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# **A systematic review and qualitative synthesis of the experience of living with colorectal cancer as a chronic illness.**

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## **Abstract**

**Objective:** Advances in detection and treatment mean that over 50% of people diagnosed with colorectal cancer can expect to live for more than ten years following treatment. Studies show that colorectal cancer patients can experience numerous physical and psychological late effects. The aim of this study was to conduct a systematic review and qualitative synthesis on the experiences of living with colorectal cancer as a chronic illness.

**Methods:** Electronic searches of online databases were undertaken of peer reviewed and grey literature. Forty-three papers were eligible for inclusion in the review, capturing the experiences of over 600 participants, the findings from which were analysed using thematic synthesis.

**Results:** Three higher order concepts were identified which were prevalent across studies and countries and which related to the supportive care needs of patients; common physical and psychological late effects of cancer; and methods of psychosocial adjustment to living with and beyond colorectal cancer.

**Conclusion:** The results are considered in the context of existing theoretical approaches to chronic illness and the need to develop a theoretical approach which fully encapsulates the experience of living with colorectal cancer as a chronic illness in order to inform interventions to support patient adjustment.

## **Key Words**

Systematic review; qualitative; thematic synthesis; colorectal cancer; chronic illness

Word Count – 7,819

## Background

Colorectal cancer has been described as a major public health concern being the third most commonly diagnosed, and fourth most common cause of cancer death in the world (Favoriti et al., 2016). Annually there are 17 million incidences of cancer diagnosed worldwide with this number anticipated to rise by over 50% in the next two decades (Cancer Research UK, 2020). Whilst incidences of colorectal cancer are decreasing (Ahnen et al., 2014), advances in detection and treatment mean that roughly 50% of those diagnosed in 2019 can expect to survive for at least 10 years (Cancer Research UK, 2018). Due to the large number of individuals who transition into survivorship the World Health Organization classifies cancer as a chronic illness (Jiwa et al., 2008). However, this definition is not universally accepted as cancer is typically characterised by an acute phase of illness, followed by the experience of chronic side effects (McGeechan et al., 2018). Whilst there are some commonalities between cancer and other chronic illnesses, the differences are perhaps too significant to categorise cancer in such a way (Tritter & Calnan, 2002).

The impact that colorectal cancer will have on the lives of those living with and beyond the illness will vary greatly depending on stage of diagnosis and treatment modality. However, it is clear that there is a need to adapt to both the physical and the psychological consequences of both the disease itself and its treatment (Drageset et al., 2016). Indeed, it is common for colorectal cancer patients to experience a number of late effects, which can be either physical or psychological in nature. For example patients have reported problems with sexual functioning (Bregendahl et al., 2015), incontinence (Restivo et al., 2016), reduced stamina (Wieldraaijer et al., 2018), fear of cancer recurrence (Mullens et al., 2003; Steele et al., 2007), and anxiety (Cheung et al., 2003). These late effects can surface at any time following treatment, can be long-lasting, and may have implications for how an individual copes as they transition into the survivorship phase of their cancer journey (Appleton et al., 2013; McGeechan et al., 2018).

However, evidence suggests that patients may be dissatisfied with the treatment information they are provided with (Brown et al., 2016), as well as being dissatisfied with the level of supportive care they receive following a diagnosis. Indeed, within the United Kingdom (UK), the National Health Service (NHS) commissioning board has identified supportive care following cancer as falling short of what patients need (Independent Cancer Taskforce, 2015). Therefore, it is essential that studies highlight the psychosocial consequences of living with cancer as a chronic illness in order to inform clinicians of areas where patients feel they need more support.

