Rural Primary Care Offices and Cancer Survivorship Care: Part of the Care Trajectory for Cancer Survivors

Health Services Research and Managerial Epidemiology Volume 6: 1-7 © The Author(s) 2019 Article reuse guidelines: sagepub.com/journals-permissions DOI: 10.1177/2333392818822914 journals.sagepub.com/home/hme



Maresi Berry-Stoelzle¹, Kim Parang¹, and Jeanette Daly¹

Abstract

Background: A cancer diagnosis is a monumental event in a patient's life and with the number of cancer survivors increasing; most of these patients will be taken care of by a primary care provider at some point after their cancer therapy. The purpose of this study is to identify primary care physician's needs to care for a patient who has had cancer.

Methods: A cross-sectional survey of the physician members of the Iowa Research Network was conducted. The survey was designed to measure physician confidence in cancer survivor's care, office strategies regarding cancer survivorship care, and resources available for patients with cancer. Two hundred seventy-four Iowa Research Network members were invited to participate in this survey.

Results: Eighty-two physicians (30%) completed the questionnaire with 96% reporting that they are aware of their patient's cancer survivorship status. Seventy-one physicians reported they were aware of cancer survivorship status by an oncologist sending a note to the office, 68 being diagnosed in their office, 61 by the patient keeping the office apprised, and 15 receiving a survivorship care plan. Physicians reported the top changes in a cancer survivor's physical health as fatigue (81%) and pain (59%). Sixty-two physicians reported not feeling confident for managing chemobrain, cardiotoxicity (71%), and skin changes (35%). Male physicians were significantly more confident managing patients' skin changes (P = .049) and musculoskeletal disturbances than female physicians (P = .027), while female physicians were significantly more confident managing patients (P = .027).

Conclusion: Most respondents are aware of their patients who are cancer survivors and are mostly confident in the care they provide for them related to long-term effects and side effects of cancer therapies with limited receipt of cancer survivorship care plans.

Keywords

cancer survivorship care, primary care physician, end of life, practice management, cancer survivorship care plan

Introduction

Cancer survivors are expected to make up significantly more of the US population during the upcoming years.¹ Per Cancer.org, these are defined as such "from the time of diagnosis, through the balance of his or her life."² Projected prevalence for cancer survivors in the United States is expected to increase from 13.7 million in 2012 to 18 million by 2022, with a 37% increase for those who will live 5 years or more after diagnosis.³ In the United States, 32% of those cancer survivors are seeing primary care physicians.² The relationship between the patient and their primary care physician spans from the beginning to the end of life; however, most studies focus on either the oncologist or the patient with cancer. There has been insufficient discussion in the literature about how the patient and the primary care provider relationship is affected by the cancer diagnosis, at the level of the primary care office visit. This study is of current primary care providers in a state with both a significant rural and elderly population.^{4,5} The focus is

¹ Department of Family Medicine, University of Iowa, Iowa City, IA, USA

Submitted December 11, 2018. Accepted December 11, 2018.

Corresponding Author:

Maresi Berry-Stoelzle, Department of Family Medicine, University of Iowa, 01105 PFP, 200 Hawkins Drive, Iowa City, IA 52242, USA. Email: maresi-berry@uiowa.edu



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to identify points for translational interventions to improve the care of the cancer survivor in the primary care office setting,⁶⁻⁸ with a focus on meeting the needs of the cancer survivorship care within the workflow in the primary care office.⁹

