

Participant feedback on a longitudinal discrete choice experiment (DCE) for older adults with dementia and their care partners

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INTRODUCTION

Older adults with dementia are frequently left out of decision-making, particularly as the disease progresses. The **Decision-Making in Alzheimer's Research (DMAR)** project is a 5-year NIH-funded project to develop and administer a discrete choice experiment (DCE) instrument to elicit the preferences of older adults living with cognitive impairment (PLCI) and their care partners (CP) in making supportive care decisions.

METHODS

I. DCE Survey Design

Based on input from PLCI, CP and health care providers, we developed a DCE survey instrument to better understand supportive care preferences.

II. DCE Longitudinal Study & Analysis

The DCE was administered over Zoom to PLCI and CP separately at baseline, 6, and 12 months. A split-sample analysis was performed using logit models to estimate part-worth utilities.

III. Participant Feedback

A. After each DCE session, participants were asked:

Q1. How easy or difficult was it for you to answer the survey questions? [Likert]

Q2. How certain are you of your answers? [Likert]

Q3. Do you have anything more to add about your experience with this survey? (open ended)

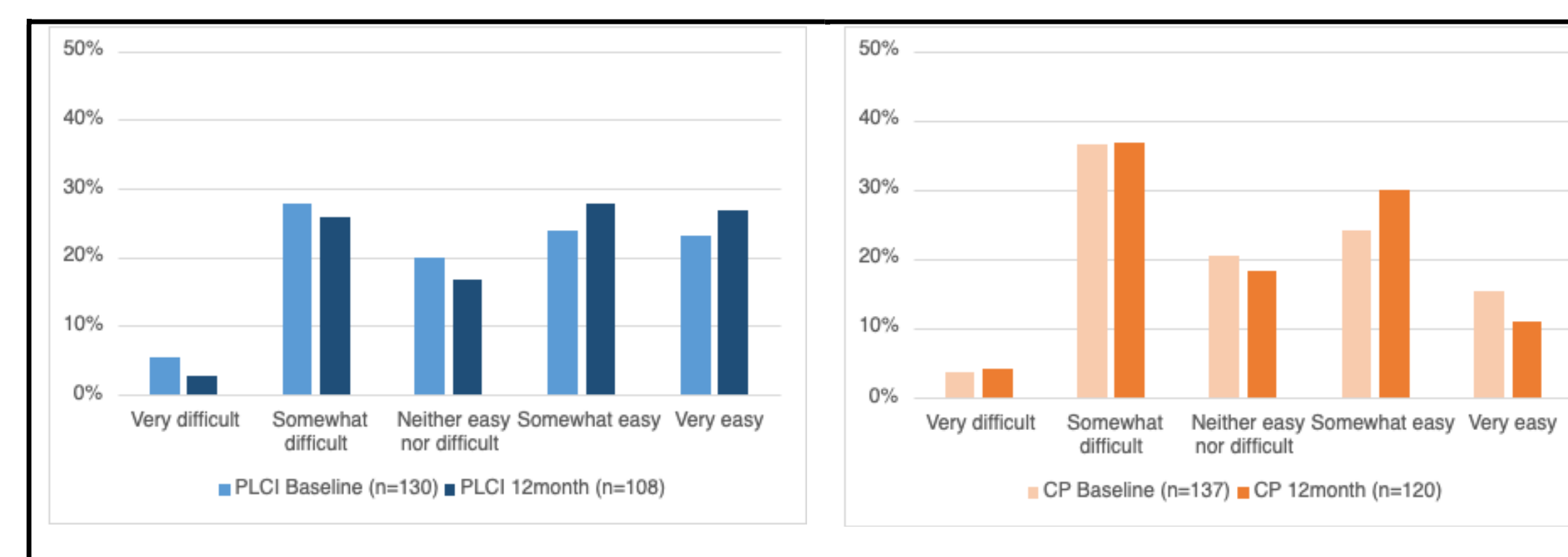
B. At the end of the study, participants were asked how the study had impacted their thinking about supportive care decisions.

All responses were coded and analyzed using constant comparative analysis to identify themes.

