

An All-Inclusive Model of Variables Linked to Subjective Views of “Living Well” With Alzheimer’s.

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ABSTRACT

Introduction : Finding the proportional contributions of life domains linked to the subjective experience of living well was our goal in trying to better understand what predicts the ability to “live well” with dementia.

Methods : Our analysis included 1547 members of the IDEAL cohort who had mild-to-moderate dementia. Utilizing metrics for well-being, life satisfaction, and quality of life, we created a latent factor called “living well.” The living well measures were correlated with factors that we found using multivariate modeling, and the relationships between the living well and five different life domains were investigated using structural equation modeling to extract latent variables.

Results : Each of the five domains was connected to leading a fulfilling life. The psychological traits and psychological health domain together were the only factors that could be used to predict living well (effect size: 3.55; 95% confidence interval (CI): 2.93-4.17). The effect sizes for physical health and fitness (1.23; 95% CI: -0.10 to 2.58), social capitals, assets, and resources (0.67; 95% CI: -0.04 to 1.38), coping with dementia in daily life (0.33; 95% CI: -0.06 to 0.71), and social location (0.08; 95% CI: -2.10 to 2.26) were smaller.

Discussion : The social, environmental, and physical elements that support good psychological states as well as psychological resources could be significant targets for programs and interventions aimed at enhancing the quality of life for those with dementia.

Keywords : quality of life, satisfaction with life, well-being, Alzheimer

In order to effectively manage long-term sickness and impairment, one must attain “the best feasible state of health that incorporates all dimensions of physical, mental, and social well-being,” which is demonstrated by “a self-perceived level of comfort, both functionality and life satisfaction.”¹ (p32) The idea of living well is now commonly used to communicate the idea that it is possible—or should be—to have a subjective feeling of “comfort, function, and contentment with life” while dealing with dementia. It is cited in policy documents and publications relevant to the condition^{2,3}. This illustrates a shift away from a focus on “deficits” and symptoms and toward a more comprehensive approach that recognizes the rights and personhood of individuals with dementia, facilitates their maximum functioning, and encourages their involvement and inclusion.

The subjective feeling of living well is commonly associated with having a high quality of life (QoL) in the context of study. A person’s “perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns” are represented by the broad construct of 4 QoL, which is influenced by a person’s “physical health, psychological state, level of independence, social relationships, personal beliefs, and relationship... to the natural world.”⁵ (page 153).

Similar to this, theoretical models of quality of life in dementia highlight the impact of numerous psychological, social, environmental, and cultural elements. Six Other possible measures of a Measures of subjective well-being and life satisfaction include a sense of “comfort, function, and contentment with life.”

Contentment with life comprises assessing one’s life as a whole, whereas subjective well-being is the result of experiencing a suitable equilibrium between happy and unhappy feelings.⁷ One way to conceptualize well-being is as a condition of balance or equilibrium that is influenced by obstacles or events in life.⁸ Less research has been done on these factors in connection to dementia.

Several independent variables have weak relationships with self-rated quality of life when measured simultaneously, but relatively few variables show moderate relationships, according to a recent systematic review⁹. They are mostly social or psychological in nature; in this review, depression was shown

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to be moderately linked with lower quality of life (effect size, -0.31), whereas higher levels of social engagement (0.31) and positive relationships with caregivers (0.38) were found to be moderately associated with higher quality of life. Just a tiny percentage of the variation in QoL scores is explained by models that combine multiple independent factors, primarily symptoms, comorbidity, and basic demographic criteria. ten to twelve Thus, the research currently available offers little advice regarding factors affecting quality of life or potential avenues for enhancing the experience of having dementia. This points to the need for two things: first, a more complete approach to modeling the elements associated with the capacity to "live well" with dementia; and second, a broader perspective on "living well" with dementia that is consistent with important definitions and theoretical models. This need has been partially addressed by the establishment of the Improving the experience of Dementia and Enhancing Active Life (IDEAL) cohort study^{13,14}, which uses a conceptual framework created theoretically as a basis for studying different influences on living effectively with dementia. According to this paradigm, the likelihood of leading a fulfilling life is determined by and represents the harmony between, the distinct resources that every individual contributes to the circumstance and the specific difficulties encountered. A person's resources are all of their combined experiences and skills. with the social capitals, assets, and resources available today in the fields of psychology, economics, socioenvironment, and physicality.^{15, 16} Challenges are the effects of the handicap brought on by the onset and advancement of dementia on a person's social, physical, mental, and economical life.¹⁷ Here, we use data from the IDEAL initial interviews to model how people with mild-to-moderate dementia living in community settings perceive their ability to "live well" with the condition in relation to the social, psychological, and physical resources they can use, as well as the unique challenges they face during the onset and progression of the condition.

