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

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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. The concept of intersectionality provides an innovative approach to dementia care perspectives and methodologies.

Objective: The aim is to define intersectionality and to provide examples of applying the concept to dementia care research, focusing on people with a migration background.

Methods: This article was conceptualized and discussed during virtual INTERDEM taskforce meetings in 2020/2021, while discussing identified literature on intersectionality, migration, and dementia care research.

Results: Using an intersectionality framework allows understanding of 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).

Conclusion: Intersectionality 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

Healthcare services · Ethnicity · Socioeconomic factors · Review literature



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Migration impacts the health of people in different ways:

- a. migration impacts sociodemographic changes in a society,
- b. ethnicity and migration are interrelated and may affect the health and access to healthcare services of the migrant population and

c. migration needs to be viewed as a life-long process to understand the impact of discrimination on health [17].

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 ethnic differences and inequalities experienced in the healthcare system within a wider social context [1].

Background

The number of international migrants amounts to 280.6 million globally and approximately 16.2% of the migrants living in Europe are 65 years or older [24]. Estimations indicate that in the European Union (EU) and European Free Trade Association (EFTA) states >500,000 people with a migration background are currently diagnosed with dementia and >100,000 in Germany [24]. The definition of the term migrant varies across Europe [23, 24]. 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, 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 common. The term culture refers to values, beliefs and attitudes that define communities. Categorization of people according to their culture has often been criticized as inflexible and has been shown to be a barrier to accessing healthcare services [5, 22]. Ethnicity emphasizes the identity of a "particular social group in respect of cultural factors and a shared history" [5]; however, this view has been criticized too. Interestingly, in the national dementia strategies and medical treatment guidelines across Europe different terms are being used and most European countries do not provide specific strategies to address migration [27]. To understand people with dementia and their health-seeking behavior, researchers need to consider "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" [26]. With our article we want to draw attention toward an intersectionality

lens and show how intersectional analysis can be applied in dementia care research and how this will contribute to overcome the critiques as described above.

Aim

To stimulate awareness of an underrepresented topic in dementia care research: intersectionality, migration and dementia.

Method

Interdem 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 Europe¹. Interdem's conceptual work is based on collaborating efforts in so-called taskforces, in our case intercultural aspects initiated during the Alzheimer Europe Conference in 2019. All authors are members of this taskforce, representing different educational and professional backgrounds as well as expertise in research on intersectionality, migration and/or dementia. In 2021 (Jan–March) the first three authors (MR, FLU, VPN) conducted a rapid search of the literature via Google search engines, targeted websites, e.g., dementia research centers, and searched in one academic electronic database (MEDLINE via PubMed) using only three key terms: intersectionality, migration and dementia. These three terms were broadly discussed beforehand (2020²) with the members of this taskforce. The aim of this search was not to conduct a typical review³ but to discuss definitions, concepts, and/or empirical studies which address the three key search terms and to better understand the intersection of these terms. The overall aim of this article is to stimulate awareness of the defined key terms by (a) providing a short explanation of the concept of intersectionality and (b) its relevance for dementia care research and

people with a migration background. The different underlying concepts were discussed with all the authors and led to the decision to focus on general definitions of intersectionality, and examples of applying intersectionality in the context of dementia migration research.

General definitions of intersectionality

Crenshaw [7], who first defined intersectionality, described the need for a different perspective and emphasized the need for critical thinking to overcome existing social inequality. For Crenshaw the new term intersectionality made it possible to analyze structural convergence to be analyzed within intersecting systems of power. From her point of view it was 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" [6]. 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. Cuesta and Rämgård [8] pointed out that intersectionality can be understood as an interactive approach as it frames structural differences from subjective perspectives and that it is important to understand fragmented perceptions within a contextualized discourse. An intersectional perspective describes the entanglement of identity categories within a specific context [13]. Koehn et al. [15] emphasized that it is how these dimensions intersect and compound that affects the health and quality of people's lives as individuals and group members. To be able to analyze intersecting systems of power Winkler and Degele [30] proposed an intersectional multilevel 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 [30]

¹ <https://interdem.org/>.

² virtual InterDem Meetings in 2020/2021.

³ Based on the baseline discussion presented here, we are preparing a scoping review.

recommended an “interplay of deductive (theory-led) and inductive (open to surprise) procedural methods” and proposed 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/ethnicity/body etc., (b) intersections, for example, of sex and dementia or dementia and migration on a microlevel, and (c) the relationships of different groups (such as inequalities between different migration groups living with dementia) can be analyzed and this analysis can contribute to an understanding of how these categories intersect.

Disparities arise, for example, from biological sex differences, gendered experience, ethnicity and class and independently affect well-being. International migration happens in Europe but has not as yet been 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 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 relationships shape social phenomena, such as being included in decision making as a person living with dementia in a specific context.

Examples of applied dementia migration research through an intersectional lens

The following examples illustrate 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.

Intersectionality in dementia care.

Bartlett et al. [3] criticized that sex/gender is a neglected dimension in public discourses related to people with dementia. For example, gender differences are socially constructed and fluid in their meaning while sex differences are explained

based on biological markers. Gender neutral terms such 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. They [3] criticized that in dementia care research studies have focused mostly on (female) caregivers rather than the citizens living with dementia. From their point of view, a feminist perspective to citizens provides a lens with which to expose and examine gendered assumptions implicit within dementia care studies. They encouraged researchers to think beyond care practices to broader issues of knowledge production and power relationships (such as dynamics within families [16] and expectations of who will take care of whom).

