

Breast Cancer Survivors' Perceptions of Survivorship Care Options

Erica L. Mayer, Adrienne B. Gropper, Bridget A. Neville, Ann H. Partridge, Danielle B. Cameron, Eric P. Winer, and Craig C. Earle

Erica L. Mayer, Bridget A. Neville, Ann H. Partridge, and Eric P. Winer, Dana-Farber Cancer Institute; Adrienne B. Gropper, Harvard Medical School, Boston, MA; Danielle B. Cameron, University of Miami Miller School of Medicine, Boca Raton, FL; and Craig C. Earle, Institute of Clinical Evaluative Sciences, Toronto, Ontario, Canada.

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Corresponding author: Erica L. Mayer, MD, MPH, Department of Medical Oncology, Dana-Farber Cancer Institute, 450 Brookline Ave, Boston, MA 02115; e-mail: emayer@partners.org.

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A B S T R A C T

Purpose

As the number of breast cancer survivors increases, a durable model of comprehensive survivor care is needed, incorporating providers and/or visit types both within and outside of oncology. The objective of this study was to explore survivors' comfort with different clinician types or with a telephone/Internet-based virtual visit as components of survivorship care.

Methods

Breast cancer survivors participating in a general survivorship survey completed an additional breast cancer-specific questionnaire evaluating the self-perceived impact of follow-up visits to various clinician types, or follow-up by a virtual visit, on survival, worrying, and stress related to cancer.

Results

A total of 218 breast cancer survivors completed the questionnaire. Most favored medical oncologist follow-up visits over those with primary care physicians (PCPs) or nurse practitioners (NPs) in terms of reduced worrying about cancer (odds ratio [OR], 2.21; $P < .001$), reduced stress around the visit (OR, 1.40; $P = .002$), and improved effect on cancer survival (OR, 2.38; $P < .001$). However, the majority also displayed substantial comfort with both PCPs and NPs in the same domains. Patients rated a virtual visit as having a less favorable impact on cancer survival and cancer-related worrying compared with in-person visits with clinicians.

Conclusion

Breast cancer survivors are comfortable with both PCPs and NPs providing follow-up care, although they indicate a preference for medical oncologists. Given patients' negative impressions of a virtual visit, increased familiarity with and research investigating this emerging concept are needed. The NP-led survivorship clinic model, with increased guidance for PCPs, offers a promising route for improving quality of and satisfaction with survivor care.

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INTRODUCTION

Improvements in screening and therapy for breast cancer have led to increased survival rates¹; in the United States, there are more breast cancer survivors than survivors of any other cancer type,² and this population will grow in the years ahead.³ Each survivor requires follow-up monitoring for disease recurrence and treatment toxicity, in addition to routine primary care services. Given the increasing population of patients with cancer overall, the growing number of breast cancer survivors, and current and projected workforce shortages in oncology and primary care, there is a great need for efficient and optimal follow-up care for survivors.

Guidelines for follow-up care of breast cancer survivors published by the American Society of

Clinical Oncology are well established.⁴ Randomized trials have suggested that either medical oncologists or primary care physicians (PCPs) are well suited to provide follow-up care, finding no difference in cancer detection outcomes in cohorts receiving care from either a PCP or an oncologist,^{4,5} and that PCP-centered follow-up is either equivalent or superior to specialist-centered follow-up in terms of health-related quality of life and satisfaction with care received.⁴⁻⁶

Although prior work has examined physician attitudes regarding survivorship care, patient preferences remain incompletely understood, and specific exploration of patient anxiety and expectations is critical. We conducted a survey of breast cancer survivors to examine their attitudes regarding follow-up care with different provider or visit types.

METHODS

General Overview

A questionnaire was developed, pilot tested, revised using a modified Delphi approach, and distributed to cancer survivors seen at the Dana-Farber Cancer Institute (as described in a prior publication of a larger parent study⁷). Any breast cancer survivor filling out the survey was requested to respond to an additional set of questions within the same questionnaire. All participants were mailed a cover letter introducing the study and inviting their participation, a survey, a postage-paid return envelope, and an opt-out card requesting basic demographic data. Two copies of a consent form were enclosed; patients were asked to sign and return one copy and keep the other. Monetary incentives of US\$2 were included. Two subsequent contact attempts were made with nonresponders at 2 and 4 weeks after the initial mailing to enhance response rates. The Institutional Review Board at Dana-Farber/Harvard Cancer Center (Boston, MA) approved this study before it was conducted between May 2006 and August 2007.

