

Special Topic Section

Reconsidering frameworks of Alzheimer's dementia when assessing psychosocial outcomes

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Abstract

The purpose of this introductory article to the special issue on psychosocial outcome measures in *Alzheimer's & Dementia: Translational Research & Clinical Interventions* is to outline new frameworks to more effectively capture and measure the full range of how people living with Alzheimer's dementia and their family caregivers experience the disease process. Specifically, we consider the strengths and weaknesses of alternative perspectives, including person-centered, strength-based, and resilience-focused approaches that may complement and extend the dominant deficit paradigm to reflect the entirety of the dementia experience. Our aim is to encourage innovative methods to measure psychosocial aspects of Alzheimer's dementia and caregiving that have not yet received sufficient attention, including resources (e.g., services and supports) and positive caregiver and care recipient outcomes (e.g., positive mood and adaptation).

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There are more than 9.9 million new cases of dementia globally each year [1]. Major national and international initiatives have elevated Alzheimer's disease and related dementias to one of the world's most pressing public health issues. In the many reports emerging from the National Plan to Address Alzheimer's [2] and related efforts in the U.S., a clear recommendation has emerged: the need to feature the voices of people with Alzheimer's dementia and their family

members in research (authors note: the 2018 edition of the Alzheimer's disease facts and figures [3] reflects a shift in understanding and terminology. "Alzheimer's disease" now refers only to the disease and disease continuum specifically, and "Alzheimer's dementia" describes the dementia stage of the continuum). Fields such as disability studies have made substantial efforts to incorporate community members and diverse stakeholders into the research process, whereas dementia research has not consistently included persons living with Alzheimer's dementia and their caregivers when selecting research goals and conducting studies [4,5]. At recent national summits on dementia care in the U.S., people living with Alzheimer's dementia and their caregivers have voiced frustration at the disconnect they perceive between scientific findings and their lived experiences [6,7]. In particular, family members and

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people living with Alzheimer's dementia express that the continual focus on Alzheimer's dementia as a period of irretrievable decline, decay, and loss does not reflect the diversity of their lived experiences. Outcome measures are often operationalized as memory impairments, neurological decline, functional impairment, and behavior "problems" and may ignore constructs such as resilience, well-being, self-efficacy, mastery, quality of life, or similar domains that may capture the experience of persons living with Alzheimer's dementia more holistically.

The purpose of this article is to outline new frameworks to measure the full range of how people living with Alzheimer's dementia and their family caregivers experience the disease process. Specifically, we consider the strengths and weaknesses of alternative perspectives, including person-centered, strength-based, and resilience-focused approaches that may complement and extend the dominant deficit paradigm to reflect the entirety of the dementia experience. We recognize that Alzheimer's dementia and the care required is potentially overwhelming and an all-encompassing experience for many families; thus, ongoing research to understand and prevent negative outcomes is important and needed [3,8,9]. However, strategies that emphasize the potential for growth and resilience during the course of Alzheimer's dementia caregiving are also valuable and necessary to reduce stigma, improve quality of life, encourage innovative interventions, and more effectively engage with those who are living such experiences routinely. Here, we outline several theoretical and empirical advances that emphasize positive, person-centered approaches in the larger adult development and aging literature. Our aim is to encourage innovative methods to measure psychosocial aspects of Alzheimer's dementia and caregiving that have not yet received sufficient attention, including resources (e.g., services and supports) and positive caregiver and care recipient outcomes (e.g., positive mood and adaptation).

1. Geriatrics, gerontology, and Alzheimer's dementia

Gerontology and geriatrics focuses on the inherent diversity of the aging experience [10–13], and this philosophical position has served as the foundation of many theories and methods adopted to study various aging processes. The gerontological/geriatric emphasis on context and holistic care has influenced how we study quality of life and well-being in persons with Alzheimer's dementia. As opposed to care based solely on a biomedical framework, effective care strategies that combine biomedical and social frameworks (particularly those that "target" or involve the family caregiver or provide people living with Alzheimer's dementia with meaningful activities [14,15]) succeed in allowing people living with Alzheimer's dementia to live well in the community. Nonetheless, even researchers interested in the psychosocial aspects of Alzheimer's dementia still tend to evaluate programs, services, and interventions based solely on assumptions of

decline and loss for people living with Alzheimer's dementia (e.g., behavior "problems" or "behavioral and psychiatric disturbances") and their family caregivers (e.g., burden, stress, and depression).

At present, few theoretical frameworks explicitly incorporate the well-being of people living with Alzheimer's dementia [16]. Interdisciplinary views and conceptualizations of well-being emphasize that there is a need to move beyond biomedical interpretations of well-being (e.g., the absence of disease) and instead adopt new theoretical, conceptual, and measurement approaches when describing and supporting the Alzheimer's dementia experience [17]. In some ways, this requires researchers to evaluate Alzheimer's dementia by not only acknowledging and accounting for neuropathological decline but also incorporating positive concepts such as reserve and resilience. There is an entire social and biological literature on concepts of reserve and resilience [18]. Models guiding research in these areas may have lessons applicable to the Alzheimer's dementia context. The field of intellectual and developmental disabilities (IDD), for example, has witnessed a seismic shift in thinking away from impairments and limitations in favor of assessing functional strengths and supports needed to maximize functioning [19]. Renaming IDD as a disability rather than a disorder recast it in terms of fit between an individual's unique capacities and the environment. This modern approach to IDD defines successful outcomes in terms of enabling improved function within the environment [20,21]. While IDD and Alzheimer's dementia diverge in important ways, this paradigm may be translated to the Alzheimer's dementia context to improve functioning and engagement for persons with Alzheimer's dementia.

In the following sections, we review two theoretical and conceptual approaches that have evolved in both gerontology (successful aging) and child development (resilience) that can better inform how we theoretically and operationally approach and measure the Alzheimer's dementia experience.

