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CLINICAL INVESTIGATION

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Life satisfaction among persons living with dementia and those without dementia

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Abstract

Background: Despite possible major adverse cognitive, physical, social, and behavioral consequences, little is known about how persons living with dementia perceive satisfaction with life, a key component of well-being. We sought to examine (i) whether persons living with dementia perceive a lower level of satisfaction compared to their peers without dementia and (ii) whether the associations between individual characteristics and life satisfaction are different between persons living with and without dementia.

Methods: Using a nationally representative sample of community-dwelling older adults aged ≥70 years in the U.S. from the Health and Retirement Study, we compared scores on the Satisfaction with Life Scale (SWLS), a self-reported 5-item scale ranging from 1 to 7 (more satisfaction), between persons with probable dementia ($n = 341$) and those without ($n = 5530$), adjusting for individual characteristics. We also tested whether the associations between the individual characteristics and SWLS differ by dementia status.

Results: Scores on SWLS did not differ between persons with probable dementia and those without when adjusting for individual characteristics including limitations in activities of daily living (ADL) (adjusted difference, −0.09; 95% CI, −0.33 to +0.15; p-value, 0.45). However, dementia status was associated with lower life satisfaction through the mediation of limitations in ADL (total effect, −0.29; bootstrapped 95% CI, −0.47 to −0.12). Most individual characteristics associated with lower life satisfaction were similar in the two groups, including younger age, more limitations in ADL, and depression. Less wealth was associated with lower satisfaction among persons without dementia but not among those with probable dementia.

Conclusions: Dementia status was only modestly associated with lower life satisfaction through the mediation of limitations in ADL among participants who were able to provide response. Future research is warranted to determine whether life satisfaction can be used as a meaningful outcome when evaluating well-being among persons living with dementia.

The content of the manuscript has never been presented in professional meetings.

KEYWORDS
dementia, life satisfaction, well-being

BACKGROUND

Given that there are currently no cures for dementia and effective treatments are limited, promoting well-being is one of the primary goals in caring for persons living with dementia.[1,2] Although there is no single, widely-accepted definition, well-being typically focuses on positive aspects of life and refers to "judging life positively and feeling good."[3,4] In the ongoing efforts to conceptualize well-being and its associated measurement in persons living with dementia, life satisfaction—a general sense of valuing life—has been identified as one of the key domains.[5]

Quality of life has been used as a key outcome for persons living with dementia, and various dementia-specific instruments have been developed. However, most measures primarily focus on symptoms and deficits in functioning and may not represent the well-being of persons living with dementia.[2,5,6] For example, the Quality of Life–Alzheimer's Disease (QOL-AD) Scale, one of the most frequently employed measures in this setting,[2,7] assesses physical health, memory, and activities of daily living (ADL), which inherently decline as the disease progresses. Moreover, multiple reviews suggested that the concept of quality of life in dementia is unsettled and each instrument evaluating the quality of life uses a different conceptual framework.[8–10] As a result, there are considerable variations in instruments in terms of domains covered (e.g., some subsume well-being or life satisfaction within one domain), type of respondent (self-, proxy-report, or both), and settings (e.g., community-dwelling, institutionalized).[5,8–10] Given these limitations, a new meaningful outcome measure for persons living with dementia focusing on positive constructs is called for.[5,11,12]

Life satisfaction is assumed to be a summary evaluation of many concrete areas of life, such as health, income, family, social relationships, and leisure ("bottom-up" theory).[13,14] Based on this theory, persons living with dementia may perceive a lower level of life satisfaction compared to their peers without dementia because persons living with dementia inevitably experience progressive cognitive, functional, behavioral, and psychological challenges. One study reported that individuals with dementia had modestly lower life satisfaction than those with normal cognition.[15] While informative, this study examined a small number of Canadians with dementia from the 1990 s. Further characterization of life satisfaction among persons living with dementia can potentially lead to future use of this measure as a meaningful outcome in clinical trials and treatments.

Key points

- Persons living with dementia who can provide responses rate life satisfaction similarly to those without dementia after adjusting for individual characteristics.
- Most individual characteristics associated with lower life satisfaction were similar in persons with and without dementia.

Why does this paper matter?

Our findings may inform future use of life satisfaction as a meaningful outcome when evaluating well-being among persons living with dementia.

Moreover, to our knowledge, no study to date has examined whether factors associated with lower life satisfaction differ between older adults with and without dementia. Prior studies suggest that a lack of social support, loneliness, depression, lower education, severe cognitive impairment, and functional limitations are associated with lower life satisfaction among persons living with dementia.[16–18] Understanding the differences in life satisfaction between older adults with and without dementia and identifying potentially modifiable factors may inform the design of interventions to treat persons living with dementia.

To address these knowledge gaps, using a U.S. nationally representative sample, we sought to (i) test our hypothesis that persons living with dementia who could rate their life satisfaction perceive a lower level of satisfaction compared to their peers without dementia and (ii) examine whether associations between individual characteristics and life satisfaction are different between older adults with and without dementia.

