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The impact of surviving bowel cancer on occupation: A scoping review

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Abstract

Introduction: The number of people surviving bowel cancer is increasing globally, with many of those affected living with long-term psychological and physical sequelae that potentially disrupt occupations.

Method: A scoping review – guided by Arksey and O'Malley's methodological framework – was conducted to provide an overview of what is known about the impact of having had bowel cancer on occupations, and to reveal the potential role of occupational therapy. A systematic search of four databases and a grey literature repository generated 244 results. Applying inclusion and exclusion criteria, 33 items addressing bowel cancer and occupations were selected and thematically analysed.

Results: Researchers have identified six domains of occupation that are impacted by bowel cancer (social activity, physical activity, sexual activity, employment and role functioning, physical functioning, and self-care) but survivors report a distinct lack of health professional support after completion of medical treatment and being left to devise self-management strategies to accommodate the long-term effects of their cancer.

Conclusion: The sequelae of bowel cancer can have a significant impact on occupational participation. There is scope for increasing and improving occupational therapy input to assist people with cancer-related loss of function to re-engage in valued occupations and improve wellbeing.

Keywords

Bowel cancer, survivors, occupations, occupational therapy

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Introduction

Bowel cancer – also known as colon, rectal or colorectal cancer (CRC) – is one of the most common cancers worldwide (Beesley et al., 2017; Pereira, 2014). Treatment for the disease is associated with various psychological and physical sequelae that may continue for years and have a considerable impact on occupational participation, such as impairing the ability to maintain employment and other productive activities (Beesley et al., 2017; Hornbrook et al., 2017). Leisure occupations can also be significantly impacted, with a reduced ability to participate in travel, recreation, sports, social and intimate activities (Shipp et al., 2015; Silver and Gilchrist, 2011). Difficulties managing activities of daily living (ADL) such as showering, dressing and eating are also common (Hubbard et al., 2010; Silver and Gilchrist, 2011). This is particularly so for older people (over 65 years old) due to functional impairment decreasing their ability to self-care in the home (Cabilan and Hines, 2017); this is a significant consideration as more than 50% of colorectal cancers are diagnosed after age 70 years (Kolligs, 2016).

Bowel cancer treatment commonly involves surgery, chemotherapy and/or radiotherapy, depending on tumour location and size, and cancer stage. One of the most radical and life-altering treatments is the surgical creation of an ostomy in the abdomen for the discharge of body wastes. The ostomy may be permanent or temporary to allow the bowel to heal and involves a stoma (the end of the bowel which protrudes through the abdomen) emptying into a bag/pouch that is regularly emptied or changed.

Early detection and advances in medical care have resulted in increasing numbers of people living longer after initial treatment completion (Lee et al., 2015), meaning that cancer is now considered a chronic condition (Hubbard et al., 2010; Pereira, 2014). The wellbeing of those affected is therefore of increasing importance (Lee et al., 2015), and yet the period following treatment is often not prioritised in cancer care, with emphasis instead on the acute treatment phase and end of life (Knowles et al., 2013).

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Recognition of the long-term effects of cancer and its treatment can contribute to the standard of health professional support provided (Hornbrook et al., 2017). The aims of the authors were to provide a broad overview of what is known about the impact of having had bowel cancer on occupations, and to reveal the potential role of occupational therapy, a profession currently with limited input at all stages following a cancer diagnosis (Pergolotti et al., 2016).

The vast majority of literature refers to those who have had cancer as 'survivors'. However, there is inconsistency regarding when an individual becomes a 'cancer survivor', with definitions beginning at diagnosis, at the end of treatment or after a disease-free period of time (Drury et al., 2017). This review focuses on the period following treatment conclusion – when the immediate sequalae of surgery/chemotherapy/radiotherapy have subsided – to gain an understanding of the longer-term, and potentially variable, occupational impact of bowel cancer.

Methods

A scoping review format was selected to gain a comprehensive understanding and synthesis (Colquhoun et al., 2014) of the published literature addressing bowel cancer and occupations, regardless of study quality. Following this format ensured richness of research findings was prioritised over the assessment of study vigour required in a systematic review (Armstrong et al., 2011; Peters et al., 2015). The scoping review approach allowed for the incorporation of both published and grey literature, making it ideal to inform both practice and further research (Arksey and O'Malley, 2005; Colquhoun et al., 2014; Levac et al., 2010; Peters et al., 2015). Arksey and O'Malley's (2005) framework was employed to provide a structured format for locating, analysing and summarising literature (McKinstry et al., 2014), and involved five stages: (a) identifying the research question; (b) identifying relevant studies; (c) study selection; (d) charting the data and (e) collating, summarising and reporting the results. This process is iterative, with steps revisited as necessary.

Identifying the research question

The broad research question, 'How are people's occupations affected by having survived bowel cancer?' was developed to achieve breadth and depth of the topic (McKinstry et al., 2014).

Identifying relevant studies

Initially, CINAHL Complete and MEDLINE databases were searched to locate studies of the occupations of participants with bowel cancer, generating 924 results. To reduce the amount of irrelevant studies generated, studies focused on cancer screening or prevention were screened out using the Boolean operator 'NOT'. See Table 1 for the final search terms.

The final search terms were then also run through AMED and OT Seeker, producing a total of 244 results. This process of revisiting and refining search terms as familiarity of the literature increases is consistent with that suggested by Arksey and O'Malley (2005).

Grey Matter – a newsletter compiled by the New Zealand Ministry of Health library providing access to a selection of NGO, Think Tank and International Government reports (Ministry of Health NZ, n.d.) – was also reviewed, generating a further four references. In addition, the term 'bowel cancer and occupations' was entered into a general Google search, producing references predominantly related to bowel cancer risks for various forms of employment. As these were not relevant to the research question, a further search was performed using the term 'bowel cancer and daily activities', generating over 23,900,000 results. Due to time constraints the first 40 results were reviewed, with three retained. Finally, reference lists were searched, generating a further five studies. One study was included from the primary author's personal library.

Study selection

Titles and abstracts of identified literature were screened by the first author (EM), with those appearing relevant to the research question retained. Secondly, two authors (EM and CH) screened full texts using initially agreed inclusion and exclusion criteria. As familiarity with the text increased, these two authors discussed and refined the criteria. The final inclusion/exclusion criteria are presented in Table 2.

Full texts were then reviewed by EM and CH. Where there was disagreement as to whether a study should be included, consultation occurred between the authors until an agreement was reached. A total of 39 met the inclusion criteria. The study selection process is presented in a PRISMA flow chart (Figure 1).

Charting the data

Data from each of the 39 publications were extracted and charted under the following headings: Author/year, methodology/publication description, location, study population and reported findings related to occupation, and are presented in Table 3. To ensure reliability and consistency, one author (EM) extracted the data and another (CH) verified a 15% sample of publications selected to span the various research methodologies and large to small participant numbers. This process was employed due to second author time constraints and was in keeping with other published scoping review methods (Leppard et al., 2018; Seida et al., 2018). The charting process was iterative, with continual extraction and updating of the table (Levac et al., 2010). During this process the decision was taken to exclude four studies predominantly addressing return to work (RTW)

Table 1. Process for identifying and refining search terms.

Final search terms	Boolean command
'bowel cancer' or 'colon cancer' or 'rectal cancer' or 'colorectal cancer' or 'colorectal carcinoma' or 'colorectal neoplasm'	AND
'occupation*' or 'daily activit*' or 'activities of daily living' or 'ADLs' or 'leisure' or 'social activit*' or 'return to work' or 'employment'	AND
'cancer N5 screening' and 'cancer N5 prevention' and 'epidemiology'	NOT

Table 2. Inclusion and exclusion criteria.

