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Hope and burden of Alzheimer disease- a scoping review

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Abstract

Introduction: For more than the last forty years, positive psychology and hope researchers have investigated many populations. Their main targets were healthy adults or adults suffering from diseases such as cancer or cardiovascular conditions. A forgotten sample is the growing group of informal caregivers supporting persons suffering from cognitive decline (preclinical symptoms, mild cognitive impairment and Alzheimer's Disease). The aim of the present manuscript is to show the complexity of the construct of hope and its influence on the caregivers' situation.

Material and methods: In this study, a scoping review of works from 2015 to 2025 on hope and dementia was performed. The systematic search yielded twenty studies conducted on different subjects (patients, informal caregivers and patients' spouses).

Results: The studies offered different views on the matter due to their differing origins. Divergent fields of research have produced a complex picture of hope and resilience studies. Current research uses multiple tools based on self-report to neuroimaging. The studies sample populations of Western and minority groups. Therefore, it was possible to show a more generalised picture of the subject group.

Conclusions: The review showed a great need for studies on caregivers and their well-being. The introduced Positive Psychology Interventions show an increase in quality of life of caregivers and decreased impact of the burden of disease. Existing models like PERMA+4 and the hope theory through personalised solutions, can enhance the well-being of the growing informal caregivers' and sandwich population.

Keywords: Hope, Alzheimer's Disease, burden of the disease

Streszczenie

Wstęp: Przez ostatnie czterdzieści lat psychologia pozytywna i badacze nadziei prowadzili badania w obrębie wielu populacji. Głównym celem stały się populacje osób zdrowych w okresie dorosłości oraz osób cierpiących na choroby między innymi choroby nowotworowe lub układu krążenia. Zapomnianą grupą są osoby będące nieformalnymi opiekunami osób chorych na zaburzenia pamięci (łagodne zaburzenia pamięci, chorobę Alzheimera lub stadia przedkliniczne). Celem obecnego artykułu jest przedstawienie zależności konstruktu nadziei oraz złożoności jej oddziaływania na sytuację opiekunów.

Materiał i metody: W obecnym artykule dokonano zakresowego przeglądu literatury w okresie od 2015 do 2025 roku na temat nadziei i zaburzeń otępiennych. Badanie zaowocowało analizą dwudziestu badań przeprowadzonymi na różnorodnych populacjach (samych chorych, nieformalnych opiekunach osób chorych i małżonkach osób chorych).

Wyniki: Badania wniosły poszerzony wgląd w temat dzięki swojemu zróżnicowanemu pochodzeniu. Ujawniono złożony obraz badań nad nadzieją i rezyliencją. Obecne badania korzystają z różnorodnych metod pomiaru, zaczynając od kwestionariuszy samoopisowych, a skończywszy na neuroobrazowaniu. W badaniach brały udział osoby z krajów zachodnich oraz grup mniejszościowych. Umożliwiło to zobrazowanie bardziej zgeneralizowanego obrazu grupy badanej.

Wnioski: Przegląd literatury wykazał potrzebę dalszych studiów nad populacją opiekunów oraz ich dobrostanem. Wprowadzenie interwencji proponowanych przez psychologię pozytywną istotnie wspomaga jakość życia opiekunów oraz obniża odczuwany przez nich ciężar choroby osób najbliższych. Istniejące modele tj. PERMA+4 i teoria nadziei poprzez zindywidualizowane podejście mogą poprawić dobrostan rosnącej tzw. populacji kanapkowej.

Słowa kluczowe: Nadzieja, choroba Alzheimera, obciążenie chorobą

Introduction

An increasing number of older adults brings to light new types of social problems. One of these is the burden of care and the mental health of the caregiver. So far, the concept of burden has been the main interest of scientists. The main triggers of the burden connected with the patient's declining health have been established and described. The caregiver's perspective is not as well documented.

The evolution of hope

Over the last two millennia, the construct of hope has been present in life and science, even though its description has continually changed [1]. The concept was initially described as the "positive mental state about the ability to achieve goals in the future" [2]. It was grounded in philosophy and religion, and therefore was strongly based on faith and virtues. The development of psychology changed the way scientists described it.

Hope was perceived as the opposite of despair or hopelessness. It was strongly connected with anxiety, the fear of the unknown or the potential loss of earthly goods and personal well-being. According to Scioli A. [1], the first definitions of hope present in the Oxford English Dictionary date back to the 11th century. They refer to hope as a means to obtain the transgression to higher virtues and as "an island in the middle of a wasteland".

In the light of current psychology, hope can be perceived as a motivational construct, personality trait, an emotion or the opposite of existential anxiety. It is important to distinguish hope from coexisting traits such as optimism, self-efficacy and self-esteem. There are correlations between the abovementioned constructs, but they are not interchangeable [2-5].

Hope as a motivational construct.

