

The Primary Care Provider (PCP)-Cancer Specialist Relationship: A Systematic Review and Mixed-Methods Meta-Synthesis

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Abstract: Although they are critical to models of coordinated care, the relationship and communication between primary care providers (PCPs) and cancer specialists throughout the cancer continuum are poorly understood. By using predefined search terms, the authors conducted a systematic review of the literature in 3 databases to examine the relationship and communication between PCPs and cancer specialists. Among 301 articles identified, 35 met all inclusion criteria and were reviewed in-depth. Findings from qualitative, quantitative, and disaggregated mixed-methods studies were integrated using meta-synthesis. Six themes were identified and incorporated into a preliminary conceptual model of the PCP-cancer specialist relationship: 1) poor and delayed communication between PCPs and cancer specialists, 2) cancer specialists' endorsement of a specialist-based model of care, 3) PCPs' belief that they play an important role in the cancer continuum, 4) PCPs' willingness to participate in the cancer continuum, 5) cancer specialists' and PCPs' uncertainty regarding the PCP's oncology knowledge/experience, and 6) discrepancies between PCPs and cancer specialists regarding roles. These data indicate a pervasive need for improved communication, delineation, and coordination of responsibilities between PCPs and cancer specialists. Future interventions aimed at these deficiencies may improve patient and physician satisfaction and cancer care coordination. *CA Cancer J Clin* 2017;**67**:156–169. © 2016 American Cancer Society.

Keywords: cancer care, cancer specialist, communication, general practitioner, models of care, oncologist, cancer, primary care provider (PCP), shared care

Introduction

Poor coordination and communication between primary care providers (PCPs) and specialist physicians contribute to avoidable patient morbidity and mortality, fragmented care, and increased costs.^{1,2} Despite intense focus on the quality and safety of cancer care during the last 15 years, the ways in which cancer specialists interact and communicate with PCPs has largely escaped attention. In the 2005 Institute of Medicine report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, coordination between specialists and PCPs was listed as one of four key components of survivorship care,³ but recommendations for how these physicians should interact during the cancer care continuum—including diagnosis, treatment, surveillance, and palliation—were lacking.

Multiple models for the PCP-specialist physician relationship have been previously described, including primary care-based, shared-care-based, and specialist-based models.⁴ These models have been investigated more thoroughly for diseases such as diabetes, in which clinical management of the disease is often chronic and within the scope of primary practice.^{5,6} While limited numbers of studies have examined shared-care models in cancer survivorship, it is uncertain whether these models are feasible or accepted throughout the cancer care continuum, in which treatment episodes may be time-limited or incompletely understood by the PCP.^{7,8} A specialist-based model entails the provision of care by cancer specialists

<p>Inclusion Criteria</p> <ul style="list-style-type: none"> Report data on the relationship, communication, or shared-care of PCPs and cancer specialists Report on data involving the diagnosis, treatment, palliation, or survivorship care of cancer patients Collected primary data Peer-reviewed <p>Exclusion Criteria</p> <ul style="list-style-type: none"> Report on data regarding the relationship or communication between patients and physicians Report on cancer screening Report on relationships or communication with non-physicians (pharmacist, nurses, managers)* Report on access or utilization of specialist care without mention of relationship or communication <p>PCP primary care physician</p> <p>*Some studies included physician extenders such as nurse practitioners or physician assistants. We included these studies and data if they also involved physicians.</p>
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FIGURE 1. Inclusion and Exclusion Criteria for Articles Included in the Systematic Review.

for most issues that arise during cancer treatment and the initial posttreatment surveillance periods, including those that may fall within the scope of primary practice. However, the growing number of cancer survivors,⁹ the projected shortage of cancer specialists,¹⁰ and the increasing complexity of patients with respect to age and comorbidities all challenge assumptions about the effectiveness of a specialist-based model as optimal for value, quality, and coordinated care.^{11,12} A fundamental component of any of these models of care and the PCP-specialist relationship is communication, and the frequency, quality, and ideal means of communication between PCPs and cancer specialists is poorly understood.

Our objective was to describe the attributes of the relationship and communication between PCPs and cancer specialists. We performed a systematic review of the literature and a meta-synthesis of qualitative, quantitative, and disaggregated mixed-methods studies. We summarized the literature with regard to key themes relating to the PCP-cancer specialist relationship throughout the cancer care continuum to determine what is currently known, to inform a preliminary conceptual model, to expose relevant gaps in knowledge, and to make recommendations for future work.

Materials and Methods

Data Sources and Searches

In November 2015, we initiated a search of the published literature using the PubMed, MEDLINE, and EMBASE databases for articles published between January 1, 2000 and October 31, 2015. As a first step, we broadly searched terms and synonyms for cancer specialist, primary care physician, communication, and relationships and then built a search string that captured the keyword search terms (see Supporting Information Table 1). Next, we limited the search to studies that related to cancer care, including diagnosis, treatment, palliation, and survivorship. Searches were limited to English language articles. All publications were then combined into a single list, and duplicates were excluded for review.

Study Selection

We reviewed abstracts and excluded studies that described the physician-patient relationship or communication, studies that addressed cancer screening in the general population, the relationship or communication between PCPs or cancer specialists and other members of the health care team (nurses, pharmacists, managers), and comparisons of how PCPs or cancer specialists treat specific conditions (Fig. 1). During data abstraction, we elected to exclude studies that only reported on the patient perspective of the PCP-cancer specialist relationship. Our rationale for excluding these articles was that our original search terms did not include terms representing patients, and we were not confident that our search had encompassed the entirety of articles that would represent the patient's perspective. We also felt that the patient perspective, attitudes, and preferences related to this relationship represented a significantly large and distinct topic as to be beyond the scope of this review. We supplemented our automated search by manually searching the bibliographies of included studies.

We developed inclusion and exclusion criteria for the systematic review using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) schema.¹³ Studies were excluded if they contained no data about cancer diagnosis, treatment, or survivorship or no data about the relationship or communication between PCPs and cancer specialists. Both quantitative and qualitative studies were eligible for inclusion. One reviewer (L.A.D.) assessed abstracts to ensure alignment with inclusion/exclusion criteria (Fig. 2). In the second round of the review, at least 2 reviewers independently reviewed the remaining full-text publications to verify eligibility (L.A.D., J.N.H., or G.P.Q.). After discussing discrepancies, reaching consensus, and adding articles identified from hand searching the references of eligible publications, the final set of eligible publications for data abstraction was identified.

