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REFERENCES

1. U.S. Food and Drug Administration. FDA Requires Strong Warnings for Opioid Analgesics, Prescription Opioid Cough

Products, and Benzodiazepine Labeling Related to Serious Risks and Death from Combined Use (online). Accessed November 17, 2021. <https://www.fda.gov/news-events/press-announcements/fda-requires-strong-warnings-opioid-analgesics-prescription-opioid-cough-products-and-benzodiazepines>

2. U.S. Food and Drug Administration. FDA Drug Safety Communication: FDA Warns about Serious Risks and Death when Combining Opioid Pain or Cough Medicines with Benzodiazepines; Requires Its Strongest Warning (online). Published September 20, 2017. Accessed November 17, 2021. <https://www.fda.gov/drugs/drug-safety-and-availability/fda-drug-safety-communication-fda-warns-about-serious-risks-and-death-when-combining-opioid-pain-or>
3. Ray WA, Chung CP, Murray KT, Malow BA, Daugherty JR, Stein CM. Mortality and concurrent use of opioids and hypnotics in older patients: a retrospective cohort study. *PLoS Med.* 2021;18(7):e1003709. doi:10.1371/journal.pmed.1003709
4. U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration. National Mental Health Services Survey (N-MHSS) 2018: Data on Mental Health Treatment Facilities (online). Published October 2019. Accessed November 17, 2021. <https://www.samhsa.gov/data/sites/default/files/cbhsq-reports/NMHSS-2018.pdf>

SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

Appendix S1. Additional information on data and analyses.

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Adding telephone follow-up can improve representativeness of surveys of seriously ill people

INTRODUCTION

A growing population of seriously ill people in the United States receives care from community-based serious illness programs.¹ Surveys of patients' experiences with these programs can help identify areas for improvement and compare care quality across programs.² However, survey respondents may be systematically different from nonrespondents in ways related to their experiences of care, which could bias the results by underrepresenting the views of underserved patient groups such as those with Medicaid coverage.³

To test whether mixed mode survey administration could improve single-mode response rates and representativeness for seriously ill patients, we conducted an experiment in which sampled patients from home-based serious illness

programs were randomized to mixed mode (mail with telephone follow-up) or mail-only survey administration.

METHODS

We surveyed patients aged 18+ receiving care from home-based U.S. serious illness programs. The survey was available in English and Spanish and designed to be completed by the patient or proxy respondent (i.e., family caregiver). The mail-only mode consisted of a pre-notification letter, followed by a mail survey 1 week later, and an additional mail survey 3 weeks later. The mixed mode consisted of a pre-notification letter, followed by a mail survey 1 week later, and up to five calls to complete the survey by phone if the mail survey was not returned after 3 weeks.

TABLE 1 Characteristics of patients sampled and responding to serious illness care survey

