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## Reducing Cancer Screening Disparities in Medicare Beneficiaries Through Cancer Patient Navigation

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### Abstract

Significant racial disparities in cancer mortality are seen between Medicare beneficiaries. A randomized controlled trial tested the use of lay navigators (care managers) to increase cancer screening of Asian and Pacific Islander Medicare beneficiaries. The study setting was Moloka'i General Hospital on the island of Moloka'i, Hawai'i, which was one of six sites participating in the Cancer Prevention and Treatment Demonstration sponsored by the Centers for Medicare and Medicaid Services. Between 2006 and 2009, 488 Medicare beneficiaries (45% Hawaiian, 35% Filipino, 11% Japanese, 8% other) were randomized to have a navigator help them access cancer screening services (experimental condition, n = 242) or cancer education (control condition, n = 246). Self-reported data on screening participation were collected at baseline and exit from the study, and differences were tested using chi-square. Groups were similar in demographic characteristics and baseline screening prevalence of breast, cervical, prostate, and colorectal cancers. At study exit, 57.0% of women in the experimental arm and 36.4% of controls had had a Papanicolaou test in the past 24 months ( $P = .001$ ), 61.7% of women in the experimental arm and 42.4% of controls had had a mammogram in the past 12 months ( $P = .003$ ), 54.4% of men in the experimental arm and 36.0% of controls had had a prostate-specific antigen test in the past 12 months ( $P = .008$ ), and 43.0% of both sexes in the experimental arm and 27.2% of controls had had a flexible sigmoidoscopy or colonoscopy in the past 5 years ( $P < .001$ ). Findings suggest that navigation services can increase cancer screening in Medicare beneficiaries in groups with significant disparities.

### Keywords

case management; community health workers; Filipinos; Native Hawaiians; navigators

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**Author Contributions:** Tsark, Thomas, Aluli, and Brazzel helped MGH write the proposal for CMS funding. They played a role in designing the study and in subject recruitment. Braun, Tsark Domingo, and Allison provided navigation training for the intervention staff and technical assistance with data collection and analyzed data. All authors participated in preparing the paper.

An estimated 44% of Americans will be diagnosed with cancer in their lifetime.<sup>1</sup> Although cancer can occur at any age, more than 75% of cancer diagnoses occur in those aged 55 and older.<sup>2</sup> Medicare covers cancer screening and treatment for its enrollees, but there are racial and ethnic disparities in cancer mortality and screening prevalence.<sup>3</sup> For example, in Hawaii's four largest ethnic groups, cancer mortality is higher for Native Hawaiians and Filipinos than for Caucasians and Japanese. Also, Native Hawaiians and Filipinos are less likely to report timely cancer screening or be diagnosed with early-stage cancer than the other ethnic groups.<sup>4</sup>

Navigation programs for individuals with cancer are designed to help them overcome the many barriers to completing recommended cancer screening and treatment in a timely manner.<sup>5,6</sup> These barriers include lack of knowledge about cancer and the power of screening to detect cancer when it is most curable, lack of ability to negotiate the healthcare system, and poor access to services or the ability to pay for them. Navigators link individuals with cancer to needed diagnostic tests and, if cancer is found, help facilitate their movement to and through treatment and recovery. Navigators help increase cancer knowledge, help people secure insurance, and transport them to appointments. Navigators also can train people to be healthcare advocates for themselves.<sup>5-7</sup>

In the United States, cancer navigation programs have been established in diverse settings (e.g., clinics, hospitals, community organizations), employ navigators from different academic backgrounds and disciplines (e.g., nurses, social workers, counselors, community health workers), and may require from 12 to 400 hours of navigation-specific training.<sup>7</sup> Despite these differences, empirical research suggests that individuals who receive such services are more likely than those who do not to receive timely, age- and sex-appropriate cancer screening.<sup>8</sup> Research also shows that navigation has been effective in increasing cancer screening prevalence in minority populations, including Native Americans,<sup>9</sup> Alaska Natives,<sup>10</sup> Asian Americans,<sup>11,12</sup> Micronesians,<sup>13</sup> Hispanics,<sup>14,15</sup> and African Americans.<sup>5,16</sup>