Data Abstraction

We developed a data-abstraction tool that captured detailed data from both quantitative and qualitative studies; these included study design, main variables, statistical analysis,

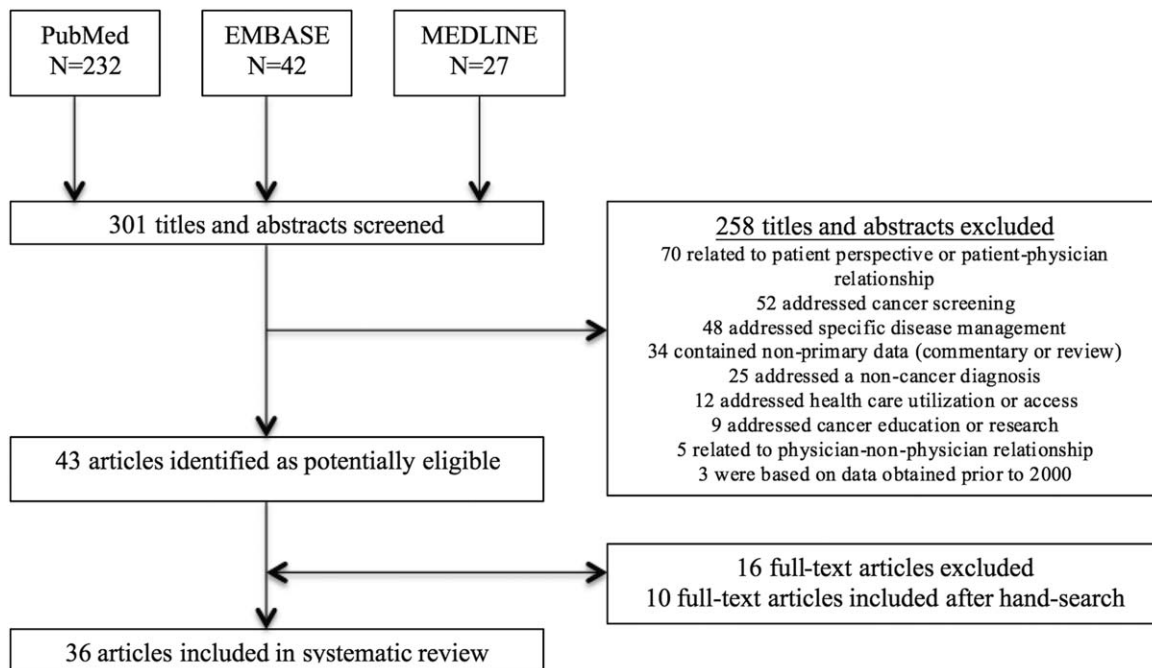


FIGURE 2. Flowchart Outlining the Literature Search and Article Evaluation Process.

results, and conclusions. For mixed-methods studies, data were abstracted for both the quantitative and qualitative components, and meta-inferences were used. Data were abstracted independently and in duplicate, and a third methodologist resolved disagreements.

Risk of Bias and Quality of the Studies

Methodological quality was assessed among quantitative and qualitative studies and, in the case of mixed-methods designs, was assessed independently for each portion of the study. We evaluated each quantitative study according to 6 criteria: assessment of reliability, validity and quality, minimization of selection and attrition bias where applicable, minimization of confounding, minimization of measurement bias, statistical tests, and whether or not the conclusions were supported by the results. We evaluated qualitative studies according to 6 separate criteria: assessment of reliability, validity and quality, sampling strategy, data reduction methods and data analysis, final themes with definitions, validation of results, and strategies for adjudication of discrepancies between coders.

Analysis

Thematic analysis was used to synthesize the quantitative and qualitative evidence into coherent themes.¹⁴ As described in a previous meta-synthesis of qualitative and quantitative studies,¹⁵ this technique specifically calls for integration of qualitative and quantitative data at the analysis and interpretation phases. We used an inductive approach, allowing the data content to direct the analysis. Each publication was read and reviewed in depth. The data

were then independently coded by at least 2 investigators and searched for significant themes related to the communication or relationship between PCPs and cancer specialists. The reviewers then discussed, compared, and contrasted the themes across studies for further refinement until consensus was reached. In each case, consensus was reached, and further adjudication was not necessary.

Results

Our initial search identified 301 citations, of which 43 were potentially eligible for inclusion. The reasons for exclusion are summarized in Figure 2. After complete review and data abstraction, 36 studies met all inclusion criteria.^{12,16–50} Among eligible studies, 23 (64%) were quantitative surveys, 11 (30%) were qualitative studies, and 2 (6%) used mixed methods. The study participants included PCPs and a variety of cancer specialists (Table 1). Among studies that included cancer specialists, 89% (n = 17 of 19) included medical oncologists; only 31% (n = 6 of 19) included radiation oncologists, and only 16% (n = 3 of 19) included surgeons or surgical oncologists. The majority of studies addressed survivorship only (n = 26; 72%), while the remaining studies addressed the relationship or communication between PCPs and cancer specialist during other phases of cancer care. Most of the studies (n = 23; 64%) were conducted in the United States, and the rest were conducted in Canada,^{18,19,39,42} the United Kingdom,^{45,47} Australia,^{34,50} New Zealand,²⁵ and the Netherlands.^{12,21,35} Three studies lacked methodological detail^{17,31,49} and were included in the final analysis with the caveat that the data should be interpreted with caution.

TABLE 1. Characteristics of Included Studies (N = 36)

CHARACTERISTIC	NO. (%)
Cancer site ^a	
Breast	14 (39)
Colorectal	7 (19)
Endometrial	1 (3)
Melanoma	1 (3)
Various, ≥3 types	18 (50)
Study location	
United States	23 (64)
Outside United States	13 (36)
Study population ^a	
Primary care/generalist physicians	30 (83)
Cancer specialists	19 (54)
Medical oncologists	17/19 (89)
Radiation oncologists	6/19 (31)
Surgical oncologists	3/19 (16)
Stage of cancer care	
Curative intent treatment	3 (8)
Survivorship	26 (72)
Cancer continuum	6 (17)

^aSome values add to more than 100, because some articles included 2 specific cancer types (ie, breast and colon) or provider types (primary care physicians and oncologists).

Major Themes

Thematic analysis of the quantitative and qualitative papers revealed 6 major themes: 1) poor and delayed communication between PCPs and cancer specialists, 2) cancer specialists' endorsement of a specialist-based model of care, 3) PCPs' belief that they play an important role in the cancer care continuum, 4) PCPs' willingness to participate in the cancer care continuum, 5) cancer specialists' and PCPs' uncertainty regarding the knowledge or training of the PCP to provide care, and 6) discrepancies between PCPs and

cancer specialists regarding roles and expectations (Table 2).^{12,16-30,32-34,37-50} Importantly, these themes crossed methodologies and were consistently identified by quantitative (Table 3),^{12,16,18,20-22,25,29,31,32,35,36,38,40,42-49} qualitative (Table 4),^{19,23,26-28,30,33,34,37,39,41} and mixed-methods studies (Table 5).^{17,24,50} Themes were incorporated into a preliminary conceptual model of the PCP-cancer specialist relationship as it pertained to the model of cancer care (Fig. 3).

