

# Breast and prostate cancer survivors' experiences of patient-centered cancer follow-up care from primary care physicians and oncologists

Shawna V. Hudson<sup>1,2,5</sup> · Pamela A Ohman-Strickland<sup>1,2,3</sup> · Alicja Bator<sup>1</sup> · Denalee O'Malley<sup>1</sup> · Daniel Gundersen<sup>1</sup> · Heather S. Lee<sup>1</sup> · Benjamin F. Crabtree<sup>1,2</sup> · Suzanne M. Miller<sup>4</sup>

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#### Abstract

*Purpose* Patient-physician relationships impact health care seeking and preventive screening behaviors among patients. At the end of active treatment some cancer survivors report feeling disconnected from their care team. This study explores cancer survivors' experiences of patient-centered cancer follow-up care provided by primary care physicians (PCP) and oncologists (ONC).

*Methods* Three hundred five early stage, breast and prostate cancer survivors at least 2 years post treatment were surveyed from four community hospital oncology programs in New Jersey. Participants reported receipt of patient-centered care measured by care coordination, comprehensiveness of care, and personal relationship with PCPs and ONCs.

*Results* PCPs received higher ratings for coordination of care and comprehensive care than ONCs from all survivors (P < 0.01). However, prostate and breast cancer survivors rated strengths of their personal bonds with the physicians

Shawna V. Hudson hudsonsh@rutgers.edu

- <sup>1</sup> Rutgers Robert Wood Johnson Medical School, Department of Family Medicine and Community Health, Rutgers Biomedical and Health Sciences, Rutgers, The State University of New Jersey, New Brunswick, NJ, USA
- <sup>2</sup> Rutgers Cancer Institute of New Jersey, New Brunswick, NJ, USA
- <sup>3</sup> Biometrics Division, Rutgers School of Public Health, Piscataway, NJ, USA
- <sup>4</sup> Fox Chase Cancer Center, Philadelphia, PA, USA
- <sup>5</sup> Department of Family Medicine and Community Health, Rutgers Robert Wood Johnson Medical School, 1 World's Fair Drive, Suite 1500, Somerset, NJ 08873, USA

differently. While prostate cancer survivors rated PCPs significantly higher for all items (P < 0.028), breast cancer survivors rated ONCs significantly higher on four out of seven items including having been through a lot together, understanding what is important regarding health, knowing their medical history and taking their beliefs and wishes into account (P < 0.036).

*Conclusions* Prostate and breast cancer survivors report different experiences with their PCPs and oncologists around the comprehensiveness and coordination of their cancer followup care in addition to the strength of their relationships with their physicians.

*Implications for Cancer Survivors* There are important differences in the experience of patient-centered care among cancer survivors that should be considered when planning care models and interventions for these different populations.

**Keywords** Cancer survivorship · Primary care · Oncology · Follow-up care · Patient-centered care

# Introduction

There are approximately 14.5 million cancer survivors in the USA [1, 2] and most were diagnosed more than 5 years ago (64 %) with approximately 15 % diagnosed more than 20 years ago [1–3]. Although oncologists are well positioned to provide monitoring regarding late and long-term effects associated with cancer treatment [4–7] it is becoming increasingly clear that declining numbers of cancer survivors continue to see their oncology providers regularly for survivor care well beyond the end of their initial cancer treatment [8–10]. A population-based study found that only one third of long-term cancer survivors continued to seek care from physicians

whose specialties are related to their original cancer after 5 years of survival. Approximately 46 % of long-term breast cancer survivors were followed by their oncologists at year 5; yet, their rates fell to 11 % in their 12th year of survival. Prostate cancer survivors were more likely to see a urologist and those proportions fell from 59 % at year 6 to 39 % at year 12 [11].

