Published in final edited form as:
Appl Nurs Res. 2018 December ; 44: 82–87. doi:10.1016/j.apnr.2018.10.005.

Utilizing Internet-based Recruitment and Data Collection to Access Different Age Groups of Former Family Caregivers

Kristin L. Corey[a], **Mary K. McCurry**[b], **Kristen A. Sethares**[b], **Meg Bourbonniere**[c], **Karen B. Hirschman**[d], **Salimah H. Meghani**[d]

[a]NewCourtland Center for Transitions and Health, University of Pennsylvania, School of Nursing, 418 Curie Blvd. Philadelphia, PA 19104 United States

[b]University of Massachusetts Dartmouth, Department of Adult Nursing, 285 Old Westport Rd, North Dartmouth, MA 02747 United States

[c]University of Rhode Island, College of Nursing, 39 Butterfield Road, Kingston, RI 02881 United States

[d]NewCourtland Center for Transitions and Health, University of Pennsylvania, School of Nursing, 418 Curie Blvd. Philadelphia, PA 19104 United States

Abstract

As Internet accessibility grows among adults in the United States, researchers' utilization of Internet-based surveys and recruitment strategies has increased, but there is a paucity of knowledge about their use in different age groups of former dementia caregivers. The purpose of this secondary analysis is to describe 1) the use of Internet-based recruitment in obtaining a sample inclusive of young and middle aged (age 18–64), young-old (age 65–74), and older-old (age 75 and older) former dementia caregivers and 2) the feasibility of collecting data using an online survey in young and middle aged, young-old, and older-old former dementia caregivers. Utilizing convenience sampling, a four-step recruitment strategy encompassing a combination of Internet-based and non-Internet-based recruitment strategies was employed. Participants (N=171) completed an online survey. Older-old, young-old, and young and middle-aged participants comprised 9%, 30%, and 61% of the sample respectively. All age cohorts provided minimal missing data using an online survey, but older-old participants required 15 additional minutes to complete the survey than young-old participants. Both cohorts of older adults were directed to the survey less frequently through online referral sources than young and middle-aged participants, and no older-old participants were referred via Facebook. All three age cohorts consisted of mostly white women. Internet-based surveys and recruitment were feasible among the age groups but may present challenges for the older-old and minorities. Further research on Internet-based data collection and recruitment is indicated in minority and older-old caregivers, focusing on trust, educational and financial disparities, and technological proficiency as potential barriers.

Keywords

older adult; family caregiving; Internet recruitment; social media; online survey

---

telephone: (215) 573-4314, coreykl@nursing.upenn.edu.

Background

As Internet accessibility increases among adults in the United States, this platform has emerged as an innovative, viable medium for data collection and participant recruitment in healthcare research (King et al., 2014). In recent years, researchers' utilization of online surveys (Remillard et al., 2014) and Internet-based recruitment strategies using social media platforms and websites relevant to a target population (Nolte et al., 2015) has grown substantially. Use of the Internet has become a daily mode of communication through interaction with websites and social media, defined as "highly interactive platforms via which individuals and communities share, co-create, discuss, and modify user-generated content" (Kietzmann et al., 2011, p. 241). Between 2000 and 2018, the prevalence of adults (aged 18 and older) in the United States using the Internet expanded from 52% to 89% (Pew Research Center, 2017a), while social media use also trended upward from 5% in 2005 to 69% in 2018 (Pew Research Center, 2017b).

The Internet facilitates access to members of a population who are difficult to reach via traditional settings, such as former dementia caregivers (King et al., 2014). Presently, there is limited research on former family caregivers following the death of a care recipient with dementia and recruiting members of this population for participation in research studies is challenged by the lack of a discrete setting where this population can be accessed. After caregiving ends, former dementia caregivers often lose their connections to support services, such as long-term care, the care recipient's health care providers, or support groups (Larkin, 2009), and can no longer be recruited from traditional settings. It remains unclear whether former caregivers continue connections with online resources (e.g. Internet-based support groups on social media websites) following a care recipient's death and can feasibly be recruited from these sources.