2. Successful Aging

The MacArthur Network on Successful Aging, spearheaded by Rowe and Kahn [22–24], proposed successful aging as an alternative to "usual aging," thereby challenging dominant conceptualizations of aging that focused on decline and loss (e.g., disengagement theory) [25]. They proposed that successful aging includes three main components: avoiding disease and disability, maintaining physical and mental function, and engaging actively with life. While acknowledging that genetics play an important role, Rowe and Kahn emphasized that environmental factors and health behaviors are also powerful determinants of health outcomes. Through positive lifestyle choices (e.g., exercise and quitting smoking), individuals can maximize their ability to live a healthy, productive, and rewarding life into their later years. This

call for gerontologists to focus on success, rather than failure, has been an influential perspective in the field with more than 6000 publications citing Rowe and Kahn [23] to date. Here, we provide a brief summary of some of the major advances that have developed since the original publication of successful aging, while also noting important critiques raised.

Successful aging is a complex, multidimensional construct, and developing an operational definition has proven challenging [26,27]. For example, Cosco et al. found 105 operational definitions across 84 studies, encompassing a range of physiological and psychological constructs such as physical and cognitive function, disability, health status, social engagement, life satisfaction, autonomy, and coping [28]. There appears to be little consensus on what the ideal measures of successful aging are, and different measures yield a wide variety of findings. Across 84 studies, the proportion of participants in each sample considered “successful agers” ranged from 0.4% to 92% [28]. One approach to addressing these definitional issues is to develop self-report measures of overall successful aging, such as the Successful Aging Inventory [29]. However, the field has yet to settle on a consensus strategy for operationalizing “success.”

A second major goal of research on successful aging is to determine what environmental and behavioral factors can contribute to successful aging. In a meta-analysis, the health, behavior, and psychological variables with the strongest association with successful aging included illness burden (i.e., overall burden caused by comorbid illnesses), pain, depression, physical function, cognitive function, ability to control, perceived health, productivity, social engagement, occupational growth, exercise, continuity of occupation, perception of the aging process, purpose in life, personal characteristics, life satisfaction, and social support [30]. There is a need to incorporate environmental perspectives into the model of successful aging [31–34], given the intersection between individual resources and the built, social, and natural environments in which we age. An environment may be an asset or a hindrance to successful aging based upon its ability to meet personal needs and preferences [35], including proximity to services and amenities, strength of local support networks, and the natural climate [36–38].

A third major strand of research explores successful aging in diverse populations and cultural contexts. Some examples include oldest-old adults (i.e., those older than 90 years) [39,40], older adults in Asia (including China, Korea, Singapore, Japan, Taiwan, and Hong Kong) [41], Alaska Native elders [42], Latino older adults [43], older adults with disabilities [44], LGBT older adults [45], people with HIV [46], and older adults with autism [47]. Many of these studies highlight ways in which the successful aging model does not fit a particular context or population. Consequently, some scholars have argued that the successful aging paradigm exemplifies a bias toward western, white, middle-class older adults [48–50] and fails to incorporate diverse perspectives. However, some cross-cultural evidence

suggests that certain aspects of successful aging are consistent across cultures and groups. For example, Phelan et al. found that both white and Japanese American older adults strongly valued maintaining physical health, ability to function independently, mental well-being, and social participation. Both groups also felt that living a very long time and being able to continue working or volunteering after age 65 were not so important [51].

Apart from the aforementioned issues, scholars have raised concerns about Rowe and Kahn’s emphasis on agency and lifestyle choice in determining one’s level of success [24,50]. In framing successful aging as a consequence of an individual’s decisions, this conceptualization may not account for structures of inequity. For example, if successful aging is primarily the result of individual choices, such perspectives may lead to the conclusion that “unsuccessful” agers have only themselves to blame, when in reality many factors outside individuals’ direct control can play a powerful role.

Nonetheless, the concept of successful aging (and the debate around it) holds important lessons when considering psychosocial outcomes in Alzheimer’s dementia. Scholarship in successful aging has generally aimed to encourage greater open-mindedness and empowerment of older adults with attention toward the positive aspects of aging [52,53]. The concept of successful aging resonates with that of living well with Alzheimer’s dementia. Relevant to the concept of living well with Alzheimer’s dementia [54], Tesch-Romer et al. have proposed a comprehensive concept of successful aging that captures the care needs and living conditions appropriate for older people with disabilities [55].

3. Resilience in child development

Research in adult and child development can also inform conceptual and methodological approaches to well-being in Alzheimer’s dementia. One such effort is the study of resilience in child development, and in particular, its emergence in response to child psychopathology and studies of children “at-risk” for various negative health or social outcomes. As Masten et al. note [56], resilience emerged as the descriptor of children who successfully adapt to adversity.

Resilience is defined as “positive adaptation in the context of significant challenges, variously referring to the capacity for, processes of, or outcomes of successful life-course development during or following exposure to potentially life-altering experiences” ([56], p. 4). Child development researchers tend to study resilience using two approaches. A variable-focused approach examines how various factors account for positive outcomes when there is a high risk for adversity (e.g., when someone has Alzheimer’s dementia). In contrast, person-focused approaches involve the identification or categorization of resilient individuals to examine how they differ/vary from those with worse outcomes. Gaugler et al. used a person-focused approach in a study of resilience in

Alzheimer's dementia family caregivers [57], where they categorized caregivers as "high resilience" if these individuals reported low burden in the face of high care demands. The findings demonstrated that highly resilient caregivers were less likely to institutionalize their relatives over a 3-year period. In the child psychopathology literature, identifying high resilient and low resilient individuals often demonstrates important differences in resources or assets that are potentially modifiable. However, relationships between protective factors, risk, and resilience are often complex and necessitate the inclusion of low-risk groups that "do well" on selected outcomes (i.e., the third person-focused resilience approach).

There is an appeal to approaching the study of well-being in Alzheimer's dementia from a resilience perspective. Although some advances have been made with variable-focused approaches, fewer efforts have adopted person-focused strategies. The latter may represent a promising area for future inquiry, particularly in the study of secondary datasets or reanalysis of existing intervention studies [58]. Specifically, subgroups of people living with Alzheimer's dementia and their family caregivers (or resilient dyads or households) could be identified for further analysis to ascertain how and why these individuals are resilient via lower scores on commonly used decline/detriment-focused measures in these data sources.

