Short Report

Positive Life Experiences Following a Dementia Diagnosis

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Abstract:

Background: Given the stigma and fear associated with Alzheimer's disease (AD), combined with the progressive nature of the disease, the diagnosis of AD or mild cognitive impairment (MCI) is often very difficult; yet, there may still be ways to experience some positive outcomes following diagnosis. We aim to assess the psychological impact of a diagnosis of MCI or early dementia on positive well-being.

Methods: Individuals with a diagnosis of MCI or AD were mailed surveys with the Silver-Lining Questionnaire.

Results: Completed surveys were returned from 38 individuals and were analyzed in relation to demographic and cognitive data. All respondents reported at least one positive response to diagnosis, with just over a quarter reporting positive responses to at least half of the items. Positivity was not significantly related to any of the demographic or cognitive variables examined.

Conclusions: These results suggest the importance of diagnostic disclosure and the need for additional research to better understand how to maximize the likelihood of a positive responses and support healthy behaviors and future care planning.

Keywords
Diagnosis; well-being; positive outlook; disclosure; survey

1. Introduction

Stigma surrounding Alzheimer's disease (AD) is pervasive; individuals worry that sharing a diagnosis with others could result in a loss of social support, fewer social interactions, and discrimination [1]. Negative perceptions of and stigma surrounding AD can result in delayed diagnosis and underutilization of community and supportive services. AD has been found to be the most feared diagnosis by older adults [2]. Accordingly, the diagnosis of mild cognitive impairment (MCI) or early dementia is frequently a difficult and prolonged experience [3]. However, studies of other chronic health conditions suggest that "even the darkest cloud may have a silver lining" [4].

Prior research suggests that positivity following illness may relate to personality traits such as extroversion, as well as spiritual and religious beliefs, and emotional support [4]. For those with COPD and cardiac disease, participation in a rehabilitation program improved psychological outcomes [5]. Gaining a better understanding of individuals' responses to new diagnoses would assist in the development of strategies to help the newly diagnosed maximize wellbeing and quality of life. However, to date few studies have examined the psychological impact of a diagnosis of MCI or AD on positive wellbeing [6-8].

The number of Americans living with AD is expected to grow to 16 million by 2050 [9]. With research targeting individuals earlier and earlier in the disease process, the value of early detection and diagnosis is becoming increasingly recognized and the range of cognitive screening tools to detect cognitive impairment has proliferated. Since individuals can receive a diagnosis of MCI or AD while functionally independent and free of other chronic disease or physical ailments, individuals may live with this diagnosis for many years. Accordingly, having a positive psychological response to this diagnosis may have benefits for both an immediate acclimation to the diagnosis and for years to come. While previous research has suggested positive emotional responses to chronic, incurable diagnoses are possible, and perhaps even more likely than negative responses [6], a comprehensive look at the psychological experiences and responses to the diagnoses of MCI or dementia is currently lacking. While this study does not completely fill this void, it provides valuable insights into the nature of psychological responses to memory impairment diagnoses.

In the earlier stages of memory loss, it is common for individuals to have varying levels of insight into their deficits. Insight refers to one's ability to recognize or have awareness of their

cognitive deficits and their potential implications. Many individuals diagnosed with early stage dementia are able to comprehend their diagnosis and seek out information and support to cope and manage their symptoms. As a result, early diagnosis allows people to plan ahead while they still have the capacity to make important decisions regarding their healthcare. The receipt of an AD diagnosis can provide individuals and their families with relief; diagnosis can provide an opportunity for an improved understanding of the problems the individual is experiencing, opportunities for decision making and future planning, and increased access to available treatment and support services. However, the psychological impact of diagnosis remains unclear. The purpose of this study is to assess the psychological impact of diagnosis of MCI or early dementia on positive well-being using the Silver Lining Questionnaire (SLQ) [10].