### *Theoretical approaches to understanding chronic illness*

A number of theoretical approaches have been applied to the experience of living with colorectal cancer as a chronic illness in previous research. Perhaps the most widely

researched theoretical concepts in relation to cancer in general, are biographical disruption (Bury, 1982), loss of self (Charmaz, 1983) and liminality (Turner, 1969). Biographical disruption was first proposed as a method of describing people's experience of chronic illness (Hubbard et al., 2010) and relates to the disruption caused to one's everyday life following the onset of a chronic illness. Biographical disruption attempts to explain how patients comprehend, and cope with the disruption to their sense of self (McGeechan et al., 2018). The onset of illness, and chronic illness in particular, can be seen as a disruptive event where the structures of everyday life and one's assumptions and knowledge about their life are thrown into chaos. It leaves individuals with the need to consider a life of pain, suffering and even their own mortality which previously would have been dismissed as a distant possibility (Bury, 1982). In terms of coping, Bury suggests that individuals adapt as they learn to live with their condition and that they tolerate their symptoms, often minimalising the actual impact of their condition so as to not disrupt their previously held sense of self (Bury, 1982). Conversely patients may re-construct their identity to a 'new normal' which encompasses their illness as part of who they are (Hubbard et al., 2010). In terms of colorectal cancer, research has suggested that patients may experience disruptions to their identity in terms of a loss of sexuality due to complications from surgery (Gilbert et al., 2013) or the impact of functional impairment such as loss of employment (Salamonsen et al., 2016).

Another prominent theoretical approach to the understanding of the experience of chronic illness is loss of self (Charmaz, 1983). Charmaz discusses the concept in terms of symbolic interactionism which suggests that our sense of self is social in nature, defined in terms of how we see ourselves, and how others see us. The onset of chronic illness therefore can impact on sense of self, as we become acutely aware of taken for granted aspects of our life that have become altered or gone, or when images of self are reflected to the chronically ill which may not be consistent with their own sense of self. Loss of self may also occur through a desire to return to normal and a realisation that this may not be possible, or will take longer than first envisioned (Foster & Fenlon, 2011). Charmaz highlights that often patients with a chronic illness are treated within an acute medical framework which can result in fragmented care, a deficit in information provision, and overburdened carers leaving individuals to make sense of their illness as best they can (Charmaz, 1983). Like Bury, Charmaz postulates that chronic illness forces people to confront their mortality and that this is particularly problematic for younger patients who see themselves as being too young to die, or have regarded themselves as healthy with minimal previous experience of illness (Hubbard et al., 2010). Previous research into loss of self in relation to cancer has focussed on gender differences in the experience of chemotherapy-induced alopecia (Rosman, 2004), self-management and recovery in a range of cancers including breast and colorectal cancer (Foster & Fenlon, 2011; Hubbard et al., 2010).

A further theoretical concept, which has been proposed to explain the experience of cancer, is that of liminality. Liminality primarily focusses on rites of passage and milestones that individuals are expected to pass through in life. Liminality occurs when a person's

characteristics are incompatible with socially constructed categories (Navon & Morag, 2004) such as a young woman who does not have children being seen as 'lacking' in some respects (Parton et al., 2019). However, it also accounts for unexpected transitions such as moving from a state of previous wellness to one of ill health and the ambiguity this causes to one's life story. This can leave patients in a state of limbo whereby they are trapped between two subjective identities in health and wellness – the patient, and the survivor who has returned to a pre-cancer normal (Trusson et al., 2016). This state of liminality is perpetuated by the threat of recurrence leaving patients in a constant state of uncertainty. However, previous research has identified that feelings of fear of recurrence may be temporary, or only emerge at certain key times in the cancer journey (McGeechan et al., 2018). Furthermore, there has been limited research looking at the concept of liminality in colorectal cancer survivors (Blows et al., 2012).

Whilst there is a wealth of qualitative research describing the experiences of living with and beyond colorectal cancer there has been no previously published systematic review which combines this evidence. Systematic reviews of qualitative evidence are recognised as a valuable tool for the facilitation of effective and appropriate health care (Thomas & Harden, 2008). There is a lack of psychosocial interventions for patients living with and beyond cancer, and research indicates that two-thirds of patient require psychosocial support following cancer, with only one-third feeling that they receive adequate support (All.Can, 2019). Therefore, the aim of this study was to collate and synthesise evidence on the experiences of living with colorectal cancer as a chronic illness with a view to informing new, patient-informed interventions for the supportive care of patients living with and beyond colorectal cancer.

