

Colorectal Cancer Knowledge, Attitudes, Screening, and Intergenerational Communication Among Japanese American Families: An Exploratory, Community-Based Participatory Study

Denys T. Lau · Sayaka Machizawa · William Demonte ·
Kenzie A. Cameron · Naoko Muramatsu ·
Raymond D. Henker · Frances Chikahisa ·
Michael Tanimura

Published online: 22 December 2012

© Springer Science+Business Media New York 2012

Abstract Adults of Japanese descent (Nikkei) in the United States have higher risk for colorectal cancer (CRC) than their white counterparts. Family norms toward CRC screening may influence screening behaviors of Nikkei adults. This community-based participatory research study explores if mailing educational pamphlets to Nikkei families can influence CRC knowledge, attitudes, and screening adherence; and trigger intergenerational communication about CRC. Among 56 parent-offspring dyads contacted, 24 were eligible (e.g., no

D. T. Lau

Department of Pharmacy Administration, University of Illinois at Chicago, College of Pharmacy, Chicago, USA

S. Machizawa

Department of Community Partnerships, The Chicago School of Professional Psychology, 325 N. Wells Street, Rm 322, Chicago, IL 60654, USA
e-mail: smachizawa@thechicagoschool.edu

W. Demonte

The Chicago School of Professional Psychology, 325 N. Wells Street, Chicago, IL 60654, USA
e-mail: wdd0441@ego.thechicagoschool.edu

K. A. Cameron

Department of Medicine, Northwestern University, Feinberg School of Medicine, 750 North Lakeshore Drive, 10th Floor, Chicago, IL 60611, USA
e-mail: k-cameron@northwestern.edu

N. Muramatsu

University of Illinois at Chicago, School of Public Health, Division of Community Health Sciences, and Institute for Health Research and Policy, 1603 W. Taylor Street, Chicago, IL 60612, USA
e-mail: naoko@uic.edu

R. D. Henker

The Chicago School of Professional Psychology, 325 N. Wells Street, Chicago, IL 60654, USA
e-mail: rdh5119@thechicagoschool.edu

prior CRC screening/diagnosis) and were randomized into 3 cohorts defined by the “target recipient(s)” of study pamphlets about CRC screening: parent only, offspring only, and both parent and offspring. Among the 19 completed dyads (79.2 % = 19/24), results showed that CRC knowledge of most pamphlet recipients increased in all cohorts; however, some misinformation and attitudinal barriers persisted. Although some parent-offspring communication about CRC increased after mailing pamphlets to offspring, only spousal communication occurred after mailing pamphlets to parents. Additional benefits were not observed in increasing parental screening intent/behavior after mailing pamphlets to both parent and offspring. At the end, among the 10 parents who reported developing CRC screening intent or having scheduled a CRC screening, 8 attributed to study pamphlets and 2 to communication with their offspring. Self-reported barriers preventing screening and parent-offspring communication about CRC were identified. This exploratory study describes preliminary findings that will inform future research aimed to promote CRC screening and reduce racial/ethnic disparities at the community level by enhancing intergenerational communication among Nikkei families.

Keywords Colorectal cancer screening · Preventive care · Japanese Americans · Older adults

Introduction

Colorectal cancer (CRC) is the second leading cause of cancer death in the United States (Jemal et al. 2010). Adults of Japanese descent (Nikkei) in the U.S. have significantly higher risk for CRC diagnosis and mortality compared to non-Hispanic Whites (McCracken et al. 2007). The United States Preventive Services Task Force (USPSTF) recommends routine CRC screening for all adults age 50–75, and selectively for adults age 76–85 based on individual risks (Zauber et al. 2008). Although these recommendations have resulted in an overall increase in screening uptake, Asian American adults continue to have the lowest CRC screening adherence rate of any racial/ethnic groups (Lau and Kirby 2009).

Low CRC screening rates among Nikkei have been associated with demographic, socioeconomic, and psychological factors. One study found that over half of Nikkei adults who did not have up-to-date CRC screening were uninformed of the available screening options and one in five listed “absence of health problems” as their primary reason for not getting screened (Maxwell et al. 2010). Psychological barriers, including fear of learning CRC diagnosis, embarrassment with screening procedures, and concerns about discomfort, are associated with

F. Chikahisa

The Japanese American Service Committee, 4427 North Clark Street, Chicago, IL 60640, USA
e-mail: counsel@jasc-chicago.org

M. Tanimura

The Japanese American Service Committee, 4427 North Clark Street, Chicago, IL 60640, USA
e-mail: mike@sicreative.com

D. T. Lau (✉)

833 S. Wood Street (m/c 871), Chicago, IL 60612, USA
e-mail: denystlau@yahoo.com

Present Address:

D. T. Lau

Centers for Disease Control and Prevention, National Center for Health Statistics, Division of Health Care Statistics, 3311 Toledo Road, Hyattsville, MD 20782, USA

reduced CRC screening adherence in this population (Honda 2004). While similar barriers have been reported in the overall elderly population in the U.S. (Beydoun and Beydoun 2008), psychological barriers may have greater adverse impact on Nikkei than other ethnic/racial subgroups because the Japanese culture has been described as a “shame culture,” which further hinders Nikkei from accessing screening. A recent study of five different Asian American groups found that fear of pain and embarrassment were more likely to be the reasons for not obtaining endoscopy by Japanese Americans than by Korean or Vietnamese Americans (Honda 2004).