2. Methods

2.1 Measures

Participants in the University of Kentucky Alzheimer's Disease Center (ADC) longitudinal cohort participate annually in clinical examinations and neuropsychological testing. Demographic and cognitive variables were extracted from each participant's visit closest to the time of the SLQ. Clinical Dementia Rating (CDR) scores were assigned based on clinician assessments/interviews with the participant and their study partner at the time of that visit. For CDR scores, higher scores indicate greater levels of functional impairment [11]. The Mini Mental State Examination (MMSE) is a brief test that is administered by a trained tester to assess the severity of cognitive impairment [12]. The Geriatric Depression Scale (GDS) is a 15-item series of yes/no questions designed to screen for depression in older adults; a score of five or more is considered to be an indicator of possible depression [13]. The CDR, MMSE, and GDS are all widely used measures with strong psychometric properties. The SLQ is a validated questionnaire that assesses the psychological impact of chronic health conditions on positive wellbeing [10]. The SLQ has 38 questions that include statements related to how an individual has responded to a new diagnosis each with a 5-point Likert scale ranging from 1, "strongly disagree", to 5, "strongly agree" to measure agreement with the given item.

2.2 Participants

The SLQ along with a prepaid return envelope was mailed to 113 individuals with MCI or early dementia from the ADC longitudinal cohort. Individuals were mailed a survey if their CDR global was less than or equal to 0.5. This cut-off was chosen to identify those who were believed to be capable of completing the survey independently. Questionnaires were mailed rather than administered in-person to limit social desirability biases that may be activated in a face-to-face context. This study was approved by the University of Kentucky Institutional Review Board (IRB# 88-0102).

2.3 Analysis

Responses from all returned surveys were entered into a Microsoft Access database. The SLQ was scored using a dichotomous method where any positive item endorsed received a 1 and all

other responses were coded as a 0. In this method, 38 would be the maximum SLQ score. While several of the questions from the SLQ are less inherently positive depending on the respondent's ultimate assessment, e.g. "My illness made me think about the true purpose of life," these were still considered as positive as this process of self-reflection is considered to be a part of personal growth.   In preliminary analysis the SLQ was also evaluated as a continuous measure, but the results remained unchanged. Accordingly, we used the dichotomous measure to provide a more easily interpretable indicator of positive responses following a diagnosis and to be consistent with prior research [5]. To evaluate for differences between respondents and non-respondents Fisher's Exact Test was used for categorical variables, due to the small sample sizes, and independent samples t-tests were used for continuous variables. Assumptions for parametric tests were met, supporting the use of the t-test. No formal analysis was done for the CDR Global differences due to assumptions not being met for this variable, given the lack of variability. Standard descriptive statistical methods were used to evaluate subjective perceptions of positive change as a result of MCI or AD. Fisher's Exact and Pearson correlations were used to explore relationships between demographic variables and SLQ scores. Results were considered significant at *p*<.05.

3. Results

Surveys were received from 38 participants, representing a 34% response rate. There were no statistically significant differences between respondents and non-respondents for age, MMSE, CDR score (global or summary), GDS score, sex, or race, p>.05. Respondents were significantly more likely (89.5%) to be married or partnered than non-respondents (69.3%), p=.018. Respondents had significantly more years of education (Mean = 16.55) than non-respondents (Mean = 15.05), p=.012. There were no significant differences between respondents and non-respondents in terms of the prevalence of common comorbidities (See **Table 1**).

Of the 38 SLQ respondents, 30 had MCI and 8 had early AD. Respondents were predominately male (65.8%) with an average age of 77.82 years (range 58-91). Participants were highly educated, with a mean 16.55 years of education (range 12-25). The vast majority (92.1%) were Caucasian. Their mean MMSE score was 26.65 (range 20-30); the CDR global score for all respondents was 0.5 and the mean CDR sum of boxes mean was 1.66 (range 0.5-3.5). The mean GDS score was 2.27 (range 0-10).

The mean SLQ dichotomous score was 14.2 (range 1-37). All respondents reported at least one positive response to diagnosis. If you consider a generally positive response to diagnosis as endorsing half or more of the positivity items, 26.3% of respondents reported an overall positive SLQ. For the individual items, half or more of all respondents endorsed positive responses to ten questions (See **Table 2**). The most frequently endorsed items included: "My illness made me think about the true purpose of life" (73.7%), "My illness encouraged me to reflect on how I feel about myself" (68.4%), and "Because of my illness I find it easier to accept what life has in store" (65.8%). There were no statistically significant relationships between age, education, gender, race, marital status, diagnosis (MCI or dementia), MMSE, CDR score, or GDS score and SLQ summary scores, p>.05.