4. Reframing Alzheimer's dementia

Alzheimer's dementia has long been stigmatized as a disease in which the person living with dementia is depersonalized and discounted [59]. The traditional perception of Alzheimer's dementia is one in which the person living with Alzheimer's dementia is viewed as having no voice and is incapable of making their own decisions. This model creates additional barriers for people living with dementia to engage in society [60]. For example, a report from the U.K. Alzheimer's Society estimates that less than half of individuals living with Alzheimer's dementia feel part of the community and only 10% leave the house once a month or more [61]. In reality, most people living with Alzheimer's dementia can and want to remain a part of their community, participate in their care, and maintain meaningful social relationships [62-64].

There is now an ongoing effort to reframe Alzheimer's dementia and dementia caregiving from a negative medicalized experience (i.e., one of inexorable loss) to one that is a social process [65-68]. "Social process" refers to the experience of dementia as one that is susceptible to sociocultural factors such as positive and negative cultural attitudes and/or exclusion from social roles and relationships. Efforts to reframe Alzheimer's dementia explicitly seek to incorporate the voice of the person living with Alzheimer's dementia by giving them an active role in their care and society [69]. Several studies have documented positive aspects of Alzheimer's dementia [68,70]. By reframing Alzheimer's

dementia as a social process, the emphasis shifts from the limitations of the person living with Alzheimer's dementia to structural limitations of the physical and social environment that inhibit their ability to engage [65,67,70,71]. Reframing Alzheimer's dementia moves the narrative of Alzheimer's dementia from solely a negative experience to one that also incorporates instances where individuals continue to learn, make meaningful contributions, and age successfully. In the following part of the article, we highlight two areas of scholarship that attempt to reframe Alzheimer's dementia to enhance care delivery (person-centered care) and developments in Europe that strive to more fully conceptualize Alzheimer's dementia in the context of well-being, rather than disease/decline.

5. Person-centered care

Carl Rogers first proposed a person-centered approach in psychotherapy based on acceptance, caring, compassion, understanding, and active listening to nurture optimal human growth [72]. Furthermore, he contended that human capacity for growth does not diminish with age nor does the need for growth become less relevant in old age ([73], p. 2). Kitwood pioneered the application of a person-centered approach to Alzheimer's dementia care to distinguish from the 'old culture of care' based upon medicalized and behavioral management of Alzheimer's dementia [74]. He argued that traditional Alzheimer's dementia care practices developed in medical settings did not put the person first, such as using tranquilizers to manage inconvenient behavior instead of considering what might be appropriate to the person's specific needs. Moving away from such practices (what Kitwood termed 'malignant social psychology'), person-centered Alzheimer's dementia care focuses on well-being and quality of life as defined by people living with Alzheimer's dementia and allows them to contribute to their own care through joint decision-making, equal communication, and shared respect. A central feature of person-centered Alzheimer's dementia care is the concept of personhood. This is "a standing or status that is bestowed upon one human being, by others" ([74], p. 8) implying recognition, respect, and trust. People living with Alzheimer's dementia are more likely to experience the opposite. Kitwood [74] contends that their personhood is diminished as the values of personhood are neglected in care environments. This is not purposeful malicious intent by healthcare professionals, rather specialists tend to be unaware of and/or uneducated regarding the specific needs of individuals. Among the core needs of people with Alzheimer's dementia are comfort (the feeling of trust that comes from others), attachment (security and finding familiarity in unusual places), inclusion (involvement in others' lives), occupation (involvement in the processes of normal life), and identity (what makes a person unique) ([75], p. 47). Kitwood envisioned a new paradigm in the care of those with Alzheimer's dementia focused on

retaining and enhancing personhood, recognizing that all people are unique and individual—irrespective of their diagnosis [74].

Brooker ([72], p. 216) outlines four key components for person-centered Alzheimer's dementia care: (1) valuing people living with Alzheimer's dementia and their caregivers, (2) treating people as individuals with unique needs, (3) regarding the world from the perspective of the person living with Alzheimer's dementia, and (4) a positive social environment so the person living with Alzheimer's dementia can experience relative well-being. Building on this, Fazio et al. ([76], p. S18) provide six practice recommendations for person-centered care that now serve as the foundation not only of Alzheimer's dementia care but also in informing a new generation of psychosocial measures in Alzheimer's dementia which is the focus of this special issue: (1) know the person living with Alzheimer's dementia, (2) recognize and accept the person's reality, (3) identify and support ongoing opportunities for meaningful engagement, (4) build and nurture authentic, caring relationships, (5) create and maintain supportive community for individuals, families, and staff; and (6) evaluate care practices regularly and make appropriate changes.

Putting person-centered care into practice requires multilevel commitment and investment in multifactorial interventions. This includes environmental enhancement, leadership and management changes, and novel staffing models. The complexity of interventions and wide range of outcomes evaluated in trials makes it challenging to derive precise conclusions regarding the impacts of person-centered care interventions in long-term care [73,76–79]. In addition, some person-centered interventions might be associated with unintended consequences such as an increased risk of falls [73]. Additional research is necessary to assess intervention outcomes, risks, and implementation [76]. Person-centered care now exists within a larger culture-change effort to transform other residential environments from impersonal health-care institutions into person-centered homes with long-term care services. Koren [80] articulates that this movement reorients facilities' principles and practices to honor residents' rights and equally offer quality of life and quality of care. It gives frontline workers more control over their work environment and values all staff members' contributions to pursuing excellence. Awareness of culture change is growing, but adoption lags behind awareness.