Inclusion	Exclusion
Published in English and available in full text	
Studies published from 2000 onward[a]	
Bowel cancer survivors who have completed primary and adjuvant treatment (reported separately from any who have not completed)	Bowel cancer survivors still receiving treatment not able to be distinguished from those who have completed
Literature that addresses multiple cancers if bowel cancer findings reported to be not statistically different to other cancers	Literature that addresses multiple cancers if bowel cancer findings amalgamated with other cancers
	Individuals with metastatic bowel cancer make up more than 5% of study population (or where proportion with metastatic cancer was unable to be identified[b])
Literature that addresses occupations or daily activities	Studies that focused predominantly on demographics and proportion of people who return to work[b]
	Individuals with recurrent bowel cancer make up more than 5% of study population

[a] The early 2000s saw the advent of platinum-based chemotherapeutic drugs, which induce worse side effects, particularly peripheral neuropathy, which has a close relationship with physical and quality of life impairment. Studies published prior to 2000 may therefore misrepresent the outcomes of individuals diagnosed in the last 2 decades.

[b] Criteria added during data charting process.

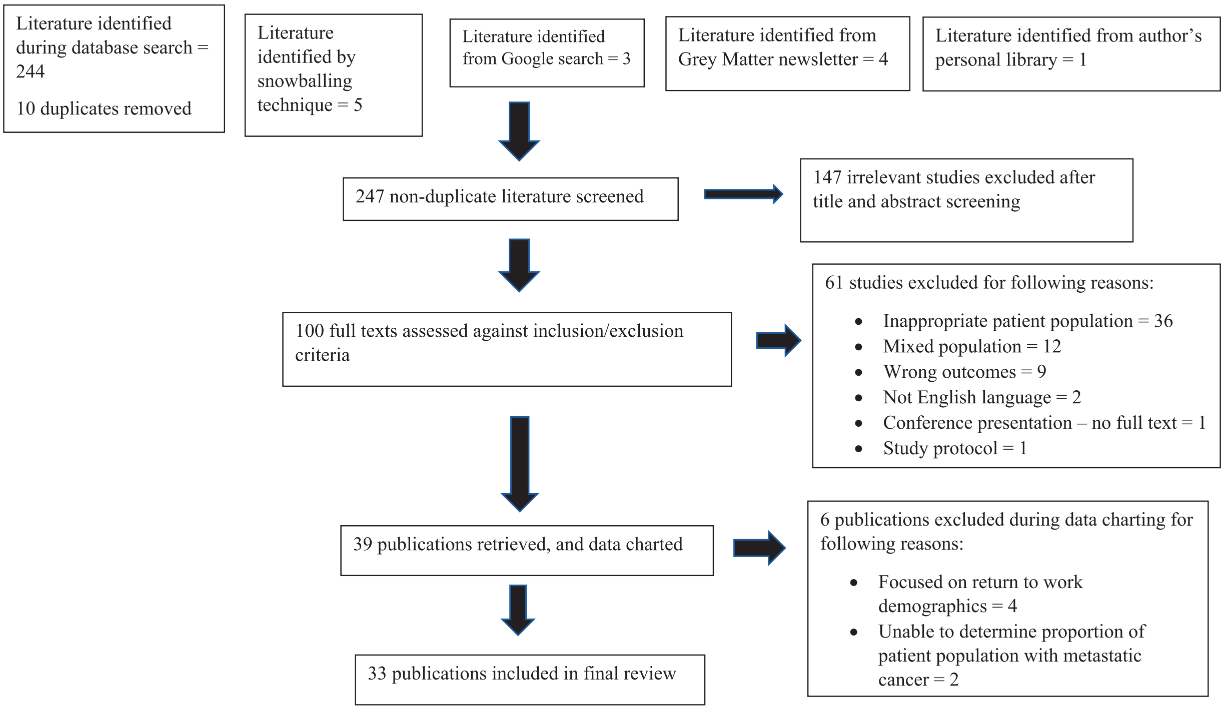

Figure 1. Study selection process.

demographics. This ensured the focus remained on the research question addressing how occupations (in this case work occupations) were impacted, rather than whether or not people returned to work. An additional two studies were excluded as they combined numbers of survivors diagnosed with stages three and four cancer, making it impossible to determine the proportion with metastatic disease. In total 33 articles were included.

Table 3. Literature review findings.

Author/s, year	Methodology Publication description	Origin/location	Study population (Months/years post diagnosis/treatment)	Reported findings related to occupation
Appleton et al., 2013	Qualitative Oncology nursing journal	UK	13 CRC CS, 5 months–5 years post treatment. Mean age = 67 years	• Enabler of transition back to normal roles – making jokes about having cancer, welcoming social attitudes as work/hobbies resumed • Incremental increase in occupation (walk on golf course/pick up golf balls/play nine holes; walk further each day) • Accept requests to talk to other CRC patients/attend support groups/participate in research • Develop strategies to adapt to changes, for example adjust to loss of status with retirement, stop carrying things up/down stairs, use pads/wet wipes (faecal incontinence), not eat as much • Maintain routines and normality (not doing anything different)
Arndt et al., 2004	Quantitative (population-based cohort study) Cancer journal	Germany	309 CRC CS 1 and 3 years post diagnosis 186 CC (12 with ostomy), 119 RC (47 with ostomy) Mean age = 66 years (SD 9.2 years) 241 alive at 3-year follow up Response rate 82% at 1 year and 92% at 3 years	*Functioning: CS vs GP at 3 years (EORTC QLQ-C30 mean scores, 95% CI)* • SF: 72.8 vs 86.8; PF: 78.7 vs 81.0; RF: 78.1 vs 79.9 • Absolute prevalence of functional limitations higher in elderly *RF: 1 to 3 years (EORTC QLQ-C30 and QLQ-CR38 mean scores)* • Ostomy vs non-ostomy: 69.1 vs 78.8 at 1 year; 76.5 vs 78.8 ($p = 0.04$) at 3 years *Attributes to decline in RF and SF:* • Adjuvant chemo- and/or radiotherapy *Sexual activity: 1 to 3 years (EORTC QLQ-CR38 mean scores)* • 38.3 to 30.8 ($p = <0.01$)
Beesley et al., 2017	Quantitative (prospective registry-based study) Psycho-oncology journal	Australia	148 CRC CS in paid workforce 12 months post diagnosis Mean age = 56.3 years (range = 45-64)	• Physical wellbeing significantly worse CS (SF12: 44.8 mean) than GP (52.0 mean) ($p = 0.001$). CS who maintained/increased work had similar physical and mental wellbeing to GP • Functional wellbeing improved significantly more over time in CS who maintained or increased work
Cabilan and Hines, 2017	Systematic review Systematic review database	Australia	CRC CS ≤12 months from end of treatment (date of surgery or last dose of adjuvant treatment)	*Maintenance of functional independence* • Declined from 69.8% to 57% (1 study); decreased from 84% to 26.7% at 3 months, 29.7% at 6 months and 24.4% at 12 months (1 study); declined by 12.8% (not statistically significant) (1 study) • Declined by 57.3% at 3 months, 54.4% at 6 months, 57.2% at 9 months and 59.6% at 12 months (1 study – elderly nursing home patients) *Functional QoL (mean difference from baseline)* • Within 3 months −8.98 (95% CI −18.13, 0.18) (3 studies); at 6 months −3.79 (95% CI −8.67, 1.10) (4 studies); 12 months 15.31 (95% CI −8.08, 38.70) (2 studies) *Social QoL (mean difference from baseline)* • Within 3 months −1.52 (95% CI −4.18, 1.14) (3 studies); 6 months 0.55 (95% CI −1.50, 2.60) (4 studies); 12 months 8.69 (95% CI 1.10, 16.27) (2 studies) *Attributes to decline in physical and functional QoL* • Ageing, poor functional status, comorbidities, advanced stage cancer and adjuvant therapy (3 studies)

(continued)

