of this limitation. To give an example, a pa-

tient with a confirmed joint contracture in his shoulder who also suffers from a coronary heart disease may have impairment in the category ‘d4501 – walking long distances’ which is not associated with the joint condition. This impairment would not contribute to the prevalence of the category ‘d4501’.

As participants were likely to be frail and may have difficulties concentrating over a longer period of time, the interviewers could also obtain information by asking relatives or caregivers. Those answers were marked as ‘proxy’; if more than 50% of the items were answered by proxy, the entire questionnaire was reported as such.

As ICF provides over 1400 categories, a pre-selection had to be made. We used the ICF Checklist which is a reduced list of ICF categories proposed by WHO for generic purposes [23] supplemented by categories derived from results of a recent qualitative study [24]. The final questionnaire for patients with joint contractures comprised 124 categories of the ICF classification as presented in Figure 1; 28 categories of the component ‘Body Functions’, 80 categories of the component ‘Activities and Participation’ and 16 of the component ‘Environmental Factors’. For the component ‘Body Structures’ the localization of the contracture was reported.

Socio-demographic and disease specific data, i.e. age, sex, living situation, and medical diagnosis, were collected. A 10-point Likert scale assessed the self-rated general health where 10 indicates optimal health and 0 indicates the worst health. To describe the level of nursing care needed, we used the levels as assessed and reported by experts of the medical service of the German long-term care insurance system (none; 1=considerable; 2=severe; 3=most severe) [25]. To describe the status of activities of daily living, the Barthel Index [26] was completed by either nurses or the interviewer.

Data collection procedures

Patients were recruited during their hospitalization. They were informed either by their physician, nurse or therapist and asked to participate. Health professionals trained in the application and principles of the ICF, who were not part of the healthcare team, carried out the interview. Anonymous and standardized data collection forms with consecutive numbers were provided. Before the start of an interview, the patient’s medical record was checked and relevant information on socio-demographic data and diagnoses was extracted. Hospital staff in charge of the patient was asked to assess whether the patient was eligible for a face-to-face interview, e.g. due to his/her current memory or mental functions. If information was not obtainable from the patient, health professionals in charge, relatives or caregivers were asked.

Quality assurance procedures

A pilot-study with eight patients was carried out in January 2013 to assess the feasibility of the data collection procedure. The length of the interview in the pre-test ranged from 30-45 minutes.

The two interviewers were trained during a structured one-day meeting and provided with a manual. They were supervised continuously and had monthly meetings with the supervisor of the study. Each interviewer was obliged to check the data collection form immediately after the interview, to correct unclear statements and to add comments. A second researcher checked all data forms for completeness and plausibility. Patients who declined to participate during the interview were asked for the reason of refusal. The interviewers recorded the data using the double entry method. Data were checked for consistency, outliers and duplication.

Data analysis

For the ICF components 'Body Functions' and 'Activities and Participation', absolute and relative frequencies (prevalence) of impairments and limitations in the study population were calculated. In the ICF component 'Activities and Participation', the prevalence of limitations and restrictions for patients with isolated lower limb contracture and isolated upper limb contracture was calculated additionally. The qualifier scale of the respective categories was cut into a dichotomized scale by categorizing the participants as either limitation or restriction present (1 through 2 on the scale) or absent (0 on the scale). For 'Environmental Factors' absolute and relative frequencies (prevalence) of persons who regarded a specific category as either a barrier or a facilitator were calculated.

5.4 Results

The mean age of the 145 participants was 82.5 years (SD: 7.4), 64.8% were female. Sixty-four percent of the participants had joint contractures localized in at least one shoulder, 37.9 % in at least one hand and 32.4% in at least one knee. Relatives, caregivers and legal guardians of the patients contributed information in 2.1% (n=3) of all the interviews. Although the length of the interviews ranged from 35 to 50 minutes, patients' compliance to the interview was good and no interview had to be cut short. Patients' characteristics are displayed in Table I.

Twenty-nine persons (20.0%) had isolated lower-limb contractures, 65 persons (44.8%) had isolated upper-limb contractures and 51 persons (35.2%) had joint contractures in both regions of the body. The prevalence of limitations and restrictions of each category of the component 'Activities and Participation' with respect to the localization of the joint contracture are shown in Figures 2 and 3.

Most frequent medical diagnoses were musculoskeletal disorders (n=86), hypertension (n=70) and joint derangements (n=41). Diagnoses corresponding with a prevalence of at least 10% are shown in Table II.

Tables III to V present the prevalence of the graded impairment or restriction as well as the absolute frequency of each qualifier. In the component 'Body Functions' the categories most frequently impaired were 'muscle power functions (b730)' (95.9%) and 'gait pattern function

(b770)' (73.1%). The most prevalent limitations in the component 'Activities and Participation' were the categories 'driving human-powered transportation (d4750)' (89.6%), 'walking long distances (d4501)' (81.4%) and 'kneeling (d4102)' (77.9%). At least 60% of the patients reported limitations of 'muscle power functions (b730)', 'gait pattern functions (b770)' and restrictions in other categories that are related to movement.
In the component 'Environmental Factors' the category 'health services, systems and policies (e580)' (98.6%) was the most frequently reported facilitator, while 'design, construction and building products and technology of buildings for public use (e150)' (60%) and 'design, construction and building products and technology of buildings for private use (e155)' (60%) were the most frequently reported barriers.
The detailed results are shown in Tables III to V.

