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A Systematic Review of Patient Perspectives on Surveillance after Colorectal Cancer Treatment

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Abstract

Purpose—Surveillance after colorectal cancer (CRC) treatment is routine, but intensive follow-up may offer little-to-no overall survival benefit. Given the growing population of CRC survivors, we aimed to systematically evaluate the literature for the patient perspective on 2 questions: (1) How do CRC patients perceive routine surveillance following curative treatment and what do they expect to gain from their surveillance testing or visits? (2) Which providers (specialists, nursing, primary care) are preferred by CRC survivors to guide post-treatment surveillance?

Methods—Systematic searches of PubMed MEDLINE, Embase, the CENTRAL Register of Controlled Trials, CINAHL and PsycINFO were conducted. Studies were screened for inclusion by 2 reviewers, with discrepancies adjudicated by a third reviewer. Data were abstracted and evaluated utilizing validated reporting tools (CONSORT, STROBE, CASP) appropriate to study design.

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Compliance with Ethical Standards:

Conflicts of Interest: The authors declare that they have no conflict of interest.

Statement of human rights and the welfare of animals: This article does not contain any studies with human participants or animals performed by any of the authors.

Results—3691 citations were screened, 91 full-text articles reviewed, and 23 studies included in the final review, 15 quantitative and 8 qualitative. Overall, 12 studies indicated CRC patients perceive routine surveillance positively, expecting to gain reassurance of continued disease suppression. Negative perceptions described in 6 studies included anxiety and dissatisfaction related to quality of life or psychosocial issues during follow-up. Although 5 studies supported specialist-led care, 9 studies indicated patient willingness to have follow-up with non-specialist providers (primary care or nursing).

Conclusions—Patients' perceptions of follow-up after CRC are predominantly positive, although unmet needs included psychosocial support and quality of life.

Implications for Cancer Survivors—Survivors perceived follow-up as reassuring, however, surveillance care should be more informative and focused on survivor-specific needs.

Keywords

Colorectal cancer surveillance; follow-up care; patient-centered care; survivorship

INTRODUCTION

Colorectal cancer (CRC) remains the third most common cancer in the United States.[1] With the 5-year survival rate reaching 90% among patients with localized disease, there are an estimated 1.4 million CRC survivors in the United States.[2] This growing population of cancer survivors provides incentive for improving healthcare delivery. In 2005, the Institute of Medicine released a report to improve the care provided to cancer survivors, increasing awareness of medical, functional and psychosocial needs throughout survivorship.[3]

After curative treatment, recommended CRC surveillance varies with a combination of office visits, laboratory tests, imaging and endoscopy. With a range of different surveillance guidelines,[4–9] the optimal strategy is controversial. Receipt of follow-up care is highly variable, characterized by both over- and under-treatment. Adherence to surveillance guidelines ranges from 12% to 87%.[10] Furthermore, many patients receive non-recommended tests for metastatic disease during follow-up.[11, 12]

Surveillance aims to detect recurrence or new disease at a sufficiently early stage to facilitate curative treatment, presumably to reduce mortality. Among CRC survivors, recurrence rates vary from 10% to over 50% dependent upon patient and tumor-related prognostic factors. [13–15] Recent evidence suggests that intensive follow-up strategies have little or no effect on overall survival, although they may detect recurrence earlier with more salvage surgery. [15, 16] Without a clear survival benefit, these studies call into question the current paradigm of follow-up care. Surveillance may pose risks for over-diagnosis and the need for invasive procedures. Moreover it can lead to significant anxiety. For the 1.4 million CRC survivors in the United States, intensive follow-up may detect only a small number of recurrent cases, with a smaller proportion eligible for resection and an even smaller number achieving cure.

The growing population of cancer survivors and evolving concepts of survivorship care necessitates a full understanding of patient preferences. Given the lack of clarity on optimal

surveillance, widely variable receipt of follow-up care and a need to re-focus care on patient-centered priorities, CRC survivors can provide critical insight into surveillance care. Though systematic reviews have examined survival benefits and adherence patterns associated with colorectal cancer surveillance, there is no systematic review of the patient perspective. The aim of this systematic review was to explore the literature for 2 key patient-centered questions: (1) How do CRC patients perceive routine surveillance following curative treatment and what do they expect to gain from their surveillance testing or visits? (2) Which types of providers are preferred by survivors to guide post-treatment surveillance?

