

## Intersektionalität und ihre Bedeutung für die Demenzforschung bei Menschen mit Migrationshintergrund

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**Intersectionality and its relevance for research in dementia care of people with a migration background.**

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## **Intersectionality and its relevance for research in dementia care of people with a migration background.**

### **abstract**

**Background:** Despite the care and support needs of migrants affected by dementia differing from the population of the country where they live now, most European countries do not provide specific strategies to address migration in their national dementia plans. There is a need to understand dementia not only from a (bio)medical, but also from a socio-cultural perspective by considering the personality, biography, general health, and the socio-cultural circumstances surrounding a person. However, neither culture, ethnicity nor migration were addressed when operationalizing the social health concept for dementia care and research in recent years. The concept of intersectionality provides an innovative approach in dementia care perspectives and methodologies. **Objectives:** to define intersectionality and provide examples of applying the concept to dementia care research - with a focus on people who are immigrations. **Methods:** This paper was conceptualized and discussed during virtual IINTERDEM taskforce meetings in 2020/21, while building a basis for future dementia care research grounded in intersectionality. **Results:** Using an intersectionality framework allows for understanding a person's lived experience by considering the dimensionality, co-occurrence, and interlocking of factors (e.g., sex/gender, socioeconomic status, ethnicity, migration status, geographic location/place). **Conclusions:** Intersectionality and intersectional analysis can be applied as a conceptual and methodological approach to identify and address gaps in perspectives and in (dementia care) research to overcome the threat of ignorance, exclusion and discrimination.

**Keywords:** dementia, migration, intersectionality

### **Abstract deutsch**

**Hintergrund:** Obwohl die Bedürfnisse und Bedarfe für Pflege und Unterstützung für Menschen mit Migrationshintergrund und ihr Zugang zu Gesundheitsleistungen sich oft von anderen Menschen, die von Demenz betroffen sind, unterscheiden, adressieren die meisten Europäischen Länder Migration nicht in ihren nationalen Demenzstrategien. Es ist notwendig Demenz nicht nur aus einer (bio-)medizinischen Perspektive heraus zu verstehen. In den letzten Jahren wurden jedoch weder Kultur noch Migration oder Ethnizität bei der Operationalisierung des Social-Health Konzeptes bei Demenz adressiert. Das Konzept der „Intersektionalität“ bietet einen innovativen methodologischen und perspektivischen Zugang zu Demenz. **Ziel der Arbeit:** ist es Intersektionalität zu definieren und Anwendungsbeispiele des Konzeptes im Kontext der Demenzversorgungsforschung – mit Fokus auf Menschen mit Migrationshintergrund – aufzuzeigen. **Methoden:** Dieser Artikel wurde im Rahmen virtueller INTERDEM Taskforce Treffen in 2020/21 konzipiert und diskutiert um eine auf Intersektionalität fundierte Basis für zukünftige Demenzforschung zu formulieren. **Ergebnisse:** Die Anwendung von Intersektionalität als analytischem Rahmen erlaubt es die gelebte Erfahrung einer Person zu verstehen indem die Dimensionalität, das gleichzeitige Auftreten sowie die Verschränkung von Faktoren wie z.B. geschlechtliche Identität, sozioökonomischer Status, Ethnie, Migrationsstatus, geographischer Ort beachtet werden. **Diskussion:** Intersektionalität und intersektionale Analysen können als konzeptioneller und methodologischer Zugang angewendet werden um Lücken in der Demenzversorgung und -

forschung zu identifizieren, zu adressieren, und damit möglicher Ignoranz, Exklusion und Diskriminierung entgegenzuwirken.

**Schlüsselbegriffe:** Demenz, Migration, Intersektionalität

## Introduction

Migration impacts the health of people in different ways: (a) migration impacts socio-demographic changes in a society, (b) ethnicity and migration are interrelated and may affect the health and access to health care services of the migrated population, and (c) migration needs to be viewed as a life-long-process to understand the impact of discrimination on health [20]. There is a necessity to give voice to the lived experience of migrants living with dementia. The authors believe, that dementia care research can benefit from an intersectional perspective to better understand the experienced ethnic differences and inequalities in the health care system within a wider social context [1].