Cancer survivorship as a construct captures a heterogeneous population of patients who often have quite different diseases, varying treatments and potential late and long-term effects. In addition, the effects of the cancer and the side effects of the therapies will be factors in the patient's physical and mental health for the rest of their lives, whether or not the cancer contributes to the patient's cause of death or the patient passes from unrelated causes. This was outlined by the initiative from the Institute of Medicine to address cancer survivorship in 2006, and continues today.² Cancer survivorship, like other medical conditions managed over time, requires a structured approach to effectively address the wide-ranging and timesensitive needs of survivors. The elevation of the survivorship care plan to a necessary document at the conclusion of cancer therapy is surely a good first step. The long-term utility data of the cancer survivorship care plan are missing.^{10,11} There is no widespread mechanism to retroactively provide care plans for those who do not have them who did not receive a survivorship plan at the end of their therapy. The fragmentation of the US health system complicates the long-term usefulness of any documentation. Combining this with population mobility complicates ensuring that essential medical information continues to be associated with the patient in a timely and accurate manner, cancer or otherwise.^{12,13} Sixty-four percent of patients with a cancer diagnosis are expected to live more than 5 years.¹⁴ Cancer survivors are a significant and growing population who routinely need primary care and usually see a primary care provider.

This study is part of a project to (1) examine how primary care providers are already deeply involved in survivorship care and (2) identify what the resources and training needs are which could improve this care. There has been a growing body of literature in modeling the care of cancer survivors as chronic disease.¹⁵⁻¹⁷ Although there are valuable insights through this approach, we feel the chronic disease model does not adequately address the paradigm shift of a new cancer diagnosis and the accompanying follow-up and treatment. A multidimensional model, which illustrates the relationship between the providers and patients during their cancer survivorship and the trajectory of survivors' care, is provided.

Cancer Survivorship Care Trajectory and Communication Between Care Providers

Oeffinger and McCabe offer a shared-care model for cancer survivors delineating that, in most instances, the primary care physician refers the patient to an oncologist for therapy while, at the same time, provides their routine health care.¹⁸ When therapy is completed, the patients' transitions back to the primary care physician who, when appropriate, would refer them back to the oncologist or provide consultation when needed. Mayer and colleagues note the focus of care shifts over time based on the needs of the survivor.¹ Jacobs and Shulman note that cancer survivorship care can be offered by different established models of care, such as the chronic care model,^{19,20} risk-stratification model,¹⁸ and the transition models.²¹

The shared-care model reinforces a continuous communication between the primary care provider and the oncologist. These patients still have regular follow-up with their oncologist, but receive at least some significant care from the primary care provider.²² This care could be for either acute or chronic conditions. These patients have often completed therapy, but have multiple diseases which are not related directly to their cancer. We can expand upon this model to incorporate a group of patients who have discontinued any scheduled follow-up with their oncology provider. These patients' only regularly planned visits are with their primary care provider. This scenario may occur through an expected transition or an unplanned transition, through a geographic move or a change in insurance. Managing the movement of patients through different categories of survivorship is a special problem among survivors of childhood malignancies.¹⁵ Their disease is in the distant past, and will increase in all groups as adult survivors live longer and have more mobile lives.^{23,24} Yet another group is comprised of those "lost to follow-up," who at the treating cancer center is over 50%of patients for many malignancies.²⁴⁻²⁷ Encouragingly, it is possible to manage cancer survivorship needs as the patient moves between the different dimensions of care as needed.²⁴

Patients may transition from one group to another at any time in their survivorship journey. Therefore, a clear and uniform survivorship care plan should accompany the patient as they transition between these scenarios. A literature review showed that, although there is awareness of the need for communication between the primary care provider and the oncologists, this need is not fulfilled by a single document faxed from one office to another.^{28,29} This poses a problem as primary care for a cold or needs an annual exam,³⁰ and is responsible for providing care for the patient across the spectrum of their medical care. A gap in cancer survivorship care and barriers to care research is evident in the primary care office setting.³¹

After treatment for cancer, cancer survivorship becomes an important part of the patient's medical identity and future providers should be aware of the cancer history. Care plan summaries and survivorship care plans are some of the most commonly used terms for documents provided to the cancer survivor and their future medical providers.³² However, this information is often very one-dimensional as the oncologist often focuses on the cancer history to the exclusion of the rest of the patient's medical history.³³ This poses a problem for primary care providers as primary medical care expands to comorbidities, preventive care, and life goals, as primary care providers are often also the ones providing cancer survivorship care in the general medical care setting.³⁴ This discrepancy in information increases the risk that primary care provider may receive documentation which cannot be integrated into the clinic workflow.³⁴ At this time, the flow of information is primarily from the oncologist to the patient and primary care

providers.³⁵ In the face of such challenges, this study aims to identify primary care physicians' needs for care of a patient who has had cancer.