METHODS

Search Strategy

This systematic review was guided by the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) statement. The study protocol was published online in the Prospero International prospective register of systematic reviews.[17] The search strategy was developed by study authors (JB, AC, GC, LO) and run by LO in the following databases: MEDLINE (pubmed.com), Embase (embase.com), Cochrane Central Register of Controlled Trials (CENTRAL) on the Wiley platform, CINAHL (Ebsco) and PsycINFO (Ebsco). Search strategies were adapted for each database from the MEDLINE search strategy (See Online Resource 1). All databases were searched back to their inception; no language or date limits were applied. The search included combinations of terms for colorectal cancer, patient perceptions, and surveillance or follow-up. Patient perception terms included attitudes, expectations, reactions, opinions and acceptance. Surveillance or “follow-up” focused on the receipt of surveillance monitoring, continuity of care and survivorship care for CRC patients following initial treatment.

Inclusion and Exclusion Criteria

Studies were considered eligible if they included: (1) a population of adults (age ≥ 18 years) who had undergone treatment, including surgical resection, for CRC of all stages; (2) data on patient perceptions or expectations of care; (3) surveillance care in the form of follow-up visits, imaging, blood tests and/or colonoscopy; and (4) primary study data (not a review, editorial or commentary). Articles that focused on CRC “surveillance” or “screening” in the setting of inflammatory bowel disease, familial adenomatous polyposis or hereditary nonpolyposis CRC/Lynch syndrome were not considered eligible. Articles were excluded if they failed to provide patient perspectives on surveillance, were not about surveillance care or were abstracts only. A pilot screen of the first 100 citations from the search strategy was performed to refine criteria and ensure consistency between raters. All articles, including the first 100, were subject to the final inclusion and exclusion criteria.

Selection of Studies

Studies were selected through a multi-step process. Two reviewers (JB and AC) independently reviewed titles and abstracts, categorizing articles as “Yes”, “No” or “Maybe” with regard to full-text review. Articles marked “Yes” or “Maybe” were moved to full-text review, performed independently by both reviewers to determine final inclusion in the study.

Discrepancies between reviewers were adjudicated through discussion until consensus was reached, or referred to a third reviewer (GC) as a tie-breaker.

Data Extraction

Two reviewers (JB and AC) extracted relevant information regarding the study country of origin, patient population, eligibility criteria, duration of follow-up, study design, analysis and results. One reviewer completed the extraction while the other verified abstracted data.

Quality of Evidence

Quality assessments were completed using standard frameworks: the CONSORT and STROBE checklists were applied to randomized and observational studies, respectively; qualitative articles were assessed according to criteria on the CASP tool.[18] Using the STROBE and CONSORT checklist, studies were assessed for completeness of reporting on each element, rating each according to the following criteria: “yes, explicitly reported by study authors,” “inferred by raters but not explicitly reported by study authors” or “no, not reported by study authors.” Using the CASP tool, there were 9 components assessed according to: “yes,” “raters unable to determine” or “no”.

RESULTS

Searches returned a total of 3691 articles for title/abstract screen, with 91 selected for full-text review; 23 studies[19–41] were included in the final review (Fig. 1). These latter included 15 quantitative and 8 qualitative studies conducted across the United States (3 studies), United Kingdom (8), Italy (2), Denmark (1), Netherlands (2), Sweden (1), Canada (3) and Australia (3), (Table 1). Among the 15 quantitative studies, the most common research design was a cross-sectional survey (n=10). Among the 8 qualitative studies, 4 utilized semi-structured interviews. The 23 studies were published between 1997 and 2014. All included CRC patients who had undergone treatment, with 4 studies including other cancer types.

