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The hidden burden: chronic sequelae of colorectal cancer survivorship and the impact on family members—a narrative review

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Abstract

Advances in colorectal cancer diagnosis and treatment have led to a growing population of long-term survivors. Many experience persistent physical and psychological sequelae after surgery, radiotherapy, and systemic treatment, affecting not only patients but also partners, adult children, and other close family members, who often assume caregiving roles. This narrative review summarizes current knowledge on the burden experienced by family members of colorectal cancer survivors. It covers the chronic sequelae most relevant to family life, the psychological burden on caregivers, including depression, anxiety, and fear of recurrence, and the relational and dyadic impact on couples. It also addresses the practical, occupational, and financial challenges faced by families, the protective factors that promote resilience, and current intervention strategies and support models. Registry data consistently show that partners of cancer patients have a higher risk of depression, anxiety, and psychiatric hospitalization, a burden that often persists many years after treatment. Emotional distress within couples, fear of recurrence, and difficulties with intimacy and communication are mutually reinforcing. Everyday challenges such as bowel dysfunction, including low anterior resection syndrome, stoma care, and fatigue, add further strain. Couple-based and digital interventions show some benefit, but effects are generally modest. Across healthcare systems, family involvement in survivorship care remains inconsistent. Surgical and cancer care teams have an important opportunity to identify families at risk early, set realistic expectations, and connect them with appropriate psychosocial support.

Keywords

colorectal cancer, survivorship, family caregiver, low anterior resection syndrome, stoma, dyadic distress, psychosocial oncology, chronic sequelae

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Introduction

Colorectal cancer is the third most frequently diagnosed malignancy and the second most common cause of death from cancer worldwide, with nearly 1.93 million new cases and approximately 904,000 deaths in 2022. Projections point to a further substantial rise by 2050, driven by demographic and lifestyle changes [1, 2]. Stage migration toward earlier detection, combined with advances in minimally invasive and function-preserving surgery, optimized neoadjuvant regimens, and more effective systemic therapy, has yielded five-year relative survival rates exceeding 65% in many high-income settings and above 90% for localized disease [1, 3]. The consequence is a rapidly expanding population of long-term survivors who live for years or decades with the functional and psychosocial consequences of their treatment [4].

These consequences rarely remain confined to the patient. Chronic bowel dysfunction, stoma dependence, urogenital and sexual sequelae, persistent fatigue, fear of recurrence, and financial strain reshape daily life for the household, and partners, adult children, and parents take on informal caregiving roles that may extend for years [5]. Informal caregivers in cancer absorb a well-documented load of practical, emotional, and economic tasks, and their mental and physical health is both an ethical concern and a determinant of patient outcomes [6, 7]. In colorectal cancer specifically, the stigma and intimate nature of bowel and stoma symptoms give the family burden a distinctive profile that remains poorly characterized in clinical practice [8, 9].

The aims of this narrative review are (1) to summarize current knowledge about the impact of chronic colorectal cancer sequelae on family members, including the psychological, relational, practical, and financial challenges experienced by family members; (2) to identify protective factors, review supportive interventions, and propose implications for family-centered survivorship care.

While the psychosocial burden on cancer caregivers has been extensively documented across oncology more broadly, colorectal cancer presents a distinctive combination of chronic sequelae, including bowel dysfunction, stoma dependence, and sexual and urogenital dysfunction, whose intimate and often stigmatized nature likely shapes family life differently than in other cancer types. However, most existing caregiver evidence is either extrapolated from populations combining multiple cancer types or focused on the patient's own outcomes rather than the family's experience. This review brings together, for the first time in a single narrative synthesis, the literature on sequelae specific to colorectal cancer and the family and caregiver burden literature, to make this gap and its clinical implications explicit.

Methods

This narrative review is based on a non-systematic search of the literature, primarily using PubMed and Google Scholar. The reference lists of all included studies and relevant review articles were manually screened to identify further potentially eligible studies. Searches combined terms related to colorectal cancer, survivorship, caregiver burden, family members, and the specific sequelae discussed in this review (e.g., low anterior resection syndrome (LARS), stoma, sexual dysfunction, and fear of recurrence). Searches were limited to papers published after 2010, and there were no language restrictions. Given the broad and multidisciplinary scope of the topic, articles were selected based on relevance to the aims of the review rather than through a predefined systematic protocol. Priority was given to recent systematic reviews, meta-analyses, and large cohort or registry studies where available. Studies were prioritized for inclusion when they reported outcomes specific to colorectal cancer populations; where such evidence was unavailable, studies drawing on mixed cancer populations were included and are identified as such in the text. Given the narrative, non-systematic nature of this review, formal screening using predefined eligibility criteria and multiple independent reviewers was not undertaken; article selection instead relied on the authors' clinical and topical expertise to align sources with the aims of this review.