METHODS

Design

in the domains of psychology, economics, socioenvironment, and physicality, with the social capitals, assets, and resources at hand.^{16, 15} Challenges are the consequences of the impairment caused by the beginning and progression of dementia on an individual's mental, physical, social, and financial well-being.¹⁷ In this case, we model how community-dwelling individuals with mild-to-moderate dementia view their capacity to "live well" with the condition in light of the available social, psychological, and physical resources and the particular difficulties they encounter as the condition develops. The data from the IDEAL initial

interviews is used in this model.

Participants

Between July 2014 and August 2016, participants were gathered via the NHS memory services, other specialized clinics, and the UK Joint Dementia Research portal (www.joindementiaresearch.nihr.ac.uk). The Mini-Mental State Examination¹⁸ score of ≥ 15 and a clinical diagnosis of dementia (any subtype) were the only requirements for inclusion. Participants also had to be living in the community at the time of enrollment, excluding those with terminal illnesses, those unable to give informed consent, and any known risk that home visits would pose to researchers. A total of 3105 dementia sufferers were contacted regarding participation; 363 of them were deemed ineligible, and 1106 of them declined. Of the 1636 who gave their consent, 81 withdrew and 8 later proved to be ineligible. This had the effect of in a sample of 1547 dementia patients (a response rate of 57% among dementia patients who met the eligibility criteria). A family member or other informal caregiver who consented to participate in the study was present in the majority of participants (1283, 82.9%), and 1045 (67.6%) of them shared a residence with the participating caregiver.

Metrics for Assessing "Live Well" Capability

According to people with dementia, living well was defined as including subjective assessments of quality of life, life satisfaction, and overall wellbeing. Higher scores imply more favorable perceptions of QoL. The 13-item Quality of Life in Alzheimer Disease measure (QoL-AD)^{19,20} was used to assess QoL. Responses to each item were given on a 4-point scale (1 to 4) and the scores were summed to create a total score out of 52. The 5-item Satisfaction with Life Scale (SwLS) was used to measure life satisfaction. better scores indicate better satisfaction. 21 items are assessed on a 7-point scale (1 to 7), and responses are added up to provide a total score out of 35. The World Health Organization-Five Well-Being Index (WHO-5) was used to measure well-being.²² responses have a 6-point rating. scale (0–5), added together to yield a total score out of 25, and then multiplied by four to yield a score out of 100. better scores suggest better levels of well-being.

Metrics of the Resources and Difficulties That May Be Related to "Living Well"

Our framework is based on definitions of "living well" and theoretical models of quality of life in dementia. The domains of psychological traits and psychological health (such as personality, optimism, loneliness, and depression), physical fitness and physical health (such as exercise, diet, and vision), social capitals, assets, and resources (such as education, income, cultural capital, and social networks), and social location (perceptions of one's place in society, such as social

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class, social status) are all included in the terms of resources. There are difficulties in managing day-to-day living with dementia (e.g., cognition, functional capacity), as well as associated symptoms and their impacts.

Details regarding the variables taken into account in each domain and their methods of measurement can be found in Supplementary Table 1 (Supplemental Digital Content 1, <http://links.lww.com/WAD/A210>). All information was derived from self-report.

Statistical Methods

A phased method was used to conduct the analysis. We looked at potential factors within each area in relation to clinical relevance as well as statistical significance. The Wald test was used to examine statistical significance. To be deemed clinically relevant, an unstandardized regression coefficient's effect size had to be greater than 1.5 for QoL-AD or SwLS and greater than 5 for WHO-5. Within each domain, preliminary analysis was conducted in relation to the multivariate outcome (QoL-AD, SwLS, and WHO-5). A multivariable, multivariate analysis includes factors that were determined to be significant in a univariable investigation. In order to simplify the model, variables were recoded (from groups to binary variables, or from continuous to ordinal groups), but effect sizes remained the same. To account for the missing response data, multiple imputation using chained equations was used. Age, sex, and dementia subtype were adjusted for in the full model by regressing the latent variables representing the five domains on the living well latent factor. The parameters of the model are designed to highlight favorable correlations that point to improved living conditions. If there was no zero in the 95% confidence interval (CI) of a coefficient estimate, it was considered significant. More information on statistical methodologies can be found in the Supplementary Section (Supplemental Digital Content 1, <http://links.lww.com/WAD/A210>).

