

RESEARCH ARTICLE



Colorectal cancer patients' preferences for type of caregiver during survivorship care

T. Wieldraaijer^{a*}, L. A. M. Duineveld^a, S. C. Donkervoort^b, W. B. Busschers^a, H. C. P. M. van Weert^a and J. Wind^a

^aDepartment of Primary Care, Academic Medical Centre, Amsterdam, The Netherlands; ^bDepartment of Surgery, OLVG Hospital, Amsterdam, The Netherlands

ABSTRACT

Purpose: Colorectal cancer (CRC) survivors are currently included in a secondary care-led survivorship care programme. Efforts are underway to transfer this survivorship care to primary care, but met with some reluctance by patients and caregivers. This study assesses (1) what caregiver patients prefer to contact for symptoms during survivorship care, (2) what patient factors are associated with a preferred caregiver, and (3) whether the type of symptom is associated with a preferred caregiver.

Methods: A cross-sectional study of CRC survivors at different time points. For 14 different symptoms, patients reported if they would consult a caregiver, and who they would contact if so. Patient and disease characteristics were retrieved from hospital and general practice records.

Results: Two hundred and sixty patients participated (response rate 54%) of whom the average age was 67, 54% were male. The median time after surgery was seven months (range 0–60 months). Patients were divided fairly evenly between tumour stages 1–3, 33% had received chemotherapy. Men, patients older than 65 years, and patients with chronic comorbid conditions preferred to consult their general practitioner (GP). Women, patients with stage 3 disease, and patients that had received chemotherapy preferred to consult their secondary care provider. For all symptoms, patients were more likely to consult their GP, except for (1) rectal blood loss, (2) weight loss, and (3) fear that cancer had recurred, in which case they would consult both their primary and secondary care providers. Patients appreciated all caregivers involved in survivorship care highly; with 8 out of 10 points.

Conclusions: CRC survivors frequently consult their GP in the current situation, and for symptoms that could alarm them to a possible recurrent disease consult both their GP and secondary care provider. Patient and tumour characteristics influence patients' preferred caregiver.

ARTICLE HISTORY

Received 21 September 2017
Accepted 8 December 2017

KEYWORDS



Colorectal cancer; survivorship care; patients; preferences; symptoms

Introduction

Colorectal cancer (CRC) is one of the most common types of cancer with well over a million new cases being diagnosed worldwide every year [1]. The number of CRC diagnoses in Europe continues to rise due to an increasing incidence combined with growing and aging populations [2]. Moreover, early detection through screening and improved treatment have led to a decrease in mortality and consequent increase in the number of CRC survivors [1,2].

CRC survivors are patients living with a diagnosis of colorectal cancer after primary treatment and are checked regularly for possible recurrent or metastatic disease [3]. Traditionally, in most countries across Europe, this survivorship care of CRC is organized in a

secondary care setting and consists of periodic CEA blood testing, imaging and colonoscopy [2]. Survivorship care, however, entails more than detection of recurrent disease and should include rehabilitation, management of physical and psychosocial consequences of the disease and its treatment, and management of common comorbidities [4–6]. Primary care providers are used to deliver comprehensive generalist care, including psychosocial support [5]. Therefore, health care providers and policy makers argue that primary care might be a better setting for CRC survivorship care [7–9]. In the Netherlands, each patient is registered with a general practitioner (GP) who is the caregiver of first contact, refers patients to secondary care if necessary, and provides continuity of care after conclusion of treatment in secondary care.

CONTACT T. Wieldraaijer  t.wieldraaijer@amc.uva.nl  Department of Primary Care, AMC-UvA, 1100 DD, Amsterdam 22660, The Netherlands

*All authors contributed equally to this manuscript.

© 2018 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original work is properly cited.

While there is some research that seems to indicate that CRC survivorship care in primary care appears to be safe, adequate and cost-effective [10–12], some caregivers and patients feel reluctant towards primary care-led survivorship care [13–15]. Patients, in particular, seem to be undecided with some favouring secondary care and others favouring primary care [13,16]. It is unknown why certain patients prefer a certain type of caregiver, and to what extent symptoms that patients have influence this preference.

In order to clarify this, we collected cross-sectional characteristics and information of patients that were currently in a survivorship care program after having been treated for CRC and explored their preferred caregiver for a variety of symptoms. The aim of this paper is to assess: (1) what caregiver patients prefer to contact for symptoms during survivorship care, (2) what patient factors are associated with a preferred caregiver, and (3) whether specific symptoms are associated with a preferred caregiver.

