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Short Communication

Engaging Patients to Design the Systematic Multi-Domain Alzheimer's Risk Reduction Trial (SMARRT) Intervention: Findings from a Web-Based Survey

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Abstract. We administered a web-based survey to a convenience sample of 561 patients in a large health system to assess patient attitudes toward dementia prevention in the context of designing a multi-domain Alzheimer's risk reduction intervention. The majority of respondents reported being very concerned about Alzheimer's disease, wanted to know their personal risk factors, and were highly motivated to make healthy lifestyle changes to lower dementia risk. The areas they were most interested in targeting to reduce dementia risk included physical activity, cognitive stimulation, nutrition, and sleep. These results provided strong support for our conceptual framework to target higher-risk patients with a personalized risk reduction strategy.

Keywords: Alzheimer's disease, dementia, patient participation, primary prevention

INTRODUCTION

Primary prevention of Alzheimer's disease and related dementias (ADRD) is increasingly studied as a risk reduction strategy in the absence of any currently available disease-modifying treatments [1, 2]. Several interventions studied to-date have had mixed results, and a frequent barrier to these programs

has been adherence [3]. One way to potentially improve adherence to risk reduction interventions is to engage patients in the design of the trial, especially when designing a personalized, multi-domain intervention. Yet, little is known about patient attitudes toward dementia risk reduction interventions, such as whether knowing their personal risk would motivate them to change their behaviors, or which behaviors they would be most interested in changing.

The Systematic Multi-Domain Alzheimer's Risk Reduction Trial (SMARRT; NCT03683394) is a randomized controlled trial that will pilot-test a personalized, pragmatic, multi-domain Alzheimer's

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disease (AD) risk reduction intervention delivered through an integrated healthcare system in the U.S. [4]. Employing a personalized intervention will target only those risk factors that are relevant to each participant. Ideally, this approach enhances the effectiveness of the intervention, but the personalized approach makes it important to engage patients in the planning of the intervention. Thus, the objective of this survey was to describe patient attitudes toward dementia prevention and a multi-domain AD risk reduction program as part of the process of patient engagement in intervention design. Our overall goal is to aid discussions on future dementia prevention trial design since little is currently reported on how interventions are developed using patient input. While our survey results may not generalize to other patient groups, we present our process and results in the spirit of conveying the value of patient engagement in this growing field.

MATERIALS AND METHODS

Survey design and participants

We created an 11-item survey to address patient attitudes toward dementia prevention and the possible components and delivery of a multi-domain Alzheimer's risk reduction program. The first four items targeted patient attitudes toward dementia prevention, asking the following questions: 1) how important is preventing dementia for you personally? (choices included: very important, somewhat important, a little important, not at all important, or unsure); 2) if we could estimate your personal risk for developing dementia, would you want to know this information (choices included: yes, no, or unsure); 3) how much would knowing about your personal dementia risk factors motivate you to make healthy lifestyle changes? (choices included: it would be very motivating, somewhat motivating, a little motivating, not at all motivating, or unsure); and 4) how much would having a healthier lifestyle need to delay dementia for you to be interested in making such changes? (choices included: 6 months, 1 year, 2 years, 5 years or more, or unsure). The next three items addressed patient attitudes toward the delivery of a dementia prevention intervention. The items asked: 1) who would you feel comfortable working with in changing your lifestyle to reduce your dementia risk (choices included: my physician, another member of my health team, a health coach, or any of the

above); 2) if you were going to work with someone to make lifestyle changes, how would you like to work with that person? (choices included: one-on-one in a clinic setting, in a group with others led by a health counselor, through a website or phone application that tailors information to you, through e-mail, one-on-one visits in your home, by phone, or through printed educational materials mailed to you); and 3) how often would you want to interact with someone as part of an intervention to help reduce your risk of dementia? (choices included: weekly, every other week, monthly, or quarterly). In addition, patients were asked to identify which of a series of lifestyle changes they would be interested in making if it could reduce their risk of developing dementia, as well as which outcomes would be most important to them if they were in a study of lifestyle interventions to lower their dementia risk. Finally, patients were asked to report their age (50–59, 60–69, 70–79, 80–89, or 90+ years) and gender.