Table 3. Continued

Author/s, year	Methodology Publication description	Origin/location	Study population (Months/years post diagnosis/treatment)	Reported findings related to occupation
Cengiz and Bahar, 2017	Qualitative Nursing journal	Turkey	12 individuals with ostomy, 9 CRC CS Mean age = 54.41 years (SD = 19.14)	• *Dressing and clothing choice*: Loose clothes to hide ostomy and pouching system; some clothing created pressure against the ostomy • *Bathing*: Only on days when changed pouching system; cover ostomy with a thin film dressing • *Muslim religious practices*: Reluctance to attend prayers with faeces in bag; ablution before every prayer • *Sleep*: Inability to fall asleep, remain asleep or sleep in a favoured position due to fear of damaging ostomy; need to wake up to evacuate pouch • *Sexual activity impairment*: Concern partner disturbed by physical changes in body; loss of libido, retrograde/no ejaculation • *Daily PA*: Reluctance to go out or go for a walk • *Social life*: Avoidance of social activities, keep ostomy secret • Positive impact of support from family/friends • Ostomy management, for example leakage/flatulence – teacher not drinking water during day for fear of leakage
Chambers et al., 2012	Quantitative (prospective correlational survey) Clinical oncology journal	Australia	1966 CRC CS at 5, 12, 24 and 36 months post diagnosis Age categories at 36 months: 20–49 years (7.7%), 50–59 (19.1%), 60–69 (35.7%), 70+ (37.4%) Strength: population-based, large cohort Limitation: low response rate (29% of eligible respondents at 36 months)	• Increased PA over time • Higher levels of somatisation and anxiety associated with lower levels of PA, with further decline if distress increases (but association with PA did not hold for depression or threat appraisal) • Fatigued CS 50% more likely to be inactive or insufficiently active • Positive threat appraisal corresponds to higher PA level
Cotrim and Pereira, 2008	Quantitative (descriptive cross-sectional study with a correlational design) Oncology nursing journal	Portugal	153 CRC CS, 6–8 months post-surgery (47 rectal, 106 colon, 46 with ostomy) Mean age = 64.64 years (SD = 10.74; range = 27–88) 96 informal caregivers	*Function scales (EORTC QLQ-CR 30) ostomy vs non-ostomy:* • PF: 61.1 vs 70.78 ($p = 0.009$) • RF: 19.57 vs 45.95 ($p < 0.001$) • SF: 27.90 vs 43.93 ($p = 0.007$) • Sexual function: 16.29 vs 30.67 ($p = 0.005$)
Dennis et al., 2013	Mixed method cross-sectional survey Oncology journal	Canada	CRC CS: pre-treatment ($N = 54$), undergoing treatment ($N = 62$), finished treatment <6 months ($N = 67$) or >6 months ($N = 178$) Mean age = 69 years (range: 36–91 years)	• 75% moderately active ≥4 times per week (gardening, climbing stairs, walking, housework), 17.5% 1–3 times, 5.3% <1 time • 42.4% vigorously active <1 time per week (less than normal controls), 29.6% 1–3, 18.0% ≥4 times • Bowel issues provided barrier to increasing activity • 39.3% made dietary changes, 21.1% increased PA, 39.1% wanted to increase PA • Lack of support to make lifestyle changes

(continued)

Table 3. Continued

Author/s, year	Methodology Publication description	Origin/location	Study population (Months/years post diagnosis/treatment)	Reported findings related to occupation
Domati et al., 2011	Quantitative (observational retrospective study) Medical journal	Italy	220 CRC CS ≥5 years post-surgery Mean age = 66.6 years (range 43–81) 79.9% CC, 20.1% rectal 10% with permanent ostomy	• *SF-36 average value scoring*: ♂ CS 18 points lower than ♂ GP; ♀ CS 31 points lower than GP; ♀ CS 20 points lower than ♂ CS ($p < 0.05$) • *RF due to emotional health*: ♀ CS 10 points lower than GP ♀; ♀ CS 17 points lower than ♂ CS ($p < 0.05$) *Lifestyle aspects* • Social relations: 14.1% improved, 79.1% unchanged, 2.8% worsened • Cultural relations: 10% improved, 80% unchanged, 5% worsened • Physical interests: 12.7% improved, 80.9% unchanged, 3.8% worsened • Activity: 11.8% improved, 66.4% unchanged, 14.5% worsened • Sexual activity: 4.4% improved, 60.9% unchanged, 31.3% worsened • Religious aspects: 15.9% improved, 75.9% unchanged, 5.5% worsened • Work activity: 3.7% improved, 64.5% unchanged, 31.9% worsened
Grant et al., 2011	Qualitative Oncology nursing journal	USA	33 CRC CS with ostomies ≥5 years post diagnosis Mean age = 69.75 years	• *Eating*: Discover which foods to eat to avoid gas and rapid transit through gastrointestinal tract, limit food to control output, grazing rather than big meals, chew food slowly, not drinking before eating • *Impact on PA*: Change from running to walking; inability to lift heavy weights; ceasing of some activities; resumption of hiking, bowling, gardening after adapting to ostomy • *Employ strategies to avoid offending others*: Swim early in the morning, not revealing presence of ostomy • *Changes in sleep*: Sleep on back to avoid pouch bursting, restlessness at night • *Modify clothing* to protect ostomy from excess pressure and/or wear loose clothes so pouch not seen, self-acceptance and reveal colostomy to clothing sale staff • *Sexual activity*: Reluctance to take off clothes due to partner's reaction, inability to have sex • *Adapting to travel*: Preparation of extra supplies such as clothes, wipes, ostomy supplies; stay at hotel rather than with friends/relatives • Embarrassment when having faecal accidents at work

(continued)

Table 3. Continued

Author/s, year	Methodology Publication description	Origin/location	Study population (Months/years post diagnosis/treatment)	Reported findings related to occupation
Hamaker et al., 2015	Systematic review Geriatric oncology journal	The Netherlands	CRC CS	• *Reduction in PF after treatment for RC*: Mean score 7% lower than baseline at 6 months, 5% lower at 12 months using QLQ-C30 or SF-36/SF-12 (16 studies). −4%/−10% respectively using SF-36 (1 study of CC only); −23%/−7% respectively using SF-36 (1 study of CRC) • *Reduction in RF after colorectal surgery* (SF-36 or QLQ-C30, 16 studies): 8% lower at 6 months (range −23% to 6%), 5% lower at 12 months (range −17% to 10%); values returned to baseline at 1 year (1 study of CC); mean −46% at 6 months, −10% at 1 year (1 study of CC and RC) • Elderly patients experience the greatest and most persistent decline in self-care capacity (up to 61% reduction in IADL at 1 year post diagnosis, two studies) • 1 year post diagnosis not resumed housework (40%), driving (23%), shopping (50%) (1 study) • *Factors associated with delayed/greater loss of physical or role functioning*: Pre-op radiotherapy, older age, being single or ♂ (6 studies)
Hardcastle et al., 2017	Qualitative Psycho-oncology journal	Australia	24 CRC CS completed treatment within past 2 years Mean age = 69.38 years (SD = 4.19)	• Developing fixation with bowel function • Need for easy access to toilet facilities affecting social life
Hewes and Graney, 2014	Opinion piece Rehabilitation counselling journal	USA	Author CRC survivor	• Adaptations to job role suggested, for example reduce weight lifting requirements, assignment to alternative tasks • Extended bathroom time/privacy issue concerns on RTW • Changed experience of showering due to difficulty observing stool in pouch
Ho et al., 2016	Qualitative Psycho-oncology journal	Canada	30 CRC CS completed treatment Median age = 60 years (range 41–75) 57% CC, 43% RC.	• Difficulty transitioning from active cancer patient to survivor; calming anxiety over time to return to normal life • Developing interest in talking about CRC to raise its public profile; support advocacy and recently diagnosed CS • Realisation toileting is changed dramatically
Hornbrook et al., 2017	Quantitative survey Medical journal	USA	577 (60.5% response rate) RC CS $\geq$5 years post diagnosis Mean age = 73.1 years	• ♂ reported substantially higher frequency of soilage of undergarments • CS with anastomoses more likely to be productive than those with permanent ostomies
Kang et al., 2014	Quantitative (cross-sectional study) Cancer journal	Korea	427 CRC CS – different stages and medical statuses 47.1% < 60 years	*Greatest perceived exercise barriers post treatment* (mean values using adapted Exercise Barrier Questionnaire for Older Adults five-point Likert scale; higher mean value indicates greater barrier) • Fatigue: 2.58 (SD = 0.08 $p = 0.767$) • Low level of physical fitness: 2.36 (SD = 0.08 $p = 0.163$) • Poor health: 2.24 (SD = 0.08 $p = 0.005$) • Tumour location (colon vs rectal), cancer stage (I–II vs III–IV), surgery (Yes vs No), and ostomy (Yes vs No) not significant factors that could affect exercise barriers • Need to educate CS on the positive effects of exercise