METHODS

Data source and study participants

We used the data from the 2012 and 2014 waves of the Health and Retirement Study (HRS), a nationally

representative longitudinal survey of adults aged 51 years and older.[19] Every 2 years until death, HRS participants undergo "core" face-to-face interviews that collect information about demographics, physical and cognitive function, and medical conditions (a proxy is allowed to assist with interviews).[19] In addition, participants are asked to complete and return by mail a supplemental hardcopy survey called Psychosocial and Lifestyle Questionnaire (PLQ).[20] PLQ collects information about participants' evaluations of their life circumstances, subjective well-being, and lifestyle.[21] If proxies assisted the respondents, this was indicated in the survey. PLQ utilizes a rotational study design containing two equally sized samples that are surveyed once every 4 years (e.g., one-half of the HRS longitudinal panel received the PLQ in 2012, and the other half received it in 2014). Response rates of HRS core interviews were 89.1% in 2012 and 87.1% in 2014,[22] while the response rates of the PLQ were 72.7% in 2012 and 77.8% in 2014.[21]

We first categorized the HRS participants eligible for the PLQ in 2012 and 2014 into two groups (i) individuals with probable dementia ("probable dementia group") and (ii) those without probable dementia ("non-dementia group") and then identified those who completed the PLQ by themselves for each group. Probable dementia was defined as the probability of dementia of 50% or greater, which was calculated and provided by HRS researchers using the information from the HRS core interviews, such as cognitive batteries (e.g., backward counting from 20 and delayed word recall) and self-reported difficulty in ADL.[23,24] The cut-off of 50% has been demonstrated to classify 88% of participants correctly and employed in previous studies.[25,26] In HRS, the probability model for dementia was validated and calculated only for participants aged 70 and older with self-reported race/ethnicity of non-Hispanic white, non-Hispanic black, or Hispanic. Therefore, we excluded those less than 70 years and those with other self-reported race/ethnicity groups. We also excluded participants who were living in a nursing home at the time of the interview and/or those whose PLQ was completed by a proxy because HRS assigns zero weights to these participants. We also excluded participants with missing data on essential variables. See Figure 1 for a flow chart.

To examine the response rate to PLQ by the severity of dementia, we defined the severity of dementia (mild, moderate, or severe) based on the Clinical Dementia Rating (CDR), a commonly used dementia severity

