


BRIEF REPORT

Potential impact of the COVID-19 pandemic on everyday preferences for persons with cognitive impairment

James M. Wilkins,¹  Joseph J. Locascio,^{2,3} Teresa Gomez-Isla,²
Bradley T. Hyman,² Deborah Blacker,^{2,4} Brent P. Forester,¹ and Olivia I. Okereke^{2,4}

¹Division of Geriatric Psychiatry, McLean Hospital, Harvard Medical School, Belmont, MA, USA

²Department of Neurology, Massachusetts Alzheimer's Disease Research Center, Massachusetts General Hospital, Harvard Medical School, Boston, MA, USA

³Harvard Catalyst Biostatistical Consulting, Harvard Catalyst/CTSA, Harvard Medical School, Boston, MA, USA

⁴Department of Psychiatry, Massachusetts General Hospital, Harvard Medical School, Boston, MA, USA

ABSTRACT

The COVID-19 pandemic and subsequent social distancing guidelines and restrictions brought on changes in the everyday experiences of older adults. It is not clear, however, to what extent the pandemic has impacted the importance of everyday preferences for persons with cognitive impairment (CI) or the proxy ratings of those preferences. The sample of this study included 27 dyads of persons with CI and their care partners. The Preferences for Everyday Living Inventory was used to assess importance of preferences among persons with CI; care partners completed concurrent proxy assessments. Mixed random and fixed effects longitudinal models were used to evaluate changes in ratings and concordance levels between persons with CI and care partners prior to and during the COVID-19 pandemic. Persons with CI rated autonomous choice preferences as significantly more important during the COVID-19 pandemic than before; there was no association between the COVID-19 pandemic and change in other everyday preferences domains or discrepancy in proxy assessments of everyday preferences. Identifying avenues to support and provide for autonomy in the decision-making of older adults with CI may offer a way forward in mitigating the psychological and behavioral impacts of the COVID-19 pandemic in this population.

Key words: Dementia, autonomy and self-efficacy, decision-making

Introduction

As the COVID-19 pandemic took hold, there was increasing concern for impacts on older adults, not only due to increased risk for morbidity/mortality but also concerns for isolation and loneliness due to social distancing (Callow *et al.*, 2020). Early in the pandemic, a common experience for older adults was lower quality of life (Hamm *et al.*, 2020). There appeared to be evidence for lifestyle changes as a means to cope with the pandemic and as a result of restrictions of the pandemic (e.g., less physical activity) (Callow *et al.*, 2020). The pandemic brought increased stress for caregivers of older adults, particularly those with dementia (Altieri and Santangelo, 2021).

Prior to the COVID-19 pandemic, our group had been evaluating longitudinal changes in everyday

preferences for persons with cognitive impairment (CI) as well as discrepancy in preferences assessment between persons with CI and proxy assessments made by care partners (Wilkins *et al.*, 2021). These results showed that preferences ratings for persons with CI and discrepancy in proxy assessments were relatively stable over time. Although the COVID-19 pandemic appears to have impacted everyday lifestyle behaviors for older adults, it is not clear to what extent the pandemic impacted the importance of everyday preferences for persons with CI or care partners' proxy ratings.

The aims of this study are (1) to assess changes in ratings of everyday preferences among persons with CI during the COVID-19 pandemic and (2) to assess changes in discrepancy in care partners' proxy ratings for persons with CI during the pandemic. Given social distancing guidelines, we hypothesized that the pandemic would be associated with changes in social engagement preferences for persons with CI. Additionally, we hypothesized changes in discrepancy with proxy ratings during the COVID-19 pandemic; previous work showed

Correspondence should be addressed to: J. M. Wilkins, Division of Geriatric Psychiatry, McLean Hospital, 115 Mill Street, Belmont, MA, 02478, USA. Phone: 617-855-3982; Fax: 617-855-3246. Email: jwilkins1@mclean.harvard.edu. Received 22 Jun 2023; revision requested 11 Jul 2023; revised version received 26 Jul 2023; accepted 27 Jul 2023. First published online 25 August 2023.

association between psychological well-being of care partners and discrepancy in proxy assessments for persons with dementia (Schulz *et al.*, 2013).