Besides intrapersonal factors, interpersonal factors—e.g., family/friends influence—may interact with psychological barriers toward CRC screening among Nikkei. Research finds that family/friend norms toward health screening may positively influence a Nikkei’s screening behavior, if his/her family or friends believe CRC screening is needed (Honda and Kagawa-Singer 2006). Social support also may lead to negative affect if information about negative screening experiences is exchanged (Honda and Gorin 2005). Traditional Japanese culture which emphasizes close family ties (familialism) may promote family interactions and therefore can play a key role in enhancing shared values and attitudes toward CRC screening. No intervention studies to our knowledge have taken an approach to educate families and promote communication to increase screening among Nikkei.

A previous needs assessment of Nikkei elders in the Chicago metropolitan and suburban areas (“Chicagoland”) finds that there exists no community-based programs on CRC screening targeting Nikkei (Machizawa and Lau 2007). To address this need, the Japanese American Service Committee (JASC), a not-for-profit social services agency serving Japanese Americans and the greater multicultural community in the Midwest, has partnered with several Chicago academic institutions to conduct a small community-based participatory research (CBPR) study (Minler and Duran 2008). This study aims to explore if mailing existing educational printed materials *can* trigger communication between Nikkei parents and their adult offspring about CRC and promote screening among parents. Two health behavior theories guided our intervention approach. First, according to the Health Belief Model (Rosenstock et al. 1988), we believe that the educational pamphlets used in this study would prompt individual CRC screening by influencing a reader’s net appraisal of his/her perceived susceptibility and severity of getting CRC, perceived barriers and benefits of screening options, and self-efficacy to get screened. Second, according to the Social Support/Networks Framework, increasing CRC knowledge could invoke emotional response to communicate within a family network about screening to reduce the likelihood for CRC-related mortality; therefore, educational pamphlets can promote screening directly by informing/motivating the reader, as well as indirectly by transferring informational and emotional support among members of a family unit (Heaney and Israel 1997).

In this exploratory study, parent-offspring communication was chosen as the initial focus because adult offspring themselves are aging as the next target generation for CRC screening and because one of JASC’s priority interests is to promote intergenerational interactions among Nikkei families. Further, mailing existing pamphlets was identified as the most cost-effective choice of intervention. Although mailing pamphlets can improve CRC knowledge and screening adherence (Partin et al. 2004), little is known about the effect of mailing pamphlets to family members on communication and screening behaviors.

This “proof-of-concept” study specifically will explore if mailing CRC pamphlets to different recipients has the ability to: (1) improve Nikkei parents’ CRC knowledge, attitudes, and screening intent/behaviors; (2) trigger parent-offspring communication about CRC and improve parents’ screening intent/behaviors; (3) yield different effects on communication about CRC and parental screening intent/behaviors based on target recipients of study pamphlets (Nikkei parents, their offspring, or both); and (4) benefit adult offspring by improving their

knowledge/attitudes toward CRC screening. Due to the study's exploratory nature, we will not aim to have sufficient statistical power to test hypotheses. Instead, we seek preliminary insight and assess feasibility to further refine future intervention approaches to address racial/ethnic disparities in CRC screening.

Methods

Research team

Typical of the CBPR approach, academic researchers provided scientific expertise while partnering with community providers who upheld cultural competence in all research activities. Based on CBPR best practices (Newman et al. 2011), we also consulted a panel of five selected community advisors—family physician, nurse, clinical psychologist, social scientist, and community organizer—with professional expertise in promoting Nikkei health in Chicagoland. Four of the five advisors were Nikkei, thus integrating the “voice” of community members into the study process. Advisors attended two 3-hour, in-person meetings to: (1) help select pamphlets for use as study interventions and refine survey guides; and (2) help interpret findings and suggest recommendations for future research and programming efforts.

Setting/study participants

JASC staff advertised the study through electronic-listservs, posting flyers, and advertisements in local newspapers. Using convenience sampling, we recruited dyads of Nikkei parent and his/her offspring. Eligibility criteria included: (1) Nikkei parent aged 50–85, no basic functional limitations, cognitively intact, no cancer diagnosis or prior CRC screening, and English-speaking; (2) offspring (blood-related, adopted, or in-law) aged 18+, no cancer diagnosis or prior CRC screening, and English-speaking; and (3) parent and offspring lived together or communicated with each other at least once a week. If more than one parent or offspring met the eligibility criteria, the family chose the participant based on availability. We restricted our study to English-speaking individuals because over 95 % of Nikkei adults living in Chicagoland were known to be English proficient according to prior research projects (Lau et al. 2012) and JASC's 65-year history of serving the Chicagoland's Nikkei community. Institutional Review Board approved this study; parents and offspring consented to participate in the study.