Intersectionality, migration, and older adults.

Mengxing and Hoshi [20] 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 an intersectional lens is needed to understand multiplicity and social diversity, especially structural inequality and disadvantages faced by a person or group of people, and can be used to conceptualize a social problem. Older migrants often experience disadvantages within multiple dimensions and modalities of oppression. By applying an intersectional lens, the degree of these challenges and the resources to buffer their effects can be understood and the influence of, for example, migration pathways can be analyzed [20]. 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 et al. [10] stated that people are best understood and studied through the dimensionality, co-occurrence, and interlocking of factors (e.g., immigrant status, and geographic location or place). From their point of view, it is important to understand the unique needs, stressors, and strengths of multicultural and ethnic family caregivers in a society. This includes the need to analyze and

understand the history of people (e.g., native, enslaved, immigrants), the culture of the dyad (care recipients and caregivers), the identity, norms, values, beliefs, and their ways of being and doing as well within the context of social determinants of health, thereby enabling an understanding of social structure. They also [10] criticized that men’s caregiving experience is seldom researched. An intersectional lens can contribute to an explanation of findings in relation to masculinity and help to create inclusive ways of conceptualizing multicultural and ethnic family caregiving research.

Intersectionality, migration and transnational families.

Lafleur and Vivas-Romero [19] combined transnational and intersectional approaches to immigrants’ social protection. They point out that there is a need to analyze the multiple axes of inequalities to understand the mechanisms of inequality in contemporary societies. Intersectionality should be used to understand power relationships inside one particular nation-state [21]. Methodological nationalism has been criticized [29], which does not address that there is an increasing number of individuals living lives that span across the borders of nation-states. An intersectional approach could reveal how the immigrant position (e.g., in terms of class, gender) produces different effects in the sending and receiving country and to go beyond what has sometimes 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 we aimed to raise awareness of potential benefits of including an intersectional lens 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 revealed that people living with dementia still experience discrimination [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.

By adopting 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, specifically for people with dementia. For example, intersectional analyses have shown that focusing on "the migrant" may ignore the locally situated life [11] 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 [19] pointed out, we need to overcome intersectional nationalism. Furthermore, participatory research approaches have not been seen in studies providing results from an intersectional analysis. While there is considerable support for black and minority ethnic (BME) involvement, it is limited to some research phases and particular subgroups [9]. 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 Europe is increasing [12]. There still seems to be a blind spot in (inter)national reports to address the lived experiences of people who are migrants and are living with dementia [4, 14], despite the published international reports, such as minority ethnic dementia care [12]. Thus, we need to critically reflect on 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, people with dementia having a family of choice, 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 recently published (EU/World) reports are proof that these socially diverse groups remain invisible and we need to ask ourselves if these groups are missed in research, does dementia possibly escalate the ignorance mentioned above?

Conclusion

Adopting an intersectional perspective in research means 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 homogeneous [18]. 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" [25]. Linking intersectional analysis and participatory research will significantly change dementia care research. The message "nothing about us without us" [28] challenges researchers and requests that the involvement of people with lived experiences will highlight the need for diverse voices in health services research, specifically in dementia care research.

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Declarations

Conflict of interest. M. Roes, F. Laporte Uribe, V. Peters-Nehrenheim, C. Smits, A. Johannessen, G. Charlesworth, S. Parveen, N. Mueller, C. Hedder Jones, R. Thyrian, J. Monsees and H. Tezcan-Güntekin declare that they have no competing interests.

For this article no studies with human participants or animals were performed by any of the authors. All studies mentioned were in accordance with the ethical standards indicated in each case.

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Intersektionalität und ihre Bedeutung für die Demenzforschung bei Menschen mit Migrationshintergrund

Hintergrund: Obwohl sich die Bedürfnisse und Bedarfe an Pflege und Unterstützung für Menschen mit Migrationshintergrund sowie deren Zugang zu Gesundheitsleistungen oft von denen anderer Menschen, die von Demenz betroffen sind, unterscheiden, adressieren die meisten europäischen Länder Migration nicht in ihren nationalen Demenzstrategien. Das Konzept der „Intersektionalität“ bietet einen innovativen methodologischen und perspektivischen Zugang zu Demenz.

Ziel der Arbeit: Ziel ist es Intersektionalität zu definieren und Anwendungsbeispiele des Konzepts im Kontext der Demenzversorgungsforschung – mit Fokus auf Menschen mit Migrationshintergrund – aufzuzeigen.

Methoden: Dieser Artikel wurde im Rahmen virtueller INTERDEM-Taskforce-Treffen 2020/2021 konzipiert und diskutiert, um eine auf Intersektionalität fundierte Basis für zukünftige Demenzforschung zu formulieren. Dabei wurde die identifizierte Literatur zu Intersektionalität, Migration und Demenzversorgungsforschung betrachtet.

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 geschlechtlicher Identität, sozioökonomischem Status, Ethnie, Migrationsstatus und geografischem Ort beachtet werden.

Schlussfolgerung: 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.

Schlüsselwörter

Gesundheitsversorgung · Ethnie · Sozioökonomische Faktoren · Übersichtsbeitrag

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