Eligibility

Eligible survivors were identified as having at least one component of their cancer management at Dana-Farber Cancer Institute; English speaking; more than 2 years since diagnosis; still alive according to the National Death Index; and not undergoing chemotherapy-based treatment at the time of identification. Ongoing endocrine therapy was allowed. The questionnaire asked respondents whether they were cancer free; if they answered no, their survey was excluded.

Patient Questionnaire

The complete questionnaire used for the parent study is described elsewhere⁷; the version used in the breast cancer substudy is included in Data Supplement. The patient opt-out card included four questions about age, sex, and type and diagnosis date of the primary cancer.

Expectations of Patients Regarding Provider Roles

Patients were first queried regarding their expectations for follow-up care, specifically their number of follow-up visits and whether they felt that number was “too many,” “too few,” or “just enough.” Patient perceptions of provider responsibility were then assessed for follow-up for primary cancer recurrence, screening for other cancers, general preventive health care, and treating other medical problems. Provider categories included “Cancer doctor,” “PCP,” or “Other doctor” (identified by the patient in a provided space). Responsibility levels were collapsed for analysis purposes into the following categories: none (“None,” “A little”), some (“Some”), and full (“A lot,” “Full”); and frequencies were calculated as a percentage of total sample size. To assess the relationship between physician type and the dependent variable for physician responsibility level, univariate logistic regression clustered by patient was performed predicting the odds of “a lot/full” versus “none/a little/some.” Odds ratios (ORs) and 95% CIs were reported with PCP as the referent group.

Expectations of Patients Regarding Effect of Visit on Anxiety and Cancer Outcomes

For the remaining questions, the follow-up modalities considered included five types of clinicians (medical oncologist, radiation oncologist, surgeon, nurse practitioner [NP], and PCP) and a virtual visit, which was defined on the questionnaire as a “conversation by phone or over the Internet with a breast cancer doctor or nurse which could safely replace a clinic visit.” The perceived impact of each follow-up modality on patient survival, worrying, and visit-related stress was evaluated using a 5-point scale with gradations of “will decrease,” “may somewhat decrease,” “neither increase nor decrease,” “may somewhat increase,” and “will increase.” Responses were collapsed into the following three categories: decrease (“will decrease” or “may somewhat decrease”), no effect (“neither increase nor decrease”), or increase (“may somewhat increase” or “will increase”); and frequencies were calculated. Univariate logistic regression clustered by patient was then performed with provider type as the independent variable and effect of visit as the outcome (decreasing worry, decreasing stress, and increasing survival). ORs and 95% CIs were reported with PCP as the referent group.

Patients were then asked to rank the different types of follow-up modalities regarding their perceived effect on survival, worrying, and visit-related

stress. Provider types were ranked for each outcome, and then mean and median ranks were reported where increasing rank corresponded to least likely to decrease worry, least likely to increase survival, and least likely to find the visit stressful. Outcomes were dichotomized, and univariate logistic regression models clustered by patient were created with provider type as the independent variable. The outcomes for the three models were as follows: most likely to decrease worry (a rank of 1), most likely to increase survival (a rank of 1), and least likely to find the visit stressful (a rank of 6). ORs and 95% CIs were reported with PCP as the referent group.

Statistical Analyses

Baseline demographics and characteristics for the patient cohort were summarized using frequencies for categorical variables, and median and range for continuous variables. Sensitivity analyses were conducted comparing respondents to nonrespondents based on age, sex, cancer type, and diagnosis date. All statistical analyses were conducted using SAS version 9.2 (SAS Institute, Cary, NC).

RESULTS

Patient Characteristics

A total of 547 questionnaires were sent to breast cancer survivors. Thirteen patients (0.2%) were dead or ineligible, 23 (4.2%) were unable to be located, 190 (34.7%) did not respond, and 36 (6.6%) opted out. The overall response rate was 53% (285 of 534 patients). An additional 67 patients (23.5% of 285 patients) were then removed who were either currently receiving various nonendocrine cancer treatments or said they were not cancer free. Therefore, 218 eligible breast cancer survivors completed the breast cancer subsection questionnaire and were considered participants in this study.

Within the cohort, there were no significant differences between patients who opted out and those who responded with respect to year of diagnosis. However, patients who opted out were significantly older than those who responded (age 62.5 v 57.5 years, respectively; $P < .02$). Baseline characteristics of the cohort are listed in Table 1.