Including older adults (age 65 and older) in studies of former dementia caregivers is paramount, as older adults age 65–74 and 75 and older comprise 12% and 7% of the caregiver population in the United States respectively (National Alliance for Caregiving and AARP Public Policy Institute, 2015). Recruiting older adults through Internet-based referral sources may be influenced by several possible barriers to Internet use in this population, such as less trust in information found on the Internet, less education and income, sensory perceptual or motor deficits, and failure to perceive the Internet as useful (Braun, 2013; Choi & DiNitto, 2013; Hong & Cho, 2017; Remillard et al., 2014). However, Internet use is growing rapidly among older adults in the United States, increasing from 14% to 64% between the years 2000 and 2016 (Pew Research Center, 2017a). In 2016, about one third of older adults utilized at least one social media site, such as Facebook, Twitter, or Instagram, and Facebook remained the most commonly used social media site in this age group (Pew Research Center, 2017b). Social media platforms are emerging as a feasible modality for recruiting older study participants (Coelho et al., 2017). Further, research indicates older adults can deliver quality data via online surveys, as evidenced by only 2% missing responses on a 121-item survey (Nahm et al., 2011).

Understanding the potential role of Internet and social media use in studies of older adults is impeded by a prominent gap in the research. When describing the characteristics of the Internet users in their studies, researchers often do not acknowledge rates of Internet use in different age cohorts of older adults, instead reporting findings on the general population of older adults aged 65 years or older (Pew Research Center, 2017a). By grouping all adults age 65 or older into one category, important information about potential differences in Internet use among young-old adults (age 65–74) and older-old adults (age 75 and older) may be negated. The cohort of older adults currently between the ages of 65 and 72 are Baby Boomers, a segment of the population known to have greater access to and experience with technology (LeRouge et al., 2014). Internet use among adults aged 75 and older is considerably less than in the general population of older adults (age 65 and older), with rates of Internet use ranging from 9–15% (Choi & DiNitto, 2013) as opposed to 64% in the general older adult population (Pew Research Center, 2017a). Further, adults aged 80 and older demonstrated lower response rates to an online survey (10%) when compared to telephone survey (60%) (Sims et al., 2017), suggesting that response bias may be a significant consideration when utilizing the Internet in studies including older-old adults. The usefulness of online surveys and Internet-based recruitment strategies differs significantly among the different age cohorts of older adults; therefore, their use in studies of former dementia caregivers may hinder recruitment of a sample that is representative of the caregiver population with regard to age. The purpose of this secondary analysis is to: describe the use of an Internet-based recruitment strategy in obtaining a sample inclusive of young and middle aged (age 18–64), young-old (age 65–74), and older-old (age 75 and older) participants in a study of former family caregivers of people with dementia and their completion of an online survey. Two objectives guided this study:

1. To explore the utilization of Internet-based referral sources, specifically content-relevant websites and the social media platform, Facebook, in recruiting a sample of former dementia caregivers that is inclusive of young and middle-aged adults, young-old adults, and older-old adults.
2. To examine the feasibility of an online survey for collecting data from three age cohorts of former dementia caregivers (young and middle-aged adults, young-old, and older-old).

Methods

This study is a secondary analysis of the recruitment methods and completeness of data collected from former family caregivers of persons with dementia. The parent study aim was to explore associations between caregiver characteristics, psychological distress, and sleep quality (Corey et al., in press). Participants in the parent study were eligible for the study if they: were age 18 or older, were English speaking, provided informal, unpaid care to a person with dementia for at least six consecutive months prior to the care recipient’s death, and if the care recipient was deceased. Data for the parent study were collected between January 2017 and February 2017. Only the recruitment methods, ages of respondents, and demographics are presented.

