J Cancer Surviv (2016) 10:1067–1077
DOI 10.1007/s11764-016-0550-7

Trends in cancer survivors' experience of patient-centered communication: results from the Health Information National Trends Survey (HINTS)

Danielle Blanch-Hartigan[1] · Neetu Chawla[2] · Richard P. Moser[3] · Lila J. Finney Rutten[4] · Bradford W. Hesse[3] · Neeraj K. Arora[5]

Received: 8 December 2015 / Accepted: 3 May 2016 / Published online: 19 May 2016

Abstract

Purpose Two Institute of Medicine reports almost a decade apart suggest that cancer survivors often feel "lost in transition" and experience suboptimal quality of care. The six core functions of patient-centered communication: managing uncertainty, responding to emotions, making decisions, fostering healing relationships, enabling self-management, and exchanging information, represent a central aspect of survivors' care experience that has not been systematically investigated.

Methods Nationally representative data from four administrations of the Health Information National Trends Survey (HINTS) was merged with combined replicate weights using the jackknife replication method. Linear and logistic regression models were used to assess (1) characteristics of cancer survivors ($N = 1794$) who report suboptimal patient-centered communication and (2) whether survivors' patient-centered communication experience changed from 2007 to 2013.

Results One third to one half of survivors report suboptimal patient-centered communication, particularly on core functions of providers helping manage uncertainty (48 %) and responding to emotions (49 %). In a fully adjusted linear regression model, survivors with more education (Wald $F = 2.84$, $p = .04$), without a usual source of care (Wald $F = 11.59$, $p < .001$), and in poorer health (Wald $F = 9.08$, $p < .001$) were more likely to report less patient-centered communication. Although ratings of patient-centered communication improved over time (p trend = .04), this trend did not remain significant in fully adjusted models.

Conclusions Despite increased attention to survivorship, many survivors continue to report suboptimal communication with their health care providers.

Implications for Cancer Survivors Survivorship communication should include managing uncertainty about future risk and address survivors' emotional needs. Efforts to improve patient-centered communication should focus on survivors without a usual source of care and in poorer health.

Keywords Patient-centered care · Patient-provider communication · Cancer survivorship · Emotions · Uncertainty

Introduction

In 2013, the Institute of Medicine (IOM) released the report "Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis" which called for increased patient-centered care to meet the needs of a cancer care delivery system facing increased complexity and barriers to quality [1]. This report follows almost a decade after the IOM's 2006 report, "From Cancer Patient to Cancer Survivor: Lost in Transition", which highlighted the complexities and uncertainties in care experienced by patients transitioning from active treatment to survivorship [2]. Since the release of this seminal report, increased research and clinical attention have

---

✉ Danielle Blanch-Hartigan
danielleblanch@gmail.com

[1] Department of Natural and Applied Sciences, Bentley University, Jennison 103, 175 Forest Street, Waltham, MA 02452, USA

[2] Division of Research, Kaiser Permanente Northern California, Oakland, CA, USA

[3] Division of Cancer Control and Population Sciences, National Cancer Institute, National Institutes of Health, Bethesda, MD, USA

[4] Robert D. and Patricia E. Kern Center for the Science of Health Care Delivery, Mayo Clinic, Rochester, MN, USA

[5] Improving Health Systems, Patient-Centered Outcomes Research Institute, Washington, DC, USA

focused on improving the patient-centered care experiences of cancer survivors [3, 4]. Recommendations for survivorship care plans explicitly state that patient-centered care should be promoted among cancer survivors [5]. The central components of patient-centered care lie in the communication between cancer patients and their providers [4, 6]. Cancer patients who experience more patient-centered communication with their providers report more positive care experiences, including increased satisfaction, reduced distress, and better quality of life outcomes [7–9].

In the NCI monograph by Epstein and Street, patient-centered communication in cancer care has been described as having six central functions: (1) fostering a healing patient-provider relationship through building rapport and trust; (2) exchanging clinical information and understanding patients' representations of that information; (3) responding to patients' emotional needs; (4) helping patients manage uncertainty; (5) involving patients in the decision-making process; and (6) enabling patient self-management through supporting patient autonomy and providing appropriate resources [10]. These functions are essential to meet the complex needs of cancer survivors, which include management of late and long term effects of treatment, psychosocial needs such as fear of recurrence, and care coordination across multiple providers.

Despite the growing significance of this research area, cancer survivors' experiences of patient-centered communication have not been systematically investigated on a population level. To address this critical need, we used nationally representative data pooled across four iterations of the Health Information National Trends Survey from 2007 to 2013 to analyze: (1) the prevalence of cancer survivors who report suboptimal patient-centered communication; (2) predictors of suboptimal patient-centered communication, including socioeconomic status and time since diagnosis; and (3) national trends in patient-centered communication for cancer survivors since the 2006 IOM report. Findings from this study will fill an important gap in existing research on patient-centered communication among survivors and have implications for improving cancer care delivery.

Methods

Survey design

The Health Information National Trends Survey is a nationally representative probability survey funded by the National Cancer Institute designed to track changes in the health communication environment [11]. We combined data from the four iterations of HINTS that included the patient-centered communication questions: HINTS 3 (fielded Jan–May 2008, response rate = 30.99 %), HINTS 4 cycle 1 (fielded Oct 2011–Jan 2012, response rate = 36.7 %), HINTS 4 cycle 2 (fielded July–Nov 2012, response rate = 39.97 %), and HINTS 4 cycle 3 (fielded April–July 2013, response rate = 35.19 %). To maintain consistency with the HINTS 4 cycles in how the survey was administered, we included only respondents from the mailed survey for HINTS 3; we did not include respondents who answered by phone. For additional information about survey design, the split frame administration of HINTS3, and the complete list of questions, please visit hints.cancer.gov.