| Characteristic | Eligible sampled (<i>N</i> = 6210) (%) | Mail-only (<i>N</i> = 3102) RR in category (%) | Mixed (<i>N</i> = 3108) RR in category (%) | Adjusted OR of responding by mixed mode versus mail only (<i>p</i> -value) ^a |
|-----------------------------|--|---|--|---|
| Any | 100.0 | 30.4 | 42.5 | 1.74 (<i>p</i> < 0.01) ^b |
| Sex | | | | |
| Female (reference) | 59.7 | 29.2 | 42.4 | 1.90 (<i>p</i> < 0.01) |
| Male | 40.3 | 32.1 | 42.8 | 1.59 (<i>p</i> < 0.01) |
| Age | | | | |
| 18–54 | 5.9 | 16.9 | 35.9 | 2.54 (<i>p</i> < 0.01) |
| 55–64 | 10.3 | 25.9 | 40.5 | 1.84 (<i>p</i> < 0.01) |
| 65–69 | 7.0 | 30.0 | 43.3 | 1.87 (<i>p</i> < 0.01) |
| 70–74 | 10.9 | 29.2 | 42.6 | 1.89 (<i>p</i> < 0.01) |
| 75–79 | 13.1 | 29.7 | 39.4 | 1.67 (<i>p</i> < 0.01) |
| 80–84 | 16.3 | 31.7 | 45.1 | 1.90 (<i>p</i> < 0.01) |
| 85–89 | 17.6 | 36.1 | 45.2 | 1.54 (<i>p</i> < 0.01) |
| 90 or older (reference) | 19.0 | 31.5 | 42.9 | 1.63 (<i>p</i> < 0.01) |
| Residential setting | | | | |
| Unknown | 23.3 | 23.9 | 40.7 | 2.22 (<i>p</i> = 0.13) |
| Facility | 8.1 | 19.5 | 26.8 | 1.76 (<i>p</i> = 0.04) |
| Home (reference) | 68.6 | 33.9 | 44.9 | 1.64 (<i>p</i> < 0.01) |
| Primary diagnosis | | | | |
| Cancer | 15.6 | 25.4 | 37.9 | 1.85 (<i>p</i> < 0.01) |
| Alzheimer's or dementia | 10.2 | 27.2 | 40.2 | 2.07 (<i>p</i> < 0.01) |
| Other (reference) | 74.3 | 31.9 | 43.7 | 1.72 (<i>p</i> < 0.01) |
| Number of in-person visits | | | | |
| Unknown | 24.7 | 23.9 | 40.3 | 1.63 (<i>p</i> = 0.17) |
| 1–2 times | 15.4 | 28.5 | 31.5 | 1.36 (<i>p</i> = 0.09) |
| 3–4 times | 12.2 | 27.2 | 41.4 | 2.11 (<i>p</i> < 0.01) |
| 5–6 times | 9.8 | 33.0 | 43.4 | 1.98 (<i>p</i> < 0.01) |
| 7 or more times (reference) | 37.9 | 35.9 | 48.2 | 1.91 (<i>p</i> < 0.01) |
| Primary payer | | | | |
| Medicare (reference) | 48.1 | 32.1 | 40.6 | 1.55 (<i>p</i> < 0.01) |
| Medicaid | 8.5 | 17.9 | 43.8 | 3.50 (<i>p</i> < 0.01) |
| Private | 18.9 | 40.5 | 49.6 | 1.57 (<i>p</i> = 0.01) |
| Other or unknown | 24.5 | 23.5 | 40.3 | 2.00 (<i>p</i> = 0.10) |

Note: Percentages were calculated excluding missing values for all variables that had negligible missingness (<4%). For the three variables with non-negligible missingness (residential setting, number of in-person visits, and primary payer), we included missing/unknown as a separate category. *p*-values from joint significance tests for interactions with mode were 0.12 (sex), 0.81 (age), 0.87 (residential setting), 0.59 (primary diagnosis), 0.25 (number of in-person visits), and 0.01 (primary payer). We imputed missing patient-level characteristics with the program mean for that variable, except for the three variables with non-negligible missingness (residential setting, number of in-person visits, and primary payer), for which we included missing/unknown as a separate category. If the variable was missing for the entire program, it was imputed with the overall mean. To ensure results were not sensitive to treatment of missing values, we conducted a sensitivity analysis that removed the small number of programs (4 of 32) that had an entire variable missing, and a complete case analysis. Results from main effects models as well as models that added interaction terms were not sensitive to treatment of missing values.

Abbreviations: OR, odds ratio; RR, response rate.

^aOR represent odds of responding by mixed mode, relative to mail-only mode, for patients having the specified characteristic. *p*-values correspond to the *p*-value for the effect of mixed mode within the stratum, holding all other variables at their mean values. Results are from a logistic regression model for the probability of response, including all characteristics listed in the table, mode, and interaction terms between mode and all characteristics. The model includes program fixed effects.

^bOR represents odds of responding by mixed mode, relative to mail-only mode, from a logistic regression model for the probability of response including only main effects for the characteristics listed in the table and program fixed effects.

