Supporting resilience of older adults with cognitive decline requires a multi-level system approach

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Abstract

The concept of resilience, i.e., the capacity of a system to bounce back after a stressor, is gaining interest across many fields of science, policy, and practice. To date, resilience research in people with cognitive decline has predominantly addressed the early stages of decline. We propose that: (1) resilience is a relevant concept in all stages of cognitive decline; and (2) a socio-ecological, multisystem perspective on resilience is required to advance understanding of, and care and support for people with cognitive decline and their support networks. We substantiate our position with literature and examples. Resilience helps understand differences in response to risk factors of (further) cognitive decline and

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informs personalised prevention. In a curative context, interventions to strengthen resilience aim to boost recovery from cognitive decline. In care for people with dementia, resilience-focused interventions can strengthen coping mechanisms to maintain functioning and well-being of the individual and their support network. A good example of improving resilience in the social and policy context is the introduction of age-friendly cities and dementia-friendly communities. Good care for people with cognitive decline requires a health and social care system that can adapt to changes in demand. Given the interdependency of resilience at micro-, meso- and macro-levels, an integrative socio-ecological perspective is required. Applying the concept of resilience in the field of cognitive decline opens new horizons for research to improve understanding, predicting, intervening on health and social care needs for the increasing population with cognitive decline.

Introduction

The concept of resilience is being used increasingly in research on ageing [1]. This aligns with the urge of older persons for a shift from a focus on frailty, which they generally perceive as stigmatising and negative, towards a more positive approach focussing on (remaining) strengths [2]. It also aligns with a broader development towards a more positive and actionable approach in health and social care and research, such as positive psychology, positive health, intrinsic capacity, living well, and reablement [3–8]. Furthermore, strengthening resilience is a priority shared by Health 2020 and the Sustainable Development Goals [9, 10].

The concept of resilience is gaining traction across many fields of science and practice. For example, resilience testing in mice has revealed novel insights in the brain ageing processes [11], while policymakers show an increasing interest in the mechanisms of psychological, social, and societal resilience as a resource to empower vulnerable groups in society [12]. Resilience provides a focus on recovery and adaptation that is meaningful across all phases of the (ageing) lifespan [13]. On the topic of cognitive resilience, the number of publications rose from eight in 2010 to 203 in 2021, which reflects the increasing interest in this topic. However, in cognitive neuroscience so far the application of resilience has been limited to explaining differences in cognitive outcomes between individuals with similar levels of brain damage.

We believe that the fields of ageing research and care could benefit from a broader application of the concept of resilience in relation to cognitive decline.

The authors of this paper form the interdisciplinary Dutch consortium on resilience and dementia. In this position paper, the consortium proposes that the concept of resilience can be used in a broad range of contexts and on micro-, meso-, and macro-levels to improve the health and social care for people with cognitive decline. We propose that the concept of resilience can be used to: (i) identify characteristics and mechanisms that help the "system" (refer to next paragraph for definition) deal with stressors, (ii) improve predictions of the system's ability to cope with future stressors, and (iii) better understand the capacities and resources of systems and the role of positive and negative experiences in strengthening resilience. We adopt an interdisciplinary perspective and postulate that:

- Resilience is a relevant concept at all stages of cognitive decline; and
- A socio-ecological, multi-level (micro, meso, macro) perspective on resilience is required to advance understanding of, and care and support for, people with cognitive decline and of their networks.

In the following, we further support this position with evidence from literature and relevant examples.