There are rising numbers of cancer survivors who rely upon their primary care providers for their long-term follow-up care needs [11]. Data from the 2009 Behavioral Risk Factor Surveillance System (BRFSS) survey found that only 20 % of survivors report receiving the majority of their health care from a cancer specialist [12]. These survivors have a variety of needs for follow-up care [12, 13]. A study from Lafata et al. [9] compared receipt of preventive care for breast and colorectal cancer survivors with age and gender-matched controls with no history of cancer. Though receipt of mammography, colorectal cancer screening, and bone density testing were higher among survivors than controls, the rates were suboptimal given their history of cancer. It also noted gaps for cancer survivors around cholesterol testing. As shared care models [8, 14, 15] involving both oncologists and primary care in cancer management and follow-up care evolve in the cancer survivorship context, the roles of different physicians may need clarification to align patient expectations with the care teams' understood roles. Discordant expectations about survivorship care roles have been reported between patients, their primary care physicians, and oncologists [16, 17]. A study by Cheung et al. found that patients expect more cancer specialist involvement than their oncologists report in managing ongoing cancer screenings post treatment [16]. They also expect less involvement from their primary care physicians (PCPs) for primary cancer follow-up than their PCPs reported [16]. In primary care, unmet patient expectations have been shown to negatively impact patient and physician satisfaction with visits and can weaken patients intentions to adhere to medical advice provided [18].

The Institute of Medicine proposes that survivorship care include care focused on cancer prevention and detection of new cancers, cancer surveillance for spread or recurrence, intervention for late and long-term effects of treatment and coordination of care among multiple providers [19]. These are the patients for whom new models of patient-centered care [20] such as the patient-centered medical homes were developed. The patient-centered medical home (PCMH) is a philosophy of primary care that is patient-centered, comprehensive, team-based, coordinated, accessible, and focused on quality and safety. The model unites four areas of health reform activity and has as pillars access to first-contact care, coordinated care, comprehensive care, and sustained personal relationships [21, 22].

While there are studies that focus upon the implementation and conceptualization of PCMHs, [21–29] there are relatively few empirically based studies that explore patient experiences of patient-centered care [25, 29, 30] and only one published study that has explored it in a cancer survivorship context [31]. Little is known regarding cancer survivors' understanding of what to expect from a PCMH or patient-centered care and how it impacts their long-term cancer follow-up care. Therefore, this study focuses long-term breast and prostate cancer patients with localized disease and their experiences of patient-centered care from their oncologists and primary care physicians during their extended follow-up care after cancer treatment.

## Methods

## Setting and sample

This descriptive study recruited breast and prostate cancer survivors in New Jersey who had received their cancer treatment from one of four community oncology hospitals that were part of the Rutgers Cancer Institute of New Jersey's network of affiliated hospitals (CentraState Medical Center, Cooper Cancer Institute, Somerset Medical Center, and University Hospital). These institutions were chosen to represent the diversity of the area's majority of American College of Surgeons Commission on Cancer accredited community oncology cancer treating facilities (i.e., comprehensive community cancer programs and academic comprehensive cancer programs). The Rutgers University Biomedical and Health Sciences Institutional Review Board approved this study. Written informed consent was received from all patients who participated in the study.

## **Data collection**

Patients with early stage cancer diagnoses (stage 1 or 2) were identified for recruitment from May 2012-June 2013 through their oncology treatment offices. Four oncology hospital settings referred patients to the study. Patients had to have completed their active treatment for breast or prostate cancer a minimum of 2 years from the date of recruitment. Patients were not required to have a primary care provider as inclusion criteria for the study. Patients were identified by research team members at the sites who used one of two mechanisms: approaching patients about the study at their follow-up visits or using an on-site patient registry. Survivors received a survey in the mail with a cover letter from the facility where they received their cancer care as well as from the study PI that introduced and explained the study. If after 2 weeks, the survey had not been returned, a reminder post card was sent to the participant. At 1 month, a second and final survey was sent to the participant. If it was not returned, the participant was counted as a refusal. Response rates across recruitments sites for the study averaged 60 %.