5.5 Discussion

This cross-sectional study identified the most frequent problems in functioning and disability in patients with joint contractures in specialized geriatric rehabilitation facilities using the ICF. The participants presented a broad spectrum of limitations and restrictions. The most frequent problems were identified in the chapters 'neuromusculoskeletal and movement-related functions (b7)' and 'mobility (d4)'.
Almost all participants reported impairments of muscle power, muscle tone and gait pattern. In line with the literature [27, 28], pain did not emerge as a predominant consequence of contractures in our study. In 52% of the participants in our study, moderate to complete problems in 'tactile perception (b1564)' were reported. This is a new aspect and has not been reported in studies so far.
Most participants reported the inability to drive human powered transportation, e.g. riding a bicycle, while all other categories referring to transportation were hardly restricted. In contrast, moving around within the home or moving around using equipment was frequently restricted. This is in line with several studies that report a high correlation between joint contractures and impaired mobility [29-31]. Likewise, restrictions of categories of the ICF chapter 'community, social and civic life (d9)' were frequently reported as restricted in our study, e.g. crafts, engaging in hobbies or sports, and participating in arts and culture. Restricted social participation as a consequence of joint contractures is frequently reported in the literature [32, 33].
Not surprisingly, persons with contractures of the upper limbs were more restricted in the domain of carrying, moving and handling objects including fine hand use. Clearly, this translates into greater disability regarding writing and self-care. While we did not systematically test these differences, they contribute to the face validity of our results.

Within the component ‘Environmental Factors’, health services were perceived as important facilitators by almost all interviewed patients. This is consistent with current literature showing that patients with joint contractures depend heavily on quality of care, the accessibility of social systems and the availability of healthcare services [6-8]. Likewise, the design, construction and technology of private and public buildings such as the design of stairs, doors and elevators were frequently perceived as barriers. These environmental issues refer to problems typically associated with reduced mobility [34].

Some potential concerns need to be mentioned. First, in an aged population, multimorbidity is highly prevalent and may equally be responsible for limitations of activities. However, during the interview participants were reminded that impairment or restriction should only be reported if being a direct consequence of the contracture. Also, in a previous study older persons with joint contractures could accurately evaluate whether a restriction was caused by the contracture or by another health condition [24]. Furthermore, the selection of the participants might be biased towards those with less disability who are still able to provide information. Still, the amount of restriction encountered here is considerable. The results of our study may therefore be a valid contribution to estimate the burden of disability attributable to joint contractures. Lastly, further research should be focused on the development of measures for patient-relevant outcomes based on the most salient domains such as mobility. Interventions targeted at the individual and interventions targeted at environmental barriers could then be validated in a more evidence-based way.

5.6 Conclusions

Aged persons with joint contractures experience high levels of disability. Specifically, mobility, participation restrictions and interactions with the environment emerged as important issues of our study.

5.7 Supplement

Funding

This project is funded by the German Federal Ministry of Education and Research under the grant codes: 01GY1113A and 01GY1113B.

Conflicts of interest

The authors declare that they have no conflicts of interest. The authors bear full responsibility for the content of this publication.

Acknowledgements

We would like to express our gratitude to the participants of the survey. We also thank the teams of the acute geriatric wards, especially A. Deuschl and Dr. S. von Clarmann for their support. Our special thanks goes to the research assistant A. Frank for her commitment and support. We thank A. Phillips for copy-editing the manuscript.

Authors' contributions

MM, EG and GM designed the study and acquired the funding. UF and GB developed the questionnaire. UF supervised data collection and data processing. UF analysed the data, interpreted the results and drafted the manuscript. All authors read and approved the final manuscript.

Corresponding author

U. Fischer M.A.
Institute for Medical Information Processing, Biometrics and Epidemiology,
Ludwig-Maximilians-Universität, Marchioninistraße 17, 81377 Munich, Germany
Email: uli.fischer@med.uni-muenchen.de
Phone: +49 (0) 89 2180-72433

Key words

Contracture (MeSH)
Geriatric assessment (MeSH)
Outcome assessment (health care) (MeSH)
Social participation (MeSH)
Cross-sectional studies (MeSH)

5.8 References

[1.] Harrington, C., Nursing Facilities, Staffing, Residents and Facility Deficiencies, 2003 Through 2008. 2009, Department of Social and Behavioral Sciences, University of California.

[2.] Mollinger, L.A. and T.M. Steffen, Knee flexion contractures in institutionalized elderly: prevalence, severity, stability, and related variables. Physical therapy, 1993. 73(7): p. 437-44; discussion 444-6.

[3.] Souren, L.E., E.H. Franssen, and B. Reisberg, Contractures and loss of function in patients with Alzheimer's disease. Journal of the American Geriatrics Society, 1995. 43(6): p. 650-5.

[4.] Fergusson, D., B. Hutton, and A. Drodge, The epidemiology of major joint contractures: a systematic review of the literature. Clinical orthopaedics and related research, 2007. 456: p. 22-9.

[5.] Rabiner, A., et al., Characteristics of Nursing Home Residents with Contractures. Physical & Occupational Therapy in Geriatrics, 1996. 13(4): p. 1-10.

[6.] Wagner, L.M., et al., Contractures in frail nursing home residents. Geriatric nursing (New York, N Y), 2008. 29(4): p. 259-66.

[7.] IQP, I.f.Q.i.d.P.-. Kontrakturprävention in der Langzeitpflege Älterer. Stand der Forschung und Bedeutung für die Praxis. 2011.

[8.] Fox, P., et al., Effectiveness of a bed positioning program for treating older adults with knee contractures who are institutionalized. Physical therapy, 2000. 80(4): p. 363-72.