Despite the promise of navigation in increasing screening rates in minority populations, there is little research on the use of navigators to increase cancer screening in the Medicare population. The majority of research has tested whether navigation services increase breast, cervical, and colorectal cancer screening in young and middle-aged adults.<sup>8-18</sup>

The only known project to focus specifically on reducing cancer-related racial and ethnic disparities in older adults was the Cancer Prevention and Treatment Demonstration sponsored by the Centers for Medicare and Medicaid Services (CMS). Although approximately 17% of Medicare beneficiaries are younger than 65 and are eligible for Medicare because of disability, the majority of beneficiaries are aged 65 and older. It was hypothesized that navigators could help increase the prevalence of cancer screening in Medicare beneficiaries with low screening participation and reduce cancer health disparities in the Medicare population.<sup>3</sup> Moloka'i General Hospital (MGH), on the rural island of Moloka'i, Hawai'i, was one of six sites participating in this CMS demonstration. The purpose of this article is to present findings from this randomized controlled trial (RCT) of

the use of navigators to reduce disparities that Asian and Pacific Islander Medicare recipients experience in accessing breast, cervical, prostate, and colorectal cancer screening.

## METHODS

### The Intervention and Setting

The CMS Cancer Prevention and Treatment Demonstration operated from 2006 to 2010.<sup>3</sup> The six participating sites included Johns Hopkins (Baltimore, MD), MD Anderson (Houston, TX), Henry Ford Health System (Detroit, MI), New Jersey School of Medicine and Dentistry (Newark, NJ), the Huntsman Cancer Institute (Salt Lake City, UT), and MGH (Moloka'i, HI). The institutional review boards of the Native Hawaiian Health Care Systems and The Queen's Medical Center (parent organization of MGH) approved the study in Hawai'i.

Moloka'i is one of seven inhabited islands in the state of Hawai'i. More than 92% of the island's population of 7,345 are Native Hawaiian or Filipino.<sup>19,20</sup> Approximately 18% of the Moloka'i population live below the federal poverty level, compared with approximately 10% of the state population.<sup>21</sup> The Health Resources and Services Administration has designated Moloka'i as a medically underserved area and a primary healthcare professional shortage group area. Screening prevalence for breast, cervical, and colorectal cancers on Moloka'i are below the state average, and cancer mortality is higher.<sup>21</sup>

Navigation services for individuals with cancer were initiated at MGH as part of the CMS demonstration. The program was named *Kukui Ahi*, a Hawaiian phrase meaning to show the way.<sup>7</sup> MGH employed lay navigators from the community, one Native Hawaiian and one Filipino, along with a supervisor. The navigators were not certified healthcare providers, but they completed a 48-hour evidence-based navigator training program and participated in quarterly continuing education sessions to extend their navigation skills. Early in the project, a nurse supervised them, but starting from the second year, a young woman with a college degree in business and two physicians affiliated with the hospital supervised them.

The CMS demonstration aimed to test the effect of navigation on cancer screening and treatment of older, Medicare-eligible adults.<sup>3</sup> This article reports only on the screening-related findings.

CMS did not specify a specific navigation model or require a specific set of services. The *Kukui Ahi* model was based on social cognitive theory, which guides practitioners to consider how individuals' knowledge and environment affect their behaviors.<sup>22</sup> Types of tasks that *Kukui Ahi* navigators performed included outreach, education, making appointments, sending reminders, providing transportation to appointments, communicating with providers, and completing paperwork.

### Sample

The CMS demonstration project required a RCT design.<sup>3</sup> MGH navigators were provided with a list of Medicare beneficiaries on the island enrolled in Medicare Parts A and B but not in a managed care plan. (The latter eligibility requirement did not affect Moloka'i

participants, because there were no managed care plans on the island at the time of the demonstration.) Navigators found the contact information for individuals on the list and called them on the telephone or made home visits to recruit them for the study.