Study participants completed a short survey that took approximately 15 min. The survey asked about their health and medical history, use of and satisfaction with primary and oncology care for follow-up, health related quality of life, knowledge about cancer follow-up care, and patient activation.

## Measures

The study instrument included survey items that assessed patient demographics, diagnoses, comorbid conditions, and items measuring patient-centered medical home constructs of comprehensive care, coordination of care, and personal relationship over time as measured by the Components of Primary Care Instrument [32–34].

## Comprehensive care

Comprehensive care included provision of services that account for the majority of patient needs, including emergency care, chronic disease, and disease prevention. Patients were asked to agree or disagree with a series of statements about their care from their PCPs and ONCs (see Table 2) using a Likert scale from 1 = strongly disagree to 5 = strongly agree.

#### Coordination of care

Coordination of care involved guiding focused care such as tracking both health care and individual tests, tracking specific health problems, and communicating with and following up with other physicians and health care professionals. Patients were asked to agree or disagree with a series of statements on coordination by their PCPs and ONCs (see Table 2) using a Likert scale from 1 = strongly disagree to 5 = strongly agree.

## Personal relationship over time

Personal relationship over time included having a physician who knew not only about the patient but also about their family history, their medical history, who understood their beliefs and desires and understands the patient as a person. Patients were asked to agree or disagree with a series of statements about the quality of their relationships with their PCPs and ONCS (see Table 2) using a Likert scale from 1 = strongly disagree to 5 = strongly agree.

## Patient demographics

We examined patient age, comorbidity as measured by the Charlson comorbidity index, [35] gender, race/ethnicity, education, treatment location, marital status, employment status and health insurance status for cancer survivors, and subgroups of cancer survivors with a specific history of breast or prostate cancer.

## Statistical analyses

Descriptive statistics, including proportions for all categorical descriptors and means with standard deviations for continuous descriptors, were calculated to describe the study population of patients. To explore differences in responses to each item describing PCP and ONC care, means were compared using paired t tests, both for the entire sample as well as for the breast and prostate cancer subsamples. Generalized Linear Modeling (GLM) was used to adjust for any potential impact of additional covariates on descriptions of PCP and ONC patient-centered care. The SAS/STAT software (SAS system for Windows, Version 9.1.3) was used for all statistical analyses.

While referring sites verified that all patients were at least 2 years out from their last active treatment, there were 20 individuals who indicated on the survey that their last cancer treatment was less than two years ago. We have excluded those cases from the analysis resulting in an analytic dataset where n = 305 patients—breast (n = 204) and prostate (n = 101) cancer survivors.

# Results

Demographic characteristics for the sample are shown in Table 1. Two thirds of participants were female breast cancer survivors and 33 % were male prostate cancer survivors. The mean age was 64 years (SD=10.8). The mean score on the Charlson comorbidity index was 2.5 (SD=1.9). Over three-quarter reported being white or Caucasian (78 %). The majority were married or living with partner (71 %). Over half of the sample had less than a 4-year college degree (57 %), 30 % were employed full-time, and 45 % reported being retired. Nearly all had medical insurance (97 %). The majority were treated at academic medical sites (65 %).

The demographic characteristics were similar for breast and prostate cancer survivors with some exceptions. Breast cancer survivors were more likely to be divorced (13 vs. 4 %) or widowed (12 vs. 5 %) and to be employed full time (35 vs. 19 %). Prostate cancer survivors had greater mean age (M=70.3, SD=8.3 vs. M=61.3, SD=10.7), were more likely to be married or living with partner (79 vs. 67 %) and retired (61 vs. 37 %). Lastly, prostate cancer survivors had higher mean score on the Charlson comorbidity index (M=2.9, SD=2.1 vs. M=2.3, SD=1.7).