The Definition of Resilience

The concept of resilience intuitively appears to be straightforward and is generally defined as the capacity of a system to bounce back after a stressor [14–16]. However, multiple terms in this definition need further operationalisation before the concept can be meaningfully applied, particularly "the system," "the stressor," and "bouncing back," and their time and space dimensions. These terms are intuitively understandable but often not clearly defined, leading to a large variety of theoretical and empirical applications of resilience in general [17] and specifically in gerontology and geriatrics [16]. Therefore, it is important to clarify how we apply these terms in our position. Depending on the level of analysis, i.e., micro, meso, or macro, the "system" may be defined, respectively, as a person at risk of or experiencing cognitive decline; as the person and their formal and/or informal care network; as the health and social care system; or as the societal policy system. Thus, at the micro-level, the focus is on resilience of the individual and their personal network. At the meso- and macro-levels, the resilience
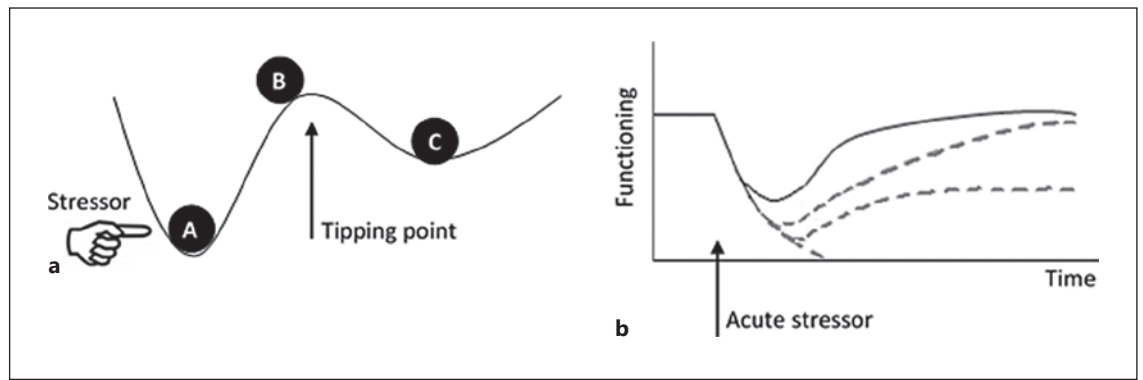
Fig. 1. Visualisation of the concept of resilience. **a** This graph shows a landscape model of resilience with periods of high (A) and low resilience (B) [18]. In response to a stressor, the system (visualised by the ball) may move from a stable, resilient state (A) via an unstable state (B) to a new stable but less resilient state (C). The steepness of the slope and the depth of the pit indicate the resilience of the state. The difference in height position between A and C has no meaning with regard to health or resilience. In state A, a larger perturbation is needed to shift to a different state than in state C. This reflects a more resilient state in A than in C. State B illustrates the transitional phase between states, during which interventions are needed to prevent tipping to a less desirable state. **b** This graph illustrates potential trajectories of recovery in response to an acute stressor, e.g., an infection causing a delirium. A person with good resilience (solid line) will show less decline and a quick, and (near) full recovery following the stressor. A person with poor resilience (dashed lines) has a delayed or incomplete recovery, or the most severe decline resulting in death. This figure is based on similar figures previously published in the literature (e.g., [19–21]).

questions concern the resilience of the organisational system in the context of dealing with cognitive decline. Note that operationalising the system at a given level does not mean that other levels are disregarded as the system can be understood as an open system which interacts with its environment. We define "stressor" as an event or situation that pushes the system away from a stable state. Stressors may be acute and temporary, or chronic and persistent. At the micro-level, the stressor may be a disease mechanism resulting in accumulating cellular damage, a disease in its totality (e.g., Alzheimer's disease), a treatment, a life event, a relevant change in a person's social situation (e.g., illness of informal carer) or an environmental or policy factor that disrupts the equilibrium of the person and their direct social environment. In the meso- or macro-level, the stressor may represent changes in organisational structure, policy, workload/demand, resources, etc., that disrupt the equilibrium of the organisational system. With "bouncing back," we refer to the response to the stressor and the recovery to the equilibrium state after an unstable state. Often this is not the same state as before the stressor occurred [16]. Under "bouncing back," we also include the ability to resist a change and maintain the current equilibrium. The choice of outcome depends on the context and may include (but is not limited to) measures of cognitive, social, emotional, physical or daily functioning or well-being of an individual, or functioning of an organisation, network, or community.

Figure 1a visualises this concept of resilience in a socalled landscape model with periods of high and low resilience [18].

A distinct feature of resilience research is that it focuses on the dynamic, adaptive processes that change the system's state [18, 22]. Resilience research involves repeated measures of (positive) recovery outcomes, such as functioning, participation, well-being, or quality of care. This sets resilience apart from other geriatric concepts, particularly frailty, which is defined as "a medical syndrome with multiple causes and contributors that is characterized by diminished strength, endurance, and reduced physiologic function that increases an individual's vulnerability for developing increased dependency and/or death [23]." Frailty constructs are validated to predict negative outcomes such as death or hospitalisation [24]. Frailty (or its opposite robustness) is not the same as resilience, as frailty reflects a generalised presence or absence of vulnerability, while resilience is a dynamic state or process that is specific for a given stressor and outcome. Whitson et al. (2018) explain the difference between frailty and resilience as follows: "If the spectrum from robustness to frailty reflects the amount of physiological potential one has to react to stressors, physical resilience refers to the actualization of that potential" [13]. The ability to adapt as a feature of resilience is nicely illustrated by the observation that many older adults maintain a satisfactory quality of life despite (cognitive)

disabilities (the so-called disability paradox), e.g., through assigning higher priority to domains in which their functioning is still good and lower priority to domains in which their functioning is declining [25, 26].

