

Review

Interdisciplinary and Transdisciplinary Perspectives: On the Road to a Holistic Approach to Dementia Prevention and Care

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Abstract. Dementia, of which the most frequent form is Alzheimer's disease, is a chronic and terminal condition with multi-factorial causes and numerous consequences on a patient's life. Combining perspectives from different disciplines seems necessary for unraveling dementia's entangled issues. Current dementia management is a multidisciplinary effort; however, integrating different disciplines as a holistic treatment process is often hindered due to different responsibilities, various conceptual approaches, and distinctive research methods. With this paper, we raise some of the challenges that need to be addressed in order to initiate an interdisciplinary or even transdisciplinary research agenda. We also outline recommendations on how to integrate multiple disciplinary perspectives in dementia care and research. We see opportunities for young investigators to draw from different fields of research in dementia as their research focus is still developing. By establishing common objectives with investigators from other fields, we can pursue the goal of improving treatment and care as a team—meaning accomplishing different tasks but sharing a common purpose. It is necessary to address the communication between fields that limits the understanding of connections between cognitive symptoms, biological processes, treatment, lifestyle, and care giving in order to reach the aim of developing a holistic, person-centered, patient-first approach. Associating biomedical research to field experience from care professionals and the study of human science will promote a more independent, social, and sustainable lifestyle for people with dementia.

Keywords: Alzheimer's disease, dementia, interdisciplinary, research methods, treatment

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INTRODUCTION

Dementia, its most common type being Alzheimer's disease, is leading health statistics worldwide [1]. More than 48 million people are currently living with a dementia diagnosis [2]. Estimations suggest that by 2050 the global prevalence will be 115 million people [2]. Whereas Western Europe will experience a proportionate increase in dementia prevalence by 100%, North America (170%), China/Western Pacific (336%), and Latin America (393%) will face even greater challenges [3]. Dementia is a clinical syndrome characterized by impaired mental processes that greatly disturb one's ability to manage daily life [4]. This clinical syndrome can be triggered by several genetic and lifestyle risk factors, leading to different brain pathologies [5]. Dementia comprises Alzheimer's disease, the most common form of dementia, as well as vascular dementia, frontotemporal dementia, and Lewy body disease to name a few. Evidently, distinguishing the type of dementia is relevant for treatment planning. Often, however, dementia patients do not have only one but several pathologies. For instance, more than 80% of those with Alzheimer's disease pathology also have vascular pathologies [6]. Multiple microinfarct or large macroinfarcts and vascular lesions in diverse subcortical regions can lead to atypical patterns of symptomatology [7]. The heterogeneity of the pathology and of the symptomatology requires a person-tailored treatment plan. Moreover, dementia prognosis, treatment, and care challenges have heterogeneous consequences on the diagnosed individual, but also their families, healthcare providers, and caregivers [8]. The multi-factorial causes of dementia, the multi-faceted nature of dementia symptoms, and the numerous consequences of a patient's cognitive impairment begs for the development of a holistic approach to dementia prevention and care that allows for tailored treatment and intervention plans.

In the current dementia healthcare setting, patients expect their doctors to give them answers concerning the causes of their symptoms (diagnosis) and which medications could cure them (treatment) [9]. Medical professionals are thus faced with an important responsibility. Yet, patients' expectations do not always include only cognitive and biomarker profiles and prescriptions, but guidance concerning how to live their life with dementia [10]. This latter issue goes beyond what a behavioral neurologist