## **Methods**

In order to address the above aim we conducted a systematic review and thematic synthesis of qualitative studies (Thomas & Harden, 2008). The study protocol was registered on PROSPERO (CRD42018106509). We have reported our results in line with the ENTERQ guidelines for the reporting of thematic synthesis (Tong et al., 2012) (Supplementary File 1), with quality assessment of included studies assessed using the appropriate CASP checklist (Critical Appraisal Skills Programme, 2018).

### *Literature Search*

To identify relevant publications, the following databases indexing scientific studies were searched: PsychInfo, MEDLINE, SCOPUS, CINAHL, Proquest Nursing and Allied Health Source. The search was supplemented by the grey literature sources MEDNAR and Google Scholar, in order to avoid publication bias, with the first 10 pages of results included. Search terms included key terms for cancer, colorectal cancer, survivorship and qualitative research. An example search strategy can be found in Supplementary File 2. The initial search was conducted in August 2018, which was updated in August 2019.

### *Inclusion and Exclusion Criteria*

We included papers published in any language, at any time, provided they had an English title and abstract, and could be translated, which reported on the qualitative experiences of patients living with and beyond colorectal cancer. Studies which included both patients and family members, or patients and healthcare professionals were included if the qualitative data could be separated. Furthermore, studies involving patients with different tumour locations, and patients with different health conditions were also included provided the data from the colorectal cancer patients could be identified. Papers which detailed qualitative evaluations of specific interventions were excluded.

#### *Study screening and data extraction.*

Following the completion of the searches, all potentially eligible papers were imported into EndNote x9, a reference manager software. One author (GM) screened all eligible titles and abstracts, with an independent author (NC or MC) screening a random 20% of titles and abstracts. Any discrepancies were resolved through discussion. Those papers which were still eligible after the initial screen proceeded to the second stage of screening, which involved accessing the full article and assessing it against the inclusion and exclusion criteria for this review. Each paper was independently screened by two authors (GM and JE) except for one paper which was authored GM. This paper was independently screened by JE and KB. Any disagreement at this stage was resolved through consensus, and a third reviewer was consulted if agreement could not be reached.

A data extraction table was created in Microsoft Word and piloted with two studies initially, with amendments made if necessary. Extracted data included study authors, year of publication, qualitative methodology, sample size, participant characteristics, stage of diagnosis, and emergent themes. In cases with multiple participant groups, details on the sample as a whole and the sub-group of colorectal cancer patients were extracted. One author (GM) extracted data for all eligible studies, with another author (KB) checking 20% of eligible papers for accuracy.

#### *Thematic Synthesis*

The findings from the included qualitative studies were synthesised using thematic synthesis (Thomas & Harden, 2008). Thematic synthesis involves systematic, line by line coding of extracted quotations followed by the development of descriptive and analytical themes. Verbatim quotations from patients living with and beyond colorectal cancer were extracted onto a Microsoft Excel spreadsheet, along with information on theme, and sub-theme they were assigned to in the original study. All quotations were then copied and pasted into a Microsoft Word document (without accompanying theme details) to create the study transcript. This was then imported into Nvivo software with quotations coded according to their meaning and context by one author (GM). An independent author (KS) checked the coding for agreement and made suggestions to the re-ordering of the themes and sub-themes. The study team as a whole agreed upon the final set of themes and sub-themes. Following the final stage of analysis, the study team generated third-order interpretations

which moved away from the original content of the studies and gave a broad overview of the experience of living with colorectal cancer as a chronic illness.