Inherent to the definition provided above, resilience is a dynamic property specific to the system, stressor, and outcome at hand. Therefore, there is not one established method to measure or quantify resilience. Various methods have been described in the literature [27, 28]. A good description of these methods can be found elsewhere [28] and is beyond the focus of this position paper.

"Resilience" as a Relevant Concept in All Stages and Contexts of Cognitive Decline

In research on cognitive decline, to date, resilience is applied predominantly in cognitive neuroscience to explain differences in cognitive outcomes between individuals with similar levels of brain damage. In this micro-level focus on resilience, cognitive resilience encompasses cognitive reserve [29–33]. The cognitive reserve model assumes flexibility and adaptability of cognitive and brain networks that allow the brain to actively resist the effects of age- or disease-related changes [34]. Evidence for this model comes from studies that have shown that education modifies the association between brain metabolism and biomarkers of Alzheimer's Disease pathology [35] and studies that show that better lifestyle is associated with a lower risk of progressing to dementia in people with mild cognitive impairment [36].

Such neuroscience insights may inform strategies to prevent or slow down cognitive decline. While valuable, these insights predominantly address the early stages of cognitive decline.

We postulate that resilience is also useful in other stages of cognitive functioning, spanning the cognitively healthy stage to advanced dementia. Moreover, the concept of resilience can be applied to not only prevent cognitive decline but also to understand its bidirectional associations with outcomes, such as daily functioning, well-being, and social behaviour. Ultimately, new insights in cognitive functioning and related outcomes from a resilience perspective may inspire new options for personalised prevention, prognosis, cure/rehabilitation, care/management, and policy. Below we describe and illustrate how resilience may be applied across the full spectrum of cognitive decline with examples in the contexts of prevention, prognostics, cure, care, support, and social policies.

In a *preventive context,* interventions to strengthen resilience aim to reduce the likelihood of passing a tipping point towards decline in cognition (shown in Fig. 1a, remain at, or revert back to state A). Looking at prevention through a resilience lens helps understand differences in responses to risk factors of (further) cognitive decline. For example, traumatic brain injury (TBI) is commonly believed to be a risk factor for dementia, although studies have provided inconsistent findings [37, 38]. A series of reviews have aimed to better understand this presumed relationship by exploring the roles of TBI-pathology [39], the type of injury, and the type of dementia [40]. Examining this association from a resilience perspective advances our understanding of why some but not all people with TBI develop dementia. That may inform preventive interventions to reduce the risk of developing dementia after TBI. For example, improving sleep time and not taking alcohol or drugs may make TBI patients more resilient to the high energy burden of a brain trauma [41]. In addition, having social, physical, and societal environments that are stimulating, safe, inclusive, and accessible to resources and support, has been found to boost resilience and prevent decline [42].

In prognostics, resilience may help predict recovery potential after adversity. This may, e.g., be applied by analysing the reaction of a person with cognitive decline to a COVID-19-induced delirium. Studies in older populations including people with cognitive decline and dementia have shown that analysing time series of postural balance and well-being adds prognostic power to static, cross-sectional measures of health for predicting successful ageing and recovery after hospital admission [43, 44]. Using methods adopted from ecology and animal studies [45], measures of variance, auto-correlations, and cross-correlations between subsystems derived from time series data can be converted into dynamic indicators of resilience. Such dynamic indicators of resiliences can help predict recovery potential after adversity, e.g., illness. Figure 1b visualises the potential recovery trajectories following an (acute) stressor. The ability to predict recovery potential prior to occurrence of a stressor supports shared decision-making and opens up opportunities to strengthen resilience when occurrence of a specific stressor can be expected. One example is monitoring psychological well-being after a dementia diagnosis, to better understand the impact of the diagnosis and inform improvement of the post-diagnostic care to maintain well-being. Another example is training sessions for informal and formal caregivers in coping with neuropsychiatric problems in people with dementia. In summary,

in prognostics, the focus is on predicting who or which systems may benefit from resilience strengthening interventions.

In a *curative or rehabilitation context*, interventions to strengthen resilience aim to increase the likelihood of returning to a better equilibrium state (shown in Fig. 1a, move from state C to A or deepen the valley in state C) or to increase the likelihood of returning to the pre-stressor state (shown in Fig. 1b) [2, 22, 45]. Being able to quantify resilience may help optimise treatment for that person (e.g., choosing the optimum dosage of dexamethasone in a patient with COVID-19 and delirium based on the CO-VID-19 stage and cognitive resilience for the corticosteroid challenge on brain function) [46]. A rehabilitation context also includes the influencing factors of, or collaboration with, social, physical, and societal environments. For example, rehabilitation may focus on coaching a person with progressive aphasia and their family in finding new methods to communicate, so that the person can maintain their social role in the family. Other examples are physical and cognitive exercise and clever design of the social and built environment to facilitate and maintain current levels of functioning and prevent behavioural symptoms [47–50].