Poor and Delayed Communication Between Cancer Specialists and PCPs

Many of the included studies reported on the frequency, quality, or timing of the communication between cancer specialists and PCPs, with many studies emphasizing survivorship communication.^{12,17,19,21,23-25,28,30,32,37-39,43,46-48,50}

Frequency of communication

In one study, 60% of PCPs indicated that the frequency of communication they received was "not enough" and expressed a desire to be more closely informed by either telephone or e-mail.⁴³ In another survey of PCPs, 44% indicated that they "sometimes," "rarely," or "never" were informed of the diagnosis or outcomes of their patients in the postreferral period, and they described a significant gap in communication between diagnosis and the end of treatment.²⁴ Oncologists also endorsed infrequent communication with PCPs. In one survey, only 40% reported communication on an ongoing basis,³² and, in interviews, specialists expressed that the frequency of communication with PCPs could be improved.³⁷ Cancer specialists described the complicated nature of cancer care, the logistical challenges of treatment, and the multiple providers involved in care among the barriers to

TABLE 2. Organization of References Into Themes

CHARACTERISTIC	QUANTITATIVE STUDIES (n = 22)	QUALITATIVE STUDIES (n = 11)	MIXED STUDIES (n = 2)
Poor and delayed communication between PCPs and cancer specialists	Blaauwbroek 2007, ¹² Roorda 2013, ²¹ Donohue 2015, ²² Babington 2003, ²⁵ Merport 2012, ³⁸ Salz 2012, ⁴³ Nissen 2008, ⁴⁶ Watson 2010, ⁴⁷ Forsythe 2013 ⁴⁸	Haq 2013, ¹⁹ Cunningham 2013, ²³ Mayer 2012, ²⁶ Hewitt 2007, ²⁷ Sada 2011, ²⁸ Prouty 2014, ³⁰ O'Toole 2009, ³² Kantsiper 2009, ³⁷ O'Brien 2015 ³⁹	Dulko 2013, ¹⁷ Shen 2015, ²⁴ Jefford 2008 ⁵⁰
Cancer specialists endorse a specialist-driven model of care	van Hezewijk 2011, ⁴⁴ Donnelly 2007 ⁴⁵	Haq 2013, ¹⁹ Hewitt 2007, ²⁷ Sada 2011, ²⁸ O'Toole 2009, ³² Rychetnik 2012, ³⁴ Kantsiper 2009 ³⁷	
PCPs believe they play an important role in the cancer continuum	Del Giudice 2009 ⁴²	Dicicco-Bloom & Cunningham 2013, ²³ Hewitt 2007, ²⁷ Sada 2011, ²⁸ Rayman & Edwards 2010, ³³ O'Brien 2015 ³⁹	Shen 2015 ²⁴
PCPs are willing to play a role in the cancer care continuum	Blaauwbroek 2007, ¹² Roorda 2013, ²¹ Dittus 2014, ²⁹ Cheung 2009, ⁴⁰ Del Giudice 2009, ⁴² Nissen 2008, ⁴⁶ Papagrigoriadis & Koreli 2001 ⁴⁹	Dicicco-Bloom & Cunningham 2013, ²³ Rayman & Edwards 2010, ³³ O'Brien 2015, ³⁹ Shalom 2011 ⁴¹	
Oncologists and PCPs are uncertain of PCPs' knowledge or ability to provide care	Smith 2011, ¹⁸ Potosky 2011, ²⁰ Roorda 2013, ²¹ Dittus 2014, ²⁹ Salz 2012, ⁴³ Donnelly 2007, ⁴⁵ Nissen 2008, ⁴⁶ Papagrigoriadis & Koreli 2001 ⁴⁹	Haq 2013, ¹⁹ Rayman & Edwards 2010, ³³ Kantsiper 2009 ³⁷	Dulko 2013, ¹⁷ Jefford 2008 ⁵⁰
Discordance among expectations and perceived roles	Cheung 2010, ¹⁶ Potosky 2011, ²⁰ Dittus 2014, ²⁹ Cheung 2009 ⁴⁰	Sada 2011, ²⁸ Rayman & Edwards 2010 ³³	

Abbreviation: PCPs, primary care physicians.

TABLE 3. Summary of Findings From the Quantitative Literature

ARTICLE	PARTICIPANTS	STUDY DESIGN	FINDINGS
Blaauwbrock 2007 ¹²	233 PCPs	Cross-sectional survey of PCPs attending a refresher course on survivorship care of adult survivors of pediatric cancer	Ninety-seven percent (97%) of PCPs were willing to participate in a shared care model for follow-up. Sixty-four percent (64%) of PCPs felt that it was their responsibility to be in charge. PCPs desired guidelines (64%), information about the patient's medical history (37%), and direct communication lines with oncologists (45%). Lack of communication was a barrier to shared care.
Cheung 2010 ¹⁶	255 PCPs, 123 medical oncologists, 232 PCP-oncologists pairs	Cross-sectional survey of cancer survivors 2 y from active treatment with NED and their self-identified PCP and oncologist	Survivorship care expectations were most discrepant between PCPs and oncologists; patient-PCP expectations were more concordant than patient-oncologist expectations. Patient-oncologist discussions regarding survivorship improved patient-PCP expectations, but not PCP-oncologist concordance.
Smith 2011 ¹⁸	590 PCPs	Cross-sectional survey of PCPs providing follow-up care for patients with nonmetastatic breast cancer	PCPs were most confident in screening for recurrence and managing anxiety and were least confident in managing lymphedema and providing psychosocial counseling. Most PCPs found discharge letters from oncologists to be helpful, particularly when including a treatment summary and recommendations for surveillance.
Potosky 2011 ²⁰	1072 PCPs, 1130 medical oncologists	Cross-sectional survey of PCPs and medical oncologist identified via AMA Master file	Compared with PCPs, oncologists were less likely to believe PCPs had the skills to conduct appropriate testing for breast cancer recurrence or to care for late effects of breast cancer. Only 40% of PCPs were confident in their knowledge of testing for recurrence.
Roorda 2013 ²¹	502 PCPs	Cross-sectional survey of all PCPs in 3 northern provinces of the Netherlands	Forty percent (40%) of PCPs were willing to accept exclusive responsibility of follow-up care sooner than 5 y after active cancer treatment. Perceived barriers included poor communication with cancer specialists, patient preference for specialist follow-up versus PCP, and PCPs lack of oncology knowledge.
Donohue 2015 ²²	92 PCPs	Cross-sectional survey of PCPs who were seeing survivors enrolled into a survivorship clinical trial	Eighty-eight (88%) of PCPs regarded EMR-generated SCPs as useful in communicating and coordinating care.
Babington 2003 ²⁵	80 specialists, 182 PCPs	Cross-sectional survey of PCPs who had referred patients to an oncologist and the corresponding oncologist	The majority (72%) of cancer specialists generated a letter following consultation, but only 58% of PCPs received that letter. Expectations of what the letter should include differed between PCPs and oncologists.
Dittus 2014 ²⁹	39 PCPs	Cross-sectional survey of PCPs caring for cancer survivors	Nearly all PCPs (90%) endorsed SCPs as useful in providing survivorship care, but clear delineation of provider roles was lacking.
Blanch-Hartigan 2014 ³¹	1072 PCPs, 1130 medical oncologists	Cross-sectional survey of PCPs and medical oncologist identified in the AMA Master file	A majority of oncologists (64%) reported always/most always discussing survivorship care recommendations with survivors, but only 32% discussed who they should see for follow-up, and only 5% provided SCPs.
O'Toole 2009 ³²	39 oncologists	Cross-sectional survey of patients with advanced cancer diagnoses and their oncologist	One-half of oncologists (50%) reported themselves as the PCP for at least 25% of their patients.
Ezendam 2013 ³⁵	266 PCPs	Cluster randomized controlled trial of PCP practices	Only one-third of PCPs reported receiving SCPs. Those receiving SCPs were more likely to have communication with cancer specialists.
Salz 2014 ³⁶	191 PCPs	Cross-sectional survey of medical and radiation oncologist practicing at NCCCP sites	A majority (87%-89%) of oncology providers believed receiving an SCP was very important to the PCP, but 38% did not feel it was their responsibility to provide the SCP.
Merport 2012 ³⁸	108 cancer specialists, 400 PCPs	Cross-sectional survey of cancer specialists and PCPs in Massachusetts	Only 14% of cancer specialists reported preparing SCPs, citing a lack of training, reimbursement, and templates as barriers to use.
Cheung 2009 ⁴⁰	255 PCPs, 123 medical oncologists, 232 PCP-oncologists pairs	Cross-sectional survey of cancer survivors 2 y from active treatment with NED and their self-identified PCP and oncologist	PCPs and oncologists showed high discordance in perceptions of their own roles for primary cancer follow-up, cancer screening, and general preventative health (3%, 44%, and 51% agreement rates, respectively).