Procedures

A Combined Approach to Participant Recruitment—

In accordance with the recommendations of Nahm and colleagues (2011), a combination of Internet- and non-Internet-based recruitment strategies was developed, including the use of social media (Facebook), websites with content relevant to dementia or caregiving, and referrals from the principal investigator's (PI) colleagues working in healthcare and dementia support group leaders across the United States. Because Internet-based recruitment has not been studied in former dementia caregivers, it was unknown if the target sample was available. Therefore, the Internet-based strategies (social media, content-relevant websites) were implemented first, and non-Internet-based strategies (referrals from colleagues and support group leaders) were used later in the recruitment process when referrals declined after three weeks of Internet-based recruitment. Facebook and websites relevant to the population of interest were selected because both of these strategies demonstrated greater effectiveness in recruiting participants from non-caregiving populations in previous research (Khatri et al., 2015). Utilizing convenience and snowball sampling, a four-step recruitment strategy was employed (Figure 1), through the following modalities:

1. First, a Facebook page dedicated to the study was created and managed solely by the PI. On the Facebook page, the PI posted an invitation to participate in the study, detailing the study purpose and eligibility criteria, and included the link to the online survey at the end of the invitation. The Facebook page was open to the public. The post containing the invitation and survey link on the study's Facebook page was then shared on the PI's personal Facebook page. In the post, the PI requested that potential participants like and share the survey link to their own Facebook timelines to generate a snowball effect and promote participant recruitment (Nolte et al., 2015).
2. Second, the invitation to participate in this study and the survey link were posted on the websites of organizations related to caregivers and dementia (Alzheimer's Association and Family Caregiver Alliance), following review and approval from the organization.
3. Third, the invitation to participate in the study and the survey link were shared on 16 Facebook pages of groups relevant to dementia, aging, and caregiving, after obtaining permission from the appropriate contact person (e.g. executive director, social media manager). The invitation to participate in the study and the survey link were sent to the contact person and posted on the respective Facebook page by the website administrator. The Facebook pages were organized by Alzheimer's or senior resource centers and online caregiver support groups, and provided access to online communities whose members were likely to meet the study eligibility criteria (Bern-Klug, 2008). To include minority participants, the PI contacted the administrators of websites and Facebook pages targeting the needs of black and Hispanic caregivers.
4. Following completion of the first three steps, the invitation to participate in the study and survey link were provided via email to the PI's professional contacts currently working in healthcare and to dementia support group leaders

throughout the United States. The PI requested that they forward the invitation and link to former dementia caregivers meeting the eligibility criteria.

Prior to recruitment and data collection, the study, including all recruitment procedures, was reviewed and approved by the Institutional Review Board at the University of Massachusetts Dartmouth.

An Internet-based Approach to Data Collection Using an Online Survey—All participants who consented and entered the survey on the Qualtrics LLC© platform (Qualtrics, 2016) were asked to complete six standardized assessment instruments and 19 demographic items. In alignment with the recommendations of King and colleagues (2014), a progress bar was included to display the participant's progression through the survey, and the total number of survey questions was limited to less than 200 to reduce survey fatigue and maximize rates of survey completion. Further, longer instruments (>20 items) were formatted in matrix format to improve readability and maximize ease of use.

Data Analyses

The feasibility of the online survey among the three age cohorts was examined by measurements of incomplete surveys, missing data, and survey completion time. Incomplete surveys were measured by computing the number of surveys with more than 15% of responses missing (Polit & Beck, 2012). Within the completed surveys, missing data were calculated by dividing the total number of missing responses by the total number of items and multiplying by 100. The average survey completion time was determined for each age cohort by computing the mean value in minutes and one-way ANOVA was calculated to evaluate differences in survey completion time among the three age cohorts.