From the provided lists of Medicare-eligible residents, MGH navigators recruited 488 for the RCT and collected baseline information. These data were entered into the study database (which all six sites used), and study arm was determined using a random number generator. Lay navigators assisted the 242 participants randomized to the experimental group in accessing breast, cervical, colorectal, and prostate cancer screening in accordance with Medicare coverage policy for preventive services.<sup>23</sup> The 246 participants randomized to the control group received nutrition education and relevant cancer education materials from another healthcare entity on the island.

## Measures

Participants completed Cancer Status Assessment surveys at baseline and at exit from the study. The survey asked about demographic characteristics, use and outcomes of screening, self-rated health and disability, access to care, and (for individuals in the experimental group only) satisfaction with navigation services. Data presented here are from a national data set that included data that all six sites submitted, which CMS checked for completion and accuracy. Information on detailed ethnicity and age was not included in data provided to sites, but MGH provided age and ethnicity distributions to the first author.

## Statistical Analysis

Moloka'i General Hospital data were isolated from the national data set. Group means and percentages were compared at study entry to ensure comparability of the intervention and control groups. Screening use was then compared at the end of the study to examine differences in cancer screening prevalence. No attempt was made to compare MGH findings with findings from the other five sites; this information is available in another report.<sup>3</sup>

## RESULTS

Tasks that *Kukui Ahi* navigators performed for the Medicare recipients randomized to the experimental arm of the RCT are shown in Table 1. Specifically, navigators helped more than 95% of these Medicare recipients to access cancer screening by providing information about screening, mailing reminders that screening was due, and calling to remind them to schedule screening appointments. For 65%, navigators scheduled initial or follow-up appointments or both. They helped approximately one-third arrive on time for appointments and arranged transportation for approximately 10%. They helped approximately 16% complete paperwork, 15% talk with doctors and staff, and 11% find ways to pay for care. Three individuals needed help arranging care for a dependent spouse or child so they could participate in cancer screening.

The characteristics of the experimental and control groups were similar (Table 2). In each group, approximately 47% were male and 53% female. Mean age was 68.4 in the experimental group (29.8% <65) and 66.7 in the control group (24.8% <65). Approximately 45% were Native Hawaiian (experimental 43.0%, control 47.2%), 35% Filipino, 11%

Japanese, <1% Chinese, and 8% another ethnicity (e.g., Mexican, Portuguese, Samoan, Caucasian). In both, approximately one-third did not complete high school (experimental 38.8%, control 35.0%), another one-third had a high school degree (experimental 32.6%, control 28.5%), and the final one-third had some college or training beyond high school (experimental 27.7%, control 35.8%). Approximately half were married (experimental 51.7%, control 52.4%). Almost all (approximately 97%) had lived in the United States for longer than 10 years, and 82% used English as their primary language.

As shown in Table 3, the experimental and control groups were similar at baseline in terms of comorbidities, physical and mental health limitations, and self-rated health. On average, they reported 2.2 chronic conditions, including hypertension (60%), arthritis (31%), diabetes mellitus (27%), and chronic obstructive pulmonary disease (12%). Fewer than 10% reported emotional or psychiatric problems. Approximately 72% reported no problems walking, 88% had no problems with self-care, 72% had no problems performing their usual activities, and 75% were not anxious or depressed. Approximately 30% rated their health as very good, 42% as good, and 16% as fair.

As shown in Table 4, there were no significant differences at baseline in prevalence of screening for breast, cervical, prostate, and colorectal cancers between the experimental and control groups, although significant differences were seen in screening prevalence at the end of the study. Specifically, 57.0% of women in the experimental arm and 36.4% of controls had had a Papanicolaou test in the past 24 months ( $P = .001$ ), 61.7% of women in the experimental arm and 42.4% of controls had had a mammogram in the past 12 months ( $P = .003$ ), 54.4% of men in the experimental arm and 36.0% of controls had had a prostate-specific antigen test in the past 12 months ( $P = .008$ ), and 43.0% of both sexes in the experimental arm and 27.2% of controls had had a flexible sigmoidoscopy or colonoscopy in the past 5 years ( $P < .001$ ).