Methods

Study sample

The sample included dyads comprising persons with CI (Clinical Dementia Rating (CDR) global score ≥ 0.5) and their care partners. Persons with CI were recruited from the Massachusetts Alzheimer's Disease Research Center Clinical Core cohort, as described previously (Wilkins *et al.*, 2020). The study involved one baseline and up to two follow-up assessments per dyad. Baseline data were collected over a 24-month period from 2017 to 2019 ($n = 116$). First follow-up assessments were completed over a 17-month period from 2018 to 2020 ($n = 48$), and second follow-up assessments were completed over a 31-month period from 2019 to 2022 ($n = 27$). Research visits were postponed from March 2020 due to the COVID-19 pandemic and resumed in January 2021. Reasons for not completing follow-up visits included death or withdrawal from the study for the person with CI, cognitive impairment too severe to complete study measures, and care partner absent at study visit or different care partner informants at different study visits. It appeared that those cohort participants who did not complete all follow-up visits had higher levels of CI than those cohort participants who completed all three assessments (average CDR sum of boxes [CDR-SB] score at baseline 3.15 vs 1.74). Cohort participants provided informed consent. The MassGeneralBrigham Institutional Review Board approved this study.

Measures

Persons with CI and their care partners complete annual evaluations per the Alzheimer's Disease Centers Uniform Data Set protocol. These evaluations include collection of demographic data for persons with CI and care partners, cognitive assessments for persons with CI (i.e., the CDR and CDR-SB), and neuropsychiatric assessments for persons with CI (i.e., Neuropsychiatric Inventory brief Questionnaire [NPI-Q] and 15-item Geriatric Depression Scale [GDS-15]). To assess importance ratings for everyday preferences, persons with CI completed the Preferences for Everyday Living Inventory (PELI) during the annual evaluations; the PELI is a validated preferences assessment tool for older adults rating preferences on a 4-point Likert scale from 1 (most important) to

4 (not at all important) (Van Haitsma *et al.*, 2013). Care partners completed proxy PELI assessments for persons with CI (i.e., acting as surrogate decision-makers). Our previous work identified four PELI domains: autonomous choice, social engagement, personal growth, and keeping a routine (Wilkins *et al.*, 2020). For each participant, a mean domain score was calculated as the average of nonmissing importance ratings for the PELI items of that domain; a preference discrepancy score was computed for each dyad by subtracting the mean domain score for the care partner from the value for the corresponding person with CI.

Statistical analyses

For dyads with data collected at all three timepoints, mixed random and fixed effects longitudinal analyses were run across time in the study, employing a backward elimination algorithm ($p < 0.05$ cutoff) on an initial pool of fixed predictors and variances/covariances of random terms. In one set of models, the dependent variables were preferences domain scores for persons with CI in separate analyses; in the other set of models, the dependent variables were preferences discrepancy scores between persons with CI and care partners. The time predictor was the linear component of days in the study from baseline to follow-up assessments; mean follow-up for first follow-up assessments was 503.5 days (standard deviation [SD] 117.2) from baseline, and mean follow-up for second assessments was 1,127.3 days (SD 268.8) from baseline.

Fixed terms in analysis of preference scores for persons with CI were GDS-15 score (time varying), NPI-Q score (time varying), CDR-SB score (time varying), age (at baseline), gender (at baseline), years of education (at baseline), and whether the data were collected after the start of the COVID-19 pandemic (yes/no, time varying). Per declaration of the World Health Organization, the start of the COVID-19 pandemic was March 11, 2020; as such, for $n = 7$ dyads all three timepoints occurred prior to the start of the COVID-19 pandemic and for $n = 20$ dyads the third timepoint occurred after the start of the COVID-19 pandemic.

Fixed terms in analysis of discrepancy between persons with CI and proxy care partner ratings were GDS-15 score (person with CI, time varying), NPI-Q score (person with CI, time varying), CDR-SB score (person with CI, time varying), age and gender (for both person with CI and care partner, at baseline), relationship status between the person with CI and care partner, and whether data were collected after the start of the COVID-19 pandemic (yes/no, time varying). All statistical analyses were

Table 1. Description of persons with cognitive impairment (CI): neuropsychiatric, cognitive, and preferences for everyday living inventory (PELI) characteristics at baseline and follow-up. All scores based on $n = 27$, unless otherwise noted