Sample

For all analyses, we used the subsample of respondents who reported a personal history of cancer. We further limited our sample to survivors who reported seeing a health care provider in the previous year to be consistent with the patient-centered communication items ($n = 1794$).

Measures

Predictor variables Respondents reported basic demographic (age, gender, education level, race/ethnicity, insurance status, and household income) and clinical characteristics (general health status, whether or not they had a usual source of care, frequency of provider visits in the previous year, cancer type, and time since cancer diagnosis).

Outcome variables Survivors reported patient-centered communication experience with all health care providers in the previous year on six items which correspond directly to the six functions of patient-centered communication outlined in the NCI Monograph and are consistent with recommendations for a systematic approach to measuring patient-centered communication in cancer patients [10, 12]. The item asked how often providers did each of the following: "Help you deal with feelings of uncertainty about your health or health care" (managing uncertainty); "Give the attention you needed to your feelings and emotions" (responding to emotions); "Involve you in decisions about your health care as much as you wanted" (making decisions); "Make sure you understood the things you needed to do to take care of your health" (enabling self-management); "Give you the chance to ask all the health-related questions you had" (exchanging information); and "Feel you could rely on your doctors, nurses, or other health care professionals to take care of your health care needs" (fostering healing relationships). Response options were always, usually, sometimes, and never.

An overall patient-centered communication score for each respondent was calculated by averaging scores on the six individual items and transforming them to a 0–100 scale. In addition, responses for each function were dichotomized as always vs. usually/sometimes/never, with the latter considered suboptimal communication for each function, following an approach previously used with HINTS data [13]. A sensitivity analysis dichotomizing each function as always/usually vs. sometimes/never was also conducted.

Data analysis

The four HINTS data sets were merged into a stacked dataset which included a variable to indicate iteration. The dataset contained a final sample weight for population-level point estimates and replicate weights to calculate standard errors of estimates using the jackknife replication method. Univariate statistics include weighted distributions and 95 % CI or weighted mean (SE), in the combined sample of cancer survivors using our merged weights, and separately for each HINTS iteration. Separate weighted and adjusted linear and logistic regression models were used to regress the continuous patient-centered communication variable and each dichotomized patient-centered communication function on predictor variables.

Results

Sociodemographic characteristics of the combined sample and each individual sample are summarized in Table 1. Table 1 also presents demographic differences and trends across iterations. The majority of the sample was non-hispanic white (83.2 %), with some college education or more (62 %). Most of the respondents reported having a usual source of care (88.7 %) and health insurance (94.4 %).

Prevalence of cancer survivors who report suboptimal patient-centered communication

In the combined sample, survivors generally reported high patient-centered communication experience (weighted mean = 80.3; SE = .80; Table 2). However, sizeable proportions reported suboptimal communication on each of the six functions (Fig. 1). Approximately half of respondents reported that providers did not always help them manage uncertainty (49.0 %) nor attend to their emotions (48.0 %). Approximately 40 % of survivors felt they could not always rely on providers to take care of their needs (39.7 %), involve them in decisions as much as they wanted (41.1 %), or make sure they fully understood what was needed to care for their health (37.8 %). One in three reported providers did not always allow them to ask all of their questions (34.4 %).

Predictors of patient-centered communication

In a fully adjusted linear regression model of the combined sample, survivors with more education (Wald $F = 2.84$, $p = .04$), without a usual source of care (Wald $F = 11.59$, $p < .001$), and in poorer health (Wald $F = 9.08$, $p < .001$) were more likely to report lower patient-centered communication scores (Table 3).

Predictors of optimal communication for each of the patient-centered communication functions in our adjusted logistic regression models of the combined sample are presented in Table 4. Health status and usual source of care were the most consistent predictors of patient-centered communication across all patient-centered communication functions. Survivors in good or fair/poor health status were consistently less likely than those with excellent/very good health to report optimal levels of patient-centered communication, while lacking a usual source of care was significantly associated with suboptimal communication for all of the patient-centered communication functions, except managing uncertainty.

Income and gender were significant overall predictors of providers always helping survivors to manage uncertainty (Wald $F = 2.32$, $p < .05$, and Wald $F = 4.78$, $p < .05$, respectively). Survivors with incomes less than $20K (OR = 1.79) per year and between $35–50K (OR = 1.89) were significantly more likely to report providers always helped them manage their uncertainty than those survivors with incomes of $75K or more (all $p < .05$). Female survivors (OR = 1.39) were more likely to report providers always helped them to manage their uncertainty. Compared to those with a college education or higher, survivors who were high school graduates were more likely to report they could always rely on their health care providers (OR = 1.66, $p < .05$).

In both unadjusted and adjusted analyses of the combined sample, neither overall patient-centered communication score (Table 3) nor any of the six functions (Table 4) varied by time since diagnosis or age.

Five-year trends in patient-centered communication for cancer survivors

Overall, average patient-centered communication scores among survivors varied by iteration in unadjusted analyses. There was a significant linear trend of increasing patient-centered communication scores over the 5-year time period (p trend = .04). The weighted mean of the patient-centered communication score rose from 78.1 (SE = 1.1) in HINTS3 in 2007 to 81.9 (SE = 2.2) in HINTS 4 cycle 3 in 2013. Looking at each function separately, we saw a linear decrease over time in the percentage of survivors reporting suboptimal care for each of the six core functions of patient-centered communication (Table 2).