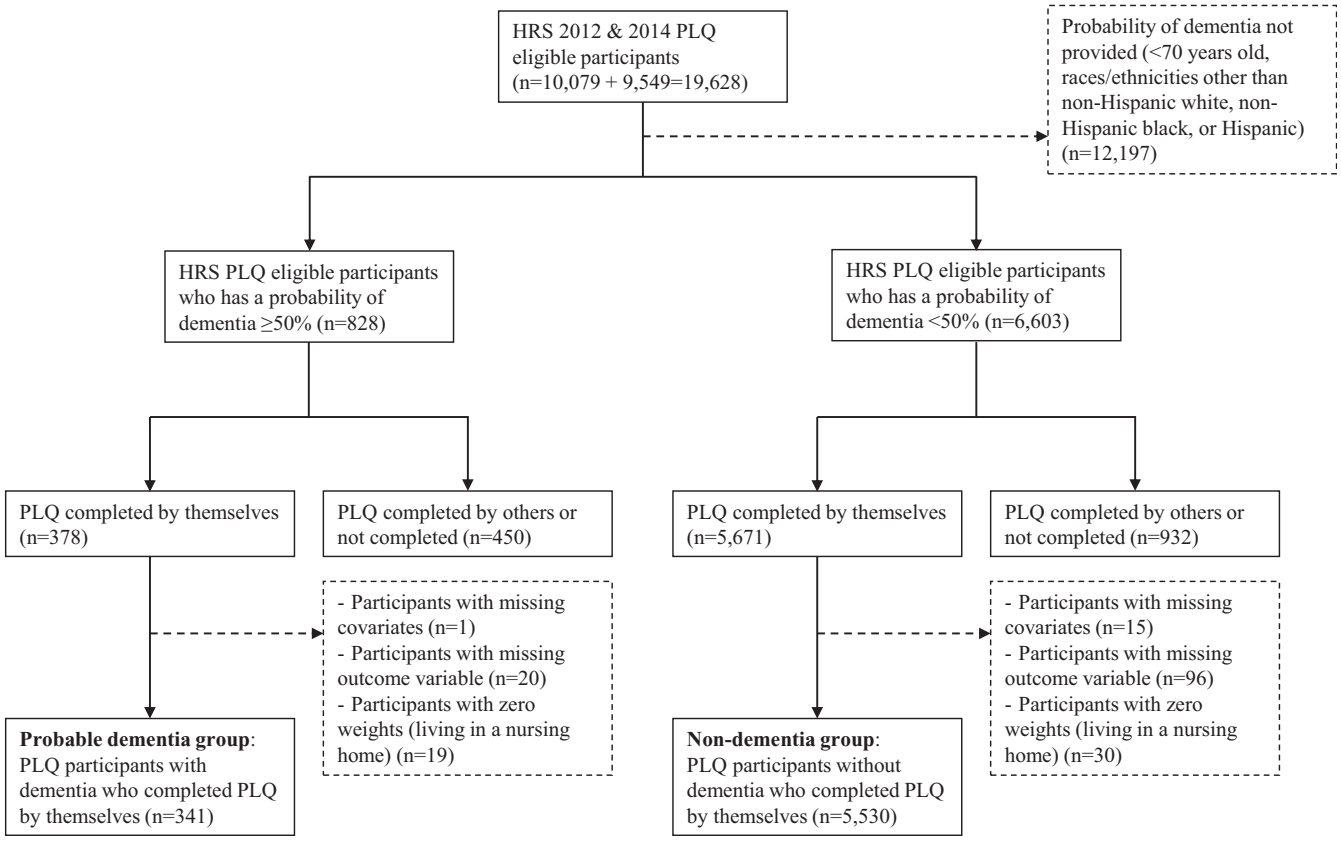

FIGURE 1 Flow chart for the study population. HRS, Health and Retirement Study; PLQ, Psychosocial and Lifestyle Questionnaire.

scale, using the information on ADL in HRS (see Methods S1 for more details).[27]

Outcome variable

HRS collected the Satisfaction with Life Scale (SWLS), a well-established measure of satisfaction with life as a whole.[28] Participants were asked to rate their agreement on a 7-point scale (1 = Strongly disagree, 2 = Somewhat disagree, 3 = Slightly disagree, 4 = Neither agree nor disagree, 5 = Slightly agree, 6 = Somewhat agree, 7 = Strongly agree) to each of the following five statements: (1) In most ways my life is close to my ideal; (2) The conditions of my life are excellent; (3) I am satisfied with my life; (4) So far I have gotten the important things I want in life; and (5) If I could live my life over, I would change almost nothing. We calculated the SWLS by averaging the scores across all five items (i.e., SWLS ranges from 1 to 7, with a higher score indicating more satisfaction).[21,29] The HRS reported Cronbach's Alpha of 0.88 and 0.89 using the data from the HRS participants in 2012 and 2014.[21]

Exposure variables

Our primary exposure variable of interest was dementia status (i.e., probable dementia vs. non-dementia groups). We also included the following exposures variables in our regression models: age group (70–79, 80–89, or 90+), sex (male or female), self-reported race/ethnicity (non-Hispanic White, non-Hispanic Black, or Hispanic), educational attainment (less than high school versus more), wealth categorized in quartiles (defined as the net value of total wealth including secondary residence less all debt), whether a participant was covered by Medicaid, composition of a social network (described below), basic activities of daily living (BADL) limitation score (as a categorical variable of 0, 1–3, or 4–6), instrumental activities of daily living (IADL) limitation score (as a categorical variable of 0, 1–3, or 4–5), dummy variables for each of eight comorbidities (heart disease, hypertension, diabetes, lung disease, arthritis, stroke, cancer, and depression), whether a participant had a usual source of care, and whether a participant stayed in a hospital overnight over the last 2 years. We also included geographic location (categorized into nine Census divisions and foreign countries) as fixed effects. While most factors are not modifiable, ADL and composition of a social network might be potentially modifiable.

Composition of a social network was categorized into three categories (0, 1–2, or 3–4) based on the number of affirmative responses to the following four questions[21]: (1) Do you have a husband, wife, or partner with whom you live? (2) Do you have any living children? (3) Do you have any other immediate family, for example, any brothers or sisters, parents, cousins, or grandchildren? (4) Do you have any friends? A BADL limitation score was defined as the number of basic daily activities requiring assistance out of six activities (walking, toileting, bathing, transferring, eating, and dressing) based on self-report. An IADL limitation score was defined as the number of instrumental daily activities requiring assistance out of five activities (preparing meals, shopping for groceries, making phone calls, taking medications, and managing money) based on self-report.

While we defined seven comorbidities (heart disease, hypertension, diabetes, lung disease, arthritis, stroke, and cancer) based on self-reports, depression was assessed using the eight-item Center for Epidemiological Studies Depression (CES-D) scale.[30,31] Participants were asked whether they experienced eight specific symptoms (i.e., I felt depressed; I felt everything I did was an effort; My sleep was restless; I was happy; I felt lonely; I enjoyed life; I felt sad; I could not get going) for much of the past week. We defined depression by the number of endorsed symptoms (positive symptoms were reverse-coded) of four or more.[32]

Statistical analysis

First, we estimated a multivariable linear regression model to compare SWLS between probable dementia versus non-dementia groups, adjusting for other exposure variables.

Second, because dementia status may affect life satisfaction through impairment in BADL and IADL, we conducted a mediation analysis using the causal mediation approach.[33,34] We implemented mediation models using the PARAMED command in Stata to decompose the effects of dementia status on life satisfaction into direct effects and indirect effects mediated by impairment in BADL and IADL.[35,36] We estimated the controlled direct effect, natural indirect effect, and total effect, using linear regression models controlled for covariates as well as bias-corrected bootstrap confidence intervals. In order to implement the PARAMED command, we used a continuous variable for age and dummy variables for categorical variables (the command only allows continuous variables) as well as a summary ADL limitation score by summing BADL and IADL limitation scores (the command does not allow multiple mediators). In addition, we were unable to account for the complex survey design of HRS because the command does not allow it.