Methods

Institutional Review Board approval was obtained for this research. Participants chosen for the study were Iowa Research Network (IRENE) members. The IRENE was established in 2001 through the joint efforts of the members of the Iowa Academy of Family Physicians (IAFP), the University of Iowa Department of Family Medicine, and the IAFP Foundation. The mission of IRENE is to improve clinical practice, especially in rural communities. Two hundred seventy-four active IRENE members were sent a cover letter, a Care of Cancer Survivors questionnaire, and postage-paid return envelope in November 2017, inviting them to participate in the study.

Instrument

An initial questionnaire was developed by the authors based on literature about the side and long-term effects of cancer and cancer therapies.^{2,36,37} The draft Care of Cancer Survivors questionnaire was reviewed and revised at a weekly research faculty meeting. The resulting 59-item questionnaire included 2 questions regarding patient demographics, 3 questions on office electronic medical record (EMR) capabilities, 10 questions on office policies regarding care of cancer survivors, 2 questions regarding physicians' awareness of history of persons with cancer in the office and how they knew of cancer survivorship status, 15 Likert-style questions on the physician's confidence managing mental health and side effects of cancer therapies, 13 questions regarding the availability of resources for cancer survivors, 5 questions on survivorship care, 3 questions on changes in psychosocial and physical health of cancer survivors and time frame of effects of cancer treatment, 3 questions on the concerns and barriers for cancer survivor patients, and 3 questions on the quality of life of the cancer survivors.^{2,36} Office policy and EMR questions were modeled off another questionnaire the researchers had previously used.³⁷

Mailing

A second duplicate mailing was sent to the nonresponders within 3 weeks of the first mailing. Each mailing included a postage-paid return envelope. In the cover letter, individuals were informed they could opt out of the questionnaire if they chose to do so and not receive the follow-up mailing of the questionnaire.

Data Analysis

All questionnaires were double entered and verified. Descriptive statistics, such as means and frequencies, were calculated. The 15 confidence questions' answer foils were collapsed into 2 categories: "Not confident at all" and "not very confident" were collapsed to "not confident" and "somewhat confident" Table 1. Demographic Characteristics of Respondents.

 Demographics	n (%)
Physician sex, n = 82	
Male	51 (62)
Female	31 (38)
Age, n = 82	
<60 years	37 (46)
\geq 60 years	44 (54)
Organizational characteristics	
Electronic medical record (EMR), $n = 82$	
Yes	76 (93)
No	6 (7)
EMR queries for list cancer survivors, $n = 72$	
Yes	10 (14)
No	14 (19)
Unsure	48 (67)
EMR queries for list of cancer survivorship care plans, $n = 73$	
Yes	2 (3)
No	23 (31)
Unsure	48 (66)
Office policy for care of cancer survivors, $n = 68$	
Yes	I (I)
No	69 (89)
Unsure	8 (10)
Rural–urban continuum codes, n = 82	
Metropolitan	37 (45)
Nonmetropolitan	45 (55)

and "very confident" were collapsed to "confident." Pearson χ^2 tests were used to compare the association between physicians' confidence in managing specific health care and metropolitan/ nonmetropolitan categories, age group, and gender. Fisher exact test was used to compare the association between metropolitan/nonmetropolitan areas for the resources available for cancer survivors in their community.

The 2013 rural–urban continuum codes were assigned to each respondent based on their respective zip code and classified using the Office of Management and Budget metropolitan and nonmetropolitan 9 categories by county. Categories 1 to 3 are deemed metropolitan and 4 to 9 are deemed nonmetropolitan. Respondents' rural–urban continuum codes ranged from 2 to 9. Thirty-seven (46%) respondents were younger than 60 years and 44 (54%) were 60 years and older.