6. European advancements: social health & dementia

In 2015, the European Union's Joint Programme Neurodegenerative Disease Research (JPND) highlighted a number of recommendations to broaden the consideration of outcomes in Alzheimer's dementia research ([17], pp. 13–15). Measurement approaches that better reflect the shifts in mood and well-being that often accompany Alzheimer's dementia were identified. In addition to developing entirely new measures of positive outcomes and those that are

appropriate for people living with Alzheimer's dementia at various stages, attempting to avoid using negative terms (e.g., cognitive impairment and caregiver burden) was also recommended. Focus group research with people living with Alzheimer's dementia regarding appropriate outcome measurement reinforces the JPND recommendations [81]. Concepts such as self-efficacy, control, and confidence were seen as desirable outcome measures among people living with Alzheimer's dementia. Such insights are aligned with positive psychology and recent conceptualizations of well-being in Alzheimer's dementia [82,83].

The efforts of JPND reiterate the amount of work necessary to change how the Alzheimer's dementia care experience is conceptually framed and measured. Requirements for classically validated measures in extramurally funded research discourage researchers from using new measures (although JPND did identify several validated measures designed to assess positive constructs in Alzheimer's dementia). To expedite the culture shift in Alzheimer's dementia care science, recommendations such as relabeling and interpreting the results of existing measures (e.g., via person-focused resilience approaches, see Section 3) and utilizing existing frameworks, such as successful aging or those more specific to Alzheimer's dementia (e.g., person-centered care), could better inform the selection of positive constructs.

A task force of European researchers (i.e., the INTERDEM Social Health Taskforce) attempted to synthesize recent efforts and reach consensus in reframing well-being in Alzheimer's dementia by creating a new definition of health that considers the experiences of older adults living with Alzheimer's dementia [83]. The World Health Organization defines health as “a state of complete physical, mental, and social well-being.” However, many older adults manage to live well, despite having chronic health conditions. The updated definition of health relevant to Alzheimer's dementia emphasizes the importance of social health, or the degree to which an individual is able to participate in social life. According to the INTERDEM Social Health Taskforce, there are three main tenets of social health for people living with Alzheimer's dementia. First is functioning in a way that maximizes one's abilities. Second is maintaining autonomy and coping effectively with the consequences of Alzheimer's dementia. Third is engaging in meaningful social activities and relationships. Together, these three aspects emphasize the dynamic nature of health and the potential to experience a fulfilling life despite chronic health concerns.

The incorporation of the voices of people living with Alzheimer's dementia is required to build more appropriate conceptual models. In the U.K. and in other countries, patient and -public involvement is becoming part of the Alzheimer's dementia care research infrastructure, where people living with Alzheimer's dementia and their families provide input to and eventually approve research ideas [84]. This more robust structure of engagement has begun to inform the development of new measures [82].

7. A new framework for assessing psychosocial outcomes of person-centered care across the dementia journey

The Alzheimer's Association has engaged in multiple efforts to reframe dementia and dementia care research. For example, the Alzheimer's Association has undertaken efforts to support living well with Alzheimer's dementia [81]. This includes the initiation of an early stage advisory group comprised of persons living with Alzheimer's dementia and their caregivers. Members of the early stage advisory group help raise awareness and reduce stigma by publicly telling personal stories of living with Alzheimer's dementia, and they provide input into the development of association programs and services. In addition, the Alzheimer's Association developed LiveWell e-learning modules to offer free online learning experiences regarding quality of life for individuals living in the early stage of Alzheimer's dementia.

These community-engaged efforts have directly influenced recent research recommendations to improve how Alzheimer's dementia care is delivered. The Alzheimer's Association published new dementia care practice recommendations (DCPR) that place individuals and families at the center of the care pathway: from detection and diagnosis through ongoing care and across the numerous transitions that individuals face during their journey (Fig. 1 from DCPR, [85]). These recommendations, in combination with the 2015 evidence-based JPND recommendations [17], provide a foundation to operationalize key outcomes in Alzheimer's dementia from a well-being perspective. The DCPR also offer insights as to how various domains are interrelated and identifying where intervention might be possible to promote well-being.

Adopting a new psychosocial measurement framework necessitates a markedly different approach than what is currently state-of-the-art, including evaluating existing methodologies and developing new tools. We are at a pivotal point in the evolution of research on Alzheimer's dementia and its care that demands progression from the theoretical/conceptual approaches summarized previously to the development of appropriate measures and analytic techniques. We propose a new framework that reorients how researchers think about life with Alzheimer's dementia. It requires methodologies to assess outcomes that highlight resilience, adaptability, and positive milestones across the Alzheimer's dementia journey, thereby emphasizing the possibility of maintenance and improvement in the presence of decline. It will consider care preferences and other factors that are meaningful to families at key transition points in the Alzheimer's dementia journey. For example, at the time of diagnosis, it is important to assess not just negative responses such as fear, anxiety, and depression but also the services and supports offered to the person living with Alzheimer's dementia by their family members to optimize quality of life. Focusing on resilience and well-being demonstrates to providers what can be achieved through a

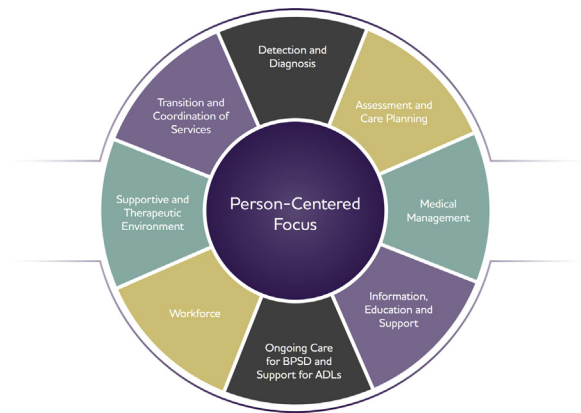


Fig. 1. Dementia Care Practice Recommendations.

strength-based approach. When outcome measures report only negatives (e.g., anxiety and depression in response to a diagnosis), providers become accustomed to orienting care around and prioritizing these characteristics. In contrast, the use of strength-based measures could support a more positive perspective that influences care as well. Validation studies are needed to test whether the use of more holistic outcome measures actually influences how dementia care is delivered, the quality of such care, and key outcomes on the part of the people living with Alzheimer's dementia and those who care for them. Crafting this new operational model of the Alzheimer's dementia journey will require evaluating existing measures to determine how successful they have been in capturing the full spectrum of the Alzheimer's dementia experience (both positive and negative) and adapting these measures or developing new ones.