Mean ratings of PCPs and ONCs' for each variable comprising the comprehensive care, coordination of care, and personal relationships over time domains are presented in Table 2, overall and by cancer type. Overall, PCPs scored

#### **Table 1**Demographics of breast and prostate cancer survivors (all and by diagnosis)

| Variable                      | All              |                        | Breast cancer survivors |                        | Prostate cancer survivors |                        |
|-------------------------------|------------------|------------------------|-------------------------|------------------------|---------------------------|------------------------|
|                               | No. of survivors | Mean (SD) <i>n</i> (%) | No. of survivors        | Mean (SD) <i>n</i> (%) | No. of survivors          | Mean (SD) <i>n</i> (%) |
| Age                           | 302              | 64.0 (10.8)            | 203                     | 61.3 (10.7)            | 99                        | 70.3 (8.3)             |
| Charlson comorbidity index    | 305              | 2.5 (1.9)              | 204                     | 2.3 (1.7)              | 101                       | 2.9 (2.1)              |
| Gender                        | 305              |                        | 204                     |                        | 101                       |                        |
| Male                          |                  | 101 (33 %)             |                         | 0 (0 %)                |                           | 101 (100 %)            |
| Female                        |                  | 204 (67 %)             |                         | 204 (100 %)            |                           | 0 (0 %)                |
| Race                          | 305              |                        | 204                     |                        | 201                       |                        |
| White or Caucasian            |                  | 239 (78 %)             |                         | 164 (80 %)             |                           | 75 (74 %)              |
| Black and/or African American |                  | 42 (14 %)              |                         | 28 (14 %)              |                           | 14 (14 %)              |
| Latino/a and/or Hispanic      |                  | 11 (3 %)               |                         | 3 (1 %)                |                           | 8 (8 %)                |
| Asian or Pacific Islander     |                  | 8 (3 %)                |                         | 5 (3 %)                |                           | 3 (3 %)                |
| Other                         |                  | 5 (2 %)                |                         | 4 (2 %)                |                           | 1 (1 %)                |
| Education                     | 297              |                        | 202                     |                        | 95                        |                        |
| High school/GED               |                  | 79 (27 %)              |                         | 49 (24 %)              |                           | 30 (32 %)              |
| Some college                  |                  | 89 (30 %)              |                         | 68 (34 %)              |                           | 21 (22 %)              |
| 4-year college                |                  | 59 (20 %)              |                         | 39 (19 %)              |                           | 20 (21 %)              |
| Grad school, Masters, PhD     |                  | 70 (23 %)              |                         | 46 (23 %)              |                           | 24 (25 %)              |
| Site                          | 305              |                        | 204                     |                        | 101                       |                        |
| Academic                      |                  | 196 (65 %)             |                         | 160 (78 %)             |                           | 36 (36 %)              |
| Community                     |                  | 109 (35 %)             |                         | 44 (22 %)              |                           | 65 (64 %)              |
| Marital status                | 303              |                        | 203                     |                        | 100                       |                        |
| Single/never married          |                  | 26 (8.6 %)             |                         | 15 (8 %)               |                           | 11 (11 %)              |
| Married/partnered             |                  | 215 (71 %)             |                         | 136 (67 %)             |                           | 79 (79 %)              |
| Divorced                      |                  | 31 (10 %)              |                         | 27 (13 %)              |                           | 4 (4 %)                |
| Widowed                       |                  | 30 (10 %)              |                         | 25 (12 %)              |                           | 5 (5 %)                |
| Other                         |                  | 1 (0.4 %)              |                         | 0 (0 %)                |                           | 1 (1 %)                |
| Employment status             | 304              |                        | 204                     |                        | 100                       |                        |
| Full-time                     |                  | 91 (30 %)              |                         | 72 (35 %)              |                           | 19 (19 %)              |
| Part-time                     |                  | 32 (10 %)              |                         | 24 (12 %)              |                           | 8 (8 %)                |
| Not employed                  |                  | 30 (10 %)              |                         | 22 (11 %)              |                           | 8 (8 %)                |
| Disability/not employed       |                  | 14 (5 %)               |                         | 10 (5 %)               |                           | 4 (4 %)                |
| Retired                       |                  | 137 (45 %)             |                         | 76 (37 %)              |                           | 61 (61 %)              |
| Medical insurance             | 304              |                        | 204                     |                        | 100                       |                        |
| Yes                           |                  | 294 (97 %)             |                         | 202 (99 %)             |                           | 92 (92 %)              |
| No                            |                  | 10 (3 %)               |                         | 2 (1 %)                |                           | 8 (8 %)                |
| Cancer stage <sup>a</sup>     | 252              |                        | 203                     |                        | 49                        |                        |
| Stage 1                       |                  | 131 (52 %)             |                         | 108 (53 %)             |                           | 23 (47 %)              |
| Stage 2                       |                  | 121 (48 %)             |                         | 95 (47 %)              |                           | 26 (53 %)              |