Results

Of the 274 individuals the questionnaire was sent, 82 (30%) completed the questionnaire. Fifty-one (62%) were male, the mean age of respondents was 57 years, and the age range was 32 to 84 years. Thirty-seven (45%) respondents lived in metropolitan areas (see Table 1). Seventy-six (93%) of the physicians' offices had an EMR system, with 38 (46%) of those using EPIC. Ten (14%) physicians reported their EMR could query the patients who are cancer survivors and 2 (3%) said they were able to query the patients who had a cancer survivor care plan. One physician reported his office had an office policy regarding cancer survivors' plan of care during and

after cancer treatment. Respondents' offices served a mean of 9453 patients per year with a range of 350 to 40 999 patients (median 6000).

Seventy-nine (96%) physicians were aware of their patients with a history of cancer. Sixty-seven (82%) reported the percentage of patients with cancer in their office with a mean 10% and a range from 0.2% to 60%. Seventy-one (87%) physicians reported they were aware of cancer survivorship status by an oncologist sending a note to the office, 68 (83%) being diagnosed in their office, 61 (74%) by the patient keeping the office apprised, and 15 (18%) receiving a survivorship care plan.

At the time of a primary care medical appointment for cancer survivors, 44 physicians (56%) ask whether the patient has completed their cancer treatment, 4 (5%) ask whether they have a survivorship care plan, 53 (69%) ask what type of cancer treatment they received, and 53 (68%) asked the year the cancer treatment occurred. During an office visit, 20 physicians (27%) reported that topics related to the previous cancer diagnosis arise about every month, 26 (35%) about every week, and 11 (15%) about every day. Sixty-nine physicians (84%) reported a mean of 5 minutes, with a range of 0 to 35 minutes devoted to issues surrounding survivorship care each visit. Fifty physicians (67%) felt their patients did not know about their survivorship care plans. Twenty-one physicians (28%) reported that, if there is a survivorship care plan, the patients are more informed of their care.

Fifty-five physicians (70%) reported their office screens for depression; 53 (65%) reported they screen with the Physician Health Questionnaire (PHQ)-9, 11 (13%) reported they screen with the Geriatric Depression Scale, and 5 (6%) screen with the PHQ-2. Six physicians (8%) reported they always screen for anxiety, while 51 (66%) sometimes screen for anxiety and 9 (12%) never screen for anxiety. Regarding the cancer survivors' psychosocial health, 57 physicians (70%) reported changes in depression, 62 (76%) reported changes in anxiety, 50 (61%) reported changes in sleep disturbance, and 2 (2%) reported changes in alcohol use and changes in other substance use. The majority of physicians felt somewhat to very confident managing these problems (see Table 2).

Physicians reported the top 5 changes in a cancer survivor's physical health as fatigue (81%), pain (59%), lymphedema (52%), incontinence (44%), and sexual dysfunction (38%). Physicians felt somewhat to very confident caring for fatigue, pain, musculoskeletal disturbances, lymphedema, sexual dysfunction, incontinence, and early-onset menopause (see Table 2). Fifteen physicians (20%) felt the effects of cancer and cancer treatment persisted 1 to 5 years, while 48 (64%) felt it persisted lifelong. The top 3 concerns physicians reported that patients had were patients' cancer recurrence, physical health, and side effects of chemotherapy. Patient concerns were addressed primarily during the office visit and within the same network of providers. The top 3 barriers for providing patients cancer survivorship care in their office were lack of time by 55 (67%) physicians, lack of appropriate patient education materials by 40 (49%), and lack of a tracking system for patients by 38 (46%).

 Table 2. Physician Confidence in Managing Cancer Survivors' Physical and Psychosocial Health.