Research design

Enrolled dyads were assigned based on a computer-generated random number (from 1 to 3 for n times) into three cohorts defined by the “target recipient(s)” of pamphlets: only the parent (Cohort 1), only the offspring (Cohort 2), and parent+offspring separately received pamphlets (Cohort 3). Three waves of data collection included: (1) a baseline in-person survey at a location of the participant's choice; (2) a follow-up phone survey (~2 weeks later) with the target pamphlet recipients; and (3) a final phone survey (~2 more weeks later) with each dyad member.

Pamphlets

Based on thorough online searches, two educational pamphlets were chosen as the study's interventions. Both pamphlets were: (1) free, (2) sponsored by authoritative health agencies, (3) judged as written appropriately for persons with low literacy by researchers and project

advisors, and (4) judged as culturally appropriate for Nikkei by researchers and advisors. The first pamphlet, sponsored by the U.S. Centers for Disease Control and Prevention (CDC 2009), was designed for the general population and mailed between the first two waves of data collection. The second pamphlet targeting Asian Americans was based on an existing Maryland Department of Health and Human Services (Maryland DHHS) pamphlet that was shortened to include only CRC information and was mailed between the last two waves of data collection.

Survey guides

Investigators drafted survey guides containing open- and closed-ended items based on prior community needs assessment (Machizawa and Lau 2007). Draft surveys were evaluated and refined by project advisors using a Delphi method (Dalkey et al. 1969). Advisors rated survey items based on accuracy, relevance, comprehension, and cultural appropriateness.

Surveys included items on age, sex, generation in the U.S., highest education, cohabitation with parent/adult offspring, annual income, and self-rated overall health (see Table 1 for response categories). Only parents were asked the number of prescription medications taken, if they saw a primary care physician regularly, and health insurance.

Health literacy was assessed using validated items (Chew et al. 2004; Wallace et al. 2006) that measured the degree (not at all, a little bit, somewhat, quite a bit, extremely) of confidence in filling out medical forms; and the frequency (never, occasionally, sometimes, often, always) of needing assistance in reading hospital materials and difficulty in understanding written medical information and doctor's explanation. "Somewhat" or "sometimes" were cut-off points to identify individuals with limited health literacy. The quality of parent-offspring relationship was assessed using the validated Mutuality Scale (Archbold et al. 1990), which measured the extent ('not at all' to 'very much') to which respondents enjoyed spending time together, felt emotionally close to the other person, shared similar values, and confided in each other.

Opinions and reactions toward pamphlets were assessed among target recipients after each mailing. Respondents reported to what extent ('not at all' to 'very much') the pamphlet was clear, informative, trustworthy, useful, and relevant. Respondents also reported if they showed the pamphlet or discussed its content with someone else (if so, with whom).

Only target recipients were asked items about knowledge and attitudes toward CRC disease at baseline and final surveys. Items were selected from validated questionnaires (Sessa et al. 2008; Wolf et al. 2005) that were derived from the Health Belief Model (Rosenstock et al. 1988) and the National Health Interview Survey (Benson and Marano 1994). Knowledge items about CRC included identifying 7 risk factors among 12 choices (less than vs. more than 50 % of the correct risk factors), answering the recommended starting age of screening (correct vs. incorrect age), and naming CRC screening tests (zero vs. at least 1 correct test). Attitudes about CRC were assessed by asking to what extent ('definitely no' to 'definitely yes') respondents thought CRC could be cured if found early, they were at risk for CRC, and they wanted to know if they had CRC.

Items on knowledge/attitudes toward CRC screening were asked based on the tests named by the respondent. For example, respondents who named colonoscopy were asked how frequent colonoscopy should be screened if the results were normal (1×/year, 1×/2 years, 1×/5 years, 1×/10 years), and how worried ('not at all' to 'very much') were they about colonoscopy being painful, embarrassing, and giving wrong diagnosis.

CRC screening intention and behavior items were asked only of parents in the final survey. At the end of the study, parents were asked if they got screened, scheduled to get screened, or