In April 2015, the study team worked with the Group Health (now Kaiser Permanente Washington) Governance team to include a Web-based survey link in the April version of eNews, a newsletter for Kaiser Permanente Washington healthcare system members. Given the dynamic nature of the newsletter roster and lack of sociodemographic data on registrants, we do not know how representative our sample was of the broader population. The survey was publicly available for 10 days. No incentives were provided for completing the survey.

Data management

We exported data from Survey Monkey to calculate descriptive statistics.

Because this was a publicly-posted survey and only aggregate results were provided to the study team, no institutional review board approval was required.

RESULTS

A total of 561 members responded, representing nearly 2% of the eNews registrants (approximately 29,000 at the time). Respondent age categories were as follows: 50–59 years (15.3%), 60–69 years (41.4%), 70–79 years (31.4%), 80–89 years (10.7%), and 90+ years (1.3%). The vast majority of respondents were female (77.1%).

The vast majority of respondents (89%) reported that preventing dementia was very important to them personally, and 86% indicated that they would want

Table 1
Patient attitudes toward dementia prevention (n = 561)

Survey item	N	%
<i>How important is preventing dementia for you personally?</i>	–	–
Very important	498/559	89.1
Somewhat important	42/559	7.5
A little important	6/559	1.1
Not at all important	7/559	1.2
Unsure	6/559	1.1
Skipped	2	–
<i>If we could estimate your personal risk for developing dementia, would you want to know this information?</i>	–	–
Yes	480/556	86.3
No	16/556	2.9
Unsure	60/556	10.8
Skipped	5	–
<i>How much would knowing about your personal dementia risk factors motivate you to make healthy lifestyle changes?</i>	–	–
It would be very motivating	472/560	84.3
Somewhat motivating	65/560	11.6
A little motivating	10/560	1.8
Not at all motivating	3/560	0.5
Unsure	10/560	1.8
Skipped	1	–
<i>It's possible that having a healthier lifestyle would not prevent dementia completely but would delay it. How much would these changes need to delay dementia for you to be interested in making them?</i>	–	–
6 months	127/557	22.8
1 year	75/557	13.5
2 years	73/557	13.1
5 years or more	173/557	31.1
Unsure	109/557	19.6
Skipped	4	–

to know their personal risk for developing dementia (Table 1). Moreover, 84% indicated that knowing about their personal dementia risk factors would strongly motivate them to make healthy lifestyle changes. Nearly half (49%) were willing to adopt a healthier lifestyle to achieve a delay in dementia onset of two years or less, while slightly less than one-third (31%) wanted such changes to delay dementia by 5 or more years, and 20% were unsure.

Most respondents (78%) would feel comfortable working with any member of their healthcare team or a health coach who is not part of their healthcare team (Table 2). The venues that patients were most interested in using to make lifestyle changes were one-on-one in a clinic setting (38%), in a group with others led by a health counselor (26%), through a website or phone application that tailors information specifically to them (17%), and through e-mails (e.g., patient portal) (16%). Patients were less interested in telephone interactions (8%) and printed materials (6%). Patients most commonly wanted monthly interactions with someone as part of an intervention to help reduce their risk of dementia.

The behavior changes patients were most interested in making included increasing physical activity (79%), cognitive stimulation (69%), having a healthier diet (69%), and getting better sleep (63%) (Table 3). When given a list of important potential outcomes to choose from if they were in a study of lifestyle interventions to lower dementia risk, the majority (59%) of patients responded that they were all equally important. However, among the individual outcome options, the ability to perform daily activities (33%) and delaying dementia onset (30%) were most frequently cited.

DISCUSSION

In this survey of a convenience sample of older adults enrolled in a healthcare delivery system in the U.S., we found that the vast majority were concerned about AD and wanted to know their overall risk and personal risk factors. In addition, most older adults indicated that knowing their risk factors would strongly motivate them to make healthy lifestyle changes. Nearly half of older adults were

Table 2
Patient attitudes toward dementia prevention intervention: delivery (n = 561)

