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Preparing Surrogates for Decision-Making: Development and Pilot Testing of PREPARE For THEIR Care

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Abstract

Context: Surrogate decision-makers have expressed the need for better preparation around communication and medical decision-making.

Objectives: This mixed-methods feasibility study aimed to assess the feasibility and usability of an online program to prepare surrogates for their role.

Methods: We developed a 2-part program for surrogates called PREPARE For THEIR Care with a diverse group of Community Advisory Board members and caregivers recruited from the National Patient Advocacy Foundation. We conducted pilot testing of the program with caregivers. Using validated surveys, we assessed the feasibility and usability of the program and measured pre-to-post Advance Care Planning (ACP) Engagement among caregiver participants.

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Author contributions
Study concept and design: RS
Acquisition of subjects/data: LL, BL, CF, DF, AV, RS
Interpretation of data: LL, AV, RS
Preparation of manuscript: All authors

Conflict of interest: All authors report no conflicts of interest.

Declaration of competing interests: All authors declare that they have no known competing financial interests or personal relationships that could have biased the work reported in this paper.

Results: Of the 26 pilot participants, mean age was 52±12.7 years; 27% were men, 4% were non-binary, 27% identified as Asian, 27% Black, 11% Multi-Racial, and 35% White. Participants found the program to be informative, comprehensive, and easy to use. Ease-of-use was rated 9.6±0.92 on a 10-point scale; and, on 5-point scales, comfort using the program was rated 4.8±0.51, helpfulness 4.6±0.65, and likelihood to recommend to others 4.7±0.53. There was improvement comparing pre- and post-surveys in readiness to engage in ACP for others (4.23(±0.67) to 4.47(±0.73), p=0.04) and for self (3.55 (±1.36) to 3.89(±1.06), p=0.02).

Conclusion: In this pilot study, the PREPARE For THEIR Care program resulted in high user satisfaction and improved pre-to-post surrogate readiness to engage in ACP. Larger trials are needed to evaluate the impact of the program on surrogate readiness and confidence.

Key Message: PREPARE For THEIR Care was co-created with caregivers and provides step-by-step guidance to prepare individuals as surrogate decision-makers. This pilot study found that the program is easy-to-use, has high user satisfaction, and may improve caregivers' readiness to engage in advance care planning for others and for themselves.

Keywords

Surrogate decision maker; advance care planning; care planning continuum; surrogate preparation

Introduction

In recent years, the definition of advance care planning (ACP) has expanded to include preparation for surrogate decision-makers (surrogates).[1] The surrogate experience is complex; the process in which surrogate decisions are made is nuanced and can be incredibly distressing.[2] Previous studies have found that surrogates need preparation and guidance to initiate ACP conversations, to advocate for patients by communicating with clinicians, and to make informed medical decisions.[3–5]

PREPARE For Your Care (www.prepareforyourcare.org) – a multimedia website with videos and easy-to-read advance directives – improves patient-reported engagement in ACP for Spanish- and English-speaking older adults.[6–9] However, programs developed to prepare surrogates, who frequently must initiate ACP conversations with family and friends and make challenging medical decisions for others, have been lacking. The objectives of this study were to (1) evaluate the feasibility and usability of a novel online program called PREPARE For THEIR Care to prepare surrogates (i.e., current surrogates or caregivers who are potential future surrogates) for their role and (2) gather pilot data on the impact of this program on ACP engagement among a group of caregivers.

Methods

We conducted an iterative co-development process with a Community Advisory Board (CAB) and caregivers (individuals who reported providing care for someone else, such as a family member or friend, and who may have experience with surrogate medical decision-making). We included 7 CAB members (i.e., 2 patient and caregiver advisors, 1 geriatrician, 3 palliative care clinician-researchers, 1 chaplain) to provide feedback in focus groups. We recruited caregivers from the National Patient Advocacy Foundation (NPAF) and through purposeful and snowball sampling until thematic saturation for feedback about the program was reached. Caregivers were included if they were English-speaking, ≥ 18 years old, did not have cognitive impairment, had access to a computer and phone, and had prior experience as caregiver and/or surrogate decision-maker for an adult with or without dementia. We prioritized recruitment of individuals from racially or ethnically minoritized groups. CAB members and caregiver participants were offered an honorarium. This study was approved by the Institutional Review Boards at the University of California San Francisco and considered exempt.