The most popular motivational theory is Snyder's concept of hope as a two-fold construct: agency (goal-directed energy) and pathways (the plan and knowledge of how the goal could be achieved) [6-7]. Hope as agency is "the perceived capacity to use one's pathways so as to reach desired goals" [8]. High-hope people tend to use self-talk in the form of agentic phrases like "I will make it", "OK, you can do it". It is far more than just affirmation: inner speech can provide alternative solutions in the moments of doubt and crisis. Hope as pathways is connected with understanding the complexity of the goal-oriented action necessary to undertake in order to fulfil the goal. High hope persons tend to be more focused on the information, regardless of whether it is positive or negative in valence, required to increase the chances of fulfilling the goal. Therefore, they can undertake prophylactic actions in order to reduce the chances of failure. Traits such as optimism, self-efficacy and self-esteem are moderators in the above-mentioned relationships [8]. They are often used while describing the well-being of the caregivers and their personality traits. Optimism, resilience and hope are then shown as key factors in maintaining well-being with the increasing burden of the disease.

It is worth mentioning that Snyder's theory is not the only explanation of hope as a motivation factor. Schrank, Stanghellini, and Slade identified and described forty-nine definitions of hope [1]. They were later grouped into seven dimensions: time, likelihood of success, an undesirable starting point, goals, locus of control, relations and personal characteristics. This also corresponds with the Dufault and Martocchio model of hope [1,4].

Hope as a motivational construct may be described as a temporal agent. It is strongly connected with planning the potential outcomes of the current situation. It is oriented towards the future but deeply rooted in the present. The perceived outcome is moderated by current knowledge of the event, perception of personal strengths and weaknesses, potential support (relationships and social networks). Perceived probability of success would be moderated by the locus of control. It is important to underline that between particular constructs the dense network of feedback and feedforward loops is observed. Hope as a motivational factor in the research focusing on the welfare of different patients' groups is connected with undertaking the constructive treatments and focusing on their outcomes.

Hope as a virtue and transgression factor.

Hope as a virtue was introduced to psychology by Erik Erikson in the 1960s. He claimed that during the first three years of human development due to the first interactions with the caregiver the child establishes the foundation of "basic hope" [9]. This construct and its quality will shape all relationships of the person in the future. Hope is connected with trust but with self-efficacy as well. The sense of mutual cooperation with the external world and collaboration to the common good is in the core of Erikson's concept of hope as a virtue. Humans, due to positive early relationships, can develop both. What is more, it is realistic. Hope in this sense can be associated with the position of the caregiver and the patient in the treatment team. The basic hope construct can determine if the caregiver and the patient will interact with trust and collaborate in the shared efforts undertaken. It also determines the relationship between caregiver and patient.

Hope as goal-oriented force

Hope is usually connected with the cognitive domain rather than emotions although it coexists with optimism.

Mowrer in his two-factor theory of learning indicates that hope is crucial in fear reduction [1, 4]. Positive emotions connected with hope of the intended outcome will introduce appetitive behaviours. On the other hand, Ortony, Clore, and Collins describe hope as a prospective emotion [10]. Focusing on the future outcome increases the current state of the agent and intensifies efforts to obtain the required goal. Hope is the opposite of fear.

Hope as a strong positive force is crucial in Seligman's theory of happiness [3, 11]. The optimistic attributional style is a pattern of external, variable, and specific attributions for failures. Seligman also introduced the concept of the "hope circuit" which corresponds with the activation observed in the medial prefrontal cortex, later decreased activation in the dorsal raphe nucleus. It is suggested as an indicator of learned control and to prevent dispositional helplessness [12]. The locus of control and the ability to internalise one's efforts is crucial in adequate therapy. The compatibility of patients' needs and the therapy introduced is a key factor in a positive outcome.

Hope as the opposite to despair is measured with the Beck's Hopelessness Scale [1, 13]. One of the most popular tools of assessment contains three factors: feelings, expectations regarding the future, and loss of motivation. Their co-occurrence are well known to all practitioners.

Hope as a part of psychological capital

Hope is also perceived as an important factor in multilevel models such as PERMA+4 [14] or EEMM (Extended Evolutionary Meta-Model) [15]. It is defined as a part of psychological capital (PsyCap) increasing a person's potential for general well-being in different contexts. PsyCap can be described as an indicator of a positive mindset containing: striving for goals with necessary alternative solutions (hope), confidence in pursuing success (self-efficacy), ability to overcome the difficulties (resilience) and positive attributions (optimism) (HERO). It can be boosted by a sufficient level of gratitude. So far it has been widely used in the general public research.

Hope as an object of health care research

Hope in health care can be conceptualised as: expectation, resilience or desire [16]. Expectation is a positive, but realistic appraisal of an uncertain outcome. It is commonly measured using self-report scales as a perceived outcome of a particular disease. Hope as resilience is described in terms of strategies introduced in order to decrease the negative aspects of a current disease. It can be described as a coping strategy to endure adversity. In mental illness research, it is associated with positive recovery, empowerment and resistance. Hope as a desire is connected with the aspiration for the recovery of a life worth living. It increases quality of life, one's sense of life meaningfullness and significant value.