RESULTS

Participants Characteristics

summarizes the 1547 participants' attributes and their results on the three living well measures. The overall mean scores and standard deviations for QoL-AD were 36.8 (5.9), SwLS was 26.1 (6.1), and WHO-5 was 60.9 (20.6). The mean ratings were lower for younger individuals, those with Parkinson disease dementia, and those with dementia with Lewy bodies, but there were no variations based on sex.

Factors Incorporated into the Analysis

lists the variables that were chosen for each domain using univariable multivariate modeling. Comprehensive information regarding the modeling stages can be found in

Supplementary (Supplemental Digital Content 1, <http://links.lww.com/WAD/A210>).

Connections Among the Hidden Variables

illustrates the association between each domain and the living well latent; more information, including correlations between domains, is given in Supplementary Table 3 (Supplemental Digital Content 1, <http://links.lww.com/WAD/A210>). For the psychological characteristics and psychological health domain, the individual associations with living well were 4.86 (95% CI: 4.54-5.18), for social location, -4.66 (95% CI: -5.72 to -3.60), for physical fitness and physical health, 2.83 (95% CI: 2.23-3.44) for social capitals, assets, and resources, and 1.98 (95% CI: 1.61-2.35) for managing daily life with dementia. The model reveals that the psychological traits and psychological health domain were most substantially associated with living well (3.55; 95% CI: 2.93-4.17) after multiple imputation analysis and after correction. The effect sizes for the other domains were as follows: managing daily life with dementia: 0.33; 95% CI: -0.06 to 0.71; social location: 0.08; 95% CI: -2.10 to 2.26; physical fitness and physical health: 1.23, 95% CI: -0.01 to 2.58; social capitals, assets, and resources: 0.67; 95% CI: -0.04 to 1.38). When these variables were combined with the psychological traits and psychological health domain, they did not independently correlate with a happy existence. The psychological and physical domains have particularly substantial connections (>0.7) with social location when the correlations between the latent components for the five domains are examined.

Effects of Score Modifications on Living Well Measures

display the corresponding change in scores on the outcome variables, these effects from the standardized analysis were converted back. We show the changes in living well measure scores that correspond with each unit rise in the latent score for each domain. According to these findings, which are displayed in Table 3, a 1 unit increase in psychological traits and psychological health was linked to an

DISCUSSION

Utilizing information from 1547 individuals with mild-to-moderate dementia who took part in the IDEAL project, we have developed a thorough model of the variables linked to the perception of being able to live well with dementia, which is defined as balancing difficulties and resources. IDEAL is one of the only large-scale research that examines how persons in the mild-to-moderate stages of dementia who live in the community—with or without the assistance of a caregiver—perceive their ability to live well with the condition. It stands out for integrating the concepts of quality of life, life satisfaction, and well-being to offer a comprehensive assessment of living

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well across a broad spectrum of psychological, physical, social, and environmental aspects.

evaluated, and in selecting a research population from a variety of socially and ecologically many regions of Great Britain. This model demonstrates that when domains are taken into account separately, the domains of psychological traits and psychological health are most strongly linked to concurrent perceptions of living well, followed by social locations and physical fitness and physical health. The domains of social capitals, assets, and resources, as well as managing daily life with dementia, showed relatively smaller effect sizes. The psychological domain in the model is dominating when all domains are taken into account. Upon being consulted regarding the model, the members of the ALWAYSs involvement group felt that it was reasonable, easy to comprehend, and supported their perception of the critical elements that contributed to their capacity to manage the disease properly. numerous areas of the United Kingdom. This model shows that when domains are considered independently, concurrent judgments of living well are most highly correlated with the domains of psychological traits and psychological health, followed by social places and physical fitness and physical health. Relatively smaller effect sizes were observed in the domains of managing daily life with dementia and social capitals, assets, and resources. When considering all of the domains in the model, the psychological domain is dominant. After consulting with each other about the model, the ALWAYSs participation group members said it made sense, was simple to understand, and validated their understanding of the essential components that enabled them to effectively manage the illness.