However, the increasing trend in overall patient-centered communication score did not remain significant after adjusting for demographic and clinical predictors (Table 3). Looking separately at each function, the increased proportion of cancer survivors who reported their provider fostered a healing relationship was the only trend to remain significant

Table 1 Characteristics of cancer survivors across HINTS survey iterations

Variable	Combined Sample of cancer survivors *N* (weighted %)	HINTS 3 cancer survivors (mail respondents only)	HINTS 4 cycle 1 cancer survivors	HINTS 4 cycle 2 cancer survivors	HINTS 4 cycle 3 cancer survivors	*p* value for linear trend analysis	*p* value for comparison by iteration (unadjusted)
Date fielded		Jan–May 2008	Oct 2011–Jan 2012	July– Nov 2012	Apr–July 2013		
Sample size	1794	436	517	419	422	–	
Gender						ns	ns
Male	720 (42.4)	173 (42.4)	211 (42.4)	181 (44.8)	155 (40.1)		
Female	1044 (57.6)	263 (57.6)	290 (57.6)	233 (55.2)	258 (59.9)		
Age						ns	ns
18–49	208 (17.0)	52 (15.4)	53 (13.2)	54 (18.4)	49 (20.9)		
50–64	591 (33.0)	157 (36.8)	185 (33.9)	120 (30.9)	129 (31.1)		
65–74	484 (23.9)	103 (20.5)	134 (25.8)	116 (23.9)	131 (25.0)		
75+	482 (26.1)	116 (27.4)	133 (27.2)	126 (26.9)	107 (23.0)		
Education						.057	ns
Less than high school	179 (14.4)	44 (14.5)	52 (14.2)	40 (17.2)	43 (11.6)		
High school graduate	418 (23.6)	104 (26.5)	126 (25.0)	94 (18.9)	94 (24.1)		
Some college	516 (31.1)	116 (29.2)	147 (26.4)	130 (37.7)	123 (31.1)		
College graduate	654 (30.9)	168 (29.8)	181 (34.3)	152 (26.3)	153 (33.1)		
Annual income						.094	.003
<$20 K	346 (17.2)	78 (20.0)	113 (20.5)	70 (14.8)	85 (13.8)		
$20K to <$35K	242 (13.1)	59 (14.0)	82 (15.0)	58 (13.0)	43 (10.5)		
$35K to <$50K	251 (14.2)	67 (16.1)	72 (15.0)	55 (13.4)	57 (12.4)		
$50K to <$75K	263 (15.2)	67 (14.2)	72 (13.7)	57 (15.2)	67 (17.6)		
$75K or more	429 (26.3)	106 (23.9)	114 (23.3)	104 (26.2)	105 (31.5)		
Missing	263 (14.0)	59 (11.8)	64 (12.5)	75 (17.3)	65 (14.3)		
Race/ethnicity						ns	ns
NH white	1296 (83.2)	346 (83.7)	388 (83.6)	292 (80.9)	270 (84.6)		
NH black	150 (7.0)	34 (8.0)	47 (6.4)	36 (6.6)	33 (7.0)		
Hispanic	113 (6.3)	21 (5.5)	22 (4.6)	37 (9.3)	33 (5.6)		
NH other	71 (3.6)	17 (2.8)	25 (5.4)	15 (3.2)	14 (2.8)		
Time since diagnosis						ns	.092
≤1 year	203 (11.7)	41 (10.9)	56 (10.5)	52 (10.4)	54 (14.8)		
2 to 5 years	447 (27.9)	111 (26.9)	120 (23.9)	104 (28.6)	112 (32.2)		
6 to 10 years	333 (19.7)	77 (19.0)	94 (21.3)	78 (19.7)	84 (18.5)		
11+ years	720 (40.7)	183 (43.1)	218 (44.3)	168 (41.2)	151 (34.5)		
Cancer site						.034	.021
Breast cancer only	262 (13.5)	59 (11.4)	71 (10.9)	62 (13.3)	70 (18.1)		

Table 1 (continued)

Variable	Combined Sample of cancer survivors *N* (weighted %)	HINTS 3 cancer survivors (mail respondents only)	HINTS 4 cycle 1 cancer survivors	HINTS 4 cycle 2 cancer survivors	HINTS 4 cycle 3 cancer survivors	*p* value for linear trend analysis	*p* value for comparison by iteration (unadjusted)
Colorectal cancer only	82 (4.2)	22 (6.3)	30 (5.0)	15 (2.8)	15 (3.0)		
Prostate cancer only	173 (8.9)	27 (4.9)	49 (9.9)	49 (11.5)	48 (8.7)		
Melanoma only	83 (5.6)	22 (6.7)	25 (5.4)	18 (4.6)	18 (5.7)		
Other female cancers only	187 (11.2)	49 (12.3)	59 (14.0)	40 (11.2)	39 (7.4)		
Other cancers	657 (39.4)	165 (39.3)	181 (37.8)	148 (38.0)	163 (42.6)		
Multiple cancers	314 (17.3)	80 (19.1)	94 (17.1)	78 (18.6)	62 (14.5)		
Health status						ns	ns
Excellent/very good	699 (40.1)	183 (39.1)	199 (39.0)	156 (40.2)	161 (41.8)		
Good	656 (38.6)	163 (37.8)	198 (38.9)	136 (35.0)	159 (42.4)		
Fair/poor	396 (21.4)	84 (23.0)	117 (22.0)	109 (24.8)	86 (15.8)		
Usual source of care						ns	ns
Yes	1565 (88.7)	389 (89.1)	449 (86.3)	367 (89.1)	360 (90.5)		
No	203 (11.3)	39 (10.9)	63 (13.7)	51 (10.9)	50 (9.5)		
Has health insurance						ns	ns
Yes	1691 (94.4)	391 (93.2)	495 (93.7)	394 (93.4)	411 (97.4)		
No	84 (5.6)	28 (6.8)	21 (6.3)	25 (6.6)	10 (2.6)		
Frequency of provider visits						<.001	<.001
1–3	738 (40.9)	120 (24.9)	237 (45.4)	202 (49.5)	179 (41.5)		
4 or more	1056 (59.1)	316 (75.1)	280 (54.6)	217 (50.5)	243 (58.5)		

