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Impact of Family History Assessment on Communication with Family Members and Health Care Providers: A report from the Family Healthware™ Impact Trial (FHITr)

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Abstract

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Objective—This study examines the impact of Family Healthware™ on communication behaviors; specifically, communication with family members and health care providers about family health history.

Methods—A total of 3786 participants were enrolled in the Family Healthware™ Impact Trial (FHITr) in the United States from 2005-7. The trial employed a two-arm cluster-randomized design, with primary care practices serving as the unit of randomization. Using generalized estimating equations (GEE), analyses focused on communication behaviors at 6 month follow-up, adjusting for age, site and practice clustering.

Results—A significant interaction was observed between study arm and baseline communication status for the family communication outcomes (ps<.01), indicating that intervention had effects of different magnitude between those already communicating at baseline and those who were not. Among participants who were not communicating at baseline, intervention participants had higher odds of communicating with family members about family history risk (OR=1.24, p=0.042) and actively collecting family history information at follow-up (OR=2.67, p=0.026). Family Healthware™ did not have a significant effect on family communication among those already communicating at baseline, or on provider communication, regardless of baseline communication status. Greater communication was observed among those at increased familial risk for a greater number of diseases.

Conclusion—Family Healthware™ prompted more communication about family history with family members, among those who were not previously communicating. Efforts are needed to identify approaches to encourage greater sharing of family history information, particularly with health care providers.

Keywords

family history assessment; family communication; provider communication; dose effects; chronic disease

Introduction

Family health history is considered a genomic tool and proxy to genetic predisposition that can serve as a means to better guide and personalize medical care and disease prevention [1-4]. Family Healthware™, developed by the Centers for Disease Control and Prevention, is a self-administered web-based family history tool that assesses familial risk for six common chronic conditions and provides personalized prevention messages based on risk [5]. The Family Healthware™ Impact Trial (FHITr) set out to examine whether the provision of personalized prevention messages, based on family history risk for coronary heart disease, stroke, diabetes, and colon, breast and ovarian cancers would result in changes in corresponding screening and lifestyle behaviors. Previously reported results from the overall trial demonstrated that intervention participants, who completed Family Healthware™ and received tailored preventive messages based on family history risk for six conditions (heart disease, stroke, diabetes, and colon, breast, and ovarian cancer), were more likely to improve in self-reported physical activity and fruit and vegetable intake at follow-up, irrespective of risk levels, compared to control participants who received a standard preventive message

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[6]. Conversely, cancer screening behaviors did not differ across study arms and improved over time for all risk groups [7].

In its simplest form, family health history risk information was anticipated to motivate lifestyle behavior change through its influence on disease risk perceptions and communication behaviors (see conceptual model in Figure 1, based on prior empirical evidence and theories of health behavior [8-15]). As previously reported, the provision of personalized risk based on family history assessment significantly increased disease risk perceptions among those who underestimated their risk at baseline, particularly for the metabolic conditions included within the tool [16]. However, an underlying goal behind national efforts to promote the collection and documentation of family history is to foster greater communication about familial disease with family members and health care providers [1, 2]. Prior studies suggest that efforts to increase communication within the family may have beneficial outcomes. For example, frequency of health-specific communication with family members is directly associated with health behaviors including diet and exercise [17]. Moreover, population-based surveys have shown that a positive family history is associated with greater discussion of cancer screening and diet and exercise recommendations with clinicians, and greater reported rates of screening adherence and lifestyle changes among patients [18-20], suggesting that efforts to increase awareness of family history might promote health behaviors directly, as well as indirectly via increased communication.

To date, few studies have examined whether interventions to increase family history awareness and documentation increase the extent to which this information is discussed within families or shared with health care providers [21, 22]. As such, the purpose of this study was twofold. First, the impact of Family Healthware™ on communication behaviors was examined. Specifically, communication about family health history with family members and with primary care physicians was examined. Second, this study examined whether there were differences in communication outcomes based on the number of diseases (i.e. dose effect) for which a person was deemed at elevated risk by the program, as prior studies have shown this to correspond with disease risk perceptions [23, 24].

Methods

Participants

A total of 3786 patients were enrolled in the Family Healthware™ Impact Trial (FHITr) between 2005-2007, recruited from primary care practices among 13 states in the U.S. Participants (aged 35-65) had no prior history of any of the six conditions contained within Family Healthware™. They were also ineligible for the trial if they were pregnant or did not speak or read English. Of note, two patients were assigned wrongly to the intervention arm within a practice site that was designated to be a control site. Their data was excluded from further analysis making the final number of analyzable subjects 3784.