Hope can be measured on physiological, psychological and social levels. Physiological measurements range from immune and cardiovascular indicators to specific activations observed in PET, fMRI and other neuroimaging [12, 17-18]. Psychological assessment covers the individual sense of well-being and life satisfaction connected with achieving particular goals. The overlap of hope levels within a group can increase the hope levels of its members [19].

Caregivers' protective factors and the burden of Alzheimer's Disease

Looking after another person and providing everyday care can be an extremely demanding activity. The amount and intensity of care are constantly increasing in the case of patients suffering from Alzheimer's disease . The types of activities undertaken are mostly repetitive and with short-lasting effects. All of the above can lead to caregiver burnout. The amount of work and emotional, financial and physical involvement is referred to as the burden of the disease. Its toll is different depending on the interpersonal predispositions of the person, but it is also correlated with socioeconomic status, knowledge of the disease's characteristics and its outcome [20-21]. It is worth mentioning that the majority of the informal caregivers are the family members of the patients. Most of this group are women. The unique population of caregivers are the persons who manage the joint care of their elderly parents and grown children [22-25]. Their engagement in caring for two generations was the origin of the sandwich population.

Purpose of the Scoping review

The aim of the current scoping review is to bring together the up-to-date overview on the subject of hope in health sciences and to describe the current state of research on hope's role in the dyad of the MCI/AD patient and informal caregiver. The aim of the current scoping review is to establish whether the construct of hope:

- Is recognised as an important factor of protective measure for caregiver burnout
- Shows the complexity of the caregivers population, differences in situation and understanding hope as a co-factor of well-being
- Is well described and universally measured within the empirical studies
- Is described by the well-defined psychological theory

The following research questions have been posed: What is the state of the current science in the subject of hope? Can the level of hope predict the state of well-being reported by the caregiver? Is the level of well-being reported differently across particular manuscripts and groups of caregivers?

Method

The current study is based on the scoping review guidelines [26]. Three databases were searched: PubMed, ScienceDirect, and Google Scholar. The detailed protocol of the search strategy and the results are available in the supplementary material.

Prior to target search, two general filters were applied to all browsers: date of publication (2015-2025) and the study population (human). The applied keywords were: hope, theory of hope, resilience, burden of disease, Alzheimer. All keywords were searched as a single word and later the AND/OR operators were added. The search sometimes provided a ridiculously high number of hits. The great majority of these hits were observed in Google Scholar. After the inspection of the titles and abstracts of randomly selected manuscripts the reason became clear. Due to the common usage of "hope" as a part of expression "We hope that our research…" false positive results were reported. Such cases were less frequently observed within the PubMed and ScienceDirect browsers. The initial search results were also numerous, but after applying more specific filters the amount of manuscript hits was narrowed. Due to the inadequate algorithm of the search the records obtained via Google Scholar were discarded.

Using the scoping review methodology [26], the final sample of 280 manuscripts was investigated. The inclusion criteria were: a study based on the sample of persons dealing with the toll of AD (as a patient or caregiver). Other causes of disabilities were excluded. The second criterion was the measurement of hope as a factor in the caregiver's well-being. Due to many discrepancies in the methodologies of studies on hope the following guidelines were applied. Hope was perceived as either a construct defined in Snyder's theory or a factor increasing the resilience and well-being by focusing the persons' assets and positive emotions. The main exclusion criteria were resilience understood as a capability to keep the cognitive skills and not in the sense of positive psychology.

The first revision based on the titles and abstracts excluded 240 manuscripts. Studies were devoted to pathophysiology of the disease where the term resilience is commonly used as a description of protective factors connected to the pace of cognitive decline. The next selection was based on the group of participants described in the manuscript. Works on burden of Alzheimer's disease and the 'sandwich generation' were included in the review, formal caregivers were excluded. The following step yielded 18 publications. The snowball procedure resulted in 2 more. During the scoping literature review it was possible to gather 20 publications.

Results

The obtained results cover a wide range of different types of publications: systematic review, single intervention assessment, qualitative and quantitative studies. Studies present the standpoint of diverse groups of respondents , such as preclinical patients, patients' spouses, and informal family caregivers. The construct of hope is operationalised differently in particular groups of reported manuscripts.

The first group of manuscripts refers to hope as a transcendental factor enhancing quality of life and providing a sense of purpose [27-31]. Within those studies religiosity and spirituality are underlined. Only two of them [27, 30] report conducting cognitive screening of the Alzheimer's disease participants. The remaining studies simply report the existence of the diagnosis of dementia. Three of the manuscripts used questionnaire-based methods to estimate the intensity of the main variables. The Ryff's Psychological Well-Being Scale was used to assess the purpose of life in two studies [27, 31]. One study used six different questionnaires to establish participants' well-being [30]. Two of the studies were based on semi-structured interviews [28-29].