In elderly adults receiving navigation services, satisfaction was high (data not shown in table). Specifically, 94% reported that they valued working with the navigator, 95% would recommend this service to others, and 93% rated their overall experience with the navigator as excellent (77%) or very good (16%).

## DISCUSSION

Findings from this RCT suggest that navigation services have been effective in increasing breast, cervical, prostate, and colorectal cancer screenings in Asian and Pacific Islander Medicare beneficiaries residing on Molokai.

There are several strengths of this study, including its randomized controlled design and adequately powered sample, but several limitations were noted. First, the navigation staff collected baseline and exit data. Baseline data were collected before randomization, so no bias was expected, but data collectors were not blinded to RCT group assignment when collecting exit data. Second, the analysis relied on self-report of screening behaviors by study participants. In the national analysis, the CMS contractor checked self-reported screening data against Medicare claims data,<sup>3</sup> whereas the current analysis was restricted to

the self-reported survey data. The CMS contractor was able to match and extract Medicare usage and cost data for 377 of the 488 MGH enrollees, and usage findings were similar to those of the current study. Significant increases in cancer screening were seen for all four cancers.<sup>3</sup> The CMS contractor's analytical sample excluded participants with unmatchable identification numbers and with <6 months of enrollment in the demonstration, but this exclusion did not change the demographic composition of the sample.

Third, Medicare screening coverage guidelines differ from the recommendations of the U.S. Preventive Services Task Force (USPSTF).<sup>24</sup> For example, Medicare has no upper age limit for breast, cervical, or colorectal cancer screening and continues to reimburse for the prostate-specific antigen test. The USPSTF recommends against cervical cancer screening for normal-risk women aged 65 and older, against mammography screening in women aged 75 and older, against colorectal cancer screening in normal-risk adults aged 75 and older, and against prostate cancer screening altogether. Although some demonstration sites imposed upper age limits on some cancer screening tests over the course of the trial (2006–2011), MGH did not.<sup>3</sup>

Fourth, the study was conducted on Moloka'i, a small, isolated, medically underserved island, limiting the generalizability of findings. Approximately 27% of the entire sample was younger than 65, much higher than the 17% seen nationally. These younger individuals are eligible for Medicare because of disability, and some may have been too young to start prostate, colorectal, and breast cancer screening. Age was not provided in the national database. Nevertheless, the CMS contractor used logistic regression to control for demographic differences between intervention and control groups and still found that MGH demonstrated improvements in screening for all four study cancers.<sup>3</sup>

CMS funded MGH to gather data on elderly Asians and Pacific Islanders in general. Although the sample reflected the ethnic diversity of Moloka'i, where the majority of the residents are Native Hawaiian and Filipino, it did not reflect the range of Asian and Pacific Islander groups in the United States. In Hawai'i, Native Hawaiians and Filipinos experience pronounced cancer health differences from older Caucasians but also from elderly adults of Japanese and Chinese ancestry.<sup>4</sup> By virtue of being conducted on Moloka'i, study participants may have been more likely to benefit from navigation services than Hawai'i residents of other Asian ethnicities and more likely to benefit than residents of other islands (which have more medical care services).

Qualitative reports that the MGH navigators provided support this hypothesis, suggesting a low knowledge of cancer and cancer screening of elderly adults on Moloka'i. For example, there is no word for cancer in Tagalog or Ilokano (the two Filipino dialects that *Kukui Ahi's* Filipino clients speak). This required navigators to develop analogies: "It's like when you plant *talong* (eggplant), sometimes weeds start to grow. The plant is your good cells, and the cancer is the weeds. You have to get rid of the weeds, or the good cells will die. When you go for screening, the doctor is looking for cancer while it is small. Just like in farming, you want to get rid of the small weeds right away... you don't wait for the weeds to take over the *talong*."<sup>7</sup> In Hawaiian culture, there is the belief that saying the word "cancer" may bring it on and that cancer screening procedures are painful. Continuous outreach and education and

finding elderly adults willing to “take a leap of faith to get screened” overcame reluctance of elderly adults to discuss cancer or participate in screening.<sup>7</sup> That the majority of those screened did not have or get cancer helped convince others to try it.