In addition to the foundation of person-centered care practices, the DCPR model identifies new topic areas essential to person-centered care (see Fig. 1). Within each of these areas, research is needed to develop measures that:

- Directly assess people living with Alzheimer's dementia rather than relying solely on informants and carers;
- Assess resource utilization across the Alzheimer's dementia journey;
- Work across the continuum of this progressive disease, particularly at key events and transition points;
- Work across different settings, that is, home, health-care settings, and long-term care environments;
- Capture the diversity of experiences across the Alzheimer's dementia journey;
- Emphasize positive milestones across the Alzheimer's dementia journey, such as maintaining cognitive function in the presence of Alzheimer's dementia;
- Emphasize the possibility of maintenance and improvement in the presence of diminished cognitive or physical function by creating scales that capture change in both positive and negative directions;

- Capture what matters to both formal and informal caregivers across different settings; and
- Work within the context of different family dynamics, including absence of family caregivers.

Similarly, Gitlin and Hodgson recently built upon Lawton's "Good Life" model [86] to propose an integrative framework for understanding quality of life among individuals with dementia [16]. The original model suggests four main components of a good life: Behavioral competencies include physical health and function, activities, and behavioral and cognitive symptoms. Psychological well-being reflects subjective states of positive or negative affect. Perceived valuation or appraisal of life refers to a sense of meaning and personal agency in life. Finally, objective environment captures the physical and social environment around a person. Applied to Alzheimer's dementia, this model provides a framework for assessing an individual's strengths, resources, and needs within each quadrant and developing care models that address all areas of concern in an integrated and coordinated way. Gitlin and Hodgson [16] further emphasize the need to consider the ways in which various levels of the sociocultural environment interact in determining positive or negative outcomes from the scale of the individual with Alzheimer's dementia to the caregivers and family, the neighborhood and community, health and human service organizations, and national-level policies and agencies. A final factor this model considers is time, including the way that needs and resources may vary as time passes. Researchers may focus on any one of these levels without losing track of the broader multi-scalar context. Together, the DCPR and Gitlin and Hodgson's model provide useful, organizing frameworks to inform the systematic development of measures that capture the full spectrum of the Alzheimer's dementia experience [16].

8. Rationale for adopting a new perspective

Measuring the effectiveness of person-centered care interventions has largely relied on measures developed for use in evaluating new drugs based on declining health or cost considerations. Such measures do not capture complex individual experiences of living with Alzheimer's dementia over time, including the universe of diverse caregivers and their experiences [87]. Even psychosocial interventions have been typically evaluated according to this well-developed and rigid drug development framework [88]. While the drug evaluation framework is essential to meet requirements of the Food and Drug Administration and other regulatory agencies, the measures and methodologies used may not be sufficient when assessing the potential broader benefits of person-centered psychosocial interventions. Even studies that assess behavior, emotions, and sleep typically use instruments designed only to measure impairment in these domains. A drug-centered paradigm that also includes measures to evaluate person-centered care should enable the

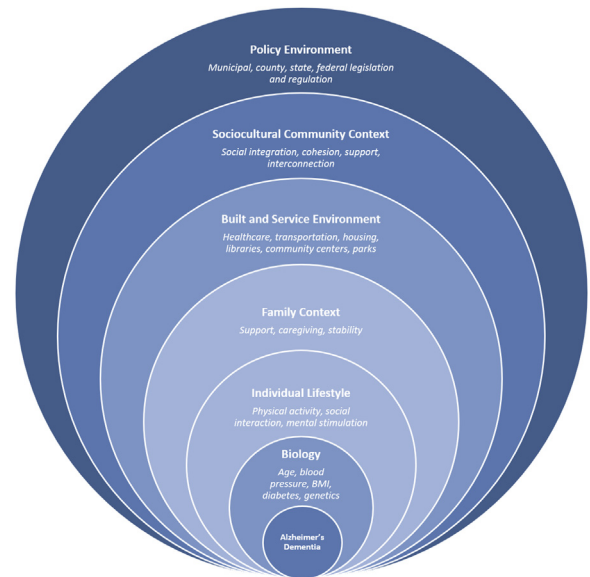


Fig. 2. Socioecological Model of Alzheimer's Dementia.

identification of improved well-being and the services and policies that support these improvements.

Research on the Alzheimer's dementia pathway has failed to assess factors that are meaningful to families, such as the care preferences that will allow the person living with Alzheimer's dementia and family caregivers to live well. Ideal measures could help inform people living with Alzheimer's dementia and caregivers about what is possible at a given point in time and in their particular environment. For example, evaluating the psychosocial impact of delivering a diagnosis of Alzheimer's dementia in terms of the support, information, and resources received by the person and family rather than simply their emotional reactions to the diagnosis (e.g., shock, sadness) could allow people with Alzheimer's dementia, family members, and their care providers map for themselves an alternative "dementia journey" that maximizes quality of life and avoids situations that are potentially harmful. Measures should capture the diversity of experience and should be evaluated according to their content (e.g., overly negative terminology), validity, reliability, and who is the best respondent.

9. From well-being perspectives to the operationalization of measures

To apply this person-centered framework to measurement, a systems perspective and new analytical methods are required that not only capture structures, processes, and outcomes but also information about the status and well-being of the person at the individual, familial, and ecological levels across the Alzheimer's dementia journey (Fig. 2). In subsequent articles in this special issue, we will consider each domain depicted in Fig. 1 separately, exploring how to use existing measures developed using the deficit approach and whether new measures and

methodological perspectives are needed. We will rethink how to consider outcomes, including the use of nonstigmatizing terminology, and consider the implications of these outcomes for practice and policy-making, such as incentivizing good care that results in positive outcomes and by providing policy makers with evidence that the person-focused care model yields such benefits (e.g., Fig. 2).