The second group of manuscripts refers to hope as part of psychological capital [32-41]. The main correlating constructs include: resilience, self-efficacy, quality of life, burden of the disease and anxiety. Most of the manuscripts declare using questionnaires to measure the main variables [33-39, 41]. Half of them performed a cognitive assessment of the patient [35, 37-39, 41]. The following studies reported using the Zarit Burden Interview to measure the burden of the disease [34-36, 38-39].

The third group of manuscripts focuses on hope as a virtue of trust in the relationships [23, 42-44]. The main correlating variables are quality of life, anxiety and burden of the disease. Three of them used questionnaires to assess the level of main variables [23, 42-43]. Two of them provided cognitive screening of the patients at the time of assessment [23, 43].

Only one manuscript described hope within the framework of Snider's theory [45]. The main variables were measured with questionnaires (Zarit Burden Inventory, 12-item Adult Hope Scale and Neuropsychiatric Inventory Questionnaire). The study did not perform the cognitive screening of the patients nor give an approximate level of the disease.

The general conclusion of the scoping review is:

- lack of unified protocols for assessing hope as a psychological variable.

Table 1. The scoping review results.

Publication	Hope	MCI/AD patient	Informal caregiver	Questionnaires used	Neuro-imaging	Outcome
Abellaneda-Pérez K. et al., 2023 Longitudinal experimental study	As to transcendental factor enhancing quality of life	624 preclinical middle-aged adults	n/a	The Ryff's Psychological Well-Being Scale Cognitive assessment: Digit Span, Trail Making Test (A&B), Matrix Reasoning, Rey Auditory-Verbal Learning Test, Block design Test, Letter-Number Sequencing, Digit-Symbol Substitution Test and Cancellation subtests of WAIS-IV, Corsi block-tapping test	fMRI- white matter analysis; resting-state functional connectivity	First assessment was run before clinically observed cognitive decline. Study is longitudinal and still running. Neuroimaging showed greater white matter lesions (WML) correlated with less efficient cognitive functions in low purpose of life group. No differences were reported in neuropsychological status in high (HP) and low purpose of life groups (LP). Persons with higher purpose of life show more resilience to WML. Denser network (DMN) was observed in HP. HP individuals had greater inter-network connectivity between dDMN nodes and the rest of the brain.
Agil O. et al., 2015 Systematic review (11 articles)	As to transcendental factor enhancing quality of life	460 Alzheimer's disease patients, 1598 other dementia patients	n/a	Behavioural Religiosity Scale (BRS), Francis Short Scale Cognitive assessment: MMSE CDR NPI	n/a	High level of religion in Alzheimer's disease patients correlates with a slower cognitive and behavioural decline. Spirituality supports coping strategies to deal with their disease and have better quality of life.
Creighton A.S. et al., 2017 systematic review (34 studies)	As a virtue of trust in the relationships	Older adults staying in residential aged care facilities (total number of participants 1543554).	n/a	Hospital Anxiety and Depression Scale, QLQ-C15-PAL, Purpose-in-life test	n/a	High hope, well-being and intrapersonal self-transcendence lowers the anxiety level. Systematic review focuses on different groups in term of cognitive abilities. The main focus is on the correlation of anxiety in the end of life.
Daley R.T. et al., 2017 qualitative and quantitative study	As a virtue of trust in the relationships	11 AD patients	11 AD patients' spouses	Beck Anxiety Inventory, Centre for Epidemiological Studies Depression Scale, Burns Relationship Satisfaction Survey, Zarit Burden Interview, Positive Aspects of Caregiving scale Cognitive assessment: MoCA CDR	n/a	Aim of the study was to measure the impact of perception of social relationship (we/us and I/me) on the burden of the disease. No statistical differences in burden of the disease, depression and anxiety level in caregivers groups.

