Helping Older Adults Assess Their Need for Future Home-Support Services

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ABSTRACT

Objective: Few seniors consider the future home support and health needs they may require as they age. We sought to assess the efficacy of the tool PlanYourLifespan.org (PYL) in influencing seniors' planning behaviors, communication of plans and perception of planning, knowledge of home care services, and confidence in accessing services for future needs.

Method: Randomized controlled trial (RCT) of community-dwelling adults aged 65 and older in urban, suburban, and rural areas in Texas, Illinois, and Indiana.

Results: Among 385 participants, the mean age was 71.9 years and 79.5% were female. Between baseline and 1-month follow-up, the average planning behavior score increased 0.22 points in the PYL arm and dropped 0.92 points in the attention control (AC) arm. After controlling for baseline, the mean 1-month planning behavior and communication score was significantly higher in the PYL arm than in the AC arm (1.25 points; CI, 0.37-2.12; p = 0.0054). For the knowledge/understanding of home services score at 1-month follow-up, the intervention group had a 0.6-point change (SD = 1.6), and the control group who had a –0.1-point change in knowledge score. Linear mixed modeling results suggested that sex, health literacy level, level of education, income, and history of high blood pressure/kidney disease were significant predictors of knowledge over time. Controlling for these variables, treatment effect remained significant (p < 0.0001). Though not statistically significant, secondary outcomes (1) perception of importance of planning (0.60 points; CI, –0.06-1.27; p = 0.0766) and (2) confidence accessing home services (0.47 points; CI, –0.04-0.97; p = 0.0683) mean scores also exhibited an average overall increase at 1-month follow-up in the active intervention arm compared with the control. Secondary analyses of primary outcome via longitudinal linear mixed modeling suggested a marginal study arm-by-time interaction effect for both planning behavior (p = 0.0470) and perception of importance (p = 0.0522). Significant baseline covariates for primary outcome included self-efficacy, education, perceived social support, power of attorney, and history of stroke.

Conclusions and Practice Implications: PYL proved effective in helping seniors plan for and communicate their health and support needs as well as in increasing knowledge and understanding of home-based services. This free, nationally available tool may help individuals understand, plan, and communicate their options for their future support needs.

BACKGROUND

Aging in Place Is a Priority for Many Seniors.[1-4] A common fear among seniors is removal from their homes and placement in long-term care institutions.[5,6] When people enter their 70s, 80s, and 90s—the "fourth quarter" of life—aging in place is no longer a simple outcome of being present in a home. Rather, seniors have to be safe, handle their own needs, or access services that can fulfill those needs.[7-11] One of the Healthy People 2020 objectives is to reduce the proportion of noninstitutionalized older adults who have unmet needs for long-term services and support. Having unmet needs carries a high price for seniors, their loved ones, and the health care system. People with unmet health and home-based needs face increased rates of hospitalizations, rehospitalizations, morbidities, and institutionalization, which can be devastating to individuals and result in greater health system and Medicare costs.

Unfortunately, seniors and their families often lack knowledge of available home care services.[12,13] Further, seniors often do not understand their health trajectory or plan accurately for future needs, which leads to them not remaining safely in their homes as long as they could.[14,15] As a result, when seniors become sick and are hospitalized, families must react to the emergency.[16] While the senior is incapacitated in a hospital bed, families select subacute rehabilitation facilities, consider placement in long-term institutions, or hire caregivers to help after the senior is discharged.[17-20] Often—because they have never had specific discussions about the senior's future needs—these families are making decisions without knowing their loved one's preferences. Subsequently, seniors may find themselves having little or no voice in their future care.

A gap exists in understanding, planning, and accessing support services in the home among seniors and their families; our patient partners and stakeholders have readily identified this need in their communities. To our knowledge, no prior interventions have addressed the health decisions and resources needed during this fourth quarter of life.

Through partnerships with seniors, senior community groups, area agencies on aging (AAAs), and home care agencies, we sought to do the following:

- **Aim 1:** Develop, pilot test, and refine a PlanYourLifespan.org (PYL) tool to assist seniors in making informed choices about issues in their health trajectory that influence their ability to remain in their homes.

- **Aim 2:** Conduct a randomized controlled trial (RCT) of the PYL tool to determine understanding of home care services, health trajectory, and other patient-centered outcomes.

- **Aim 3:** Disseminate nationally the PYL tool via senior-focused organizations (eg, Home Care Association of America, Village to Village Network).

METHODS

Aim 1: *Develop, pilot test, and refine a PYL tool to assist seniors in making informed choices about issues in their health trajectory that influence their ability to remain in their homes.*

<u>Overview of PYL</u>

Simply put, PYL is not used for planning for end of life; rather, it is used to plan for the 10 to 20 years before end of life, when more assistance is needed in the home. When a senior is hospitalized, family must react quickly and decide where the senior should go for rehabilitation (eg, choose a skilled nursing facility) or support the senior when her or she returns home. When a senior with Alzheimer's faces worsening memory loss, family members must either find a caregiver or become caregivers themselves. Most of these decisions are made in the midst of a health crisis. PYL educates seniors about the health events that often occur with age and connects users to locally and nationally available home-based resources that can assist now or in the future. PYL is personalized, accessible, dynamic, and adaptable—all health data can be saved, along with the patient's log-in information, and changed according to the senior's wishes or changing health needs.