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Sample Recruitment and Randomization

The Family Healthware™ Impact Trial employed a two-arm cluster-randomized design, with primary care practices serving as the unit of randomization. A total of 41 primary care practices, affiliated with one of three academic sites (Evanston Northwestern Healthcare – now NorthShore University HealthSystem, University of Michigan, and Case Western Reserve University/American Academy of Family Physicians' National Research Network), were recruited to the trial. Site-specific study protocols were approved by the IRBs at each of the academic sites, and a combined protocol was approved by the CDC's IRB. Participants were identified from practice records according to each site's approved protocol and sent letters signed by their primary care physicians inviting them to take part in the trial. Randomization to either the intervention or control arm was executed with site-specific randomization schemes. Participants at the majority of practices had upcoming appointments with a primary care physician, but those affiliated with University of Michigan were recruited without regard for a scheduled physician visit. Additional details on study recruitment and randomization are provided elsewhere [25]. The study CONSORT diagram is presented in Figure 2.

Intervention and Control Arms

Participants in the Family Healthware™ intervention study arm completed an online baseline survey followed by the tool, which assessed familial risk and presented personalized prevention messages, tailored to familial risk for each of the six conditions. Messages based on risk status were focused on the following: weak familial risk – reinforcement of standard prevention recommendations; moderate familial risk – provision of personalized prevention recommendations; strong familial risk – provision of personalized prevention recommendations and referral to specialist. Participants in the control study arm also completed the online baseline survey, but were not provided access to the tool until after completion of the 6 month follow-up survey. Control messages were general prevention messages, not tailored to familial risk, and delivered following completion of the baseline survey. Additional details on the Family Healthware™ tool and risk algorithms are available elsewhere [5-7]. Samples of both intervention and control arm messages are also available online as supplemental information [6].

Study Measures

Familial risk—Risk based on family history was calculated using the Family Healthware™ tool, which determined familial risk based on self-reported health history for oneself and first/second-degree relatives. A designation of weak, moderate, or strong was made for each of the six conditions. A weak family history was indicated when no family history, or late-onset disease in a single second-degree relative was reported. Moderate familial risk included those with a first-degree relative with late-onset disease or two second-degree relatives from the same lineage with late onset disease. Strong familial risk included a first-degree relative with early-onset disease, multiple affected relatives, or indications of a hereditary syndrome [5]. For the analyses to examine dose effects, familial risk was dichotomized as non-elevated (weak risk) versus elevated (moderate/strong risk) and aggregated to create a total number of diseases at elevated risk (ranging from 0-6).

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Communication with family members—Two separate questions were used to assess communication with family members, administered at baseline and 6-month follow-up. The first item asked, "Have you talked with any of your family members about your family health history?" Response options included: "Yes, but more than 6 months ago, Yes, within the past 6 months, No, but I intend to in the next 30 days, No, but I intend to in the next 6 months, and No, and I do not intend to in the next 6 months." The second communication item asked participants, "Have you ever/In the last 6 months, have you actively collected health information from your relatives for the purposes of recording a family health history?" (yes/no).

Communication with health care providers—A single item was administered at baseline and 6-month follow-up that asked respondents "Have you talked with any of your health providers about your family health history. Response options included: "Yes, but more than 6 months ago, Yes, within the past 6 months, No, but I intend to in the next 30 days, No, but I intend to in the next 6 months, and No, and I do not intend to in the next 6 months."

Analytic plan

Demographic characteristics were compared between study arms using Chi-square and independent sample t-tests. Baseline communication status was compared between the study arms using Chi-square tests for the three different communication variables. The impact of Family Healthware™ and level of familial risk on communication behaviors at follow-up was assessed using clustered logistic regression models for each of the communication outcomes. For the communication items assessing 'talking with' family members or providers, an affirmative response on communicating in the past 6 months defined an individual as communicating at follow-up, with any other response considered not communicating. A generalized estimating equations (GEE) approach with an exchangeable working correlation structure was adopted to account for practice clustering. Models included experimental arm and number of diseases at elevated risk as the main predictors of interest and controlled for age, gender, study site and communication at baseline. Communication at baseline was dichotomized into communicating (a response of 'yes' to the active collection question, or 'yes, within the past 6 months' to the family members and health care provider communication) or not communicating (any other response). An interaction between experimental arm and baseline communication status was also included to determine whether the intervention had similar impact between those already communicating at baseline and those not communicating at baseline.