The perspectives outlined in this article and in subsequent ones of this special topics issue are intended to generate novel, person-centered research methodologies (i.e., how we “think” about methods) and methods (how we “do” research). Each article will explore the challenges and potential operationalization of each of the psychosocial domains in Fig. 1 to guide how we capture the experiences of people living with Alzheimer’s dementia and their family caregivers, and perhaps more importantly, how we can more effectively maintain well-being in Alzheimer’s dementia. This is part of a concerted effort to encourage people living with Alzheimer’s dementia and their family caregivers that researchers are working to capture their full experience.

RESEARCH IN CONTEXT

1. Systematic review: The purpose of this article is to outline new frameworks to more effectively capture and measure the full range of how people living with Alzheimer’s dementia and their family caregivers experience the disease process. Our aim is to encourage innovative methods to measure psychosocial aspects of Alzheimer’s dementia and caregiving that have not yet received sufficient attention, including resources (e.g., services and supports) and positive caregiver and care recipient outcomes (e.g., positive mood and adaptation).
2. Interpretation: We considered the strengths and weaknesses of alternative perspectives, including person-centered, strength-based, and resilience-focused approaches that may complement and extend the dominant deficit paradigm to reflect the entirety of the dementia experience.
3. Future directions: The perspectives outlined in this article and in subsequent ones of this special topics issue are intended to generate novel, person-centered research methodologies (i.e., how we “think” about methods) and methods (how we “do” research). This is part of a concerted effort to encourage people living with Alzheimer’s dementia and their family caregivers that researchers are working to capture their full experience.

References

- [1] Alzheimer’s Disease International. Dementia Statistics. 2018. Available at: <https://www.alz.co.uk/research/statistics>. Accessed October 8, 2018.
- [2] Assistant Secretary for Planning and Evaluation. National plans to address Alzheimer’s disease. 2018. Available at: <https://aspe.hhs.gov/national-plans-address-alzheimers-disease>. Accessed October 8, 2018.
- [3] Alzheimer’s Association. 2018 Alzheimer’s disease facts and figures. *Alzheimer’s Demen* 2018;14:701.
- [4] Walmsley J. Normalisation, emancipatory research and inclusive research in learning disability. *Disabil Soc* 2001;16:187–205.
- [5] Strnadova I, Walmsley J. Peer-reviewed articles on inclusive research: Do co-researchers with intellectual disabilities have a voice? *J Appl Res Intellect Disabilities* 2018;31:132–41.
- [6] U. S. Department of Health & Human Services. National research summit on care, services and supports for persons with dementia and their caregivers (Day 1). 2017. Available at: <https://videocast.nih.gov/summary.asp?Live=26257&bhcp=1>. Accessed October 8, 2018.
- [7] U. S. Department of Health & Human Services. National research summit on care, services and supports for persons with dementia and their caregivers (Day 2). 2017. Available at: <https://videocast.nih.gov/summary.asp?Live=26261&bhcp=1>. Accessed October 8, 2018.
- [8] Eters L, Goodall D, Harrison BE. Caregiver burden among dementia patient caregivers: a review of the literature. *J Am Acad Nurse Pract* 2008;20:423–8.
- [9] Dodge MD, Kiecolt-Glaser JK. Caregiver stress and possible solutions. In: Scharre DW, ed. *Long-term management of dementia*. Boca Raton, FL: Taylor & Francis; 2010.
- [10] Butler RN. The life review: an interpretation of reminiscence in the aged. *Psychiatry* 1963;26:65–76.
- [11] Butler R. *Why Survive? Being Old in America*. New York: Harper & Row; 1975.
- [12] Warren MW. Care of chronic sick. *Br Med J* 1943;2:822.
- [13] Warren MW. Activity in advancing years. *Br Med J* 1950;2:921.
- [14] Gitlin LN, Winter L, Dennis MP, Hodgson N, Hauck WW. A biobehavioral home-based intervention and the well-being of patients with dementia and their caregivers: the COPE randomized trial. *JAMA* 2010;304:983–91.
- [15] Gitlin LN, Winter L, Vause Earland T, Adel Herge E, Chernett NL, Piersol CV, et al. The Tailored Activity Program to reduce behavioral symptoms in individuals with dementia: Feasibility, acceptability, and replication potential. *Gerontologist* 2009;49:428–39.
- [16] Gitlin LN, Hodgson NA. *Better Living with Dementia*. London: Academic Press; 2018.
- [17] JPND - EU Joint Programme - Neurodegenerative Disease Research. *Dementia Outcome Measures: Charting New Territory*; 2015.
- [18] Staudinger UM, Marsiske M, Baltes PB. Resilience and reserve capacity in later adulthood: potentials and limits of development across the life span. *Developmental Psychopathology* 1995;2:801–47.
- [19] Buntinx WHE. Understanding disability: a strengths-based approach. In: Wehmeyer ML, ed. *The Oxford Handbook of Positive Psychology and Disability*. New York: Oxford University Press; 2013.
- [20] Wehmeyer ML. Disability, disorder, and identity. *Intellect Dev Disabil* 2013;51:122–6.
- [21] Shogren KA, Bradley VJ, Gomez SC, Yeager MH, Schalock RL, Borthwick-Duffy WS, et al. Public policy and the enhancement of desired outcomes for persons with intellectual disability. *Intellect Dev Disabil* 2009;47:307–19.
- [22] Rowe JW, Kahn RL. *Successful Aging*. New York: Random House; 1998.
- [23] Rowe JW, Kahn RL. Successful aging. *Gerontologist* 1997;37:433–40.
- [24] Katz S, Calasanti T. Critical perspectives on successful aging: does it “appeal more than it illuminates”? *Gerontologist* 2015;55:26–33.