or psychiatric geriatrician can provide. Nonetheless, patients and families need this guidance as dementia severely affects every-day functioning. As causes of cognitive impairment are multiple [11], every individual's symptoms are different, and every family is diverse [12, 13], the responses given by medical professionals and communities should be as personalized as possible. Accordingly, an interdisciplinary approach to dementia prevention and care is essential for tackling the complex questions surrounding this heterogeneous disease. Interdisciplinary research is "a mode of research by teams or individuals that integrates information, data, techniques, tools, perspectives, concepts, and/or theories from two or more disciplines or bodies of specialized knowledge to advance fundamental understanding or to solve problems whose solutions are beyond the scope of a single discipline or area of research practice" [14]. Integration of knowledge from several disciplines on dementia and the achievement of a synthesis [15] is necessary to develop optimized person-tailored treatment plans. There is still a long way to go to achieve such a coordinated combination of different disciplines in dementia care and research; however, it is a necessary next step for unraveling dementia's entangled issues. Ultimately, the goal should be the establishment of transdisciplinary dementia research and care management, in which professionals jointly create a new framework that comprises scientific and practical solutions to meet the complex challenges of dementia [16, 17].

CURRENT SOLUTIONS OF INTERDISCIPLINARY DEMENTIA MANAGEMENT

Dementia management is already a multidisciplinary effort. Professionals and health care providers work simultaneously, yet independent with the patient. Some teams have initiated approaches to develop new advances in interdisciplinary, that is integrated, dementia management. The National Center for Geriatrics and Gerontology, for instance, has begun to provide educational support for family caregivers through interdisciplinary programs [18]. The program includes education on treatment (medical care, medication) and care (nursing care, welfare), and was effective in helping patients and family members to understand dementia better. Another example is the Texas Christian University that formed an interdisciplinary team of an attending physician, speech

pathologist, recreational therapist, and geropsychiatric clinical nurse to improve the management of behavioral disturbances. A constant feedback loop that incorporated assessment, intervention, evaluation, documentation, and problem-solving seemed to be an effective management strategy [19]. Other dementia management teams across the world initiate similar interdisciplinary programs. A review of all interdisciplinary interventions in nursing homes points out that communication—formal team meetings and coordination among team members—seems the most effective strategy [20].

Despite the efforts made, dementia puts major challenges on everyone involved. Interdisciplinary collaboration may be the key to finding solutions for dealing with those challenges. The Marian S. Ware Alzheimer Program [21] emphasizes that interdisciplinary dementia management should go beyond nursing and should 1) improve the integration and continuity of Alzheimer's disease care; 2) identify biomarkers that detect the earliest presence of Alzheimer's disease and related neurodegenerative cognitive disorders; 3) enhance both the design and conduct of clinical trials as well as review their results to more effectively test new Alzheimer's disease therapies and translate valuable therapies into clinical practice; and 4) discover and develop novel disease-modifying small molecule treatments for Alzheimer's disease. One of the most advanced concepts of interdisciplinary dementia care is advocated in Germany. The standards for care of patients with dementia (S3 guidelines) [22] require medical professionals who manage dementia patients to involve interdisciplinary staff for social support, care management, caregiving, psychotherapy, physical activity, and even music therapy, among others in the treatment [23]. This comprehensive approach goes far beyond the traditional care models and is probably the first in the world to include psychosocial domains as well as caregiving.

The transition from this advanced approach on paper to implementation in the community is unfortunately not as easy as it sounds. Achieving interdisciplinary or even transdisciplinary disease management requires an ambitious multidisciplinary team effort. Interdisciplinary collaboration is when researchers from different disciplines work together to solve a common problem and transdisciplinary collaboration is when researchers bring together discipline-specific knowledge to create new knowledge and new solutions [17]. An important example for interdisciplinary collaboration is, for instance, the