Results

Participant Characteristics

Of the 3784 participants whose data were analyzed, 3344 completed the entire protocol (Table 1). Participants had a mean age of 50.6 years, with the majority being White (91%), female (70%), college educated (72%), married or living with partner (79%), and with a reported income greater than $75,000 per year (55%). Based on Family Healthware™ assessment, 82% of participants were categorized as having a moderate or strong familial

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risk for at least one of the six conditions contained within the tool. Significant differences were observed between experimental arms with respect to age, gender, and income; the control arm had higher average age (p=0.006), more male participants (p=0.034) and a greater percentage of individuals in the higher income category (p=0.001), compared with the intervention arm. No other demographic differences were observed between groups. Although there was a difference in income level across the study arms at baseline, the models presented in the article are not adjusted for income primarily due to a high level of missing data (457 missing values). Additional analyses adjusting for income were conducted, however, results did not differ qualitatively from those presented here (data not shown).

Baseline Communication

Table 2 presents baseline levels of family history communication with family members and health care providers. Approximately 41.9% of participants had talked to family members about their family health history in the last 6 months with an additional 40.6% reporting they communicated, but more than 6 months ago. Conversely, only 27.6% of patients reported talking about family history with health care providers in the last 6 months, however 62% had done so more than 6 months ago. In addition, only 22.8% of participants indicated at baseline that they had ever actively collected health information from relatives for the purposes of recording a family health history. There were no significant differences across study arms in any of the baseline communication variables (all p's>.05).

Impact of Family Healthware™ on Communication Behaviors

Table 3 presents the models examining the impact of Family Healthware™ on communication behaviors. Most notably, there was a significant interaction observed between study arm and baseline communication status for family member communication (p=.006) and active collection outcomes (p=.003), indicating that intervention had effects of different magnitudes between those already communicating at baseline and those who were not. Among those who were not communicating at baseline, intervention participants were significantly more likely to report communication with family members about family history (34% vs. 29%, OR=1.24; 95% CI: 1.01-1.53, p=0.042) and active collection family history information (13% vs. 5.4%, OR=2.67; 95% CI: 2.01-3.54, p=0.026) at follow-up compared to control participants. There was not a significant intervention effect among those who were already communicating at baseline on family communication (61% intervention vs. 65% control, OR=0.82; 95% CI: 0.66-1.02, ns) or active collection (32% intervention vs. 26% control, OR= 1.26; 95% CI: 0.91-1.75, ns). There was a marginal effect of the intervention on communication with health care providers among those not communicating at baseline (40% vs. 35%, OR= 1.23; 95% CI: 1.00-1.51, p=.055), but no group differences among those already communicating at baseline (49% vs. 46%, OR= 0.92; 95% CI: 0.70-1.21, ns). The interaction between study arm and baseline provider communication was not significant.

Communication with family members and providers did not vary by age or gender, but active collection of family history information did. Older participants were less likely to collect information (OR=0.97; 95% CI: 0.96-0.98, p<0.001) compared to younger

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participants. Females had higher odds of collecting family history information at follow-up (OR =1.35; 95% CI: 1.09–1.66, p=.006) compared to males. Study site had an impact on all three communication measures with communication about or active collection on family history being significantly greater at study sites that recruited patients with upcoming appointments (Case Western/Evanston), compared to the study site that did not (Michigan, see Table 3).

Dose Effects on Communication Behaviors

Communication with family members and health care providers about family history and active collection of family history information varied as a function of the "dose" or number of diseases a person was deemed at elevated risk for (see Table 3). As dose increased, the odds of communication, with both family and health care professionals, and collection of family history information at follow-up also increased. The effect of dose did not vary by study arm (interaction data not shown).

Discussion

The family health history offers an ideal proxy to assess genomic risk and is the simplest applied genomic tool available [26]. National efforts to promote awareness of the importance of family history often emphasize the importance of communication and the sharing of this information with family members and health care providers, which may serve as an intermediary goal towards improved prevention and care [1, 26, 27].

This present study is the first large-scale trial to examine the impact of family history assessment on communication with family members and providers. In this study, we found a positive effect of family history assessment in prompting discussions and active collection about family history with family members, among those not doing so in the 6 months preceding study entry. A borderline difference was also noted for provider communication among noncommunicators at baseline. These findings support the results from prior studies examining the impact of family history interventions, which have also reported a positive impact on family communication [28] but not provider communication [21, 22].