<u>Content of PYL Tool</u>

In aim 1, we conducted focus groups with 68 seniors, aged ≥ 65 years (mean age 73.8 years), living in the community (rural, urban, and suburban), using open-ended questions about perceptions of future heath events, needs, and planning. Three investigators coded transcriptions using constant comparative analysis to identify emerging themes, with disagreements resolved via consensus. We then published these qualitative results.[11] We identified major themes—ie, which advanced life events (ALEs) would affect aging in place—as hospitalizations, falls, dementia, spousal loss, and inability to keep up the home. We organized PYL around the 3 health-related ALEs for which seniors would least likely have a voice: hospitalizations, falls/functional loss, and dementia.

Our team of researchers and patient partners/stakeholders then critically discussed each ALE to determine which information and resources should be part of the PYL tool. Seniors, caregivers, and patient advocates brought forth their personal perspectives on information

they wished they had. Social workers, home caregiver agencies, and AAA representatives canvassed what resources were available both nationally and locally.

Each section of PYL starts with an introduction, with subcategories providing information on what to expect and the types of resources available to support home needs. It can be highly personalized; users can log in and make specific choices for themselves. For example, by entering their zip code, the user can discover the closest AAA, which services are provided there, what home caregiver agencies or services exist in their area, or which senior community groups are nearby (Figure 1).

Figure 1. CONSORT Diagram
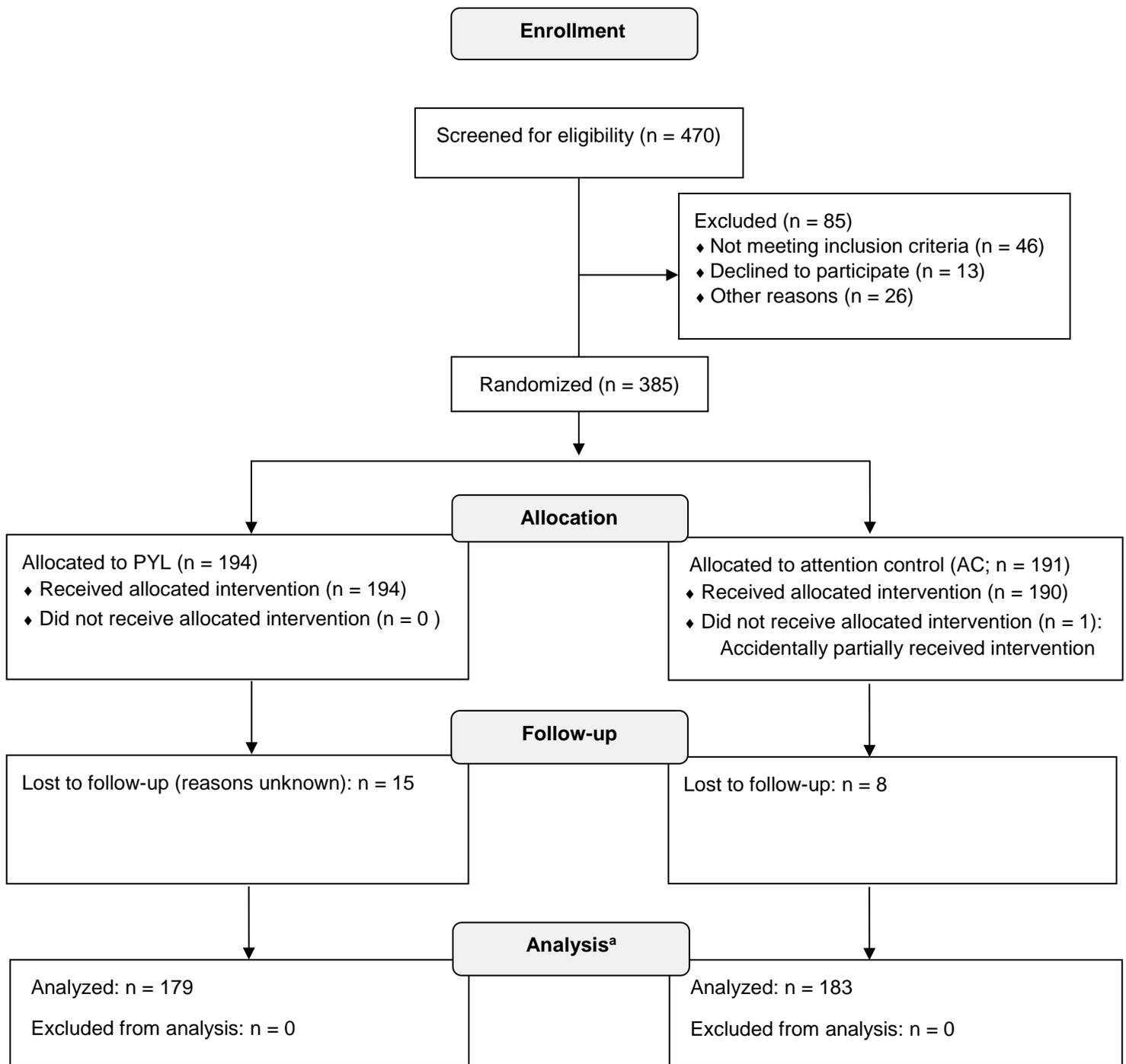
PYL Strategies to Enhance Family and Caregiver Involvement in Older Adult Care

From our focus group analysis, many seniors frequently expressed reliance on family or offspring for navigating ALEs, although many stated that they had not discussed their needs with their families. In addition, some of the seniors who had tried to discuss their future care needs with their families reported having experiences in which their offspring indicated they did not want to talk about the need for future care.