Faith-Based Partnerships to Foster Community Intervention Translation for diabetes, in which strategies to improve self-management were taught to individuals with type 2 diabetes which included healthcare patterns, diabetes knowledge, physical activity, nutritional practices, and physiological outcomes and lead to significant improvements in disease parameters [24]. Other examples are, for smoking, the *Community Intervention Trial for Smoking Cessation* (COMMIT) and, for heart disease, the *Multiple Risk Factor Intervention Trial* (MRFIT) [25]. Transdisciplinary programs are more challenging to implement because they aim at synthesizing theories and methods to a problem area [26] in order to achieve a co-evolution of understanding and harmonized action across disciplines [27]. An advantage of transdisciplinary research efforts is that they grasp the complexity of the disease by taking into account diversity, linking knowledge, and developing knowledge that is useful for the society [28]. As human health is the “outcome of complex processes in the physical, psychological, social and ecological systems” [29], research should mirror this to provide the best solution for society. Examples for transdisciplinary research efforts are the *Future Earth*, a 10-year international initiative on global sustainability research launched during the Rio + 20 United Nations Conference on Sustainable Development [30] and the *Transdisciplinary Tobacco Use Research Centers* (TTURCs) initiated by the National Institutes of Health and the Robert Wood Johnson Foundation through an investment of \$86 million [31]. Dementia research and care could follow this example and adopt transdisciplinary programs that not only translate basic science and clinical practice in the community setting but that advance a common methodology and action plan.

DIFFICULTIES IN INTER- AND TRANSDISCIPLINARY WORK

Interdisciplinary and transdisciplinary efforts are often hindered by several obstacles. One set of challenges are the different conceptual approaches and distinctive research methods [32]. Each medical professional and every researcher have different objectives and different sets of responsibilities. It is easy to ignore a symptom because it is not perceived as relevant for one's own work. Therefore, being open for communication is already a huge step in the right direction. Further, integrated work of different

disciplines is very challenging because it incorporates many different dimensions of the disease. At the clinical stage, the focus is on symptomatology [33], which is easy to study independently. In neurology research today, an increasing focus is put on the preclinical stages of dementing disorders [11], the stage at which pharmacological interventions might be most efficient and yet also the stage at which the benefit of interdisciplinary collaboration between biomedical and human sciences might be the least obvious. For instance, the disclosure of biomarker results at the preclinical stage raises ethical challenges that go far beyond the primary aims of the research studies in which these biomarkers are evaluated. Only a collaboration between disciplines can find solutions for such complex questions.

Another obstacle in creating inter- and transdisciplinary dementia management is that every researcher uses different language in terms of professional terminology [34]. Language determines our focus and can easily lead to misunderstandings. While the nurse is concerned with an excessively high activity level, the psychiatrist is concerned about a low activity level as it is a symptom of apathy or depression, whereas the epidemiologist posits that a high activity level is important to slow cognitive decline. Getting to know each other's research fields and learning to understand the connections between the cognitive and physical symptoms of the diseases—the biological processes (as observed using biomarkers, genetics, and epigenetics studies, animal models), the lifestyle risk factors (epidemiology, public health), the various forms of treatments (symptomatic and disease-modifying drugs, cognitive rehabilitation, behavioral and various forms of psychotherapy), and caregiving (spouses, relatives, primary care physician, nursing, palliative care)—is essential to achieve an effective dementia care management. Dementia, as any complex issue, comprises a number of interconnected issues at the interface of several disciplines, and can thus only be understood through integrated expertise spread across these different schools of thought [35]. Our increased knowledge of the biological processes at work in dementia should not prevent us from pursuing research efforts that investigate associations between biological processes and other disciplines involving cognitive, occupational, or psychological therapies and daily life management.

Transdisciplinary work may be the only strategy to find effective solutions for dementia on the societal level. As people live around 5 to 10 years with demen-