(continued)

Table 3. Continued

Author/s, year	Methodology Publication description	Origin/location	Study population (Months/years post diagnosis/treatment)	Reported findings related to occupation

Knowles et al., 2013	Quantitative (cross-sectional survey)
	Oncology nursing journal
		Scotland	381 CRC CS (138 rectal, 243 colon) ≥ 2 years post-surgery (median time interval 4.4 years)
			Median age $= 67.3$ years (interquartile range 60.1, 74.3)
			57% response rate
				• 8% of RC survivors documented problems with stool leakage 'always', and 8% 'most of the time' vs 1% and 3% of CC survivors
				• Protective pad 'always' required by 17% of RC survivors vs 5% of CC survivors
				• 9% of RC survivors 'always' had to alter activities due to bowel function vs 1% of CC survivors
				• Dietary modification to control bowel movements reported by 30% of RC vs 15% of CC survivors
				• *EORTC QLQ-C30 and EORTC QLQ-CR38 scores:*
				  • Reduced RF and SF in RC vs CC
				  • In ♂, greater sexual dysfunction in RC vs CC (median 66.67 vs. 50.00 $p = 0.009$)
				  • *Within RC group, receipt of preoperative radiotherapy vs no radiotherapy*: increased defecation problems (median 23.81 vs. 19.05 $p = 0\ .005$), reduced SF (median 83.33 vs. 100 $p = 0\ .048$), and greater financial difficulties (13% 'quite a bit'; 4% 'very much' $p = 0.049$)

Krouse et al., 2017	Quantitative (cross-sectional survey)
	Quality of life journal
		USA	557 RC survivors ≥ 5 years post diagnosis
			Mean age $= 72.6$ years
			Mean years since surgery $= 12.9$
			Response rate 60.5%
				• Of CS who reported PA helped with BF, walking most common (76%), followed by cycling (7%), gardening (6%), swimming (6%)
				• *Increases in function (using SF12) correlates with PA levels*. Adjusted mean 'non-active' to 'meeting guidelines' adjusted mean scores:
				  • PF: 40.6 to 48.0
				  • SF: 46.0 to 51.4
				  • RF: 42.2 to 46.8
				• ♂ with ostomies had consistently worsening scores on all BF scales with increasing PA; ♂ without ostomies had no change or slightly improved scores on all BF scales with increasing PA. ♀ with or without ostomies had consistently higher scores on all BF scales with PA
				• *Barriers to PA*: Hernia, skin problems, fistula, neuropathy, pain, fear of stool leakage, having an ostomy and persistent fatigue

Kunitake et al., 2017	Quantitative (cross-sectional survey) Cancer journal	USA	708 CRC CS ≥ 5 years post diagnosis Mean age $= 66.19$ (SD $= 10.63$) Median survival time since surgery 8.2 years (range 5–19.5 years) 96% CC, 4% RC	• CS had higher overall HRQL and functional capacity compared with agegroup-matched non-cancer controls • Good functional capacity: 98% able to perform all IADL activities

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Table 3. Continued

Author/s, year	Methodology Publication description	Origin/location	Study population (Months/years post diagnosis/treatment)	Reported findings related to occupation
Landers et al., 2011	Literature review Oncology nursing journal	Ireland	RC CS following sphincter-saving surgery (also includes individuals with chronic bowel disease)	• *Dietary modifications to manage bowel symptoms*: Increase or decrease vegetable intake (two studies); decrease of red meat, salt and sugar (one study); diets high in fibre and low in fat content (one study) • 53% of participants wore absorbent pads to manage faecal incontinence (one study) • Use of barrier cream and moist wipes to reduce anal soreness due to frequency of bowel movements (one study) • Location and availability of a bathroom key considerations when outside the home (two studies) • Threat of faecal incontinence led to fear of social engagements (one study) • Meticulousness in choosing strategies to avoid embarrassment and humiliation when away from home (two studies)

Lynch et al., 2011	Quantitative (longitudinal cross-sectional study)
	Cancer journal
		Australia	1966 CRC CS at 5, 12, 24 and 36 months post diagnosis
			1266 completed all time frame interviews
			Age category at 6 months post diagnosis (%): 20–49 (8.5), 50–59 (19.4), 60–69 (33.7), 70+ (38.4)
				Interactions between TV viewing time and PA (FACT-C)
				• *Physical wellbeing score*
				  • Inactive CS with up to 5 hours TV/day vs ≤2 hours TV/day were 21% lower (95% CI: 13%, 27%)
				  • Sufficiently active CS with up to 5 hours TV/day vs ≤2 hours TV/day – no significant difference
				• *Functional wellbeing score*
				  • Inactive CS – 30% difference between top and bottom television viewing categories (95% CI: 22%, 36%)
				  • Sufficiently active CS with up to 5 hours TV/day vs ≤2 hours TV/day – 16% (95% CI: 5%, 26%) lower

Lynch et al., 2016	Quantitative (prospective, population-based study) Cancer journal	Australia	239 middle-aged (45–64 years) CRC CS (in paid workforce at diagnosis) at 6 and 12 months post diagnosis Median age (25th, 75th percentile) = 57 years (52, 61) Response rate 34%	• Individuals sleeping ≥9 hours/day 2.69 times more likely to reduce work time or retire (relative to those sleeping the recommended 7–9 hours) (95% CI 1.06, 6.87; $p = 0.038$) • Individuals who have received chemotherapy and/or radiotherapy 3.06 times more likely to reduce work or retire (95% CI 1.61, 5.80; $p < 0.01$)
Macmillan Cancer Support, 2017	Report Publication for CS	UK	General CS completed treatment	• Benefit of support provided by attending cancer groups • Lack of support to get life ‘back on track’
McGrath et al., 2017	Mixed method (including prospective population-based study) Cancer nursing journal	Australia	171 middle-aged (45–64 years) CRC CS at 6 months and 12 months post diagnosis Median age = 56 years (range 51–60) (25th and 75th percentiles)	• *Reasons for leaving work*: Difficulties with bowel function, having ostomy (difficulty bending and lifting heavy weights), reduced strength, neuropathy (limited use of hands and feet), medication adverse effects and cognitive difficulties • *Benefits of RTW*: Social support, increased sense of worth, structured routine, distraction from illness, financial benefit, return to normality • Importance of effective communication and a cooperative and adaptable workplace • Cancer experience changing perception of the importance of work

(continued)