Third, we examined whether the associations between the individual characteristics and SWLS differ by dementia status. To do so, we first estimated multivariable linear regression models to evaluate the association between individual characteristics and SWLS for probable dementia and non-dementia groups separately, then estimated *p*-values for the interaction terms between dementia status and all the individual characteristics using the total sample.

Lastly, as a sensitivity analysis, we additionally fit a linear regression model similar to the main analysis but the main exposure variable being a categorical variable for dementia severity (no dementia, mild, moderate, or severe dementia). We did not include BADL or IADL limitation score in the model because we defined the severity of dementia using the information on ADL.

All analyses accounted for the complex survey design of HRS using survey weights specified for PLQ participants (except for the mediation analysis as described above).[37] Statistical analyses were conducted using SAS version 9.4 and Stata/MP version 16.1 with two-sided tests and a significance level of 0.05. This study was deemed exempt by the Cedars-Sinai Institutional Review Board.

RESULTS

Of the 7431 participants who were eligible for 2012 and 2014 HRS PLQ and had the probability of dementia assessed, 828 (11.1%) had probable dementia (Figure 1). Only 378 (45.7%) of the 828 participants with probable dementia completed PLQ by themselves whereas 5671 (85.9%) of the 6603 participants without dementia completed the PLQ by themselves. The proportions of participants with probable dementia who completed PLQ by themselves varied by the severity of dementia; 67.8%, 51.2%, and 24.3% of those with mild, moderate, and severe dementia, respectively, were able to do so. After excluding participants with a missing SWLS (outcome variable) or zero-weights, the analyses included 5871 participants, of whom 341 (5.8%) had dementia (Figure 1).

Characteristics of the study population by dementia status

Participants in probable dementia group were older, were less likely to be male or non-Hispanic white, had less education and wealth, had smaller social networks and more limitations in ADL, and were more likely to have stroke and depression, compared to those in the non-dementia group (Table 1).

Association between dementia status and life satisfaction

Adjusted mean SWLS did not differ between probable dementia versus non-dementia groups (4.93 vs. 5.02; adjusted difference, −0.09; 95% CI, −0.33 to +0.15; *p*-value, 0.45) (Table 2). Individual characteristics associated with lower SWLS in the entire analytic sample included younger age, less wealth, more limitations in ADL, and depression. We assessed the degree of multicollinearity using the variance inflation factor (VIF) and found that the VIF was less than five for each variable, except for the "having usual source of care" variable, which had a VIF of 7.1.

Our mediation analysis suggested that dementia status was associated with lower SWLS (total effect, −0.29; bootstrapped 95% CI, −0.47 to −0.12) and the summary ADL limitation score (i.e., the sum of BADL and IADL limitation scores) was a significant mediator of the association between dementia status and SWLS (natural indirect effect, −0.21, bootstrapped 95% CI, −0.30 to −0.15), equating to 71.6% of the total effects being mediated. The controlled direct effect (−0.08; bootstrapped 95% CI, −0.28 to +0.10) was similar to the estimate in the main analysis even though our medication analysis was unable to account for the complex survey design of HRS and used somewhat different variables.

Association between individual characteristics and life satisfaction by dementia status

We observed similar associations between individual characteristics and SWLS among probable dementia and non-dementia groups including the findings that younger age, more limitations in ADL, and depression were associated with lower SWLS (Table 3). Less wealth was associated with lower SWLS among the non-dementia group, but not among probable dementia group (*p*-for-interaction = 0.03). Similarly, diabetes and stroke were associated with higher and lower SWLS, respectively, among probable dementia group, but not among the non-dementia group (*p*-for-interaction = 0.02 for both).

Association between dementia severity and life satisfaction (sensitivity analysis)

We found that adjusted mean SWLS differed between severe dementia versus non-dementia groups (4.36 vs. 5.04; adjusted difference, −0.68; 95% CI, −1.12 to −0.24; *p*-value, 0.003) while there was no evidence that