> *"I have a daughter who works in the field, and she said, 'Oh no, you're much too old to start becoming demented now. Don't worry about it. You're not going to get Alzheimer's,' and I have such relief, so whether it's true or not, I'm freed."*

> *"I don't have a way to discuss that too much with my daughter because she doesn't want to hear it."*

As many family members are not directly involved in the care of the older adult, we created a section on communication to facilitate discussion between seniors and family about home support needs. PYL presents seniors/families with conversation starters and techniques on how to communicate and be involved in the decision process about home care services.

Users can save their preferences for home services and revisit their choices at any time. As needs change, they may want to revisit certain home resources options or make changes to their long-term plans. To further support communication and involvement between older adults and their families, a summary of their long-term choices—with specifics on available home resources—can be printed or emailed to relevant parties. For example, a senior uses PYL and makes decisions about living with family in the future versus hiring caregivers. The senior can email these choices to his or her daughter, which can stimulate a conversation about future needs and expectations.

In response to refinement feedback from our patient partners and stakeholders, the PYL tool also includes short, 1- to 3-minute videos of seniors and their family members who have had to use home services and make decisions during or due to ALEs. Each video is transcribed in large print for the hearing impaired. These personal stories have helped drive home the message about which services are useful to age in place.

<u>Sensitivity to Health Literacy and Cognitive Impairment Levels</u>

Because health literacy and cognitive challenges increase with age,[21] the PYL tool presents information that is understandable at all levels of health literacy and is sensitive to cognitive load. We used a health literacy perspective and Doak, Doak and Root's Suitability Assessment of Materials to guide development of PYL.[22] This perspective incorporates adult learning principles in the creation of health materials so they are accessible and useful for patients with limited literacy skills, utilizing criteria for assessment of content, literacy demand, graphics, layout and typography, and learning simulation. We also considered cognitive load theory, in recognizing that the cognitive load, or demand, that health information presents to an individual can ultimately influence the comprehension of that material.[23,24] For example, health instructions could strain cognitive processes if they are too complex. PYL uses simplified and less dense text, with familiar terms to reduce the cognitive demand required to process new information.

<u>PYL: Electronic and Paper Versions</u>

PYL is available in both electronic and paper versions; creating a paper version allowed seniors who do not use computers to still obtain benefit. Developing PYL in an electronic format enabled quicker dissemination to seniors and their supporters. We have found that seniors are becoming more electronically savvy and embracing web-based applications. Such compatible development (in both paper and electronic formats) has allowed the PYL tool to be widely disseminated and universally used by seniors and their families.

Aim 2: *Conduct a randomized controlled trial of the PYL tool to determine understanding of home care services, health trajectory, and other patient-centered outcomes.*

<u>Study Design and Randomization</u>

To test the effectiveness of the PYL intervention, we conducted a 2-armed (attention control [AC] and PYL intervention), parallel, randomized controlled trial. Participants were randomly assigned to 1 of the 2 interventions via a pregenerated central randomization list using equal (1:1) allocation and random permuted block design to ensure relatively equal allocation throughout the study. The AC condition exposed participants to the National Institute on Aging–sponsored website Go4Life.com, which is an educational website on physical activity

relevant to seniors. This site's design and layout are comparable to PYL, but Go4Life.com does not include information about advanced planning. The AC condition controlled for the possibility that regular contact with the study team may improve outcomes in participants randomized to the PYL website.

We conducted the trial from October 2014 to September 2015 in Chicago, Illinois; Fort Wayne, Indiana; and Houston, Texas. Inclusion criteria were the following: aged 65 and older, English-speaking, scoring ≥ 4 questions correctly on the Brief Cognitive Screen,[25] and current self-reported use of a computer or smartphone with internet. We excluded participants if they had previously participated in the PYL-building focus groups or in the beta testing of the PYL website.

Community-based patient partners and stakeholders drove subject recruitment in their communities through word of mouth, emails, newsletters, and flyers. At the AAA and community centers where services are provided, such as food vouchers and case management, potential participants were recruited on site; they were given a flyer about the study and contact information if they were interested. At the clinical sites, staff was informed about the study, and they were able to refer potential participants. Study materials such as flyers and information sheets were also located in the clinic waiting rooms. The Villages, nonprofit, grassroots membership organizations that are redefining aging by being a key resource to community members wishing to age in place, heavily relied on electronic recruitment using their regular e-newsletters and email listservs to recruit potential participants. We also placed study flyers at local senior centers and senior housing buildings. To keep potential participants from experiencing long wait times to be screened and scheduled for their interviews by study staff, we staggered recruitment across the sites. Interested older adults contacted research staff, who then reintroduced the study and assessed their eligibility. Eligible subjects were scheduled for a face-to-face study interview at the site of their choosing, as many older adults have issues with transportation and mobility. For this study, interviews took place at either the recruitment site (eg, agency, center) or a community setting (eg, library). A few interviews were completed during in-home visits with participants who were already receiving in-home services.

At the in-person interview, subjects completed a written consent form, answered baseline questions, and received randomization to either arm. Subsequently, research staff introduced subjects to one of the websites and provided instructions on its use. Research staff were present to assist with questions on navigation as needed but did not assist with decision making. A minimum of 15 minutes and a maximum of 45 minutes were allotted for navigating the websites. After completing the time allotted for either website, participants were given an immediate post-test survey. At both 1 month and 3 months after the face-to-face encounter, research staff contacted participants over the phone to complete a post-test survey (see Table 1 for outcomes measured at each time point).