Table 3. Continued

Author/s, year	Methodology Publication description	Origin/location	Study population (Months/years post diagnosis/treatment)	Reported findings related to occupation
McMullen et al., 2017	Quantitative (observational study with longitudinal and cross-sectional components) Medical journal	USA	567 RC CS $\geq$5 years post diagnosis Mean age = 72.5 years 61% response rate	• Participation in activities strongest predictor of QoL • *Association of surgery type with activity participation* (mean scores 0 = worst, 5 = best): Sphincter-sparing surgery 2.9, ostomy 2.0, temporary ostomy 2.9 ($p < 0.0001$) • For CS with sphincter-sparing surgery, participation in activities associated with soilage ($p < 0.0001$; 2.1 and 4.1 in those with the most vs least soilage, respectively) and radiation therapy ($p = 0.0006$; 2.6 and 3.2 in those with and without radiation therapy, respectively) • *Barriers to participation (similar across surgery types):* ○ *RTW* – Bowel dysfunction, depression, fatigue, pain ○ *Social activities away from home* – Need to control diet, access to bathrooms, ostomy self-care routines, unpredictability of severe constipation or diarrhoea ○ *Sexual or intimate contact* – Pain, impotence, embarrassment, partner's reactions after surgery ○ *PA* – Neuropathy, weakness, poor balance
Ramirez et al., 2009	Qualitative Women and health journal	USA	30 ♀ CRC CS with ostomies $\geq$5 years post diagnosis. Mean age = 70 years (range 44–93 years)	*Group 1: no long-term sexual difficulties (N = 11)* • Minor modifications to intercourse • Ostomy management techniques, for example new or empty pouch in place before sex; covering of pouch to keep stable and hidden. • Importance of supportive spouse *Group 2: long-term sexual difficulties (N = 7)* • Painful intercourse; inability to have intercourse due to vaginal changes following treatment; feeling undesirable due to pouch • Retrospective desire for more information prior to surgery about potential long-term effects on intimacy • Masturbation in place of intercourse *Group 3: lifecourse, age-related changes in sexuality (N=3)* • Intercourse no longer important to maintain harmonious marital relationship – attributed to growing older • Engagement in non-sexual acts of intimacy and love, for example picking flowers for partner *Group 4: no sexual experience post-surgery (participants with no partner) (N=9)* • Barriers to having sexual partner: perceived smell of ostomy; apprehension of potential partner's reaction
Ruakere, 2016	Qualitative Doctoral thesis	New Zealand	10 Maori CRC CS Mean age = 52.5 years	• Increased time spent on personal hygiene due to increased bowel movements; changing of undergarments due to soilage • Preparations (for example extra clothes) when leaving the home • Replace toilet paper with baby wipes after bowel motion to reduce chaffing

(continued)

Table 3. Continued

Author/s, year	Methodology Publication description	Origin/location	Study population (Months/years post diagnosis/treatment)	Reported findings related to occupation
				• Disrupted sleep due to bowel movements at night • Try different foods and drinks to improve bowel function, for example reduce red meat • Reluctance to manage personal ostomy care due to cultural issue (ostomy perceived as dirty and normal process of excreting waste from body has been altered)
Shipp et al., 2015	Qualitative Occupational therapy journal	Australia	4 ♂CRC CS >40 years Mean age = 58 years	• *Barriers to leisure participation*: Fatigue, cognitive decline, lack of motivation, body changes, environmental factors, need for close proximity of bathroom • *Enablers to leisure participation*: Positive attitude, social support • Replacing PA (golf) with sedentary activities (reading and watching movies); gradual return to physically demanding activities following treatment

Spence et al., 2011	Qualitative
	Cancer journal
		Australia	10 CRC CS completed adjuvant chemotherapy treatment within past 4 weeks.
			Mean age = 57.8 years
			CC, 4 RC
				• Structured exercise programme contributed to
				  • Increased confidence to exercise, do ADL and RTW
				  • Increased fitness and reduced fatigue
				  • Improved flexibility
				  • Greater sense of health/wellbeing/control
				  • Increased self-esteem and positive outlook
				  • Development of healthy lifestyle habits, for example planning to maintain exercise schedule
				  • Knowledge of importance of exercise and training techniques
				• Enjoyment of regular social contact with trainer
				• Importance of benefits of maintaining routine recognised

Tomruk et al., 2015	Quantitative (correlation study) Cancer journal	Turkey	42 CRC CS ≥6 months post treatment Mean age = 60.58 (SD=9.02)	• PS significant predictor of FC • FC significantly correlated with QoL, PS, impact of fatigue on daily functioning and age

Vironen et al., 2006	Quantitative (cross-sectional)
	Colorectal disease journal
		Finland	82 RC CS ≥1 year post curative surgery
			Mean age = 68 years
			Median follow up time: 21 months
				• *SF-36 mean scores (GP vs RC survivors):*
				  • PF: 74.8 vs 73.9 ($p = 0.79$);
				  CS 65–79 years 59.8 vs 71.3 ($p = 0.01$); no differences between CS 40–64 years and GP.
				  • SF: 79.9 vs 68.9 ($p = 0.002$)
				• Comparison of surgery types (HAR: high anterior resection; LAR: low anterior resection; APR: abdominoperineal incision) RAND 36 mean scores:
				  • PF: HAR 72.1; LAR 74.6; APR 66.0 ($p = 0.06$)
				  • PP: HAR 46.4; LAR 57.1; APR 55.8 ($p = 0.8$)
				  • RE: HAR 54.8; LAR 65.7; APR 59.0 ($p = 0.4$)
				  • SF: HAR 70.6; LAR 68.9; APR 67.5 ($p = 0.5$)

(continued)

Table 3. Continued

Author/s, year	Methodology Publication description	Origin/location	Study population (Months/years post diagnosis/treatment)	Reported findings related to occupation

				• Major bowel dysfunction impaired SF significantly ($p = 0.05$) for those who had undergone HAR and LAR compared with those without bowel dysfunction. Incontinence ($p = 0.02$) and urgency ($p = 0.01$) impaired SF ($p = 0.01$).
				• Individuals with urinary dysfunction worse SF than patients with no urinary dysfunction
				• ♂ *sexual activity:*
				  • Changes in sexual function in 63% sexually active pre-surgery
				  • Sexual dysfunction more common after APR (87%) than after LAR or HAR (50%) ($p = 0.01$)
				  • Preoperative radiation had no statistically significant effect on incidence of sexual dysfunction ($p = 0.08$) in ♂
				• ♀ *sexual activity:*
				  • Changes in sexual function in 33% sexually active pre-surgery

Wilson et al., 2010	Qualitative Colorectal disease journal	UK	20 postoperative CRC CS Mean age = 62 years 9 with ostomy (6 reversed)	• Social networks developed with other CS • Outside activities restricted to places with familiar toilet facilities • Permanent ostomates returning to normality through establishing and modifying daily routines; temporary ostomates putting lives on hold until reversal • Use of pattern recognition, experimentation, manipulation of environment (for example keeping record of effects of foods and medication on bowel function)
Yau et al., 2009	Quantitative (longitudinal study) Colorectal disease journal	UK	186 RC survivors at 1 and 3 years post-adjuvant chemotherapy completion 93 with ostomy (46 temporary, 47 permanent) (median age = 61 years, range 38–78) 93 non-ostomy (median age = 62 years, range 32–79) 85% completed questionnaires at 3 years	• EORTC SF scores at 3 years (permanent ostomy vs prior temporary ostomy vs no ostomy) 87 vs 87 vs 97 ($p = 0.009$); no significant difference in other EORTC functioning domains

ACS: The American Cancer Society; ACSM: the American College of Sports Medicine; BF: bowel function; CC: colon cancer; CI: confidence interval; CRC: colorectal cancer; CS: cancer survivor; EORTC: European Organisation for Research and Treatment of Cancer; FACT-C: Functional Assessment of Cancer Therapy – Colorectal Cancer; FC: functional capacity; GP: general population; HRQL: Health Related Quality of Life; IADL: instrumental activities of daily living; PA: physical activity; PF: physical functioning; PS: performance status; QLQ-C30: Quality of Life Questionnaire of cancer patients; QLQ-CR38: Quality of Life Quistionnaire Colorectal Cancer Module; QoL: quality of life; RC: rectal cancer; RF: role functioning; RTW: return to work; SD: standard deviation; SF: social functioning; SF-36: RAND Short Form Survey Instrument; UK: United Kingdom; USA: United States of America; ♀: Female; ♂: Male.