Prototype Development and Design

We developed an initial Prototype that included storyboards focused on improving surrogate preparedness based on five themes from thirteen prior semi-structured focus groups with experienced Spanish- and English-speaking surrogates ≥18 years of age (Figure 1, Prototype 1.0).[3,10] All content was written at a 5th-grade reading level. We then conducted two focus groups with 7 CAB members to review the storyboards and provide feedback about the content and format, resulting in Prototype 2.0 (video scripts) and Prototype 3.0 (recorded videos that contained educational text and modeling of conversations with actors). These videos were housed on a dedicated homepage within the PREPAREforYourCare.org website. We then conducted cognitive interviews with 10 NPAF caregivers to review and refine Prototype 3.0. Feedback resulted in a two-part online program to (a) show caregivers how to help family and friends with medical planning and (b) how to make medical decisions for others (Prototype 3.1). The program included 13 narrated videos that were approximately 2 to 7 minutes in length. In addition to a brief introductory video on how to use the program and navigate the website, the program offered a range of topics such as learning about forms for medical planning, how medical planning is different for each person, how to bring up the topic of medical planning, how to ask other people about their medical wishes, and how to ask medical providers questions. Each video offered step-by-step guidance and conversation starters for preparing caregivers for medical planning and decision-making. Several videos also included role-play scenarios by professional actors that simulated real-life challenges for caregivers that were obtained from prior focus groups.

Pilot testing

We conducted an initial round of pilot testing of the online videos using Prototype 3.1 with 5 NPAF caregivers in February 2023 (Figure 1). Next, the videos and website underwent additional edits to create Prototype 4.0, which we then used to conduct additional pilot testing from September to October 2023 with 21 caregivers. There was no overlap with caregivers who participated in the cognitive testing during Prototype development and design. The 26 caregivers who underwent pilot testing reviewed functionally similar Prototypes and received identical survey questions on usability. All testing was conducted via Zoom Video Communications, Inc., 2022. The sessions lasted approximately 2 hours. Survey responses were recorded directly into REDCap.[11] Open-ended feedback was audio-recorded and transcribed. Study staff wrote detailed field notes regarding participants' responses and experiences after watching each video.

Outcomes and measures

We collected self-reported age, gender identity, relationship status, education, health status[12], health literacy (single validated question),[13] and comfort with using the internet (5-point Likert scale). Given known disparities in ACP among minoritized patients,[14,15] we asked participants to report their race and ethnicity. Participants were asked to describe the relationship with the person (family member or friend) they currently provide care for or have provided care for in the past, duration of caregiving years, and whether the care recipient had dementia or Alzheimer's disease. They were also asked about prior experience with surrogate decision-making and completion of their own advance directive.

During pilot testing, we asked participants open-ended questions about usability for each video and overall website. Through Zoom screen sharing, we observed whether participants had difficulty navigating the website. At the end of the session, participants completed validated acceptability surveys that assessed ease-of-use of the program (on a 10-point scale, 10 being "very easy") and on a 5-point Likert scale, comfort with and helpfulness of the program and the likelihood they would recommend the website to others.[8]

At baseline and one week after the pilot, participants completed an adapted version of the validated Surrogate ACP Engagement survey about their confidence and readiness to engage in ACP for others and themselves.[16,17] We measured participants' confidence and readiness in discussing a family/friend's medical wishes, communicating with family/friend's doctor about their medical wishes, and making medical decisions on behalf of the individual if they were to lose capacity. Responses on a 5-point Likert scale (scores ranged from 1–5; 5= "extremely confident" or "extremely ready"). We also asked participants about their own medical planning using the validated 4-item ACP Engagement Survey with questions about their readiness to formally designate and talk with a surrogate, talk to their doctor about their own medical wishes, and sign an advance directive.[18]

Analyses

We conducted descriptive analyses of sociodemographic and acceptability data. The feasibility pilot was not powered to detect statistically significant pre-to-post differences. However, a ≥ 0.2 increase from pre- to post-survey score has been associated with documentation of advance care planning in the medical record. [18–20]We used Wilcoxon signed rank tests to determine differences between pre- and post-surveys in ACP engagement overall and for individual questions. Quantitative analyses were conducted using STATA 17.[21] For the open-ended responses, two coders (BL and LL) independently reviewed interview responses from participants, developed codes to identify key concepts and emerging themes, and evaluated the open-ended data using thematic content analysis[22] and investigator triangulation.