To assess the adequacy of the online recruitment approaches, the composition of the sample with regard to age was examined by calculating the percentage of the total sample made up by each age cohort. Further, the percentage of each age cohort referred to the survey by Internet-based sources was calculated and the demographic characteristics of the cohorts were reviewed to explore the heterogeneity of the three age groups. Finally, the total time required to recruit the target sample size was calculated (Sidani & Braden, 2011).

Results

Use of Online Survey in Older Adult Participants

A total of 200 former dementia caregivers who met the eligibility criteria consented to participate in the study, and 171 participants, or approximately 86% of consenting participants, completed the survey. Twenty-nine responses were omitted because the percentage of incomplete items surpassed 15% (Polit & Beck, 2012). Cohorts of older-old, young-old, and young and middle-aged former dementia caregivers included 15, 51, and 105 participants respectively. Of the 29 incomplete responses, 20 participants reported their age. Two incomplete surveys were submitted by young-old participants and one older-old participant did not complete the survey. The remaining 17 incomplete surveys were submitted by young and middle-aged participants.

The total sample of former dementia caregivers (N=171) demonstrated minimal missing data (0.25%). Missing data among the surveys submitted by older-old (0.32%), young-old (0.15%), and young and middle-aged (0.22%) cohorts were also minimal and comparable to the percentage of missing data demonstrated by the total sample. Both the young and middle-aged participants and young-old participants completed the online survey in approximately 23 minutes, on average, while the older-old participants submitted the survey in about 38 minutes. The ANOVA revealed significant differences in survey completion time between the older old cohort and both the young-old cohort and the young and middle-aged cohort ($p = .002$). There were no statistically significant differences in survey completion times among the young-old cohort and the young and middle-aged cohorts.

Use of Online Referral Sources in Older Adult Participants

Older-old, young-old, and young and middle-aged participants comprised 9%, 30%, and 61% of the full sample respectively. Referral sources for the total sample and three age cohorts are provided in Table 1. Both cohorts of older adults were less frequently directed to the survey through caregiving- or dementia-related websites or Facebook than young and middle-aged participants (62.8%), but rates of referral through online sources were comparable between the older-old subsample (46.7%) and the young-old subsample (47%) (Figure 2). However, none of the older-old participants were directed to the survey via the social media platform, Facebook.

The demographic characteristics of the total sample and three age cohorts are detailed in Table 1. All three age cohorts consisted of mostly white women, and the two older cohorts consisted of a higher percentage of white participants. The majority of the older age cohorts were widowed spouses or partners of the deceased care recipients, while most of the young and middle-aged participants were adult children. The sample (N=171) was recruited over 5 weeks.

Discussion

Knowledge about Internet-based approaches to data collection and recruitment in different age groups of former dementia caregivers, particularly older adult caregivers, is limited. This paper described the feasibility of a predominantly Internet-based approach to data collection and participant recruitment among young and middle-aged, young-old, and older old former dementia caregivers.

Consistent with the findings of Nahm and colleagues (2011), both cohorts of older caregivers provided minimal missing data using an online survey. These findings support the feasibility of online surveys in older former caregivers. However, the older-old group spent significantly more time completing the survey than the young-old and young and middle-aged groups, suggesting that the older-old group experienced more survey fatigue. The extended time requirement for survey completion may be explained by prior research that highlighted older adults’ lack of proficiency in computers as one prominent barrier to Internet use (Remillard et al., 2014).

Although both older adult cohorts were less commonly referred to the survey via online sources than young and middle-aged caregivers, rates of online referrals were comparable among the two older adult groups (47%). However, the older-old caregivers were directed to the survey through caregiving- and dementia-related websites only. Although 17–24% of adults age 75 years or older engage in social media websites, no older-old caregivers (n=15) accessed the survey via Facebook, suggesting that social media use among older-old adults may not be sufficient to support its utilization in this age group, and supplementary recruitment strategies (e.g. websites, referrals from support group leaders) are indicated to recruit members of the older-old age group (Anderson & Perrin, 2017).