Table 2 Patient-centered communication in cancer survivors across iterations

	Combined sample	HINTS 3 (Jan–May 2008)	HINTS 4- cycle 1 (Oct 2011–Jan 2012)	HINTS 4- cycle 2 (July–Nov 2012)	HINTS 4- cycle 3 (Apr–July 2013)	Test statistic and *p* value for comparison by iteration (unadjusted)	Test statistic and *p* value for trend analysis (unadjusted)
Patient-centered communication score (weighted mean, SE)	80.3 (0.8)	78.1 (1.1)	78.0 (1.3)	82.9 (1.6)	81.9 (2.2)	2.92 (.04)	4.66 (.03)
6 functions[a] (*N*, weighted % suboptimal[b])							
Exchanging information	633 (34.4)	170 (41.0)	191 (37.9)	145 (30.7)	127 (28.7)	3.07 (.03)	7.36 (.01)
Responding to emotions	834 (48.0)	213 (54.2)	247 (51.3)	190 (43.8)	184 (43.8)	2.57 (.06)	5.58 (.02)
Making decisions	731 (41.1)	204 (49.6)	219 (44.5)	150 (33.6)	158 (37.6)	4.51 (.004)	7.81 (.01)
Enabling self-management	660 (37.8)	185 (43.8)	196 (39.7)	141 (35.0)	138 (33.4)	2.610 (.05)	5.84 (.02)
Managing uncertainty	834 (49.0)	218 (55.6)	251 (52.8)	184 (42.9)	181 (45.6)	2.91 (.04)	6.29 (.01)
Fostering healing relationships	719 (39.7)	184 (43.0)	220 (43.9)	168 (37.6)	147 (34.7)	1.72 (.16)	3.94 (.05)

[a] Assessed by asking asked how often providers did each of the following in the past year: "Give you the chance to ask all the health-related questions you had" (exchanging information); "Give the attention you needed to your feelings and emotions" (responding to emotions); "Involve you in decisions about your health care as much as you wanted" (making decisions); "Make sure you understood the things you needed to do to take care of your health" (enabling self-management); "Help you deal with feelings of uncertainty about your health or health care" (managing uncertainty); and "Feel you could rely on your doctors, nurses, or other health care professionals to take care of your health care needs" (fostering healing relationships)

[b] Response options were always, usually, sometimes, and never. Suboptimal communication defined as responses of usually/sometimes/never

in the fully adjusted model, increasing in a linear fashion across HINTS iterations (Wald $F = 3.98$, $p < .05$; Table 4).

Discussion

This study sought to examine patient-provider communication among cancer survivors using a large population-based data resource. Our conceptual framework for measurement of patient-centered communication came from the NCI monograph produced by Epstein and Street [10]. Overall, we found that cancer survivors rated their communication with providers positively. However, there were significant proportions of survivors reporting suboptimal communication for each of the six patient-centered communication functions ranging from one-third to one-half of survivors. In this analysis, we defined optimal communication as "always" experiencing patient-centered communication. We also conducted a sensitivity analysis defining high quality care as reporting the provider "always" or "usually" communicated a topic area and found a similar pattern of results. However, to be consistent with prior research using these measures, we dichotomized the outcome to be "always" versus all other responses [13].

Suboptimal patient-centered communication was especially prevalent in two of the patient-centered communication functions, helping survivors manage their uncertainty and responding to their emotional concerns. This finding is not surprising given that existing research has shown that providers often fail to discuss psychosocial concerns with their cancer patients and there is disagreement about who should be responsible for survivors' psychosocial needs [14]. Survivors have many emotional needs, including depression, anxiety, feelings of loneliness, self-consciousness about physical changes, stress about re-engaging in activities, and changing social relationships as they readjust their lives to a "new normal" after cancer [15].

Managing uncertainty is another challenge for many survivors, as they experience cancer-related worry about risk of recurrence and long-term survival [16]. Cancer survivors also feel uncertain about care going forward, with feelings of abandonment by the health care system [2]. Communicating with a provider who addresses the context of concerns about recurrence and uncertainty can improve the survivors care experience [17]. The present analysis suggests that lower income individuals reported better communication about uncertainty with providers. This may suggest that providers recognize a need to alleviate uncertainty in low income patients and provide more counseling about risk. There may be sociodemographic differences in interpretation of the question itself. Providers may be less likely to provide choices or acknowledge the uncertainty in those options with lower income survivors. However, the present study does not provide a

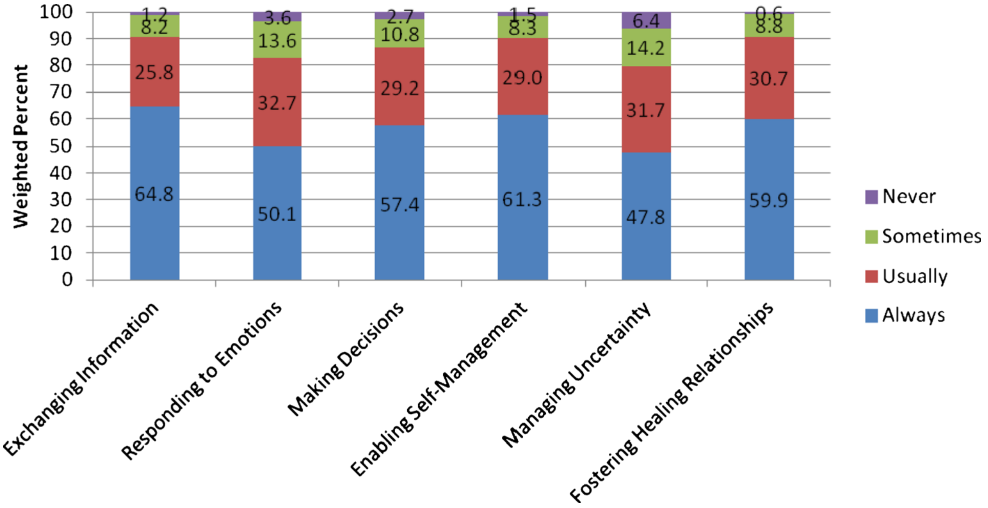

Fig. 1 Cancer survivors' experiences of six patient-centered communication functions

causal explanation or possible mechanism for this relationship, and additional research is needed to replicate this finding.