Quality of Evidence

There was variability in the quality of evidence across studies. Of the 15 quantitative studies, 13 were observational studies assessed with the STROBE checklist. These ranged in quality from low (5 of 22 STROBE elements) to high (21 of 22). Two randomized trials were assessed with the CONSORT checklist; both reported 16 of 22 CONSORT elements. The 8 qualitative studies were assessed with the CASP tool, ranging in quality from low (5 of 9 CASP elements) to high (9 of 9). The most consistent weakness among the qualitative studies was lack of consideration regarding the relationship between the researcher and the participants (7 studies). (See Online Resource 2)

Question 1: Patient Perceptions of Routine Surveillance

Sixteen studies provided information regarding patient perceptions and expectations of routine surveillance after treatment for CRC. Findings pertaining to both positive and negative perceptions of surveillance are summarized in Table 2.

Twelve (75%) of the 16 studies identified positive perceptions of CRC surveillance. Positive perceptions included high rates of overall satisfaction with follow-up care[19, 31, 32, 36], with one study identifying a correlation between longer patient-physician relationship and perceived quality of follow-up care[19]. Compared to an infrequent follow-up group, patients with more frequent follow up visits had greater confidence in the visits and believed that such follow-up care could improve survival[28]. The majority of patients believed that evaluation for recurrence was the most important reason for follow up[25, 32]. Patients valued receipt of tangible information regarding their disease and surveillance[22, 39], and desired providers to review the information with them, including the nature of tests and frequency of visits[39]. When examined, issues of access to care and frequency of visits were satisfactory[19, 31, 36].

Several articles emphasized that patients receive emotional reassurance from follow-up[24, 28, 31, 33–36]. Followup tests that confirmed the absence of disease were highly valued, described in one qualitative study as “better than winning the lottery”[33]. Most patients reported no more anxiety than usual the week before a visit[31]; fear and worry over follow-up testing was rare[34, 35].

Several studies directly compared the potential stressors of follow-up to the benefits, finding that the stress and anxiety of follow-up tests was perceived as minimal for the benefit received by routine surveillance visits[24, 31, 34, 36]. In a study focused on Carcinoembryonic antigen (CEA) testing, patients explicitly wanted to continue tests despite the possibility of false positive results, and stated they would want to be informed of a recurrence even if it were incurable[34]. Similarly, patients reported a desire to continue regular follow-up visits with their physician regardless of survival benefit and wished to be informed of a recurrence, even if there were no survival or treatment benefit offered[31].

Six (37.5%) of the 16 studies described negative perceptions of follow-up. These included anxiety or stress related to follow-up visits or tests, unmet expectations regarding information exchange, lack of psychosocial evaluation and emotional support and overall dissatisfaction. Patients felt they were not encouraged to ask questions and did not receive satisfactory answers, with most noting that physicians lack knowledge of how CRC affects quality of life[19]. Patients were dissatisfied with available information regarding how treatment would affect their body and sexuality, communication between providers and the extent to which their family was included and considered in care planning[22]. Some patients experienced anxiety and stress associated with follow-up[29, 33]; concern over cancer recurrence was worse among patients with young children[34]. Patients often displayed a state of “guarding” associated with anxiety about recurrence, loss of confidence in health and perceived loss of control over one’s body[38]. Patients felt that evaluating unpleasant emotional states (including anxiety, restlessness and depression) was an important part of follow-up, a priority not shared among surgeons[25]. Though the majority of patients wanted counselling from their physicians, only a minority received such counselling[30].

Question 2: Patient Preference for Delivery of Surveillance by Provider-Type

The question of surveillance care delivery was addressed by 14 studies (Fig. 2). There were 8 quantitative and 6 qualitative study designs, and study findings for this set were heterogeneous. Studies addressed the perceived role of the following 3 provider-types: specialist nurse, the general (GP) or family practitioner (FP) or the specialist (surgeon or oncologist). None suggested complete exclusion of the specialist. Five studies suggested patients were open to or supportive of nurse-led follow-up.[20–23, 37] Benefits to nurse-led follow up included improved access to care, continuity, patient education and perceived support in coping with their disease.[21, 23] Four studies suggested willingness to engage the GP or FP in a larger role in follow-up[26, 27, 33, 40]. This was particularly favored among patients who endorsed a strong patient-physician relationship with their GPs[33], however, some patients expressed concern about losing contact with specialists [27]. Finally, 5 studies demonstrated a preference for specialists[31, 35, 36, 39, 41]. Regardless of having an engaged GP or FP, patients found comfort in the authority and expertise associated with specialist care[39]. Patient satisfaction with follow-up was generally high regardless of the type of provider delivering surveillance care.