TABLE 3. Continued

ARTICLE	PARTICIPANTS	STUDY DESIGN	FINDINGS
Del Giudice 2009 ⁴²	330 PCPs	Cross-sectional survey of PCPs across Canada	PCPs were willing to assume exclusive responsibility for follow-up care 2-3 y after active treatment. The most useful modalities in assisting the transition were a letter from the specialist, printed guidelines, expedited re-referral, and access to investigations when recurrence was suspected.
Salz 2012 ⁴³	191 PCPs	Cross-sectional survey of PCPs caring for patients with colorectal cancer	Most PCPs reported receiving too little information about the patients' clinical course and the oncologists plan for monitoring other cancers.
Hezewijk 2011 ⁴⁴	130 cancer specialists (surgeons, medical, radiation oncologists)	Cross-sectional survey of breast cancer members of a Dutch comprehensive cancer center	Forty-four percent (44%) of breast cancer specialists believed a breast surgeon should always be involved in breast cancer follow-up, whereas only 9% believed a PCP should always be involved, and 24% believed a PCP should never be involved.
Donnelly 2007 ⁴⁵	256 breast cancer specialists	Cross-sectional survey of breast specialist in the United Kingdom	Breast cancer specialists viewed a "lack of PCP experience or training in oncology" and a "loss of patient outcome data" as barriers to early discharge to PCP follow-up.
Nissen 2007 ⁴⁶	132 PCPs	Cross-section survey of PCPs practicing in a single health system in the United States	Most (52%) PCPs were comfortable with responsibility for cancer surveillance. More than one-half rated transfer from oncologists to PCPs as fair or poor. PCPs endorsed uncertainty for the type and duration of surveillance testing, which varied depending on cancer type.
Watson 2010 ⁴⁷	100 oncologists, 200 PCPs	Cross-sectional survey of oncologist and PCPs who were members of doctors.net	Less than one-half of PCPs were satisfied with aspects of communication with cancer specialists, including the content of discharge letters and the ease of getting patients seen between routine appointments.
Forsythe 2013 ⁴⁸	1020 PCPs, 1130 medical oncologists	Cross-sectional survey of PCPs and medical oncologist identified in the AMA Master file	Nearly one-half of oncologists reported always/almost always providing treatment summaries, but only 20% provided SCPs. One-third of PCPs reported always/almost always receiving treatment summaries, but only 13% reported routinely receiving SCPs. PCP receipt of SCP was associated with better PCP-reported care coordination, physician-physician communication, and confidence in survivorship ($P < .05$).
Papagrigroriadis & Koreli 2001 ⁴⁹	164 PCPs	Cross-sectional survey of all PCPs in 83 practices in the United Kingdom	A majority of PCPs considered the follow-up of patients with colorectal cancer an interesting (50%) or a natural part of their work (37%). The main reservations to providing follow-up care were work burden (60%), lack of guidelines (59%), lack of cancer knowledge (51%), and delays of re-referral to specialists (41%).

Abbreviations: AMA, American Medical Association; EMR, electronic medical record; NCCCP, National Cancer Institute Community Cancer Centers Program; NED, no evidence of disease; PCP(s), primary care provider(s); SCP(s), survivorship care plan(s).

frequent communication.³⁰ In a study that examined preferences regarding care models, 13% of PCPs indicated that infrequent communication was a major barrier to implementation of a shared-care model.¹²

Quality and timing of communication

Even when communication was transmitted by the cancer specialist and received by the PCP, PCPs noted deficiencies in content, mode, volume, and style that limited the usefulness of the information. In one study, PCPs described a lack of information regarding exactly what communication

content the patient had received that led these PCPs to report being "out of the loop."³³ Some PCPs reported that the sheer volume of correspondence made it difficult to assess a patient's status in a timely fashion.²⁷ In another study, PCPs noted that the mode and style in which information was shared lacked coordination with care episodes and coherence.¹⁹ In a study that audited letters from oncologists to PCPs, only 20% contained information regarding prognosis, 55% described what the patient was told, and only 10% included when or how to contact the oncologist.²⁵