Table 1 Characteristics of parents and adult offspring who completed the study

	Parents (<i>n</i> =19)	Adult Offspring (<i>n</i> =19)
Age (years), Mean [range]	62 [51–85]	35 [18–55]
Sex, Female	14 (74 %)	15 (79 %)
Generation in the U.S.		
Nisei (second-generation)	3 (16 %)	
Sansei (third-generation)	16 (84 %)	3 (16 %)
Yonsei (fourth-generation)		16 (84 %)
Education		
No college degree	5 (26 %)	6 (32 %)
College degree only	8 (42 %)	8 (42 %)
Graduate/professional degree	6 (32 %)	5 (26 %)
Time living in Chicago (years), Mean [range]	49 [5–68]	29 [15–47]
Communicate with parent (or offspring) in English	19 (100 %)	19 (100 %)
Live with parent (or offspring)	8 (42 %)	8 (42 %)
Annual household income		
≤ \$35,000	3 (15.8 %)	2 (10.6 %)
\$35,001–\$50,000	2 (10.5 %)	5 (26.3 %)
\$50,001–\$65,000	4 (21.1 %)	5 (26.3 %)
\$65,001–\$80,000	2 (10.5 %)	2 (10.5 %)
> \$80,000	5 (26.3 %)	5 (26.3 %)
refused	3 (15.8 %)	0 (0.0 %)
Self-rated health		16 (84 %)
Excellent/very good/good	16 (84 %)	3 (16 %)
Fair/poor	3 (16 %)	
Questions for parents only:		
No. of prescribed medications, Mean [range]	1.5 [0–7]	
See primary care physician regularly	13 (68 %)	
Medicaid insurance	2 (11 %)	
Understanding health information:		
Not at all/a little confident filling out medical forms alone	1 (5 %)	2 (11 %)
Always/often have someone help read hospital materials	2 (11 %)	2 (11 %)
Always/often have problems learning medical conditions due to difficulty in understanding written information	0 (0 %)	1 (5 %)
Always/often have difficulty understanding what doctor tells me about medical conditions	0 (0 %)	1 (5 %)
Parent-offspring relationship quality:		
Very much/somewhat feel close to the other person	19 (100 %)	19 (100 %)
Very much/somewhat is attached emotionally to the other person	19 (100 %)	19 (100 %)
Very much/somewhat feel that both share the same values	19 (100 %)	17 (89 %)
Very much/somewhat feel they laugh together	18 (95 %)	17 (89 %)
Very much/somewhat feel they confide in the other person	15 (79 %)	13 (68 %)
Very much/somewhat enjoy the time both spend together	18 (95 %)	18 (95 %)

intended to get screened for CRC. Open-ended items solicited reasons for the parents' screening intent/behaviors. Parents also listed motivating factors to get CRC screening.

Analysis

Descriptive statistics were calculated using frequency distributions for categorical variables, and measures of central tendency and dispersion (e.g., means and ranges) for continuous variables. Inferential statistics were not performed due to limited sample size. For open-ended items, content analysis was performed by interviewers WD and RH, who developed the initial set of topic codes, grouping similar responses. Investigators DL and SM reviewed and validated the coding definition and strategies. Group consensus was reached among the research team on discrepant codes to ensure analytical consistency (Miles and Huberman 1994).

Results

A total of 56 parent-offspring dyads were contacted for the study. Three dyads declined to participate. Twenty-nine dyads were ineligible mainly due to parents having had CRC screening. The remaining 24 eligible dyads were randomized into 3 cohorts as previously described: 9 to Cohort 1; 9 to Cohort 2; and 6 to Cohort 3. Among them, 19 dyads (79 %) completed the study. All 5 drop-outs (21 %) were from Cohort 2 after the first pamphlet mailing to offspring: 3 mother-and-daughter, 1 father-and-daughter, and 1 father-and-son. (See Discussion for potential reasons.) This paper reports findings of the 19 dyads with complete data.

Characteristics

Table 1 presents parental and offspring characteristics. There were no notable differences among the three cohorts (data available upon request). Overall, the mean age of Nikkei parents was 62 and adult offspring was 35. Most parents were *sansei* (third-generation), female, and college-educated; similarly, most offspring were *yonsei* (fourth-generation), female, and college-educated. Less than half of the dyads lived together; about one-half of the parents had an annual household income of over \$65,000 and about one-quarter of the offspring had income in the same range. Most parents and offspring reported "good" to "excellent" health.

Almost all parents reported adequate health literacy, with two parents needing someone to help read hospital materials. Four offspring indicated some degree of limited health literacy; one had difficulty understanding written medical information and information from her doctor and had low confidence completing medical forms. Almost all adults and offspring characterized their relationship quality as high.

Opinions/reactions toward pamphlets

To keep this report brief, data for this section are available upon request. Almost all parents and offspring found that both pamphlets were "very much" clear, informative, trustworthy, and useful; ratings on relevance among offspring were lower than those among parents. Several recipients preferred the second mailing targeting Asian-Americans. One Cohort-2 offspring noted, "I liked the Asian-focused [pamphlet]...it made me look more closely."

A total of eight recipients in different dyads reported sharing pamphlet's information. Two "target recipient" parents in Cohort 1 discussed the pamphlet with their spouse, and three "target recipient" offspring in Cohort 2 discussed with their parent. In Cohort 3, three parents discussed the pamphlet with their spouse and one offspring in another dyad discussed with her parent. Reasons why parents or offspring did not share pamphlet's information included "not thinking about it," "maintaining privacy," and "awkward." One offspring reflected on the Nikkei cultural norm saying, "Culturally, it is difficult to openly talk about health issues. It's hard to ask questions about health." Unique to Cohort 3, parents and offspring assumed that there was no need to discuss the pamphlet information because both members of the dyad received the pamphlets. One offspring noted, "We haven't discussed...[My mom] had her own copy."