Farina N. et al., 2017 Systematic review (41 studies)	As a virtue of trust in the relationships	n/a	AD patients‘ caregivers (total 5539 participants)	Quality of life: Short Form 36 (SF-36), Quality of Life in AD (QOL-AD), Short Form 12 (SF-12) Cognitive assessment: MMSE CDR	n/a	Meaning of caring and coherence increased QOL. Self-efficacy and lower burden correlate with higher QOL. Systematic review provided wide range of studies with different groups of participants (spouses, children and other relatives). The cognitive state of the study patients was known at the time of assessment.
Gallagher E. et al., 2020 Qualitative study	As a virtue of trust in the relationships	11 AD patients	11 AD patients‘ spouses	Semi-structured interview	n/a	High relationship closeness inclines positive outlook on day-to-day problems.
García-Toro M. et al., 2020 Qualitative study	As to transcendental factor enhancing quality of life	n/a	27 caregivers of early-onset AD patients sharing the genetic mutation E280A	Semi-structured interview	n/a	Caregivers are also carers of the genetic mutation. Conscious decision of care is connected with higher level of self-efficacy. Other reasons for being the caregiver increases burden of the disease. Coping strategies include positive re-evaluation, resignation and humour. Caregivers viewed more favourably their ability to respond to relatives‘ difficult behaviours if they understood the disease.
Han S. et al., 2019 Qualitative study	As a part of psychological capital	n/a	39 family caregivers of hospice patients with dementia	Ecological model, semi-structured interview	n/a	Caregivers who properly use positive appraisal through self-monitoring, self-management and self-evaluation can enhance their confidence and caregiving skills.
He J. et al., 2022 Systematic review (31 studies)	As a part of psychological capital	2839 AD patients	Dyads, informal AD caregivers and professional caregivers 3939 in total	Nottingham Health Profile, Mood Improvement Questionnaire, Perceived Change Index, Positive Affect and Negative Affect Schedule, Care-Related Quality of Life Instrument-Visual Analogue Scale, Centre for Epidemiologic Studies Depression Scale, Self-Rating Depression Scale, Geriatric Depression Scale, Patient Health Questionnaire, Beck Depression Inventory II Cognitive assessment: MMSE CDR	n/a	The 10-month intervention increased the mean score of resilience in the intervention group during the follow-up period, while the mean score of the control group decreased; resilience of the caregiver did not improve. Meta-analyses showed low to moderate effects on subjective well-being, depression, and burden of caregivers, and a moderate to high effect on caregiver anxiety.

Jütten J.H. et al., 2019 Quantitative study	As a part of psychological capital	n/a	201 informal dementia patients' caregivers	Caregiver Reaction Assessment Dutch (CRA-D), Hospital Anxiety and Depression Scale (HADS), Interpersonal Reactivity Index (IRI), Perspective Taking (PT) and Empathic Concern (EC).	n/a	In caregivers group there was a negative quadratic relationship between depression and cognitive empathy, and a positive linear relationship between anxiety and affective empathy, irrespective of sociodemographic characteristics.
Kimura N.R.S. et al., 2019 Quantitative study	As a part of psychological capital	43 early onset dementia patients	43 early onset dementia patients' caregivers	Beck Hopelessness Scale (BHS), Resilience Scale of Wagnild and Young, Beck Depression Inventory, Beck Anxiety Inventory, QoL-AD, Zarit Burden Interview (ZBI), 12-item Neuropsychiatric Inventory, The Cornell Scale for Depression in Dementia. The Assessment Scale of Psychosocial Impact of the Diagnosis of Dementia, Pfeffer Functional Activities Questionnaire (FAQ) Cognitive assessment: MMSE CDR	n/a	No significant relationship was found between carers resilience and care recipient sociodemographic and/or clinical characteristics. Inverse correlation between resilience and carer's depressive symptoms, anxiety and hopelessness was observed. Resilience is likely an individual characteristic of the carer.
McCarthy V.L. et al., 2015 Quantitative study	As a transcendental factor enhancing quality of life	20 preclinical older adults	n/a	Self-transcendence Scale, Life satisfaction Index for the Third Age, Acceptance & Action Questionnaire II, Philadelphia Geriatric Center Morale Scale, Proactive Coping Subscale, Geriatric Depression Scale, Short Form-20 Health Survey, Version 2 Cognitive assessment: Mini-Cog Dementia Scale	n/a	No statistically significant differences between groups were observed in depression, acceptance, well-being, proactive coping or health-related quality of life. Significant improvement was observed in life satisfaction.
McGee J.S. et al., 2024 Quantitative study	Based on Snyder's theory	n/a	155 AD patients' caregivers	Zarit Burden Inventory, 12-item Adult Hope Scale, Neuropsychiatric Inventory Questionnaire	n/a	Hope-agency moderated the insensitivity of distress effects on perceived burden of the disease. Quantitative study, self-administered questionnaires, no cognitive screening of Alzheimer's disease patients (disease severity unknown) Statistical analysis on effects- hierarchical regression.