## Background

According to the Migration Data Portal the total number of international migrants amounted to 280.6 million globally (mid 2020) and ~ 16.2% of the migrants living in Europe are 65 years or older [28]. Conservative estimations indicate that in the EU and EFTA states >500.000 people with a migration background are currently diagnosed with dementia, >100.000 in Germany [28]. The definition and usage of the term *migrant* varies across Europe: e.g., in Germany the term migrant is based on the individual's and parents' citizenship, whilst in the U.K. it primarily focuses on the country of birth which needs to be different from the country of residency [27, 28]. Additionally, the terms *race*, *culture* and *ethnicity* are often used interchangeably, although there is a general understanding of their different meanings: *race* based on biological differences, which is a controversial term that has been criticized worldwide. When describing minority populations, the terms *black*, *Asian* and *minority ethnic* (BAME) or *black*, *Asian*, *minority ethnic*, and *refugee* (BAMER) are in common use. The term *culture* refers to values, beliefs and attitudes, that define communities and produces a system of meanings and symbols. Categorization of people according to their culture has often been criticized as inflexible, and has been shown to be a barrier to accessing health care services due to culturally determined view such as 'I thought dementia only affected white people' [6]. *Ethnicity* or ethnic group emphasizes the identity of a 'particular social group in respect of cultural factors and a shared history' [6], however this view has been criticized too. We therefore need to critically reflect on our own work, since researchers from all over the world tend to use the categorization of ethnicity or race to present their research and describe their participants, as illustrated by titles of published papers '(...) in the Mexican-Origin Population' [31]; '(...) within Alaska Native Communities' [23] or '(...) African American Persons Living with Dementia' [5]. Furthermore, in the National Dementia Strategies and medical treatment guidelines across Europe different terms are being used and interestingly most European countries do not provide specific strategies to address **migration** [33]. Which may lead to ignore – for example - three phenomena that can be observed in Germany: migrants are in need of nursing care earlier than the population of the country of residency, the intensity of care needed by migrants is higher and, migrants who need care receive care are more likely to receive support at home and only from family members [26, 30].

To understand people with dementia and their health-seeking behavior, researchers need to provide ‘an overview that includes personality, biography, general health, and the socio-cultural circumstances surrounding the person. Families and individuals that believe that dementia has a psychological, social, or spiritual origin may not see the relevance of seeking help within the frames of a (bio)medical model and/or delay seeking help due to associated stigma’ Segbakken [32]. The Social Health Taskforce of the European INTERDEM network<sup>1</sup> published a consensus-based operationalization of the concept of social health in dementia care [13]. The authors emphasize the psycho-social perspective of health and its impact for dementia care and research within three domains: ‘the capacity to fulfil one’s potential and obligations’, ‘the ability to manage life with some degree of independence’, and ‘participation in social activities’. This perspective is clearly linked to the need, to the proposition that dementia can be understood not only from a (bio)medical, but also from a socio-cultural perspective. However, we need to point out, that neither culture, ethnicity nor migration were addressed when the social health concept was operationalized for dementia care and research; limitations which beg attention [13].

With our article we want to draw attention toward an innovative methodological approach – an intersectionality lens and intersectional analysis, which will help researchers to overcome the critiques as described above.

## **Aim**

To provide a general understanding of *how to define intersectionality* and its *methodological approach*. We provide examples, how *dementia care research* - with a special focus on people with a migration background - can benefit from an intersectional lens and therefore – in the long run – influence performance and quality of care.

