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WCET® Webinar for

World Colorectal Cancer Month – March 2020

Living Well With & Beyond Metastatic Colorectal Cancer

By

Dr. Claire Taylor, PhD, RGN, MBE

Moderator: Carmen George, RN, ET – United Kingdom

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IOG Guideline

Wound Education Toolkit
WCET®-ASCN UK 2020 Joint Congress!

11-14th October 2020

Early Bird Registration (until 30th June): £335 (members); £435 (non-members)
Standard Registration (1 July-30 Aug): £375.00 (members); £475.00 (non-members)
Late Registration: £415.00 (members); £515.00 (non-members)

WCET® NNGF Congress Travel Scholarship Application Deadline 30th March 2020

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Living Well With & Beyond Metastatic Colorectal Cancer

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The World Council of Enterostomal Therapists®
www.wcetn.org
Contents

• Prevalence and incidence of colorectal cancer (CRC) and metastatic colorectal cancer (mCRC)
• Treatment options and outcomes for mCRC
• Treatment consequences
• Cancer survivorship
• Interventions aimed to help people with mCRC live well/better
Colorectal cancer (CRC)

Globally, CRC is the 3\textsuperscript{rd} most commonly diagnosed cancer in males and 2\textsuperscript{nd} in females.

1.8 million new cases and almost 861,000 deaths in 2018 according to the World Health Organization (GLOBOCAN, 2018).
Changes in CRC incidence

- Decreasing incidence globally in those >50yrs
- Increasing in those <50yrs

(SEER database) free in public domain at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6791134/
Staging and Site of Disease

**STAGE 1 (I) ACPS/DUKES’ A**
T1 OR T2, NO MO

**STAGE 2 (II) ACPS/DUKES’ B**
T3 OR T4, NO MO

**STAGE 3 (III) ACPS/DUKES’ C**
ANY T, N1 OR N2 MO

**STAGE 4 (IV) ACPS/DUKES’ D**
ANY T, ANY N, M1

Tumour has invaded several layers of bowel but has not spread outside the wall.

Cancer has grown through the muscle layer of the bowel or rectum and invaded nearby tissue, but has not spread to the lymph nodes.

Cancer has spread to nearby lymph nodes, but not to other parts of the body.

This is also known as METASTATIC BOWEL CANCER. The cancer has spread from where it started in the colon or rectum, to other organs often the liver and lung.

Bowel cancer UK publication approved use: Your pathway: https://www.bowelcanceruk.org.uk/about-bowel-cancer/our-publications/
Bowel cancer 5yr survival by stage

English adults diagnosed 2013-2017

Permission to use from www.cancerresearchuk.org/health-professional/cancer-statistics
In 2014, around a quarter (26%) of people have metastases at diagnosis (stage IV)

NICE 2014 Colorectal Cancer: The Diagnosis and Management of Colorectal Cancer. (UK data)
Metachronous Metastases

A further 20%–25% develop mCRC after initial curative intent treatment of their primary tumour (CRUK)

= 45% of all patients diagnosed

De Greef (2016) Multidisciplinary management of patients with liver metastasis from CRC. World journal of gastroenterology, 22(32), 7215–7225
Sites of metastatic disease at 1st presentation of colorectal cancer

- Liver: Colon 71, Rectum 60
- Peritoneal: Colon 23, Rectum 4
- Distant LN: Colon 17, Rectum 14
- Lung: Colon 17, Rectum 30
- Other: Colon 15, Rectum 17

Adapted from Holch et al 2017 data in Cancer Visc Med 33:70–75
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Get Personal: Unlocking treatment options for advanced bowel cancer

Our campaign aims to improve survival and quality of life for everyone diagnosed with advanced bowel cancer

Advanced bowel cancer is when cancer spreads to other parts of the body including: liver, lungs, pelvis

Also known as: stage 4, secondary, or metastatic bowel cancer

Over 10,000 people are diagnosed with advanced bowel cancer each year

40% diagnosed as an emergency have advanced bowel cancer compared to 8% diagnosed via screening

Survival rates are poor. Less than 1 in 10 survive

We need to reduce the chance of a late diagnosis and improve access to effective treatment and care

Our survey showed:
- People have difficulty being diagnosed
- They do not get access to effective treatment options including specialists
- Support is not personalised to individual needs

UK Survey

We are calling for:
- New models of care that can reduce late stage diagnosis
- All advanced bowel cancer patients must have the right specialists involved in their treatment
- Clear, accessible information and support to navigate the treatment and care pathway

Advanced bowel cancer is personal. Treatment and care should be too

21% saw their GP 5+ times before they were diagnosed

21% did not have access to a liver specialist

26% did not have access to a lung specialist

56% were not offered a molecular test to help inform treatment options

89% experienced side effects of treatment

20% did not get enough emotional support

Used with permission from Bowelcanceruk.org.uk/campaigning/get-personal/
What Determines Prognosis?