Patients and methods

Patients

We performed a cross-sectional study in patients that had been treated with curative intent for colorectal cancer (stages 1–3) at different time points after treatment. Recruitment was done at the outpatient clinics of the departments of surgery, oncology and gastroenterology of six Dutch hospitals. Patients were also eligible if they had a (temporary) stoma or if they had received adjuvant chemotherapy or neoadjuvant chemoradiation. Patients were excluded in case of stage 4 disease, hereditary colorectal cancer, cancer in a patient with inflammatory bowel disease, (sub)total colectomy, history of other primary cancer, or any other condition where specialised survivorship care was needed. The inclusion period was November 2013 until November 2014.

Methods

All patients received written study information. After consent was obtained, patients were asked to complete a survey within one week. This survey contained questions on sociodemographic background and general appreciation of caregivers given on a Likert-scale ranging from 1 (entirely unsatisfied) to 10 (entirely satisfied). For fourteen different symptoms, patients were asked to indicate if they would consult a caregiver, and if so, what caregiver they would consult. The options were ‘nobody’, ‘primary care nurse’, ‘general practitioner’,

‘hospital nurse’ and ‘medical specialist’. More than one option could be indicated for each symptom and patients could comment on their responses. The symptoms that patients were asked about were (1) abdominal pain, (2) fatigue, (3) nausea, (4) diarrhoea, (5) constipation, (6) fever, (7) rectal blood loss, (8) weight loss, (9) pain, (10) reduced stamina, (11) trouble sleeping, (12) fear that cancer had recurred, (13) social issues, and (14) work-related issues.

Information about cancer characteristics, staging, treatment modality, comorbid conditions and medication use was obtained from patients’ hospital records and general practice records.

Statistics

The data were collected using an online survey programme (SurveyMonkey) and analysed using SPSS Statistics 23 and MLwiN version 2.32. We performed an independent samples *t*-test and Chi-squared test for comparison between participants and non-participants. In order to assess caregiver preference based on patient characteristics, we marked all answers as a preference for either (1) primary care (primary care nurse or GP), (2) secondary care (hospital nurse or specialist), or (3) no preference (no caregiver or any caregiver). Using a mixed multinomial model, we then compared odds ratios for caregiver preference for different patient characteristics while taking into account that multiple answers had been given by the same patient.

Ethical statement

The Medical Ethics Committee of the Academic Medical Centre in Amsterdam reviewed the protocol. All participants received study information and provided verbal and written consent.

Results

From the six participating centres, 483 eligible patients were contacted of whom 260 agreed to participate (response rate 54%). Characteristics of participants and non-participants are presented in [Table 1](#). Patients that did not participate were older (average of 72 vs. 67 years, $p < .001$) but otherwise similar to the participating group. Reasons for not participating were: too much effort ($N = 66$), did not wish to disclose a reason ($N = 47$), lack of interest ($N = 41$), the study being too confrontational ($N = 36$), feeling too old or feeble ($N = 20$), or other reasons ($N = 13$).

The average age of the participants was 67 years (range 32–94), and 54% were male. The median time

after surgery was seven months (range 0–60). There were fairly equal number of patients with tumour stage 1–3. One in three participants had undergone adjuvant chemotherapy after surgery. Most participants lived together with someone (77%) and most were retired (74%). Sixty percent of patients had

one or more chronic comorbid condition, most frequently cardiovascular disease (45%), severe arthrosis (16%), or diabetes mellitus (15%). Nearly half of the participants used prescribed medication, with an added quarter of participants using over-the-counter medication only.

Table 1. Characteristics of participants and non-participants.