In advanced stages of cognitive decline, when improvement of cognitive function is no longer feasible and the emphasis is on *care and management*, interventions may aim to strengthen adaptability and flexibility to adjust to stressors and maintain the optimal equilibrium for as long as possible (shown in Fig. 1a, remain in state A). In the care for a community-dwelling person, examining stress factors and resilience of the informal care system may predict the breakdown of the social system. Monitoring stress factors and resources (e.g., access to formal home care, day care services, supportive social network, financial situation, perceived carer burden) that influence the informal caregivers' resilience enables timely interventions to prevent crisis ad224-missions [51–54].

Finally, a good example of improving resilience in the *social and policy* context is the introduction of age-friendly cities and dementia-friendly communities [55, 56]. The initiative of age-friendly cities has shown how the resilience of ageing populations can be improved by redesigning social and physical environments [55]. A stimulating and challenging environment is an important condition for improving resilience [42].

Examining responses to stressors also provides the opportunity to examine resources that facilitate optimal recovery patterns. Such resources may be intrinsic resources, such as personality, intellectual, and spiritual resources, but may also be extrinsic resources, such as social support and financial situation. In the contexts described above, the role of these resources may vary.

A phenomenon that cannot be examined nor explained from a risk factor perspective is that experiencing adversity may also boost psychological resilience. Specifically, the posttraumatic growth model explains potential positive personal transformations in response to highly stressful situations [57]. Caring for a person with dementia is perceived as stressful resulting in a third of carers experiencing depressive symptoms [58]. In a cross-sectional study of 124 caregivers, caregivers of people with dementia experienced a moderate level of posttraumatic growth, measured as the degree of change experienced in interpersonal relationships, new possibilities, personal strengths, spiritual changes, and appreciation of life [59]. That study's findings suggest that adopting positive coping strategies when experiencing the negative impact of caring may promote the posttraumatic growth of caregivers [59]. Thus, the resilience lens provides a framework to better understand the role of positive and negative experiences in withstanding and/or recovering from stressors that goes beyond insights obtained from a risk factor perspective.

A Multi-Level Systems Perspective on Resilience

From a socio-ecological systems approach, resilience can be examined at the micro-, meso- and macro-levels [60, 61]. At the meso- and macro-levels, the resilience perspective can inform policymakers, communities, and organisations to prepare for influences that could stabilise or destabilise the health and social care system as a whole or how to make environments safe, accessible, and inclusive. Given the resilience of a system, upcoming changes in needs (e.g., the number of people requiring care, type of care needs) and resources (e.g., available support for the relevant network, trained care providers, housing, day care facilities, funding, psychological, and social empowerment) should be anticipated. Sudden system changes are hard to prepare for, but resilience data can be used as relevant prognostic signals. The micro-, meso-, and macro-levels are complex and interact. The socio-ecological approach proposes that these levels work together to influence resilience on one of these levels. Below we illustrate how the concept of resilience may be applied at the micro-, meso-, and macro-levels, respectively, using a socio-ecological systems approach.

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Micro-Level

As the cognitive and daily functioning declines in a person with dementia, the need for support from family and professional caregivers increases. The resilience of the person with dementia becomes increasingly dependent on the resilience of their social system. A small change in that system, e.g., a change in health of an informal caregiver, can already cause a disequilibrium in the care receiver-care giver dyad (shown in Fig. 1a, shift from A to B). For example, the main reason for a crisis admission of a person with dementia is that the care burden exceeds the capacity of the caregiver. The stress perceived by people living with dementia and their carers is not only caused by the pathology in the brain and resulting cognitive and behavioural problems but also the availability of professional care and welfare services and societal beliefs of what people with dementia are and are not able to do. This illustrates the need for a systems perspective in micro systems.