Table 1 Respondent and non-Respondent characteristics

	Respondents (n=38) N (%)	Non-Respondents (n=75), N (%)	*p*-value
Sex			.418
Male	25 (65.8)	42 (56.0)	
Female	13 (34.2)	33 (44.0)	
Race			.169
Caucasian	35 (92.1)	61 (81.3)	
Other Race	3 (7.9)	14 (18.7)	
Marital Status			.020*
Married/Partnered	34 (89.5)	52 (69.3)	
Single	4 (10.5)	23 (30.7)	
Age (mean, standard deviation)	77.82 (8.57)	77.91 (8.79)	.958
Education, years (mean, standard deviation)	16.55 (3.33)	15.05 (2.75)	.012*
MMSE (mean, standard deviation)	26.65 (2.49)	25.77 (2.62)	.093
CDR Global (mean, standard deviation)	.5 (0)	0.49 (0.15)	NS
CDR Sum of boxes (mean, standard deviation)	1.66 (.90)	1.89 (1.51)	.410
Geriatric Depression Scale (mean, standard deviation)	2.27 (2.58)	2.54 (2.76)	.620
Comorbidities			
Diabetes	7 (18.42)	16 (21.33)	.808
Hypertension	21 (55.26)	55 (73.33)	.060
Hypercholesterolemia	23 (60.53)	51 (68.00)	.530
Depression	15 (39.47)	30 (40.00)	1.00

*indicates statistically significant at p<.05 level

Note: MMSE = Mini-Mental State Examination, CDR = Clinical Dementia Rating

Table 2 Silver lining questionnaire responses

Item #	Item	Positive Responses N (%)
1	**I appreciate life more because of my illness**	**19 (50.0)**
2	My illness gave me a new start in life	6 (15.8)
3	My life is much better now than it was before	4 (10.5)
4	**My illness has made me live life to its fullest**	**19 (50.0)**
5	**Because of my illness I find it easier to accept what life has in store**	**25 (65.8)**
6	**My illness made me think about the true purpose of life**	**28 (73.7)**
7	My religious/spiritual beliefs deepened because of my illness	18 (47.4)
8	I am now more open to other religions because of my illness	5 (13.5)*
9	My illness made me a better person	11 (28.9)
10	I became a happier person because of my illness	5 (13.2)
11	I am a calmer person because of my illness	11 (29.7)*
12	My illness made me more mature	14 (36.8)
13	**My illness made me a more tolerant person**	**19 (50.0)**
14	My illness made me realize that I matter as a person	16 (43.2)*
15	My illness gave me more confidence	9 (23.7)
16	**I am less concerned about failure because of my illness**	**24 (63.2)**
17	My illness gave me permission to do things for myself	12 (31.6)
18	My illness made me a more determined person	18 (47.4)
19	My illness helped me find myself	12 (31.6)
20	My illness made me more aware of my strengths	18 (48.6)*
21	Through my illness I discovered a talent I didn't know I had	7 (18.4)
22	I can face whatever is around the corner because of my illness	18 (47.4)
23	**My illness encouraged me to reflect on how I feel about myself**	**26 (68.4)**
24	**My illness made me face up to problem areas of my life**	**19 (51.4)***

25	**My illness strengthened my relationships with others**	**23 (60.5)**
26	My illness made me less concerned with the approval of others	15 (40.5)*
27	Because of my illness I have more to offer other people	7 (18.4)
28	My illness made me more at ease with others	15 (39.5)
29	I see others in their true colors because of my illness	8 (21.1)
30	**My illness gave me the opportunity to meet new people**	**20 (52.6)**
31	My illness taught me how to stand up for myself	9 (25.0)*
32	My illness made me put an end to troublesome relationships	9 (23.7)
33	My illness made me less judgmental of others	18 (48.6)*
34	I have been an inspiration to others	12 (31.6)
35	People can be more open with me since my illness	11 (28.9)
36	My illness changed other people for the better	7 (18.9)*
37	My illness changed other people's perception of me for better	9 (23.7)
38	Other people appreciate me more because of my illness	13 (34.2)

Note: Bolded responses indicate 50% or more of respondents had positive responses to the item; *Indicates missing responses for that item; percentages are based out of completed responses. For item #32 two individuals did not provide a response. For all other items with missing data, only one individual did not provide a response.