Chronic sequelae of colorectal cancer relevant to the family

Understanding the family burden requires a clear view of the patient's experience after curative treatment. Table 1 summarizes the main categories of chronic sequelae and their family-level impact.

Table 1. Spectrum of chronic sequelae after colorectal cancer treatment and their domains of impact on family members.

Sequela	Estimated prevalence in survivors	Clinical features	Family and relational impact	Key references
Bowel dysfunction/LARS	50–90% bowel dysfunction and 40–50% major LARS after sphincter-preserving rectal surgery 20–39% bowel dysfunction after colon cancer resection	Urgency, frequency, clustering Incontinence, emptying difficulty	Restricted social and sexual life Partner as 'silent co-pilot' Toilet planning; hypervigilance	[5, 10–15]
Permanent or temporary stoma	15–25% of rectal cancer cases Selected colon cancer	Appliance management, leakage Skin complications Body image change	Intimacy avoidance; stigma Spouse-reported information and support gap	[8, 9, 16–18]
Sexual dysfunction	Erectile/ejaculatory dysfunction in up to 50% of men Dyspareunia/dryness in up to 40% of women	Autonomic and somatic nerve damage Body image issues Fatigue-related reduced desire	Most persistent unmet need Mutual withdrawal if unaddressed Partner rarely prepared	[16, 17, 19–21]
Urinary dysfunction	20–40% after pelvic surgery or radiotherapy ~50% moderate to severe long-term symptoms	Urgency, frequency Incomplete emptying, nocturia	Sleep disruption for both partners Shame; reduced social participation	[22, 23]
Fatigue, CIPN, and chronic pain	Fatigue in 25–40% CIPN in 30–40% after oxaliplatin	Persistent tiredness Sensory/motor symptoms Pelvic or neuropathic pain	Shift of household workload Caregiver fatigue and sleep disturbance Role renegotiation	[4, 24]
Fear of cancer recurrence	Clinically significant in ~45–55% of survivors ~40–50% of caregivers	Intrusive worry, avoidance Scan-triggered distress	Dyadic fear of cancer recurrence loop Predictor of later depression and anxiety in both partners	[25–27]
Psychological sequelae and body image	Depression in ~19%; anxiety in ~21% of long-term survivors (vs. 12.8%/11.8% in matched norm population)	Altered self-image (scars, stoma, functional loss) Low self-esteem	Increased risk of partner depression and anxiety Marital strain	[7, 28, 29]

CIPN: chemotherapy-induced peripheral neuropathy; LARS: low anterior resection syndrome.

The following sections examine each of these sequelae in more detail, beginning with the most prevalent: bowel dysfunction and LARS.

Bowel dysfunction and low anterior resection syndrome

Many colorectal and anal cancer survivors experience persistent bowel dysfunction following treatment, including urgency, frequent bowel movements, incontinence, and difficulties in managing everyday activities [10]. Among patients undergoing sphincter-preserving surgery for rectal cancer, 50–90% develop some degree of bowel dysfunction, and 40–50% meet the criteria for major LARS. LARS is a constellation of urgency, frequency, clustering, incontinence, and emptying difficulties that may persist for years [11, 12]. This wide prevalence range partly reflects definitional heterogeneity: LARS was originally defined pragmatically as disordered bowel function causing quality-of-life detriment, a characterization that does not allow precise prevalence estimation and has prompted efforts toward a more standardized consensus definition [11]. Qualitative studies consistently describe how unpredictability of bowel problems erodes work, sleep, sexuality, social activity, and how the partner becomes a silent co-pilot who tracks toilets, meals, medications, and journeys [5, 13]. Interviews with survivors identify the partner and close family as the single most important buffer against the psychological impact of LARS, while also highlighting the lack

of information many households receive after discharge [5, 14]. Bowel dysfunction may also restrict participation in activities outside the home, creating social difficulties and leading many survivors to avoid restaurants, dinner parties, cinemas, and other social events because of concerns about their bowel symptoms [30].