Table 1: Data collected across 4 time points and their outcomes

Outcome	Baseline	Immediate Post-tool	1 Month	3 Month
Planning behavior and communication of plans	X	x	x	x
Perception of importance of planning	X	x	x	x
Knowledge of home services	X	x	x	x
Confidence in accessing home services	X	x	x	x
Satisfaction with website		x	x	x

Research staff attempted to reach participants 3 times by phone. Staff entered data into Research Electronic Data Capture survey software.[26] This study was approved by the Northwestern University IRB.

Analysis

Planning Behaviors and Communication of Plans

The primary end point for this study was the behavior of planning and communicating about future preferences for hospitalizations, falls, and Alzheimer's disease/memory loss. After we presented an exhaustive literature review at an initial stakeholder meeting, the group felt

that no existing measures suited the study outcomes. Consequently, patient partners/stakeholders and study staff worked together to develop the scales, emphasizing the practicality of the questions being asked (stakeholders wanted participants to be able to relate these questions to "real-life situations") and keeping the language simple and the questionnaires brief. We consequently used these scales in the pilot testing, and we refined them slightly for the main trial. Although using a validated outcome measure would have been ideal, none existed that assessed whether a person understood his or her future needs or could plan to use available resources. As a result, we created the primary and secondary outcomes measures with the input of our patient partners/stakeholders, but they were not validated prior to starting this trial. However, post hoc Cronbach α calculations illustrated reasonable reliability for these scales ($\alpha = 0.82$ for behavior and $\alpha = 0.82$ for perception).

At baseline, 1-month, and 3-month follow-up time points, 5 statements were presented to participants, and they were asked if they strongly disagreed, disagreed, felt neutral/unsure, agreed, or strongly agreed with each. These statements were the following:

1. I have made a new plan or changes to an existing plan for an unexpected hospitalization.
2. I have made new plans or changes to existing plans to make changes to my home to decrease my risk of falls.
3. I have communicated my preferences for my future health care to people who may need to make decisions for me.
4. I have communicated my preferences about issues related to Alzheimer's to people who may need to make decisions for me.
5. I have communicated my preferences about issues related to memory loss to people who may need to make decisions for me.

We calculated planning behavior and communication scores as the sum of the 5 questions (each scored from 1 = strongly disagree to 5 = strongly agree), with a possible range of 5 to 25.

Perception of Importance of Planning

To determine perceptions about the importance of planning, we provided participants with 5 statements at baseline, immediate post-test, 1-month, and 3-month follow-up time

points and asked if they thought each statement was not at all important, slightly important, moderately important, very important, or completely important. These statements were the following:

1. It is important that I plan for an unexpected hospitalization.
2. It is important that I make changes to my home to decrease my risk of falls.
3. It is important that I communicate my preferences for my future health care to people who may need to make decisions for me.
4. It is important that I communicate my preferences about issues related to Alzheimer's to people who may need to make decisions for me.
5. It is important that I communicate my preferences about issues related to memory loss to people who may need to make decisions for me.

We calculated perception of the importance of planning scores as the sum of the responses to the 5 statements (each scored from 1 = not important to 5 = completely important), with a possible range of 5 to 25.

Knowledge of Home Services

To determine knowledge and understanding about home services, we provided participants with 6 statements and asked them to give the correct answer at baseline, immediate post-test, 1-month, and 3-month follow-up time points. The knowledge items were the following:

1. When people are hospitalized, they often become weak and need to get stronger before returning home. If subacute rehabilitation is planned, it would be done in *X*.
2. Medicare rates the quality of *X*.
3. When necessary, Medicare can assist with paying for *X*.
4. If people need home services but cannot afford to pay for them, they should contact *X*.
5. If people need help making changes to their home, such as installing a ramp, they should contact *X*.
6. If people need a paid caregiver to assist them 24 hours a day, they should contact *X*.

We calculated knowledge of home services scores as the sum of the responses to the 6 statements (each scored 0 if incorrect and 1 if correct), with a possible range of 0 to 6.

Confidence in Accessing Home Services

Study stakeholder partners and staff felt it important to capture any changes in *confidence* in accessing home services, not just measuring *knowledge* of home services. To determine confidence in accessing home services, we provided participants with 5 statements at baseline, immediate post-test, 1-month, and 3-month follow-up time points and asked if they strongly disagreed, disagreed, were neutral/unsure, agreed, or strongly agreed. The statements were the following:

1. I am confident that I know how to contact my local AAA.
2. I am confident that I can find a senior village in my area.
3. I am confident that I can find a paid caregiver or hire a caretaker to help me in my home, if needed.
4. I am confident that I know where I can receive physical therapy after a hospitalization.
5. I am confident that I will know how to access home services if I need them in the future.

We calculated confidence in accessing home services scores as the sum of the responses to the 5 statements (each scored from 1 = strongly disagree to 5 = strongly agree), with a possible range of 5 to 25.