	Not Confident, n (%)	Confident, n (%)
Physical health		
Chemobrain, $n = 74$	62 (84)	12 (16)
Fatigue, n $=$ 75	16 (21)	59 (79)
Pain, $n = 75$	5 (7)	70 (93)
Cardiotoxicity, n = 75	53 (71)	22 (29)
Skin changes, $n = 75$	26 (35)	49 (65)
Musculoskeletal disturbances, $n = 74$	15 (20)	59 (80)
Lymphedema, n $=$ 75	24 (32)	51 (68)
Sexual dysfunction, $n = 75$	25 (33)	50 (67)
Bowel or bladder incontinence, $n = 75$	18 (23)	57 (76)
Early-onset menopause, n $=$ 75	15 (20)	60 (80)
Psychosocial health		
Depression, $n = 78$	0	78 (100)
Anxiety, $n = 78$	0	78 (100)
Alcohol use, $n = 77$	14 (18)	63 (82)
Sleep disturbances, n $=$ 78	L (L)	77 (99)
Other substance abuse, $n = 77$	29 (38)	48 (62)

Physicians reported for the most part that cancer survivors had access to many resources, with only survivorship resources, such as clinics for cancer survivors, cancer survivor support groups, and prosthetics not available for most (see Table 3). Seventy (90%) physicians felt it was easy to refer patients to needed resources. Thirty-five (43%) physicians reported the resources were in the medical network and 26 (32%) said they had a good working relationship with the resource provider. Three physicians wrote in it would be easier for resource referral if there was a person who knew all the resources or a list of resources with contact and insurance coverage information. Overall, 54 (76%) physicians reported their cancer survivor patients' view their quality of life as good to very good and 37 (49%) reported, over time, that view changes and improves.

No significant differences were noted for the confidence questions, physician age, having an office policy for care planning, and screening for depression regarding the metropolitan/ nonmetropolitan practice area of the respondents. Physicians aged 60 years and older were significantly more likely to be confident in managing patients' skin changes (P = .008). Male physicians were significantly more confident managing patients' skin changes (P = .008) and musculoskeletal disturbances than female physicians (P = .027), while female physicians were significantly more confident managing early-onset menopause than male physicians (P = .027). Resources, cancer survivor support groups, availability of prosthetics, and clinics for cancer survivors for patients living in nonmetropolitan areas were significantly less than metropolitan areas (see Table 3).

Discussion

Primary care providers are seeing a significant number of cancer survivors in their practices. They are aware of the long-term

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	Available n (%)	Not Available/Unsure	Metro	Metropolitan		Nonmetropolitan	
		n (%)	Yes n (%)	No n (%)	Yes n (%)	No n (%)	P Value
Cancer survivor support group, $n = 77$	59 (77)	18 (23)	33 (43)	1 (1)	26 (34)	17 (22)	.000
Prosthetics, $n = 78$	57 (73)	21 (27)	30 (38)	4 (5)	27 (35)	17 (22)	.100
Clinic for cancer survivors, $n = 76$	20 (26)	56 (74)	14 (18)	20 (26)	6 (8)	36 (48)	.100
Occupational therapists, $n = 77$	75 (97)	2 (3)	33 (43)	L (I)	42 (55)	I (I)	NS
Physical therapists, $n = 78$	76 (97)	2 (3)	33 (43)	L (Í)	43 (55)	I (I)	NS
Community nurses, $n = 76$	70 (92)	6 (8)	30 (39)	3 (4)	40 (53)	3 (4)	NS
Psychologists, $n = 78$	71 (91)	7 (9)	32 (4I)	2 (3)	39 (50)	5 (6)	NS
Counselors, $n = 78$	74 (95)	4 (5)	33 (42)	L (Í)	41 (53)	3 (4)	NS
Social workers, $n = 78$	73 (94)́	5 (6)	33 (42)	L (Í)	40 (51)	4 (5)	NS
Nutritionist, $n = 78$	70 (90)	8 (10)	32 (41)	2 (2)	38 (49)	6 (8)	NS

Table 3. Resources Available in the Community (Metropolitan/Nonmetropolitan) for Cancer Survivors.