Stoma-related sequelae

A proportion of colorectal cancer survivors live permanently or temporarily with an intestinal stoma. Stoma construction improves disease-specific outcomes in selected cases but introduces body-image, sexual, occupational, and relational challenges that extend to the spouse or partner [8, 16]. A recent systematic review and meta-analysis confirmed that patients with an ostomy report significantly greater body-image disturbance and sexual dysfunction than their non-ostomy counterparts [16]. Qualitative work with spouses of ostomy carriers describes insufficient information and support, along with restrictions on social and sexual life. It also reveals a frequent mismatch between the clinical focus on the patient and the partner's very practical anxieties regarding odor, leakage, intimacy, and travel [8, 17, 18].

Sexual and urogenital dysfunction

Pelvic surgery and radiotherapy commonly result in erectile dysfunction, ejaculatory disturbance, dyspareunia, vaginal dryness, and urinary symptoms [20, 22, 23]. These effects are compounded by the fatigue, body-image changes, and altered self-esteem associated with stomas and bowel dysfunction [16, 18, 19]. Sexual difficulties are among the most consistently unmet supportive care needs reported by both patients and their partners, which tend to worsen over time when unaddressed, and patients are frequently unprepared for them [17, 19]. A qualitative study found that more than half of male patients did not recall receiving preoperative information about erectile dysfunction risk and emphasized that partner attendance at preoperative counselling facilitated postoperative communication regarding these difficulties [21]. Urinary dysfunction, including urgency, frequency, and nocturia, affects 20–40% of patients after pelvic surgery or radiotherapy, and approximately half experience moderate to severe long-term symptoms. Disrupted sleep, altered social planning, and occasional need for practical assistance with continence products place a tangible burden on partners that is rarely anticipated or addressed in clinical follow-up [22, 23]. When sexual and urinary dysfunction goes unaddressed, the consequences extend beyond the individual patient, affecting intimacy, communication, and everyday family life in ways that partners are rarely prepared for [17, 21].

Fatigue, pain, neuropathy, and fear of recurrence

Cancer-related fatigue, chemotherapy-induced peripheral neuropathy (CIPN), and chronic pelvic pain complete the physical picture for many survivors [4, 24], potentially affecting their ability to maintain precancer levels of activity and participation in everyday life, with possible consequences for partners and family members. Layered over these somatic sequelae is the cognitive and affective experience of fear of cancer recurrence, which has emerged as one of the most prevalent and disabling long-term concerns in cancer survivorship. Fear of cancer recurrence is present in approximately half of survivors and caregivers at clinically meaningful levels and is strongly correlated within the dyad [25, 26, 31].

The psychological burden on family members

The dimensions of caregiver burden in colorectal cancer survivorship are summarized in Table 2.

Table 2. Dimensions of caregiver burden in colorectal cancer survivorship.

Domain	Typical features in colorectal cancer caregivers	Indicative prevalence/effect size	Key references
Psychological—depression, anxiety, fear of recurrence, chronic sorrow	Clinically significant depressive and anxiety symptoms persisting past curative treatment	Depression 30–50% Anxiety up to 50%	[25–28, 32–35]
	Dyadic fear of cancer recurrence; grief reactivation around milestones and scans	Elevated psychiatric hospitalization in spouses of cancer patients (HR 1.3–1.5)	

Table 2. Dimensions of caregiver burden in colorectal cancer survivorship. (*continued*)

Domain	Typical features in colorectal cancer caregivers	Indicative prevalence/effect size	Key references
Relational—communication, sexuality, role strain	Avoidance of difficult conversations	Worse dyadic adjustment with longer disease duration	[36–39]
	Sexual withdrawal; role shift with illness course	Bidirectional distress within couples	
	Bidirectional distress within couples		
Practical—symptom management, logistics	Stoma care, toileting, medication	High task intensity independently associated with increased subjective burden	[6, 40, 41]
	Appointment coordination		
	Information brokerage		
	High task intensity associated with increased subjective burden		
Occupational and financial	Work reduction, leave, early retirement	48% of colorectal cancer informal caregivers report high financial toxicity	[42–44]
	Out-of-pocket costs, reduced household income	25% make major employment changes	
Physical health of caregiver	Sleep disturbance, somatic symptoms	Sustained burden associated with worse caregiver general and sleep health	[6, 34, 40]
	Reduced self-care, delayed own health checks	Strongest in prolonged high-dependency caregiving	
Social—isolation, stigma	Reduced social participation	Lower social support independently predicts higher caregiver distress and fear of cancer recurrence	[34, 39, 45, 46]
	Stigma around bowel and stoma symptoms		
	Loneliness		

HR: hazard ratio.

Each of these domains is examined in turn below, beginning with the psychological burden of depression, anxiety, and psychiatric morbidity.