Six months after using Family Healthware™, fewer than half of participants in the intervention arm reported communicating with their health care providers about their family history information, regardless of baseline communication status. The lack of impact of the intervention on communication with health care providers may be reflective of several issues noted within our trial, including logistics (e.g., did not see a clinician over the 6 month follow-up period of the study) and the receipt of low familial risk evaluations. Others reasons might also include competing demands, clinical routines, and/or patient uncertainty about how to communicate with their provider. Prior qualitative research has noted that participants were uncertain about how their relatives or providers would react to discussions about family history [22], suggesting that there are barriers in communication that may need to be addressed to facilitate greater sharing of family history information.

Not surprisingly, our study found that women were more likely to actively collect family history information from relatives following familial risk assessment, which is consistent

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with prior findings examining the collection of family health history [29, 30], as well as other studies examining frequency of family history discussions [27]. We previously reported that males were less responsive to changing risk perceptions compared with females within the FHITr trial [16], which may have also influenced whether they felt any further action or communication with family members was warranted following use of the tool. These findings also concur with our prior finding that females know more about their family histories compared to males [31], perhaps due to a greater propensity to talk with family members about family history. In addition, study findings provide a possible explanation as to why others have reported greater inaccuracies in the reporting of paternal compared to maternal family histories [32, 33], which has implications for the clinical validity of family history assessment.

Communication with health care providers at follow-up was more likely at sites that enrolled patients with upcoming medical appointments, but did not differ between intervention and control groups. This finding suggests that the timing and implementation of family history assessment will be an important consideration in efforts to increase clinical use of the information [27, 34].

In this study, we found evidence of a dose effect, such that those who were at elevated familial risk for more diseases were more likely to report talking with family members and providers following receipt of risk information. We examined whether there was a significant interaction between dose and experimental arm and found none (data not shown). Thus, our results indicate that communication behaviors in general vary as a function of the collective disease risk for an individual. Dose of familial risk was previously found to also influence disease risk perceptions [23, 24, 35], suggesting that efforts to better understand the impact of risk information should take into consideration potential dose effects, particularly when risk for multiple diseases is conveyed.

Computerized tools such as Family Healthware™ may help to highlight disease risks among family members and facilitate the identification of previously unknown family history, which would reduce the chances for risk misclassification due to lack of awareness. Family Healthware™ has been available in the past to investigators doing research but never publically available. Currently, there are no plans to update Family Healthware™ for release to the general public (Muin Khoury, personal communication). Rather, other publically available tools such as the US Surgeon General's My Family Health Portrait (https://familyhistory.hhs.gov/) have undergone recent updates to include risk algorithms for some conditions including colorectal cancer [36] and type 2 diabetes and may be used to facilitate the collection and sharing of family health history.

This study had several limitations. Study participants were predominately White, well-educated, and recruited through primary care settings, which may limit the generalizability of results to other populations and settings. In addition, although the present study reported on the impact of family history assessment on communication behaviors, other concepts related to family communication, such as family closeness, cohesion and structure [8, 37], were not explored or assessed. This is a limitation in the conceptualization of program impact, which focused more on the lifestyle behavioral outcomes. Additional studies

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examining the role of these and other constructs [27] associated with the sharing of family health history are needed. Finally, the communication items used in the trial that focused on the timing of communication (i.e., “yes, within the last 6 months” or “yes, more than 6 months ago”) presented challenges in the interpretation of the tool's communication impact, since individuals endorsing “yes, but more than 6 months ago) may have communicated years ago and may not have engaged in new communication during the trial timeframe. As such, our analyses defined only those who indicated “yes, within the past 6 months” as having communicated, both at baseline and follow-up, in efforts to best capture individuals who may have been prompted to communicate during the trial period.

Conclusion

Family Healthware™ prompted more communication about family history with family members, particularly among those who were not previously communicating. Efforts are needed to understand potential reasons for not communicating and identify approaches to encourage greater sharing of family health history information, particularly with health care providers.