RESULTS

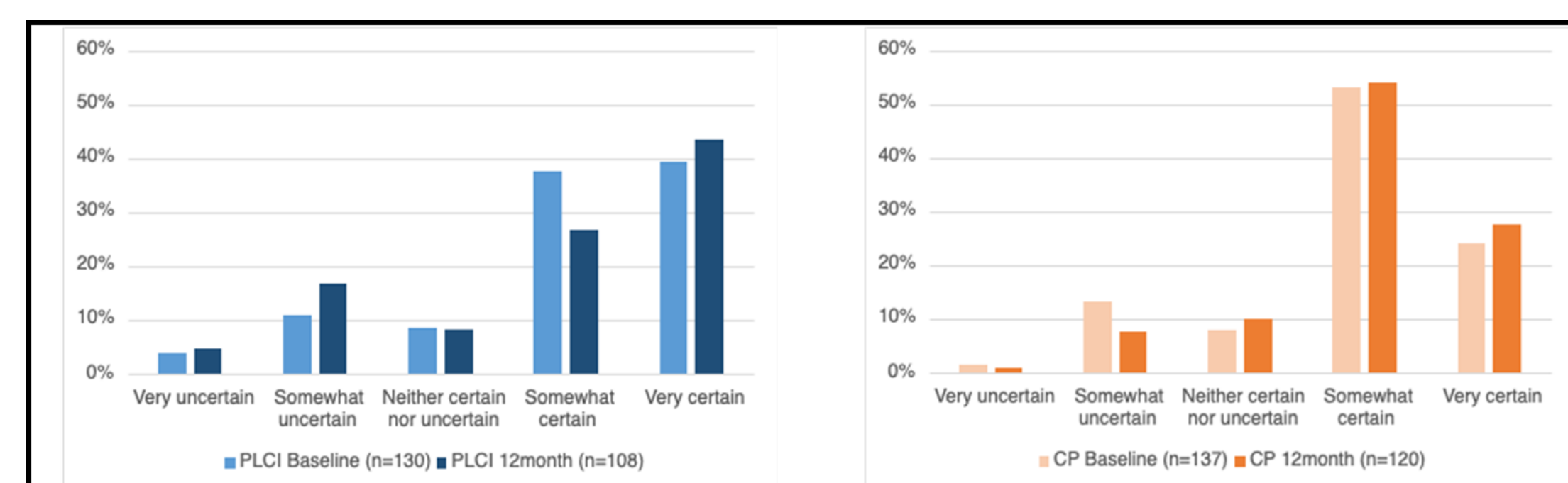
In total, 268 participants (131 PLCI, 137 CP) completed the baseline DCE, and 228 participants (108 PLCI, 120 CP) completed the DCE at 12 months (85%) retention.

Q1. Difficulty answering DCE questions



Few participants found the DCE to be 'very difficult'. The perceived difficulty of the DCE was evenly spread across levels, especially for PLCI. More CP reported the DCE to be 'somewhat difficult', and PLCI were more likely to say it was 'somewhat easy' or 'very easy' to complete.

Q2. Certainty of answers



Few participants were "very uncertain" about their DCE answers. Both PLCI and CP reported high certainty in their responses to DCE questions across all timepoints. A greater proportion of PLCI reported being "very certain" at both timepoints.

Responses to both questions remained similar between baseline and 12-months.

Q3. Experience (open-ended)

A. Facilitators to understanding



Human-administered DCE study session
"I'm glad I didn't have to do this on paper and send it in, because it would have been totally different." (PLCI, baseline)



Prior experience with dementia caregiving
"Her mother had Alzheimer's also. I knew what to expect. That helped quite a bit." (CP, 12-months)

B. Barriers to understanding



Engaging with DCE's fixed scenarios / options:
"...the situation is so fluid and so much fluctuations. That's why it's somewhat difficult..." (CP, baseline)



Difficulty imagining the future:
"I have a good situation right now so it's hard to imagine a situation where I don't have the same level of support I do now." (PLCI, baseline)

Q4. Perceived impact on decision-making



Increased willingness to discuss and think about future supportive care decisions:

"We've talked about it, and we would have never talked about it before" (PLCI, 12-months)

CONCLUSION

Despite challenges, PLCI and CP meaningfully engaged in the longitudinal DCE and provided valuable feedback through open-ended questions. Participants reported that the DCE survey helped clarify their values pertaining to supportive care and prompted conversations about future care decisions.

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