### *Quality Assessment*

Each included study was assessed for quality using the CASP tool for appraisal of qualitative studies (Critical Appraisal Skills Programme, 2018). One study author (GM) quality assessed all but one study in which he was an author with an independent author (KB) quality-assessing this paper. A second author (EG) checked the quality assessment ratings of 20% of included papers. Any disagreements between study ratings were agreed through discussion by the respective authors. No judgment in suitability was derived from the quality assessment (provided in Supplementary File 3); rather it was used as a means of evaluating the strengths of different synthesised findings.

### **Results**

The PRISMA diagram below (Figure 1) outlines the results of the search and screening process. After removing duplicate papers, the search process identified 4,198 references, of which 43 papers were included in the final review (See Supplementary File 4 for article references).

Figure 1: PRISMA Flowchart

### *Study Characteristics*

Full details on the study characteristics have been provided in Supplementary File 5. The 43 included papers reported on 38 unique studies. Across all included studies, 684 participants living with and beyond colorectal cancer took part. Of the papers reporting the gender of participants approximately 47% were women; three papers included only women<sup>3,31-32</sup>, three included only men<sup>6,13,41</sup> and three did not specifically report the gender of CRC survivors<sup>28-29,40</sup>.

Of the studies reporting ethnicity approximately 43% of participants were from a White ethnic background. Seven papers included only white participants<sup>4,6-7,9,15,23,26</sup>, whereas four studies included no white participants<sup>1,10,24,42</sup>. However, more than half of the included studies either did not report ethnicity, or it was not possible to separate the data for the CRC survivors from the overall sample<sup>5,8,11-14,16-22,25,27-29,34,36-41</sup>.

The reported age range for participants across all of the included studies was between 27-92 and the pooled mean age for the sample was 69. However, as with gender and ethnicity the reporting of age ranges was inconsistent such that it was neither reported nor possible to calculate the mean age of participants in 15 studies<sup>2,8,14,16,19-20,24,27-29,34,37-40</sup>.

Of the included studies 13 were conducted in the United States of America (USA), which contributed 15 of the included papers<sup>2-3,6,15-16,24,27-28,30-32,35,37-38,43</sup>; nine studies were conducted in the UK<sup>4-5,7-9,12,23,26,41</sup>; two studies were conducted in Australia, which contributed four papers<sup>17-18,25,34</sup> four studies were conducted in Canada<sup>14,19,33,39</sup>; three were conducted in the Netherlands<sup>11,13,20</sup>; two were conducted in Sweden<sup>21-22</sup>; and one study each



was conducted in Hong Kong<sup>10</sup>; China<sup>40</sup>; Norway<sup>36</sup>; Iran<sup>42</sup>; and one jointly in Australia and Jordan<sup>1</sup>. One study did not report the location<sup>29</sup>.

The most commonly used analysis technique was a form of thematic analysis which was used in 15 of the included papers<sup>2,6-7,13,17-18,20,23,25,27,29,34,39-40</sup>. This was followed by content analysis which was reported in nine papers<sup>10,16,19,30,35-37,42-43</sup>; grounded theory which was reported in six papers<sup>11,14-15,22,28,32</sup>; framework analysis was used in four papers<sup>4,8-9,38</sup> and interpretative phenomenological analysis was reported in three papers<sup>5,26,33</sup>. Constant comparison<sup>12</sup>, , phenomenology<sup>21</sup> and theoretical narrative analysis<sup>31</sup> were each utilised in one paper each whilst three papers did not report the analysis technique used<sup>1,3,24</sup>.

### *Synthesis of extracted findings*

Study authors used a variety of terms and structures to order the presentation of their findings; for example, themes and sub-themes, or core categories, categories and sub-categories. Collectively these shall be referred to as codes, a total of 286 of which were extracted from the 43 included papers in this review which included a total of 591 extracted quotations.

Following analysis, we initially grouped these codes into 13 emergent themes. The final stage of analysis involved third-order interpretations which are concepts generated by the study team which go beyond the original content of the studies (Thomas & Harden, 2008). These third level interpretations led to the further refinement of the findings and the identification of three higher-order concepts consisting of 10 emergent themes, and 26 sub-themes, as outlined in Table 1. Below, each of the themes and sub-themes are detailed in line with the higher-order concepts with some illustrative quotations. More detailed extracts can be seen in Supplementary File 6.