Expectations of Patients Regarding Provider Roles

Respondents self-reported the number of times a year they were seen for breast cancer follow-up, with the majority reporting two visits (49.1%), followed by three visits (17.9%) and four visits (11.9%). Most patients (86.2%) considered their current schedule to be just enough. Patients were surveyed regarding their expectations for provider responsibilities (Table 2). The majority of patients (89.0%) identified their oncologist as mostly responsible for follow-up for cancer recurrence (OR, 20.27 for oncologist v PCP; $P < .001$). In contrast, most patients selected their PCP as mostly responsible for general preventative health care (89.9%; OR, 0.01 for oncologist v PCP; $P < .001$) and treatment of other medical problems (87.2%; OR, 0.01 for oncologist v PCP; $P < .001$). However, 70.2% also identified their PCP as having some or full responsibility to follow up for cancer recurrence, suggesting interest in a shared care model. PCPs were also the provider type most consistently identified as responsible for screening for other cancers (72.0% full responsibility and 11.9% some responsibility).

Expectations of Patients Regarding Effect of Visit on Anxiety and Cancer Outcomes

Patients were queried about how visiting specific providers would affect stress at each follow-up visit (Table 3). The greatest decrease in stress (45.0%) was predicted with visiting a medical oncologist (OR, 1.40 v PCP; $P < .001$). In contrast, the greatest increase in

Table 1. Baseline Demographics and Clinical Characteristics of Breast Cancer Survivor Respondents

Demographic or Clinical Characteristic	No. of Respondents (N = 218)	%
Sex		
Female	216	99.1
Male	2	0.9
Race		
White	206	94.5
African American	6	2.8
Asian	3	1.4
Multiracial	1	0.5
Other	2	0.9
Hispanic		
No	213	97.7
Yes	5	2.3
Age, years		
Median	57.5	
Range	30-86	
Marital status		
Single	13	6
Married	170	78
Separated/divorced/widowed	35	16.1
Education level		
No college	62	28.4
Completed college	154	70.6
Missing	2	0.9
Employment (can select more than one)		
Full/part time	218	100
Homemaker	35	16.1
Retired	46	21.1
Unemployed	3	1.4
Income (total household in last calendar year)		
< \$20,000	4	1.8
\$20,000-\$39,999	15	6.9
\$40,000-\$59,999	19	8.7
\$60,000-\$79,999	25	11.5
\$80,000 or more	110	50.5
Prefer not to answer	35	16.1
Missing	10	4.6
Year of diagnosis		
Before 2000	7	3.2
2001-2003	205	94
2004-2006	6	2.8
Received endocrine therapy	169	77.5
Received chemotherapy	129	59.2
Received surgery	209	95.9
Received radiation therapy	164	75.2

stress (21.1%) was predicted with a virtual visit, which patients perceived as significantly more stress inducing than a visit with a PCP (OR, 0.26 for decreased stress; $P < .001$). Visit-related stress around seeing an NP or a PCP was statistically equivalent, with the majority of patients (69.7% and 68.8% for NPs and PCPs, respectively) feeling that such visits would decrease or have no effect on stress level. In terms of rankings, 22% patients reported that no provider would cause increased stress, and for those who ranked providers, all median and mean ranks for providers were in the "less likely to find the visit stressful" range. A number of patients misinterpreted this question, and further quantitative analysis of rankings could not be performed.

Patients were also asked about the effect of various follow-up visits on cancer-related worrying (Table 3). Medical oncology visits were most frequently reported (by 78.0%) to decrease cancer-related worrying (OR, 2.21 for decreasing worry compared with PCP; $P < .001$). However, visits with a surgeon, a radiation oncologist, an NP, or a PCP were also felt by most to decrease cancer-related worrying (58.7%, 53.7%, 56.9%, and 61.0%, respectively). These provider types were statistically equivalent in this respect. Virtual visits were the modality felt most likely to increase worrying about cancer (21.1%; OR, 0.15 for decreasing worry compared with PCP; $P < .001$). When patients were asked to rank their choice of provider visit in this regard (Table 4), medical oncologists were consistently ranked as most likely to decrease cancer-related worrying (average rank, 1.6, with 1 being most likely to decrease worrying; OR, 35.71 v PCP; $P < .001$). Virtual visits were consistently ranked as least likely to decrease worry (average rank, 6, with 6 being least likely to decrease worrying; OR, 0.23 v PCP; $P = .003$). NP visits were ranked similarly as PCP visits, without significant difference in decreasing worry.