There were 3 studies examining quality of life (QOL) as an outcome[26, 36, 40] and one examining healthcare resource utilization and patient safety[37]. Frequency and timing of follow-up visits did not affect QOL[36]. Comparing GP-led and surgeon-led follow-up, there was no difference in health-related quality of life, anxiety or depression[26, 40]. Compared to surgeon-led follow-up, nurse-led follow up was associated with longer consultation times and more blood tests, though there was no difference in radiologic studies ordered[37].

DISCUSSION

Post-treatment CRC surveillance monitors patients for the development of recurrence, promotes prevention and health maintenance, and provides important emotional and psychosocial support. The 23 articles identified in this systematic review offered insight into patient perspectives on surveillance after CRC treatment. The articles originated from a diverse range of countries using a variety of methodologies. Overall, positive perceptions predominated, with follow-up providing emotional reassurance of being cancer-free. Patients reported high satisfaction with follow-up and believed that continued follow-up was important for the detection of recurrence. There were widely variable preferences for a given type of provider to conduct follow-up surveillance; however, satisfaction was generally high regardless of care by specialists, primary care providers or nurse specialists.

Reassessing the patient perspective on survivorship and follow-up has wide-reaching, international importance. In the United States, the Patient-Centered Outcomes Research Institute (PCORI) places emphasis on patient-centered clinical comparative effectiveness research. Three studies from the United States[19, 32, 35] were included in this review, all demonstrating positive perceptions of surveillance care, with two of the three identifying room for improvement in patient education and information exchange[32, 35]. The National Health Service in the United Kingdom begins its manual on CRC services with a chapter concerning patient-centered care.[42] This review included eight studies from the United

Kingdom[21–23, 27, 31, 33, 34, 38], with findings that reflect a wide range of patient-perspectives, from the positive role of reassurance[31] to the anxieties and guarding experienced by survivors[38]. A Canadian report called for better identifying survivors' needs during follow-up, developing and implementing appropriate models for care and increasing collaboration between the healthcare system and the community.[43] Three Canadian studies[24, 30, 39] underscore the positive importance of follow-up for CRC survivors and the need to improve patient education. Given high survival rates and an aging global population, many countries have responded with a renewed focus on the patient.

The optimal follow-up strategy after treatment for CRC remains controversial. A 2016 Cochrane systematic review of 5403 CRC patients in 15 randomized controlled trials found that despite more salvage surgery with intensive follow-up, there was no significant difference in overall or relapse-free survival compared with less-intense followup.[16] From the specialist provider's perspective, follow-up for the detection of local recurrence or distant metastasis may not be justified if increased intervention has no effect on survival. In contrast, the patient perceives follow-up for a complimentary, but not identical, purpose—confirmation of a disease-free state, the value of which extends beyond survival alone. Primary care providers and specialist nurses could potentially bridge this gap, however, there is considerable variability in perceived roles and responsibilities among PCPs and specialists regarding surveillance care[44]. A survey of cancer specialists in Canada found that at least half believed primary care providers may better deliver psychosocial support for colorectal cancer survivors[45]. In a nationally-representative US sample, approximately half of oncologists and primary care providers self-report providing broad psychosocial care to cancer survivors, however, both groups saw themselves as the main providers[46]. Beyond the need to educate providers, improved survivorship care will require better coordination and delineation of different roles in multidisciplinary management. Furthermore, this review identified variability in preferences for specialist, nurse and GP-led surveillance, yet persistently high rates of satisfaction for different provider-types across studies. Opportunities for future work exist in educating patients about the potential roles for multiple different provider-types and further evaluating patient perspectives on their follow-up needs. Research on decision-making interventions must incorporate patient perspectives, as tools that rely solely on the likelihood of recurrence and potential for cure may inadequately address survivorship needs.