Results

Participant demographics

Of the 26 participants in the feasibility pilot, the mean age was 52 years (SD±12.8, range 33–79), 18 (69%) were women, 1 (4%) identified as non-binary, 7 (27%) Asian, 7 (27%) Black/African American, 3 (12%) multi-racial/ethnic, 12 (46%) were married or living with a partner, 21 (81%) had college/graduate degree, 25 (96%) reported good health, and 3 (11%) reported limited health literacy (Table 1). Sixteen (61%) caregivers provided care for a parent, and 5 (19%) for a spouse. Four (15%) caregivers had experience providing care for someone with dementia. They had on average 10 (±5.4) years of caregiving experience. Of the 21 participants who had answered questions about prior ACP experience, 10 (48%) had prior experience as surrogates and 9 (43%) had completed an advance directive for themselves.

Post-Pilot Program feasibility and usability

Table 2 shows feedback from focus groups. Participants described the overall program content as "*relatable*," "*comprehensive," and "straightforward."* They reported that the videos *(1)* emphasized the importance of ACP – *"[This program] is really needed. We [as surrogates] need to know [about medical wishes] so we don't get caught in the end wondering what we should do"*, (2) validated the caregiving experience –*"I'm glad to see that a situation I've experienced was shown*", (3) demonstrated diversity of representation –*"I see people who look and talk like me*", (4) provided education –*"It's important for us to think about what other people want… not just what we want",* and (5) were easy to use –"*I can see my 85-year-old mother using this program on her own."* Many participants found the step-by-step guidance and conversation starters to be helpful for preparing and empowering surrogates for difficult conversations (e.g., initiating ACP for people who are reluctant, asking doctors about prognosis, being involved in the decision-making process when the caregiver/care partner is not the designated surrogate). Participants also reported feeling validated while watching videos that normalized the challenges around decision-making – "[*The program] reminded me it's important as a caregiver to make time for self.*" Several participants reported that the videos on palliative care provided important education on its role for people with serious illnesses and how it differs from hospice – "*I was aware of hospice… but this is the first time I am hearing about palliative care*."

Key suggestions for improvement included adding more challenging communication scenarios (e.g., when families do not agree), improving usability (e.g., adding chapter markers for videos), emphasizing that ACP is not just for older adults or people at end-of-life.

Participants rated ease-of-use a mean of 9.6 (±0.9) on a 10-point scale. On a 5-point scale, comfort of use was rated 4.8 (±0.5), helpfulness 4.6 (±0.6), and likelihood they would recommend the website 4.7 (±0.5). Participants did not report, nor did staff observe, difficulties navigating the website or accessing the videos on their own.

ACP Engagement

Among the 26 pilot participants, the mean pre-to-post 5-point surrogate readiness score increased (4.23(±0.67) to 4.47(±0.73), p=0.04) with a trend for improved confidence and combined confidence and readiness scores (Table 3). There was improvement in mean pre-to-post overall score for participants' readiness to engage in one's own ACP, to discuss medical wishes with their doctor, and to sign advance directive. Readiness to talk with their own surrogate about their medical wishes and sign papers to name a surrogate showed trends towards improvement.

Discussion

PREPARE For THEIR Care is an online program developed for surrogates (i.e., current surrogate decision makers or caregivers who are potential future surrogates) to prepare them to help other people with medical planning and decision-making. It is designed to be used with an existing patient-facing program called PREPARE For YOUR Care. Through iterative cycles of feedback from caregivers, PREPARE For THEIR Care was found to be feasible, informative, relatable, easy-to-use, inclusive, resulted in high user satisfaction, and improved caregivers' readiness to engage in ACP for others and for themselves.