• Do synchronous metastases have worse prognostic value clinicopathological features (cf) metachronous metastases?

• People initially diagnosed with metastases confined to one organ, i.e. primarily the liver may have a superior prognosis, due to the option of metastectomy with curative intent?

• Location of metastases e.g. peritoneal or distant lymph node metastases as well the number of metastatic sites also may be of prognostic value?

Mekenkamp et al 2010
Median survival time (years), by period of diagnosis and cancer

Median survival time has been more than 10 years since the early 1970s for six cancers (not presented in this graph): testis, uterus, larynx, Hodgkin’s lymphoma, melanoma and cervix.
Treatment Options

• Surgery to resect locoregional disease
• Surgery for metastatic disease in liver & lung
• Cytoreductive surgery and HIPEC
• Local ablative therapies for metastases
• Stereotactic body radiotherapy (SBRT)
• Palliative chemotherapy/targeted therapy
• Immunotherapy

https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(19)32319-0/fulltext
Surgical Pathways for mCRC

• Major developments in surgical resection of metastatic diseases
• Multimodal regimes – Chemotx pre/post-op
• ? primary tumour resection in the presence of synchronous inoperable metastatic disease
• ? Sequencing of pelvic surgery and liver/lung surgery – possibly concurrently, if operable
• ? interplay with natural history of the disease

Xu et al, 2018
Resectability of Colorectal Metastases: being realistic about what we can offer patients

• Resectable
• Potentially resectable
• Incurable.. but still treatable

Graphic available free in public domain
Just because we can, does it mean we should?
What does the patient want?

**Cure?**

Currently, only patients with low-burden, circumscribed metastases are potentially curable.

Where achievable, complete R0 resection of isolated liver mets offers 5-yr survival >50%.

**Quality of life?**

Multimodality therapy combining downstaging systemic therapies, resection and ablation of the majority of multiorgan mCRC may allow prolonged survival with good health-related quality of life

Hadden et al, 2016
Many patients are candidates for further treatment

- After 2+ lines of treatment* a significant number of patients with mCRC are able and willing to receive more treatment\(^1\)

Adapted from Hind et al following expert opinion from medical and clinical oncologists, NB number of patients in each category is representative of England only\(^2\)

Despite advances, the prognosis of mCRC patients pretreated with all available agents is poor and there is a high unmet need for newer treatments\(^3\)

* After exposure to oxaliplatin- and irinotecan-based treatment.
Treatment Decision Making

‘for those with treatable but not curable cancer ..identifying the point when the potential benefit of living longer no longer outweighs the impact that the treatment is having on that person physically or emotionally, especially when there is no hope of recovery, is critical in order to avoid over-treatment’.

Prof Jane Maher,
Macmillan UK
Best supportive care

• When to refer?

• Aims to improve symptoms, improve care planning, add support and enhance quality of life

• May enhance survival ??

• Referral to palliative care services (SPCS) occurs often too late in the illness trajectory
What might people with incurable disease expect in terms of quality of life?

Good days and bad days (Charmaz, 1993)

Contradictory accounts

• certainty and uncertainty
• recovery and death
• hope and despair

Carduff et al (2018)
PROM qualitative analysis of patients’ comments

• Unmet needs are widespread and enduring

• **physical** (continence, pain, sexual difficulties, cognitive changes, fatigue, neuropathy, co-morbidities)

• **psychological** (fear of recurrence, impact on family, future planning, body image, reduced confidence, depression)

• **social** (caring for others, financial problems, return to work).