The follow-up visit presents an opportunity to fulfill unmet patient needs after treatment for CRC. Beyond reassurance that patients remain cancer-free, the visit provides an opportunity for education, rather than delivery of a binary answer. Many patients are unaware how recurrence risk changes over time. For example, conditional survival of stage IIIC colon cancer improves dramatically from 42% to 80% over the first 5 post-treatment years,[47] with similar improvements in rectal cancer[48]. This review identified room for improvement in information exchange, sensitivity toward psychosocial and quality of life issues and emphasis on general health maintenance and prevention. Failure to address psychosocial concerns can have significant health consequences on depression and anxiety[49], quality of life[50], adherence to recommended surveillance protocols[51] and even survival[52–54]. The Institute of Medicine has highlighted psychosocial care as a critical component of survivorship care[3] and subsequently produced important guidance

on the development and implementation of survivorship care plans[55]. Key areas for improvement at the provider-level may include better coordination in follow-up visits, utilizing multidisciplinary healthcare professionals to implement screening for psychosocial distress, and better tailoring follow-up care to the individual patient[56]. Further advances may require engagement of professional organizations in developing and disseminating coordinated efforts such as best practice guidelines.[57] Finally, incorporating patient-priorities into survivorship care demands continued focus on better understanding patient-perspectives. This review identified studies with wide-ranging quantitative and qualitative methodologies, however, many quantitative studies focused predominantly on satisfaction and quality of life. The field of survivorship care, including its related literature, may benefit from research that expands beyond these concepts, reaching to improve processes of care (e.g., individualized decision support tools) and outcomes that matter most to patients (e.g., patient-reported outcomes). Focusing on patient-centered priorities may provide new purpose for routine follow-up care in the face of equivocal survival outcomes.

This study has several limitations. First, the generalizability of these findings across healthcare systems is uncertain. Single vs multi-payer systems differ significantly in the distribution of costs; single-payer systems have greater incentive to maximize the role of primary or nursing care. Hence, our findings related to patient preferences for a given provider-type may have less direct relevance in the United States, where not all patients have access to primary care. Second, patient perspectives are subjective endpoints, posing a challenge to the reproducibility of our review. We attempted to minimize bias with the development of a review protocol,[17] and by conducting the review in duplicate. Third, use of qualitative studies in a systematic review is challenging. Despite debate, qualitative studies can provide critical data otherwise unrepresented through quantitative methodologies.[58–60]

In conclusion, this systematic review indicates that CRC patients hold a positive view of follow-up care as a mechanism to provide reassurance. However, there is a persistent need to improve patient-centeredness by enhancing communication about the expectations for surveillance and increasing sensitivity to psychosocial and quality of life concerns.

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Figure 1.

Flowchart.

Search criteria were applied to PubMed MEDLINE, Embase, CENTRAL, CINAHL and PsycINFO for a total of 3691 citations. The titles/abstracts were screened, with 91 articles selected for full-text review, and 23 articles included in the final review.

Figure 2.
Patient preferences on provider-type delivering surveillance care.
Fourteen articles addressed preferred provider-type to guide post-treatment surveillance: specialists (including surgeons and oncologists), primary care providers or general practitioners (GPs), and nurses or nurse-specialists (RNs)