## **External factors influencing recovery**

### Sources of Support

#### *Religion and spirituality*

Religion and spirituality was not commonly discussed by patients living with and beyond colorectal cancer, being identified in only four papers<sup>10,24,35,37</sup>. However, for those who did discuss these, there was a strong sense of an external health locus of control (Wallston & Wallston, 1978) in that God was seen as a key actor in patients dealing not only with their cancer diagnosis, but also their transition into survivorship.

#### *Perceived abandonment*

Perceived abandonment was discussed in seven of the included papers<sup>11,17,19,27,33,36,38</sup>. This related to patients' perceptions of deficiencies in supportive care from clinical staff resulting in a state of isolation following treatment and being left to navigate the next steps in their cancer journey. Some patients expressed a desire for clinical staff to check in with them every now and then to see how they were progressing, and to identify any areas where they may

need continued support. Some patients did however feel that the clinical support provided was effective and stayed with them after they left hospital.

### *Social Support*

Social support was one of the most commonly reported themes, being discussed in 29 of the included papers<sup>2-6,8-9,11-12,14-15,18-22,24-27,29-30,34-39,43</sup>

Whilst some patients felt that social support could be lacking, a number of studies reported on the positive impact that social support from friends, families and other cancer patients could have in helping patients transition into living with colorectal cancer as a chronic illness. In particular, support from a partner was repeatedly mentioned as a positive influence on their recovery through acts such as arranging follow-up appointments and providing emotional support. On the other hand, when partners did not provide the level of support that patients needed, then this could be particularly distressing.

Several studies also reported on the role of patients themselves in providing support to others who had been treated for colorectal cancer. There was a sense of a community of patients who were there to help each other, with many patients willing to offer support to others.

### Supportive Care Needs

#### *Health information needs*

Health information needs were discussed in 19 of the included papers<sup>1,4,7-11,14-15,17,20,30-31,34-35,37-40</sup>. With regards to these needs, participants described two broad areas: lifestyle information and self-care advice. It was clear that health information needs were only partially being met, as at times patients felt the information they received could be ambiguous. In other instances, patients felt that they just did not receive appropriate health information at all.

It might therefore be important to consider the timing of lifestyle information to ensure that the patient is ready to take the information on board; *'I thought that was the appropriate time to be told about this information'*<sup>39</sup>. It was also evident that patients were not always receiving appropriate advice, with staff sometimes not being experienced enough to offer the necessary support with issues such as irrigation, or general stoma care.

#### *Delivery of health information regarding side effects*

Delivery of health information regarding side effects was another common point of discussion and was evident in nine of the included papers<sup>7-9,14,17,19,36,38,40</sup>. Several studies discussed the timing of giving health information to patients in relation to possible side effects and it is clear that there was a fine line between ensuring patients are fully informed, but without causing them too much anxiety. This suggests that careful consideration needs to be given to delivering compassionate advice, at a time that is right for that patient.

## **Psychophysiological consequences of colorectal cancer**

### Psychological consequences of colorectal cancer

Several psychosocial consequences of colorectal cancer were reported in the included studies such as body image concerns, and fear of cancer recurrence.

#### *Body image concerns*

Whilst living with a stoma could be a source of psychological distress for patients this was not commonly discussed in the included papers, with only four papers contributing to this sub-theme<sup>31-33, 36</sup>. The wearing of a colostomy bag can be seen as a constant reminder of the patients illness and can impact on their self-image due to adapting to a future of wearing a colostomy bag.

This could also have implications for patients' sex life as they may become anxious, or worried about the impact of having a colostomy bag during times of intimacy with their partner; '*No, I don't feel sexy with a bag of stuff hanging off the side of me*'<sup>32</sup>. However, other participants discussed that they were more concerned about living a healthy life than how they looked.