- [25] Cumming EE, Henry WE. *Growing Old: The Process of Disengagement*. New York: Basic Books; 1961.
- [26] Martin P, Kelly N, Kahana B, Kahana E, Willcox BJ, Willcox DC, et al. Defining successful aging: a tangible or elusive concept? *Gerontologist* 2014;55:14–25.
- [27] Phelan EA, Larson EB. “Successful aging”—where next? *J Am Geriatr Soc* 2002;50:1306–8.
- [28] Cosco TD, Prina AM, Perales J, Stephan BC, Brayne C. Operational definitions of successful aging: a systematic review. *Int Psychogeriatrics* 2014;26:373–81.
- [29] Troutman M, Nies MA, Bentley M. Measuring successful aging in southern black older adults. *Educ Gerontol* 2010;37:38–50.
- [30] Kim S-H, Park S. A meta-analysis of the correlates of successful aging in older adults. *Res Aging* 2017;39:657–77.
- [31] Wahl HW, Fange A, Oswald F, Gitlin L, Iwarsson S. The home environment and disability-related outcomes in aging individuals: what is the empirical evidence? *Gerontologist* 2009;49:335–67.
- [32] Wahl HW, Gitlin LN. Future developments in living environments for older people in the United States and Germany. In: Schaie KW, Wahl H-W, Mollenkopf H, Oswald F, eds. *Aging Independently: Living Arrangements and Mobility*. New York: Springer; 2003.
- [33] Wahl HW, Iwarsson S, Oswald F. Aging well and the environment: toward an integrative model and research agenda for the future. *Gerontologist* 2012;52:306–16.
- [34] Wahl HW, Gitlin LN. Linking the socio-physical environment to successful aging: from basic research to intervention to implementation science considerations. In: Fernandez-Ballestreros R, Robine JM, Benetos A, eds. *The Cambridge Handbook of Successful Aging*. London: Cambridge University Press; 2018.
- [35] Mejía ST, Ryan LH, Gonzalez R, Smith J. Successful aging as the intersection of individual resources, age, environment, and experiences of well-being in daily activities. *J Gerontol Ser B Psychol Sci Soc Sci* 2017;72:279–89.
- [36] Finlay JM, Gaugler JE, Kane RL. Ageing in the margins: expectations of and struggles for ‘a good place to grow old’ among low-income older Minnesotans. *Ageing & Society* 2018;1–25.
- [37] Finlay JM, Kobayashi LC. Social isolation and loneliness in later life: a parallel convergent mixed-methods case study of older adults and their residential contexts in the Minneapolis metropolitan area, USA. *Social Sci Med* 2018;208:25–33.
- [38] Finlay JM. ‘Walk like a penguin’: older Minnesotans’ experiences of (non) therapeutic white space. *Social Sci Med* 2018;198:77–84.
- [39] Cho J, Martin P, Poon LW, Study GC. Successful aging and subjective well-being among oldest-old adults. *Gerontologist* 2014; 55:132–43.
- [40] Nosratty L, Jylhä M, Raittila T, Lumme-Sandt K. Perceptions by the oldest old of successful aging. *Vitality 90+ Study*. *J Aging Stud* 2015;32:50–8.
- [41] Cheng S-T, Chi I, Fung HH, Li LW, Woo J. *Successful Aging: Asian Perspectives*. Dordrecht: Springer; 2015.
- [42] Lewis JP. Successful aging through the eyes of Alaska Native elders. What it means to be an elder in Bristol Bay, AK. *Gerontologist* 2011;51:540–9.
- [43] Hilton JM, Gonzalez CA, Saleh M, Maitoza R, Anngela-Cole L. Perceptions of successful aging among older Latinos, in cross-cultural context. *J Cross-Cultural Gerontol* 2012;27:183–99.
- [44] Minkler M, Fadem P. “Successful Aging:” A disability perspective. *J Disabil Policy Stud* 2002;12:229–35.
- [45] Fredriksen-Goldsen KI, Kim H-J, Shiu C, Goldsen J, Emler CA. Successful aging among LGBT older adults: Physical and mental health-related quality of life by age group. *Gerontologist* 2014; 55:154–68.
- [46] Solomon P, Letts L, O’Brien KK, Nixon S, Baxter L, Gervais N. ‘I’m still here, I’m still alive’: understanding successful aging in the context of HIV. *Int J STD AIDS* 2018;29:172–7.
- [47] Hwang YI, Foley K-R, Trollor JN. Aging well on the autism spectrum: an examination of the dominant model of successful aging. *J Autism Developmental Disord* 2018;1–10.
- [48] Kendig H. The social sciences and successful aging: issues for Asia–Oceania. *Geriatr Gerontol Int* 2004;4:S6–11.
- [49] Ng SH, Cheung C-K, Chong AM, Woo J, Kwan AY, Lai S. Aging well socially through engagement with life: adapting Rowe and Kahn’s model of successful aging to Chinese cultural context. *Int J Aging Hum Development* 2011;73:313–30.
- [50] Martinson M, Berridge C. Successful aging and its discontents: a systematic review of the social gerontology literature. *Gerontologist* 2014;55:58–69.
- [51] Phelan EA, Anderson LA, Lacroix AZ, Larson EB. Older adults’ views of “successful aging”—how do they compare with researchers’ definitions? *J Am Geriatr Soc* 2004;52:211–6.
- [52] Rowe JW, Kahn RL. Successful aging 2.0: conceptual expansions for the 21st century. *J Gerontol Ser B* 2015;70:593–6.
- [53] Society MFRNoAA. *Policies and politics for an aging America*. Contexts 2010;9:22–7.
- [54] Gitlin LN, Maslow K. *National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers: Report to the National Advisory Council on Alzheimer’s Research, Care, and Services*; 2018. Washington, D.C.
- [55] Tesch-Romer C, Wahl HW. Toward a more comprehensive concept of successful aging: disability and care needs. *J Gerontol B Psychol Sci Soc Sci* 2017;72:310–8.
- [56] Masten AS, Cutuli JJ, Herbers JE, Reed M-GJ. Resilience in development. In: *The Oxford Handbook of Positive Psychology*. 2 ed. New York: Oxford University Press; 2009 [Internet]. online.
- [57] Gaugler JE, Kane RL, Newcomer R. Resilience and transitions from dementia caregiving. *J Gerontol Psychol Sci* 2007;62:P38–44.
- [58] Joling KJ, Windle G, Dröes RM, Meiland F, van Hout HP, Vroomen JM, et al. Factors of resilience in informal caregivers of people with dementia from integrative international data analysis. *Demen Geriatr Cogn Disord* 2016;42:198–214.
- [59] Ballenger JF. Framing confusion: dementia, society, and history. *AMA J Ethics* 2017;19:713–9.
- [60] Bender M, Cheston R. Inhabitants of a lost kingdom: a model of the subjective experiences of dementia. *Ageing Soc* 1997; 17:513–32.
- [61] *Alzheimer’s Society. Dementia 2014: Opportunity for Change*. London: Alzheimer’s Society London; 2014.
- [62] Heid AR, Bangerter LR, Abbott KM, Van Haitsma K. Do family proxies get it right? Concordance in reports of nursing home residents’ everyday preferences. *J Appl Gerontol* 2017;36:667–91.
- [63] Reamy AM, Kim K, Zarit SH, Whitlatch CJ. Understanding discrepancy in perceptions of values: individuals with mild to moderate dementia and their family caregivers. *Gerontologist* 2011; 51:473–83.
- [64] Lyons RF, Sullivan MJ, Ritvo PG, Coyne JC. *Relationships in Chronic Illness and Disability*. Sage Publications, Inc; 1995.
- [65] Beard RL, Knauss J, Moyer D. Managing disability and enjoying life: how we reframe dementia through personal narratives. *J Aging Stud* 2009;23:227–35.
- [66] Sabat AR, Napolitano L, Fath H. Barriers to the construction of a valued social identity: a case study of Alzheimer’s disease. *Am J Alzheimer’s Dis Other Demen* 2004;19:177–85.
- [67] Thomas C. *Female forms: Experiencing and Understanding Disability*. UK: McGraw-Hill Education; 1999.
- [68] Roth DL, Dilworth-Anderson P, Huang J, Gross AL, Gitlin LN. Positive aspects of family caregiving for dementia: differential item functioning by race. *J Gerontol Ser B Psychol Sci Social Sci* 2015; 70:813–9.
- [69] Groen-van de Ven L, Smits C, de Graaff F, Span M, Eefsting J, Jukema J, et al. Involvement of people with dementia in making decisions about their lives: a qualitative study that appraises shared decision-making concerning daycare. *BMJ Open* 2017; 7:e018337.
- [70] Beard RL. In their voices: identity preservation and experiences of Alzheimer’s disease. *J Aging Stud* 2004;18:415–28.