	BASELINE	FOLLOW-UP 1	FOLLOW-UP 2
Neuropsychiatric Inventory brief Questionnaire Score (mean ([S.D.]))	2.68 (3.54) ^a	3.17 (3.89) ^b	2.96 (3.62) ^c
Geriatric Depression Scale, 15-item Score (mean ([S.D.]))	1.83 (2.37) ^d	1.92 (2.04) ^a	3.46 (2.99) ^b
Clinical Dementia Rating Sum of Boxes Score (mean ([S.D.]))	1.74 (1.07)	2.04 (1.65)	2.61 (2.53)
Days from Baseline to Follow-Up (mean [S.D.])	–	503.5 (117.2)	1,127.3 (268.8)
Mean PELI Domain Score (mean [S.D.])			
Autonomous Choice	2.07 (0.57)	2.04 (0.43)	1.94 (0.35)
Social Engagement	1.90 (0.37)	1.90 (0.35)	1.89 (0.40)
Personal Growth	2.12 (0.37)	2.16 (0.29)	2.11 (0.33)
Keeping a Routine	2.40 (0.69)	2.36 (0.55)	2.29 (0.46)
Mean PELI Discrepancy Score (mean [S.D.])			
Autonomous Choice	0.12 (0.56)	– 0.03 (0.38)	– 0.03 (0.30)
Social Engagement	– 0.14 (0.48)	– 0.22 (0.39)	– 0.21 (0.44)
Personal Growth	– 0.03 (0.41)	– 0.01 (0.37)	– 0.07 (0.34)
Keeping a Routine	0.10 (0.70)	0.08 (0.41)	0.05 (0.41)

PELI items are ranked on a 4-point Likert scale with 1 = very important; 2 = somewhat important; 3 = not very important; and 4 = not at all important; SD = standard deviation.

^a $n = 25$.

^b $n = 24$.

^c $n = 26$.

^d $n = 23$.

Table 2. Results of longitudinal mixed effects model for importance scores by persons with cognitive impairment for “autonomous choice” and “social engagement” domains of the preferences for everyday living inventory (PELI), showing fixed effect predictors retained in the final model

PREDICTOR	AUTONOMOUS CHOICE			SOCIAL ENGAGEMENT		
	REGRESSION COEFFICIENT ^a	STANDARD ERROR	P-VALUE	REGRESSION COEFFICIENT ^a	STANDARD ERROR	P-VALUE
COVID-19 pandemic	0.15 ^b	0.07	0.03			
GDS-15 Score (points)				0.04	0.02	0.02

^a The regression coefficient is the unstandardized partial regression coefficient.

^b The regression coefficient is equivalent to the difference in adjusted means between data collected prior to the COVID-19 pandemic and data collected during the COVID-19 pandemic.

performed using SAS Version 9.4 (SAS, Cary, NC, USA).

Results

The sample of persons with CI was just over half women, predominately non-Hispanic white, married, and highly educated; care partners were mostly women, non-Hispanic white, spouses/partners, highly educated, with long relationships with the persons with CI (Supplementary Material, Table 1). Neuropsychiatric burden for persons with CI (NPI-Q and GDS-15 scores) and level of CI for persons with CI (CDR-SB scores) are listed in Table 1.

In the mixed effects longitudinal analyses of change in preference scores for persons with CI over time, the term for the COVID-19 pandemic

was statistically significant in the final model for autonomous choice: persons with CI rated autonomous choice preferences significantly more important during the COVID-19 pandemic than before (Table 2). Effect size as determined by Cohen's d was small-moderate (0.26). The COVID-19 pandemic did not appear to affect preference ratings for the other PELI domains. Severity of depression (i.e., GDS-15 score) was significantly associated with lower importance ratings of social engagement preferences over time (Table 2).

The COVID-19 pandemic was not associated with discrepancy scores for the PELI domains. It was noted that gender of care partners was significantly associated with discrepancy in autonomous choice ratings: care partners who were men significantly underestimated the importance of these

Table 3. Results of longitudinal mixed effects model for difference in the importance scores for “autonomous choice” and “social engagement” domains of the preferences for everyday living inventory (PELI) between persons with cognitive impairment (CI) and proxy ratings of care partners, showing fixed effect predictors retained in the final model

PREDICTOR	AUTONOMOUS CHOICE			SOCIAL ENGAGEMENT		
	REGRESSION COEFFICIENT ^a	STANDARD ERROR	P-VALUE	REGRESSION COEFFICIENT ^a	STANDARD ERROR	P-VALUE
Care Partner Gender	− 0.33 ^b	0.11	0.007			
CDR-SB Score (points)				− 0.06	0.03	0.049
Person with CI Gender				− 0.23 ^c	0.11	0.044

^aThe regression coefficient is the unstandardized partial regression coefficient.

^bThe regression coefficient is equivalent to the difference in adjusted means between men care partners and women care partners.

^cThe regression coefficient is equivalent to the difference in adjusted means between men with CI and women with CI.

preferences compared to care partners who were women (Table 3). For social engagement preferences, there was significantly more underestimation by care partners in importance ratings of men with CI relative to women with CI (Table 3). Additionally, there was significant association between discrepancy in ratings of social engagement preferences and CI; higher levels of CI (increasing CDR-SB score) were associated with increasing underestimation of preferences by care partners (Table 3).