<sup>a</sup> Inclusion criteria for the study required that all participants were diagnosed as stage 1 or 2 cancer and had completed active treatment at least 2 years prior to data collection. One data collection site provided staging information in aggregate for their participants resulting in missing data

significantly higher on all comprehensive care variables except "this doctor handles emergencies." For coordination of care, PCPs (M=4.25, SD=0.86) scored higher than ONCs (M=3.66, SD=1.22) on "this doctor keeps track of all my health care" (P<0.001), whereas ONCs (M=3.74, SD=1.08) scored higher than PCPs (M=3.56, SD=1.11) on "this doctor communicates with other health care professionals I see"

(P<0.01). In the personal relationships over time domain, ONCs had higher mean scores than PCPs for "this doctor and I have been through a lot together" (M=3.83, SD=1.18 vs. M=3.48, SD=1.24; P<0.001) and "this doctor understands what is important to me regarding my health" (M=4.25, SD=0.82 vs. M=4.04, SD=0.88; P<0.01). In contrast, PCPs (M=4.2, SD=0.82) had higher mean score

|                                 |  | Overall          |                          | Breast cancer<br>survivors |                          | Prostate cance<br>survivors |                          |
|---------------------------------|--|------------------|--------------------------|----------------------------|--------------------------|-----------------------------|--------------------------|
|                                 |  | PCP<br>Mean (SD) | ONC                      | PCP<br>Mean (SD)           | ONC                      | PCP<br>Mean (SD)            | ONC                      |
| Comprehensive care              | This doctor handles emergencies.   | 3.79 (0.90)      | 3.75 (1.02)              | 3.79 (0.92)                | 3.76 (1.04)              | 3.78 (0.87)                 | 3.71 (0.97)              |
|                                 | This doctor takes care of almost any medical problem   | 4.02 (0.88)      | 3.24 (1.25) <sup>‡</sup> | 4.03 (0.90)                | 3.26 (1.26) <sup>‡</sup> | 4.01 (0.86)                 | 3.18 (1.21) <sup>‡</sup> |
|                                 | I go to this doctor to care for ongoing medical problems.  | 4.15 (0.90)      | 3.05 (1.37) <sup>‡</sup> | 4.18 (0.87)                | 3.12 (1.38) <sup>‡</sup> | 4.11 (0.96)                 | 2.88 (1.36) <sup>‡</sup> |
|                                 | I go to this doctor for a checkup to prevent illness.  | 4.29 (0.82)      | $3.44~(1.38)^{\ddagger}$ | 4.30 (0.79)                | 3.51 (1.42) <sup>‡</sup> | 4.27 (0.87)                 | 3.26 (1.28) <sup>‡</sup> |
| Coordination of care            | This doctor keeps track of all my health care.   | 4.25 (0.86)      | 3.66 (1.22) <sup>‡</sup> | 4.28 (0.82)                | $3.82~(1.16)^{\ddagger}$ | 4.19 (0.94)                 | 3.21 (1.27) <sup>‡</sup> |
|                                 | This doctor follows up on a problem I've had, either at  | 3.99 (1.02)      | 3.91 (1.10)              | 3.99 (1.00)                | 3.99 (1.05)              | 3.98 (1.07)                 | 3.68 (1.20)*             |
|                                 | the next visit or by mail, email, or phone.<br>This doctor follows up on my visit to other health care | 3.75 (1.15)      | 3.61 (1.19)              | 3.73 (1.15)                | 3.73 (1.15)              | 3.79 (1.15)                 | 3.28 (1.24) <sup>‡</sup> |
|                                 | professionals.   |                  |                          |                            |                          |                             |                          |