- [71] Cohen-Mansfield J, Golander H, Arnhem G. Self-identity in older persons suffering from dementia: preliminary results. *Social Sci Med* 2000;51:381–94.
- [72] Brooker DB. What is person-centred care in dementia? *Rev Clin Gerontol* 2003;13:215–22.
- [73] Brownie S, Nancarrow S. Effects of person-centered care on residents and staff in aged-care facilities: a systematic review. *Clin Interventions Aging* 2013;8:1.
- [74] Kitwood T. *Dementia Reconsidered: The Person Comes First*. Buckingham: Open University Press; 1997.
- [75] Mitchell G, Agnelli J. Person-centred care for people with dementia: Kitwood reconsidered. *Nurs Stand* 2015;30.
- [76] Fazio S, Pace D, Flinner J, Kallmyer B. The fundamentals of person centered care for individuals with dementia. *Gerontologist* 2018; 58:S10–9.
- [77] Kim S, Park M. Effectiveness of person-centered care on people with dementia: a systematic review and meta-analysis. *Clin Interv Aging* 2017;12:381–97.
- [78] Epp T. Person-centred dementia care: a vision to be refined. *Can Alzheimer Dis Rev* 2003;5:14–9.
- [79] Jutkowitz E, Brasure M, Fuchs E, Shippee T, Kane RA, Fink HA, et al. Care-delivery interventions to manage agitation and aggression in dementia nursing home and assisted living residents: a systematic review and meta-analysis. *J Am Geriatr Soc* 2016;64:477–88.
- [80] Koren MJ. Person-centered care for nursing home residents: the culture-change movement. *Health Aff* 2010;29:312–7.
- [81] The Boston Consulting Group. *Care and Support Strategic Assessment*. Presented Alzheimer's Assoc November 9, 2015; 2015.
- [82] Oksnebjerg L, Diaz-Ponce A, Gove D, Moniz-Cook E, Mountain G, Chattat R, et al. Towards capturing meaningful outcomes for people with dementia in psychosocial intervention research: a pan-European consultation. *Health Expect* 2018;21:1056–65.
- [83] Dröes RM, Chattat R, Diaz A, Gove D, Graff M, Murphy K, et al. Social health and dementia: a European consensus on the operationalization of the concept and directions for research and practice. *Aging Ment Health* 2017;21:4–17.
- [84] Gove D, Diaz-Ponce A, Georges J, Moniz-Cook E, Mountain G, Chattat R, et al. Alzheimer Europe's position on involving people with dementia in research through PPI (patient and public involvement). *Aging Ment Health* 2017;1–7.
- [85] Fazio S, Pace D, Maslow K, Zimmerman S, Kallmyer B. Alzheimer's Association Dementia care practice recommendations. *Gerontologist* 2018;58:S1–9.
- [86] Lawton MP. Environment and other determinants of well-being in older people. *Gerontologist* 1983;23:349–57.
- [87] Li J, Porock D. Resident outcomes of person-centered care in long-term care: a narrative review of interventional research. *Int J Nurs Stud* 2014;51:1395–415.
- [88] Spector A, Thorgrimsen L, Woods B, Royan L, Davies S, Butterworth M, et al. Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: randomised controlled trial. *Br J Psychiatry* 2003;183:248–54.