Satisfaction with Website

To measure satisfaction with either PYL or the control website, we presented participants with 10 statements at the immediate post-test, 1-month, and 3-month follow-up time points. They were asked if they strongly disagreed, disagreed, were neutral/unsure, agreed, or strongly agreed. The statements were the following:

1. This website is easy to use.
2. Terminology used on this website is clear.
3. The content on this website met my expectations.
4. This website is visually appealing.
5. It was easy to move from one page to another.
6. I was able to complete my tasks on the website in a reasonable amount of time.
7. I would be likely to use this website in the future.
8. I would recommend this website to others.

9. I have shared this website with others.

10. This website will affect my advanced health planning.

Statement 6 was asked only at the immediate post-test, and statement 9 was asked only at the 1-month and 3-month follow-up time points.

Covariates

We obtained via self-report from each participant demographic information; health; importance of religion; and existence of a power of attorney, living will, and/or advanced directive (eg, Provider Orders for Life-Sustaining Treatment (POLST)). Participants were asked about their general and social self-efficacy using the validated Self-efficacy Scale[27] and about their social support using the Lubben Social Network Scale-6.[28] We also collected health literacy information via the Rapid Estimate of Adult Literacy in Medicine (REALM)-Short Form.[29] Comorbidities was also assessed using a 9-item dichotomous response item to assess the burden of the disease in study participants. This comorbidities assessment, developed by stakeholder partners and study staff, is an abbreviated list of diseases found in the Charlson Comorbidity Index. The team felt that the entire validated index would be too difficult to administer and too burdensome for participants, given its length.

Statistical Analysis

We analyzed data on baseline, 1-month, and 3-month time points. We conducted primary end-point analyses using an analysis of covariance (ANCOVA), comparing the mean planning behavior assessment score at 1-month postintervention/attention control while controlling for the baseline planning score. Secondary end-point analyses employed longitudinal linear mixed modeling to assess a time-by-arm interaction, both unadjusted and adjusted for potentially confounding factors. A series of post hoc ANCOVAs also explored the primary end-point results at 3 months, along with relevant secondary outcomes: perception of importance of planning score and confidence in accessing home services. Additional secondary end-point analyses for these 2 outcomes also utilized longitudinal linear mixed modeling; these models included fixed arm, time, and time-by-arm effects as well as a random participant effect to account for within-participant associations over time. We compared fixed baseline variable effects (current utilization of services, physical function, comorbidities, social support, health

literacy, self-efficacy, and sociodemographics) with each outcome (one at a time). We considered for inclusion in the overall model selection process those with a significant association with outcome in these longitudinal models. A backward stepwise model building procedure determined an overall parsimonious, adjusted model for each outcome.

We analyzed data from complete cases. We included all randomized participants with a complete planning behavior and communication score at the 1-month time point in the 1-month analyses; we included those participants with a complete planning behavior and communication score at either 1 month or 3 months in the 3-month analyses.

RESULTS

Participants

Among 470 participants screened for eligibility, 385 were randomized and included in the study of the 191 participants allocated to the AC group, 1 participant partially received the PYL intervention. The mean age of participants was 71.9 (SD = 5.6); 79.5% were female; 64.4% identified as white and 24.2% identified as African American (Table 2). Baseline characteristics were similar in both groups.

Table 2. Participant Baseline Characteristics

| | Treatment Arm | | | | |
| | AC | | PYL | | |
	N = 191	%	N = 194	%	*P* Value
Mean age (± SD)	72.1 (5.6)		71.7 (5.6)		0.51
Sex					
Female	157	82.2	149	76.8	0.19
Male	34	17.8	45	23.2	
Race					
White	125	65.4	117	60.3	0.30
Nonwhite	66	34.6	77	39.7	
Marital status					
Single, never married	27	14.1	23	11.9	
Married	75	39.3	85	43.8	0.58
Widowed	44	23.0	36	18.5	
Divorced/separated	45	23.6	50	25.8	
How would you rate your health?					
Poor	4	2.1	4	2.1	
Fair	22	11.5	18	9.3	
Good	76	39.8	81	41.7	0.78
Very good	62	32.5	70	36.1	
Excellent	27	14.1	21	10.8	
Do you have a power of attorney?					
No	88	46.1	99	51.0	
Yes	102	53.4	91	46.9	0.26
Don't know	1	0.5	4	2.1	
Do you have a living will?					
No	88	46.1	92	47.4	
Yes	102	53.4	98	50.5	0.68
Don't know	1	0.5	4	2.1	

	Treatment Arm				
	AC		PYL		
	N = 191	%	N = 194	%	P Value
Do you have an advanced directive (such as a DNR, POLST, code status)?					
No	91	47.6	107	55.2	0.22
Yes	88	46.1	80	41.2	
Don't know	12	6.3	7	3.6	
Household income					
Less than $20 000	45	23.6	43	22.2	
$20 000-$40 000	50	26.2	54	27.8	
$40 001-$60 000	31	16.2	27	13.9	
$60 001-$80 000	25	13.1	26	13.4	0.90
$80 001-$100 000	19	10.0	17	8.8	
More than $100 000	13	6.8	18	9.3	
Don't know	4	2.1	2	1.0	
Prefer not to say	4	2.1	7	3.6	
Education					0.57
High school or less	33	17.3	40	20.6	
Some college	55	28.8	59	30.4	
College graduate	103	53.9	95	49.0	
How important is religion in your life?					
Not at all important	15	7.9	14	7.2	
Not very important	15	7.8	16	8.3	
Somewhat important	34	17.8	34	17.5	0.99
Very important	59	30.9	64	33.0	
Extremely important	67	35.1	65	33.5	
Not sure/don't know	1	0.5	1	0.5	
REALM score					0.85
Third grade and below	1	0.5	0	0.0	
Fourth to sixth grade	2	1.1	1	0.5	
Seventh to eighth grade	29	15.2	28	14.4	
High school	159	83.3	165	85.1	
Have you or a member of your household been hospitalized in the past 3 years?					0.31
No	104	54.5	96	49.5	
Yes	86	45.0	98	50.5	
Don't know	1	0.5	0	0.00	
With whom do you live?					0.36
Live alone	104	54.5	94	48.5	
Live with one other person	75	39.3	90	46.4	
Live with multiple other people	12	6.3	10	5.1	
If yes, with whom do you live?	73	38.2	86	44.3	0.22