[9.] Fried, L.P. and J.M. Guralnik, Disability in older adults: evidence regarding significance, etiology, and risk. Journal of the American Geriatrics Society, 1997. 45(1): p. 92-100.

[10.] Williams, B.C., et al., Activities of daily living and costs in nursing homes. Health care financing review, 1994. 15(4): p. 117-135.

[11.] Kaegi, C., et al., Absence of Change in the Passive Joint Movements of Long Term Care Patients Following the Application of a Passive Range of Motion Exercise Program. Physical & Occupational Therapy in Geriatrics, 1995. 13(1-2): p. 81-100.

[12.] Light, K.E., et al., Low-load prolonged stretch vs. high-load brief stretch in treating knee contractures. Physical therapy, 1984. 64(3): p. 330-3.

[13.] Gnass, I., et al., Joint contractures in older age. A systematic literature review. Z Gerontol Geriatr, 2010. 43(3): p. 147-57.

[14.] Offenbacher, M., et al., Contractures with special reference in elderly: definition and risk factors - a systematic review with practical implications. Disabil Rehabil, 2013.

[15.] Cress, M.E., et al., Relationship between physical performance and self-perceived physical function. Journal of the American Geriatrics Society, 1995. 43(2): p. 93-101.

[16.] Kim, F.S., et al., Experience with corrective surgery for postburn contractures in Mumbai, India. J Burn Care Res, 2012. 33(3): p. e120-6.

[17.] Laird, N.M. and F. Mosteller, Some statistical methods for combining experimental results. Int J Technol Assess Health Care, 1990. 6(1): p. 5-30.
[18.] World Health Organisation, International Classification of Functioning, Disability and Health: ICF. 2001, Geneva: WHO.
[19.] Grill, E. and G. Stucki, Criteria for validating comprehensive ICF Core Sets and developing brief ICF Core Set versions. Journal of rehabilitation medicine : official journal of the UEMS European Board of Physical and Rehabilitation Medicine, 2011. 43(2): p. 87-91.
[20.] Muller, M., et al., Validation of the comprehensive ICF Core Sets for patients receiving rehabilitation interventions in the acute care setting. Journal of rehabilitation medicine : official journal of the UEMS European Board of Physical and Rehabilitation Medicine, 2011. 43(2): p. 92-101.
[21.] Muller, M., et al., Validation of the comprehensive ICF Core Sets for patients in early post-acute rehabilitation facilities. Journal of rehabilitation medicine : official journal of the UEMS European Board of Physical and Rehabilitation Medicine, 2011. 43(2): p. 102-12.
[22.] Stier-Jarmer, M., et al., Validation of the comprehensive ICF Core Set for patients in geriatric post-acute rehabilitation facilities. Journal of rehabilitation medicine : official journal of the UEMS European Board of Physical and Rehabilitation Medicine, 2011. 43(2): p. 102-12.
[23.] World Health Organization ICF Checklist. Version 2.1a. Clinician Form for International Classification of Functioning, Disability and Health. 2003.
[24.] Fischer, U., et al., Patients' view on health related aspects of functioning and disability of joint contractures: A qualitative interview study based on the International Classification of Functioning, Disability and Health (ICF). Disability & Rehabilitation, 2014.
[25.] Dalichau, G., H. Grüner, and L. Müller-Alten, Pflegeversicherung, Sozialgesetzbuch (SGB), Elftes Buch. (XI), Kommentar. 2002.
[26.] Mahoney, F.I. and D.W. Barthel, Functional Evaluation: The Barthel Index. Md State Med J, 1965. 14: p. 61-5.
[27.] Saar, J.D. and P.C. Grothaus, Dupuytren's disease: an overview. Plast Reconstr Surg, 2000. 106(1): p. 125-34; quiz 135-6.
[28.] Willig, T.N., et al., Correlation of flexion contractures with upper extremity function and pain for spinal muscular atrophy and congenital myopathy patients. Am J Phys Med Rehabil, 1995. 74(1): p. 33-8.
[29.] Clavet, H., et al., Joint contractures in the intensive care unit: association with resource utilization and ambulatory status at discharge. Disability & Rehabilitation, 2011. 33(2): p. 105-112.
[30.] Lang, I.A., et al., Neighbourhood deprivation and incident mobility disability in older adults. Age Ageing, 2008. 37(4): p. 403-10.

[31.] Resnick, B., Functional performance and exercise of older adults in long-term care settings. Journal of gerontological nursing, 2000. 26(3): p. 7-16.
[32.] Clavet, H., et al., Joint contracture following prolonged stay in the intensive care unit. CMAJ, 2008. 178(6): p. 691-7.
[33.] Katalinic, O.M., L.A. Harvey, and R.D. Herbert, Effectiveness of stretch for the treatment and prevention of contractures in people with neurological conditions: a systematic review. Physical therapy, 2011. 91(1): p. 11-24.
[34.] Laksmi, P.W., et al., Management of immobilization and its complication for elderly. Acta Med Indones, 2008. 40(4): p. 233-40.