Meso-Level

A meso-level systems perspective on resilience in dementia care is seen in community initiatives to move towards a more dementia-friendly society. "Dementia friendly" is the label given to cities, neighbourhoods, businesses, service providers, health care centres, or other communities that have implemented improvements in their community to enable people with dementia to live longer in their own environment and maintain social participation and well-being [62]. Dementia-friendly communities are communities where people with dementia and their carers feel understood, respected, have access to support, and feel confident they can contribute to, participate, and engage in community life. In a Dementia Friendly Community, the physical and social environment is responsive to the needs of a person with dementia. This means that people are aware of, and try to understand people with dementia and their caregivers, so that both feel included and involved, and are supported to have control over their day-to-day lives [63–65]. An example is collaboration of art and care professionals in local cultural initiatives with frail older persons, such as participation in choirs for persons with dementia. Such initiatives have shown positive effects on the physical activity, social participation, happiness, meaningfulness, greater empowerment, and resilience of the participants [66].

Other examples of meso-level systems interventions in the healthcare system are the DementiaNet approach and the Social Trials approach. The DementiaNet approach aims to improve the resilience of the person with dementia and the informal care system by delivering integrated medical-nursing and social networked care. This network approach results in better collaboration, efficiency, and quality of care [67, 68]. The Social Trials approach teaches health care providers to approach people with dementia not solely as patients, but also as a professional, parent, neighbour or any other social roles that they may have. When the disease is less on the forefront, a more holistic approach of problem solving can be adopted that aligns better with the social needs of the person. The quality of life of the person with dementia improves and they can maintain their social position for longer [69].

Macro-Level

Over the past decades, many countries have developed national dementia strategies. These strategies describe the national plans for improving care and assisted living for people with dementia. The strategies provide a means for policymakers, researchers, and care providers to work towards shared goals. The main motivation for countries to formulate such strategies is to prepare for future threats to the sustainability of the health and social care systems due to an anticipated increase in absolute numbers of people living with dementia. Examples of priorities formulated in these strategies include:

- Netherlands: tailored support when living with dementia [70].
- Ireland: integrated services, supports, and care for people with dementia and their carers [71].
- Norway: enable people with dementia to live an active life, and provide support and respite for their carers [72].
- Canada: prevention of dementia [73].

Addressing the priorities listed in the national dementia strategies requires a socio-ecological systems approach, including the micro-, meso-, and macro-levels. To be able to provide integrated, tailored support, policymakers, care providers, and volunteers need information on the needs at these three levels to provide adequate services. Moreover, as needs may shift over time and generations, due to technological developments and demographic changes, the system needs to be set up in such a way that it can adapt to those changes. An integrated system guided by shared goals will be better able to cope with these changes in needs [18].

Also in prevention, a socio-ecological systems approach is required. For example, consider a person who wants to reduce their risk of developing dementia by adopting a healthy diet and thus avoid obesity and

hypertension [74]. That person's ability to maintain a healthy diet may be challenged when only unhealthy options are available, affordable, or socially accepted within the person's peer group [75]. A supportive environment can strengthen the person's resilience to maintain a healthy diet. To be successful at a societal scale, cognitive decline prevention strategies require system involvement of all stakeholders, including policymakers, health insurers, and businesses, and their efforts need to be tailored to the social and cultural context [42].

Although the distinction between micro-, meso-, and macro-levels is analytically helpful, in real life, these levels interact and form a complex whole. For instance, the (meso-level) large-scale closing of residential homes by the national policy of ageing in place in the Netherlands has been a stressor on both the micro-level and macro-level systems. On the micro-level, the policy disrupted the equilibrium state of well-being of many older people and their caregivers [52]. On the meso- and macro-levels, the policy caused a dramatic shift in workload from care homes to home care.

Recommendations for Research

In summary, we propose that there are ample opportunities for applying a multi-systems resilience perspective in research on cognitive decline, also beyond cognitive neuroscience and in all stages of cognitive functioning. The resilience approach has the potential to advance our understanding of cognitive decline, improve prediction, and inform intervention design and policy. The resilience approach is complementary to the traditional biomedical science approaches. Benefits include the positive perspective, ability to explore resources contributing to resilience and opportunity to examine the phenomenon that adversity can lead to increased resilience. Good resources are available to design resilience research, such as a practical description of approaches to quantify resilience [28] and a tool to design resilience research [76].

Conclusion

In this position paper, we demonstrated with literature and pertinent examples that applying a multi-systems resilience perspective to cognitive decline may facilitate next steps in understanding, predicting and intervening to boost (cognitive) functioning, well-being, and health and social care that are highly complementary to the

ongoing basic biomedical science approaches. Importantly, applying a resilience approach aligns with the wish of people with cognitive decline for a more positive perspective on cognitive ageing. Embracing the concept of resilience can add exciting new research horizons and policy opportunities for people with cognitive decline, their carers, professionals involved, and dementia-friendly communities and societies.

Conflict of Interest Statement

The authors declare to have no conflicts of interest.

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Author Contributions

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