	Treatment Arm				
	AC		PYL		
	N = 191	%	N = 194	%	P Value
Spouse					
Son/daughter	15	7.9	16	8.3	0.89
Other relative	10	5.2	10	5.2	0.97
Friend	1	0.5	0	0.0	0.50
Other	1	0.5	1	0.5	0.50
High blood pressure					
No	71	37.2	62	32.0	0.28
Yes	120	62.8	132	68.0	
Diabetes					
No	152	79.6	155	79.9	0.98
Yes	38	19.9	39	20.1	
Don't know	1	0.5	0	0.0	
Lung disease, such as emphysema or chronic bronchitis					
No	178	93.2	170	87.6	0.11
Yes	13	6.8	22	11.4	
Don't know	0	0.0	2	1.0	
Asthma					
No	167	87.4	162	83.5	0.27
Yes	24	12.6	32	16.5	
Stroke					
No	169	88.5	177	91.2	
Yes	20	10.5	14	7.2	0.27
Don't know	2	1.0	3	1.6	
Cancer					
No	144	75.4	141	72.7	
Yes	47	24.6	52	26.8	0.60
Don't know	0	0.0	1	0.5	
Kidney disease					
No	179	93.7	185	95.4	0.32
Yes	11	5.8	7	3.6	
Don't know	1	0.5	2	1.0	
Heart failure					
No	176	92.1	181	93.3	
Yes	13	6.8	10	5.2	0.50
Don't know	2	1.1	3	1.5	
Arthritis					
No	72	37.7	66	34.0	

	Treatment Arm				
	AC		**PYL**		
	N = 191	**%**	**N = 194**	**%**	***P* Value**
Yes	116	60.7	124	63.9	0.47
Don't know	3	1.6	4	2.1	
How comfortable are you using the internet?	3.6 (1.0)		3.8 (0.8)		0.12
Self-efficacy score	68.2 (8.0)		67.4 (7.9)		0.35
Social support score	6.4 (2.1)		6.3 (2.1)		0.66

Abbrev: DNR= Do Not Resuscitate; POLST= Provider Orders for Life-Sustaining Treatment

Primary Outcome: Planning Behavior and Communication Score

Mean planning behavior and communication score overall was 16.88 (SD = 4.48), with comparable scores in both arms at baseline (Table 3). Between baseline and 1-month follow-up, the planning behavior score decreased, on average, by 0.37 points, with the AC group seeing an average decrease of 0.92 points and the PYL arm an average increase of 0.22 points. After controlling for baseline planning behavior score, mean planning behavior score at 1 month was significantly higher in the PYL arm than in the AC arm (1.25 points; CI, 0.37-2.12; p = 0.0054). Though marginally significant (p = 0.0444), we observed similar results at the 3-month follow-up time point.

As a secondary analysis, we examined planning behavior using longitudinal generalized linear mixed modeling. With this approach, 9 baseline covariates were significant to 1:1 comparison: prior hospitalization, arthritis, nonwhite, power of attorney, presence of living will or advanced directive, self-reported health, annual income, self-efficacy score, and support score. However, the power of attorney, living will, and advanced directive variables were highly correlated. We felt that if an individual had a power of attorney, then he or she most likely also had a living will and advanced directive; therefore, we performed the model selection process using the power of attorney variable. After model selection, there were 4 significant baseline covariates: self-reported health rating (p < 0.001), self-efficacy score (p < 0.001), support score (p < 0.002), and power of attorney (p < 0.001). Higher self-efficacy score, higher support score, and having a power of attorney were correlated with higher planning behavior scores, while higher self-reported health rating was correlated with a lower planning behavior score. Controlling for these variables, treatment effect remained significant (p = 0.014), with

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participants in the treatment group experiencing a change in score that was, on average, 0.63 points higher than that of those in the control group. At the 3-month time point, self-efficacy score (p = 0.007), support score (p = 0.010), and power of attorney (p < 0.001) all remained significant covariates, in addition to education level (p = 0.006) and history of stroke (p = 0.005). Controlling for these covariates, treatment effect over the 3-month period remained marginally significant (p = 0.064), with a score that was, on average, 0.97 points higher than that of those in the control group (Table 4).