	Participants (N = 260)		Non-participants (N = 223)	
Age (mean years, SD ^a)	67	(SD 10.1)	72	(SD 10.2)
Male (%)	141	(54%)	105	(47%)
Average time after surgery (months, IQR ^b)	7	(4–13)	6	(4–12)
Tumour stage ^c				
I (%)	73	(28%)	53	(24%)
II (%)	88	(34%)	83	(37%)
III (%)	99	(38%)	87	(39%)
Location of tumour				
Colon	231	(88%)	207	(93%)
Rectum	29	(12%)	16	(7%)
Type of surgery				
(extended) Right hemicolectomy	117	(45%)	99	(44%)
Transverse colectomy	6	(2%)	3	(1%)
(extended) Left hemicolectomy	21	(8%)	25	(11%)
Sigmoid colectomy	55	(21%)	49	(22%)
Recto-sigmoid resection	56	(22%)	41	(18%)
Abdominoperineal resection	5	(2%)	6	(3%)
Patients that underwent neo-adj. CRTx ^d	14	(5%)	11	(5%)
Patients that underwent adj. CTx ^e	86	(33%)	74	(33%)
Living situation				
Living together	199	(77%)		
Living alone	61	(23%)		
Employment status				
Active	46	(18%)		
(Partly on) sick leave	21	(8%)		
Inactive (mostly retired)	193	(74%)		
Educational attainment				
Primary or none	12	(5%)		
Secondary	150	(58%)		
Vocational education	70	(27%)		
University	28	(11%)		
Chronic comorbid condition				
Cardiovascular disease	118	(45%)		
None	105	(40%)		
Severe arthrosis	41	(16%)		
Diabetes mellitus	40	(15%)		
Asthma/COPD	22	(9%)		
Depression	22	(9%)		
Central nervous system disorders	18	(7%)		
Other ^f	64	(25%)		
Stoma	38	(15%)		
Medication use				
Prescribed medication	116	(45%)		
Over-the-counter medication only	67	(26%)		
None	77	(30%)		

^aSD: Standard Deviation;

^bIQR: interquartile Range;

^cTumour stage was defined using the TNM5 criteria;

^dNeo-adj. RTX: neo-adjuvant chemoradiotherapy; given only in rectal carcinoma;

^eAdj. CTx: adjuvant chemotherapy;

^fReported by less than 5% of respondents; renal failure, liver disease, skin disease, peptic ulcers and various other disorders.

Preferred caregiver

Most participants reported to have their GP involved in the course of their disease; 77% had contact with their GP in the weeks before being diagnosed with cancer, and 72% had contact with their GP in the first few weeks after being diagnosed with cancer. Patients' appreciation of all caregivers, given on a Likert-scale from 1–10 was alike; with GPs scoring 8 out of 10 (IQR 7–9), hospital nurses scoring 8 out of 10 (IQR 7–9), and medical specialists scoring 8 out of 10 (IQR 8–8).

The results for caregiver preference are shown in [Figure 1](#). Men, patients older than 65 years, and patients with chronic comorbid conditions preferred to consult their GP, while women, patients with stage 3 disease, and patients that had been treated with chemotherapy preferred their secondary care provider. Lastly, a higher appreciation of their GP was correlated with a preference for primary care consultation (OR 1.24 [1.16–1.34]). Please note, [Figure 1](#) expresses the odds ratios with secondary care preference as a reference; this results in odds ratios higher than one in preference for secondary care, and odds ratios lower than one in preference for primary care.

Type of symptom

[Table 2](#) shows the number of patients consulting a caregiver for each different symptom, and the type of caregiver the patients preferred to consult. More than one type of caregiver could be indicated, so these consultation numbers overlap. Most patients would consult a caregiver for rectal blood loss (N = 252; 97%), and fewest patients would for problems at work (N = 28; 11%). The average number of patients that would consult a caregiver for the fourteen symptoms that they were presented with was 154 (62%).

For all symptoms, 43% would consult their GP and 21% would consult a secondary care provider. For each symptom, patients would rather consult their GP than their secondary care provider, except for (1) rectal blood loss, (2) weight loss, and (3) fear that cancer had recurred. For these three symptoms, there was no preference for type of caregiver. This is shown in the two rightmost columns of [Table 2](#).