In this study, the total sample was representative of the caregiver population with regard to age, but all age cohorts were overrepresented by white, educated former dementia caregivers. This finding is congruent with previous research that noted higher Internet usage among adults with more education (Pew Research Center, 2017a). Despite efforts to include minorities, the combination of Internet-based and non- Internet-based strategies did not yield a diverse sample. However, available survey data revealed similar rates of Internet use among white (88%), black (85%), and Hispanic (88%) adults in the United States; therefore, the low number of responses from minorities may originate from other barriers to Internet use such as lack of trust in online surveys or reduced income (Pew Research Center, 2017a).

Conclusion

This descriptive secondary analysis supported four major conclusions:

1. Young and middle-aged, young-old, and older-old former dementia caregivers are capable of providing minimal missing data using an online survey; however, older-old caregivers may experience more survey fatigue than younger caregivers, contributing to response bias.
2. Websites are useful referral sources when recruiting former dementia caregivers across all age groups but provide greater access to young and middle-aged adults than older adults. Therefore, researchers may consider supplementing this referral method with non-Internet sources to avoid omitting older participants in study samples.
3. Facebook is effective in recruiting young and middle-aged and young-old caregivers but may not be useful in recruiting older-old caregivers; however, further research on social media recruitment in older-old adults using larger samples is indicated.
4. An Internet-based recruitment approach is insufficient in recruiting a sample that is diverse in racial or ethnic background across all age groups of former dementia caregivers.

Further study of Internet-based data collection and recruitment is indicated in two specific cohorts of former dementia caregivers: minorities and older-old adults. Despite comparable rates of Internet use among white, black, and Hispanic adults, all age cohorts in this study lacked racial diversity, and future studies could focus on the role of trust, educational and financial disparities, and technological proficiency as barriers to recruiting minority groups online. Future investigations of Internet-based data collection and recruitment in caregivers or other study populations would be most valuable and informative if their use in young-old and older-old participants was analyzed separately to facilitate greater understanding of their feasibility in older-old study participants. Finally, while the Internet provides a viable medium for recruiting and collecting data, researchers must consider the prominent differences in Internet and social media use among young and middle-aged, young-old, and older-old former caregivers when conducting studies that employ Internet-based approaches to data collection and recruitment, and tailor their approaches to the unique technological capabilities of different age groups.

Acknowledgements

Funding: KLC acknowledges support from the Ruth L. Kirschstein National Research Service Award training program *Individualized Care for At Risk Older Adults* at the University of Pennsylvania, funded by National Institute of Nursing Research T32NR009356.

References

Anderson M, & Perrin A (2017). Tech adoption climbs among older adults Retrieved on January 15, 2017 from http://www.pewinternet.org/2017/05/17/tech-adoption-climbs-among-older-adults

Bern-Klug M (2008). The emotional context facing nursing home residents' families: A call for role reinforcement strategies from nursing homes and the community. Journal of the American Medical Directors Association, 9, 36–44. doi: 10.1016/j.jamda.2007.08.010 [PubMed: 18187111]

Braun MT (2013). Obstacles to social networking website use among older adults. Computers in Human Behavior, 29, 673–680. 10.1016/j.chb.2012.12.004

Choi NG, & DiNitto DM (2013). The digital divide among low-income homebound older adults: Internet use patterns, eHealth literacy, and attitudes toward computer/Internet use. Journal of Medical Internet Research, 15(5), doi:10.2196/jmir.2645

Coelho J, Rito F, & Duarte C (2017). "You, me & TV"- Fighting social isolation of older adults with Facebook, TV and multimodality. International Journal of Human-Computer Studies, 98, 38–50. 10.1016/j.ijhcs.2016.09.015

Corey KL, McCurry MK, Sethares KA, Bourbonniere M, Hirschman KB, & Meghani SH (in press). Predictors of psychological distress and sleep quality in former family caregivers of people with dementia. Aging & Mental Health