Depression, anxiety, and psychiatric morbidity

Evidence from population-based registries consistently shows that spouses and close relatives of cancer patients face an elevated risk of psychiatric morbidity. A linked Danish and Swedish registry study of more than 500,000 spouses found an excess hazard of depression, anxiety, and stress-related disorders compared with matched controls, with the highest risks clustering around diagnosis and treatment and persisting during survivorship [28]. This registry-based estimate, drawn from over 500,000 spouses with adjusted hazard ratios and long-term follow-up, offers considerably stronger causal and epidemiological inference than the smaller, single-country correlational sample underlying some of the colorectal cancer-specific caregiver estimates reported below [6]. An earlier nationwide Danish cohort found a 39% increased risk of hospitalization for affective disorders among male partners of women with breast cancer [32], and follow-up analyses of antidepressant initiation corroborate a measurable pharmacological footprint in partners [33]. Although comparable registry work specifically for spouses of colorectal cancer patients is sparser, cross-sectional and longitudinal studies from surgical oncology units consistently report clinically relevant depression in 30–50% and anxiety in up to 50% of caregivers [6, 7, 34].

A longitudinal multicenter study in colorectal cancer demonstrated that caregiver burden follows distinct trajectories, with a substantial proportion of caregivers maintaining moderate-to-high burden levels for more than a year after curative treatment [34]. A separate longitudinal study of primary caregivers during postoperative chemotherapy similarly identified two distinct burden trajectories, with 65.3% of caregivers remaining in a persistently high-burden group; risk factors included lower education, being the patient's adult child, absence of alternative caregivers, and caregiving exceeding 12 hours daily [47]. Patient self-efficacy, social support, and caregivers' own care ability are key modifiable determinants of these trajectories [34].

Fear of recurrence in caregivers

A meta-analysis of caregiver fear of recurrence found that fear of cancer recurrence is at least as common among caregivers as among patients and is strongly associated with depression, anxiety, and impaired quality of life [25]. Within couples, patient and caregiver fear of cancer recurrence levels are dynamically linked, and caregiver fear of cancer recurrence independently predicts later patient distress [26, 31]. These findings have spurred the development of caregiver-targeted fear of cancer recurrence therapies, including online adaptations, whose feasibility is now being tested [27].

Chronic sorrow and anticipatory grief

Beyond diagnostic categories, family members describe a pervasive, cyclical sense of loss, termed chronic sorrow, triggered by anniversaries, scans, scares, and visible reminders of illness [48]. For colorectal cancer, a stoma change, a near-incontinence episode in public, or a delayed follow-up appointment can each reawaken grief for the precancer life. In bereaved caregivers, preloss mental burden robustly predicts postloss distress, underscoring that psychological morbidity during survivorship has prognostic implications for long-term family outcomes [35].

Relational and dyadic impact

Couples, communication, and sexuality

The couple is one of the core units in which colorectal cancer sequelae unfold. Longitudinal dyadic data show that a partner's cancer onset increases depressive symptoms, with the magnitude moderated by preexisting marital quality and by the intensity and structure of caregiving [36]. Communication disturbances are central: avoiding difficult conversations about bowel symptoms, odor, intimacy, and prognosis erodes dyadic coping and predicts worse psychological outcomes for both partners [26, 31, 37]. Sexual difficulties are widespread, under-addressed in routine follow-up, and often act as a silent amplifier of relational distress [16–18].

Dyadic distress and mutual influence

Dyadic distress describes the bidirectional relationship in which psychological distress in one member of a couple influences, and is influenced by, distress in the other, so that patient and caregiver emotional states become interdependent rather than independent [38]. Mixed-methods studies of colorectal cancer patient–caregiver dyads highlight the close interrelationship between patient and caregiver well-being. Patient distress and physical symptom burden predict increased caregiver distress, which in turn may affect survivors' adaptation, self-management, and adherence to follow-up [38]. Furthermore, family resilience and positive relationship dynamics appear to buffer the impact of caregiving demands and reduce perceived burden, highlighting potential targets for family-centered interventions [39].

Practical, occupational, and financial burden

Caregiving for a colorectal cancer survivor with chronic sequelae is a demanding, sustained activity. Tasks range from stoma care, wound management, and medication administration to dietary planning, appointment logistics, and emotional support [6, 40, 49]. The intensity of tasks, the patient's level of dependence, and the caregiver's own health status together drive subjective burden [6, 40, 49].