Our approach's merits are found in the comprehensive model we give, which reflects the relative connections between five unique categories of latent factors and subjective evaluations of the ability to live well with dementia. This model is based on a sizable sample of individuals with mild-to-moderate dementia.

A thorough analysis of the missing data and repeated imputation adjustments were part of the modeling process. Both the measured variables and the outcomes showed missing data; the percentage of missing data for QoL-AD was greater at 9.4%, compared to low levels (<3%) for the SwLS and WHO-5.

Continuous, ordinal, and binary variables were all supported by the maximal information modeling technique.

There are a few restrictions to take into account. It is not possible to determine the causation direction of our investigation since it only evaluates the effects of factors related to living well at the same timepoint. While every variable had the potential to be significant, a certain amount of selection was necessary in order to develop the model.

In the initial stage of modeling, some factors did not exhibit statistical significance despite the high sample size, or they showed significance but were deemed less clinically relevant. The components that shown domain-specific relationships were the ones that remained within the latent structure. Therefore, it's possible that certain little effect sizes were overlooked during the last modeling phase. A few elements evaluated in IDEAL lacked linear properties, making them unsuitable for inclusion in structural equation modeling.

Relationships with indicators of a healthy lifestyle. Some variables, like judgments of the strength of the relationship with the carer, were removed because they were only available to individuals who had a participating caregiver. Some, like pain in the physical health domain, were only available through single questions incorporated into other measures, making them less conducive to inclusion. Further research has to be done on these variables. The dementia participants' self-ratings form the basis of our model. Although there have been worries in the past about the possible impact of a lack of awareness on self-ratings of variables like quality of life, prior research has demonstrated that awareness differences are not very significant in this regard.¹² The reliability of self-ratings that represent the subjective opinions of those suffering from mild to moderate dementia is The results of this study imply that addressing many social issues in addition to enhancing physical and psychological health may help people with dementia live better. All five domains and each individual factor within the five domains were separately connected with the perceived ability to live well with dementia, even though positive changes in factors within the psychological domain are anticipated to yield the biggest gains in living well ratings. Every area has a number of changeable factors, even though some are unlikely to be amenable to intervention. For instance, even though some traits—like dispositional optimism and the personality trait of neuroticism—are covered by the variables contained in the psychological characteristics and psychological health domain, they might not be direct targets for intervention. other factors like Loneliness and despair may present greater opportunities for transforming; when feasible, enhancing physical health; and Improving people's ability to live well may also result from helping them manage their disabilities more skillfully. social elements that influence on psychological experience may also offer quick possibilities for intervention; for instance, neighborhood trust building, social engagement, and isolation management initiatives could aid in the treatment of depression and loneliness. Our results also point to the possibility of creating an integrated method of outcome evaluation that takes demands and experiences into account. by developing a new scale to measure "living well" with dementia in individuals with the disease. Our findings highlight the significance of considering both disease-related and various personal and societal aspects that have an impact

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on a person's ability to "live well" with dementia. Ultimately, this research offers fresh insights into the variables linked to the subjective perception of a well-lived life with mild-to-moderate dementia and suggests avenues for early intervention. The domains of physical fitness and health, social capitals, assets, and resources, managing daily life with dementia, and social location all contribute to the overall evaluation of living well when taken into account individually. We have adopted a broad perspective on living well and demonstrated that, while in a combined analysis the domain of psychological characteristics and psychological health is most strongly associated with living well. New methods for improving the capacity to live well with dementia will be produced by a deeper comprehension of the role played by these diverse psychological and social elements.