Hong YA, & Cho J (2017). Has the digital health divide widened? Trends of health-related Internet use among older adults from 2003 to 2011. Journals of Gerontology: Social Sciences, 72(5), 856–863. doi:10.1093/geronb/gbw100

Khatri C, Chapman SJ, Glasbey J, Kelly M, Nepogodiev D, Bhangu A, & Fitzgerald JE (2015). Social media and Internet driven study recruitment: Evaluating a new model for promoting collaborator engagement and participation. PLoS ONE 10(3), doi:10.1371/journal.pone.0118899

Kietzmann JH, Hermkens K, McCarthy IP, & Silvestre BS (2011). Social media? Get serious! Understanding the functional building blocks of social media. Business Horizons, 54, 241–251.

King DB, O'Rourke N, & DeLongis A (2014). Social media recruitment and online data collection: A beginner's guide and best practices for accessing low-prevalence and hard-to-reach populations. Canadian Psychology, 55(4), 240–249. 10.1037/a0038087

Larkin M (2009). Life after caring: The post-caring experiences of former carers. British Journal of Social Work, 39, 1026–1042. 10.1093/bjsw/bcn030

LeRouge C, Van Slyke C, Seale D, & Wright K (2014). Baby boomers' adoption of consumer health technologies: Survey on readiness and barriers. Journal of Medical Internet Research, 16(9), doi: 10.2196/jmir.3049

Nahm E, Bausell B, Resnick B, Covington B, Brennan PF, Mathews R, & Park JH (2011). Online research in older adults: Lessons learned from conducting an online randomized controlled trial. Applied Nursing Research, 24, 269–275. doi: 10.1016/j.apnr.2009.09.004 [PubMed: 20974077]

National Alliance for Caregiving and AARP Public Policy Institute. (2015). Caregiving in the U.S. 2015 Retrieved on August 5, 2016 from http://www.caregiving.org/wpcontent/uploads/2015/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf

Nolte MT, Shauver MJ, & Chung KC (2015). Analysis of four recruitment methods for obtaining normative data through a Web-based questionnaire: a pilot study. HAND, 10, 529–534. [PubMed: 26330790]

Pew Research Center (2017a). Internet/broadband fact sheet Retrieved on April 10, 2018 from http://www.pewinternet.org/fact-sheet/internet-broadband.

Pew Research Center (2017b). Social media fact sheet Retrieved on April 10, 2018 from http://www.pewinternet.org/fact-sheet/social-media.

Polit DF, & Beck CT (2012). Nursing research: Generating and assessing evidence for nursing practice, 9th Ed. Philadelphia, PA: Lippincott Williams & Wilkins.

Qualtrics LLC (2016). Security statement Retrieved October 25, 2016, from www.qualtrics.com/

Remillard ML, Mazor KM, Cutrona SL, Gurwitz JH, & Tjia J (2014). Systematic review of the use of online questionnaires of older adults. Journal of the American Geriatrics Society, 62, 696–705. doi: 10.1111/jgs.12747 [PubMed: 24635138]

Sidani S, & Braden CJ (2011). Testing the acceptability and feasibility of interventions. In Design, evaluation, and translation of nursing interventions (1st ed., pp. 163–196). Chichester, West Sussex: Wiley-Blackwell.

Sims T, Reed AE, & Carr DC (2017). Information and communication technology use is related to higher well-being among the oldest-old. Journals of Gerontology: Psychological Sciences, 72(5), 761–770. doi:10.1093/geronb/gbw130

Highlights:

1. Former dementia caregivers of all ages provided minimal missing data using an online survey, but older-old (75 years and older) caregivers may experience more survey fatigue.
2. Internet-based referral sources are more commonly used by young and middle-aged caregivers than older caregivers.
3. Facebook may not be useful in recruiting older-old former dementia caregivers.
4. Across all age groups, an Internet-based recruitment approach may not be sufficient in recruiting a sample of former dementia caregivers that is diverse in racial and ethnic background.