TABLE 1

Characteristics of Included Articles

First Author, Year	Study Design	Study Population	Country	Stated Study Aims	Results
Arora 2011[19]	CS survey	N=623, leukemia, bladder and CRC pts, (n=373 CRC), dx 1999–2001 (2–5 years prior)	US	1. To develop/test a survey to assess cancer survivors' perceptions of quality of follow-up (FU) care; 2. To identify sociodemographic, clinical and FU care-related factors associated with quality assessments; 3. To evaluate the association between assessments of quality with overall ratings of care.	Perceived quality of care was positive on 9 of 11 scales, lowest for discussions about health promotion and physician knowledge of the whole patient. Duration of the pt-physician relationship was significantly associated with survivors' quality assessments.
Baravelli 2009[20]	CS survey	N=20, CRC pts, (unknown survivorship duration)	Australia	To establish the acceptability of survivorship care plans (SCP) within a local population [...] To explore the attitudes of CRC survivors, GPs, and hospital-based healthcare professionals [...] regarding adequacy of current information and FU care, and views regarding the development and communication of a SCP.	Survivors supported the need for SCPs, and the need for psychosocial and supportive care. No consensus was reached on who should prepare and discuss the SCP with survivors.
Beaver 2010[21]	In-depth interviews	N=27, CRC pts, mean time from dx 26 months	UK (England)	To explore pt perceptions of experiences of FU care after treatment for CRC	The dominant theme ("knowing what to expect") emerged with sub-themes (living with altered bowel function, learning through trial and error, and information and support from specialist nurses). The colorectal nurse specialist was considered vital for continuity of care and tailoring information to individuals.
Beaver 2011[22]	CS survey	N=187 CRC pts, mean time from dx 34.9 months	UK (England)	To explore pt satisfaction on different aspects of FU service provision following treatment for CRC and amenability to an alternative strategy for FU care	There were high rates of satisfaction on most outcomes, but suboptimal satisfaction related to genetic risk, sexual attractiveness and self-care. There was high satisfaction with nurse specialists and acceptance of nurse-led telephone FU.
Browne 2011[23]	Semi-structured interviews	N=19, CRC pts, FU at 12-months after dx	UK (Scotland)	To explore CRC pts' experiences of psychosocial problems and their management in primary and specialist care	Physical, psychological and social needs were identified. Participants noted GPs were less involved but still provided support after treatment; the clinical nurse specialists provided continuity and psychological support.
Cardella 2008[24]	Retrospective cohort	N=96, CRC pts, median FU 34 months	Canada	To evaluate compliance with a CRC FU protocol adopted by a multidisciplinary gastrointestinal	Guideline surveillance targets were met for 70% of clinic visits, 49% of carcinoembryonic antigen (CEA)

First Author, Year	Study Design	Study Population	Country	Stated Study Aims	Results
				cancer group, to describe pt and physician perspectives on CRC FU, and to examine perceived barriers to adherence with CRC FU	determinations, and 62% of imaging studies. Barriers to FU included access to testing and confusion about which provider ordered investigations.
DiFabio 2008[25]	CS survey	N=62, CRC pts, mean 37.2 months since treatment (range 14–74)	Italy	To analyze pts' self-reported QOL during long-term FU and investigate surgeons' awareness of pts' needs	Rectal cancer pts reported lower QOL for defecation-related problems than colon cancer pts ($p=0.0001$). There was a mismatch between pt- and surgeon-perceived importance of addressing emotional problems: 26% of pts believed addressing emotional problems during FU was important, neglected by surgeons ($p=0.03$).
Gall 2007[26]	Quasi-experimental: randomized + pt-preference assignment	N=338, colon cancer pts Randomization: (1) GP FU arm N=97 (2) surgeon (S) FU arm N=107 Pt preference: (1) GP arm N=61 (2) S arm N=74	Australia	To assess HR-QOL longitudinally after treatment for carcinoma of the colon, and pt satisfaction with two different settings of FU (GP vs surgeon)	Elderly, less educated pts preferred GP follow up. No difference in HR-QOL between GP and surgeon groups; no difference in anxiety or depression; pts were highly satisfied in both arms.
Hall 2011[27]	Mixed methods, semi-structured interviews	N=18, (n=4 CRC, n=14 other), (unknown duration)	UK (Scotland)	To explore the views of potential recipients of "shared" FU of cancer (a model using GPs); to conduct a modelling exercise for shared FU and to explore the opinions and experiences of both pts and GPs involved	Pts appreciated having FU available near to home for ease of travel, time-saved, parking and continuity. Pts expressed concern regarding extra training needed by GPs, and loss of contact with specialists.
Kjeldson 1999[28]	CS survey	N=320, CRC pts, mean time since surgery 7.1 years	Denmark	To evaluate the influence of FU examinations after curative surgery for CRC on health-related quality of life (HR-QOL) and to assess the attitude of the pts to FU	Pts with more intense (every 6 months) FU had greater confidence in the check-ups compared with less-intensive (every 5 years). HR-QOL was marginally better (non-significant) for those with intense FU.
LiDestri 2000[29]	Prospective cohort	N=100 CRC pts, mean FU duration 38.4 months (range 12–60)	Italy	To assess whether a postoperative FU program after CRC treatment causes stress or provides reassurance for the pts	Pts may repress worries about cancer; women had higher stress and anxiety scores.
Miedema 2003[30]	CS survey	N=183 cancer pts, (n=22 CRC), mean 6.7 years after dx	Canada	To assess, from pts' perspectives, where gaps exist in cancer FU care and to discover how satisfied pts are with the FU care they received from FPs and specialists	More than a third of participants (36%) expressed uncertainty about which physician was in charge of cancer FU. Majority (80%) would like counselling from family physicians or specialists, only 20% received it. Dissatisfaction higher for family physicians than specialists ($P<.001$).
Papagrigoriadis 2003[31]	CS survey	N=95 CRC pts majority (n=60) had surgery	UK (England)	To investigate pts' views and experiences of FU of CRC, and to	Majority of pts expressed a high degree of satisfaction with hospital FU. Majority (78%) stated they would value