## **Method**

The authors defined<sup>2</sup> *key terms* which we deemed necessary for readers to understand the topic *intersectionality*. We decided to (a) provide a short explanation of the ideas underlying of the concept of *intersectionality* and (b) its relevance for dementia care research and our specific target group: people with a migration background. We discussed the different underlying concepts with all authors and decided to focus on *definitions and concepts of intersectionality and intersectional analysis, core constructs of intersectionality*, and providing examples of *applying intersectionality in context of dementia migration research*. This article is linked to a scoping review on intersectional analysis in dementia research, which is in preparation.

## **Definitions of Intersectionality and intersectional analysis**

Crenshaw [8] who defined and described the need for a different perspective and emphasized the need for critical thinking to overcome existing social inequality. For her, the *new term intersectionality* allowed to address structural convergence to be analyzed within intersecting systems of power. As a woman of color, she felt that she was marginalized twice: first because she was black and second because she was a woman. From her standpoint of view, it was

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<sup>1</sup> [INTERDEM](http://www.interdem.org) is a pan-European network of researchers collaborating in research on and dissemination of Early, Timely and Quality Psychosocial Interventions in Dementia aimed at improving the quality of life of people with dementia and their supporters, across Europe. [www.interdem.org](http://www.interdem.org).

<sup>2</sup> virtual InterDem Meetings in 2020/2021

important to recognize ‘the significance of social structural arrangements of power, how individual and group experiences reflect those structural intersections, and how political marginality might endanger new subjectivity and agency’ [7]. Intersectionality has been defined as a concept that seeks to explore how social locations and identities converge to create conditions of inequality and privilege that intersect to result in more or less social capital and privilege. Everyone occupies multiple social locations that need to be considered when analyzing structural power [9]. Cuesta and Rämngård [10] point out, that intersectionality can be understood as an interactive approach, since it frames structural differences from subjective perspectives. Therefore, it is important to understand fragmented perceptions within a contextualized discourse. An intersectional perspective thus describes the entanglement of identity categories that make up an individual within a specific context [16]. Koehn et al. [18] emphasize that it is *how* these dimensions intersect and compound that affects the health and quality of people’s lives as individuals and group members. Winkler and Degele [37] describe *intersectional analysis* as an intersectional multi-level analysis which takes the various levels (such as level of identity, symbolic representation, and social structure) and their reciprocal effects into account. Conducting an intersectional analysis starts with observing and analyzing social practices. Winkler and Degele [37] recommend an ‘interplay of deductive (theory-led) and inductive (open to surprise) procedural methods’ and proposes that with these steps a systematic and critical (de)construction of social practices is possible. From this point of view (a) categories such as sex/gender/ethnic/race/body etc., (b) intersections for example of sex and dementia or dementia and migration on a micro level, and (c) the relations of different groups (such as inequalities between different migration groups living with dementia) can be analyzed.

### **Applying intersectionality to dementia migration research**

Disparities arise – for example - from biological sex differences, gendered experience, ethnicity and class and independently affect wellbeing. The fact that international migration happens in Europe and the differentiation from biological sex differences and gendered experience have not as yet being thoroughly addressed in recent published National Dementia Strategies. By adopting the lens of intersectionality this can be evaluated as a simultaneous social inequity because multiple dimensions of social identities (such as biological sex and minority, and/or migrant status) are being ignored by the broader system of power. The key goal of an intersectional lens is the social inclusion of voices usually heard less. Applying the intersectional lens can therefore be understood as a paradigm shift in thinking how mutually constructed power relations shape social phenomena, such as being included in decision making as a person living with dementia in a specific context (e.g., receiving home care).

The following subthemes will provide examples of how the concept of intersectionality has been applied to migration and dementia care research and to a combination thereof, illuminating the potential of this approach for future dementia care research and enhancing the concept of social health and dementia [13].