Knowledge/attitudes

Table 2 shows the baseline and final survey responses of target recipients' knowledge and attitudes toward CRC. Overall, knowledge about CRC risk factors, starting age for screening, and screening options appeared to improve among recipients of pamphlets in all cohorts. The majority of recipients (92 %) in all cohorts believed their CRC knowledge increased. Those participants not reporting an increase in knowledge were the same individuals who reported having some degree of limited health literacy.

However, attitudes, especially toward colonoscopy, did not appear to improve among recipients. For example, among individuals identifying colonoscopy as a screening option, worries regarding how painful a colonoscopy would be increased slightly from baseline (20 %) to final survey (26.1 %) as did worries regarding embarrassment (15.0 % to 26.1 %). However, concerns regarding a colonoscopy providing an inaccurate diagnosis decreased from baseline (30 %) to final survey (21.7 %).

Screening intent/behavior

Table 3 shows parents' self-reported CRC screening intent and behavior at the final survey. During the study period, one parent reported getting screened for CRC, four scheduling screening, and five intending to get screened within the next month. Percentages of CRC scheduling and positive intent were similar among all cohorts. Reasons why parents intended to or actually got screening were attributed to study pamphlets ($n=8$) and to advice from their adult offspring who discussed pamphlet's content with them ($n=2$).

Reasons parents provided for not getting screened and/or not intending to get screened included putting it off/being too busy ($n=8$), lack of doctor recommendation ($n=6$; 3 of whom reported seeing a primary care physician regularly), no symptoms/observable health problems ($n=4$), worry about the prep work ($n=3$), not thinking screening was necessary ($n=2$), and uncertainty about getting screened ($n=1$). One Cohort-1 parent said, "Unless my doctor says I need to, I don't think it's necessary [to get screened]." Parents identified factors that may motivate them to get screened, including doctor's recommendation ($n=5$), bloody stool/pain ($n=4$), family advice and help ($n=2$), family diagnosis for CRC ($n=2$), and better prep work available ($n=1$). One Cohort-3 parent said, "I'd go if my husband made the appointment for me."

Discussion

This exploratory study produced key preliminary findings regarding whether mailing existing educational pamphlets had the ability to affect parent-offspring communication about

Table 2 Target recipient's knowledge/attitudes toward colorectal cancer screening at baseline and final surveys, by study cohorts

	Cohort 1 ^a		Cohort 2 ^a		Cohort 3 ^a	
	Parent (n=9)		Offspring (n=4)		Parent (n=6)	
	Baseline	Final	Baseline	Final	Baseline	Final
Knowledge/Attitudes						
Identify > 50 % of risk factors	9 (100 %)	9 (100 %)	3 (75 %)	4 (100 %)	6 (100 %)	5 (83 %)
Identify correct age to start screening	4 (44 %)	8 (89 %)	4 (100 %)	3 (75 %)	3 (50 %)	6 (100 %)
Identify at least 1 correct screening test	8 (89 %)	8 (89 %)	4 (100 %)	4 (100 %)	6 (100 %)	6 (100 %)
Think CRC can probably/definitely be cured if found early	9 (100 %)	9 (100 %)	3 (75 %)	3 (75 %)	6 (100 %)	6 (100 %)
Think they are probably/definitely not at risk for CRC	8 (89 %)	7 (67 %)	3 (75 %)	4 (100 %)	3 (50 %)	3 (50 %)
Probably/definitely want to know if they have CRC	9 (100 %)	9 (100 %)	4 (100 %)	4 (100 %)	6 (100 %)	6 (100 %)
Probably/definitely believe their knowledge re: CRC's increased	–	8 (89 %)	–	4 (100 %)	–	5 (83 %)
Identify colonoscopy as a screening option	n=8	n=8	n=3	n=3	n=5	n=6
Should be screened once every 10 years	2 (25 %)	5 (63 %)	0 (0 %)	2 (67 %)	0 (0 %)	5 (83 %)
Somewhat/very much worry that the test would						
Be painful	0 (0 %)	0 (0 %)	0 (0 %)	1 (33 %)	1 (20 %)	2 (33 %)
Be embarrassing	1 (13 %)	1 (13 %)	0 (0 %)	1 (33 %)	0 (0 %)	2 (33 %)
Give the wrong diagnosis	1 (13 %)	2 (25 %)	1 (33 %)	0 (0 %)	2 (40 %)	2 (33 %)

^a Among the 19 completed parent-offspring dyads, 9 dyads were randomly assigned to Cohort 1 (target pamphlet recipients = parents); 4 dyads to Cohort 2 (target pamphlet recipients = offspring); 6 dyads to Cohort 3 (target pamphlet recipients = parents and offspring)

Table 3 Parents' self-reported colorectal cancer screening intent and behavior at final survey, by study cohorts