|                                 | This doctor helps me interpret my laboratory tests, X-rays,<br>or visits to other doctors.             | 4.01 (0.97)      | 4.02 (1.05)              | 4.04 (0.97)                | 4.16 (0.98)              | 3.95 (0.96)                 | 3.62 (1.13) <sup>†</sup> |
|                                 | This doctor communicates with other health professionals   | 3.56 (1.11)      | $3.74~(1.08)^{\dagger}$  | 3.49 (1.14)                | $3.86~(1.03)^{\ddagger}$ | 3.7 (1.02)                  | $3.43 (1.14)^{\dagger}$  |
|                                 | I see.   |                  |                          |                            |                          |                             |                          |
| Personal relationship over time | This doctor knows a lot about my family medical history.   | 3.91 (1.04)      | 3.86 (1.07)              | 3.94 (1.05)                | 4.10(0.91)               | 3.87 (1.04)                 | 3.18 (1.21) <sup>‡</sup> |
|                                 | This doctor and I have been through a lot together.  | 3.48 (1.24)      | $3.83~(1.18)^{\ddagger}$ | 3.38 (1.30)                | $4.05~(1.08)^{\ddagger}$ | 3.67 (1.11)                 | 3.22 (1.25)              |
|                                 | This doctor understands what is important to me regarding my health.                                   | 4.04 (0.88)      | 4.25 (0.82) <sup>†</sup> | 4.01 (0.94)                | 4.37 (0.71) <sup>‡</sup> | 4.10 (0.75)                 | 3.90 (0.99) <sup>†</sup> |
|                                 | This doctor knows my medical history very well.  | 4.13 (0.85)      | 4.12 (0.93)              | 4.1 (0.89)                 | $4.29(0.86)^{*}$         | 4.18 (0.76)                 | $3.63(0.94)^{\ddagger}$  |
|                                 | This doctor takes my beliefs and wishes into account in  | 4.13 (0.82)      | 4.27 (0.79)              | 4.17 (0.84)                | $4.41 (0.70)^{\dagger}$  | 4.06(0.80)                  | $3.88(0.91)^{*}$         |
|                                 | caring for me.   |                  |                          |                            |                          |                             | *                        |
|                                 | This doctor knows whether or not I exercise, eat right,<br>smoke, or drink alcohol.                    | 4.20 (0.82)      | $4.11 (0.89)^{*}$        | 4.2 (0.82)                 | 4.23 (0.83)              | 4.20 (0.83)                 | 3.76 (0.99)*             |
|                                 | This doctor knows me well as a person (such as hobbies, job, etc.).                                    | 3.48 (1.21)      | 3.41 (1.15)              | 3.38 (1.27)                | 3.48 (1.19)              | 3.69 (1.07)                 | 3.22 (1.01) <sup>†</sup> |
|                                 |  |                  |                          |                            |                          |                             |                          |

Scores ranged from 1--strongly disagree to 5--strongly agree

PCP primary care provider, ONC oncologist

\*P < 0.05 comparing PCP to ONC;  $\ddagger P < 0.01$  comparing PCP to ONC;  $\ddagger P < 0.001$  comparing PCP to ONC

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Table 2 Mean scores on variables for comprehensive care, coordination of care, and personal relationships over time for primary care providers and oncologists—overall and by cancer type

than ONCs (M=4.11, SD=0.89) on "this doctor knows whether I exercise, eat right, smoke, or drink alcohol (P < 0.05).