**Intersectionality in dementia care:** Bartlett et al. [3] criticize that sex/gender is a neglected dimension in public discourses related to people with dementia. For example, gender differences are being socially constructed and fluid in their meaning while sex differences are explained based on biological markers. Gender neutral terms as ‘people with dementia’ and ‘family carers’ are used, and therefore it seems as if gender does not matter, when clearly it does since there is valuable evidence of how gender differences matter in the context of

dementia care. Findings reinforce the point that others have made about factoring in such differences when policies and strategies are developed. Bartlett et al. [3] criticize that in dementia care research studies have focused mostly on (female) caregivers rather than the citizens living with dementia. From her point of view, a feminist perspective to citizenship provides a lens with which to expose and examine gendered assumptions implicit within dementia care studies. She encourages researchers to think beyond care practices to broader issues of knowledge production and power relations (such as dynamics within families [19] and its expectations who will take care of whom).

**Intersectionality, migration, and older adults:** Mengxing and Hoshi [24] define 'intersectionality' as a theoretical approach that considers people's overlapping identities and experiences to understand the complexity of discrimination and prejudice. The authors argue that the intersectional lens is needed to understand multiplicity and social diversity, especially structural inequality and disadvantages faced by a person, group of people, and can be used to conceptualize a social problem. Older migrants often experience challenges, such as language barriers, racism and discrimination as well as negotiating cultural influences. Disadvantages are experienced within multiple dimensions and modalities of oppression. Mengxing and Hoshi [24] discuss that by applying an intersectional lens, the degree of these challenges and the resources to buffer their effects can be understood and the influence of gender, socioeconomic status (SES), cultural backgrounds, and migration pathways can be analyzed. This in turn will lead to improvements in understanding and addressing inequality within and between migrated and native groups.

**Intersectionality in dementia care and diversity:** Dilworth-Anderson [12] states, that people are best understood and studied through the dimensionality, co-occurrence, and interlocking of factors (such as race, gender, socioeconomic status, immigrant status, and geographic location or place). From her point of view it is important, to understand the unique needs, stressors, and strengths of multicultural and racial-ethnic family caregivers in a society, which includes the need to analyze and understand the history of people (e.g. native, enslaved, immigrants), the culture of the dyad (care recipients' and caregiver) and the identity, norms, values, beliefs, and their ways of *being* and *doing as well* within the context of social determinants of health, which enables an understanding of social structure. Dilworth – Anderson [12] furthermore criticizes that men's caregiving experience is seldom researched in terms of relational factors or outcomes of caregiving. An intersectional lens can contribute to an explanation of findings in relation to masculinities and help to create inclusive ways of conceptualizing caregiving research.

**Intersectionality, migration and transnational families:** Lafleur and Vivas-Romero [22] combine transnational and intersectional approaches to immigrants' social protection. They point out, that there is a need to analyze the multiple axes of inequalities beyond gender to understand the mechanisms of inequality in contemporary societies. In particular, intersectionality should be used to understand power relations inside one particular nation-state [25]. They criticize a methodological nationalism [36] which ignores that there is an increasing number of individuals living lives that span across the borders of nation-states. The authors advocate for an intersectional approach that could reveal how the immigrant position (e.g., in terms of class, gender, and race) produces different effects in the sending and receiving country and to go beyond what sometimes has been called domestic intersectional studies. There is a need to understand inequalities in a transnational context characterized by the geographical separation of immigrant family members and their simultaneous social, economic and political involvement in different nation states. It is necessary to understand

and accept, that immigrant families may actively design their social protection strategies to counterbalance the less advantageous position they have in one space (e.g., being born in a country without specialized dementia care services) with a more privileged position they have in the other (e.g., now living in a country with a specialized dementia service but not knowing about it, or if they do, thinking it does not apply to them).

## **Discussion**

In our brief overview of definitions, concepts and methods relating to intersectionality and intersectional analysis, we aimed to raise awareness of potential benefits of including immigrants within dementia care research. By addressing research gaps and accepting the critique articulated, intersectional analyses demonstrate how to overcome conceptual boundaries that are linked to the complexity of the everyday experience of our research participants.