Discussion

This study offers insight into impacts of the COVID-19 pandemic on importance of everyday preferences for persons with CI, notably that autonomous choice preferences were rated as more important during the pandemic compared with ratings prior to the pandemic. Autonomous choice preferences include items such as doing one’s favorite hobbies, spending time by one’s self, and choosing when to do daily activities (e.g., getting up, going to bed, and eating). It did not appear that the COVID-19 pandemic had a significant association with importance ratings of other preference domains or with discrepancy between assessments of persons with CI and care partners’ proxy assessments in any of the preferences domains.

Ostensibly due to restrictions during the COVID-19 pandemic, older adults were noted to experience changes in both physical and social activities leading to more physical deconditioning and social isolation (Hoffman *et al.*, 2022). Physical deconditioning was associated with increased fall risk, while social isolation was associated with increases in feelings of loneliness and social disconnectedness (Hoffman *et al.*, 2022; Holaday *et al.*, 2022). Despite these physical and social changes during the COVID-19 pandemic, there is evidence to suggest that older adults also showed

increases in feelings of self-efficacy and confidence in managing social interactions (Lindquist *et al.*, 2022).

A speculative interpretation of the results of the current study could be that increasing feelings of self-efficacy in older adults during the COVID-19 pandemic is reflected in higher valuing of everyday preferences related to autonomous choices. As the uncertainty of the pandemic played out with increasing restrictions on personal choices (e.g., going outside, going to restaurants, and masking guidelines), it may be that a compensatory mechanism for older adults is to focus more on the everyday choices that are more readily under one’s control. In looking at the other preferences domains for persons with CI, our previous work showed an association between higher level of depressive symptoms and less importance of social engagement preferences over time (Wilkins *et al.*, 2021); this association was again noted in the current study with additional follow-up data.

We did not observe an association between the COVID-19 pandemic and discrepancy in assessment of everyday preferences between persons with CI and their care partners. The COVID-19 pandemic has been associated with increased stress among care partners of persons with dementia (Altieri and Santangelo, 2021); indeed, care partners with higher levels of depression and caregiving burden were noted to have a more negative bias in their proxy assessments of quality of life for persons with dementia (Schulz *et al.*, 2013). Although care partners’ levels of caregiving burden and depressive symptoms were not measured directly in this study, it may be that any putative impact of CI on caregiver burden or depression was modest in this sample, despite any potential exacerbating impacts of the COVID-19 pandemic. Severity of CI was associated with discrepancy in proxy assessments of social engagement preferences; the pattern of results indicated that as CI progressed, care partners

tended to under-value the importance of social engagement preferences relative to the ratings by persons with CI.

Strengths of this study include longitudinal analysis over multiple timepoints spanning before and after the start of the COVID-19 pandemic, use of comprehensive assessment of everyday preferences, and detailed assessments of cognitive and neuropsychiatric functioning. Study limitations include small sample size with limited racial and ethnic diversity, higher levels of education compared to similar-aged adults in the general population, and multiple significance tests, raising concern for type I errors. Further limitations include a complete case approach whereby only dyads with three data points were included in analyses; this approach is more intuitively interpretable but could potentially introduce bias if missingness is related to exposure, outcome, or important covariates, such as severity of CI. Overall, this work enhances understanding of the potential for change in everyday preferences among older adults with CI, including in the face of major temporal events such as the COVID-19 pandemic. Identifying avenues to support and provide for autonomy in the decision-making of older adults with CI may offer a way forward in mitigating any lingering psychological and behavioral impacts of the COVID-19 pandemic in this population.

Conflict of interest

None.

Author contributions

James M. Wilkins, MD, DPhil (study concept and design, acquisition of participants and/or data, analysis and interpretation of data, and preparation of manuscript); Joseph J. Locascio, PhD (study concept and design, analysis and interpretation of data, and preparation of manuscript); Teresa Gomez-Isla, MD (study concept and design, acquisition of participants and/or data, and preparation of manuscript); Bradley T. Hyman, MD, PhD (study concept and design, acquisition of participants and/or data, and preparation of manuscript); Deborah Blacker, MD, ScD (study concept and design, acquisition of participants and/or data, analysis and interpretation of data, and preparation of manuscript); Brent P. Forester, MD, MSc (study concept and design, analysis and interpretation of data, and preparation of manuscript); Olivia I. Okereke, MD, SM (study concept and

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Supplementary material

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