Collating, summarising and reporting the results

Firstly, data contained in Table 3 were analysed numerically to produce a summary of the data characteristics. Secondly, findings relating to occupation in the final table column were analysed thematically to generate themes and a narrative report.

Findings

Characteristics of data

The majority of publications originated in Australia ($N = 9$), followed by the United States of America (USA) ($N = 7$) and the United Kingdom (UK) ($N = 5$). Sixteen studies employed quantitative methods, 10 qualitative methods, two were mixed method and three were systematic/literature reviews. The majority ($N = 19$) were published in oncology/cancer journals (including those specialising in nursing, geriatrics and psychology), three in colorectal disease journals and three in medical journals. Most studies had study populations combining colon and rectal cancer survivors ($N = 26$), with six including only rectal cancer participants.

Themes

The review identified six domains of occupation impacted by a bowel cancer diagnosis and treatment. These are presented in sequence from the most frequently addressed in the literature to the least acknowledged, and discussed in terms of impact on occupation, impediments to participation and strategies to resume occupations.

Social activity. Four studies reported that the experience of bowel cancer had a positive social impact through the formation of new connections with fellow survivors – including individually supporting those recently diagnosed, attendance at cancer support groups, and through supporting advocacy by publicising and raising the public profile of the disease (Appleton et al., 2013; Ho et al., 2016; Macmillan Cancer Support, 2017; Wilson et al., 2010).

However, four studies reported a reduction in social quality of life (QoL) and functioning as a result of bowel cancer (Arndt et al., 2004; Cabilan and Hines, 2017; Domati et al., 2011; Knowles et al., 2013), with the greatest effect on social participation being reported by those with an ostomy (Cotrim and Pereira, 2008; McMullen et al., 2017; Shipp et al., 2015; Yau et al., 2009). Ostomates articulated how they avoided social situations due to the fear of malfunction of their stoma, the need to regularly change the bag, negative body image and a general feeling of being uncomfortable amongst large groups of people (Cotrim and Pereira, 2008; McMullen et al., 2017; Ruakere, 2016; Shipp et al., 2015). Embarrassment that the pouch may be visible through clothing (Ruakere, 2016) was referred to, with some ostomates reporting they kept their ostomy a secret, impacting relationships (Cengiz and Bahar, 2017). The detrimental effect on social functioning was reported to continue even after stoma reversal, possibly due to impairment of rectal sensation or rectal capacity influencing continence (Yau et al., 2009).

Significant impact was also reported due to the resulting bowel dysfunction experienced by survivors without an ostomy who described how unpredictability of bowel movements, urgency and diarrhoea necessitated closeness to toilet facilities, intensifying anxiety and fear and leading to the subsequent avoidance of social activities away from home (Arndt et al., 2004; Hardcastle et al., 2017; Landers et al., 2011; McMullen et al., 2017; Ruakere, 2016; Vironen et al., 2006). Locations with unfamiliar toilet facilities were avoided, as were time periods when the bowels were not quiescent (Hardcastle et al., 2017; Wilson et al., 2010), with one survivor explaining, ‘It’s the bowel, the uncertainty of it that keeps me in’ (Wilson et al., 2010: 765). Survivors explained how friends eventually stopped inviting them to social engagements due to continual refusal and the embarrassment felt when talking about the bowel problems being experienced (Hardcastle et al., 2017; Landers et al., 2011).

Both survivors with and without an ostomy avoided eating out due to the necessity of a diet that did not increase bowel activity and subsequently bathroom visits (McMullen et al., 2017; Shipp et al., 2015; Wilson et al., 2010). Additionally, one ostomate explained the discomfort and embarrassment of knowing her bowels were moving while she was eating with friends and as a result would go to a restaurant but not eat until she returned home (Ruakere, 2016). Additional factors negatively impacting social participation included urinary dysfunction as a result of bowel cancer surgery (Vironen et al., 2006) and ongoing effects of adjuvant chemotherapy and/or radiotherapy (Knowles et al., 2013; Yau et al., 2009).

Both the presence of a stoma and bowel dysfunction dissuaded survivors from travelling or holidaying with others, especially when it involved having to share a room, long periods of time spent on transport and eating different foods (Grant et al., 2011). When out of the house, survivors adopted meticulous strategies to avoid embarrassment and humiliation (Landers et al., 2011). One of the main strategies employed by survivors to ease travel experiences was taking extra provisions in the form of clothing, ostomy supplies, toilet rolls, pads, wet wipes and/or a plastic bag to wrap soiled clothing in – which were all kept in an easily and quickly accessible location (Appleton et al., 2013; Grant et al., 2011; Hardcastle et al., 2017; Ruakere, 2016). Another approach was to stay in a hotel, as opposed to at a relative or friend’s house, when visiting (Grant et al., 2011).

Physical activity. Bowel dysfunction – including frequency, looseness, constipation and poor reactions to certain foods – provided a significant impediment to physical activity, as did the presence of an ostomy (Arndt et al., 2004; Cengiz and Bahar, 2017; Dennis et al., 2013; Grant et al., 2011; Knowles et al., 2013; Krouse et al., 2017; Shipp et al., 2015; Wilson et al., 2010). Additional barriers included fatigue (a greater reported obstacle for women than men), pain, somatisation, neuropathy, poor balance, low level of fitness, poor health and lack of motivation (Chambers et al., 2012; Kang et al., 2014; Krouse et al., 2017; McMullen et al., 2017; Shipp et al., 2015; Tomruk et al., 2015), with the receipt of radiation therapy associated with less physical activity (McMullen et al., 2017). Negative associations were found between the sedentary occupation of television viewing and functional and physical wellbeing, especially in less active survivors, with a gradual increase in TV-watching time from 12 to 36 months post diagnosis for those viewing 3–4 hours per day (Lynch et al., 2011). In contrast, studies addressing bowel cancer survivors as a homogenous group – rather than according to their prior activity levels – report some survivors decreased passive activities, such as reading and watching TV, replacing them with more active pastimes such as sport as the length of time since diagnosis increased (Chambers et al., 2012; Dennis et al., 2013; Shipp et al., 2015). The benefits of an increase in physical activity included improved energy levels, improved functional capacity, the confidence to carry out ADL and RTW, and a sense of wellbeing (Dennis et al., 2013; Krouse et al., 2017; Spence et al., 2011; Tomruk et al., 2015). In addition, physical activity – particularly walking – was found to improve bowel function for females with and without ostomies; in contrast, bowel function for male ostomates worsened with increasing activity, and did not change or only slightly improved for those without ostomies (Krouse et al., 2017).

One strategy employed to resume physical activity was the setting of personal goals and targets. Examples recounted include walking an increased distance each day round a golf course, with the final aim of playing a round of golf (Appleton et al., 2013), and reintroducing walking outside as energy levels increased, with the goal of returning to gardening (Shipp et al., 2015). Such a form of personal motivation aligns with a positive threat appraisal of the impact of cancer and resulted in survivors being more likely to be active and desire an increase in physical activity (Chambers et al., 2012; Dennis et al., 2013; Shipp et al., 2015). One cited way to achieve this increase was through a structured personal exercise programme after adjuvant chemotherapy treatment, leading to reduced fatigue, increased energy and the confidence to carry out daily occupations. The programme gave the survivors a greater sense of wellbeing – in contrast to how they had felt when receiving chemotherapy – which in turn provided an increased motivation to exercise further as a means of returning to normality and increasing their sense of health (Spence et al., 2011).