Survivorship care planning is one approach to directly managing survivor uncertainty and addressing emotional needs [2] and provision of survivorship care plans is associated with more perceived patient-centered communication [18]. However, communication about psychosocial concerns and expectations for survivorship care are often left out of survivorship care plans [19]. Survivorship care plans should incorporate all six functions of patient-centered communication because addressing the patient as a whole person is critical to patient perceptions of their care [13, 20, 21].

Two socio-demographic factors emerged as consistent predictors of optimal patient-centered communication both overall and for the six patient-centered communication functions: having a usual source of care and better health status. Having continuous care is associated with not only satisfaction but also effective, patient-centered care [22, 23]. Increased continuity of care during survivorship may be achieved by better care coordination with the primary care physician. This can be aided by the use and discussion of a survivorship care plan [24, 25]. Although consistent with previous research on cancer survivors' experiences with care [13] and the general health literature showing that providers often report liking healthier patients more [26], the relationship between better health status and patient-centered communication is problematic given that cancer survivors who are in poorer health are likely most in need of patient-centered communication. Interventions to address survivorship needs should consider targeting patients in poorer health who may not have a usual source of care.

Because of the growth of research and focus on the needs of cancer survivors, it is encouraging to see improvements in patient-centered communication over time. However, with the exception of relying on health care providers, these trends do not remain significant in fully adjusted models. It may be that trends are emerging differently in certain subgroups. We must continue to track these trends going forward to assess changes to patient-centered communication and the six functions after as recommendations from the Commission on Cancer and other organizations specific to survivorship care are implemented more broadly [27]. Wide-scale implementation of quality survivorship care is still lacking. The Commission on Cancer, for example, found only one of five programs had implemented survivorship care planning and less than 40 % felt completely confident in their ability to do so [27].

One notable factor that did not emerge in any of our models was time since cancer diagnosis. Given the difficulties faced by cancer survivors during their care transition [9], we may have expected increased patient-centered communication as survivors got further away in time from their cancer diagnosis and treatment. Unfortunately, no trend for time since diagnosis may suggest that patient-centered communication does not improve as survivors get further from their transition. A sizeable group of survivors 10 or more years since diagnosis are still experiencing suboptimal patient-centered communication. It may be that cancer survivors are not just "lost in transition" but also feeling lost beyond that transition. Efforts to improve patient-centered communication may need to target survivors at all stages of survivorship care. Early in survivorship, interventions may focus on communication with oncology providers; however, later in survivorship, interventions to improve patient-centered communication should incorporate a wider range of providers including primary care.

These data are the first attempt to look at predictors of patient-centered communication over time in a nationally representative sample of cancer survivors. They also represent a significant contribution to our knowledge because they address each of the functions of patient-centered

Table 3 Predictors of patient-centered communication score

Model 1: patient-centered communication score	(beta)	SE	*p* value
Age	Wald *F* = .51		.67
18–49 (ref)	–		–
50–64	1.45	2.92	.62
65–74	3.32	3.08	.28
75+	2.23	2.94	.45
Education	Wald *F* = 2.84		.04
Less than high school	2.96	3.51	.40
High school graduate	4.84	2.01	.02
Some college	−.12	2.18	.96
College graduate (ref)	–		–
Race/ethnicity	Wald *F* = 1.87		.14
NH white (ref)	–	–	–
NH black	5.64	2.61	.03
Hispanic	−2.91	4.02	.47
NH other	2.79	5.83	.63
Annual income	Wald *F* = 1.17		.32
Missing	3.95	3.03	.19
<$20K	1.75	3.55	.62
$20K to <$35K	2.67	3.14	.40
$35K to <$50K	5.26	2.59	.04
$50K to <$75K	2.14	2.60	.41
$75K or more (ref)	–	–	–
Has health insurance	Wald *F* = .13		.72
Yes (ref)	–	–	–
No	2.03	5.56	.72
Gender	Wald *F* = .53		.47
Male (ref)	–	–	–
Female	.99	1.36	.47
Health status	Wald *F* = 9.08		.0002
Excellent/very good (ref)	–	–	–
Good	−5.51	1.75	.002
Fair/poor	−9.01	2.33	.0002
Usual source of care	Wald *F* = 11.59		.0008
Yes (ref)	–	–	–
No	−10.79	3.17	.0008
Time since diagnosis	Wald *F* = 1.20		.31
≤1 year (ref)	–	–	–
2 to 5 years	−3.31	2.97	.27
6 to 10 years	−.99	3.32	.77
11+ years	.39	2.69	.88
Iteration	Wald *F* = 2.02		.11
Hints3 (ref)	–	–	–
Hints4Cycle1	−.51	1.85	.78
Hints4Cycle2	4.31	2.04	.04
Hints4Cycle3	2.23	2.81	.43
Frequency of visits	Wald *F* = 3.14		.08
1–3 (ref)	–	–	–
4+	−3.34	1.88	.08
Time since DX linear trend	Wald *F* = .16		.69
Iteration linear trend	Wald *F* = 1.82		.18

communication. However, there are a number of notable limitations that merit mention. The cancer survivors in HINTS represent a heterogeneous group as cancer type was not included in the model due to small cell sizes; however, we adjusted for it in sensitivity analysis and found similar results. In addition, we do not have a direct comparison in these analyses of survivors to those without a history of cancer. These data are cross-sectional and based on self-reported experience. Although cancer survivors demonstrate willingness to share their experiences of patient-centered communication, especially after treatment is completed [28], there may be recall bias or other biases influencing their responses. The survey items themselves may not be responsive to changes in communication over time. Objective measures of patient-centered communication, such as ratings of audio/videotaped visits, may yield different results. The HINTS survey and these data do not address patient preferences for these patient-centered communication functions; it may be that some of the survivors do not want to discuss their uncertainty or emotional experience with their providers. Another