tia [36], and symptoms start long before a dementia diagnosis is made, there is a substantial amount of time with the disease that has to be managed. Therefore, research on dementia must also investigate implications on the ability to manage daily activities. Strategies to manage dementia might be differentially efficient according to the actual pathology, the disease stage, the lifestyle of the individual, and his or her relatives. Biomarkers might inform us about which individuals might be most responsive to which management plans. Yet, macro- and meso-level social exposures influence psychosocial processes and health behaviors [37]. For instance, a lower level of social engagement is associated with faster cognitive decline [38]. Knowledge from professionals caring for and working with individuals with dementia could enrich the biomedical approach of dementia as the subjective, qualitative aspect of a patient's experience is often overlooked and understudied in the field. It is important to acknowledge the individual behind the disease. Biomedical research too often uses group results to infer prediction at the individual level [39]. However, over the past decade, large sample size studies on aging, Alzheimer's disease, and related disorders have offered a great opportunity to conduct individual risk model prediction [40]. In addition, whole genome sequencing is increasingly available for the participants of these studies, allowing for a more tailored approach to the predictive power of each biomarker [41]. 'Precision systems medicine', that is healthcare that accounts for individual differences in genes, environments, and lifestyles with regard to biomarkers and health symptoms [42, 43], has officially been recognized as important by the government of the United States, when they started the largest longitudinal study on precision medicine called "PMI All of Us Research Program," including 1 million people [43]. Since numerous lifetime events, lifestyle, and genes shape dementia risk, it is important to follow this approach in dementia care and research as well. Thanks to biomarkers and other scientific advances, more knowledge about the disease and its heterogeneity was developed [44], but research stops at the institutional level and does not reach the community. Differences in social positions and obligations, asymmetries in power between professionals [45], conflicting reference systems and values [46], prolonged debates and agreement finding as well as a lack of readiness to collaborate [31] hamper advances.

Yet, integrated disciplinary efforts are urgently needed as disparities in dementia risk are attributable

to several lifetime risk factors [47]. Socioeconomic disadvantages [48], educational attainment, traumatic events, poor mental health (e.g., depression) and cultural factors such as multilingualism [49] seem to contribute to racial and ethnic disparities in dementia prevalence in the United States. Globally, lower education is one of the key risk factors for dementia in countries worldwide [50]. Some genetic predisposition are most likely subject to lifetime risk factors as genes, which are established risk factors in one country (i.e., *APOE* $\epsilon 4$ allele in the United States [51]) are less relevant regarding dementia risk in others (i.e., sub-Saharan Africa [52]). Thus far, as research has been conducted in silos and clear pathways have to be established. Biomarker and imaging studies, as well as clinical trials, usually have strict exclusion criteria leading to selected samples of the least affected people. Whether the results obtained are valid for the rest of the population remains unclear. The challenge is to widen inclusion criteria for studies and to systematically sample people from all parts of the population. Neurologic studies alone cannot solve the societal problems with dementia. Social determinants affect health and represent important opportunities for disease management [53]. Air pollution [54] and community living conditions [55] contribute to the risk for developing dementia. Research has indicated that improved living conditions even lead to lower incidence rates of dementia in younger cohorts [56]. In addition, biological models are needed to clarify associations between social determinants and dementia, which require the incorporation of epidemiological, biological and neurological research methods in a single study. To that end, dementia research must move away from convenience sampling to stratified population sampling and incorporate diverse perspectives when formulating research questions.

Yet, there remains the challenge that researchers will automatically encounter problems with culture and segregation. Culture can lead to bias in assessment due to language skills, literacy, and comprehension of the items of cognitive testing; e.g., translating a test into Spanish without checking the context in which the Spanish word is applied can lead to inaccuracies [57]. Culture can also lead to bias in participation because the sampling strategies or the methods of the interviews and examinations are not adapted to cultural norms [58]. Segregation in terms of race and ethnicity as well as in terms of socioeconomic indicators can lead to systematic gaps in research [59]. As dementia risk is substan-

tially influenced by lifestyle factors and environment, knowledge on one population might not be translatable to other ethnic groups. Treatment programs in one culture might fail in others. Only knowledge on access to resources, living conditions, and cultural norms can allow for inclusion of minority population groups. This requires the involvement of experts from the particular population group, as well as local community representatives. This calls for coordinated, multi-sector action to achieve meaningful collaboration [60].

Concerning the different conceptual approaches and distinctive research methods, it is most important to listen to one another first and get to know one other. If we understand each other's perspectives, we can pursue the goal of improving treatment and care as a team, meaning accomplishing different tasks while sharing a common purpose. This is only possible when we are capable of opening our eyes to the bigger picture and are able to acknowledge the importance of other field's contributions, despite our differences and focused specializations.