When queried about the effect of follow-up visits on survival outcomes (Table 3), a large percentage of patients (79.8%) identified medical oncology visits as likely to increase survival. Respondents were somewhat more likely to think that a medical oncology visit would improve their survival compared with a visit with a PCP (OR, 2.38; $P < .001$). Additionally, more than 50% of patients felt that NP and PCP visits were capable of increasing survival (NP, 51.4%; PCP, 59.2%; not statistically different). In contrast, only 19.7% of patients identified virtual visits as likely to improve survival, whereas 27.1% indicated that virtual visits could actually decrease survival. Virtual visits were seen as significantly inferior to a visit with a PCP in terms of survival impact (OR, 0.15; $P < .001$). Patients ranked medical oncologist visits (Table 4) as the most likely of all the provider visits to increase survival (average rank, 1.3, with 1 being most likely to increase survival; OR, 42.02 v PCP; $P < .001$). Again, all other in-person visits, including with NP, scored similarly to PCP. Virtual visits were ranked as least likely to improve survival (average rank, 5.3, with 6 being least likely to increase survival; OR, 0.18 v PCP; $P < .001$).

DISCUSSION

In this questionnaire study in an academic medical center breast cancer survivor population, patients indicated greatest comfort with medical oncologist-led follow-up care and attributed the greatest improvements in cancer-related worrying, stress around follow-up visits, and survival to follow-up with a specialist. In comparison, the alternative option of Internet-based virtual visits generated negative responses, although lack of comprehension regarding virtual visits may have contributed to this pattern of response. Patients expressed equivalent comfort with either PCP- or NP-led survivorship care visits, suggesting feasibility of non-medical oncologist care plans.

The future viability of oncologist-only survivorship care is uncertain. Despite a trend toward greater oncologist contribution to survivorship care,⁸ it is unclear that such a trajectory is beneficial. Specialists' offices are often overcrowded and farther from patients' homes, with longer wait times, shorter appointments, and a higher mean cost per visit compared with a primary care clinic.⁹⁻¹² Oncologists generally do not want to function in a primary care-like role¹³ and cite the unburdening of busy clinic schedules as a significant benefit of primary care-based follow-up.¹⁴ Furthermore, providers

Table 2. Survivor Perception of Provider Responsibility

Provider Responsible for Action	No. of Responses	Survivor Response Regarding Provider Responsibility						OR for A Lot/Full Responsibility	95% CI	P
		None		Some		Full				
		No.	%	No.	%	No.	%			
Follow-up for primary cancer recurrence										
Oncologist	213	2	0.9	17	7.8	194	89.0	20.27	11.97 to 34.32	< .001
PCP	197	44	20.2	87	39.9	66	30.3	Ref		Ref
Other provider	83	18	8.3	23	10.6	42	19.3	2.03	1.26 to 3.29	< .005
Screening for other cancers										
Oncologist	200	21	9.6	43	19.7	136	62.4	0.54	0.33 to 0.88	< .05
PCP	197	14	6.4	26	11.9	157	72.0	Ref		Ref
Other provider	63	14	6.4	7	3.2	42	19.3	0.51	0.28 to 0.91	< .05
General preventative health care										
Oncologist	181	101	46.3	53	24.3	27	12.4	0.01	0.01 to 0.02	< .001
PCP	207	0	0	11	5.1	196	89.9	Ref		Ref
Other provider	53	19	8.7	13	6.0	21	9.6	0.04	0.02 to 0.09	< .001
Treat other medical problems										
Oncologist	175	120	55.1	43	19.7	12	5.5	0.01	0.00 to 0.01	< .001
PCP	201	1	0.5	10	4.6	190	87.2	Ref		Ref
Other provider	66	25	11.5	16	7.3	25	11.5	0.04	0.02 to 0.08	< .001

NOTE. Response categories were collapsed into none ("None," "A little"), some ("Some"), and full ("A lot," "Full"). *P* values are in comparison to PCP responsibility. Percentages are calculated out of total sample size (N = 218).