This hypothesis also is supported when looking at findings from the other five CMS sites. A report to Congress noted that MGH was the only site to realize screening improvements for the four cancers targeted in the study, whereas other sites realized improvements in screening for fewer of the cancers.<sup>3</sup> In addition to Moloka‘i’s relative isolation, the Moloka‘i site also served a small geographic area, making it easy for navigators to drive to people’s homes to provide education and to transport them to screening appointments if needed.

Of interest to gerontologists are the parallels between navigation and case management, defined as “a collaborative process of assessment, planning, facilitation, and advocacy for options and services to meet an individual’s health needs through communication and available resources to promote quality cost-effective outcomes.”<sup>25</sup> Similar to case management, navigation is a process that nurses, social workers, and lay workers can provide, and the exact nature of navigation services provided varies according to the professional training and certification of the navigators.<sup>7,25</sup> Case management has also been examined for its ability to improve care with mixed results. For example, a systematic literature review of 11 randomized controlled trials of case management found that this service did not reduce unplanned hospital admissions,<sup>26</sup> although a systematic review of 89 trials of complex interventions to improve physical function and maintain independent living of elderly adults (which included multidisciplinary assessment and referral for medical and social services) suggested that these interventions reduce hospital and nursing home admissions, as well as falls, and improve physical functioning of home-dwelling elderly adults.<sup>27</sup>

There are major differences between case management for elderly adults at risk of institutionalization and a cancer navigation program. The former identifies and manages individuals with long-term care needs, whereas the latter provides shorter-term assistance with cancer screening and treatment, but a concern of both services is cost effectiveness. The national contractor analyzed cost data associated with the demonstration.<sup>3</sup> These researchers concluded that the intervention groups did not realize lower costs than the control groups, nor were they more expensive, but they found a wide variability in Medicare costs for older adults, reducing the likelihood of finding significant cost savings.

Limitations aside, findings from this study suggest that navigation services are effective in increasing cancer screening of Medicare beneficiaries from groups experiencing significant disparities and living in medically underserved communities. For this rural cohort, cancer screening navigation resulted in significant increases in cancer screening.

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**Sponsor's Role:** CMS required a randomized controlled design of all grantees. CMS approved local adaptations to the design, including the exact nature of the navigation intervention and the services provided to individuals in the control condition. CMS also provided data collection forms. CMS worked with a contractor, RTI International, which developed and managed the data entry system, and worked with MGH data enterers to ensure that data were clean. RTI analyzed data from all six study sites, and findings are included in a report from RTI to Congress submitted in 2012 and accepted in fall 2013.

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**Table 1**

Navigation Services Provided to the Experimental Group (n = 242)

<b>Service</b>	<b>n (%)</b>
Mailed reminders to individuals due for a cancer screening	234 (96.7)
Called to remind individuals to schedule screening appointments	231 (95.5)
Provided information	230 (95.0)
Scheduled appointments	169 (69.8)
Made follow-up appointments	157 (64.9)
Helped arrive on time to appointments	90 (37.2)
Helped complete paperwork	39 (16.1)
Helped individual talk with doctors and staff	35 (14.5)
Help find ways to pay for care	27 (11.2)
Talked to doctors and staff on individual's behalf	25 (10.3)
Arranged transportation to appointments	24 (9.9)
Made arrangements to take care of family while individual was at appointment	3 (1.2)

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**Table 2**

Characteristics of Moloka'i Medicare Beneficiaries Randomized to the Experimental and Control Groups (N = 488)