THE FUTURE OF INTER- AND TRANSDISCIPLINARY DEMENTIA MANAGEMENT

Integrated knowledge development from different disciplines can provide clinicians with additional tools to treat their patients. As the qualitative and subjective aspect of a patient's experience is often overlooked and understudied in the field, incorporating knowledge from professionals caring for and working with individuals with dementia could enrich the biomedical approach to dementia. We believe that searching for better treatment and better care are intimately related. Likewise, combining epidemiology of risk factors with basic neuroscience could lead to better insight in causal pathways. For instance, education [61], bilingualism [62], and/or higher socio-economic status [48] have been associated with delayed dementia symptoms [63] as well as with a better resilience to incipient tau pathology [64]. Once research limits are less narrow, there are infinite possibilities that could allow for new, multi-disciplinary developments.

Young investigators at the beginning of their career still have the chance to shape their research expertise. Even though, specialization in a field constitutes a crucial step during career development, they are still in the process of developing their specialization

and this is the opportunity to make interdisciplinary or even transdisciplinary work a part of their professional future. To realize a transdisciplinary dementia management in the future, training and leadership is necessary to produce scientists who have methodological and theoretical knowledge to implement complex transdisciplinary projects [26]. Transdisciplinary work is a co-production that requires multiple framing, interdependency, consensus-finding, and harmonized action [27, 65] that is extremely difficult to implement in the research setting of established scientists [31]. Young investigators present an opportunity to prevent prejudices between disciplines and develop specialized leaders [66]. Young investigators focusing on dementing disorders should learn early on to connect interests of biomedical and human factors. It is necessary to discuss dementia from various perspectives and encourage other scientists to join this approach. Linking basic and clinical research is one of the central challenges of inter- and transdisciplinary work. Medical research happens in a well-controlled laboratory environment, whereas clinical research usually involves observational methods. Combining both perspectives in either the same research study or the same research facility could speed up the translation from basic results to applied research. If young investigators start building up interdisciplinary networks that link basic and clinical research, we can make significant advances in the future. Interdisciplinary collaborations could take on an infinite possibility of directions: from retirement to grandchildren, from sleep to food, from socioeconomic status to social contacts, from neurobiology to psychoanalysis, from prescriptions to art therapy, from Chinese medicine to meditation, from vascular to cognitive, from mental to general health, from motor skills to accident risks, etc. Their work during the coming 50 years will shape the future of dementia care and research. Moreover, their work will generate the first coherent research frameworks for transdisciplinary teamwork that shape the way for an integrative, holistic care that takes the biological, emotional, psychological, and social well-being dimensions into consideration—and this is surely a great challenge. Young investigators today are the leaders from tomorrow. If motivated young investigators get the chance to become appropriate leaders for transdisciplinary teams, they will be able to surmount obstacles in transdisciplinary collaborations in the future and facilitate the development of new discoveries [67].

However, there are logistic challenges on a daily operational level that make it difficult to achieve

those aims. We would therefore like to make some easy to implement, hands-on recommendations (Combined approaches, Optimized research funding structure, Cross-discussion between population and basic research, Using mixed-methods, Meet together, Employing a person-centered approach, Diversify the study population, COCU MED) that could help investigators adopt a multi-disciplinary research agenda on dementia.