Survey item	N	%
<i>Who would you feel comfortable working with in changing your lifestyle to reduce your dementia risk?</i>		
My physician	130/551	23.6
Another member of my health team (e.g., nurse)	121/551	22.0
A health coach who is not part of my healthcare team	111/551	20.2
Any of the above	428/551	77.7
Skipped	10	–
<i>If you were going to work with someone to make lifestyle changes, how would you like to work with that person?*</i>		
One-on-one in a clinic setting	166/439	37.8
In a group with others led by a health counselor	117/447	26.2
Through a website or phone application that tailors information specifically to you	75/444	16.9
Through e-mail (such as the patient portal)	74/458	16.2
One-on-one visits in your home	50/402	12.4
By phone	32/417	7.7
Through printed educational materials mailed to you	27/419	6.4
Skipped	17	–
<i>How often would you want to interact with someone as part of an intervention to help reduce your risk of dementia?</i>		
Weekly	96/549	17.5
Every other week	132/549	20.0
Monthly	234/549	42.6
Quarterly	87/549	15.9
Skipped	12	–

*Numerator represents the number of respondents who ranked this venue as the method they prefer the most; denominator represents the total number of respondents who gave this response any ranking among the seven options.

Table 3
Patient attitudes toward dementia prevention intervention: components and outcomes (n = 561)

Survey item	N	%
<i>Which of these lifestyle changes would you be interested in making if it could reduce your risk of developing dementia?</i>		
Increasing physical activity	438/556	78.8
Brain training games	386/556	69.4
Healthier diet	385/556	69.2
Getting better sleep	353/556	63.5
Stopping medications that could contribute to dementia	297/556	53.4
Being more socially connected	252/556	45.3
Improving mood	242/556	43.5
Taking medications to treat chronic illnesses (diabetes, high BP)	135/556	24.3
I don't want/need to change any of these behaviors	30/556	5.4
Quitting smoking	26/556	4.7
Skipped	5	–
<i>What outcomes would be the most important to you if you were in a study of lifestyle interventions to lower your risk of dementia?*</i>		
All are equally important, cannot rank	213/363	58.7
Ability to perform daily activities (e.g., driving, managing finances, managing medications, taking care of your house, etc.)	112/341	32.8
Delaying the onset of dementia	103/341	30.2
Better quality of life in general	44/332	13.3
Stable or improved memory	42/328	12.8
Improved ability to do activities you enjoy	11/329	3.3
Better control of chronic conditions (diabetes, high BP)	5/314	1.6
Skipped	21	–

*Numerator represents the number of respondents who ranked this outcome as the one most important to them; denominator represents the total number of respondents who gave this response any ranking among the seven options.

willing to adopt a healthier lifestyle to delay dementia by 2 years or less, although one-third wanted a delay of 5 years or more. We also found that older adults desired face-to-face, one-on-one interac-

tions at least monthly when making healthier lifestyle changes and that the areas they were most interested in targeting to reduce dementia risk included physical activity, cognitive stimulation, nutrition, and

sleep. These results provided strong support for our conceptual framework in SMARRT of targeting higher-risk patients with a personalized risk reduction strategy.

The SMARRT protocol has been previously reported [4]. Briefly, the pilot trial has randomized higher-risk older adults to the two-year SMARRT intervention versus health education control. Consistent with the patient survey results, targeted risk factors include increasing physical, mental, and social activities; consuming a neuroprotective diet; and improving sleep. In addition, based on current evidence for dementia prevention [1, 2], the intervention is also aiming for optimally controlling cardiovascular risk factors (hypertension, diabetes), quitting smoking, reducing depressive symptoms, and decreasing use of potentially harmful medications. Survey respondents did not have a strong preference for who they wanted to work with to institute lifestyle changes and were open to having a non-health care team member. Accordingly, the SMARRT intervention team consists of both behavioral interventionists and a nurse care manager. Finally, survey respondents most commonly wanted monthly interactions when making healthier lifestyle changes, which the SMARRT intervention has also adopted.

Multi-domain intervention studies are now being tested around the world. A recent review of completed and prospective multi-domain lifestyle programs aimed at enhancing cognitive reserve and reducing risk of AD/DRD reported 17 studies, 13 of which are face-to-face and 4 delivered digitally [3]. One of the main barriers to multi-domain intervention studies is adherence to the intervention. For example, the FINGER study reported variable adherence to different intervention components (e.g., >90% for cardiovascular monitoring versus <50% for cognitive training) [3, 5]. More fully understanding the barriers to intervention adherence would seemingly increase the effectiveness of future multi-domain interventions. One approach is to engage patients at an early stage of intervention design [6]. While several studies have reported patient engagement activities in research on people with dementia (and their care partners), little is known about this process for studies of dementia prevention [7]. The extent of patient engagement in trial design will depend on the sample being studied and available resources [8, 9]. In addition, the nature of patient engagement in trial design will vary based on cultural and economic factors of the study setting. Regardless, we encourage

research teams designing dementia prevention trials to engage patients early in the process and to report on key lessons learned.