Characteristic	Experimental, n = 242	Control, n = 246
Sex, n (%)		
Male	114 (47.1)	114 (46.3)
Female	128 (52.9)	132 (53.7)
Age, mean	68.4	66.7
Age, n (%)		
<65	72 (29.8)	61 (24.8)
65–75	116 (47.9)	128 (52.0)
75	54 (22.3)	57 (23.2)
Ethnicity, n (%)		
Chinese	2 (0.8)	2 (0.8)
Filipino	90 (37.2)	79 (32.1)
Hawaiian	104 (43.0)	116 (47.2)
Japanese	30 (12.4)	24 (9.8)
Other	19 (7.9)	21 (8.5)
Education, n (%)		
<High school	94 (38.8)	86 (35.0)
High school graduate	79 (32.6)	70 (28.5)
>Post-high school training or college	67 (27.7)	88 (35.8)
Married, n (%)	125 (51.7)	129 (52.4)
Lived more than 10 years in United States, n (%)	239 (98.8)	237 (96.3)
Primary language English, n (%)	197 (81.4)	204 (82.9)

The groups did not differ statistically in these characteristics.

**Table 3**

Self-Reported Comorbidities, Limitations, Pain, Anxiety, and Health Status (N = 488)

	<b>Experimental, n = 242</b>	<b>Control, n = 246</b>
Comorbidity, n (%)		
Hypertension	146 (60.3)	150 (61.0)
Diabetes mellitus	64 (26.4)	73 (29.7)
Chronic obstructive pulmonary disease	29 (12.0)	30 (12.2)
Heart disease	54 (22.3)	40 (16.3)
Stroke	24 (9.9)	24 (9.8)
Gastrointestinal	20 (8.3)	19 (7.7)
Arthritis	78 (32.2)	77 (31.3)
Emotional, nervous, psychiatric problem	20 (8.3)	24 (9.8)
Memory complaint	17 (7.0)	10 (4.1)
Number of chronic conditions, mean	2.2	2.2
Mobility, n (%) <sup>a</sup>		
No problems walking	175 (72.3)	179 (72.8)
Some problems walking	57 (23.6)	58 (23.6)
Confined to bed	8 (3.3)	8 (3.3)
Self-care, n (%) <sup>a</sup>		
No problems with self-care	214 (88.4)	217 (88.2)
Some problems washing or dressing self	17 (7.0)	16 (6.5)
Unable to wash or dress self	9 (3.7)	12 (4.9)
Performing usual activities, n (%) <sup>a</sup>		
No problems	178 (73.6)	173 (70.3)
Some problems	41 (16.9)	53 (21.5)
Unable	21 (8.7)	19 (7.7)
Anxiety and depression, n (%) <sup>a</sup>		
Not anxious or depressed	181 (74.8)	188 (76.4)
Moderately anxious or depressed	48 (19.8)	49 (19.9)
Extremely anxious or depressed	11 (4.5)	8 (3.3)
Self-rated health, n (%) <sup>a</sup>		
Excellent	18 (7.4)	28 (11.4)
Very good	73 (30.2)	71 (28.9)
Good	104 (43.0)	99 (40.2)
Fair	37 (15.3)	40 (16.3)
Poor	8 (3.3)	7 (2.8)

The groups did not differ statistically in these characteristics.

<sup>a</sup>Percentages do not total 100% because of missing data.

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Screening Prevalence at Baseline and at the End of the Study for the Experimental and Control Groups (N = 488)

**Table 4**

Screening	Experimental, n = 242 (n = 128 Women; n = 114 Men)		Control, n = 246 (n = 132 Women; n = 114 Men)		Chi-Square (Degrees of Freedom), P-Value (Exit)
	Baseline	Exit	Baseline	Exit	
	n (%)				
Fecal occult blood test within past 12 months	31 (12.8)	50 (20.7)	27 (11.0)	31 (12.6)	5.16 (1), .02
Endoscopy within past 5 years	60 (24.8)	104 (43.0)	62 (25.2)	67 (27.2)	12.59 (1), <.001
Papanicolaou test within past 24 months	48 (37.5)	73 (57.0)	52 (39.4)	48 (36.4)	10.30 (1), .001
Mammogram within past 12 months	38 (29.7)	79 (61.7)	47 (35.6)	56 (42.4)	8.93 (1), .003
Prostate-specific antigen test within past 12 months	22 (19.3)	62 (54.4)	28 (24.6)	41 (36.0)	7.08 (1), .008

The groups did not differ statistically in baseline screening prevalence.