The occupational and economic consequences are substantial. A cross-sectional study of informal caregivers of individuals with colorectal cancer found high financial toxicity in nearly half of respondents, independently associated with household income, insurance status, perceived stress, and social support [42]. However, as this finding derives from a cross-sectional design, it cannot establish whether financial toxicity precedes or follows psychological and social strain, limiting causal interpretation [42]. Qualitative accounts describe caregivers commonly making substantial occupational adjustments, ranging from negotiating leave and reduced hours to resignation or early retirement, with several caregivers describing these changes as involuntary and accompanied by a sense of loss [43]. Financial toxicity is not simply an

economic problem; it correlates with treatment adherence, mental health, and self-care in both members of the dyad [42, 44].

A practical implication for surgical and oncological teams is that socioeconomic vulnerability is a risk factor for poor family outcomes and should be proactively elicited during pretreatment counselling. Figure 1 illustrates the proposed pathways from treatment-related chronic sequelae to caregiver and dyadic outcomes, operating through modifiable protective factors and moderated by socioeconomic, relational, and health-system factors, with a bidirectional relationship between caregiver distress and patient adaptation.

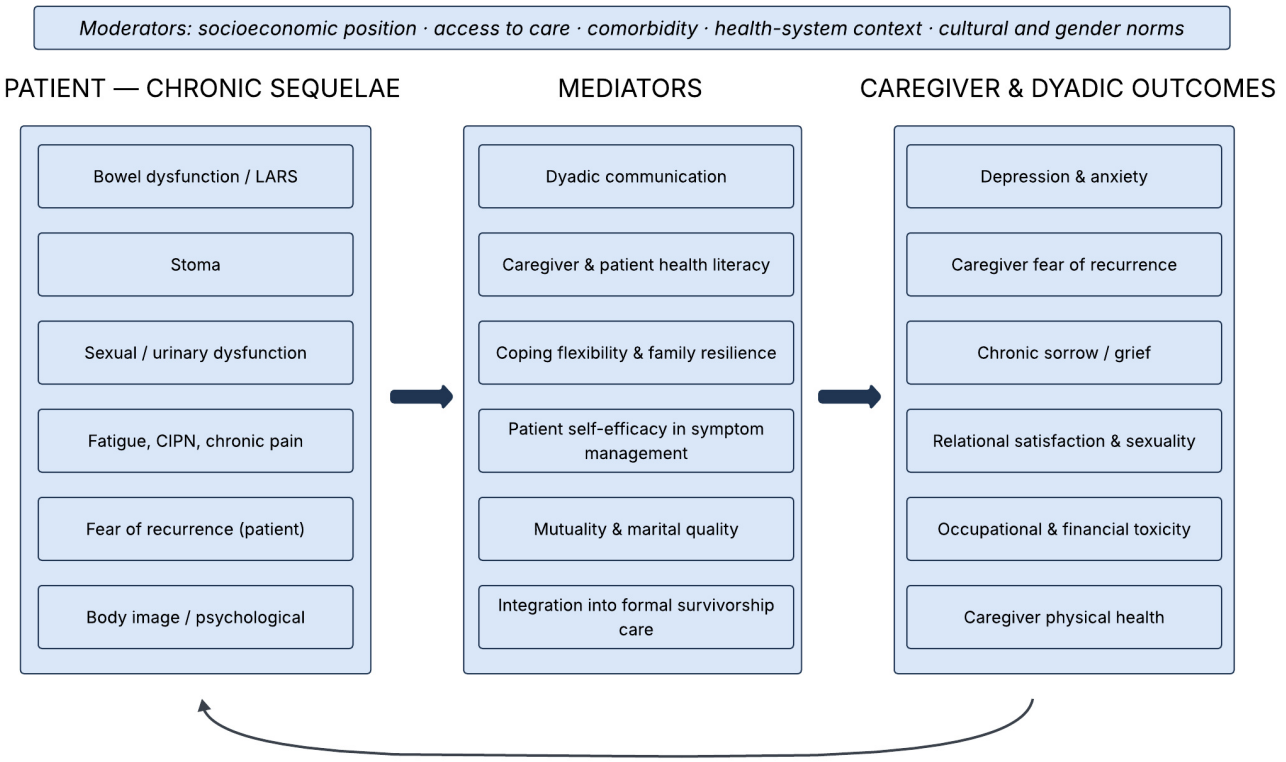


Figure 1. Conceptual model of family burden in colorectal cancer survivorship. Patient-level chronic sequelae shape caregiver and dyadic outcomes through modifiable protective factors, which represent targets for dyadic, nurse-led, or digital interventions. This pathway is moderated by socioeconomic, relational, and health-system factors, and the relationship is bidirectional: caregiver distress feeds back into patient adaptation, treatment adherence, and quality of life. LARS: low anterior resection syndrome; CIPN: chemotherapy-induced peripheral neuropathy.