McManus K. et al., 2022 Quantitative longitudinal study	As a part of psychological capital	n/a	32 dementia patients‘ caregivers	Zarit Burden Interview, Brief Resilience Scale, Quality of Life-Alzheimer's Disease Measure	n/a	Qualitative measurement-semistructured interview Hope is the quality mentioned by caregivers as an outcome of patients' interactions (sense of hope). It is treated as a factor of resilience and protection against burnout. Hope may act as a coping resource contributing to caregivers' resilience. Short effect of intervention on burden. Caregiver burden significantly declined from baseline through final follow-up. Caregiver resilience and care recipient QoL were not significantly changed but trended up during the intervention until it dropped at the end of the programme. Qualitative data suggests the reversal in resilience and QoL may be explained by caregivers' increased anxiety as the programme ended.
Monin J.K. et al., 2015 Quantitative study	As a part of psychological capital	58 AD patients	58 AD patients‘ spouses	Zarit Burden Interview	n/a	Caregiver compassionate love was significantly associated with lower burden and more positive appraisals of caregiving. However, caregiver compassionate love was marginally significantly associated with fewer depressive symptoms.
Pandya S.P., 2019 Quantitative study	As a part of psychological capital	n/a	78 AD patients‘ caregivers	Zarit Burden Interview, Revised Caregiving Self-Efficacy Scale, Resilience Scale for Adults and Caregiver Resilience Scale.	n/a	Gender and relationship with the patient were two strong moderators determining the program impact. Meditation programme in enhancing self-efficacy and resilience of home-based caregivers of older adults with Alzheimer's. Post intervention reported lower perceived caregiving burden, higher self-efficacy in obtaining respite, responding to disruptive patient behaviours and controlling upsetting thoughts, and greater resilience.

Rosa R.D.L.D. et al., 2020 Quantitative study	As a part of psychological capital	n/a	106 AD patients‘ caregivers	Resilience Scale; CQoL: Quality of Life in Alzheimer’s disease Scale, ZBI: Zarit Burden Interview, BDI: Beck Depression Inventory, BAI: Beck Anxiety Inventory, Beck Hopelessness Scale, Assessment Scale of Psychosocial Impact of the Diagnosis of Dementia, Quality of Life in Alzheimer’s disease, Quality of Life in Alzheimer’s disease Scale, Cornell Scale for Depression in Dementia Cognitive assessment: MMSE, Pfeffer Functional Activities Questionnaire, NPI, CDR	n/a	Different correlates were distinguished within particular groups of caregivers. The intensity of Alzheimer's disease symptoms predispose to different adaptation strategies. The resilience of caregivers was correlated with neuropsychiatric symptoms of the patients, appetite abnormalities, patients‘ depressive symptoms and quality of life. Resilience was inversely correlated to the caregivers’ depressive and anxiety symptoms. Caregivers with higher levels of resilience had low levels of depressive and anxiety symptoms. Awareness of the disease increased resilience. Data analysis based on quantitative measurement of the dyad questionnaire results Results are adjusted to the observed Alzheimer's disease severity.
Stansfeld J. et al., 2017 Systematic review (6 studies, 12 outcomes)	As a part of psychological capital	n/a	1795 Dementia patients‘ caregivers	The Revised Scale for Caregiving Self-Efficacy, Family Caregivers’ Self-Efficacy for Managing Dementia Scale, Sense of Competence Questionnaire, Short Sense of Competence Questionnaire, The Intrinsic Spirituality Scale, Spiritual Support Scale, Positive Aspects of Caregiving Scale, Gain in Alzheimer Care Instrument, Finding Meaning Through Caregiving Scale, Shortened Resilience Scale, Beck Depression Inventory,	n/a	Resilience was negatively correlated with reported stress of caregivers. Self-efficacy was negatively correlated with depression but positively with social support.
Wilks S.E. et al., 2018 Quantitative study	As a part of psychological capital	n/a	691 AD patients‘ caregivers	Spiritual Support Scale (SSS), Resilience Scale (RS14) Cognitive assessment: Revised Memory and Behaviour Problems Checklist subscale B (RMBPC-B)	n/a	Observed direction between spiritual support and resilience was direct. Spiritual support increased, so did the likelihood of resilience. Significantly higher resilience among married African American caregivers vs. single African American was observed. Caregivers indicating higher caregiving burden reported lower resilience.

Willroth E.C. et al., 2023 Longitudinal study Rush Memory and Aging Project (MAP)	As to transcendental factor enhancing quality of life	348 dementia patients (total 2193 preclinical patients)	n/a	Ryff Psychological Well-Being Scale, Satisfaction With Life Scale Cognitive assessment (19 tests not mentioned by name) in episodic memory, semantic memory, working memory, perceptual orientation and perceptual speed	Postmortem neuro-pathology	Linear regression models adjusted to sociodemographic characteristics, cognitive activity, medical comorbidities, neuroticism and depression show association between eudaimonic and hedonic well-being and cognitive reserve. High sense of purpose was associated with greater cognitive resilience.

- the differing understanding of hope as a theoretical concept brought to diverse methods of assessment.
- reporting of the cognitive status of the patient is not a principle in all of the studies, which can lead to false assumptions that the level of burden of the disease is universal during all dementia stages.