Corner et al, 2013 https://bmjopen.bmj.com/content/3/4/e002316
Research Findings: Impact of mCRC on Patients’ Lives

A diagnosis of mCRC can impact many aspects of a person’s life

- Lack of energy or too many constraints to have a real social life
- Need to take a break to be able to go on doing daily activities
- Stop hobbies due to impaired performance status
- Change food habits to avoid GI disorders

- Diagnosis can be alarming for patients and can impact their morale and approach to treatment
- Schedule life according to medical appointments
- Had to stop working due to recurrent treatment administration at that stage
- Interval between injections is too short to recover from side effects

Permission provided by Moira Gitsham - SoWhatGlobal
Research Findings: Literature Landscape

There was no evidence from the literature that psychologists or patient advocacy groups are involved in the majority of mCRC patient program

Data suggest that communications skills (empathy, listening, and attentiveness to patient needs) are associated with high-quality symptom management

Publications have focused on the psychological response to surviving and dying from mCRC, rather than confirming the efficacy of psychosocial interventions

Patients with more social support and no psychological distress may have better results in health related quality of life one year after surgery

Psychosocial interventions matter

Permission provided by Moira Gitsham - SoWhatGlobal
Case Study

59 year old lady, retired and recently separated

Diagnosis adenocarcinoma of the rectum diagnosed 2009

• Treatment: neo adjuvant chemoradiation followed by an APR
• 2013 – commenced XELOX for metastatic liver and lung disease
• 2014 – liver metastasis treated with radiofrequency ablation
• March ‘15 – radiofrequency ablation to the left upper lobe lesion
• July ‘15 – progressive disease: FOLFIRI and cetuximab commenced
• December’ 15– cetuximab only
• October ‘17: Ongoing 5FU and cetuximab- CT scan mixed response
• December ‘19: stable paraortic nodes; one enlarging lung nodule
• She looks well BUT she doesn’t always feel it
• She remains on treatment.
• She feels in a chemo fog
• Hair, skin and nails all different
• Fatigue unpredictable
Rethinking survivorship care in mCRC

Defining cancer survivors, their needs & perspectives on survivorship health care in the USA

https://doi.org/10.1016/S1470-2045(16)30573-3

Graphic by Dr. Claire Taylor
How do we help people to live well with and beyond cancer?
What is cancer survivorship?

- Physical concerns
- Psychological concerns
- Economic impact
- Health and lifestyle behaviours
- Consequences of cancer
- Social concerns

Modified from https://cancercontrol.cancer.gov/ocs/about/staff.html/about/staff.html
Providing Personalised Care and Support

• **Holistic Needs Assessments (HNAs)** = individual needs and concerns can be identified and addressed at the earliest opportunity.

• **Treatment summaries** = health and wellbeing can be optimised.

• Primary care **cancer care reviews** = cancer and its consequences are managed as a long-term condition.

= Recovery package

Holistic needs assessment (HNA):

<table>
<thead>
<tr>
<th>Concerns Thermometer</th>
<th>Practical Concerns</th>
<th>Physical Concerns</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>I am coping well</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extreme distress</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No distress</td>
<td></td>
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</tr>
</tbody>
</table>

INSTRUCTIONS: For each item below, please tick YES or NO if they have been a concern for you during the past week (including today). Please also tick DISCUSS if you wish to speak about it during your appointment.

<table>
<thead>
<tr>
<th>Concerns</th>
<th>Practical Concerns</th>
<th>Physical Concerns</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
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<td></td>
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</tbody>
</table>


Available free in public domain
Treatment Consequences

**Functional**
e.g. stomas
mobility

**Physical**

**Psychological**
e.g. anxiety
changes in body
image

- **Malignant**
- **Non Malignant**

- **Immune**
- **Endocrine**
- **Organ specific**

Graphic by Dr. Claire Taylor
Radiotherapy effect on a stoma

Mucositis – inflammatory response of mucosal epithelium

Summary of risk factors for gastrointestinal radiation injury

<table>
<thead>
<tr>
<th>Risk factors</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Radiation techniques</td>
<td>Treatment volume, total dose, fractionation dose and schedules</td>
</tr>
<tr>
<td>Combined modality therapies</td>
<td>Surgery</td>
</tr>
<tr>
<td></td>
<td>Chemotherapy: Particularly concurrent</td>
</tr>
<tr>
<td>Medical co-morbidities</td>
<td>Vascular disease, connective tissue disease, inflammatory bowel disease, HIV</td>
</tr>
</tbody>
</table>

(Groenwald et al, 2018)
Chemotherapy effects on stoma

Direct effects:
- Bleeding
- Swelling
- High output

Indirect:
- Sore hands
- Altered diet
- Fatigue
- Immunosuppression
MANAGING THE LONG-TERM CONSEQUENCES OF TREATMENT OF COLORECTAL AND ANAL CANCER

New guidance available early 2016.