Protective factors and resilience

Burden is not deterministic. Family resilience, defined as the family's capacity to adapt through shared meaning-making, flexible roles, and supportive communication, is associated with lower caregiver burden and better dyadic adjustment in colorectal cancer [39, 50]. At the individual level, coping flexibility, an internal locus of control, realistic expectations, and perceived social support buffer caregivers against depressive symptoms [51, 52]. Sense of coherence, an individual's confidence in understanding, managing, and finding meaning in stressors, has similarly been identified as a modifiable protective factor, with lower sense of coherence predicting membership in high-burden caregiver trajectories [47]. At the patient level, self-efficacy in managing bowel symptoms and stoma care reduces spill-over distress for the caregiver [34, 39].

Health literacy is another modifiable protective factor. Among cancer caregivers, more broadly, higher caregiver health literacy is associated with better psychological outcomes for patients, suggesting that information- and skills-transfer interventions have value for the whole dyad [53]. For the surgical and oncological team, this means a clear obligation: not only to communicate with patients, but to ensure that family members have understood the information and know how to act on it.

Interventions and models of support

Table 3 summarizes current intervention categories and their evidence base.

Table 3. Intervention approaches targeting family burden in colorectal cancer survivorship.

Intervention category	Target	Delivery mode	Strongest evidence level	Representative outcomes	Key references
Couple-based dyadic coping	Dyad	Face-to-face and/or telephone/online; 4–8 sessions	SR and meta-analysis; RCTs	Small-to-moderate reductions in distress; improved dyadic coping and relationship functioning	[54, 55]
Mutual communication intervention	Dyad	Face-to-face skills training	RCT	Improved intra-couple communication and individual functioning	[56]
Psychoeducation and caregiver skills training	Caregiver	Group or individual; nurse-led; printed/digital	SR and meta-analysis	Improved caregiver preparedness; reduced emotional burden	[57]
Nurse-led survivorship care plans with family component	Patient and caregiver	Integrated across multidisciplinary team pathway	Integrative review	Better care coordination: reduced unmet needs when family explicitly addressed	[57, 58]
Face-to-face peer support	Patient and/or caregiver	Community-based, moderated groups	SR of qualitative studies; RCT meta-analysis	Small but significant improvements in anxiety, depression, and quality of life	[45, 59]
Online peer support	Patient and/or caregiver	Closed/open platforms; 24/7 access	Cross-sectional and qualitative studies	High perceived utility; quality variable; moderation and clinician input improve benefit	[45, 46]
Web-based dyadic symptom management	Dyad	Asynchronous modules; app-based	Feasibility/protocol studies; early RCTs	Feasibility and acceptability demonstrated; efficacy data emerging	[60]
Specialized palliative care with dyadic psychological component	Dyad (advanced disease)	Home-based, multidisciplinary	RCT (Nordic)	Feasible and acceptable; caregiver burden not reduced, informative negative trial	[61]
Caregiver-targeted fear of recurrence therapy	Caregiver	Individual; online or in-person; cognitive behavioral therapy	Pilot/feasibility RCT	Feasible and acceptable in caregivers with clinically significant fear of cancer recurrence	[27]
Disease-specific educational resources (e.g., LARSCAT)	Patient and family	Co-designed printed and digital materials	Multicenter implementation studies	Improved symptom literacy and help-seeking	[14]

RCT: randomized controlled trial; SR: systematic review; LARSCAT: low anterior resection syndrome project of the Catalan Society of Surgery.

The evidence for each intervention category is discussed in more detail below, beginning with dyadic and couple-based approaches.

Dyadic and couple-based interventions

A systematic review and meta-analysis of couple-based dyadic interventions across cancers reported small-to-moderate reductions in psychological distress among both patients and partners, with stronger effects for structured, theory-based programs delivered face-to-face or via blended formats [54]. In colorectal cancer specifically, a randomized controlled trial evaluated a dyadic coping intervention delivered to 226 couples over six weekly sessions, demonstrating significant improvements in dyadic coping, adaptive outcomes, and relationship functioning [55]. A separate mutual communication intervention was feasible, acceptable, and beneficial in an Asian cohort [56]. However, this evidence base remains limited: trials are few, sample sizes modest, follow-up largely short-term, and effects are consistently characterized as small-to-moderate rather than robust [54, 55]. Web-based dyadic programs targeting psychoneurological

symptoms during chemotherapy are now being evaluated, with the potential to lower access barriers [60]. Preferences for supportive interventions often include joint sessions, communication support, symptom management training, and flexible modes of delivery [38].