Table 4 Predictors of reporting optimal (response = always) communication for six patient-centered communication functions in the combined sample

	Model 1: exchanging information	Model 2: responding to emotions	Model 3: making decisions	Model 4: enabling self-management	Model 5: managing uncertainty	Model 6: fostering healing relationships
	(OR, 95 % CI)					
Age	Wald $F = 1.23$	Wald $F = .10$	Wald $F = 1.66$	Wald $F = 1.85$	Wald $F = .51$	Wald $F = 1.02$
18–49 (ref)	–	–	–	–	–	–
50–64	1.00 (.60–1.66)	.98 (.60–1.61)	.76 (.47–1.23)	.96 (.59–1.57)	.83 (.50–1.41)	.96 (.57–1.64)
65–74	1.25 (.72–2.16)	1.10 (.64–1.90)	1.17 (.67–2.04)	1.49 (.84–2.64)	1.05 (.59–1.87)	1.34 (.81–2.23)
75+	.86 (.49–1.50)	1.03 (.60–1.75)	.97 (.57–1.66)	1.15 (.65–2.04)	1.00 (.54–1.87)	1.11 (.62–1.97)
Education	Wald $F = .72$	Wald $F = 1.80$	Wald $F = 2.33$	Wald $F = .76$	Wald $F = .41$	Wald $F = 2.94^{*}$
Less than high school	1.05 (.55–1.99)	1.10 (.61–2.00)	1.03 (.54–1.98)	1.03 (.56–1.92)	1.35 (.73–2.47)	1.61 (.88–2.94)
High school graduate	1.31 (.87–1.99)	1.53 (1.01–2.32)*	1.37 (.90–2.09)	1.24 (.81–1.89)	1.17 (.78–1.75)	1.66 (1.10–2.50)*
Some college	1.01 (.70–1.45)	1.02 (.70–1.48)	.84 (.58–1.24)	.92 (.63–1.34)	1.04 (.72–1.51)	1.01 (.69–1.47)
College graduate (ref)	–	–	–	–	–	–
Race/ethnicity	Wald $F = .86$	Wald $F = .84$	Wald $F = 2.02$	Wald $F = 1.15$	Wald $F = 2.13$	Wald $F = .95$
NH white (ref)	–	–	–	–	–	–
NH black	1.54 (.84–2.83)	1.42 (.76–2.65)	1.69 (.87–3.29)	1.66 (.88–3.13)	1.22 (.65–2.28)	1.23 (.69–2.20)
Hispanic	1.20 (.59–2.43)	1.03 (.52–2.06)	.93 (.40–2.13)	.96 (.46–2.02)	.97 (.47–2.00)	.62 (.32–1.21)
NH other	1.28 (.59–2.78)	1.67 (.73–3.83)	2.14 (1.00–4.58)*	1.58 (.71–3.55)	2.56 (1.20–5.48)*	1.17 (.51–2.73)
Annual income	Wald $F = 1.75$	Wald $F = 1.86$	Wald $F = .38$	Wald $F = .95$	Wald $F = 2.32^{*}$	Wald $F = 1.70$
Missing	2.01 (1.12–3.63)*	1.72 (.97–3.05)	1.01 (.56–1.82)	1.44 (.82–2.55)	1.68 (.95–2.97)	1.32 (.75–2.30)
<\$20K	1.45 (.84–2.50)	2.00 (1.12–3.59)*	1.10 (.60–2.02)	1.62 (.93–2.82)	1.79 (1.00–3.21)*	1.51 (.89–2.55)
\$20K to <\$35K	1.12 (.67–1.89)	1.85 (1.06–3.25)*	.98 (.57–1.68)	1.29 (.75–2.21)	1.35 (.77–2.34)	1.69 (1.01–2.82)*
\$35K to <\$50K	1.67 (1.08–2.60)*	1.91 (1.17–3.11)**	1.32 (.79–2.20)	1.61 (.99–2.61)	1.89 (1.18–3.02)**	1.90 (1.17–3.10)*
\$50K to <\$75K	1.25 (.80–1.94)	1.25 (.78–2.01)	.94 (.59–1.50)	1.29 (.81–2.06)	1.09 (.64–1.87)	1.56 (.99–2.48)
\$75K or more (ref)	–	–	–	–	–	–
Has health insurance	Wald $F = .86$	Wald $F = 2.72$	Wald $F = 1.00$	Wald $F = 1.98$	Wald $F = 1.58$	Wald $F = .06$
Yes (ref)	–	–	–	–	–	–
No	1.48 (.65–3.38)	2.28 (.85–6.14)	1.57 (.64–3.84)	1.87 (.78–4.50)	1.86 (.70–4.94)	1.12 (.44–2.80)
Gender	Wald $F = .01$	Wald $F = .70$	Wald $F = 1.94$	Wald $F = 1.31$	Wald $F = 4.78^{*}$	Wald $F = .05$
Male (ref)	–	–	–	–	–	–
Female	.98 (.74–1.31)	1.13 (.85–1.51)	1.22 (.92–1.62)	1.20 (.88–1.64)	1.39 (1.03–1.86)*	.97 (.72–1.30)
Health status	Wald $F = 3.93^{*}$	Wald $F = 6.16^{**}$	Wald $F = 9.26^{***}$	Wald $F = 7.83^{***}$	Wald $F = 5.29^{**}$	Wald $F = 11.16^{***}$
Excellent/very good (ref)	–	–	–	–	–	–
Good	.71 (.51–1.00)	.57 (.40–.82)**	.58 (.42–.80)**	.59 (.42–.82)**	.63 (.45–.88)**	.63 (.46–.87)**
Fair/poor	.58 (.38–.87)**	.56 (.37–.86)**	.44 (.29–.67)***	.53 (.36–.77)**	.51 (.32–.81)**	.35 (.23–.55)***
Usual source of care	Wald $F = 5.34^{*}$	Wald $F = 6.73^{*}$	Wald $F = 5.83^{*}$	Wald $F = 7.57^{**}$	Wald $F = 3.16$	Wald $F = 9.87^{**}$
Yes (ref)	–	–	–	–	–	–
No	.55 (.33–.92)*	.49 (.28–.84)*	.52 (.30–.89)*	.51 (.31–.82)**	.60 (.34–1.06)	.43 (.25–.73)**
Time since diagnosis	Wald $F = .25$	Wald $F = .54$	Wald $F = .25$	Wald $F = .41$	Wald $F = .75$	Wald $F = .07$
≤1 year (ref)	–	–	—	–	–	–
2 to 5 years	.86 (.49–1.53)	.72 (.43–1.21)	.87 (.51–1.48)	.78 (.44–1.38)	.81 (.47–1.41)	.90 (.52–1.57)
6 to 10 years	.87 (.48–1.58)	.85 (.47– 1.54)	.92 (.52–1.65)	.79 (.43–1.46)	1.14 (.61–2.12)	.96 (.51–1.81)
11+ years	.98 (.59–1.64)	.83 (.52–1.34)	.82 (.50–1.35)	.89 (.51–1.57)	.94 (.56–1.58)	.90 (.53–1.52)
Iteration	Wald $F = 1.62$	Wald $F = 1.08$	Wald $F = 2.44$	Wald $F = .90$	Wald $F = 1.33$	Wald $F = 1.72$
Hints3 (ref)	–	–	–	–	–	–
Hints4Cycle1	1.06 (.73–1.56)	1.11 (.78–1.57)	1.20 .84–1.70	1.14 (.83–1.57)	1.10 (.76–1.60)	1.08 (.79–1.48)
Hints4Cycle2	1.52 (.94–2.48)	1.30 (.86–1.98)	1.83 (1.16–2.89)**	1.36 (.86–2.16)	1.50 (.96–2.34)	1.46 (.94–2.26)
Hints4Cycle3	1.52 (.91–2.56)	1.52 (.88–2.60)	1.38 (.83–2.29)	1.31 (.84–2.03)	1.37 (.85–2.21)	1.52 (.92–2.53)