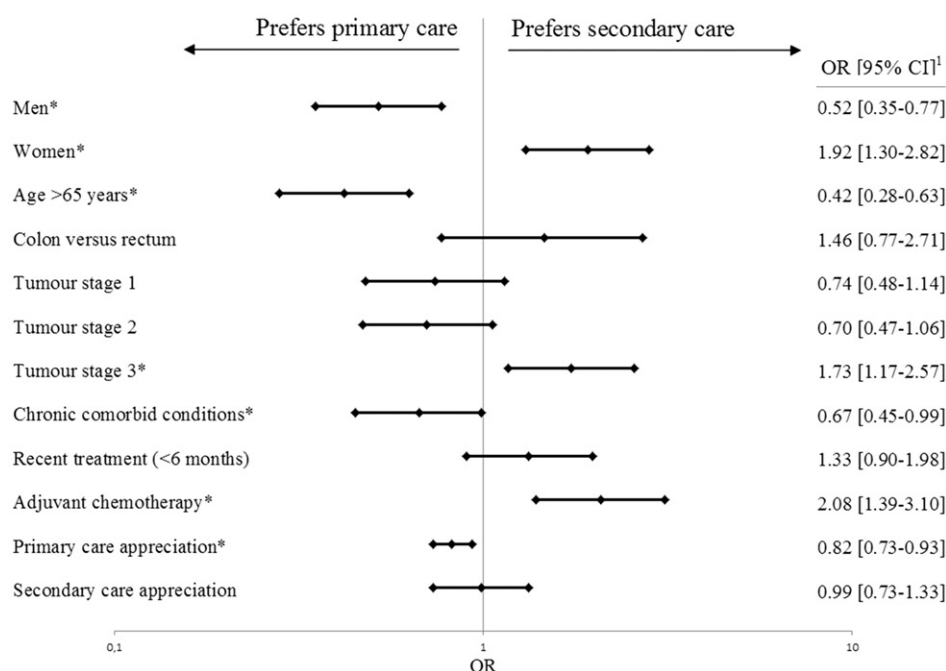


Figure 1. Characteristics influencing preferred caregiver. This figure shows the odds ratios for several patient/cancer characteristics for preferring secondary care over primary care. *Characteristics significantly influencing preferred type of caregiver. ¹Odds ratio with [95% confidence interval].

Table 2. Caregiver consultation per symptom.

Symptom	Would consult a caregiver		Would consult primary care ^a		Would consult secondary care ^a		Primary care preference for this symptom	
	N	(%)	N	(%)	N	(%)	Odds ^c	[CI]
Rectal blood loss ^b	252	(97%)	135	(52%)	139	(54%)	0.97	[0.73–1.28]
Pain	200	(77%)	154	(59%)	72	(28%)	2.30	[1.74–3.05]
Weight loss ^b	194	(75%)	120	(46%)	95	(37%)	1.29	[0.98–1.71]
Abdominal pain	190	(73%)	135	(52%)	73	(28%)	1.98	[1.50–2.62]
Constipation	180	(69%)	130	(50%)	61	(24%)	2.21	[1.67–2.92]
Diarrhoea	165	(64%)	118	(45%)	57	(22%)	2.11	[1.59–2.79]
Nausea/vomiting	162	(62%)	130	(50%)	37	(14%)	3.51	[2.66–4.64]
Fear of recurrence ^b	158	(61%)	96	(37%)	82	(32%)	1.21	[0.90–1.62]
Fever	157	(60%)	130	(50%)	40	(15%)	3.36	[2.54–4.44]
Fatigue	151	(58%)	102	(39%)	32	(12%)	3.19	[2.40–4.24]
Reduced stamina	126	(49%)	111	(43%)	30	(12%)	3.88	[2.93–5.15]
Trouble sleeping	114	(44%)	104	(40%)	17	(7%)	5.87	[4.42–7.80]
Social issues	75	(29%)	73	(28%)	10	(4%)	6.82	[5.04–9.22]
Problems at work	28	(11%)	25	(10%)	4	(2%)	6.63	[4.28–10.29]
Average	154	(59%)	112	(43%)	54	(21%)		

^aMultiple answers could be given, so primary and secondary consultation rates overlap.

^bRespondents significantly more often indicate to consult with a primary care provider for all symptoms, except (1) rectal blood loss, (2) weight loss, and (3) fear of recurrence.

^cOdds with [95% confidence interval] were calculated by comparing the odds that a patient expressed a preference for primary care compared with a secondary care provider.

Discussion

All patients that participated in this study were included in a regular survivorship care program for colorectal (CRC) cancer in secondary care.

Even though these patients were included in a survivorship care program that was organised in secondary care, more frequently, patients indicated they would consult their general practitioner (GP) for the symptoms they were presented with, sometimes alongside a secondary care provider. In part, this could

be the result of the position of the GP in the Dutch healthcare system as mentioned in our introduction, but it also reflects that many patients do not feel that the secondary care provider is the appropriate caregiver to address all of the symptoms that were mentioned [14]. Furthermore, some patients indicated that they would consult their GP first and then discuss whether further consultation would be needed.

Men were more frequently inclined to consult their GP, while women were more likely to prefer secondary

care providers (hospital nurses and specialists). We were surprised to find an influence of gender on caregiver preference. Christen et al. report that young female cancer survivors prefer survivorship care to be organized in a hospital setting over a GP setting more than their male counterparts, and speculate this might be because women expect more supportive care in a secondary care setting [17].