TABLE 4. Summary of Findings From the Qualitative Literature

ARTICLE	PARTICIPANTS	STUDY DESIGN	FINDING
Haq 2013 ¹⁹	8 PCPs, 6 cancer providers	Focus groups and in-depth interviews of patients, PCPs, and cancer specialists	PCPs expressed concerns with timeliness of information from cancer specialists and a lack of understanding/knowledge regarding cancer staging and SCPs.
DiCicco-Bloom 2012 ²³	11 PCPs	Interviews of PCPs in practices that employed at least one nurse practitioner and who cared for cancer patients	PCPs find patient visits during cancer treatment important. They note differences in communication between community and academic oncologists, and they develop strategies to obtain information to account for information deficits.
Mayer 2012 ²⁶	5 PCPs	Interviews of PCPs identified from a family practice listserv	PCPs endorsed SCPs as helpful communication tools. If used alone, SCPs would be insufficient to ease the transition to follow-up care with PCPs. Improved communication and care coordination were identified as important for survivorship care.
Hewitt 2007 ²⁷	20 oncologists (medical, radiation, urology, gynecology), 14 PCPs	Focus groups and telephone interviews of providers identified at ASCO's annual meeting or through telephone recruitment	PCPs viewed themselves as playing an important role during the posttreatment periods and indicated that a written care plan for follow-up would help them improve their survivorship care. Oncologists admitted rarely discharging their patients to PCPs for follow-up after active cancer treatment.
Sada 2011 ²⁸	14 physicians (PCPs and medical oncologists)	Cross-sectional, semistructured interviews of providers associated with an integrated health system	Physicians reported that EMRs improved communication within their system, but that communication across systems was difficult. PCPs expressed uncertainty regarding their role in the care of survivors, although medical oncologists emphasized PCPs' role in managing comorbidities.
Prouty 2014 ³⁰	59 physicians (PCPs, oncologists, surgeons, gynecologists)	Focus groups of a convenience sample of PCPs and medical, surgical, and radiation oncologists	Provider perceptions of the causes of communication breakdown in cancer care included issues related to providers and health care systems.
Rayman & Edwards 2010 ³³	11 PCPs	Focus groups of PCPs from rural, federally funded community health centers	Providers' relationships were characterized as being with women who have breast cancer and comprised an active, behind-the-scenes role in supporting their patients through treatment decisions and processes. Three themes emerged: knowing the patient, walking through treatment with them, and losing the patient to the system.
Rychetnik 2012 ³⁴	16 surgical oncologists	Interviews of surgical oncologists and dermatologist serving in melanoma units in Australia	Cancer specialists use various models of shared care, depending on their preferences and those of their patients.
Kantsiper 2009 ³⁷	15 PCPs, 16 cancer specialists	Focus groups of PCPs and oncology providers from Johns Hopkins Community Physician Network	Specialists struggle with discharging survivors due to protective relationships PCPs expressed concerns over time and training to provide survivorship care and over communication with oncologists.
O'Brien 2015 ³⁹	18 PCPs	Interviews of PCPs participating in a randomized controlled trial evaluating SCPs	Most PCPs were comfortable providing breast cancer survivorship care 3-5 y after diagnosis but desired timely and informative communication from oncologists.
Shalom 2011 ⁴¹	15 PCPs	Interviews of UCLA-affiliated PCPs who had previously received an SCP	PCPs were more confident and prepared for survivorship care after receiving an SCP. PCPs reported a willingness to accept either sole or shared responsibility for routine follow-up care.

Abbreviations: ASCO, American Society of Clinical Oncology; EMRs, electronic medical records; PCP, primary care provider; SCP survivorship care plan; UCLA, University of California, Los Angeles.

Survivorship communication

In one study, only 56% of PCPs involved in cancer survivorship reported that the specialist communicated transfer of survivorship care to the PCP,²¹ a finding that was supported in another study in which 56% to 62% of PCPs indicated that transfer communication was infrequent.⁴⁶ Several studies looked specifically at how discharge letters or survivorship

care plans (SCPs) impacted communication between PCPs and cancer specialists.^{22,27,29,31} In one study, 89% of oncology providers felt it was very important for PCPs to receive SCPs, but 38% did not feel it was their responsibility to provide these plans.³⁶ In another study, only 14% of cancer specialists reported providing care plans to PCPs, citing limited training, no available template, and a lack of reimbursement

TABLE 5. Summary of Findings from the Mixed Methods Literature

ARTICLE	PARTICIPANTS	STUDY DESIGN	FINDING
Dulko 2013 ¹⁷	39 PCPs	Cross-sectional survey of PCPs who received an SCP; interviews of oncology providers	Sixty-four percent (64%) of PCPs cited limited access to survivors, 58% cited insufficient knowledge of cancer survivor issues, and 49% cited inadequate recommendations by oncologists. Oncology providers cited barriers to providing SCPs, including lack of time, poor reimbursement, and lack of guidelines.
Shen 2015 ²⁴	18 PCPs (qualitative), 128 PCPs (quantitative)	Interviews and cross-sectional surveys of PCPs practicing in underserved minority communities	There is a gap in PCP-oncologist communication occurring between diagnosis and treatment. PCPs wanted more communication with oncologists, updates on their patient's prognosis throughout treatment, and to be contacted via telephone or email. PCPs saw their roles as crucial in providing supportive care for their patients.
Jefford 2008 ⁵⁰	81 PCPs	Focus groups and surveys of PCPs in an randomized controlled trial evaluating faxed tailored chemotherapy information	PCPs in the intervention group demonstrated significantly greater increases in confidence and satisfaction compared with usual care, reflecting a 7.1% and 10.5% difference in scores, respectively.

Abbreviations: PCPs, primary care providers; SCPs, survivorship care plans.

as barriers to this particular form of communication.³⁸ SCPs were generally a desired form of communication by PCPs. In one survey, 88% of PCPs believed that electronic medical record (EMR)-generated SCPs were useful in coordinating care.²² In another study, 85% of PCPs believed that SCPs helped them to understand their roles.

Strategies used by PCPs to overcome inadequate communication

In some situations in which communication was inadequate, PCPs reported that they relied on the patient for updates.^{26,27} PCPs also described a strategy of re-referral of the patient to the cancer specialist when a question arose,

given the reported difficulty in speaking directly with cancer specialists.³⁹

Factors enhancing communication

Five studies identified conditions that facilitated satisfactory communication.^{18,26,28,39,50} One described a Canadian centralized cancer care system with synoptic discharge communication in which PCPs were satisfied with discharge communication from oncologists.¹⁸ In another study of PCPs, communication from oncologists was variable but improved when the PCP and oncologist had a preexisting relationship and practiced in the same health care system.²⁶ In a study of PCPs and cancer specialists in a