5.9 Figures and tables

Table I - Characteristics of the study population (n=145)

Characteristics		Mean	SD	Range
Age, years		82.5	7.4	65-99
Barthel Index[1]		46.7	19.1	5-90
Living with contractures, years		14.1	18.2	0-85
		n	**%**	
Number of 'proxy' interviews		3	2.1	
Sex	female	94	64.8	
Living situation	alone	55	37.9	
	with family	76	52.4	
	nursing home	14	9.7	
Support at home[2]	none	14	9.7	
	family/relatives	121	83.4	
	professionals	48	33.1	
Nursing care level[3]	none	85	58.6	
	1	47	32.4	
	2	11	7.6	
	3	2	1.4	
Number of contractures per person[4]	1	41	28.3	
	2	41	28.3	
	3	22	15.2	
	≥ 4	41	28.3	
Localization of contracture[4]	neck	2	1.4	
	shoulder	93	64.1	
	elbow	21	14.5	
	hand	55	37.9	
	hip	36	24.8	
	knee	47	32.4	
	ankle	32	22.1	

[1] Barthel Index: 1-100; indicating 100 = no impairment in activities of daily life

[2] The questions were: Do you have a caregiver at home? Who is it? Multiple answers were possible.

[3] Nursing care level (assessed by the 'medical service of the German long-term care insurance system): none, 1-3; indicating 1 means up to 90 minutes care requirement per day, 2 means up to 180 minutes/d, 3 up to 300 minutes/d

[4] We counted every single joint contracture in every limb separately.

Table II - Most frequent diagnoses of the study population (ICD-10) (n=145) in at least 10% of participants

ICD code	ICD label	n	% of participants
M62	Other disorders of muscle	86	59.3
I10	Essential (primary) hypertension	70	48.3
M24	Other specific joint derangements	41	28.3
M81	Osteoporosis without pathological fracture	32	22.1
Z96	Presence of other functional implants	29	20.0
R26	Abnormalities of gait and mobility	24	16.6
E66	Obesity	20	13.8
M79	Other soft tissue disorders, not classified elsewhere	19	13.1
I63	Cerebral infarction	16	11.0
M17	Gonarthrosis	16	11.0
S42	Fracture of shoulder and upper arm	16	11.0

Table III – International Classification of Functioning, Disability and Health (ICF) categories of the component 'Body Functions' – numbers and relative frequencies (%), rated as a problem from the participants (n=145)

ICF code	ICF label	mild to moderate problems		complete problems	
		n	%	n	%
b1263	Psychic stability	14	9.7	2	1.4
b1265	Optimism	33	22.8	1	0.7
b1266	Confidence	12	8.3	2	1.4
b130	Energy and drive functions	20	13.8	3	2.1
b134	Sleep functions	42	29.0	3	2.1
b152	Emotional functions	15	10.3	2	1.4
b1564	Tactile perception	66	45.5	8	5.5
b160	Thought functions	8	5.5	1	0.7
b2401	Dizziness	43	29.7	2	1.4
b265	Touch function	62	42.8	6	4.1
b280	Sensation of pain	90	62.1	4	2.8
b2800	Generalized pain	4	2.8	2	1.4
b28010	Pain in head and neck	6	4.1	1	0.7
b28013	Pain in back	17	11.7	2	1.4
b28014	Pain in upper limb	58	40.0	2	1.4
b28015	Pain in lower limb	51	35.2	1	0.7
b28016	Pain in joints	6	4.1	3	2.1
b435	Immunological system functions	18	12.4	0	0.0
b515	Digestive functions	7	4.8	1	0.7
b525	Defecation functions	7	4.8	0	0.0
b530	Weight maintenance functions	21	14.5	1	0.7
b6201	Frequency of urination	14	9.7	1	0.7
b6202	Urinary continence	14	9.7	2	1.4
b730	Muscle power functions	136	93.8	3	2.1
b735	Muscle tone functions	96	66.2	3	2.1
b770	Gait pattern functions	96	66.2	10	6.9
b810	Protective functions of the skin	30	20.7	1	0.7
b820	Repair functions of the skin	29	20.0	1	0.7

Table IV – International Classification of Functioning, Disability and Health (ICF) categories of the component 'Activities and Participation' – numbers and relative frequencies (%), rated as a problem from the participants (n=145)

ICF code	ICF label	mild to moderate problems		complete problems	
		n	%	n	%
d110	Watching	8	5.5	0	0.0
d115	Listening	16	11.0	0	0.0
d155	Acquiring skills	37	25.5	2	1.4
d166	Reading	12	8.3	1	0.7
d170	Writing	36	24.8	5	3.5
d177	Making decisions	12	8.3	1	0.7
d210	Undertaking a single task	13	9.0	0	0.0
d230	Carrying out daily routine	19	13.2	3	2.1
d240	Handling stress and other psychological demands	19	13.2	0	0.0
d350	Conversation	14	9.7	0	0.0
d3600	Using telecommunication devices	4	2.8	2	1.4
d4100	Lying down	67	46.2	10	6.9
d4101	Squatting	86	59.3	21	14.5
d4102	Kneeling	74	51.0	39	26.9
d4103	Sitting	65	44.8	7	4.8
d4104	Standing	87	60.0	7	4.8
d4105	Bending	81	55.9	13	9.0
d4106	Shifting the body's centre of gravity	60	41.4	6	4.1
d415	Maintaining a body position	72	49.7	4	2.8
d4150	Maintaining a lying position	54	37.2	1	0.7
d4153	Maintaining a sitting position	42	29.0	3	2.1
d4154	Maintaining a standing position	57	39.3	11	7.6
d4200	Transferring oneself while sitting	39	26.9	4	2.8
d4201	Transferring oneself while lying	44	30.3	7	4.8
d4300	Lifting	71	49.0	11	7.6
d4301	Carrying in the hands	78	53.8	11	7.6
d435	Moving objects with lower extremities	50	34.5	3	2.1
d440	Fine hand use	59	40.7	10	6.9
d4400	Picking up	56	38.6	10	6.9
d4401	Grasping	59	40.7	10	6.9
d4402	Manipulating	56	38.6	10	6.9
d445	Hand and arm use	74	51.0	8	5.5
d4451	Pushing	63	43.5	4	2.8
d4452	Reaching	69	47.6	9	6.2
d4453	Turning or twisting the hands or arms	69	47.6	9	6.2
d4455	Catching	63	43.5	17	11.7
d450	Walking	94	64.8	15	10.3
d4500	Walking short distances	81	55.9	14	9.7
d4501	Walking long distances	37	25.5	81	55.9
d4502	Walking on different surfaces	83	57.2	23	15.9