For ostomates, approaches taken for resuming occupations such as swimming were to not disclose anything about their appliance (due to a fear of offending and a lack of knowledge and understanding from others), timing swims for early in the morning, and not eating beforehand (Grant et al., 2011). For other sporting activities, precautions taken included only exercising near bathrooms, having a spare pouching system available, and shaving hair around the stoma to limit dislodgment due to perspiration (Krouse et al., 2017). Survivors also commented on the advantages of social support when returning to physical activity and leisure occupations (Shipp et al., 2015).

Sexual activity. A change in sexual activity was reported for both males and females, with impairment affecting between 31% and 67% of survivors (Arndt et al., 2004; Cengiz and Bahar, 2017; Cotrim and Pereira, 2008; Domati et al., 2011; Grant et al., 2011; Ramirez M et al., 2009; Vironen et al., 2006). Males are more commonly impacted, particularly those whose cancer was in the rectum and following abdominoperineal resection (APR) surgery (Knowles et al., 2013; Vironen et al., 2006). A proportion of males attributed decreased sexual activity to reduced erectile function, retrograde ejaculation and impotence (Cengiz and Bahar, 2017; McMullen et al., 2017; Vironen et al., 2006). Women reported that anatomical changes after surgery made sexual intercourse painful or even impossible (Grant et al., 2011; Ramirez M et al., 2009; Vironen et al., 2006). They also described how the presence of an ostomy provided a substantial barrier when seeking a sexual partner, due to the perceived smell and reactions to the sight of the pouching system (Grant et al., 2011; Ramirez et al., 2009). Some survivors reported they had ceased all partnered sexual activity, with celibacy or masturbation preferred to accommodating changes in their body (Ramirez et al., 2009). For some older survivors, sex was no longer considered important to maintain a happy marital relationship and was replaced with non-sexual acts of intimacy and love, such as picking bunches of flowers for a partner (Ramirez et al., 2009).

As a means of resuming sexual activity, female survivors described the importance of a supportive spouse and the instigation of practices related to ostomy management. These included ensuring the bag was new or emptied of all faecal matter before sex and then covering it with a towel or item of clothing (Ramirez et al., 2009).

Employment and role functioning. Employment was affected in terms of leaving work or reducing hours, and changes in tasks or productivity (Beesley et al., 2017; Domati et al., 2011; Hamaker et al., 2015). Health and medical reasons were specified as reasons for not returning by most survivors (80%), whereas for others cancer potentially contributed to a reassessment and change in mindset regarding the importance of work and provided the catalyst for retirement plans (Appleton et al., 2013; McGrath et al., 2017). Although it is stated that most survivors who returned to employment did not experience difficulties (McGrath et al., 2017), others felt their work participation was significantly compromised (Beesley et al., 2017).

Studies utilising QoL measures also considered employment combined with other forms of occupation. Findings identified role limitations, particularly for those who had received adjuvant chemo or radiotherapy and rectal cancer survivors and as a result of a decline in emotional health in women (Arndt et al., 2004; Domati et al., 2011; Knowles et al., 2013; Vironen et al., 2006). Reduced role functioning and productivity is reported for survivors with an ostomy in comparison to those without (Cotrim and Pereira, 2008; Hornbrook et al., 2017); this conflicts with Yau et al. (2009), who found no significant differences between the two groups. Ostomates experienced difficulties with physically demanding tasks such as bending and lifting heavy objects, privacy issues and the extended bathroom time required (Beesley et al., 2017; Hewes and Graney, 2014; Hornbrook et al., 2017; McGrath et al., 2017). For those without an ostomy, the disruption and social embarrassment resulting from altered bowel habits provided a barrier to employment (Beesley et al., 2017; Grant et al., 2011; Hornbrook et al., 2017; McGrath et al., 2017; McMullen et al., 2017). Other factors negatively influencing RTW include loss of strength, older age, fatigue, pain, depression, excessive sleep, and receipt of chemotherapy and/or radiotherapy (Beesley et al., 2017; Lynch et al., 2016; McGrath et al., 2017; McMullen et al., 2017). Chemotherapy can specifically result in neuropathy (contributing to limited use of hands and feet affecting tasks such as writing and using keypads) and cognitive difficulties (causing reduced concentration and short-term memory issues) (McGrath et al., 2017).

Resumption of employment can be eased by emotional and practical support from co-workers and supervisors, and adaptations to the work day such as starting later, the reduction of business travel, and assignment to less physically and mentally demanding tasks (Appleton et al., 2013; Hewes and Graney, 2014; Hornbrook et al., 2017; McGrath et al., 2017). Reported benefits of RTW for bowel cancer survivors included improved functional wellbeing and overall QoL, social support, a structured routine, an increased sense of worth, distraction from illness, financial benefit and a feeling of returning to normality (Appleton et al., 2013; Beesley et al., 2017; McGrath et al., 2017).

Physical functioning. Some bowel cancer survivors, particularly the elderly, experienced a distinct, sometimes permanent, decline in physical functioning, with significant contributary factors including having an ostomy, receipt of chemotherapy and/or radiotherapy, and having undergone APR surgery (Arndt et al., 2004; Cabilan and Hines, 2017; Cotrim and Pereira, 2008; Hamaker et al., 2015; Tomruk et al., 2015; Vironen et al., 2006). One study reports that one year post diagnosis 40% of survivors had not resumed housework, 23% not resumed driving and 50% not resumed shopping (Hamaker et al., 2015). The extent of functional decline is influenced by duration of survivorship; improvements over time are reported, as well as only a minimal impact on physical functioning for survivors of 5 years or more (Arndt et al., 2004; Cabilan and Hines, 2017; Domati et al., 2011; Kunitake et al., 2017). In addition, poor physical functioning is associated with poor emotional and mental health in women (Domati et al., 2011).

One described strategy to maintain functional independence was to adapt tasks and take precautions. For example, one survivor no longer attempted to carry individual items up and down stairs, instead putting them all in a plastic bag (Appleton et al., 2013). The importance of maintaining routines and a sense of normality is also stressed (Appleton et al., 2013; Cengiz and Bahar, 2017; Wilson et al., 2010).

Self-care. Those without an ostomy experienced issues relating to faecal incontinence such as soilage, the use of absorbent pads, and managing functional changes (Appleton et al., 2013; Cengiz and Bahar, 2017; Hewes and Graney, 2014; Ho et al., 2016; Hornbrook et al., 2017; Landers et al., 2011; Ruakere, 2016). Practices were revealed such as using barrier cream and moist wipes to reduce anal soreness due to frequency of bowel movements (Landers et al., 2011; Ruakere, 2016).

Ostomates often reduced frequency of showering, with discomfort observing stool in the pouch, and some only showering on days when pouching systems were changed; increased time spent in the bathroom was also described, as well as practices such as covering the stoma with a thin film dressing when bathing (Cengiz and Bahar, 2017; Hewes and Graney, 2014; Ho et al., 2016). Moreover, personal cleansing times were adapted – such as before prayers in the case of Muslim survivors – and clothing chosen to accommodate an ostomy such as loose garments not tucked into trousers or skirts and bikini underwear instead of briefs (Cengiz and Bahar, 2017). Wilson et al. (2010) highlighted the speed with which permanent ostomy survivors adopted new daily routines to create their ‘new normal’, whereas those with temporary ostomies tended to put their lives on hold while waiting for their reversal as this was viewed as crucial for a return to normality. In addition, ostomates relayed the importance of becoming educated and informed as to the importance of caring for an ostomy to increase independence and confidence (Ruakere, 2016).