	Cohort 1 ^a Parent (n=9)	Cohort 2 ^a Parent (n=4)	Cohort 3 ^a Parent (n=6)
Since the study, parents who			
Got screened for CRC	1 (11 %)	0 (0 %)	0 (0 %)
Scheduled for CRC screening	2 (22 %)	1 (25 %)	1 (17 %)
Intended to get screened for CRC	2 (22 %)	1 (25 %)	2 (33 %)
<i>Total</i>	5 (55 %)	2 (50 %)	3 (50 %)
Among those parents who <i>did</i> get screened, schedule for screening, or intend to get a CRC screening:			
Reasons for doing so ^b			
Study pamphlets	5 (55 %)	0 (0 %)	3 (50 %)
Spouse was getting screened	1 (11 %)	0 (0 %)	0 (0 %)
Adult offspring advice/communication	0 (0 %)	2 (50 %)	0 (0 %)
Among those parents who <i>did not</i> get screened, schedule for screening, or intend to get a CRC screening:			
Reasons for not doing so ^b			
Putting it off/being too busy	4 (44 %)	2 (50 %)	2 (33 %)
Doctor has not recommended it	1 (11 %)	2 (50 %)	3 (50 %)
No symptoms/problems	1 (11 %)	2 (50 %)	1 (17 %)
Worry about the prep work	2 (22 %)	1 (25 %)	0 (0 %)
Think it is not necessary	0 (0 %)	2 (50 %)	0 (0 %)
Not sure if they should do it	1 (11 %)	0 (0 %)	0 (0 %)
Factors that may motivate parents to get screened ^b			
Doctor's recommendation	1 (11 %)	2 (50 %)	2 (33 %)
Bloody stool/pain	1 (11 %)	2 (50 %)	1 (17 %)
Family advice and help	1 (11 %)	0 (0 %)	1 (17 %)
Family's diagnosis for CRC	1 (11 %)	0 (0 %)	1 (17 %)
Better prep work available	0 (0 %)	1 (25 %)	0 (0 %)

^a Among the 19 *completed* parent-offspring dyads, 9 dyads were randomly assigned to Cohort 1 (target pamphlet recipients = parents); 4 dyads to Cohort 2 (target pamphlet recipients = offspring); 6 dyads to Cohort 3 (target pamphlet recipients = parents and offspring)

^b Reasons/factors are not mutually exclusive categories

CRC and influence CRC screening in Nikkei parents living in Chicagoland. First, consistent with prior research (Partin et al. 2004), our data indicated that basic CRC knowledge and screening intent/behavior increased among most parents after receiving pamphlets; however, some misinformation and attitudinal barriers persisted. Overall, many parents who received pamphlets had increased CRC knowledge regarding risk factors, starting age for screening, and screening options. Parents whose knowledge did not increase in all areas were the few who had some degree of limited health literacy, a finding consistent with prior research reporting that health literacy predicted retention of health information about CRC (Wilson et al. 2010). It was troubling to find that some parents remained misinformed about when to get CRC screening; for example, several parents said they would only get screened if they see bloody stool. Such misinformation may require more persuasive messages in future educational interventions than those in the study pamphlets.

Surprisingly, the proportion of parents' attitudes toward screening tests in some cases worsened. Concerns persisted about colonoscopy being painful, embarrassing, and giving the wrong diagnosis. A common barrier identified by parents included worries about preparing for the procedure. Such worries may have resulted as study pamphlets did not discuss anecdotal experiences, particularly positive ones, with preparing for or undergoing CRC screening.

Second, our data indicated that CRC knowledge in most offspring increased after receiving pamphlets. Offspring whose CRC knowledge did not increase overall were those reporting some degree of limited health literacy. Our data also showed that offspring attitudes toward CDC did not improve. Negative offspring's attitudes might have contributed to the overall low rates of parent-offspring communication about CRC. Although no such evidence was found in this study, offspring's negative attitudes toward CRC screening potentially could be communicated to their parent and in turn further discouraged parental screening behavior (Honda and Gorin 2005).

Third, our data indicated that some parent-offspring communication about CRC increased after mailing pamphlets to offspring, while only communication between spouses occurred after mailing pamphlets to parents. Five parents who received pamphlets communicated about CRC with their spouse, which may be beneficial as spousal support can play a key role in influencing health-seeking behaviors. Low rates of parent-offspring communication about CRC might have resulted from selection bias because parents in this study were generally healthy with no basic functional limitation; therefore, they may not have felt the need to communicate with their offspring to solicit help to get screening. Attitudinal barriers hindering parent-offspring communication also included feeling awkward and not thinking to share pamphlet's information. Neither study pamphlets contained explicit messages about discussing CRC screening with family members; including such information in future materials could be effective. Nikkei cultural norm also may hinder intergenerational communication about health issues if there is no serious health problem (Machizawa and Lau 2010). Future interventions promoting parent-offspring communication may need to address broader Nikkei cultural norms.