Abbreviation: NS, not significant.

effects of the cancer diagnoses and the therapies, which fit into the shared-care model of how cancer survivors interface with medical care throughout their survivorship. They are managing many of the side and long-term effects of both the primary cancer and the cancer therapy. However, even though the Institute of Medicine recommends survivorship care plans for cancer survivors, it is evident from the respondents of this survey that survivorship care plans are not actively being used in family physician practice settings.² Primary care providers are seeing a significant number of cancer survivors in their practices, handling a caseload of approximately 10% of patients who are identified as cancer survivors. So, what can be done? Cancer survivor care plans are worthwhile,² but a recent systematic review found limited evidence that survivor care plans improve health outcomes or health-care delivery.³⁸ A recommendation is made for all cancer survivors to be given a copy of the care plan to use for themselves and share with providers.

Eighteen percent of the respondents reported receiving a cancer survivorship care plan which is slightly higher than one cross-sectional nationwide survey of 1072 primary care providers which found 13% of primary care providers received survivorship care plans.³² This research focused on the system structures for care of cancer survivors and not specifically on the usefulness of the survivorship care plans.³⁹ It would be difficult to ascertain their usefulness when few of the physicians are receiving them. However, the 28% respondents here felt that if there is a survivorship care plan, then patients are more informed of their care.

Most of the respondents in this survey knew of the cancer diagnosis while patients were in their office. This is similar to a systematic review where 85% to 90% of the primary care providers were involved in the diagnosis.⁴⁰ This systematic review also noted that 60% to 70% of primary care providers had confidence in pain management, conveying bad news and psychological support in comparison to this study, where 93% of physicians had confidence in pain management and 100% confidence in care of anxiety and depression.⁴⁰

A recent study conducting interviews with family physicians, surgeons, and oncologists found that family physicians felt they were not informed of their patient's care and recommended that family physicians needed additional training and education for survivorship care.⁴¹ Specifically in this study, physicians reported they needed addition training in chemobrain and care of skin changes for cancer survivors.

The average primary care physician office visit duration has been self-reported in the United States as low as 15.56 minutes in 1993 to 21.07 minutes in 2012.⁴² Primary care providers seeing patients who have had cancer in this study reported spending an average of 5 minutes on the topic of cancer. This is a challenge in a setting where two-thirds of the physicians report their patients were not well informed of their survivorship care.

The main difference in metropolitan/nonmetropolitan areas was the resources available to the cancer survivors, primarily support groups and clinics specifically unavailable for cancer survivors. Another specialty service not available to those in the nonmetropolitan areas was the availability of prosthetics. One potential solution for those in rural areas could be the Internet as an available resource for cancer support groups if there is Internet capability. A 2015 broadband report indicated that throughout the United States, 55 million (17%) Americans lack access to 25 Mbps/3 Mbps service, while 53% of those are rural Americans.⁴³ So, even though cancer support groups are available online, some patients may still not have access.

One limitation of this study is the response rate of 30% and a second limitation is only Iowa family physicians being the respondents; therefore, results may not be similar in other states or countries. The members of IRENE may be different than non-IRENE members in their research interests. However, the views of the Iowa family physicians were from both rural and urban areas of the state.

Conclusion

The post-survivorship care can be better modeled as a multidimensional space where each survivor has their own trajectory. Primary care providers are a pivotal point of care. These providers are very aware that patients are affected by their cancer long after the treatment is completed. When asked about specific long-term effects, they are not confident in managing survivorship cardiology and cognitive health, but are confident in managing many of the other side effects and longterm effects. There is a gap in knowledge for issues specific to survivorship. The challenge for primary care physicians is how to integrate cancer survivorship-specific diagnostic pathways into the existing care with use of preexisting cancer survivorship plans.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Funding for this project was provided by the University of Iowa's Holden Comprehensive Cancer Center's Diana Benz Memorial Fund Seed Grant Program.

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Author Biographies

Maresi Berry-Stoelzle, MD, is a clinical assistant professor in the Department of Family Medicine at the University of Iowa. Her research areas include cancer survivorship and advance care planning in the primary care setting.

Kim Parang, MA, is a research assistant in the Department of Family Medicine at the University of Iowa.

Jeanette Daly, RN, PhD, is a research scientist in the Department of Family Medicine at the University of Iowa. Her research areas are colorectal cancer screening, elder abuse, fecal immunochemical tests, and cancer survivorship.