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. The concept of intersectionality provides an innovative approach to dementia care perspectives and methodologies. **Objectives:** to raise awareness of an intersectional lens and to provide examples of applying the concept to dementia care research - focusing on people with a migration background. **Methods:** This paper was conceptualized and discussed during virtual INTERDEM taskforce meetings in 2020/21, while discussing identified literature on intersectionality, migration, and dementia care research. **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 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 Migrationshintergund und ihr Zugang zu Gesundheitsleistungen sich oft von denen anderen 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:** 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 [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 experienced ethnic differences and inequalities in the health care system within a wider social context [1].

Background

The number of international migrants amounts to 280.6 million globally and ~ 16.2% of the migrants living in Europe are 65 years or older [24]. 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 [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 health care 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 **Inter**ventions in **Dem**entia aimed at improving the quality of life of people with dementia and their supporters, across Europe[1]. 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 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 (2020[2]) with the members of this taskforce. The aim of this search was not to conduct a typical review[3], 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.

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[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.

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 authors and led to the decision to focus on general *definitions of intersectionality*, and examples of *applying intersectionality in 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 her, the *new term intersectionality* made it possible to analyze structural convergence to be analyzed within intersecting systems of power. From her standpoint 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] point out that intersectionality can be understood as an interactive approach, since 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] 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. To be able to analyze intersecting systems of power Winkler and Degele [30] propose 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 [30] recommend an 'interplay of deductive (theory-led) and inductive (open to surprise) procedural methods' and propose 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 micro level, and (c) the relations 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 wellbeing. 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 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.

Examples of applied dementia migration research through an intersectional lens

The following examples will 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] 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 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] criticize 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 encourage researchers to think beyond care practices to broader issues of knowledge production and power relations (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, 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] state, 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] criticize that men's caregiving experience is seldom researched. An intersectional lens can contribute to an explanation of findings in relation to masculinities and help to create inclusive ways of conceptualizing multicultural and ethnic family caregiving research.

Intersectionality, migration and transnational families: Lafleur and Vivas-Romero [19] combine 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 relations 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 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 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 has 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] has 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 experience 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 recent 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 homogenous [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 change dementia care research significantly. The message 'nothing about us without us' [28] 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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