To accommodate changes in bowel function such as diarrhoea, stoma irritation and increased gas, both ostomy and non-ostomy survivors described how they recognised patterns, experimented, and developed routines. For example, some kept records of bowel movements to investigate the effect of various foods and medication, and subsequently modified diet, meal times, portion sizes and speed of eating accordingly (Appleton et al., 2013; Dennis et al., 2013; Domati et al., 2011; Grant et al., 2011; Knowles et al., 2013; Krouse et al., 2017; Landers et al., 2011; Ruakere, 2016; Wilson et al., 2010).

Changes in sleep patterns due to the inability to remain asleep or sleep in a favoured position for fear of damaging the ostomy, pouch leaks or the need to get up to empty the pouch affected ostomates (Cengiz and Bahar, 2017; Grant et al., 2011). Non-ostomates also experienced disruption as a result of increased nocturnal bowel movements (Ruakere, 2016).

Discussion and implications for occupational therapy

Some review studies indicate a good QoL and only small physical functional deficits for many bowel cancer survivors, particularly long-term survivors (Arndt et al., 2004; Kunitake et al., 2017; Vironen et al., 2006). However, it is worth considering the subjective nature of the QoL measures used and the potential impact of the response shift process. Having survived cancer, individuals' positive health perceptions could have altered from the time of diagnosis to treatment conclusion, impacting their overall view of life (Krägeloh et al., 2018; Vironen et al., 2006). Moreover, many studies report extensive physical and psychological sequalae experienced by survivors, significantly impacting their day-to-day lives, occupations and QoL.

Despite these challenges, there is a distinct lack of general health professional support after treatment, with a discrepancy between client need and service delivery. As a result, individuals feel abandoned as they struggle with the transition from active cancer patient to survivor (Drury et al., 2017; Ho et al., 2016; Knowles et al., 2013), resulting in increased depression and anxiety, and reduced QoL (Hornbrook et al., 2017). As one survivor stated, 'When you're done, there's nothing. It was kind of like bang, that's it. You're out of here. You're not important any more' (Ho et al., 2016: 1474). Despite acknowledgement of a distinct correlation between QoL and participation in activities and functional capacity (McMullen et al., 2017; Tomruk et al., 2015), the link between increased mental health and staying productive (Hornbrook et al., 2017), and the importance of socially valued roles in regaining personal identity (Appleton et al., 2013), survivors are often left to devise self-management strategies to accommodate the effects of their cancer (Appleton et al., 2013; Wilson et al., 2010).

One of the professions underrepresented and underutilised with bowel cancer survivors, and within the oncology field in general, is occupational therapy (Pergolotti et al., 2016), with a reported need for practice to be more occupation-focused (McGrath et al., 2017). The fact that occupations can be so significantly impacted by bowel cancer suggests a distinct role for occupational therapists, whose unique perspective and skills perfectly position them to facilitate bowel cancer survivors' engagement in meaningful occupations (Braveman et al., 2017). This review highlighted several considerations concerning increasing and improving occupational therapy practice for this client group.

Firstly, occupational therapy input could be initiated as soon as a bowel cancer diagnosis is received, facilitating the building of early therapeutic relationships that can be continued throughout treatment and beyond (Buckland and Mackenzie, 2017). An already-developed rapport and continuing support from a trusted occupational therapist could reduce feelings of vulnerability and abandonment at the conclusion of treatment, and contribute to open communication – a key issue in improving wellbeing for survivors (Drury et al., 2017). In addition, occupational performance issues can be identified and addressed immediately, potentially reducing functional decline and the resultant impact on occupational participation (Buckland and Mackenzie, 2017; Cabilan and Hines, 2017). Review findings highlight the unique challenges and issues of bowel cancer survivors, knowledge that when combined with early and effective occupational therapy input can optimise patient support, minimise impact on daily life and better identify those who may be at greater risk of reduced functioning and therefore benefit from therapy.

Secondly, there is a need for practice to extend beyond self-care and physical function, and be more focused on promoting occupational engagement, to ease the transition process and address the often accompanying anxiety and depression (Buckland and Mackenzie, 2017; McGrath et al., 2017). Engaging in meaningful occupations can have a healing benefit promoting self-esteem, confidence, a sense of normality, greater control, personal identity and improving overall QoL (Appleton et al., 2013; Krouse et al., 2017; McMullen et al., 2017; Ruakere, 2016; Shipp et al., 2015; Spence et al., 2011). Interventions using an integrated approach targeting psychosocial, symptom and lifestyle variables (Steginga et al., 2009) could address areas such as maintaining social networks and personal relationships, remaining productive, anxiety management, normalising experiences and validating loss of status, and engaging in leisure occupations. Such occupation-focused rehabilitation would assist people to accommodate ongoing effects and support mental health.

Finally, the findings indicate an increased presence in vocational rehabilitation would benefit bowel cancer survivors. Engagement in productive occupations has a pronounced effect on health and wellbeing, and is often viewed as a positive step on the road to recovery (Gordon et al., 2014) that provides social support, routine, financial benefit, an increased sense of worth and improved functional wellbeing over time (Beesley et al., 2017; McGrath et al., 2017). Occupational therapists can assist with adaptations to duties and the work environment, teach coping strategies to overcome functional difficulties, negotiate with employers and help with strategies to improve sleep (Beesley et al., 2017; Buckland and Mackenzie, 2017; McGrath et al., 2017).

Further research

Occupational therapy can undoubtedly benefit bowel cancer survivors, but current input is limited. This is possibly due to a lack of research into the disease's impact on occupations and specific strategies to manage those impacts, thus resulting in occupational therapists being ill-equipped to gain a role in this field. The fact that this review generated 33 publications, only one of which was authored by occupational therapists (Shipp et al., 2015), highlights this discrepancy. Further research could focus specifically on occupational impacts for bowel cancer survivors. Enhanced knowledge of occupational engagement for bowel cancer survivors would enable therapists to view their clients as occupational beings and use occupation therapeutically (Hocking, 2009). Findings could help define the role of occupational therapy within bowel cancer survivorship and recommend potential interventions to improve participation.

Limitations

Several limitations of the study are recognised. Firstly, as the initial literature search and screening of titles and abstracts was conducted by one reviewer (EM), literature could have been missed that may have been identified by multiple reviewers. Secondly, as this review was conducted as part of a doctoral study, data charting was predominantly performed by one author. To address the issue of bias, final headings in the chart were developed after negotiation between all three authors and a second author (CH) verified a 15% sample of publications.

Conclusion

The scoping review findings provide an overview of occupational engagement, disruption, enablers and self-management strategies for bowel cancer survivors and suggest an obvious role for occupational therapists to assist people with cancer-related loss of function to re-engage in valued occupations and improve wellbeing. This enhancement in knowledge regarding the impact on occupations, and strategies employed to facilitate participation, can assist both survivors and the practitioners working with them. Drury et al. (2017) suggested health professionals have a duty to ensure bowel cancer survivors' health, information and supportive care needs are met after treatment conclusion; this is a duty potentially eased when armed with knowledge of the likely impact on, and ways to manage, day-to-day life.

Key findings

- Several occupational domains are impacted by bowel cancer
- Health professional support after treatment conclusion is lacking
- Occupational therapy is ideally positioned to facilitate bowel cancer survivors' engagement in occupations

What the study has added

This review reveals the impact of surviving bowel cancer on occupational participation, and the potential for an increase and improvement in occupational therapy input for those affected.

Research ethics

Ethical approval was not required for this scoping review.

Consent

Consent was not applicable to this scoping review.

Declaration of conflicting interests

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Contributorship

All authors framed the research question and initial inclusion/exclusion criteria and search terms. Elizabeth Martin conducted the database/literature search and screened titles and abstracts. Elizabeth Martin and Clare Hocking screened full texts and refined the inclusion/exclusion criteria. Elizabeth Martin extracted data and Clare Hocking verified a sample. Elizabeth Martin collated and summarised the data in consultation with Clare Hocking, and wrote the first draft. All authors reviewed and edited the manuscript and approved the final version.

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