TABLE 1 Characteristics of the study population by dementia status

Characteristics	Total ($n = 5871$)	With probable dementia ($n = 341$)	Without probable dementia ($n = 5530$)	p-value
Age group				<0.001
Age 70–79	3863 (63.3)	76 (19.7)	3787 (67.1)	
Age 80–89	1750 (30.4)	175 (48.7)	1575 (28.8)	
Age 90+	258 (6.3)	90 (31.6)	168 (4.1)	
Female	3451 (57.7)	217 (64.4)	3234 (57.1)	0.003
Race/ethnicity				<0.001
Non-Hispanic white	4733 (84.4)	251 (73.4)	4482 (85.4)	
Non-Hispanic black	673 (8.3)	52 (14.7)	621 (7.7)	
Hispanic	465 (7.3)	38 (11.9)	427 (6.9)	
Less than high school education	4750 (80.5)	114 (39.4)	1007 (17.8)	<0.001
Wealth				<0.001
Lowest quartile	851 (15.1)	80 (26.9)	771 (14.0)	
Second quartile	1318 (21.4)	102 (29)	1216 (20.7)	
Third quartile	1775 (29.1)	88 (24.2)	1687 (29.6)	
Highest quartile	1927 (34.4)	71 (19.8)	1856 (35.7)	
Covered by Medicaid	439 (7.6)	66 (22.3)	373 (6.3)	<0.001
Social network				<0.001
0	60 (0.9)	10 (2.0)	50 (0.8)	
1–2	1096 (20.5)	95 (29.3)	1001 (19.7)	
3–4	4715 (78.6)	236 (68.7)	4479 (79.5)	
BADL limitation score				<0.001
0	5379 (89.9)	217 (56.2)	5162 (92.9)	
1–3	424 (8.2)	92 (28.7)	332 (6.4)	
4–6	68 (1.9)	32 (15.2)	36 (0.7)	
IADL limitation score				<0.001
0	4919 (81.2)	130 (31.1)	4789 (85.7)	
1–3	842 (15.4)	143 (39.3)	699 (13.2)	
4–5	110 (3.4)	68 (29.6)	42 (1.1)	
Severity of dementia				
Mild dementia	N/A	189 (45.8)	N/A	N/A
Moderate dementia		79 (23.8)		
Severe dementia		73 (30.4)		
Heart disease	2038 (34.9)	133 (40.1)	1905 (34.5)	0.12
Hypertension	4175 (69.7)	247 (72.3)	3928 (69.5)	0.26
Diabetes	1530 (25.2)	104 (30.2)	1426 (24.8)	0.09
Lung disease	721 (12.4)	46 (14.3)	675 (12.2)	0.33
Arthritis	4322 (73.5)	242 (72.4)	4080 (73.6)	0.68
Stroke	549 (9.7)	68 (20.0)	481 (8.8)	<0.001
Cancer	1312 (22.3)	77 (21.2)	1235 (22.4)	0.58
Depression	1404 (24.7)	121 (37.6)	1283 (23.6)	<0.001

TABLE 1 (Continued)

Characteristics	Total ($n = 5871$)	With probable dementia ($n = 341$)	Without probable dementia ($n = 5530$)	*p*-value
Had usual source of care	5006 (85.2)	266 (77.4)	4740 (85.8)	<0.001
Hospitalization within 2 years	1793 (31.2)	122 (39.1)	1671 (30.5)	0.01

Note: The numbers are No. (%) based on the Health and Retirement Study data 2012–2014. Presented proportions are weighted to be nationally representative of older adults. *p*-values are from chi-squared tests comparing the characteristics of participants with probable dementia and those without probable dementia. Wealth refers to the net value of total assets, including secondary residence less all debt. Social network refers to the number of affirmative responses to the four questions asking if a participant has a partner, living children, any other immediate family, or friends. BADL limitation score is the number of the following six daily activities requiring assistance based on self-report: walking, toileting, bathing, transferring, eating, and dressing. IADL limitation score is the number of the following five daily activities requiring assistance: preparing meals, shopping for groceries, making phone calls, taking medications, and managing money based on self-report. Severity of dementia was defined using BADL and IADL (see the main text and Methods S1 for detail).
Abbreviations: BADL, basic activities of daily living; IADL, instrumental activities of daily living.

TABLE 2 Association between individual characteristics and Satisfaction with Life Scale

Variable	Category	Adjusted SWLS (95% CI)	Adjusted difference (95% CI)	*p*-value
Dementia status	With probable dementia	+4.93 (+4.70 to +5.16)	−0.09 (−0.33 to +0.15)	0.45
	Without probable dementia	+5.02 (+4.96 to +5.08)	Ref.	
Age group	Age 70–79	+4.97 (+4.90 to +5.05)	−0.37 (−0.58 to −0.15)	0.001
	Age 80–89	+5.02 (+4.95 to +5.10)	−0.32 (−0.52 to −0.12)	0.002
	Age 90+	+5.34 (+5.16 to +5.53)	Ref.	
Sex	Female	+5.06 (+5.00 to +5.12)	+0.11 (+0.03 to +0.19)	0.009
	Male	+4.95 (+4.87 to +5.02)	Ref.	
Race/ethnicity	Non-Hispanic white	+5.02 (+4.96 to +5.09)	Ref.	
	Non-Hispanic black	+4.89 (+4.76 to +5.02)	−0.13 (−0.29 to +0.02)	0.08
	Hispanic	+5.01 (+4.80 to +5.22)	−0.02 (−0.24 to +0.21)	0.89
Education	Less than high school	+5.15 (+5.03 to +5.28)	+0.17 (+0.04 to +0.31)	0.01
	High school or more	+4.98 (+4.92 to +5.04)	Ref.	
Wealth	Lowest quartile	+4.65 (+4.51 to +4.79)	Ref.	
	Second quartile	+4.82 (+4.71 to +4.93)	+0.17 (+0.01 to +0.34)	0.04
	Third quartile	+5.04 (+4.95 to +5.12)	+0.39 (+0.22 to +0.56)	<0.001
	Highest quartile	+5.27 (+5.21 to +5.33)	+0.62 (+0.46 to +0.79)	<0.001
Covered by Medicaid	Yes	+5.03 (+4.87 to +5.20)	+0.02 (−0.14 to +0.19)	0.77
	No	+5.01 (+4.96 to +5.06)	Ref.	
Social network	0	+4.72 (+4.28 to +5.16)	Ref.	
	1–2	+4.83 (+4.73 to +4.94)	+0.11 (−0.35 to +0.57)	0.63
	3–4	+5.06 (+5.01 to +5.12)	+0.34 (−0.09 to +0.77)	0.12
BADL limitation score	0	+5.03 (+4.97 to +5.09)	Ref.	
	1–3	+4.90 (+4.72 to +5.08)	−0.13 (−0.34 to +0.07)	0.20
	4–6	+4.47 (+4.00 to +4.93)	−0.57 (−1.04 to −0.09)	0.02
Instrumental ADL limitation score	0	+5.08 (+5.02 to +5.14)	Ref.	
	1–3	+4.76 (+4.62 to +4.89)	−0.32 (−0.47 to −0.17)	<0.001
	4–5	+4.57 (+4.19 to +4.96)	−0.50 (−0.90 to −0.10)	0.01
Heart disease	Yes	+4.96 (+4.87 to +5.05)	−0.08 (−0.18 to +0.02)	0.10
	No	+5.04 (+4.98 to +5.09)	Ref.	