Abbreviations: OR, odds ratio; PCP, primary care physician; Ref, referent.

carrying for patients with cancer voice agreement about the need for better coordination of survivorship care and improved clarity about which aspect of care is provided in what clinic and by whom.¹⁵ When queried, both oncologists and PCPs reveal that there is much overlap in the roles they envision for themselves in follow-up.⁷ However, limited communication between the two provider types can contribute to inefficiency¹⁶ and may expose survivors to suboptimal preventative health services.^{8,17} Health maintenance and management of comorbid conditions have also been shown to be more consistently delivered by PCPs.¹⁵ In general, survivors seen by both provider types are most likely to receive all recommended care.^{8,15,17,18}

Many PCPs feel ready to be an exclusive follow-up care provider and would like to be involved early in survivor care.^{9,19} However, there is concern among PCPs that their distance from the oncology community could render them less familiar with follow-up guidelines¹⁹ or could delay the reinitiation of specialist care in the event of recurrence.⁹ Examination of one PCP cohort found that the survivorship care delivered was not fully comprehensive, and PCPs reported a desire for more training and guidelines to care for long-term cancer survivors.²⁰ Given concerns among both patients and providers regarding PCPs' expertise in cancer-specific issues, many endorse establishment of primary care clinics specifically for breast cancer survivors.²¹

There are various ways to complement survivors' primary care with additional oncology-specific knowledge, while supporting the PCP as an important component of survivorship care. One model is the NP-led survivorship clinic,²² in which cancer survivors transition from a specialist to an NP trained in cancer follow-up, who would share care responsibilities with the patient's PCP and/or oncologist.²² Nurse-led follow-up has been found to provide high overall satisfaction and satisfactory support compared with routine specialist follow-up²³ and, like PCP-led follow-up,¹¹ may allow patients increased provider time and less likelihood of a provider running late. Recent reports have identified success with clinics dedicated to survivorship care, including those

servicing socioeconomically disadvantaged cancer survivors.^{24,25} Up-front education at the time of initial diagnosis about future provider rotation may appropriately shape patient expectations. Results of this survey suggest that breast cancer survivors would be amenable to such clinics, and future piloting of this model should be considered.

Survivorship care plans, a summary of the oncology care that a patient has received as well as guidelines and recommendations for continuing care, represent another means of fortifying the role of PCPs in the shared care of cancer survivors and improving the quality of survivorship care.^{26,27} Survivorship care plans can facilitate care coordination, can clarify care recommendations on a case-by-case basis, and may relieve PCPs' anxieties about providing adequate care.²⁸ Of note, although a majority of breast cancer survivors report that survivorship care plans are useful,²⁹ a recent randomized trial did not find significant improvements in psychosocial adjustment and patient satisfaction with use of survivorship care plans.³⁰ Thus, additional investigation is needed to determine the efficacy of these plans.

Telephone- or Internet-based virtual visits are another modality of care possibly appropriate for some elements of cancer follow-up. This technique has been used in heart failure management³¹ and is under evaluation as a complement to routine primary care.^{32,33} For oncology patients, telephone-based follow-up has served as a successful method for providing psychosocial support to patients with cancer.³⁴ Additionally, an Internet-based tool for creating survivorship care plans has met with preliminary success,³⁵ and a study comparing breast cancer follow-up care through specialist appointments versus telephone conversations with trained nurses found no differences in time to recurrence detection or patient anxiety and greater patient satisfaction in the telephone intervention group.³⁶ Because patients often welcome technology-based alternatives to conventional office visits,³⁷ further investigation is needed to determine the source of

Table 3. Expectations of Patients Regarding Outcome of Follow-Up Visits

Provider Effect on Outcome	No. of Responses	Survivor Response						OR	95% CI	P
		Decrease		No Effect		Increase				
		No.	%	No.	%	No.	%			
Stress around follow-up visit*										
Medical oncologist	191	98	45.0	49	22.5	44	20.2	1.40	1.17 to 1.68	< .001
Surgeon	182	66	30.3	74	33.9	42	19.3	0.70	0.55 to 0.91	< .01
Radiation oncologist	179	62	28.4	79	36.2	38	17.4	0.76	0.61 to 0.94	.01
NP	178	73	33.5	78	35.8	27	12.4	0.92	0.75 to 1.14	.47
PCP	184	79	36.2	71	32.6	34	15.6	Ref		Ref
Virtual visit	166	27	12.4	93	42.7	46	21.1	0.26	0.17 to 0.40	< .001
Worrying about cancer†										
Medical oncologist	207	170	78.0	23	10.6	14	6.4	2.21	1.62 to 3.03	< .001
Surgeon	196	128	58.7	59	27.1	9	4.1	0.78	0.56 to 1.10	.16
Radiation oncologist	189	117	53.7	65	29.8	7	3.2	0.91	0.65 to 1.27	.57
NP	189	124	56.9	57	26.2	8	3.7	0.92	0.68 to 1.25	.58
PCP	197	133	61.0	53	24.3	11	5.1	Ref		Ref
Virtual visit	178	43	19.7	89	40.8	46	21.1	0.15	0.11 to 0.22	< .001
Improving survival‡										
Medical oncologist	208	20	9.2	14	6.4	174	79.8	2.38	1.73 to 3.28	< .001
Surgeon	183	10	4.6	70	32.1	107	49.1	0.57	0.40 to 0.82	< .01
Radiation oncologist	187	10	4.6	72	33.0	101	46.3	0.62	0.44 to 0.88	< .01
NP	179	10	4.6	57	26.2	112	51.4	0.78	0.57 to 1.07	.12
PCP	189	17	7.8	43	19.7	129	59.2	Ref		Ref
Virtual visit	174	59	27.1	72	33.0	43	19.7	0.15	0.10 to 0.23	< .001