4. Discussion

Many individuals with MCI and early dementia respond positively to various SLQ items, demonstrating positive responses to diagnoses. This is consistent with prior research suggesting that disclosure of a dementia diagnosis typically is not related to changes in depression and can actually decrease anxiety, with depression and anxiety worsening following diagnosis only in a minority of cases [14]. In instances where initial reactions to an AD diagnosis are negative, the negative consequences of diagnosis typically do not persist over time [15]. These existing studies examined negative outcomes of an AD diagnosis, but did not evaluate potential positive changes.

The data in the present study demonstrate that positive attitudes about psychological outlook on life among those who have MCI or early dementia are possible. These findings have important implications for individuals' long-term physical and mental well-being. Existing research suggests that optimism is related to better health outcomes in multiple areas including mortality, cardiovascular outcomes, immune functions, and pain perceptions [16]. Optimism may also relate to more positive health behaviors such as less smoking, moderate alcohol consumption, and more

frequent brisk walking. Positivity may also relate to lower depressive symptoms and generally better mental health [17].

With a better understanding of the benefits and potential positive outcomes of diagnosis, these results will hopefully encourage healthcare providers to discuss dementia concerns with their patients. Stress may drive the progression and exacerbate symptoms of cognitive decline [18]. Openly discussing concerning symptoms or behaviors, as well as disease management strategies and available community resources can help to alleviate several sources of stress. Existing research indicates that physicians are often reluctant to diagnose AD, in part due to potential detrimental effects on the patient [19]. The results of the present study should help to allay some of these concerns and increase open communication about cognitive impairment.

This study had several limitations. First, the response rate was only 34%, so it is possible that those who responded may have had more positive or negative responses to their diagnosis than non-respondents. The relatively small sample size and low minority participation also make it difficult to generalize results and to identify differences based on demographic or cognitive variables. Regarding generalizability, the sample was limited to those with early/mild dementia. Results may differ for those with more significant or advanced levels of cognitive impairment. Despite being earlier in the disease process, it is possible that the low response rate in the current study could reflect difficulty completing the survey. In addition, the SLQ is based on self-report and may be subject to recall or social-desirability biases. Anosognosia, or lack of awareness, may have also interfered with survey responses as even in early stages of disease individuals may fail to recognize signs and symptoms of their diagnosis, potentially leading to a bias towards positive rather than negative responses. Finally, in completing their questionnaires, many individuals wrote in a number of other chronic conditions that they were currently living with (e.g. COPD, cancer, fibromyalgia, atrial fibrillation, diabetes, and high blood pressure). Persons with dementia often experience other chronic conditions when diagnosed with MCI or dementia. Responses to diagnosis may be impacted by an overall disease identity and potentially cannot be fully understood by focusing on a single condition.

Despite these limitations, results of this study suggests that positive responses to diagnoses of MCI or dementia are possible. These "silver linings" could serve as potential targets for positive adaptive responses to support lifestyle change and future chronic care planning and help to lessen the negative burden of disease as progression occurs over time. Further studies of variables or interventions that could enhance positive wellbeing in dementia could have a positive impact on the patients that have not yet found their "silver lining". Prior research suggests that interventions can promote positive illness interpretations, but finding the best approach to do so with MCI and dementia is not yet known. Future research may be needed to better understand the factors that contribute to a positive outlook once an individual is diagnosed with or experiences symptoms of cognitive decline. The SLQ evaluates psychological responses, but does not explore the factors that contribute to an individual's adjustment to a new dementia diagnosis, including social supports, educational and supportive services, follow-up care, and intrinsic personal and coping mechanism. These factors may explain some of the variability in positivity following diagnosis.

A longitudinal analysis would also enable the ability to investigate how positive wellbeing may change throughout the disease trajectory, from MCI to more severe cognitive impairment. Such an analysis could help with tailoring interventions to individuals' disease progression so that positivity can be maximized at all stages of cognitive decline. Ideally, these research efforts will be

accompanied by advocacy and training efforts to promote more age-friendly communities and supportive healthcare systems so that society creates an environment more supportive of positive well-being across ages and cognitive abilities.

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Author Contributions

Dr. Bardach contributed to the data acquisition and analysis as well as writing of the manuscript. Ms. Moore contributed to the design, analysis, data entry, and revisions of the manuscript. Ms. Holmes contributed to the design, analysis, and revisions of the manuscript. Drs. Murphy and Gibson contributed to the revisions of the manuscript. Dr. Jicha contributed to the design, analysis, and revisions of the manuscript.

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Competing Interests

The authors have declared that no competing interests exist.

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