(Continues)

TABLE 2 (Continued)

Variable	Category	Adjusted SWLS (95% CI)	Adjusted difference (95% CI)	*p*-value
Hypertension	Yes	+5.02 (+4.96 to +5.09)	+0.04 (−0.06 to +0.14)	0.47
	No	+4.99 (+4.91 to +5.06)	Ref.	
Diabetes	Yes	+5.00 (+4.94 to +5.07)	−0.01 (−0.10 to +0.08)	0.80
	No	+5.01 (+4.95 to +5.08)	Ref.	
Lung disease	Yes	+4.83 (+4.67 to +4.98)	−0.21 (−0.37 to −0.06)	0.009
	No	+5.04 (+4.98 to +5.09)	Ref.	
Arthritis	Yes	+4.97 (+4.91 to +5.03)	−0.16 (−0.26 to −0.05)	0.003
	No	+5.13 (+5.04 to +5.22)	Ref.	
Stroke	Yes	+4.95 (+4.76 to +5.13)	−0.07 (−0.25 to +0.11)	0.43
	No	+5.02 (+4.97 to +5.07)	Ref.	
Cancer	Yes	+4.92 (+4.82 to +5.02)	−0.11 (−0.21 to −0.02)	0.02
	No	+5.04 (+4.98 to +5.09)	Ref.	
Depression	Yes	+4.53 (+4.45 to +4.62)	−0.63 (−0.73 to −0.53)	<0.001
	No	+5.17 (+5.11 to +5.23)	Ref.	
Had usual source of care	Yes	+5.04 (+4.99 to +5.10)	+0.21 (+0.06 to +0.36)	0.006
	No	+4.83 (+4.70 to +4.97)	Ref.	
Had hospitalization ≤2 year	Yes	+4.90 (+4.81 to +4.98)	−0.17 (−0.27 to −0.07)	0.001
	No	+5.06 (+5.00 to +5.13)	Ref.	

Note: We fit a linear regression model with the dependent variable being SWLS (range 1–7 with 7 being the best) and independent variables being the variables in the table as well as dummy variables for the nine Census divisions (i.e., fixed effects; coefficients not shown in the table). Adjusted SWLS are predicted SWLS adjusted for covariates using the marginal standardization method.[38] See the main text for the definitions of BADL and IADL limitation scores.
Abbreviations: BADL, basic activities of daily living; IADL, instrumental activities of daily living; SWLS, Satisfaction with Life Scale.

SWLS differed between mild or moderate dementia versus no-dementia groups (Table 4).

DISCUSSION

Using a nationally representative sample of community-dwelling older adults, we found that persons living with dementia who were able to complete a self-administered questionnaire perceived a similar satisfaction compared to those without dementia after accounting for individual characteristics. We also found, however, that dementia status is associated with lower life satisfaction with medication through limitations in ADL. Most individual characteristics associated with lower life satisfaction were similar in participants with and without dementia including younger age, more limitations in ADL, and depression. Less wealth was associated with lower life satisfaction among individuals without dementia but not among persons with dementia.

Our findings suggest that dementia status is associated with lower life satisfaction only indirectly, via limitations in ADL, but not directly in our model. Among dementia-related characteristics that are potentially associated with life satisfaction but not accounted for in our analysis are cognitive function and difficult behaviors. It may be that persons living with dementia often have reduced insight into their cognitive impairment or behaviors (i.e., anosognosia[39]) and their ratings on life satisfaction are not substantially affected by deficits in cognitive function.