NOTE. Response categories were collapsed into decrease ("Decrease," "Somewhat decrease"), no effect, and increase ("Increase," "Somewhat increase"). Frequencies are calculated out of total sample size (N = 218). ORs are with PCP as the referent group, and P values are in comparison to effect of PCP.

Abbreviations: NP, nurse practitioner; OR, odds ratio; PCP, primary care physician; Ref, referent.

*ORs are odds of decreasing stress versus no effect/increase.

†ORs are odds of decreasing worry versus no effect/increase.

‡ORs are odds of increasing survival versus no effect/decrease.

discomfort with this idea in our patient cohort. The definition of virtual visit (see Methods) in the questionnaire was by necessity concise, and it is possible that this brevity may have contributed to patient misconceptions about the potential of this option. A more thorough explanation, for example including details about the availability of video conferencing, may have improved patient satisfaction. It is likely that increased early education and reassurance about the demonstrated safety and benefits of

a virtual visit will be instrumental to increasing patient comfort with this technology-based intervention.

Several factors may limit the generalizability of these results. The breast cancer survivor cohort surveyed was composed of patients receiving care at an urban academic institution and may not reflect the larger population of patients with breast cancer in terms of education, income, and race/ethnicity. Patients were not asked which provider

Table 4. Patient Ranking of Providers

Patient Ranking of Provider Most Likely to Decrease Worry or Increase Survival	No. of Responses	Mean Ranking	Median Ranking	OR	95% CI	P
Decrease worrying about cancer*						
Medical oncologist	206	1.6	1	35.71	20.61 to 61.87	< .001
Surgeon	192	3.3	3	1.56	1.02 to 2.39	< .05
Radiation oncologist	192	3.4	3	1.62	1.02 to 2.58	< .05
NP	185	3.6	3	0.79	0.52 to 1.21	.28
PCP	194	3.3	3	Ref		Ref
Virtual visit	178	5.3	6	0.23	0.09 to 0.60	< .01
Increase chance of surviving cancer†						
Medical oncologist	209	1.3	1	42.02	23.81 to 74.15	< .001
Surgeon	199	3.2	3	1.29	0.86 to 1.95	.22
Radiation oncologist	194	3.4	3	1.24	0.80 to 1.90	.33
NP	193	3.4	3	0.79	0.52 to 1.22	.29
PCP	195	3.2	3	Ref		Ref
Virtual visit	182	5.3	6	0.18	0.08 to 0.47	< .001

Abbreviations: NP, nurse practitioner; OR, odds ratio; PCP, primary care physician; Ref, referent.

*Rank of 1 indicates most likely to decrease worrying, whereas rank of 6 indicates least likely to decrease worrying; ORs are for most likely to decrease worry.

†Rank of 1 indicates most likely to increase survival, whereas rank of 6 indicates least likely to increase survival; ORs are for most likely to increase survival.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

AUTHOR CONTRIBUTIONS

Conception and design: Erica L. Mayer, Eric P. Winer, Craig C. Earle

Financial support: Craig C. Earle

Administrative support: Craig C. Earle

Provision of study materials or patients: Erica L. Mayer, Eric P. Winer, Craig C. Earle

Collection and assembly of data: Bridget A. Neville, Danielle B. Cameron

Data analysis and interpretation: Erica L. Mayer, Adrienne B. Gropper, Bridget A. Neville, Ann H. Partridge, Eric P. Winer, Craig C. Earle

Manuscript writing: All authors

Final approval of manuscript: All authors

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