Discussion

The impact of dementia on patients is well documented, but over time the significance of caregivers' well-being has come to greater attention. The course of the disease is heterogeneous and varies across patients [30, 35]. Cognitive reserve is one of the most important factors in preserving patients' independence [23]. It is associated with the preclinical levels of cognitive functioning, lifestyle and undertaken cognitive activities. Individuals with higher education who were intellectually active tend to have higher cognitive reserve and therefore a prolonged preclinical stage of Alzheimer's disease. According to the results of studies the time of the onset of the disease and its pace of progression are key aspects of reported burden of the disease. A similar correlation is observed in the case of neuropsychiatric symptoms like aggression, increased anxiety or depression in the patient [22, 38-39]. The co-occurrence of psychotic episodes is one of the most significant factors affecting caregivers' reported mental health factor. Unfortunately, the scoping review results showed lack of unison in baseline cognitive and neuropsychological assessment of the patients. Some of the reported studies did not provided necessary information on the current level of patients' cognitive functions or the progress of the disease.

The scoping review showed different conceptualisations of hope as a psychological concept. Such variety of interpretations is visible in lack of unified means of hope assessment. The measurements used in scoping review cited studies were mostly connected with resilience, quality of life and burden of the disease. Only one study used a questionnaire dedicated to hope. The ecological approach underlines the necessity of holistic assessments of patients and their environment. Therefore, it would be reasonable to introduce the compound hope assessment tools.

Patients' environment should be understood as both: the human and material resources. The socio-economic factors connected both with the patient and caregiver are not always variable. If the basic needs of the dyad are met and work security are provided, the reported income is not statistically significant as a predictor of reported well-being [24]. High hope is not significantly related to intelligence or income. On the other hand, high hope individuals perceive obstacles as challenges and have higher adjustment rates if facing trauma [7]. The above can be questioned due to WEIRD (western, educated, industrial, rich, democratic countries) samples. A growing number of studies, also reported in current reviews, show similar patterns in minority groups and in different countries across the globe [38, 41]. The impact of the disease is much stronger in ethnic minorities and marginalised groups like: disabled people, the elderly and those less able due to underlining conditions.

More studies focus on the psychological aspects of the interaction between patient and caregiver [37-41, 43-44]. Resilience and hope are starting to be the focus of attention. In correspondence to Scioli and Biller's theory of patterns of hope [1], connections to religious and spiritual traditions reveal that hope is based on four basic human needs: connections/attachment, competence, survival, mastery and combination of the above [28, 42]. In the case of dementia patients' caregivers, all of these basic needs may be diminished due to extensive care devoted to the patients. The cited studies show the important role of hope, social connections, the need for understanding, and sense of self-efficacy. Scioli and Biller's model of hope is constructed on a four-part network: attachment, survival, mastery and spiritual subsystem. According to the current studies, it is essential to meet three categories of human need: connection, defence and advancement. Caregivers who report higher hope perceive less of an impact of the burden of the disease, seek social support or introduce a "good enough" attitude into everyday routine.

On the other hand, hope decreases if the person can no longer perform certain roles and/or experiences a loss of control [16]. Concurrent losses (health or income, loss of professional interest from others, lack of symptom control) decrease hope in patients but as well affect their significant others [46-47]. Care based on solicitude increases hope and the potential positive outcome of treatment. It is connected with compassion and empowering the patients. Such an attitude promotes social interactions and strengthens relationships.

The cited studies varied in terms of timing of the assessment. The majority of the studies focus on single-point assessment, whereas there is a growing need for longer observations. Not only in order to provide the necessary evidence for the effectiveness of the interventions, but to explain the mechanisms of patient and caregiver's well-being. Only two of the reported studies are longitudinal [27, 31].

According to the statistical data, most of the caregivers of dementia patients are the members of their family [22, 24-25]. The majority of them are women, some of whom are members of the so-called sandwich generation [23, 48]. In their case, it is important to remember that according to model of PERMA+4 positive emotions, engagement, relationships, meaning, accomplishment are the core factors of individual well-being. The recent modification of the model introduces +4: physical health, mindset (where hope is one of the factors), work environment, economic security [14]. According to the cited studies they are good predictors of life satisfaction in a sample of the general public, but as well among caregivers. It is important, the strength of these results is substantial [45].

Hope plays an important role as an individual's cognitive appraisal of internal and external resources. It determines the pursuit of a desired goal in connection with an adequate level of motivation and social support. Dispositional hope becomes an important foundation due to its baseline capacity for goal setting and pursuing when faced with barriers.

Interesting results have been brought to attention by neuroimaging studies. Observed neurocorrelates of high dispositional hope include greater spontaneous neuronal firing in the bilateral medial orbitofrontal cortices and negatively correlated with anxiety severity. Grater grey matter volume in the left supplementary motor area is correlated with greater satisfaction and higher hedonic balance ratings [27, 31].

Conclusions

Positive psychology and hope theory have been associated with samples of healthy young persons. Introducing them to the groups of healthy people dealing with the morbid illnesses of their loved ones may bring beneficial outcomes. Informal caregivers are the growing population worldwide, and their well-being should be of interest of all societies. They typically play the important roles at work, at home and within communities [24-25, 49]. Their mental health may be affected by the physical illness of the person they look after.