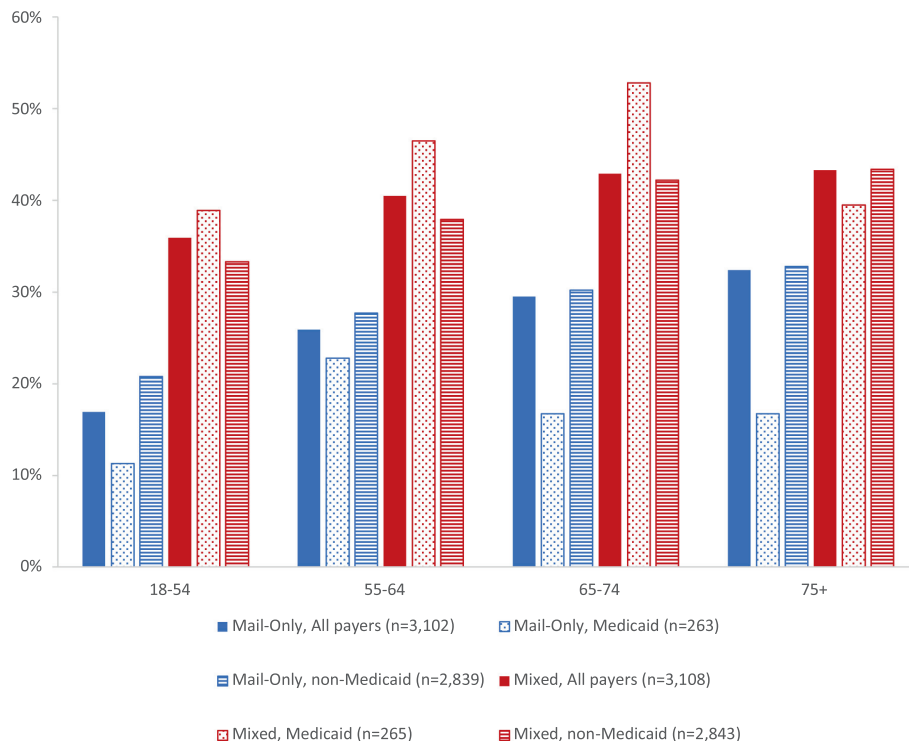


FIGURE 1 Response rates by mode of survey administration, payer, and age group. Mail-only mode response rates are shown in blue, mixed mode in red, and primary payer is distinguished by solid (all payers), dotted (Medicaid), and dashed line (non-Medicaid) shaded bars. Sample sizes are based on eligible sampled cases. The four response rates corresponding to Medicaid payer crossed with mode within the 65–74 and 75+ age groups (mail-only, Medicaid, 65–74; mail-only, Medicaid, 75+; mixed, Medicaid 65–74; mixed, Medicaid, 75+) have low precision as they are based on small sample sizes

The survey instrument contained 56 items assessing communication, care coordination, help for symptoms, planning for care, and support for family and friends.⁴ Final, more concise versions of the survey are available online.⁵

Program administrative data included the patient's sex, age, residential setting (home vs. assisted living facility), primary payer for care, and primary diagnosis, and number of in-person visits.

We predicted survey response from patient characteristics and mode of administration using multivariate logistic regression models.

To determine whether mixed mode particularly benefits some patient groups in a way that affects survey representativeness, we added interactions between mode and all patient characteristics. We also conducted a stratified analysis, fitting the main effects regression model separately for sampled cases assigned to the mail-only and mixed modes.

RESULTS

There were 2263 eligible respondents (overall response rate 36.4%; 30.4% in mail-only mode, 42.5% in mixed mode).

Response rates increased with age. Those who lived in an assisted living facility had less than half the odds of responding as those in a private home. Patients with Medicaid as the primary payer for care were less likely to respond (odds ratio [OR]: 0.69) than those with Medicare as the primary payer. The odds of response were higher for those with more in-person visits.

Mode was one of the strongest predictors of response, with mixed mode yielding 74% greater odds of responding than mail-only (OR: 1.74; Table 1). Tests for heterogeneity of the mixed mode advantage by patient characteristics found significant differences only for the primary payer ($p = 0.01$). These results suggested that mixed mode may be most beneficial for patients with Medicaid as the primary payer (OR: 3.50 for mixed vs. mail mode), with response rates of 43.8% in mixed mode and 17.9% in mail-only mode. In stratified regression models within the mail-only and mixed mode strata, patients in the mail-only mode with Medicaid as their primary payer were substantially less likely to respond than patients with Medicare as the primary payer (OR: 0.43 for Medicaid relative to Medicare; $p < 0.01$ for payer). However, in the mixed mode stratum, odds of response did not differ significantly across primary payer types (OR: 0.89 for Medicaid relative to Medicare, $p = 0.85$ for payer). Figure 1 shows that mixed mode response rates are consistently higher than mail-only for all ages, response rates are higher for older age groups, and that mixed mode is especially beneficial in increasing response rates for those on Medicaid.