Peer support, self-help groups and digital resources

Peer support, whether face-to-face, telephone-based, or online, has a small but significant positive effect on anxiety, depression, and quality of life among cancer survivors and their families, with the most consistent effects in face-to-face settings and for cancer-specific quality-of-life outcomes [59]. Online peer groups offer flexibility and round-the-clock access but vary widely in information quality and can expose members to distressing content; moderator training and selective clinician involvement improve their utility [45, 46]. Disease-specific educational initiatives, such as the low anterior resection syndrome project of the Catalan Society of Surgery (LARSCAT), illustrate the value of structured, co-designed resources for patients and families coping with bowel dysfunction [14].

Integrating family members into survivorship care

Meta-analytic evidence shows that structured interventions, including psychoeducation, skills training, and nurse-led support, improve caregiver preparedness and reduce emotional burden across cancer types [57]. Advanced practice nurses are well-positioned to design and coordinate survivorship care plans that include explicit family components, such as education on chronic sequelae, goal-setting, symptom monitoring, and referrals for psychological, sexual, and social support [58]. In the Nordic context, home-based specialized palliative care augmented with a dyadic psychological intervention was evaluated in a randomized controlled trial. Although the intervention did not reduce overall caregiver burden in advanced disease, it highlighted the feasibility and acceptability of systematically addressing the dyad rather than the patient alone [61].

Implications for surgical and oncological practice

Based on the evidence reviewed, several considerations may be relevant for clinical practice. First, including the family as part of pretreatment counselling, with realistic discussion of expected chronic sequelae such as LARS, sexual dysfunction, fatigue, and fear of recurrence, may help set expectations for both patient and partner [21]. Second, given the documented burden of psychological distress and financial toxicity among caregivers, screening with brief, validated tools, such as the Distress Thermometer or the Zarit Burden Interview, during follow-up could be considered to identify families in need of support [28, 34]. Third, clear referral pathways to psycho-oncology, stoma care specialists, sexologists, social workers, and peer-support programs may facilitate access to relevant support for affected families. Fourth, socioeconomic vulnerability and caregiver health literacy appear to be relevant factors that could inform which families may benefit from closer follow-up [53]. Finally, extending the scope of multidisciplinary team meetings to include survivorship issues, supported by structured communication templates, could be a way to ensure these topics are not overlooked [62].

Figure 2 presents a pragmatic family-centered survivorship care pathway anchored in the surgical and oncological team, organized across four phases from the perioperative period to long-term follow-up, with explicit caregiver-focused actions at each phase.

Gaps and future directions

The evidence reviewed varies substantially in methodological strength: population-based registry data on caregiver psychiatric morbidity are robust and longitudinal, whereas most colorectal cancer-specific findings on caregiver burden, dyadic distress, and intervention efficacy rely on smaller, cross-sectional, or single-country samples with short follow-up. This imbalance, together with the frequent reliance on evidence extrapolated from mixed-cancer populations, shapes the priorities outlined below.