The burdens of surrogate decision-making are multidimensional, coupled with feelings of uncertainty and unpreparedness.[5,10,23] ACP is a process that can decrease surrogate distress[2] and should be tailored to help surrogates understand and exercise their role.[1] Although surrogates have emphasized the importance of ACP,[10,23,24] they often do not know how to initiate this process and are unaware of the patient's medical preferences.[25–27] Among surrogates in prior studies, nearly half reported that patients had not discussed their medical preferences for end-of-life care, and over 50% reported that patients had not signed official papers documenting the surrogate role.[26]

Web-based tools have successfully been used to help surrogates navigate the decision-making process for critically ill patients in the intensive care unit.[28] To meet the needs of caregivers in the community, PREPARE For THEIR Care was co-created with caregivers based on their needs and experiences and provides step-by-step guidance to help others with medical planning and, when needed, making decisions for individuals.[3] The videos cover different scenarios from asking families and friends about their medical wishes to navigating family conflict. Participant feedback showed that the program helped caregivers feel more informed and empowered in their role. By presenting information in an understandable way, based on themes identified by caregivers with prior surrogate decision-making experience, along with 'how to' videos and conversation starters, the program showed potential for mitigating surrogate unpreparedness.

Alleviating surrogate distress is an important aspect of person-centered medical care.[24] Surrogate confidence and readiness are higher when patients designate a surrogate and document their medical wishes ahead of a medical crisis.[26] We found that caregivers' readiness to engage in ACP for self and others improved within one week of completing the PREPARE For THEIR Care program, suggesting surrogate preparation, in addition to patient preparation, is also an important focus for ACP.[1]

Limitations

The participants were a diverse cohort with prior caregiving and surrogate decision-making experience. Women were disproportionately represented in the study population and reflects caregiver demographics in the U.S.[29] Due to the small sample size, we did not assess inter-reliability for the open-ended survey questions and were unable to determine whether there were differences in ACP engagement among participants from different gender, racial, or ethnic groups. We also did not have information on the health condition of the care recipient which may impact the participants' perspective on surrogate decision-making. Additionally, generalizability is limited as all participants were English speaking and most had good health, high education, and internet literacy. We recruited participants through the National Patient Advocacy Foundation and snowball sampling. Thus, self-selection bias may have occurred since recruited participants had expressed interest in being a part of the study. Due to known disparities in ACP,[14,15,26,30] further efforts are needed to ensure that the program meets the needs of caregivers from different cultural, linguistic, and sociodemographic backgrounds.

Conclusion

PREPARE For THEIR Care is a feasible, easy-to-use program created with and for caregivers to prepare them to help other people with medical planning and medical decision-making. Future trials are needed to evaluate whether the program improves the experiences of surrogates from diverse backgrounds and with non-English language preferences.

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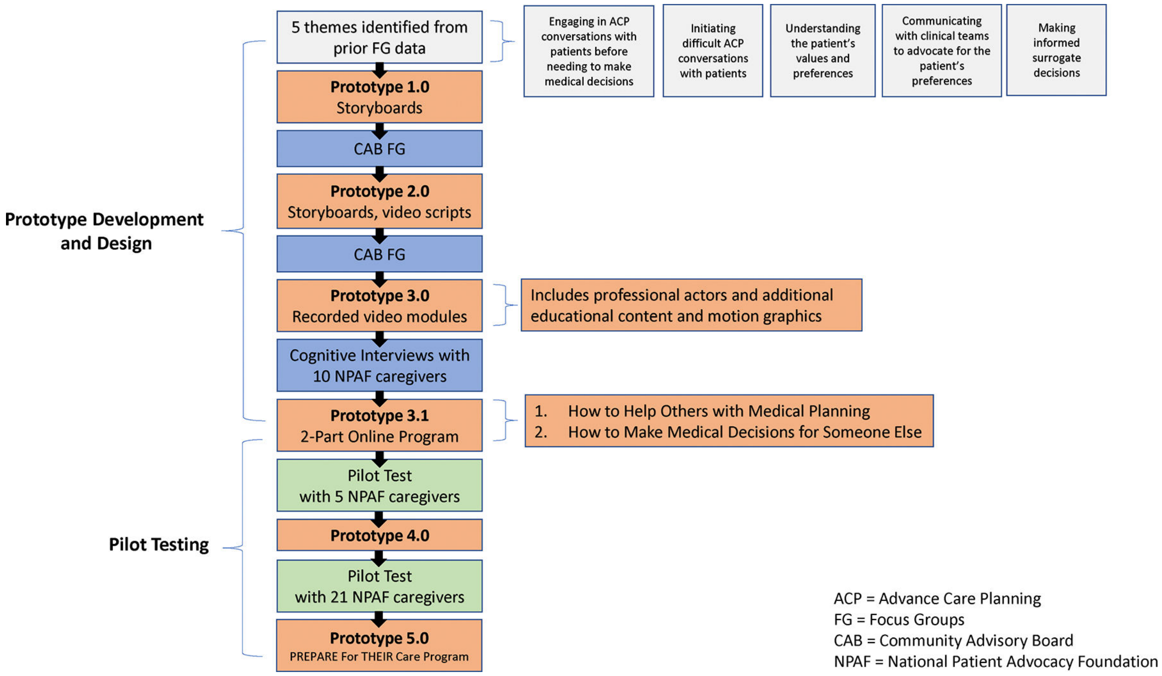