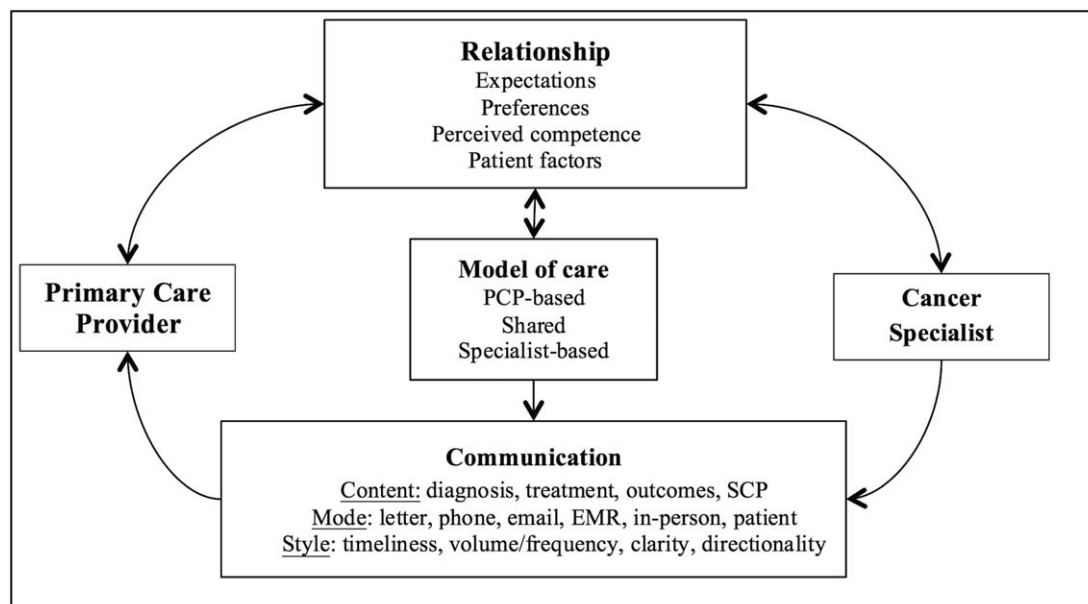


FIGURE 3. Model of the Primary Care Provider (PCP)-Cancer Specialist Relationship.

Abbreviations: PCP, primary care provider; SCP, survivorship care plan; EMR, electronic medical record.

Veterans Administration system, communication was enhanced by an integrated EMR, although these same providers reported difficulty communicating with providers external to the hospital and EMR system.²⁸ PCPs who reported satisfaction with cancer specialists' communication typically also reported ease of reaching cancer specialists by telephone or e-mail.³⁹ In a randomized trial in Australian PCPs, an increase in confidence and satisfaction with communication was noted among PCPs who received faxed, tailored chemotherapy information compared with those who received usual correspondence.⁵⁰

Cancer Specialists' Endorsement of a Specialist-Based Model of Care

Several studies described cancer specialists' preference for a specialist-based model of care.^{19,27,28,32,34,37,44,45} In one study, 50% of medical oncologists reported serving as the PCP for at least 25% of their patients (but without mention of which specific primary care services were provided).³² In another study, oncologists endorsed their preference for specialist-based care because they believed patients were not well enough to go to multiple physicians.²⁸ The preference for a specialist-based model extended into survivorship care, with 44% of breast cancer specialists in one survey stating that a breast surgeon should always be involved in breast cancer survivorship.⁴⁴ Cancer specialists also expressed uncertainty about the appropriateness of PCP-based survivorship care, and this uncertainty seemed to influence practice patterns.^{34,45} In one study of oncologists' practice related to survivorship care, oncologists admitted that they rarely discharged cancer survivors to PCPs for surveillance and survivorship, instead monitoring patients indefinitely.²⁷ Oncology providers indicated that they felt this long-term commitment provided patients with reassurance that any potential problems would be detected as early as possible. Other specialists desired to remain involved with survivors because patient contact provided positive reinforcement of the success of their therapy. In one qualitative study, oncology specialists stated that they struggled with discharging survivors because of the bonds they had established with patients and their concern for survivors' needs. They reported becoming "emotionally invested" in the success of the patient and wanted to remain involved even after the completion of active treatment.³⁷ While specialists often acknowledged the role of the PCP in addressing health concerns, they viewed cancer care as a "special domain" and acknowledged being protective and possessive of some patients. In another study, oncologists reported treating minor problems within the scope of primary practice because of uncertainty regarding the PCPs willingness or ability to address such problems.¹⁹

PCPs' Belief That They Play an Important Role in the Cancer Continuum

PCPs believed they played an important role during cancer care, specifically with regard to providing moral support, education, and management of medical issues that arose during cancer care.^{23,24,27,28,33,39,42} They characterized their care as philosophically different from that provided by oncologists and as "balancing" the oncologists' approach. Specifically, PCPs noted that they were "oriented toward the whole person" rather than focusing on "just their cancer." PCPs also thought that cancer specialists excluded them because the PCPs might be less willing to support aggressive cancer treatments in patients with poor prognoses.²³ In one study, PCPs reported that patients viewed them as trusted experts and described patients' elicitation of the PCP's opinion on recommendations regarding treatments and therapies before initiation of the treatments prescribed by the cancer specialist. They described patients' reliance on the PCP to manage symptoms, interpret information presented by the cancer specialist, and help patients make sense of their personal experience of cancer.³³ In one survey, 80% of PCPs felt they were positioned better than cancer specialists to provide psychosocial support to their patients and that, because of this, they should be involved throughout the cancer care continuum.⁴²

PCPs' Desire and Willingness to Play a Role in the Cancer Continuum

PCP views about timing of involvement

PCPs expressed a desire to remain involved in all phases of the cancer continuum and expressed frustration with the lack of interaction with patients undergoing active treatment.²⁹ They described their efforts to maintain good relationships with patients but also felt that oncologists "swallow[ed] up" the patient by providing primary as well as cancer care. PCPs complained that some patients only visited after an oncologist refused to perform a procedure, such as a Pap test, leaving them feeling exploited and "shut out."²³ In some situations, PCPs believed patient preferences contributed to the specialist-based model, with 65% of PCPs in one study stating that the patient's desire for specialist care was a barrier to PCP involvement.²¹ Only one study reported PCP ambivalence about assuming a larger role, although they felt capable of assuming the role if necessary.³⁷

PCP role in survivorship

PCPs were especially willing to participate during the survivorship phase.^{12,21,23,29,33,39-42,46,49} In a survey of PCPs who had attended a refresher course on care of adult survivors of childhood cancer, 97% of PCPs indicated that they were willing to participate in shared care of these patients, and 64% felt it was their responsibility to be in charge of

survivorship care.¹² In one study of PCPs, 32% believed that they should be involved at an earlier phase of follow-up of patients with breast cancer, and 40% were willing to accept exclusive responsibility for follow-up earlier than 5 years after active treatment. Nineteen percent (19%) were willing to assume follow-up immediately after active treatment.²¹ PCPs who were ready to assume exclusive responsibility for survivorship care 2 to 3 years after active treatment identified several modalities that would ease this transition, including a patient-specific letter from the specialist, printed guidelines, expedited access to investigations when recurrence was suspected, and expedited re-referral if necessary.⁴²

Specialists and PCPs Are Uncertain of the PCP's Knowledge or Training to Provide Care