d4503	Walking around obstacles	68	46.9	20	13.8
d4551	Climbing	79	54.5	20	13.8
d4600	Moving around within the home	47	32.4	7	4.8
d4601	Moving around within buildings other than home	83	57.2	24	16.5
d4602	Moving around outside the home and other buildings	79	54.5	28	19.3
d465	Moving around using equipment	47	32.4	3	2.1
d4701	Using private motorized transportation	79	54.5	12	8.3
d4702	Using public motorized transportation	17	11.7	85	58.6
d4750	Driving human-powered transportation	8	5.5	122	84.1
d4751	Driving motorized vehicles	4	2.8	103	71.0
d5100	Washing body parts	69	47.6	4	2.8
d5101	Washing whole body	80	55.2	8	5.5
d5102	Drying oneself	72	49.7	7	4.8
d520	Caring for body parts	80	55.2	8	5.5
d5202	Caring for hair	79	54.5	9	6.2
d530	Toileting	26	17.9	3	2.1
d540	Dressing	65	44.8	5	3.5
d550	Eating	59	40.7	5	3.5
d560	Drinking	57	39.3	2	1.4
d5701	Managing diet and fitness	21	14.5	4	2.8
d5702	Maintaining one's health	20	13.8	2	1.4
d6200	Shopping	68	46.9	31	21.4
d630	Preparing meals	58	40.0	27	18.6
d640	Doing housework	73	50.3	37	25.5
d6501	Maintaining dwelling and furnishings	70	48.3	31	21.4
d6505	Taking care of plants indoors and outdoors	52	35.9	25	17.2
d6506	Taking care of animals	8	5.5	10	6.9
d660	Assisting others	52	35.9	9	6.2
d710	Basic interpersonal interactions	11	7.6	0	0.0
d750	Informal social relationships	9	6.2	0	0.0
d760	Family relationships	11	7.6	0	0.0
d770	Intimate relationships	4	2.8	43	29.7
d865	Complex economic transactions	36	24.8	3	2.1
d910	Community life	33	22.8	6	4.1
d9201	Sports	41	28.3	44	30.3
d9202	Arts and culture	44	30.3	39	26.9
d9203	Crafts	80	55.2	30	20.7
d9204	Hobbies	73	50.3	29	20.0
d9205	Socializing	34	23.5	5	3.5
d930	Religion and spirituality	35	24.1	6	4.1

Table V – International Classification of Functioning, Disability and Health (ICF) categories of the component 'Environmental Factors' – numbers and relative frequencies (%), rated as a/no barrier or a/no facilitator from the participants (n=145)

ICF code	ICF label	barrier		no barrier		facilitator		no facilitator	
		n	%	n	%	n	%	n	%
e1101	Drugs	15	10.3	130	89.7	127	87.6	18	12.4
e115	Products and technology for personal use in daily living	15	10.3	130	89.7	126	86.9	19	13.1
e120	Products and technology for personal indoor and outdoor mobility and transportation	13	9.0	132	91.0	126	86.9	19	13.1
e125	Products and technology for communication	3	2.1	142	97.9	18	12.4	127	87.6
e150	Design, construction and building products and technology of buildings for public use	87	60.0	58	40.0	74	51.0	71	49.0
e155	Design, construction and building products and technology of buildings for private use	87	60.0	58	40.0	74	51.0	71	49.0
e225	Climate	69	47.6	76	52.4	14	9.7	131	90.3
e2250	Temperature	69	47.6	76	52.4	13	9.0	132	91.0
e310-e320	Immediate family / Extended family / Friends	2	1.4	143	98.6	136	93.8	9	6.2
e340/e355	Personal care providers and personal assistants / Health professionals	0	0.0	145	100.0	141	97.2	4	2.8
e350	Domesticated animals	0	0.0	145	100.0	23	15.9	122	84.1
e410-e420	Individual attitudes of immediate family members / extended family members / friends	3	2.1	142	97.9	138	95.2	7	4.8
e450	Individual attitudes of health professionals	2	1.4	143	98.6	142	97.9	3	2.1
e5400	Transportation services	7	4.8	138	95.2	40	27.6	105	72.4
e570	Social security services, systems and policies	1	0.7	144	99.3	142	97.9	3	2.1
e580	Health services, systems and policies	1	0.7	144	99.3	143	98.6	2	1.4

Figure 1 - Overview of International Classification of Functioning, Disability and Health (ICF) chapters containing one or more categories identified as a frequent problem, barrier or facilitator