Currently available research shows the complexity of interactions between particular psychological features like hope, resilience, emotions and burnout, as well as within social groups. The proposed future interventions should be aimed not only at patients but should be adjusted to the needs of caregivers too. Strong interactions between caregivers and care recipients should be at the core of future investigations and interventions. Previously neglected features, such as hope, show strong potential for enhancing overall quality of life and efficiency of medical interventions. The burden of the disease is correlated with reported hope, resilience and quality of life. Understanding the exact direction of these interactions should be a focus of future research.

In order to accomplish this, the necessary steps need to be undertaken. Further work on protocols of hope assessment should be performed. It would be recommended to include in the assessment the ecological approach, as well as quantitative assessment of the cognitive and neuropsychological functions of the patients. The weakest point of currently available studies is the short time of observation whereas the interaction of factors influencing hope and well-being of patients and their caregivers are long-time processes.

Supplementary material:

Hope and burden of Alzheimer's Disease scoping review protocol:

1. Database choice. Due to interdisciplinary nature of the topic of interest three databases were chosen in which medical and psychological sciences are well represented. The literature search was conducted in: PubMed, ScienceDirect and Google Scholar.
2. Time limits. It was important to include the most recent articles therefore the timeline was set to 2015-2025.
3. Subjects' group. The aim of the review was to gather up-to-date information on burden of the Alzheimer disease so the filter of human subject was set if possible.
4. Main database filters. The time line was set in above-mentioned databases. It was not possible to set database filter of the subject species in Google Scholar nor ScienceDirect was applied.
5. Main topic database filters. The keywords chosen were: hope, theory of hope, resilience, burden of the disease Alzheimer. The operators used were AND/OR.
6. Inclusion criteria. The articles were included if the

following were met:
   a) The study was run with human subjects
   b) The study referred to resilience as a psychological trait
   c) The study referred to hope as a psychological construct
   d) The study was conducted with (the MCI/AD patients) OR (spouses or caregivers of MCI/AD patients)
7. Exclusion criteria. The articles were excluded if the following were met:
   a) The study was based on an animal model
   b) The study referred to resiliency as neuroplasticity, physical capability to remain composure to the external stimuli
   c) The study referred to hope as a common phrase like "We hope our study…"
   d) The study was conducted on different disease than MCI/AD
8. Searching strategy. After applying the timeline filter (and specie in PubMed) the single keyword searches was run. The initial search yielded:
   a) PubMed- hope 39046; theory of hope 1182; resilience 34369; burden of the disease Alzheimer 4548;
   b) ScienceDirect- hope 192233; theory of hope 70205; resilience 119923; burden of the disease Alzheimer 21673;
   c) Google Scholar- hope 2100000; theory of hope 634000; resilience 1300000; burden of the disease Alzheimer 180000

   Compound searches produced fewer results of publications:
   a) PubMed- hope 39046; theory of hope 1182; resilience 34369; burden of the disease Alzheimer 4548;
   b) ScienceDirect- hope 192233; theory of hope 70205; resilience 119923; burden of the disease Alzheimer 21673;
   c) Google Scholar- hope 2100000; theory of hope 634000; resilience 1300000; burden of the disease Alzheimer 180000
9. Source type. Additional filter of article type was applied on the compound results. The results contained: meta-analyses, research articles, review articles and mini reviews.
   a) PubMed- 205 records
   b) ScienceDirect- 364 records
   c) Google Scholar- it is not possible to filter specific article type. Possible filters are "all" and "reviews". The "review" filter was applied. The record was still very high: theory of hope AND resilience 18900; (theory of hope OR resilience) AND burden of the disease Alzheimer 9430; (theory of hope AND resilience) AND burden of the disease Alzheimer 1620. The relevancy filter was applied. The author decided to check if the high number is connected with false positive results due to imprecise algorithm of search inbuilt within the search engine. Random selection of 30 articles fulfilling the title and abstract screening (in each of the compound criteria) were checked for full-text screening. Unfortunately due to the high percentage of false positives (hope as a part of common phrase "We hope our research…") the database was discarded. It was impossible to apply any other relevant filters that would increase the correctness of the search.
10. Duplicate records removal. The records obtained in PubMed and ScienceDirect search were crossed-referenced for duplicates. In total 25 duplicates were removed.
11. Initial source articles eligibility screen. Of the 544 source articles 264 contained "hope" only as a figure of speech not as a variable described in the study.
12. Title and abstracts screening. The total of 240 articles were removed due to lack of fulfilment of eligibility criteria. Most of the rejected articles were run on animal model.
13. Full text screening. In 12 source articles resiliency referred to a protective factor of cognitive decline. In 8 articles subject group consisted only of professional caregivers.
14. Final criteria met 18 articles gathered in main search sample and 2 articles obtained with snowballing procedure.
15. All steps were conducted solely by the author.

Conflict of interest

The authors have declared no conflict of interest.

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