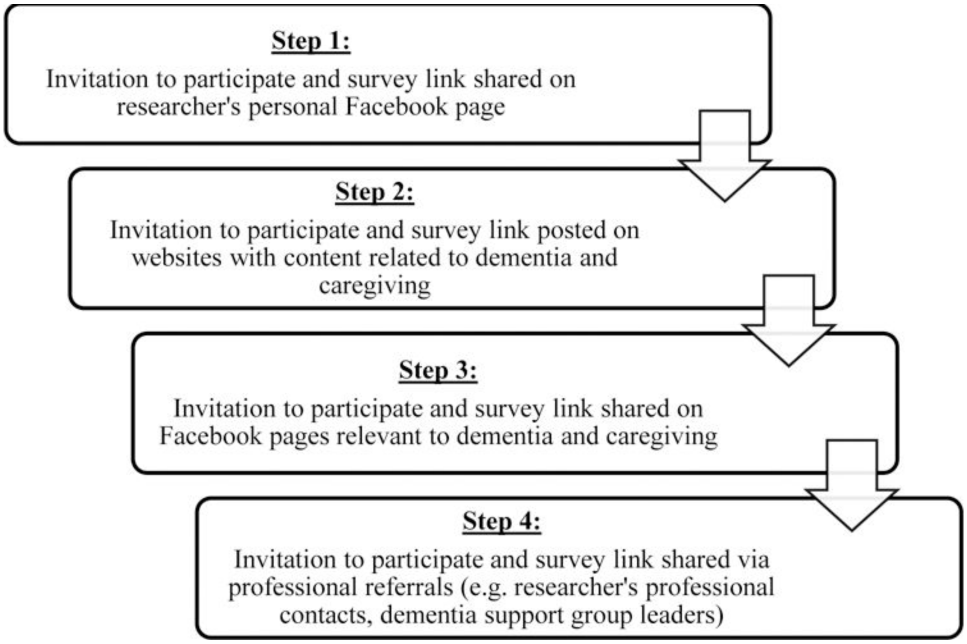

Figure 1.

A four-step recruitment strategy was used to obtain a convenience sample of former dementia caregivers.

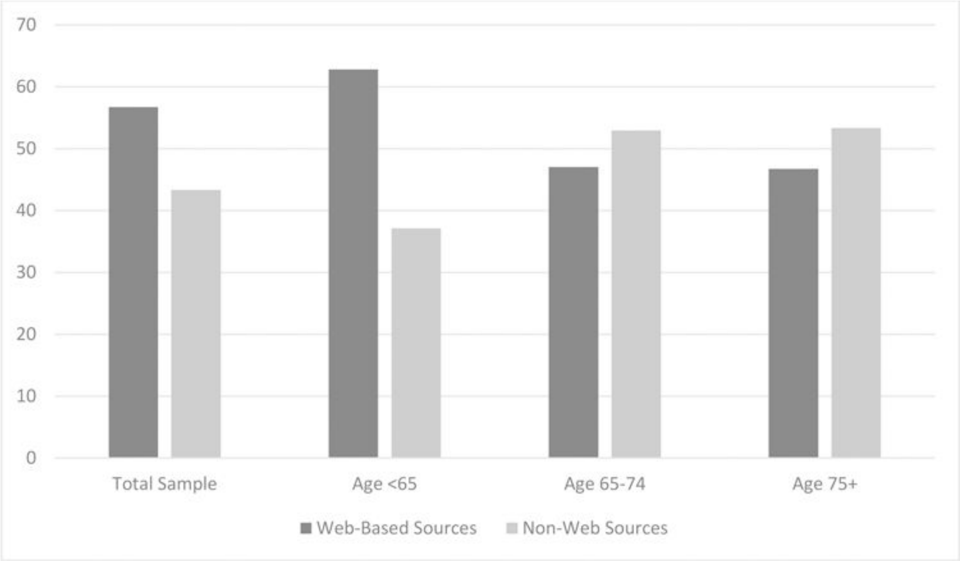

Figure 2.