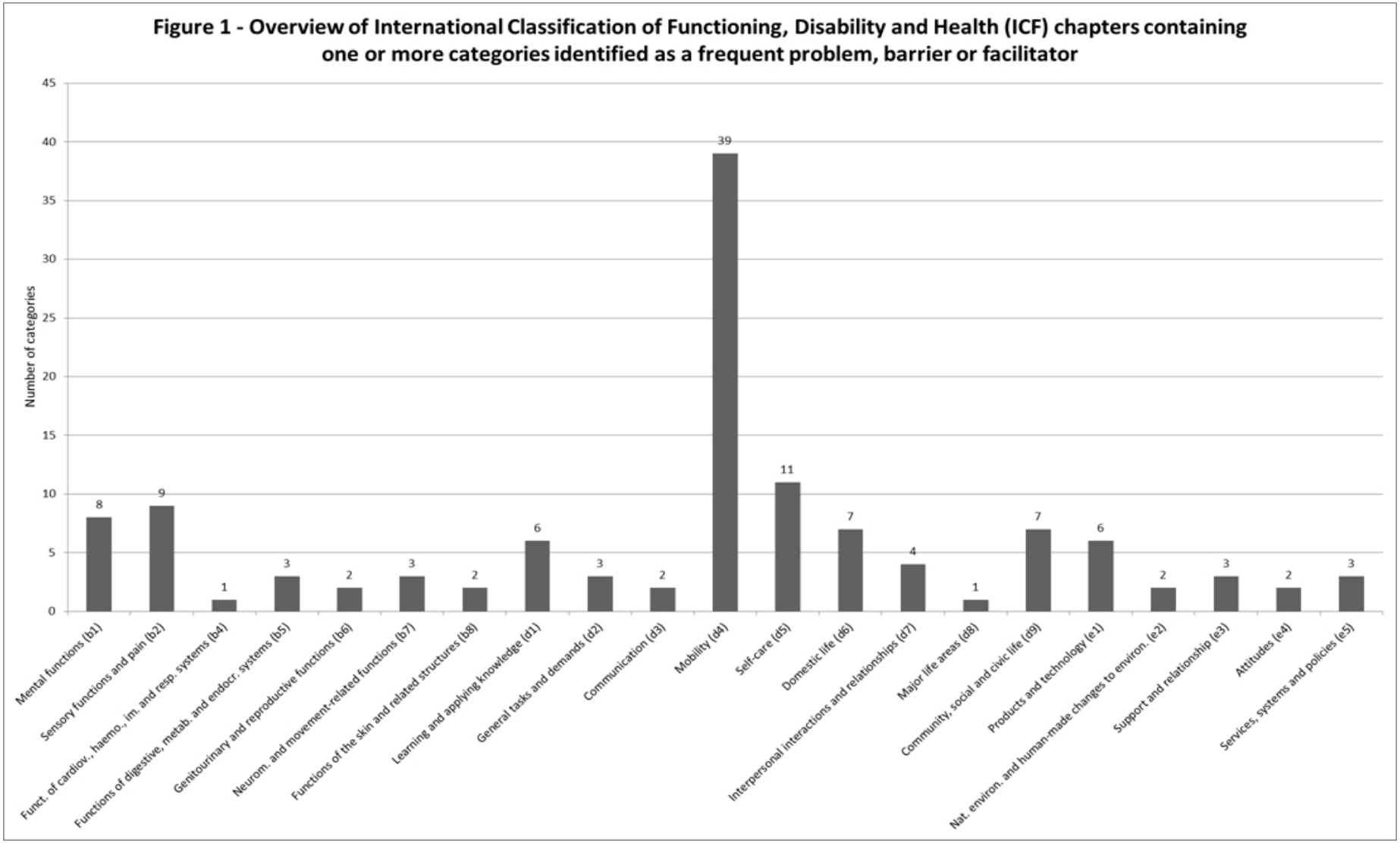
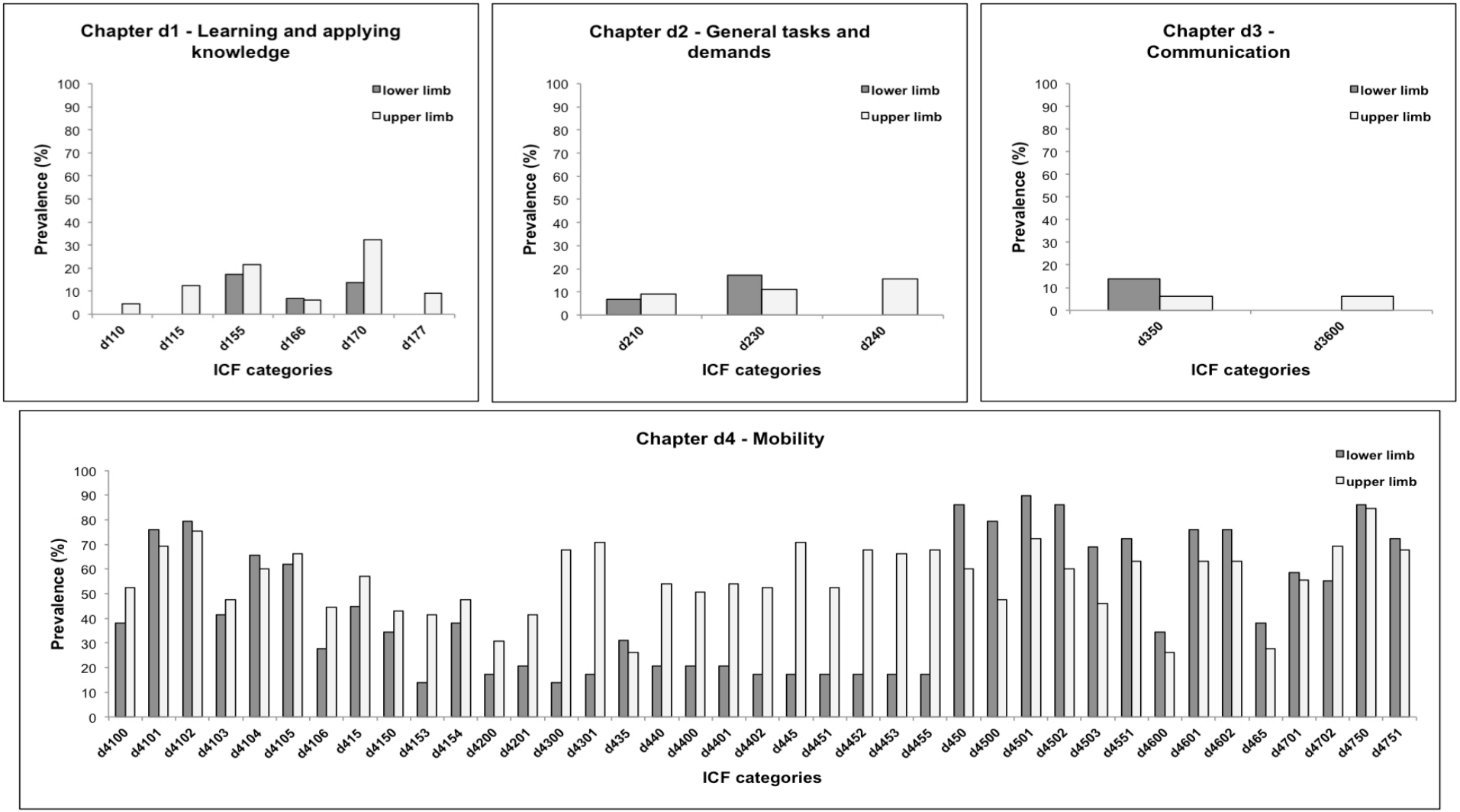