Table 3. Summary Outcome Statistics and ANCOVA Results

Outcome Measure	Time Point	Overall	AC	PYL	Arm Effect Estimate (95% CI)[a]	*P* Value
Planning behavior	Baseline	16.88 (4.48)	16.80 (4.58)	16.97 (4.38)		
	1 month	16.51 (4.56)	15.88 (4.56)	17.19 (4.48)	1.25 (0.37-2.12)	0.0054
	3 months	17.95 (4.46)	17.55 (4.41)	18.40 (4.48)	0.91 (0.02-1.79)	0.0444
Perception	Baseline	19.95 (3.84)	20.14 (3.64)	19.75 (4.02)		
	1 month	20.51 (3.65)	20.29 (3.61)	20.75 (3.69)	0.60 (−0.06-1.27)	0.0766
	3 months	20.97 (3.55)	20.81 (3.56)	21.14 (3.55)	0.56 (−0.12-1.25)	0.1074
Confidence	Baseline	20.75 (3.33)	20.68 (3.40)	20.81 (3.27)		
	1 month	21.45 (2.79)	21.19 (2.93)	21.74 (2.62)	0.47 (−0.04-0.97)	0.0683
	3 months	21.93 (2.54)	21.70 (2.71)	22.17 (2.33)	0.39 (−0.10-0.89)	0.1175

[a]*From ANCOVA model for the given follow-up time point, adjusted for the respective baseline outcome score.*

Secondary Outcome: Perception of the Importance of Planning

For participants' perception of the importance of planning (secondary outcome), the unadjusted *P* value for difference between the groups was 0.028, with participants in the PYL group having a change in score that was, on average, 0.43 points higher than that of those in the AC group. Three baseline covariates were significant to 1:1 comparison with longitudinal modeling of the perception score: comorbidity of cancer, self-efficacy score, and importance of religion in the participant's life. After model selection, the self-efficacy and religion baseline covariates remained significant; higher self-efficacy and importance of religion scores were correlated with higher perception scores. Controlling for these variables, the treatment effect remained significant (p = 0.035), with participants in the PYL group having a change in score that was, on average, 0.41 points higher than that of those in the AC group. At the 3-month

time point, baseline self-efficacy score and importance of religion remained significant covariates, in addition to gender and a comorbidity of stroke. Controlling for these covariates, the different between the treatment groups remained significant (p = 0.047), with PYL participants having a change in score that was, on average, 0.48 points higher than that of those in the control group (Table 4).

Table4. Longitudinal Mixed Model Results

Outcome Measure	Effect	Unadjusted Estimate (95% CI)	*P* Value	Adjusted Estimate (95% CI)	*P* Value
Planning behavior[a]	Time	0.282 (−0.071-0.634)	0.1173	0.322 (−0.035-0.680)	0.0771
	Arm	0.282 (−0.617-1.181)	0.5379	0.547 (−0.334-1.428)	0.2231
	Interaction	0.512 (0.007-1.017)	0.0470	0.486 (−0.028-0.999)	0.0637
Perception[b]	Time	0.215 (0.048-0.383)	0.0116	0.225 (0.057-0.393)	0.0088
	Arm	−0.038 (−0.754-0.677)	0.9163	0.094 (−0.608-0.797)	0.7927
	Interaction	0.237 (−0.002-0.476)	0.0522	0.244 (0.003-0.485)	0.0471
Confidence[c]	Time	0.318 (0.189-0.447)	<0.0001	0.331 (0.201-0.460)	<0.0001
	Arm	0.349 (−0.235-0.934)	0.2413	0.357 (−0.186-0.901)	0.1972
	Interaction	0.088 (−0.096-0.273)	0.3480	0.075 (−0.109-0.260)	0.4230

[a]*Adjusted estimate corresponds to model controlling for self-efficacy score, education, perceived support, power of attorney, and history of stroke.*
[b]*Adjusted estimate corresponds to model controlling for self-efficacy score, history of stroke, gender, and importance of religion in the participant's life.*
[c]*Adjusted estimate corresponds to model controlling for self-efficacy score, perceived support, comfort using the internet, and minority membership.*

<u>Secondary Outcome: Satisfaction with Website</u>

We calculated satisfaction scores for both websites by summing the responses for the questions posed at the immediate post-test, 1-month, and 3-month time points. We compared treatment and control groups at each time point using *t* tests, with the treatment group having significantly higher scores at every point. At the post-test time point, satisfaction scores were 31.71 ± 4.44 for the control group and 33.58 ± 3.51 for the treatment group (p < 0.0001). At the 1-month follow-up, satisfaction scores were 31.32 ± 4.58 for the control group and 33.02 ± 3.80 for the treatment group (p = 0.0002). At the 3-month follow-up, satisfaction scores were 31.26 ± 4.73 for the control group and 32.46 ± 4.24 for the treatment group (p = 0.0186).

Secondary Outcome: Confidence in Accessing Home Services

       We calculated confidence scores by summing the responses for the questions posed at the post-test, 1-month, and 3-month time points (Table 3). We compared treatment and control groups at each time point using *t* tests. For the analysis of the CAHS score, the unadjusted *P* value for difference between the groups was not significant, at 0.1335. Four baseline covariates were significant on 1:1 comparison with longitudinal modeling of behavior score: prior hospitalization in past 3 years, lung disease (such as emphysema or chronic bronchitis), asthma, and arthritis. After model selection, no baseline covariates remained significant; at the 3-month time point, the difference between groups also remained nonsignificant (p = 0.423; Table 4).

Secondary Outcome: Knowledge of Home Services Score

       At 1 month, participants in the PYL group had a 0.6-point increased change in knowledge score (SD = 1.6), and the AC group had a –0.1-point change in knowledge score (SD = 1.4; p = 0.0003). Linear mixed modeling results suggested that level of education and income were significant predictors of knowledge score over time, with higher income and education resulting in higher knowledge scores. Controlling for these variables, treatment effect remained significant (p = 0.0005), with participants in the PYL group having a change in knowledge score that was, on average, 0.28 points higher than that of those in the AC group.