Table 4 (continued)

	Model 1: exchanging information	Model 2: responding to emotions	Model 3: making decisions	Model 4: enabling self-management	Model 5: managing uncertainty	Model 6: fostering healing relationships
Frequency of visits	Wald $F = 2.04$	Wald $F = 3.97^{*}$	Wald $F = .58$	Wald $F = 3.02$	Wald $F = 2.03$	Wald $F = .62$
1–3 (ref)	–	–	–	–	–	–
4+	.76 (.52–1.11)	.68 (.47–1.00)*	.88 (.63–1.22)	.74 (.52–1.04)	.78 (.55–1.10)	.86 (.59–1.25)
Time since DX linear trend	Wald $F = .00$	Wald $F = .25$	Wald $F = .46$	Wald $F = .14$	Wald $F = .03$	Wald $F = .09$
Iteration linear trend	Wald $F = 3.88$	Wald $F = 2.85$	Wald $F = 3.06$	Wald $F = 1.91$	Wald $F = 2.70$	Wald $F = 3.98^{*}$

REF reference category

$^{*}p < .05$, $^{**}p < .01$, $^{***}p < .001$

limitation is that the questions about patient-centered communication were not specific to cancer-related providers. We are unable to assess differences in patient-centered communication based on provider type [29]. However, our results provide an overall perception of patient-centered communication in cancer survivors.

With over 14 million cancer survivors in the USA and that number growing [30], half of all survivors experiencing suboptimal patient-centered communication translate to almost 7 million survivors. Even though it has been almost 10 years since the initial IOM report on the needs of cancer survivors, there are still many survivors reporting suboptimal care [31], particularly with respect to providers helping manage uncertainty and attending to emotions. Cancer survivors face continued uncertainty and emotional adjustment as they readjust their lives to a new sense of normal. Therefore, two important functions to focus on for improving patient-centered communication going forward are managing uncertainty and responding to emotional needs. Future efforts should also focus on interventions targeted for survivors in poorer health or without a usual source of care.

Compliance with ethical standards

Funding The Health Information National Trends Survey is supported by contract number HHSN26120100064C from the National Cancer Institute. The views expressed in the manuscript do not necessarily represent the views of the US Federal Government.

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

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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

References

1. In: Levit L, Balogh E, Nass S, Ganz PA, editors. Delivering high-quality cancer care: charting a new course for a system in crisis. Washington (DC)2013.
2. Hewitt M, Greenfield S, Stovall E. From cancer patient to cancer survivor: lost in transition. Washington: National Academies Press; 2006.
3. Ganz PA, Earle CC, Goodwin PJ. Journal of Clinical Oncology update on progress in cancer survivorship care and research. J Clin Oncol. 2012;30(30):3655–6.
4. Nekhlyudov L, Levit L, Hurria A, Ganz PA. Patient-centered, evidence-based, and cost-conscious cancer care across the continuum: Translating the Institute of Medicine report into clinical practice. CA Cancer J Clin. 2014;64(6):408–21.