Fourth, our data did not indicate additional benefits in parent-offspring communication about CRC or parental screening intent/behaviors by mailing pamphlets to both parent and offspring. An unexpected barrier unique to Cohort 3 was identified that may have reduced parent-offspring communication about CRC: two offspring and one parent assumed that they did not need to discuss the information because both members of the dyad received CRC pamphlets. Interestingly, all of the parent-offspring communication about CRC occurred after the second mailing. Although recipient's positive opinions about both pamphlets were largely similar, this study could not determine whether parent-offspring communication was prompted by the second pamphlet which targeted Asian Americans or the act of receiving a second pamphlet.

Our preliminary findings may help inform future development and evaluation of CRC educational interventions for Nikkei adults. Future educational messages may need to provide examples of Asian-American individuals who have positive experiences with CRC screening to further address attitudinal barriers. More explicit messages may be needed to correct additional misinformation identified by study participants (e.g., "blood in stool may not be visible to the naked eye"). To encourage parent-offspring communication about CRC, interventions may need to provide examples of Nikkei families who have overcome the cultural norm by talking about CRC screening with each other. Strategies are needed on how to overcome awkwardness and discuss health issues in families with different situations and caregiver roles (e.g., younger adult offspring convincing their parents). Additionally, messages could explore ways to talk to spouses, peers, and healthcare professionals. Particularly, conversations about CRC should be

initiated with physicians even if screening has not been suggested. Finally, educational interventions should be presented in a comprehensive and culturally appropriate manner, especially for individuals with limited health literacy.

There were limitations in this study. First, this is an exploratory study intended to assess feasibility; therefore, causal relationships between intervention and outcomes should not be inferred. Second, the sample size is small and our convenience sampling technique limits the generalizability of our findings. Larger studies including individuals of other races/ethnicities, socio-economic status, and geographical locations are needed to replicate these findings. Although common in most health-related studies, the majority of our sample was female, also limiting the generalizability of our findings to Nikkei male. Third, all 5 drop-outs were from Cohort 2 despite multiple follow-up phone calls. Because the target pamphlet recipients in Cohort 2 were offspring, these working-age adults might have limited availability due to competing obligations or might not have felt emotionally invested in this study about CRC screening, a disease that offspring might not perceive as relevant to them. Finally, it was not feasible in this pilot study to clinically validate the parental screening intent/behaviors reported. Collectively, these limitations provide important lessons for future research.

This research report provides important preliminary insights about whether mailing existing CRC educational pamphlets can influence CRC knowledge, attitudes, information exchange, and screening intent/behaviors among Nikkei adults. This small CBPR project provides groundwork and lessons that will inform the development of future interventional studies to promote CRC screening adherence and to reduce racial/ethnic disparities at the community level by enhancing intergenerational communication among Nikkei families.

Acknowledgement The research team sincerely thanks all of the Nikkei parents and adult offspring who participated in this study for their time and insight. The team also expresses tremendous gratitude to Carol Yoshino, Sharon Harada, Mary Doi, Asayo Horibe, Denison Hunter, Eric Mizuno, Mayumi Nakamura, Bryan Robson, and Susan Tybon for their invaluable guidance and dedicated support throughout this study. We also thank the Japanese American Service Committee and its staff members for their collaboration throughout the study.

Funding source This study was made possible by the institutional funding support from the Alliance for Research in Chicagoland Communities of the Northwestern University Clinical and Translational Research Sciences (NUCATS) Institute (Academic co-PI: Denys T. Lau, PhD; Community co-PI: Frances Chikahisa, MSW, LCSW). The funding organization played no role in the design or conduct of the study; in the collection, analysis, or interpretation of the data; or in the preparation, review, or approval of the manuscript.

Conflict of interests The authors declare no conflict of interests (personal, commercial, political, academic, or financial) related to the subject matter of this manuscript.

References

- Archbold, P. G., Stewart, B. J., Greenlick, M. R., & Harvath, T. (1990). Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing and Health, 13*, 375–384.
- Benson, V., & Marano, M. A. (1994). Current estimates from the national health interview survey, 1992. *Vital and Health Statistics, 10*, 1–269.
- Beydoun, H. A., & Beydoun, M. A. (2008). Predictors of colorectal cancer screening behaviors among average-risk older adults in the United States. *Cancer Causes & Control, 19*, 339–359.
- Centers for Disease Control and Prevention. (2009). Colorectal cancer screening saves lives. Accessed on June 14, 2012. Available: http://www.cdc.gov/cancer/colorectal/pdf/SFL_brochure.pdf.
- Chew, L. D., Bradley, K. A., & Boyko, E. J. (2004). Brief questions to identify patients with inadequate health literacy. *Family Medicine, 36*, 588–594.