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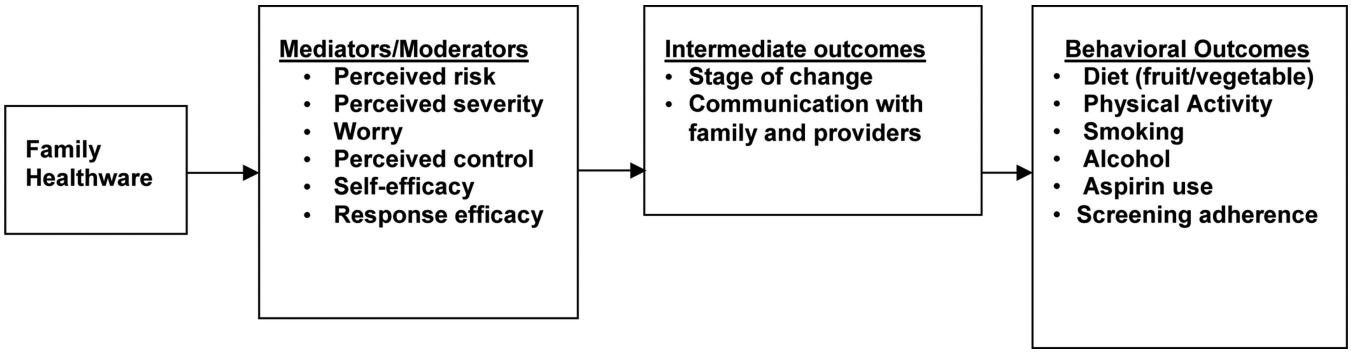

Figure 1.
Conceptual Model

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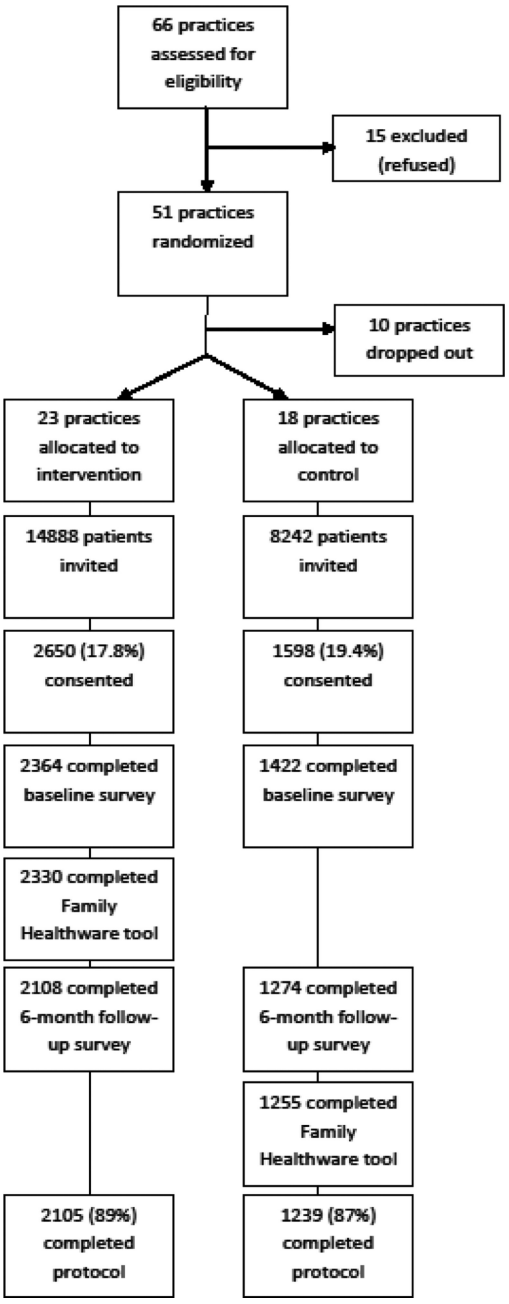

Figure 2.
Consort Diagram

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Table 1

Demographics

	Intervention Arm (N = 2362)	Control Arm (N = 1422)	Total (N=3784)
Age, Years (Mean)[a]	50.3 (8.4)	51.1 (8.0)	50.6 (8.2)
Gender, Female[b]	1675 (71%)	962 (68%)	2637 (70%)
Race			
Caucasian	2132 (90%)	1320 (93%)	3452 (91%)
African American	87 (4%)	35 (3%)	122 (3%)
Asian	70 (3%)	31 (2%)	101 (3%)
Hispanic or Latino	58 (3%)	29 (2%)	87 (2%)
Education (college degree or greater)	1698 (72%)	1025 (72%)	2723 (72%)
Married/Living with Partner	1855 (79%)	1135 (80%)	2990 (79%)
Household Income (>75,000)[c]	1261 (61%)	834 (66%)	2095 (55%)
Smoker - Current	185 (8%)	108 (8%)	293 (8%)
Family History (Moderate or Strong)	N = 2328[d]	N = 1255[d]	N=3784[d]
Heart Disease	1381 (59%)	753 (60%)	2134 (60%)
Stroke	1117 (48%)	615 (49%)	1732 (48%)
Diabetes	903 (39%)	443 (35%)	1346 (38%)
Colon Cancer	315 (14%)	186 (15%)	501 (14%)
Breast Cancer	530 (23%)	265 (21%)	795 (22%)
Ovarian Cancer	222 (10%)	120 (10%)	342 (10%)
Number of Diseases at Elevated Risk			
0	420 (18.0)	233 (18.6)	653 (18.2)
1	525 (22.6)	300 (23.9)	825 (23.0)
2	568 (24.4)	286 (22.8)	854 (23.8)
3	530 (22.8)	281 (22.4)	811 (22.6)
4	221 (9.5)	120 (9.6)	341 (9.5)
5	51 (2.2)	23 (1.8)	74 (2.1)
6	13 (0.6)	12 (1.0)	25 (0.7)