- 1) *Combined approaches*: Combinations of different approaches in dementia research studies such as pharmacological treatment and caregiving, epidemiology and genetics, social environment and behavioral problems, biomarkers and health behaviors etc. are the first step into a multi-disciplinary research agenda. Further, social and epidemiological studies must obtain access to biomarkers, not only for a subgroup of their participants, but also for all. Respective technologies must be adapted to this end. Other methods are already available, for instance using plasma amyloid- β is a very good substitute for amyloid PET scans [68].
- 2) *Optimized research funding structure*: Current research funding aims at minimizing risks, which fosters traditional approaches and gives little chance to new, innovative techniques. Projects that try to integrate many disciplines for dementia research and care come with a higher risk, yet also with more opportunities for better treatment. Trying to obtain a grant is challenging when the methodological work does not correspond to that of the discipline because reviewers are often critical of methods that are unfamiliar to them [26]. There is a lack of funding structures specifically for transdisciplinary projects [69] that are less temporarily limited [46] as transdisciplinary projects usually lack of coherent timing [70] Only by establishing funding for such long-term high-risk projects can interdisciplinary research prosper. Moreover, it is usually required that one be a professor for research grant applications. However, being a professor, especially for young investigators, comes with lots of teaching and institutional responsibilities, leaving them with little resources to coordinate a transdisciplinary project. Funding organizations that allow young investigators to have enough time to conduct long-term research activities within different disciplines need to be established.

- 3) *Cross-discussion between population and basic research*: Basic research needs to be carried into the community. Neglecting the values and expectations of society makes science a purely symbolic participator in the society, which has low innovative potential [46]. Working in a network that pays systematic attention to community-applied settings that protect psychological wellbeing [17] and developing appropriate research strategies will help scientists to make an active contribution to the social process of resolving an issue [27]. A network or a platform needs to be established to turn important scientific discoveries into policy and services to ensure that local medical practices meet current scientific standards and that living conditions are adjusted to provide the best possible care.
- 4) *Using mixed-methods*: Integrating a qualitative component to quantitative research designs appears conflicting. However, it can reveal surprising new insights into one's own work. Qualitative research discloses information that is not captured by a standardized quantitative research approach. For example, participants' individual strategies, misunderstandings, desires to fulfill a stereotype, or surprising changes in symptoms could be relevant for research outcomes. Adding qualitative questions to a study design might yield valuable results.
- 5) *Meet together*: Every new adventure starts by getting to know one another. Instead of meeting separately in separate conferences or in separate sessions, interdisciplinary meetings should be arranged for opportunities to get to know each other's work and each other's perspectives.
- 6) *Employing a person-centered approach*: Instead of calculating averages of the data and using standardized valid-for-all treatment plans, we should take on a person-centered perspective. Given the heterogeneity of dementia symptoms and pathology, a person-centered approach is more likely to bring about successful treatment and prevention. Rather than merely relying on the averages, we should identify characteristics that alter the treatment effect or the significance level, identify clusters of specific groups of people, and include a person's lifestyle and health behaviors into the decision-making process.
- 7) *Diversify the study population*: Pragmatic trials with convenience samples can lead to systematic gaps in research because the results will be valid only for the specific population group that was studied. Participation depends on exclusion criteria and access. Less narrow inclusion criteria can diversify the sample. Access includes the distance to travel to the study center and the costs as well as psychological factors such as belonging to a non-educated group, language barriers, previous experience with medical facilities, social in-group and out-group beliefs, political tension, and trust in the study team. Taking into account all of these factors leads to a more diverse study population, which will finally provide results for all of society, including the disadvantaged population groups.

CONCLUSIONS

Encouraging collaborative thinking across disciplines is essential to create a society with a holistic approach to dementia prevention and care practices. Today, there are several impediments to achieving such an ambitious program. Nonetheless, they "can be overcome through the development of an interdisciplinary culture that will change the way funding bodies, graduate schools and scientists think and act" [35]. We need healthcare providers to know more about the biological causes of dementia and how to personalize care according to pathology, family, and personality. We need to reduce the stigma around dementia and start communicating with every stakeholder for creating a society where health professionals empower patients and caregivers to be an active part in dementia management and where doctors prescribe 'arts and sciences.' A holistic person-centered, patient-first approach integrating biomedical research with human science and experience from care professionals would promote a more independent, socially integrated, and sustainable lifestyle for people with dementia.

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CONFLICT OF INTEREST

The authors have no conflict of interest to report.

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