Our study has several limitations. First, our study population was older patients from a single health-care system in the U.S., limiting the generalizability of our findings to other populations. However, the primary goal of the survey was to inform intervention design and development for older adults in the same setting. Those planning similar interventions in other parts of the world should consider using patient engagement of their target population to inform trial design. In addition, this was a Web-based survey so potential respondents without access to a computer and the Internet were not represented in these results. Additional work is needed to elicit patient attitudes toward dementia prevention efforts among different cultures and ethnicities and in different geographical locations. Moreover, we could not calculate a precise survey response rate because we were unable to determine how many people opened the electronic newsletter.

Conclusion

In conclusion, older adults enrolled at a U.S. healthcare delivery system report being very concerned about AD, wanted to know their personal risk factors, and were highly motivated to make healthy lifestyle changes to lower dementia risk. The areas they were most interested in targeting to reduce dementia risk included physical activity, cognitive stimulation, nutrition, and sleep. Dementia risk reduction trials may have better adherence and, ultimately, be more effective if they take patient preferences into consideration.

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CONFLICT OF INTEREST

The authors have no conflicts of interest to report.

REFERENCES

- [1] National Academies of Sciences, Engineering, and Medicine; Health and Medicine Division; Board on Health Sciences Policy; Committee on Preventing Dementia and Cognitive Impairment; Downey A, Stroud C, Landis S, Leshner AI, eds. (2017) *Preventing cognitive decline and dementia: a way forward*. The National Academies Press, Washington, DC.
- [2] Livingston G, Sommerlad A, Orgeta V, Costafreda SG, Huntley J, Ames D, Ballard C, Banerjee S, Burns A, Cohen-Mansfield J, Cooper C, Fox N, Gitlin LN, Howard R, Kales HC, Larson EB, Ritchie K, Rockwood K, Sampson EL, Samus Q, Schneider LS, Selbæk G, Teri L, Mukadam N (2017) Dementia prevention, intervention, and care. *Lancet* **390**, 2673-2734.
- [3] Bott NT, Hall A, Madero EN, Glenn JM, Fuseya N, Gills JL, Gray M (2019) Face-to-face and digital multidomain lifestyle interventions to enhance cognitive reserve and reduce risk of Alzheimer's disease and related dementias: a review of completed and prospective studies. *Nutrients* **11**, 2258.
- [4] Yaffe K, Barnes DE, Rosenberg D, Dublin S, Kaup AR, Ludman EJ, Vittinghoff E, Peltz CB, Renz AD, Adams KJ, Larson EB (2019) Systematic Multi-Domain Alzheimer's Risk Reduction Trial (SMARRT): study protocol. *J Alzheimers Dis* **70**, S207-S220.
- [5] Coley N, Ngandu T, Lehtisalo J, Soininen H, Vellas B, Richard E, Kivipelto M, Andrieu S; HATICE, FINGER, and MAPT/DSA groups (2019) Adherence to multidomain interventions for dementia prevention: data from the FINGER and MAPT trials. *Alzheimers Dement* **15**, 729-741.
- [6] Fleurence R, Selby JV, Odom-Walker K, Hunt G, Meltzer D, Slutsky JR, Yancy C (2013) How the Patient-Centered Outcomes Research Institute is engaging patients and others in shaping its research agenda. *Health Aff (Milwood)* **32**, 393-400.
- [7] Bethell J, Comisso E, Rostad HM, Puts M, Babineau J, Grinbergs-Saull A, Wighton MB, Hammel J, Doyle E, Nadeau S, McGilton KS (2018) Patient engagement in research related to dementia: a scoping review. *Dementia (London)* **17**, 944-975.
- [8] Dementia, risk, risk reduction, and translation into practice: an International Research Network for Dementia Prevention (IRNDP) special issue (2019) *J Alzheimers Dis* **70**, S1-S3.
- [9] Brayne C, Richard E (2019) Prevention of cognitive decline: a goal in sight? *J Alzheimers Dis* **70**, S11-S14.