Older patients and patients with chronic comorbid conditions prefer to consult with their GP. Patients with chronic comorbid conditions are likely to be older, and to visit their GP more often than younger patients without chronic conditions [5]. One reason for this preference might be that GP practices tend to be closer to the patients' home, which makes a visit easier for older patients. Another reason could be that patients with certain chronic comorbid conditions, such as cardiovascular disease and diabetes mellitus, are monitored in a regular chronic care programme at their GPs' office, which makes patients more familiar with their GP and lowers the threshold for contact in case of a symptom. In favour of this argument, we found that patients with a preference for GP consultations also tend to appreciate their GP more highly. Importantly, because of aging populations and a growing number of CRC survivors, we may expect the number of older patients with chronic comorbid conditions to increase in the future.

Conversely, patients with stage 3 disease and those who have been treated with adjuvant chemotherapy are more inclined to consult a secondary care provider in case of symptoms. Adjuvant chemotherapy is recommended after curative surgery in stage 3 disease only [2], and involves a period of intensive treatment and frequent visits to the hospital. Patients who have been treated with chemotherapy might prefer a secondary care provider because they experience symptoms more often and more seriously than patients who did not undergo chemotherapy [6] or it could be that the period of frequent hospital visits has made patients more familiar with their secondary care provider(s) and they feel more comfortable in consulting them in case of symptoms. This argument, however, is not reflected in a higher appreciation by those who prefer to consult secondary care providers.

The type of symptom strongly influenced the need to consult a caregiver, from nearly a hundred percent of patients in case of rectal blood loss, to 1 in 10 patients in case of problems at work. Incapacitating or alarming symptoms prompted the highest consultation rates. In all types of symptoms, patients would rather contact a primary care provider except in case of (1) rectal blood loss, (2) weight loss, or (3) fear that cancer had recurred. With these symptoms, patients feel

alarmed of a possible recurrent disease and they would consult primary and secondary care providers equally. In general, the patients in our study appear to be well informed about what physicians regard alarming symptoms, and know when a consultation with a physician is warranted [18]. In a few instances, however, patients indicated that in case of alarming symptoms such as rectal blood loss or weight loss, they would not immediately consult a physician; some commenting that they had been informed that such symptoms might occur, or that they would wait and see if symptoms improved spontaneously.

This study shows that for many symptoms that can occur during survivorship care, patients would consult their GP, including incapacitating and alarming symptoms. The Dutch Health Council, caregiver and patient organizations have suggested that CRC survivorship care could be performed in a primary care setting [7–9]. The results from this study imply that many symptoms during CRC survivorship care would be presented to GPs as it is, even though they are currently not managed in an organized rehabilitation programme in primary care. The step to structured primary care-led survivorship care may be smaller than thought. Certainly, the level of involvement and patient satisfaction with GPs appear to be a good start to build on.

Strengths and limitations

We included a sample of 260 patients, and although non-participants were older than participants, we think the respondents are a reliable representation of patients currently in a survivorship care program; with some patients having recently finished treatment and others having undergone treatment several years ago. Furthermore, this study offers some insight into why certain patients prefer primary or secondary care, and what type of symptoms influence this preference. As far as we know, this is the first study on caregiver preferences in CRC survivors.

A possible source of bias in our results is the response rate of 54%. To this end, we recorded patient characteristics of those not wanting to participate (and only found them to be older than patients that did participate) and presented the reasons for not participating. Another limitation of our study was that the symptoms patients were presented with represent only a selection of symptoms that patients may experience during survivorship care. However, the selection of fourteen symptoms did not attempt to be comprehensive, but rather provide an overview of symptoms in different quality of life domains. Another limitation is that our patients answered questions based on the

situation in the Dutch healthcare system, and might not readily apply to the situation in other countries. Nonetheless, certainly across Europe, many countries have organized primary and secondary care in a similar way. Lastly, we did not consider an average difference in age between men and women when analysing our results. However, given our results, it is unlikely to have affected the conclusions.

Conclusions

Colorectal cancer survivors in the Netherlands are currently included in a secondary care survivorship care programme. For many symptoms that may occur, however, patients would contact their GP. Men, older patients and patients with chronic comorbid conditions more likely prefer to consult their GP, while women patients with stage 3 disease, and patients that have been treated with adjuvant chemotherapy more likely prefer to consult a secondary care provider. Symptoms that alarm patients to possible recurrent disease, such as rectal blood loss, weight loss or the fear that cancer has recurred would prompt patients to consult either both primary and secondary care providers simultaneously, or a secondary care provider directly.

Disclosure statement

The authors declare to have no conflict of interest.