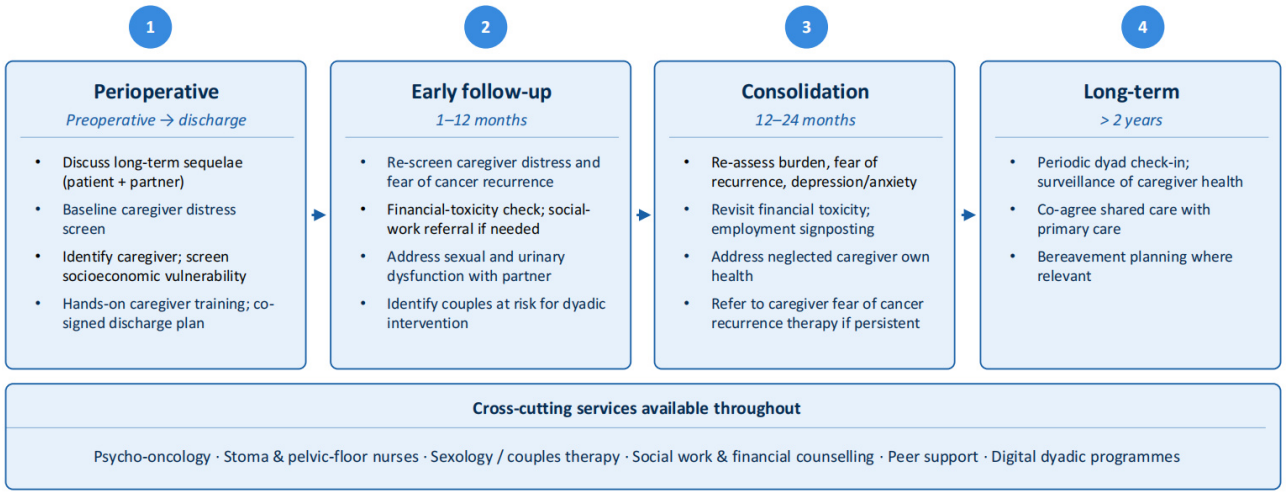


Figure 2. Pragmatic family-centered survivorship care pathway after colorectal cancer. Four phases of caregiver-focused actions are anchored around the surgical and oncological team, spanning the perioperative period to long-term follow-up (> 2 years). Cross-cutting support services are available throughout all phases.

Despite considerable progress, important gaps remain. First, longitudinal caregiver cohorts specific to colorectal cancer are still scarce, and most data are extrapolated from mixed-cancer studies. Second, male caregivers, minority and migrant families, single survivors without cohabiting caregivers, and sibling or adult-child caregivers are systematically underrepresented. While a substantial body of literature addresses children's and adolescents' psychological adjustment to parental cancer broadly, evidence specific to children of colorectal cancer patients is lacking, and existing findings are extrapolated from mixed-cancer populations. Similarly, caregiver burden within multigenerational households and across diverse cultural settings remains underexplored. Third, high-quality randomized trials of family-centered interventions with durable endpoints and economic evaluation remain limited in colorectal cancer [54, 55]. Fourth, the digital revolution in cancer care, encompassing remote monitoring, AI-assisted symptom tracking, and online peer communities, creates opportunities for families but also risks of digital exclusion and information overload that warrant explicit study [46, 60]. Finally, there is a need for robust, culturally sensitive instruments to capture family-level outcomes beyond individual questionnaires, including dyadic and systemic measures [39, 41]. This gap mirrors a broader pattern in colorectal cancer survivorship research more generally, where even patient-reported outcome measures have been shown to under-capture psychosocial constructs such as fear of recurrence, financial strain, and social reintegration [63].

Nordic health systems, with universal coverage, population-based registries, and mature survivorship research infrastructure, are uniquely positioned to generate such evidence, linking surgical, oncological, prescription, and sociodemographic data across patients and cohabiting relatives [28, 32, 33, 41].

Limitations

This review has several limitations inherent to its narrative design. The non-systematic literature search means relevant studies may have been overlooked, and selection bias cannot be excluded. As detailed above, much of the evidence is drawn from mixed-cancer populations, limiting direct transferability. As with any narrative review, interpretation bias is a risk, since the synthesis reflects the authors' judgment in weighting and selecting evidence. Finally, the available literature on caregiver burden in colorectal cancer is still limited, and conclusions should be interpreted with caution pending more and higher-quality evidence in this specific population.

Conclusions

Improvements in colorectal cancer survival have created a new clinical reality in which the long-term outcomes of treatment are experienced by both the patient and the family. Chronic bowel, urogenital, sexual, and emotional sequelae translate into measurable psychological morbidity, dyadic distress,

occupational disruption, and financial strain for caregivers. The evidence base now includes robust registry data documenting excess psychiatric risk among spouses of cancer patients, longitudinal cohort data characterizing caregiver burden trajectories in colorectal cancer, and an emerging but modest portfolio of dyadic and family-centered interventions. Surgical and oncological teams are well positioned, and arguably obliged, to move the family from the periphery to the center of survivorship care. In practice, this means structured pretreatment counselling, routine caregiver screening with validated tools, and clear referral pathways to psycho-oncology and stoma care specialists. Research priorities include longitudinal, colorectal cancer-specific caregiver cohorts capturing underrepresented groups, adequately powered randomized trials of family-centered interventions, and validated family-level outcome measures.

Abbreviations

CIPN: chemotherapy-induced peripheral neuropathy

HR: hazard ratio

LARS: low anterior resection syndrome

LARSCAT: low anterior resection syndrome project of the Catalan Society of Surgery

RCT: randomized controlled trial

SR: systematic review

Declarations

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Author contributions

LWF and BTO: Conceptualization, Data curation, Investigation, Writing—original draft, Writing—review & editing. JR: Conceptualization, Writing—original draft, Supervision, Writing—review & editing. All authors read and approved the submitted version.

Conflicts of interest

The authors declare they have no conflicts of interest.

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Consent to participate

Not applicable.

Consent to publication

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