First Author, Year	Study Design	Study Population	Country	Stated Study Aims	Results
		within 3 years of the study		assess their attitudes toward suggested changes to FU policy	knowledge of a recurrence even without survival benefit. Nearly half would reject discharge from FU (48%) or alternative forms of FU such as a specialist nurse (47%).
Pisu 2014[32]	CS survey	N=60 African-American CRC pts, 4–6 years post-dx	US	To explore survivors' understanding of surveillance instructions and purpose of CRC surveillance	Most reported receiving surveillance instructions. Most acknowledged importance of surveillance; there was variability in understanding of surveillance tests, with many relying on physicians to convey instructions.
Rozmovits 2004[33]	Mixed methods: semi structured interviews, survey	N=39 CRC pts, minimum duration FU 2 years	UK (England, Scotland, Wales)	To describe current hospital FU and to explore pts' needs and preferences for FU	Themes identified during pt interviews were the need for a responsive general practitioner and realistic information about recovery, resources and diet. Pts differed in their views of the benefits of hospital FU.
Steele 2007[34]	CS survey	N=91 CRC pts, majority (n=77) treated within 3 years	UK (Scotland)	To increase knowledge of pts' attitudes and preferences towards carcinoembryonic antigen (CEA) monitoring during FU	The majority of pts wanted to have CEA testing as part of routine FU, regardless of uncertainty in prognosis or low cure rate of recurrent disease.
Sierba 2015[35]	Mixed methods: focus groups and interviews	N=22 colon cancer pts, time since dx > 12 months for majority	US	To explore key individual, interpersonal and organizational-level factors related to colon cancer surveillance care and to identify potentially modifiable factors for surveillance care intervention targets	Survivors described strong trust in providers, with variability in how pts defined "survivorship" and "FU". Themes were having a positive attitude, relying on faith, and coping with fears. Interpersonal themes centered on interaction and communication with family and providers.
Stiggelbout 1997[36]	CS survey	N=212 CRC pts, treated within 5 years	Netherlands	To assess the effect of the FU visit on pts' QOL, attitudes of CRC pts toward FU, strength of preference for FU and to identify whether preferences are associated with pt characteristics	Pts reported positive attitude towards FU, including positive interactions with their physician, strong sense of reassurance, little nervous anticipation and few disadvantages. Pts preferred FU, even if it would not lead to earlier detection of recurrence.
Strand 2011[37]	Randomized controlled trial	N=113 rectal cancer pts, (n=56 surgeon FU, n=54 nurse FU)	Sweden	To compare pt satisfaction, resource utilization, and medical safety in pts FU by either a surgeon or a nurse	Pt satisfaction was high for both groups. Consultation time was longer for the specialist nurse (24 vs 15 min, p=.001), with more blood samples taken (29% vs 7%, p=.002). There was no difference in radiologic investigation. 13 of 182 visits required surgeon assistance. There was no difference in diagnosis of metastatic disease across groups.
Taylor 2011[38]	Longitudinal semi-structured interviews	N=16 CRC pts, 12 months post-treatment	UK (England)	To explain how fears of recurrence can affect individuals recovering from curative CRC surgery	Many participants expressed anxiety regarding the unpredictability of cancer recurrence. The primary theme was a state of "guarding", characterized by