DISCUSSION

Seriously ill patients with low socioeconomic status are at greater risk of undertreatment and lower quality care^{6,7}; consequently, it is important to ensure that their experiences are included in assessments of care, and that Medicaid enrollees are adequately represented in patient survey responses used

to measure care quality. Our results demonstrate the value of mixed mode survey administration in ensuring that the voices of these seriously ill individuals are heard.

Consistent with the findings for other patient experience surveys, we found that mixed mode of survey administration yielded a much higher response rate (42.5%) than mail only (30.4%),⁸ and that mixed mode was especially effective in increasing response rates among patients with Medicaid as the primary payer, more than doubling their response rates.⁹ This hard-to-reach group had lower response rates overall, and thus using a mixed mode of survey administration increases representativeness of survey respondents relative to the sample from which they are drawn.

Our results support the use of survey mixed mode administration to achieve broad representation of seriously ill people when evaluating quality of care.

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CONFLICT OF INTEREST


The authors have no conflicts of interest.

AUTHOR CONTRIBUTIONS


All authors have read and approved the submission of this manuscript. Maria DeYoreo, Rebecca Anhang Price, Paul D. Cleary, Joan M. Teno, and Marc N. Elliott contributed substantially to conception and design; Melissa A. Bradley and Danielle Schlang to data acquisition; and all authors to analysis and interpretation of data. Maria DeYoreo and Rebecca Anhang Price drafted the article, and all authors contributed to critical revisions of the article for important intellectual content. Maria DeYoreo, Cheryl K. Montemayor, Anagha Tolpadi, and Marc N. Elliott were responsible for statistical analysis. Rebecca Anhang Price obtained funding and provided study supervision.

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REFERENCES

- Cohn J, Corrigan J, Lynn J, et al. Community-Based Models of Care Delivery for People with Serious Illness. *NAM Perspectives, Discussion Paper*. National Academy of Medicine; 2017.
- Anhang Price R, Elliott MN. Measuring patient-centeredness of care for seriously ill individuals: challenges and opportunities for accountability initiatives. *J Palliat Med*. 2018;21(S2):S28-s35. doi:10.1089/jpm.2017.0452
- Elliott MN, Edwards C, Angeles J, Hambarsoomians K, Hays RD. Patterns of unit and item nonresponse in the CAHPS[®] hospital survey. *Health Serv Res*. 2005;40(6 pt 2):2096-2119. doi:10.1111/j.1475-6773.2005.00476.x
- Anhang Price R, Bradley M, Cleary P, et al. Reliable and valid survey-based measures to assess quality of care in home-based serious illness programs. *J Palliat Med* Forthcoming. 2022. doi:10.1089/jpm.2021.0424
- RAND Corporation. RAND Serious Illness Survey. Accessed December 20, 2021. www.rand.org/Serious-Illness-Survey
- Nelson KE, Wright R, Peeler A, Brockie T, Davidson PM. Sociodemographic disparities in access to hospice and palliative care: an integrative review. *Am J Hosp Palliat Care*. 2021;38(11):1378-1390. doi:10.1177/1049909120985419
- Elk R, Felder TM, Cayir E, Samuel CA. Social inequalities in palliative care for cancer patients in the United States: a structured review. *Semin Oncol Nurs*. 2018;34(3):303-315. doi:10.1016/j.soncn.2018.06.011
- Parast L, Elliott MN, Hambarsoomian K, Teno J, Anhang Price R. Effects of survey mode on Consumer Assessment of Healthcare Providers and Systems (CAHPS) hospice survey scores. *J Am Geriatr Soc*. 2018;66(3):546-552. doi:10.1111/jgs.15265
- Beebe TJ, Davern ME, McAlpine DD, Call KT, Rockwood TH. Increasing response rates in a survey of Medicaid enrollees: the effect of a prepaid monetary incentive and mixed modes (mail and telephone). *Med Care*. 2005;43(4):411-414.