A recent survey of the Alzheimer's Association in the USA has revealed, that people living with dementia experience discrimination individually, which is perceived as a barrier to receive (excellent) health care, to seek health care, and to negotiate health care settings [2]. The authors conclude that 'racial and ethnic disparities in health and health care (...) extend to dementia care. Stigma, cultural differences, awareness and understanding, and the ability to obtain a diagnosis, manage the disease, and access care and support services for dementia vary widely depending on race, ethnicity, geography and socioeconomic status. These disparities reach beyond clinical care to include uneven representation (...) in Alzheimer's research' [2] It seems, that researchers fail to address the heterogeneity of our societies, which results in epistemic injustice – not only in research but also in dementia care practice too. If we continue to be ignorant, we position people living with dementia who are also migrants as powerless within our societies and practice injustice because we fail to provide options to be seen and heard.

By adopting the perspective of the intersectional lens and by applying intersectional analyses dementia care research will be able to understand and overcome the reproduction of injustice experienced in our societies. For example, intersectional analyses have shown, that focusing on 'the migrant' may ignore the locally situated life [14] of the perspective of transnational families, who may access social protection through formal schemes in sending and receiving countries as well as through informal provisions based on social networks located in multiple geographical locations. As Lafleur [22] pointed out, we need to overcome intersectional nationalism. Furthermore, participatory research approaches (which are an important part of the methodological tool box in dementia care research) have not been seen in studies providing results from an intersectional analysis. For example, a recent published systematic review [11] pointed out, that while there is huge support for black and minority ethnic (BME) involvement, it is limited to some research phases and particular subgroups. We need to ask ourselves, why this is the case and how to change this? We have seen that the European initiative on social health did not address people living with dementia and migration background, although the number of older migrants in European countries is increasing [15]. There still seems to be a blind spot in (inter)national reports to address the lived experience of people living with dementia and being a migrant [4] [17], despite the published international reports, such as 'minority ethnic dementia care' [15]. Thus, we need to critically reflect, how to balance raising awareness by publishing special reports vs. integrating the perspective of 'specific groups of our societies' in reports that address issues of (inter)national importance. Otherwise, we risk perpetuating the invisibility of some social groups in care



research. For example: older refugees and asylum seekers, migrated lesbian, gay, bisexual, transgender and queer or questioning older adults, migrated older adults from the White minorities, and older parents of first-generation migrants who travel back-and-forth between their home countries and the country where their adult children are settled. The recent published (EU/World) reports are proof that these socially groups remain invisible and we need to ask ourselves: if these groups are missed in research, one could wonder, if dementia escalates the 'ignorance' mentioned above?

Globalization challenges these perspectives, and urges us to rethink assumptions on how migration affects our experience of getting old, and how these experiences can be tracked by identifying the specific localities and therefore to define intercultural differences, while ignoring intracultural ones [35]. Globalization and international migration go hand in hand, there is still locally situated life [14] which provides context to orient ourselves. However, the key question may not be 'to which locally situated life they were orienting themselves (that is, the one they came from or the one they moved to) but rather how many points of reference for their orientation shifted' [35].

## **Conclusion**

Adopting an intersectional perspective in research means to moving beyond one-dimensional categorizations. An intersectional perspective promotes the combination of several social variables and an understanding of social construction of identities that are not homogenous [21]. Intersectionality and intersectional analysis can be applied as a conceptual and methodological approach to identify and address conceptual gaps in perspectives and in dementia care research. To be able to go forward, we will also need different 'meaningful relationships between researchers and experts by experience to ensure involvement (that) is not detrimental to those involved, is meaningful and enjoyable and has a positive impact on the research' [29]. Linking intersectional analysis and participatory research will change dementia care research significantly. The message 'nothing about us without us' [34] challenges researchers and requests that the involvement of people with lived experience will highlight the need for diverse voices in health service research, specifically in dementia care research.

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