5. Commission on Cancer. Cancer program standards 2012: ensuring patient-centered care. V1.0. Chicago, IL: American College of Surgeons; 2012.
6. Epstein RM, Street RL. Patient communication in cancer care: promoting healing and reducing suffering. (NIH Publication No 07–6225). Bethesda: National Cancer Institute; 2007.
7. Fogarty LA, Curbow BA, Wingard JR, McDonnell K, Somerfield MR. Can 40 seconds of compassion reduce patient anxiety? J Clin Oncol: Off J Am Soc Clin Oncol. 1999;17(1):371–9.
8. Mallinger JB, Griggs JJ, Shields CG. Patient-centered care and breast cancer survivors' satisfaction with information. Patient Educ Couns. 2005;57(3):342–9.
9. Thorne SE, Stajduhar KI. Patient perceptions of communications on the threshold of cancer survivorship: implications for provider responses. J Cancer Surviv. 2012;6(2):229–37.
10. Epstein RM, Street RLJ. Patient-centered communication in cancer care: promoting healing and reducing suffering. Bethesda, MD: NIH Publication No. 07–6225; 2007.
11. Nelson DE, Kreps GL, Hesse BW, Croyle RT, Willis G, Arora NK, et al. The Health Information National Trends Survey (HINTS): development, design, and dissemination. J Health Commun. 2004;9(5):443–60.
12. McCormack LA, Treiman K, Rupert D, Williams-Piehota P, Nadler E, Arora NK, et al. Measuring patient-centered communication in cancer care: a literature review and the development of a systematic approach. Soc Sci Med. 2011;72(7):1085–95.
13. Arora NK, Reeve BB, Hays RD, Clauser SB, Oakley-Girvan I. Assessment of quality of cancer-related follow-up care from the cancer survivor's perspective. J Clin Oncol. 2011;29(10):1280–9.
14. Forsythe LP, Alfano CM, Leach CR, Ganz PA, Stefanek M, Rowland JH. Who provides psychosocial follow-up care for post-treatment cancer survivors?: a survey of medical oncologists and primary care physicians. J Clin Oncol. 2012;30(23):2897–905.
15. Adler N, Page A, editors. Cancer care for the whole patient: meeting psychosocial healthcare needs. Washington DC: Institute of Medicine (IOM). 2008.
16. Koch L, Bertram H, Eberle A, Holleczek B, Schmid-Höpfner S, Waldmann A, et al. Fear of recurrence in long-term breast cancer survivors—still an issue. Results on prevalence, determinants, and the association with quality of life and depression from the cancer survivorship—a multi-regional population-based study. Psycho-Oncology. 2014;23(5):547–54.
17. Clayton MF, Dudley WN. Patient-centered communication during oncology follow-up visits for breast cancer survivors: content and temporal structure. Oncol Nurs Forum. 2009;36(2):E68–79.
18. Blanch-Hartigan D, Chawla N, Beckjord EI, Forsythe LP, de Moor JS, Hesse BW, et al. Cancer survivors' receipt of treatment summaries and implications for patient-centered communication and quality of care. Patient Educ Couns. 2015;98(10):1274–9.
19. Salz T, Oeffinger KC, McCabe MS, Layne TM, Bach PB. Survivorship care plans in research and practice. CA Cancer J Clin. 2012.
20. Ayanian JZ, Zaslavsky AM, Guadagnoli E, Fuchs CS, Yost KJ, Creech CM, et al. Patients' perceptions of quality of care for colorectal cancer by race, ethnicity, and language. J Clin Oncol. 2005;23(27):6576–86.
21. Teno JM, Lima JC, Lyons KD. Cancer patient assessment and reports of excellence: reliability and validity of advanced cancer patient perceptions of the quality of care. J Clin Oncol. 2009;27(10):1621–6.
22. Connectedness and continuity: patient-provider relationships among low-income Californians. Blue Cross Blue Shield of California Foundation, 2012.
23. Finney Rutten LJ, Agunwamba AA, Beckjord E, Hesse BW, Moser RP, Arora NK. The relation between having a usual source of care and ratings of care quality: does patient-centered communication play a role? J Health Commun. 2015;20(7):759–65.
24. Blanch-Hartigan D, Forsythe LP, Alfano CM, Smith T, Nekhlyudov L, Ganz PA, et al. Provision and discussion of survivorship care plans among cancer survivors: results of a nationally representative survey of oncologists and primary care physicians. J Clin Oncol. 2014;32(15):1578–85.
25. Oeffinger KC, McCabe MS. Models for delivering survivorship care. J Clin Oncol. 2006;24(32):5117–24.
26. Hall JA, Horgan TG, Stein TS, Roter DL. Liking in the physician-patient relationship. Patient Educ Couns. 2002;48(1):69–77.
27. Shulman LN, Ferris L, Takanishi DM, McKellar D. Treatment summaries and survivorship care plans: the approach by the commission on cancer to increase use. J Oncol Pract. 2014.
28. Mazor KM, Gaglio B, Nekhlyudov L, Alexander GL, Stark A, Hornbrook MC, et al. Assessing patient-centered communication in cancer care: stakeholder perspectives. J Oncol Pract. 2013;9(5):e186–93.
29. Ross L, Petersen MA, Johnsen AT, Lundstrøm LH, Groenvold M. Cancer patients' evaluation of communication: a report from the population-based study 'The Cancer Patient's World'. Support Care Cancer. 2013;21(1):235–44.
30. Parry C, Kent EE, Mariotto AB, Alfano CM, Rowland JH. Cancer survivors: a booming population. Cancer Epidemiol Biomarkers Prev. 2011;20(10):1996–2005.
31. Ganz PA. Delivering on the promise of patient-centered care. J Natl Compr Canc Netw. 2015;13(4):495–7.