[a] p=0.006

[b] p=0.034

[c] p=0.001

[d] Sample size excludes participants without complete family history data

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Table 2

Communication with family members and health care providers, baseline, N (%)

	Intervention Arm (N=2362)	Control Arm (N=1422)	Total (N=3784)
Have you talked to any of your family members about your family health history?			
No*	411 (17.4)	254 (17.9)	665 (17.6)
Yes, within the last 6 months	1008 (42.7)	576 (40.5)	1584 (41.9)
Yes, but more than 6 months ago	943 (39.9)	592 (41.6)	1535 (40.6)
Have you talked to any of your medical providers about your family health history?			
No*	278 (11.8)	151 (10.6)	429 (11.3)
Yes, within the last 6 months	653 (27.6)	390 (27.4)	1043 (27.6)
Yes, but more than 6 months ago	1431 (60.6)	881 (62.0)	2312 (61.1)
Have you ever actively collected health information from your relatives for the purposes of recording a family health history?			
No	1819 (77.0)	1101 (77.4)	2920 (77.2)
Yes	543 (23.0)	321 (22.6)	864 (22.8)

*No responses are combined for this item and include the following: No, but I intend to in the next 30 days, No, but I intend to in the next 6 months, and No, and I do not intend to in the next 6 months.

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Table 3

Impact of Family Healthware™ on family history communication behaviors at follow-up, OR (95% CI)[a]

Predictors	Family Members N=3344[b]	Health Care Providers N=3344[b]	Active Collection (from family) N=3344[b]
Age	1.00 (0.99, 1.01)	0.99 (0.98, 1.01)	**0.97 (0.96, 0.98)**
Gender			
Male	Ref	Ref	Ref
Female	1.15 (0.99, 1.33)	1.07 (0.91, 1.26)	**1.35 (1.09, 1.66)**
Site			
Michigan	Ref	Ref	Ref
Case Western	1.24 (0.96, 1.60)	**1.68 (1.26, 2.24)**	**1.35 (1.05, 1.75)**
Evanston	**1.44 (1.21, 1.71)**	**1.71 (1.41, 2.07)**	**1.30 (1.16, 1.46)**
Baseline Communication Status[c]			
Not Communicating	Ref	Ref	Ref
Communicating	**4.56 (3.68, 5.66)[d]**	**1.68 (1.43, 1.99)[d]**	**6.26 (4.10, 9.56)[d]**
Experimental Arm			
Control	Ref	Ref	Ref
Intervention	**1.24 (1.01, 1.53)[e]**	1.23 (1.00, 1.51)[e]	**2.67 (2.01, 3.54)[e]**
Dose	**1.15 (1.09, 1.22)**	**1.12 (1.06, 1.18)**	**1.15 (1.08, 1.24)**
Baseline Communication * Experimental Arm	**0.66 (0.49, 0.89)**	0.89 (0.69, 1.14)	**0.47 (0.29, 0.78)**

[a] Communication at follow-up was a dichotomized outcome. Active collection was assessed using a yes/no response. The other communication items were dichotomized as yes (yes, within the past 6 months) or no (all other responses).

[b] Sample includes participants with valid communication data at both baseline and follow-up.

[c] Not communicating at baseline included those who responded any form of 'no' or 'yes but more than 6 months ago' and communicating at baseline included those who responded 'yes' for Active Collection or 'yes, within the last 6 months' for family member and health care provider communication.

[d] ORs and CIs for control arm.

[e] ORs and CIs for non-communicators at baseline.