Figure 1.

Prototype Development, Design, and Pilot Testing of the PREPARE For THEIR Care Program

Table 1.

Characteristics of caregivers who participated in the pilot testing

Characteristic		**Participants (N=26)**
Age, mean (SD), range		52 (12.8), 33–79
Gender[a], n (%)		
	Men	7 (26.9)
	Women	18 (69.2)
	Non-binary	1 (3.8)
Race[b], n (%)		
	Asian	7 (26.9)
	Black/African-American	7 (26.9)
	White	9 (34.6)
	Multi-racial (Black/African American, White; Black, Filipino)	3 (11.5)
Ethnicity, n (%)		
	Hispanic or Latino/a/x	1 (3.8)
	Not Hispanic or Latino/a/x	18 (69.2)
	“Afro American Black”[c]	1 (3.8)
	“American”[c]	1 (3.8)
	“Asian/Chinese”[c]	4 (15.4)
	“Filipino”[c]	1 (3.8)
Relationship status, n (%)		
	Never married/Single	8 (30.8)
	Married/Living with partner	12 (46.1)
	Separated/Divorced/Widowed	6 (23.1)
Education, n (%)		
	High school graduate/GED	2 (7.7)
	Some college/technical school	3 (11.5)
	College graduate	16 (61.5)
	Graduate degree	5 (19.2)
Self-rated Health status[d], n (%)		
	Fair-to-poor	1 (3.8)
	Good/Very good/Excellent	25 (96.1)
Health literacy[e], n (%)		
	Limited	3 (11.5)
	Adequate	23 (88.5)
Comfort level using the internet[f], n (%)		
	Somewhat	3 (11.5)
	Quite a bit/Extremely	23 (88.5)

Characteristic	**Participants (N=26)**
Prior experience with surrogate decision-making, n (%)[g]	10 (47.6)
Prior completion of advance directive, n (%)[g]	9 (42.8)
Prior years of caregiving experience, mean (SD), range	10 (5.4), 1–17
Prior caregiving experience for someone with dementia or Alzheimer's Disease, n (%)	4 (15.4)

[a] Response options also included transgender, none of these describe me, other, or prefer not to answer

[b] Response options also included American Indian/Alaskan Native/Native American/Indigenous, Native Hawaiian or Other Pacific Islander, other, or prefer not to answer

[c] Response in " " were in participants' own words

[d] Health status: 5-point Likert categories including "poor, fair, good, very good, excellent"

[e] Health literacy: 5-point Likert categories including "not at all, a little, somewhat, quite a bit, extremely" with "not at all to somewhat" categorized as limited literacy.

[f] Comfort using the internet: 5-point Likert categories including "not at all, a little, somewhat, quite a bit, extremely"

[g] Based on data from 21 of the 26 participants

Table 2.

Summary of Participant Feedback for the PREPARE For THEIR Care Program

Prototype Development and Design Phase: Themes for Implementation [a]

- Include actors from diverse racial, ethnic, and cultural backgrounds in the videos
- Use easy-to-understand lay language
- Include a transcript for each video
- Provide definitions for key terms such as “Advance Directive”
- Show a scenario of a family making decisions as a group
- Acknowledge that a situation may be hard, or bring up difficult emotions
- Address what to do if the caregiver feels overwhelmed

Provide education for how to start a conversation with a family member or friend about advance care planning

- Provide education about the difference between palliative care and hospice care

Pilot Testing Phase: Themes for Refinement and Implementation [b]

- Improve inclusivity by showing videos or images of younger people and families
- Include a scenario when the designated surrogate does not feel comfortable being the decision-maker or no longer wishes to be the decision-maker
- Include a scenario that shows family tension and how it may be navigated during the decision-making process
- Add chapter markers for organizing the longer videos into segments
- Include a FAQ page and downloadable PDF guides with resources for caregivers

[a] Feedback from community advisory board and caregivers from National Patient Advocacy Foundation (NPAF)

[b] Feedback from Experienced caregivers recruited from the community and from NPAF

Table 3.