Notes on contributors

T. Wieldraaijer is a researcher and GP in training.

L. A. M. Duineveld is a researcher and GP in training.

S. C. Donkervoort is a gastro-intestinal surgeon working in Amsterdam.

W. B. Busschers is a statistical analyst working at the Academic Medical Center in Amsterdam.

H. C. P. M. van Weert is a professor and head-of-department of the Primary Care Department of the Academic Medical Center.

J. Wind is GP and post-doc researcher at the Department of Primary Care at the Academic Medical Center.

References

- [1] Cancer WHO-IAfRo. GLOBOCAN 2012: estimated cancer incidence, mortality and prevalence worldwide in 2012. 2012. [Internet]; [cited 2017 Aug 4]. Available from: http://globocan.iarc.fr/Pages/fact_sheets_cancer.aspx.
- [2] Oncoline. National guideline colorectalcarcinoma 2014. 2016 [cited 2016 Feb 24]. Available from: <http://oncoline.nl/colorectaalcarcinoom>
- [3] Feuerstein M. Defining cancer survivorship. *J Cancer Surviv.* 2007;1:5–7.
- [4] Ogle KS, Swanson GM, Woods N, et al. Cancer and comorbidity: redefining chronic diseases. *Cancer.* 2000;88:653–663.
- [5] Heins MJ, Korevaar JC, Hopman PE, et al. Health-related quality of life and health care use in cancer survivors compared with patients with chronic diseases. *Cancer.* 2016;122:962–970.
- [6] Wieldraaijer T, Duineveld LA, van Asselt KM, et al. Follow-up of colon cancer patients; causes of distress and need for supportive care: results from the ICARE Cohort Study. *Eur J Surg Oncol.* 2017;43:118–125.
- [7] Health Council of the Netherlands. Follow-up in oncology. Identify objectives, substantiate actions. The Hague (The Netherlands): Health Council of the Netherlands; 2007.
- [8] SCK of KWF Kankerbestrijding. Aftercare in cancer; the role of primary care. Dutch Cancer Society's Signalling Committee on Cancer; 2011; 2011. Available from: <https://www.kwf.nl/SiteCollectionDocuments/rapport-Nazorg-bij-kanker-de-rol-van-de-eerste-lijn.pdf>
- [9] The Dutch College of General Practitioners (NHG). Future prospective General Practitioners care 2022. NHG. Available from: http://www.tkv2022.nl/wp-content/uploads/2012/11/LHV001-37-Toekomstvisie-Totaal-Binnenwerk_021112_WWW.pdf
- [10] Lewis RA, Neal RD, Williams NH, et al. Follow-up of cancer in primary care versus secondary care: systematic review. *Br J Gen Pract.* 2009;59: e234–e247.
- [11] Wattchow DA, Weller DP, Esterman A, et al. General practice vs. surgical-based follow-up for patients with colon cancer: randomised controlled trial. *Br J Cancer.* 2006;94:1116–1121.
- [12] Augestad KM, Norum J, Dehof S, et al. Cost-effectiveness and quality of life in surgeon versus general practitioner-organised colon cancer surveillance: a randomised controlled trial. *BMJ Open.* 2013;3: e002391.
- [13] Wind J, Duineveld LA, van der Heijden RP, et al. Follow-up after colon cancer treatment in the Netherlands; a survey of patients, GPs, and colorectal surgeons. *Eur J Surg Oncol.* 2013;39:837–843.
- [14] Nugteren IC, Duineveld LA, Wieldraaijer T, et al. Need for general practitioner involvement and eHealth in colon cancer survivorship care: patients' perspectives. *Fam Pract.* 2017;34:473–478.
- [15] Duineveld LA, Wieldraaijer T, Wind J, et al. Primary care-led survivorship care for patients with colon cancer and the use of eHealth: a qualitative study on perspectives of general practitioners. *BMJ Open.* 2016;6:e010777.
- [16] Berian JR, Cuddy A, Francescatti AB, et al. A systematic review of patient perspectives on surveillance after colorectal cancer treatment. *J Cancer Surviv.* 2017;1:542–552.
- [17] Christen S, Vetsch J, Mader L, et al. Preferences for the organization of long-term follow-up in adolescent and young adult cancer survivors. *Support Care Cancer.* 2016;24:3425–3436.
- [18] Hall N, Birt L, Banks J, et al. Symptom appraisal and healthcare-seeking for symptoms suggestive of colorectal cancer: a qualitative study. *BMJ Open.* 2015;5:e008448.