First Author, Year	Study Design	Study Population	Country	Stated Study Aims	Results
Urquhart 2012[39]	Mixed methods: focus groups and interviews	N=23 (n=10 CRC, n=13 breast cancer), minimum duration 12 months post-dx	Canada	To explore the views of breast and CRC survivors on their routine FU care, with respect to needs, preferences and quality of FU, and their views on specialist- vs FP-led FU care	Key themes: responsibility of FU care, receipt of information, complexity of care needs, being prepared and informed, the role of the FP in FU. Overall, survivors characterized FU as lacking in information and preparation, with inadequate support. Despite valuing the FP, survivors received comfort and reassurance from continued specialist care.
Watchow 2006[40]	Randomized controlled trial	N=203 colon cancer pts, randomized to GP-led (n=97) or surgeon-led (n=106) FU, minimum duration 2 years	Australia	To determine whether the setting of FU impacts HR-QOL, psychological well-being and satisfaction with care	No significant differences in HR-QOL, anxiety, depression or satisfaction between study arms at 12 or 24 months post-treatment. More fecal-occult blood tests (RR 2.4, 95% CI 1.4–4.4) ordered in the GP-group, more colonoscopies (RR 0.7, 95% CI 0.5–1.0) and ultrasounds (RR 0.5, 95% CI 0.3–1.0) in the surgeon group.
Wind 2013[41]	CS survey	N=186 colon cancer pts, 3–7 years post-surgery	Netherlands	To assess how surgeons, GPs and pts evaluate current surgeon-led colon cancer FU and to list their views on possible future GP-led FU	Pts were satisfied with surgeon-led FU, particularly recurrence detection (94%) and identification of physical problems (85%), however, less satisfied with identification of psychosocial (49%) and social problems (56%). Future GP-led FU was rated positively by 16% of pts, 30% of GPs and 49% of surgeons.

Abbreviations: CRC=colorectal cancer, CS survey=cross-sectional survey, dx=diagnosis, FU=follow-up, FP=family practitioner, GP=general practitioner, HR-QOL=health related quality of life, Pt(s)=patient(s)

TABLE 2**Perceptions of Follow-Up Care**

Theme	Positive perceptions	Negative perceptions
Emotional reactions to follow-up (E.g., positive = reassurance, negative = anxiety)	N=7 (Cardella 2008; Kjeldson 1999; Papagoriadis 2003; Rosmovitz 2004; Steele 2007; Stiggelbout 1997; Sterba 2015)	N=2 (LiDestri 2000; Taylor 2011)
Overall satisfaction or perceived quality of care	N=4 (Arora 2011; Papagoriadis 2003; Pisu 2014; Stiggelbout 1997)	N=1 (Miedema 2003)
Access to care or frequency of visits	N=4 (Arora 2011; Beaver 2011; Cardella 2008; Stiggelbout 1997)	N=0
Follow-up is important to detect recurrence	N=3 (Cardella 2008; DiFabio 2008; Pisu 2014)	N=0
Follow-up is important to improve survival	N=2 (Cardella 2008; Kjeldson 1999)	N=0
Information exchanged during follow-up (e.g., ability to ask questions, questions answered)	N=3 (Beaver 2011; Pisu 2014; Urquhart 2012)	N=2 (Arora 2011; Miedema 2003)
Communication between providers	N=0	N=2 (Beaver 2011; Miedema 2003)
Follow-up includes sufficient sensitivity to patients' quality of life	N=0	N=3 (Arora 2011; Beaver 2011; DiFabio 2008)

N=# Articles with emphasis on positive / negative perceptions according to the stated theme (row).