Despite PCPs' willingness to participate in the cancer care continuum, cancer specialists expressed skepticism that PCPs were trained to provide this care.^{19,20,45} In one study, oncologists reported treating problems within the scope of a PCP's practice because of uncertainty regarding the PCP's competence to address such problems.¹⁹ In another study, only 23% of oncologists believed that PCPs had the skills to conduct appropriate testing for breast cancer recurrence, and only 38% believed PCPs could care for late effects of breast cancer and breast cancer treatment.²⁰ A further study of breast cancer specialists cited concerns for a lack of PCP experience or training in oncology as barriers to discharge for follow-up; they indicated that increased education and training, development of shared protocols, and recruitment of primary care-based oncology nurses would facilitate early discharge to PCPs.⁴⁵

PCPs mostly endorsed this uncertainty and lack of knowledge or training.^{17-21,29,33,37,43,46,49,50} Insufficient knowledge of cancer issues was cited as a barrier to providing survivorship care by 58% of PCPs in one study¹⁷ and 79% of PCPs in another.²⁹ In one study, PCPs felt uncomfortable with patients' questions about their cancer diagnosis and described a lack of knowledge regarding current treatment protocols.³³ A group of PCPs treating breast cancer survivors expressed a lack of confidence in managing lymphedema, family planning, and psychosocial counseling.¹⁸ With regard to colorectal cancer survivorship care, PCPs desired knowledge regarding genetic counseling and testing, increased risks for second colorectal cancers, and other cancers and diseases.⁴³ In one study, PCPs relied on the Internet to stay current and to answer patient questions.³³

Discordant Expectations and Preferences Between Providers

Another dominant theme was discordance or uncertainty in provider roles and expectations throughout the cancer care

continuum as well as preferences in care models among (within) and between PCPs and oncologists.^{16,20,28,29,33,40}

In 2 studies that examined expectations of providers' roles, Cheung et al noted discrepant expectations between and among PCPs and cancer specialists.^{16,40} When considering specific components of survivorship care, PCPs and oncologists showed high discordance in perceptions of their own roles for cancer follow-up, cancer screening, and general preventive health (agreement rates of 3%, 44%, and 51%, respectively).⁴⁰ PCPs endorsed being uncertain of their roles²⁹ and not knowing which areas of patient management belonged to the PCP and which areas would be handled by the oncologist.³³ Preferences also differed among cancer specialists, with medical oncologists assuming a primary care role in some cases, while radiation and surgical oncologists expressed a preference for only managing cancer-related issues.²⁸ One study specifically addressed the preferred model of care among PCPs and oncologists—38% of PCPs preferred a shared-care model compared with only 16% of oncologists. In contrast, 57% of oncologists preferred a specialist-based model.²⁰

Discussion

The very nature of a cancer diagnosis, the complexity and toxicity of cancer treatments, and the fragmented nature of the cancer care system all pose significant challenges to high-quality coordination of care.³⁰ Key in the ability to achieve cancer care coordination is the communication and relationship between PCPs and cancer specialists. In this systematic review and meta-synthesis, we ascertained that cancer specialists' communication with PCPs lacks the frequency, timing, and content desired by PCPs. Both PCPs and cancer specialists expressed skepticism regarding the other party's ability to play their role. Cancer specialists cite PCPs' lack of familiarity with cancer treatments and surveillance, and PCPs note that cancer specialists neglect the psychosocial care they believe PCPs are better positioned and equipped to provide. In turn, expectations for care roles are discordant. Cancer specialists predominantly express a preference for specialist-based care throughout the cancer continuum, including the surveillance and survivorship phases. PCPs express a willingness/desire to be more involved during the cancer continuum and believe they can provide a perspective focused on the "whole patient" that complements and provides context for active cancer treatments.

Communication between PCPs and specialists can be difficult in general, and opportunities for building relationships are few when these relationships must span clinics or hospital systems, as is often the case in complex cancer care.^{30,51} The existing data document inadequate communication primarily from cancer specialist to PCP in terms of frequency, content, style, and mode. The inadequacies leave

<p>For the PCP</p> <ul style="list-style-type: none"> During initial referral, provide direct contact information and request follow up from cancer specialist Access referring physician portals prior to visits with patient Schedule follow-up appointment with patient after consultation with cancer specialist to address psychosocial concerns, answer patient questions and optimize co-morbidities that may impact cancer treatments Schedule preoperative visit prior to a major cancer operation to provide medical optimization and ensure patient has necessary medications supplies for postoperative period Encourage patient to schedule follow-up visits intermittently during cancer treatments to readdress psychosocial concerns and comorbidity management Utilize survivorship care plan if provided to guide history and physical exam as well as imaging <p>For the Cancer Specialist</p> <ul style="list-style-type: none"> After initial referral, contact the PCP directly and summarize diagnosis, prognosis and treatment plan Provide instructions on accessing referring physician portals if applicable Provide summarized documentation during active treatment Contact the PCP directly after major changes in patient's course or prognosis, at discharge or transition to palliative care Encourage patient to maintain regular visits with PCP and defer management of comorbidities to PCP Provide a survivorship care plan (SCP) at the end of active treatment Provide oncology related resources that provide the right information at the right time for the PCP Participate in CME events directed towards PCPs caring for cancer patients and survivors <p>For both</p> <ul style="list-style-type: none"> Avoid using the patient as a mode of PCP-cancer specialist communication

FIGURE 4. Recommendations to Improve Communication and Interaction Between Primary Care Providers (PCPs) and Cancer Specialists.

Abbreviations: PCP, primary care physician; SCP, survivorship care plan.

PCPs with the perception that the cancer specialists had “swallowed up” the patient or the feeling of being “out of the loop.” A striking absence in the identified literature relates to the extent and quality of ongoing communication from PCPs to cancer specialists with regard to changes in a patient’s overall condition, comorbidities, or concern about recurrence. It is unclear the extent to which deficiencies in PCP-cancer specialist communication impact care coordination. At a minimum, we noted that PCPs ask patients for information (which may erode trust in the health care system) or use re-referral as a strategy to overcome difficulty in directly communicating with cancer specialists. These strategies may be both inaccurate and inefficient. We did note several circumstances associated with satisfactory or enhanced communication, including the use of a shared EMR (such as in the Veterans Administration health system) and direct communication access to cancer specialists by PCPs (personal telephone or e-mail). Some cancer systems now allow access to electronic health portals for referring physicians and patients. These systems may help address communication gaps, but these portals were not considered in any of the identified studies. It is uncertain how PCPs use these systems, and the use of and satisfaction with these systems remains an area for further investigation. Outside of integrated health systems, cancer specialists do not typically have access to primary care records.