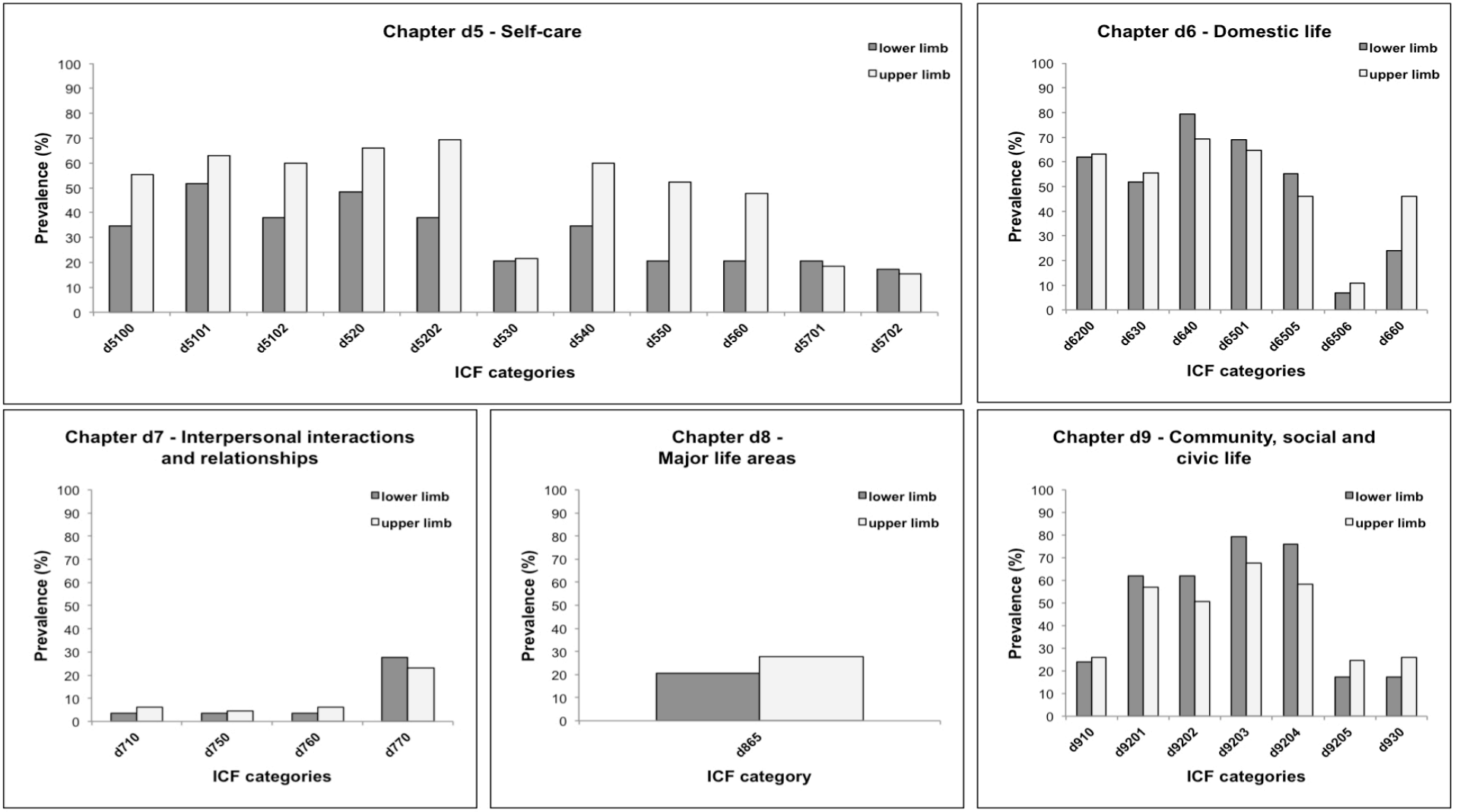