Nearly 43,000 people a year are diagnosed with a colorectal cancer in the UK. With treatment, 60% of them will survive for more than five years. Whilst the majority will not develop any long-term effects, many will develop acute consequences of treatment.


Free in public domain
Possible treatment toxicities and / or late effects’ section with colorectal specific content.

Rectal Surgery:
- Change in bowel habit that may include diarrhoea, constipation, excessive wind or difficulty controlling bowels.
- Abdominal pain.
- Urinary incontinence/difficulty controlling bladder.
- Fatigue.
- Fear of Cancer coming back.
- Concentration and memory problems.
- Appetite or taste change.
- Wound infection.
- Hernia (weakness in the abdomen at the site of the wound).
- Bowel obstruction (blockage) (Abdominal pain, distension, vomiting and bowels not working).

Please report to your doctor if it lasts more than few hours.
- Phantom rectum (a sensation that you still has the back passage) after surgery to remove the anus.
- High Stoma Output & Dehydration (ileostomy).

Men
- Some may have difficulty getting or keeping an erection, and may notice changes in the physical and emotional feelings associated with sex.

Women
- Vaginal dryness and discomfort, and may notice

B. After Radiotherapy:
- Change in bowel habit that may include diarrhoea, constipation, excessive wind or difficulty controlling bowels.
- Abdominal pain.
- Sexual Dysfunction – in particular impotence in men and dryness and shrinkage of the vagina.
- Urinary incontinence/difficulty controlling bladder.
- Fatigue.

C. After Chemotherapy:
- Peripheral Neuropathy – tingling and numbness in fingers and toes which may take up to 3 years improve.
- Concentration and memory problems.
- Appetite or taste change.
- Fatigue.
- Premature menopause.
- Nail changes/discholouration.
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Cancer Care Review

An opportunity to think through needs with their health care professional and make a plan how best to meet those needs

Cancer Therapy

Select which cancer therapy the patient is on:

- □ 7M371 - Radiotherapy NEC
- □ 8BAD0 - Cancer chemotherapy
- □ 7Q0J0 - Cancer hormonal treatment drugs Band 1

- □ Discussion about treatment (8CP - Discussion about treatment)
- □ Discussion about complication of treatment with patient (8CP3 - Discussion about complication of treatment with patient)

Medication review done

- □ Medication review done (8B3V - Medication review done)

Cancer information offered

- □ Cancer information offered (677H - Cancer information offered)

Social

- □ Benefits counselling (6743 - Benefits counselling)

Prescription payment exemption

- □ 9DD - Prescription payment exemption
- □ 9DD1 - Has free prescriptions -autum.
- □ 9DD2 - Has free prescriptions-low inc
- □ 9DD3 - Has free prescriptions-unspec.
  ... and 4 more
- □ ________

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Signpost to Further Support

1. Conversation with social prescribing champion
2. Identification of needs
3. Social prescription generated and sent to client via email/discussed
4. Follow-up

https://www.england.nhs.uk/personalsedcare/social-prescribing/
What This Means in Practice

...it is ‘more than medicine’

Graphic by Dr. Claire Taylor
Are you able to...

- Have these conversations?
- Assess patient need?
- Make specialist referrals?
- Signpost to supportive services?
- Support people living with and beyond mCRC to live as well as possible?
Summary:

• Cancer as a chronic condition – manage expectations
• Identifying need
• Planning care
• Addressing consequences
• Supporting self-management
• Promoting patient-centred care
References


Hadden, W.J. de Reuver P.R., Brown, K. et al (2016) Resection of colorectal liver metastases and extra-hepatic disease: a systematic review and proportional meta-analysis of survival outcomes,HPB 18 (3) 209-220,


Further reading

• American College of Sports Medicine (2019) ACSM Guidelines for Exercise and Cancer
  download

  e12653 https://doi.org/10.1111/ecc.12653

  Press.

  Bartlett.

• McCabe MS, Bhatia S, Oeffinger KC et al. (2013) American Society of Clinical Oncology statement: achieving

• Sodergren, S. C. Wheelwright, S. J. Permyakova, N. V. (2019) Supportive care needs of patients following
  treatment for colorectal cancer: risk factors for unmet needs and the association between unmet needs and
  health-related quality of life—results from the ColoRECTal Wellbeing (CREW) study. Journal of Cancer
  Survivorship 13 (6) 899–909.

  and Future Directions, Cellular and Molecular Gastroenterology and Hepatology, 3 (2)163-173.
Questions
Thank You!

Email your webinar questions to: WCET.webinars@wcetn.org