Intervention strategies aimed at improving and facilitating the quality of communication between PCPs and cancer specialists may improve patient and provider satisfaction while

reducing duplication (laboratory or imaging tests) or omission of important services (psychological support or management of comorbidities). We recommend (Fig. 4) that cancer specialists aim to make personal contact with PCPs after initial referral and to report major changes in a patient’s course and at discharge. When possible, cancer specialists should share direct contact information (personal mobile telephone number or e-mail address) with PCPs to facilitate timely communication and perhaps avoid the need for re-referral. Cancer centers and specialists must also emphasize (and delineate responsibility for) the provision of an SCP to the PCP at discharge. This mode of communication was nearly unanimously viewed as helpful by PCPs, providing justification to address the identified barriers to this mode of communication for the cancer specialist (cancer specialists’ lack of training in preparing SCPs and a lack of reimbursement). PCPs need to know what to watch for, when to refer back to the cancer specialists, and that cancer specialists will respond in a timely way when patients are re-referred.

Beyond improved communication, there is a need for recognition and delineation of physician roles throughout the cancer care continuum that considers the necessary contributions of both the PCP and the cancer specialist and avoids duplication or omission in important services. In the reviewed literature, cancer specialists expressed a preference for a specialist-based model in which they provide active treatment; surveillance; palliative and survivorship care; and, in some cases, services that would normally fall within the scope of primary practice. This preference seemed to be

motivated by 3 factors: 1) a belief that the patient was too ill to visit multiple physicians, 2) an obligation to the patient rooted in the belief that PCPs were ill-equipped to provide care, and/or 3) personal fulfillment in continuing to see patients during the survivorship phase. PCPs did not prefer a specialist-dominated model, especially during the advanced cancer/palliative and survivorship phases of care.²⁰ Excluding or not engaging the PCP during active treatment fails to capitalize on the patient-PCP continuity relationship and potentially erodes this relationship in a way that could have implications for both the palliative and survivorship phases of care.

Guidelines for how cancer specialists and PCPs should optimally relate and communicate during various phases of the cancer care continuum are lacking. We believe these guidelines must consider disease site, cancer prognosis, and treatment toxicity and must be in line with patient preferences and expectations. We recommend that PCPs and cancer specialists encourage patients to remain engaged with their PCPs during active cancer treatment via regularly scheduled visits. These visits should address ongoing management of comorbidities, long-term cancer or cancer treatment-related symptom management, and the patient's understanding and satisfaction with their cancer care in the context of their global health and quality-of-life preferences. We specifically recommend visits with the PCP to follow the initial consultation with the cancer specialist, to precede any major cancer operation (inpatient hospital stay or as recommended by the cancer specialist), at regular intervals during active treatments, and at the time of discharge from cancer specialist surveillance or transition to palliative care. We have proposed a preliminary conceptual model that can provide the framework for further investigations, elaboration, validation, and guideline development (Fig. 3). In this model, we propose that the relationship between PCP and cancer specialist is influenced by provider preferences, expectations, perceived competence, and patient preferences, while the quality of communication is influenced by the content, mode, and frequency of communication from cancer specialist to PCP. Together, the relationship and communication influence the shared-care model. Although we are not aware of any existing conceptual models for the PCP-cancer specialist relationship, this model does compare with a conceptual model that has been proposed for the interprofessional collaboration between obstetric physicians and midwives.⁵² Both of these conceptual models emphasize trust, respect, communication, and role clarity.

Resistance to a shared-care or PCP-based model for survivorship and palliation by cancer specialists may become problematic as the number of cancer patients and survivors increases globally. For cancer survivorship, a long-term, specialist-based model results in patients receiving specialty

care despite being well; this may negatively impact access to cancer clinics that already face shortages of specialists. For palliative care, a specialist-based model may result in patients traveling frequently or over long distances and being outside of their support communities at a time when their performance status is poor and the need for psychosocial support is a priority. At least one barrier to a transition to a shared-care or PCP-based model for palliation or survivorship is a real or perceived lack of oncology knowledge and experience by PCPs. It is unclear how much cancer specialists appropriately or inappropriately project the skills needed by PCPs. As suggested above, PCPs often feel they can competently follow and execute SCPs as well as recognize variations that require referral back to oncologists. There may be a misperception by cancer specialists that PCPs want to provide "cancer care" rather than "care for patients with cancer." We did note that PCPs often turned to Internet resources to address knowledge gaps. This finding suggests that these Web-based resources should be provided by and/or vetted by major cancer organizations and provided in a format that meets the needs of the PCP. As the numbers of patients with cancer receiving chronic, active treatments and survivors increase, PCPs will need to become increasingly familiar with short-term and long-term treatment toxicities, surveillance, and other aspects of survivorship care; and many believe they can do this through teamwork with cancer specialists. Cancer organizations, health systems, and specialists should aim to provide resources that are succinct and easily accessible to the PCPs caring for their patients. Primary care graduate medical education training programs should ensure exposure to patients with cancer in various phases of the cancer continuum, and cancer organizations should provide continuing medical education programs for PCPs who care for patients with cancer and/or survivors.

Strengths and Limitations

Our review has exposed several important themes regarding the PCP-cancer specialist relationship as well as relevant gaps in the literature. The majority of the existing literature focuses on the survivorship phase of care only. Most of the studies reviewed also focused on the perceptions and needs of the PCP. Among studies that included cancer specialists, medical oncologists were the most common group sampled. One study specifically excluded surgeons working at National Cancer Institute Community Cancer Center Programs, stating that the topic was less relevant to them.³⁶ Given these gaps in the literature, it is uncertain how these themes apply to the continuum of cancer care and the care provided by other disciplines of cancer specialists, such as surgeons and radiation oncologists, and our conceptual model will be refined as future data become available.

As with any systematic review, our search was limited by the possibility of publication and search biases. To minimize these limitations, we used broad and comprehensive search terms, searched multiple large databases, and hand searched the references of included studies. Our findings were also limited by the available literature; and, as noted above, most of the available literature sampled only medical oncologists instead of a broad range of cancer specialists, and many cancer types (outside of breast and colorectal cancer) were poorly represented. Finally, several of the included studies lacked key methodological details regarding sampling and analysis; thus, it was difficult to judge the quality of the results.

Conclusions

In summary, these synthesized data inform a preliminary conceptual model and present a compelling rationale for further investigation and targeted strategies aimed at understanding and improving the PCP-cancer specialist relationship and communication throughout the cancer care continuum. A compelling confluence of views relative to the common goal of maximizing the care of patients

with cancer unites PCPs and cancer specialists, but how to optimize the relationship needs resolution. This review suggests that improving PCP-cancer specialist communication (especially from cancer specialist to PCP), establishing guidelines for provider roles during various phases of care to maximize the skill sets and needs of both PCPs and cancer specialists, and providing well designed and timed oncology resources for PCPs may help achieve the shared goals of improving the quality and coordination of cancer care and enhancing patient and physician satisfaction. ■

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