Advance Care Planning (ACP) Engagement Scores, Pre- and Post-Pilot Testing

<table>
<tr><th colspan="4">ACP Engagement for Other People[a]</th></tr>
<tr><th></th><th>Pre-Pilot Test mean (SD) (N=26)</th><th>Post-Pilot Test mean (SD) (N=26)</th><th>P-value (Wilcoxon signed rank test)</th></tr>
<tr><td>Mean overall score</td><td>4.27 (0.63)</td><td>4.47 (0.70)</td><td>0.06</td></tr>
<tr><td>Mean score for confidence/self-efficacy</td><td>4.32 (0.66)</td><td>4.47 (0.69)</td><td>0.07</td></tr>
<tr><td>Mean score for readiness</td><td>4.23 (0.67)</td><td>4.47 (0.73)</td><td>0.04</td></tr>
<tr><td>How confident are you that you could talk to your family member or friend about the kind of medical care they would want if they were very sick or near the end of life?</td><td>4.38 (0.80)</td><td>4.54 (0.65)</td><td>0.10</td></tr>
<tr><td>How confident are you that you could talk with your family member or friend’s doctors about the care they would want if they were very sick or near the end of life?</td><td>4.38 (0.75)</td><td>4.50 (0.76)</td><td>0.63</td></tr>
<tr><td>How confident are you that today you could make medical decisions for your family member or friend if they were unable to speak for themselves?</td><td>4.19 (0.80)</td><td>4.38 (0.85)</td><td>0.15</td></tr>
<tr><td>How ready are you to talk to your family member or friend about the kind of medical care they would want if they were very sick or near at end of life?</td><td>4.15 (0.88)</td><td>4.38 (0.85)</td><td>0.09</td></tr>
<tr><td>If needed, how ready are you to talk to your family member or friend’s doctor about the kind of medical care they would want if they were very sick or near the end of life?</td><td>4.35 (0.63)</td><td>4.58 (0.70)</td><td>0.12</td></tr>
<tr><td>If needed, how ready are you to make medical decisions for your family member or friend if they were unable to speak for themselves?</td><td>4.19 (0.85)</td><td>4.46 (0.76)</td><td>0.05</td></tr>
<tr><th colspan="4">ACP Engagement for Self [b]</th></tr>
<tr><td>Mean overall score</td><td>3.55 (1.36)</td><td>3.89 (1.06)</td><td>0.02</td></tr>
<tr><td>How ready are you to SIGN official papers naming a person or group of people to make medical decisions for you?</td><td>3.88 (1.40)</td><td>4.00 (1.17)</td><td>0.67</td></tr>
<tr><td>How ready are you to TALK to your medical decision maker about the kind of medical care you would want if you were very sick or near the end of life?</td><td>3.50 (1.65)</td><td>3.85 (1.12)</td><td>0.11</td></tr>
<tr><td>How ready are you to TALK to your doctor about the kind of medical care you would want if you were very sick or near the end of life?</td><td>3.35 (1.49)</td><td>3.81 (1.20)</td><td>0.04</td></tr>
<tr><td>How ready are you to SIGN official papers putting your wishes in writing about the kind of medical care you would want if you were very sick or near the end of life?</td><td>3.46 (1.53)</td><td>3.88 (1.18)</td><td>0.01</td></tr>
</table>

[a] Responses: Not at all - 1; A little - 2; Somewhat - 3; Quite a bit - 4; Extremely 5

[b] Responses: I’ve never thought about it-1, I’ve thought about it, but I’m not ready to do it-2, I’m thinking about doing it in the next 6 months-3, I’m definitely planning to do it in the next 30 days-4, I’ve done it-5