We observed an association between dementia status and lower life satisfaction (mediated by limitations in ADL) with an effect size of 0.29 points in SLWS. While the minimal clinically important difference has not been established for SLWS, one point difference is suggested to be used to categorize SLWS into groups (e.g., 6–7 points: highly satisfied; 1–2 points: extremely dissatisfied).[40] Therefore, our observed difference would be considered modest, although statistically significant. This is consistent with a recent study, although not focusing on those with dementia, that demonstrated high life satisfaction among older adults with ADL limitation.[41] It may be that often times the progression of ADL decline is gradual

TABLE 3 Associations between individual characteristics and Satisfaction with Life Scale by dementia status

Variable	With probable dementia ($n = 341$)		Without probable dementia ($n = 5530$)		*p*-value for interaction
	Adjusted difference (95% CI)	*p*-value	Adjusted difference (95% CI)	*p*-value	
Age group					
Age 70–79	−0.40 (−0.86 to +0.06)	0.09	−0.33 (−0.56 to −0.10)	0.006	0.78
Age 80–89	−0.40 (−0.78 to −0.01)	0.04	−0.27 (−0.51 to −0.03)	0.03	0.58
Age 90+	Ref.		Ref.		
Female	+0.10 (−0.25 to +0.46)	0.56	+0.11 (+0.02 to +0.19)	0.01	0.99
Race/ethnicity					
Non-Hispanic white	Ref.		Ref.		
Non-Hispanic black	−0.11 (−0.61 to +0.39)	0.67	−0.15 (−0.30 to +0.00)	0.05	0.87
Hispanic	−0.11 (−0.88 to +0.67)	0.78	+0.01 (−0.22 to +0.25)	0.90	0.76
<high school education	+0.16 (−0.26 to +0.59)	0.44	+0.19 (+0.04 to +0.34)	0.01	0.92
Wealth					
Lowest quartile	Ref.		Ref.		
Second quartile	−0.31 (−0.87 to +0.25)	0.28	+0.26 (+0.09 to +0.43)	0.003	0.06
Third quartile	−0.04 (−0.58 to +0.49)	0.87	+0.46 (+0.28 to +0.64)	<0.001	0.08
Highest quartile	+0.05 (−0.47 to +0.57)	0.85	+0.69 (+0.50 to +0.87)	<0.001	0.03
Covered by Medicaid	+0.23 (−0.32 to +0.77)	0.40	−0.06 (−0.22 to +0.10)	0.44	0.30
Social network					
0	Ref.		Ref.		
1–2	+0.43 (−0.90 to +1.76)	0.52	+0.05 (−0.42 to +0.51)	0.84	0.60
3–4	+0.78 (−0.47 to +2.02)	0.22	+0.27 (−0.17 to +0.72)	0.23	0.47
BADL limitation score					
0	Ref.		Ref.		
1–3	−0.37 (−0.98 to +0.24)	0.23	−0.09 (−0.32 to +0.14)	0.43	0.43
4–6	−0.92 (−1.71 to −0.14)	0.02	−0.51 (−1.19 to +0.16)	0.13	0.13
IADL limitation score					
0	Ref.		Ref.		
1–3	−0.14 (−0.45 to +0.16)	0.35	−0.32 (−0.48 to −0.16)	<0.001	0.43
4–5	−0.34 (−0.95 to +0.26)	0.26	−0.68 (−1.32 to −0.04)	0.04	0.13
Heart disease	+0.32 (−0.09 to +0.73)	0.12	−0.12 (−0.21 to −0.03)	0.01	0.04
Hypertension	+0.10 (−0.31 to +0.50)	0.63	+0.03 (−0.07 to +0.12)	0.58	0.72
Diabetes	+0.34 (+0.04 to +0.63)	0.03	−0.03 (−0.12 to +0.06)	0.48	0.02
Lung disease	+0.01 (−0.49 to +0.52)	0.96	−0.23 (−0.39 to −0.08)	0.004	0.35
Arthritis	−0.25 (−0.61 to +0.12)	0.18	−0.15 (−0.26 to −0.05)	0.004	0.63
Stroke	−0.43 (−0.75 to −0.11)	0.01	−0.01 (−0.19 to +0.16)	0.88	0.02
Cancer	−0.22 (−0.55 to +0.11)	0.19	−0.10 (−0.21 to −0.00)	0.049	0.51
Depression	−0.47 (−0.86 to −0.07)	0.02	−0.66 (−0.75 to −0.56)	<0.001	0.33
Had usual source of care	+0.06 (−0.41 to +0.53)	0.79	+0.21 (+0.05 to +0.37)	0.01	0.56
Had hospitalization ≤2 year	−0.33 (−0.74 to +0.09)	0.12	−0.16 (−0.25 to −0.07)	0.001	0.42

Note: We fit linear regression models similar to the main analysis for each of the dementia and non-dementia groups separately. We then fit a linear regression model with interaction terms between dementia status and all other variables using all the study sample (both dementia and non-dementia groups) and present *p*-values for the interaction terms. See the main text for the definitions of BADL and IADL limitation scores.

Abbreviations: BADL, basic activities of daily living. IADL, instrumental activities of daily living.