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REFERENCES

1. Institute of Medicine. Living Well With Chronic Illness: A Call for Public Health Action. Washington: National Academies Press; 2012.
2. UK Department of Health. Living Well With Dementia: A National Dementia Strategy. London: Department of Health; 2009.
3. ESRO. A Good Life With Dementia. London: ESRO; 2014.
4. Small N. Living well until you die: quality of care and quality of life in palliative and dementia care. *Ann N Y Acad Sci*. 2007;1114: 194–203.
5. World Health Organization Quality of Life (WHOQOL) Group. Study protocol for the World Health Organization project to develop a Quality of Life assessment instrument (WHOQOL). *Qual Life Res*. 1993;2:153–159.
6. Lawton MP. Quality of life in Alzheimer disease. *Alzheimer Dis Assoc Disord*. 1994;8(suppl 3):138–150.
7. Diener E, Chan MY. Happy people live longer: subjective well being contributes to health and longevity. *Appl Psychol Health Well-Being*. 2011;3:1–43.
8. Dodge R, Daly AP, Huyton J, et al. The challenge of defining wellbeing. *Int J Wellbeing*. 2012;2:222–235.
9. Martyr A, Nelis SM, Quinn C, et al. Living well with dementia: a systematic review and correlational meta-analysis of factors associated with quality of life, well-being and life satisfaction in people with dementia. *Psychol Med*. 2018;48:2130–2139.
10. Naglie G, Hogan DB, Krahn M, et al. Predictors of patient selfratings of quality of life in Alzheimer disease: cross-sectional results from the Canadian Alzheimer's Disease Quality of Life Study. *Am J Geriatr Psychiatry*. 2011;19:881–890.
11. Selwood A, Thorgrimsen L, Orrell M. Quality of life in dementia—a one-year follow-up study. *Int J Geriatr Psychiatry*. 2005;20:232–237.
12. Woods RT, Nelis SM, Martyr A, et al. What contributes to a good quality of life in early dementia? Awareness and the QoL-AD: a cross-sectional study. *Health Qual Life Outcomes*. 2014;12:94.
13. Clare L, Nelis SM, Quinn C, et al. Improving the experience of dementia and enhancing active life—living well with dementia: study protocol for the IDEAL study. *Health Qual Life Outcomes*. 2014;12:164.
14. Silarova B, Nelis SM, Ashworth RM, et al. Protocol for the IDEAL-2 longitudinal study: following the experiences of people with dementia and their primary carers to understand what contributes to living well with dementia and enhances active life. *BMC Public Health*. 2018;18:1214.
15. Ferlander S. The importance of different forms of social capital for health. *Acta Sociologica*. 2007;50:115–128.
16. Savage M, Warde A, Devine F. Capitals, assets, and resources:somecriticalissues.*BrJ Sociol*.2005;56:31–47 .

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17. Verbrugge LM, Jette AM. The disablement process. *Soc Sci Med*. 1994;38:1–14.
18. Folstein MF, Folstein SE, McHugh PR. "Mini-mental state." A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res*. 1975;12:189–198.
19. Logsdon RG, Gibbons LE, McCurry SM, et al. Quality of life in Alzheimer's disease: patient and caregiver reports. In: Albert SM, Logsdon RG, eds. *Assessing Quality of Life in Dementia*. New York, NY: Springer; 2000:17–30.
20. Logsdon RG, Gibbons LE, McCurry SM, et al. Assessing quality of life in older adults with cognitive impairment. *Psychosom Med*. 2002;64:510–519.
21. Diener E, Emmons RA, Larsen RJ, et al. The Satisfaction With Life Scale. *J Pers Assess*. 1985;49:71–75.
22. Bech P. Measuring the dimension of psychological general well being by the WHO-5. *Qual Life Newslett*. 2004;32:15–16.
23. Clare L, Woods RT, Nelis SM, et al. Trajectories of quality of life in early-stage dementia: individual variations and predictors of change. *Int J Geriatr Psychiatry*. 2014;29:616–623.
24. Kobau R, Snizek J, Zack MM, et al. Well-being assessment: an evaluation of well-being scales for public health and population estimates of well-being among US adults. *Appl Psychol Health Well-Being*. 2010;2:272–297.
25. Topp CW, Østergaard SD, Søndergaard S, et al. The WHO-5 Well-Being Index: a systematic review of the literature. *Psychother Psychosom*. 2015;84:167–176.
26. Banerjee S, Samsi K, Petrie CD, et al. What do we know about quality of life in dementia? A review of the emerging evidence on the predictive and explanatory value of disease specific measures of health related quality of life in people with dementia. *Int J Geriatr Psychiatry*. 2009;24:15–24.
27. Dröes RM, Chattat R, Diaz A, 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.