- Dalkey, N., Brown, B., & Cochran, S. (1969). *The Delphi Method, III: Use of self ratings to improve group estimates*. Santa Monta: Rand Corp.
- Heaney, C. A., & Israel, B. A. (1997). Social networks and social support. In K. Glanz, F. M. Lewis, & B. Rimer (Eds.), *Health behavior and health education: Theory, research, and practice* (pp. 179–205). San Francisco: Jossey-Bass Publications.
- Honda, K. (2004). Factors associated with colorectal cancer screening among the US urban Japanese population. *American Journal of Public Health, 94*, 815–822.
- Honda, K., & Gorin, S. S. (2005). Modeling pathways to affective barriers on colorectal cancer screening among Japanese Americans. *Journal of Behavioral Medicine, 28*, 115–124.
- Honda, K., & Kagawa-Singer, M. (2006). Cognitive mediators linking social support networks to colorectal cancer screening adherence. *Journal of Behavioral Medicine, 29*, 449–460.
- Jemal, A., Siegel, R., Xu, J., & Ward, E. (2010). Cancer statistics, 2010. *CA: A Cancer Journal for Clinicians, 60*, 277–300.
- Lau, D. T., & Kirby, J. B. (2009). The relationship between living arrangement and preventive care use among community-dwelling elderly persons. *American Journal of Public Health, 99*, 1315–1321.
- Lau, D. T., Machizawa, S., & Doi, M. (2012). Informal and formal support among community-dwelling Japanese American elders living alone in Chicagoland: an in-depth qualitative study. *Journal of Cross-Cultural Gerontology, 27*, 149–161.
- Machizawa, S., & Lau, D. T. (2007). Aging alone in Chicago and aging in the suburbs: An In-depth qualitative needs assessment of isolated nikkei elders. Chicago, IL: Japanese American Service Committee Needs Assessment. Accessed on June 14, 2012. Available: <http://www.jasc-chicago.org/IsolatedNikkeiElders-FinalReport.pdf>.
- Machizawa, S., & Lau, D. T. (2010). Psychological needs of Japanese American elders: implications for culturally competent interventions. *Journal of Cross-Cultural Gerontology, 25*, 183–197.
- Maryland Department of Health and Human Services, Montgomery County. Asian American Health Initiative. Cancer facts for the Asian American community. Accessed on June 14, 2012. Available: <http://aahiinfo.org/pdf/publications/CancerFacts-English.pdf>.
- Maxwell, A. E., Crespi, C. M., Antonio, C. M., & Lu, P. (2010). Explaining disparities in colorectal cancer screening among five Asian ethnic groups: a population-based study in California. *BMC Cancer, 10*, 214.
- McCracken, M., Olsen, M., Chen, M. S., Jr., Jemal, A., Thun, M., Cokkinides, V., et al. (2007). Cancer incidence, mortality, and associated risk factors among Asian Americans of Chinese, Filipino, Vietnamese, Korean, and Japanese ethnicities. *CA: A Cancer Journal for Clinicians, 57*, 190–205.
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd ed.). Thousand Oaks: Sage.
- Minler, M., & Duran, B. (2008). *Community-based participatory research for health: From process to outcomes*. San Francisco: Jossey-Bass A Wiley Imprint.
- Newman, S. D., Andrews, J. O., Magwood, G. S., Jenkins, C., Cox, M. J., & Williamson, D. C. (2011). Community advisory boards in community-based participatory research: a synthesis of best processes. *Preventing Chronic Disease, 8*, A70.
- Partin, M. R., Nelson, D., Radosevich, D., Nugent, S., Flood, A. B., Dillon, N., et al. (2004). Randomized trial examining the effect of two prostate cancer screening educational interventions on patient knowledge, preferences, and behaviors. *Journal of General Internal Medicine, 19*, 835–842.
- Rosenstock, I. M., Strecher, V. J., & Becker, M. H. (1988). Social learning theory and the health belief model. *Health Education Quarterly, 15*, 175–183.
- Sessa, A., Abbate, R., Di Giuseppe, G., Marinelli, P., & Angelillo, I. F. (2008). Knowledge, attitudes, and preventive practices about colorectal cancer among adults in an area of Southern Italy. *BMC Cancer, 8*, 171.
- Wallace, L. S., Rogers, E. S., Roskos, S. E., Holiday, D. B., & Weiss, B. D. (2006). Brief report: screening items to identify patients with limited health literacy skills. *Journal of General Internal Medicine, 21*, 874–877.
- Wilson, E. A., Wolf, M. S., Curtis, L. M., Clayman, M. L., Cameron, K. A., Eigen, K. V., et al. (2010). Literacy, cognitive ability, and the retention of health-related information about colorectal cancer screening. *Journal of Health Communication, 15*, 116–125.
- Wolf, M. S., Rademaker, A., Bennett, C. L., Ferreira, M. R., Dolan, N. C., Davis, T. C., et al. (2005). Development of a brief survey on colon cancer screening knowledge and attitudes among veterans. *Preventing Chronic Disease, 2*, A11.
- Zauber, A. G., Lansdorp-Vogelaar, I., Knudsen, A. B., Wilschut, J., van Ballegooijen, M., & Kuntz, K. M. (2008). Evaluating test strategies for colorectal cancer screening: a decision analysis for the U.S. Preventive Services Task Force. *Annals of Internal Medicine, 149*, 659–669.