Figure 1 presents mean differences for PCPs and ONCs by cancer type for each of the variables of the respective domains. PCPs were scored significantly higher on average on all variables for comprehensive care except for "this doctor handles emergencies" among both breast and prostate cancer survivors.

For the coordination of care domain, PCPs had higher mean scores on "this doctor keeps track of all my health care" (D=0.46; P<0.001), but lower scores on "this doctor communicates with other health professionals I see" (D=-0.37, P<0.001) among breast cancer survivors. No other variables in this domain were significant for breast cancer survivors. In contrast, PCPs scored higher than ONCs among prostate cancer survivors for "this doctor keeps track of all my health care" (D=0.98; P<0.001), "this doctor follow up on a problem I've had, either at the next visit or by mail, email or phone" (D=0.3; P<0.05), "this doctor follows up on my visit to other health care professionals" (D=0.51; P<0.001), "this doctor helps me interpret my laboratory tests, x-rays, or visits to other doctors" (D=0.33; P<0.01), and "this doctor communicates with other health professionals I see" (D=0.27, P<0.01).

For the personal relationships over time domain, breast cancer survivors rated PCPs lower on "this doctor and I have been through a lot together" (D=-0.67; P<0.001), "this doctor understands what is important to me regarding my health" (D=-0.36; P<0.001), "this doctor knows my medical history well" (D=-0.19; P<0.05), and "this doctor takes my beliefs and wishes into account in caring for me (D=-0.24; P<0.01). However, among prostate cancer survivors, PCPs had higher mean scores than ONCs on "this doctor knows a lot about my family medical history" (D=0.69, P<0.001), "this doctor understands what is important to me regarding my health" (D=0.2; P<0.01), "this doctor knows my medical history

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well" (D=0.55; P<0.001), "this doctor takes my beliefs and wishes into account in caring for me" (D=0.18; P<0.05), "this doctor knows whether or not I exercise, eat right, smoke, or drink alcohol" (D=0.44, P<0.001), and "this doctor knows me well as a person" (D=0.47; P<0.01).

While age, illness burden, marital status, and employment status differed between breast and prostate cancer survivors, adjusted associations between survivor type and comprehensive care, care coordination, or personal relationship items were not substantively different from the unadjusted associations (data not shown).

## Discussion

Cancer survivorship studies have shown that when PCPs are engaged in survivorship care patients receive preventive screenings and recommended care at higher rates than those seen by an oncologist alone [36, 37]. Our study findings provide additional psychosocial and empirical support that patients' follow-up care needs may be best served when primary care and oncologic care work together in a complementary, rather than in a siloed, context. Patients in this study reported receiving different types of support from the two different types of providers. PCPs were rated more highly on providing aspects of patient-centered care than ONCs on follow-up care in terms of care coordination and comprehensiveness. This finding is particularly interesting given the lack of clear delineation of the roles of oncology and primary care in providing cancer survivorship care.

Aligning expectations about who is responsible for different aspects of care is an important aspect of survivorship care that needs attention, [16] and survivorship care plans are one response to addressing this complex problem. One study of PCPs suggests that the continued communication (which is

 Fig. 1 Differences in mean for variables for comprehensive care, coordination of care, and personal relationships over time for primary care providers and oncologists—by cancer type
 1.75
 Co

 0.75
 0.75
 0.25
 0.25

 0.25
 0.25
 0.25



highly variable depending on the cancer treatment setting) throughout the cancer care experience may be more helpful to PCPs than receiving a summary document at the completion of treatment [38]. Yet, data suggests that lack of effective communication throughout the cancer experience is the norm with less than one third of breast cancer patients reporting feeling that their PCPs and ONC communicated well [39]. Data from this study contribute to this growing body of research by adding another dimension to the discussion. What aspects of patient-centered care are being met by their different providers? Our data suggest that because patients see their PCPs and ONCs as playing different roles in care coordination and providing comprehensive care that communication between the two is of vital importance. Understanding that there is a need for different providers and that they provide different aspects of care is vital to providing better, more coordinate and comprehensive care to cancer survivors in the future.