Figure 2 – Prevalence of any limitation or restriction for patients with isolated lower limb contracture or isolated upper limb contracture in the chapters d1 to d4 in the ICF component 'Activities and Participation'[1]



[1] The qualifier scale of the respective categories was cut into a dichotomized scale by categorizing the participants as either limitation or restriction present (1 through 2 on the scale) or absent (0 on the scale).

Figure 3 – Prevalence of any limitation or restriction for patients with isolated lower limb contracture or isolated upper limb contracture in the chapters d5 to d9 in the ICF component 'Activities and Participation'[1]



[1] The qualifier scale of the respective categories was cut into a dichotomized scale by categorizing the participants as either limitation or restriction present (1 through 2 on the scale) or absent (0 on the scale).

5.10 Ethical appraisal

LMU LUDWIG-MAXIMILIANS-UNIVERSITÄT MÜNCHEN

ETHIKKOMMISSION BEI DER LMU MÜNCHEN

Ethikkommission · Pettenkoferstr. 8 · 80336 München

Frau
Prof. Dr. E. Grill
Institut f. med. Informationsverarbeitung
Klinikum Großhadern
81377 München

Vorsitzender:
Prof. Dr. W. Eisenmenger
Telefon+49 (0)89 5160 - 5191
Telefax+49 (0)89 5160 - 5192
Ethikkommission@
med.uni-muenchen.de

www.ethikkommission.med.uni-muenchen.de

Postanschrift:
Pettenkoferstr. 8a
D-80336 München

Hausanschrift:
Pettenkoferstr. 8
D-80336 München

München, 12.12.2012 Hb /sc

Titel:	**Einfluss von Gelenkkontrakturen auf die Funktionsfähigkeit und die soziale Teilhabe bei älteren Menschen - Entwicklung eines standardisierten Assessmentintruments**
Antragsteller:	**Prof. Dr. E. Grill, Uli Fischer**
Projekt- Nr.	**530-12**

Sehr geehrte Frau Kollegin Grill,

die o. g. Studie hat den Mitgliedern der Ethikkommission (EK) der Medizinischen Fakultät unserer Universität zur Prüfung vorgelegen.

Es wurden keine ethisch- rechtlichen Bedenken gegen die Durchführung der Studie erhoben. Dennoch bittet die EK, folgende Hinweise /Empfehlungen in der Probandeninformation zu beachten:

a) Es sollte auch dargelegt werden, wie mit den Fragebögen verfahren wird.

b) Die Begriffe „Autonomie" und „Partizipation" sollten laienverständlich erklärt werden.

c) Es sollte darauf hingewiesen werden, dass keine verschuldensunabhängige Versicherung abgeschlossen wurde.

Vorsorglich möchte ich darauf hinweisen, dass auch bei einer positiven Beurteilung des Vorhabens durch die EK die ärztliche und juristische Verantwortung für die Durchführung des Projektes uneingeschränkt bei Ihnen und Ihren Mitarbeitern verbleibt. Änderungen des Studienprotokolls sind der EK mitzuteilen.

Für Ihre Studie wünsche ich Ihnen viel Erfolg.

Mit freundlichen Grüßen

Prof. Dr. W. Eisenmenger
Vorsitzender der Ethikkommission

5.11 Declaration of acceptance

Von: journals.dept@minervamedica.it
An: Fischer, Uli
Thema: Manuscript no. Eur J Phys Rehabil Med-3525 - European Journal of Physical and Rehabilitation Medicine
Datum: Mittwoch, 3. September 2014 18:56:36

Dear Mr. Uli Fischer,

I am pleased to inform you that your manuscript entitled

Prevalence of functioning and disability in older patients with joint contractures: a cross-sectional study

received by the editorial office of European Journal of Physical and Rehabilitation Medicine and registered under no. Eur J Phys Rehabil Med-3525 has been accepted for publication as Original Article.

Before preparation of the proofs, the manuscript will undergo copy-editing to align it with the journal's editorial standards. You will be contacted by the editorial staff should any questions arise.

Thank you for considering the journal European Journal of Physical and Rehabilitation Medicine for publication of your paper.

Sincerely,

Prof. Stefano Negrini
Chief Editor
European Journal of Physical and Rehabilitation Medicine
.....
Edizioni Minerva Medica
Corso Bramante 83-85
10126 Torino, Italy
Phone +39-011-678282, fax +39-011-674502
www.minervamedica.it
---

6 Eidesstattliche Versicherung

Uli Fischer

Ich erkläre hiermit an Eides statt, dass ich die vorliegende Dissertation mit dem Thema

Der Einfluss von Gelenkkontrakturen auf die Funktionsfähigkeit und die soziale Teilhabe von älteren Menschen – Entwicklung eines Standard Sets auf Basis der Internationalen Klassifikation für Funktionsfähigkeit, Behinderung und Gesundheit (ICF) der WHO

selbständig verfasst, mich außer der angegebenen keiner weiteren Hilfsmittel bedient und alle Erkenntnisse, die aus dem Schrifttum ganz oder annähernd übernommen sind, als solche kenntlich gemacht und nach ihrer Herkunft unter Bezeichnung der Fundstelle einzeln nachgewiesen habe.

Ich erkläre des Weiteren, dass die hier vorgelegte Dissertation nicht in gleicher oder in ähnlicher Form bei einer anderen Stelle zur Erlangung eines akademischen Grades eingereicht wurde.

München, den 30.09.2014