DISCUSSION

Lifespan planning, or fourth-quarter planning, is fairly new compared with such other fields as end-of-life planning.[30-32] Facilitating planning for the fourth quarter is about giving a voice to seniors during a vital span in their lives and helping families facilitate this goal. To our knowledge, PYL is one of the first websites devoted to planning for the health trajectory of seniors as they age into their 70s, 80s, 90s, and beyond.

We created PYL to provide information to seniors and to connect them to resources that may be needed over the course of their remaining lifespan. Free and nationally available to the public, with links to local resources, PYL demonstrated efficacy in helping seniors plan for their future health and home needs. In addition, our results identified that seniors who had higher self-efficacy, support systems, and established powers of attorneys were more likely to plan ahead. Seniors who had completed powers of attorney had previously considered their future goals; thus, planning for their health trajectory may have become an extension of planning for end of life.

The connection between end-of-life planning and planning for a lifespan can create a unique opportunity for clinicians, as they regularly discuss code status and powers of attorneys during their end-of-life discussions with patients.[33-35] To facilitate lifespan planning, we encourage clinicians to ask patients, "What about the 10 to 20 years before you die—have you considered what you will do if you get sick or need help at home?" Clinicians can then refer patients to PYL and recommend that they discuss their choices with loved ones.

Prior research has shown that one of the barriers to lifespan planning is seniors' concern over becoming a burden on their offspring.[36] PYL provides an opportunity for seniors to proactively make plans and communicate their goals to their families, which has the potential to alleviate such worries.

A major strength of this project was our strong community partnerships. We developed PYL with significant input from our patient partners and stakeholders, which included seniors, senior community group leaders, AAAs, nurses, caregiver agency leaders, and clinicians. This patient and stakeholder engagement enabled us to create a website that was fully senior-centric. Following development, our patient partners and stakeholders were tasked with

recruiting participants for the trial. Recruiting directly through our community partners facilitated a true community representation, allowing us to reach individuals who may not normally participate in research studies. An additional study strength was that recruitment occurred at multiple sites, including rural and urban locales.

As with all studies, there were limitations. While using a validated outcome measure would have been ideal, none existed that assessed whether a person understood his or her future needs or could plan to make use of available resources. As a result, we created the primary and secondary outcomes measures with the input of our patient partners/stakeholders, but these measures were not validated prior to the trial.

Confidence in accessing home services did not differ significantly between groups. This finding may suggest that although plans can be made, many seniors remain concerned over how to implement these plans in real life. The trial was also limited by the short follow-up. At 1-month and 3-month follow-ups, it would be unusual to find that a person had actually acted on the plans created on PYL. Future studies with longer follow-up are needed to determine if plans are utilized and improve confidence in accessing home services or make a difference in the care of the senior.

Also limiting this study was that the comparator arm was an AC arm. As PYL was the first website of its kind to address planning for home services, we found no available websites or sister applications comparable to it. Our AC group controlled for the possibility that regular contact with the study team may impact the outcomes.

Another limitation relates to the generalizability of the results. Our sample had limited diversity among participants, although it was implemented in 3 distinct geographic areas. Future studies should focus on the inclusion of more racially/ethnically and socioeconomically diverse participants and the inclusion of additional research sites.

A final limitation was the potential for cross-contamination across the 2 study arms. Even though the PYL intervention website was secure during the trial, we observed more individuals (685 new users) accessing the site during the trial than the number randomized to that arm as well as over 3624 hits before ending the study. Despite this finding, significant

differences observed between the groups remained, suggesting that our estimates may be conservative.

With the conclusion of the RCT, we embarked on disseminating PYL nationally in partnership with our stakeholders and patient partners. PYL went live in September 2015; in the first 8 months, the site had more than 10 000 hits in 36 states. This widespread dissemination is a direct result of our inspiring and dedicated patient partners and stakeholders. In all, our team has presented PYL at 84 separate events, conferences, and community group meetings. Current patient and stakeholder groups (eg, seniors, AAAs, clinicians) are ready to use the results of this project. We have seen PYL introduced to new clients at AAAs by case managers, in senior community group newsletters and "coffee-corner" groups among seniors, and among clinicians as a "virtual social worker" in supporting their older patient needs. Health systems have reached out to us to tailor PYL to their organization and to disseminate it to their patients. Financial planners and estate lawyers have likewise approached us about the merits of using it with their clients.

CONCLUSIONS

PYL is the first national-level tool to assist seniors and their families in planning for those crises that may occur in the fourth quarter of life. Knowing what services are available before the need arises potentially allows seniors a voice in their future care and assists families in helping them age in place. In our study, PYL demonstrated efficacy in helping seniors plan for health and support needs that typically arise once they reach their 70s, 80s, 90s, and beyond. PYL may help individuals better understand, plan, and communicate their options for their future support needs.

Numerous potential implications exist for planning a senior's remaining lifespan. If hospitalized seniors knew their preferred skilled nursing facility for subacute rehabilitation on the first day of their hospitalization, then hospital stays could be reduced. If families knew which caregiver agencies, AAA, or senior village that their senior wished to use, and how to contact those resources, then obtaining services could be easier. PYL can facilitate these decisions and ultimately provide seniors a voice in their future care.

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