Use of Internet-based and non-Internet-based referral sources according to participant age groups and compared to the total sample.

Table 1.

Demographic Characteristics of Total Sample, Young and Middle-Aged, Young-Old, and Older-Old Cohorts

Characteristic	Total Sample N=171		<65 N=105		65–74 N=51		75+ N=15	
	n	%	n	%	n	%	n	%
Gender								
Male	15	8.8	10	9.5	3	5.9	2	13.3
Female	156	91.2	95	90.5	48	94.1	13	86.7
Marital Status								
Single	26	15.2	25	23.8	1	2.0	0	0
Married	83	48.5	59	56.2	22	43.1	2	13.3
Divorced	13	7.6	11	10.5	2	3.9	0	0
Widowed	49	28.7	10	9.5	26	51.0	13	86.7
Annual Income								
Less than $20,000	22	12.9	17	16.2	3	5.9	2	13.3
$20,000-$39,999	34	19.9	19	18.1	11	21.6	4	26.7
$40,000-$59,999	51	29.9	25	23.8	19	37.3	4	26.7
$60,000-$79,999	34	19.9	24	22.9	7	13.7	3	20.0
$80,000-$99,999	9	5.3	6	5.7	2	3.9	1	6.7
$100,000 or higher	21	12.3	13	12.4	7	13.7	1	6.7
Race/Ethnicity								
White, non-Hispanic	155	90.6	92	87.6	49	96.1	14	93.3
Black, African American	8	4.7	6	5.7	2	3.9	0	0
Hispanic, Latino, Spanish origin	3	1.8	3	2.9	0	0	0	0
Asian	3	1.8	3	2.9	0	0	0	0
Other	2	1.2	1	1.0	0	0	1	6.7
Education								
Some high school	3	1.8	2	1.9	1	2.0	0	0
High school or GED	49	28.7	28	26.7	14	27.5	7	46.7
Associate’s degree	29	17.0	24	22.9	4	7.8	1	6.7
Bachelor’s degree	46	26.9	29	27.6	12	23.5	5	33.3
Master’s degree	37	21.6	18	17.1	18	35.3	1	6.7
Doctorate	7	4.1	4	3.8	2	3.9	1	6.7
Relationship								
Spouse or partner	44	25.7	10	9.5	24	47.1	10	66.7
Adult child	102	59.6	75	71.4	25	49.0	2	13.3
Grandchild	8	4.7	8	7.6	0	0	0	0
Friend	5	2.9	3	2.9	1	2.0	1	6.7
Other	12	7.0	9	8.6	1	2.0	2	13.3
Geographic location								
Northeast	66	38.6	46	43.8	17	33.3	3	20.0
Southeast	33	19.3	16	15.2	10	19.6	7	46.7
Midwest	24	14.0	15	14.3	9	17.6	0	0

Characteristic	Total Sample N=171		<65 N=105		65–74 N=51		75+ N=15	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Southwest	26	15.2	15	14.3	8	15.7	3	20.0
West	14	8.2	9	8.6	4	7.8	1	6.7
Other	8	4.7	4	3.8	3	5.9	1	6.7
Referral Source								
Caregiving website	25	14.6	15	14.3	7	13.7	3	20.0
Dementia website	19	11.1	10	9.5	5	9.8	4	26.7
Facebook	53	31.0	41	39.0	12	23.5	0	0
Professional referrals	72	42.1	37	35.2	27	52.9	8	53.3
Other	2	1.2	2	1.9	0	0	0	0
Mean Age in years (Range)	60 (25–87)		53 (25–64)		69 (65–74)		80 (76–87)	