TABLE 4 Association between dementia severity and Satisfaction with Life Scale

Variable	Category	Adjusted SWLS (95% CI)	Adjusted difference (95% CI)	*p*-value
Dementia status	No dementia	5.04 (4.99–5.10)	Ref.	
	Mild	4.88 (4.61–5.16)	−0.16 (−0.43 to +0.12)	0.26
	Moderate	4.63 (4.21–5.05)	−0.41 (−0.83 to +0.01)	0.06
	Severe	4.36 (3.95–4.78)	−0.68 (−1.12 to −0.24)	0.003

Note: We fit a linear regression model similar to the main analysis but the main exposure variable being a categorical variable for dementia severity (no dementia, mild, moderate, or severe dementia). We did not include basic activities of daily living (BADL) and instrumental activities of daily living (IADL) limitation scores as covariates. See the main text for more details. Results for other exposure variables are not reported for brevity.
Abbreviation: SWLS, Satisfaction with Life Scale.

and older persons may reduce their expectations and adapt to limitations, and their perception of life satisfaction may not be affected significantly.[42]

Given the small magnitude of associations between patient characteristics (including ADL limitation) and life satisfaction we observed, life satisfaction alone may not be the ideal outcome when evaluating the effects of therapies targeting persons living with dementia. However, other studies suggest associations between potentially mutable patient characteristics that are not included in our studies, such as loneliness and relationship with family members or friends, and life satisfaction among older adults with ADL limitation.[41] Further research is warranted that focuses more on mutable social factors and the responsiveness of life satisfaction to treatment. Other future research directions would include assessing life satisfaction in a longitudinal manner with advancing dementia and characterizing other domains of well-being, such as emotional, psychological, and social well-being,[5] and their contributing factors to well-being among persons living with dementia.

Persons with and without probable dementia in our study had very different characteristics. Particularly, those with probable dementia seemed to have lower socioeconomic status, which is expected given that lower socioeconomic status is associated with an increased risk for dementia incidence.[43] We accounted for this in our model because previous studies suggest that lower socioeconomic status is associated with lower life satisfaction[44–47] along with other potential confounders. However, there may be unmeasured factors that lead to biased estimates. For example, subjective social status, which reflects a subjective appraisal of his or her position in the social hierarchy (rather than actual socioeconomic position), might play an important role in the perception of life satisfaction,[48,49] because life satisfaction is thought to mirror the gap between one's future expectations and one's current experience.[42]

We excluded nursing home residents, those who did not complete the questionnaire on life satisfaction, or those who required assistance when completing the questionnaire, resulting in the disproportionate exclusion of those with moderate or severe dementia. This is not only because these participants may not be able to provide meaningful responses to the questionnaire, but also because HRS assigns zero weights to these participants. However, while it implies that our findings may not be applicable to those who were excluded from our study, it does not necessarily mean that life satisfaction cannot be used as a meaningful outcome measure among these populations. For example, face-to-face interviews might allow researchers to include some of them (we used the data from the Psychosocial and Lifestyle Questionnaire, which is a supplemental hardcopy survey, separate from the HRS face-to-face interview). Future studies are needed to determine whether our findings can be replicated among these populations.

Our study builds upon previous studies that examined life satisfaction in the context of dementia care. A study conducted in Canada showed that persons living with dementia ($n = 58$) rated modestly lower level of life satisfaction compared to those with normal cognition ($n = 1468$).[15] While informative, the study may have limited generalizability because of the use of data from the 1990 s and the inclusion of a small number of persons living with dementia.[15] Several studies evaluated the association between individual characteristics and life satisfaction among persons living with dementia. A recent study in the U.K. found that a lack of social network, loneliness, depression, and functional limitations were associated with a lower level of life satisfaction among persons living with dementia.[16] Similarly, studies conducted in Malaysia and Germany showed that lower education, not being married, a lack of social support, and severe cognitive impairment were associated with lower life satisfaction among persons living with dementia.[17,18]

The limitations of this study must be recognized. First, although life satisfaction represents an important aspect of well-being in persons living with dementia,[5,18] this measure does not capture all dimensions of well-being.

Second, while our approach to identify those with probable dementia has been validated,[23,24] there are potential misclassifications. For example, probable dementia group may include those without dementia ("false positive") and the non-dementia group may include those with dementia ("false negative"). However, these misclassifications would bias our estimates toward the null producing conservative estimates. Third, our study could not identify different types of dementia (e.g., Alzheimer's disease, vascular dementia, Lewy body dementia, etc.) and life satisfaction and its associated factors may vary by the type of dementia. Lastly, because the probability of dementia is only provided for the subgroup of participants (i.e., 70 years and older with self-reported race/ethnicity of non-Hispanic white, non-Hispanic black, or Hispanic), our findings may not be generalizable to other populations, such as those with early-onset dementia.

In summary, using a nationally representative sample of older adults who were able to rate their life satisfaction, we found that dementia status was only modestly associated with lower life satisfaction through the mediation of limitations in ADL. Most factors associated with life satisfaction were similar between older adults with and without dementia. To determine whether life satisfaction can be used as a meaningful outcome when evaluating well-being among persons living with dementia, future studies are needed such as evaluating life satisfaction and well-being over time, examining other dimensions of well-being, and developing approaches to assessing well-being in those who cannot complete a short survey.

AUTHOR CONTRIBUTIONS

Study concept and design, interpretation of data, and preparation of the manuscript: Hiroshi Gotanda, Yusuke Tsugawa. Interpretation of data and preparation of the manuscript: David B Reuben. Acquisition of data, analysis and interpretation of data, and preparation of the manuscript: Haiyong Xu.

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CONFLICT OF INTEREST

The authors declare no conflicts of interest.

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The sponsor had no role in the design, methods, data, collections, analysis, and preparation of the manuscript.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

Methods S1. Definition of the severity of dementia

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