Additionally, there were important gender/disease differences between breast and prostate cancer survivors in terms of communication with other health care providers and the types of personal relationship contact that they reported from their providers. Male prostate cancer survivors more highly rated their PCPs on all aspects of their personal relationships. We hypothesize there are a number of potential reasons that may account for the differences observed. Some studies indicate that the differences may be due to gender or the nature of the disease [40]. In a number of studies, women have been shown to be more active communicators and send and receive more emotionally charged information [41, 42]. Whereas men, particularly older men, such as the prostate survivors enrolled in this study, are reported to be stoic and to disclose symptoms with less detail [43]. Because relationships with physicians are important in building healing relationships [44], this difference is worth considering when planning transitions from active cancer treatment to follow-up care.

This study also provides additional support to the existing literature that suggests that breast cancer patients may need additional intervention to engage/re-engage and build trust with their PCPs [39]. Female breast cancer patients in this study describe their oncologists communication with other providers and their personal relationships with their ONCs as stronger than their PCPs. The communication finding adds additional support to the breast cancer literature which suggests that survivors while confident in PCPs general care and psychosocial support have less confidence in their ability to provide cancer specific survivorship care [39]. In terms of personal relationship, our participants differed on dimensions that have to do with having built rapport through having been through a lot together, understanding what is important regarding their health, knowing their medical history and taking their beliefs and wishes into account when making health care decisions. This is consistent with qualitative studies among breast cancer patients who describe intense relationships with their oncology providers and reluctance to leave the specialty setting because of the reassurance that contact provided [16, 45].

While our study is the first to explore patient-centered care from a cancer survivorship patients' perspective, there are several important limitations to note. First, the lack of a large, national sample limits our ability to draw broad conclusions from the data. However, to our knowledge, there are no large nationally representative datasets available that provide these data. Second, while the study is limited to a New Jersey context, the recruitment of survivors from both academic and community oncology settings is a strength of the study design. Much of the research on adult cancer survivors has been focused on patients seen in NCI-comprehensive designated cancer center settings [12] and therefore, may not represent the broader cancer survivor experience lived by the vast majority of US cancer survivors who are seen in community settings [30, 36]. To create a fuller picture, additional studies that characterize the experiences of survivors in other community-based clinical settings are required to further expand our understandings of what happens to survivors in other oncology settings [30]. We would argue that additional studies of this type are necessary to determine if the views of our participants are representative of a broader trend in patient attitudes in the USA. Finally, this study focuses on patients' individual experiences of care and therefore does not document additional objective measures of care nor can it assess the quality of care provided.

However, bearing in mind these limitations, this study makes several important contributions to our understandings of cancer survivors' experiences of patient-centered care. Identifying and describing patient expectations, issues, and confidence in PCPs related to cancer specific care and understanding how these might influence the provider-patient relationships can help shape long-term care strategies for cancer survivors. Our findings suggest that there are important differences that should be considered when planning care models and interventions for these different populations. It is important to tease out what mechanisms account for these different experiences and to further explore these preferences with other survivor populations.

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**Compliance with ethical standards** All procedures performed in studies involving human participants were in accordance with the ethical standards of the Rutgers University Biomedical and Health Sciences Institutional Review Board and with the 1964 Helsinki declaration and its later amendments.

**Conflict of interest** The authors declare that they have no conflict of interest.

**Informed consent** Informed consent was obtained from all individual participants included in the study.

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