#### *Fear of cancer recurrence*

Fear of cancer recurrence was discussed in six papers<sup>10,26,28,30,35,40</sup>. This related to concerns that cancer could come back in the future and the actions patients may take to actively reduce this risk. However not all patients exhibited these concerns, with some actively stating that they were not concerned about recurrence. Furthermore, studies suggest that fear of recurrence may not be a stable construct but can be triggered by other events such as the onset of similar symptoms, or follow-up appointments which act as a reminder that cancer could come back; '*Tests are a constant reminder*'<sup>35</sup>. All this serves to remind patients that they are living with an uncertain future life trajectory and may not be able to experience things in the future that they would have taken for granted before their diagnosis.

### Learning to live with an ostomy

One of the physiological concerns most commonly discussed by patients was lifestyle changes they had to make in response to having either a temporary, or permanent stoma. Papers detailed patients' views on a number of impacts that a stoma had had in terms of changes to toilet habits, changes to their diet, and the impact of the stoma on their daily lives.

#### *Changes to toilet habits*

In 10 papers participants discussed how they struggled to cope with their stoma after being discharged from hospital. Procedures had to be put in place to pre-empt bowel movements to ensure that this could fit around existing routines<sup>12,16,18,21,26,31,33,35-36,43</sup>. This led to a more conscious effort to think about bowel movements and recognise cues to give as much warning as possible; '*You learn to keep up with your bowel movements*'<sup>43</sup>. There may also be a need

to plan outings and trips around the availability of bathrooms which can be accessed at a moment's notice if necessary.

### *Changes to appetite/diet*

One of the challenges that participants faced in this new normal was an altered relationship with food<sup>4,7,9,11,21,31,33,37,43</sup>. Studies highlighted participants' concerns regarding eating large meals which could lead to a rapid filling up of their colostomy bag. This could then lead to the uncomfortable sensation of things starting to back up. Other participants however did not have this concern due to a loss of appetite following surgery meaning they rarely ate enough for this to happen. *'I mean, I haven't had much of an appetite. I still haven't much. It is rare that I eat a whole portion of food. I try to drink a lot, but my appetite hasn't, it has not yet returned'*<sup>21</sup>. However, increased appetite was an unexpected surprise for some as it contradicted clinical advice and may be taken as a sign of recovery.

### *Impact of stoma on day to day life*

Living with an ostomy was a commonly discussed issue as something that impacted on the day to day lives of patients, being reported in nine papers<sup>9,17,21,30-33,37,39</sup>. For example, something simple like being comfortable whilst in a car which may have been taken for granted before, became a source of discomfort if it sat against the stoma. Additionally, participants discussed the impact of their stoma on their hobbies and activities which had been enjoyed before diagnosis. In some cases, living with a stoma limited ability to engage in hobbies. In some instances, participants felt compelled to completely abandon hobbies for fear of accidents.

### Physical consequences of colorectal cancer

In addition to the specific issues related to having an ostomy described above, there were a number of further physical consequences affecting the lives of colorectal cancer patients. One of the most widely discussed was a loss of physical stamina following their treatment, or feelings of fatigue. Furthermore, participants in several of the studies discussed cancer related pain or loss of sensation as well as impacts on sexual functioning.

### *Loss of stamina*

Participants in eight papers described the marked difference in their stamina following their treatment for colorectal cancer<sup>2,5,10,16,25-26,30,36</sup>. The sudden onset of reduced stamina could be quite alarming and for those who had previously been quite physically active there was a feeling that they had lost part of their old life. In addition to the general loss of stamina, patients were left feeling lethargic and that this was something which was happening much earlier in the day than previously; *'I'm more tired. I can feel that I'm tired in a different way and earlier in the day'*<sup>36</sup>.

However, it must be noted that not all participants attributed their lack of energy to cancer, instead describing it as just a normal process of getting older. Although in some instances there was a feeling that old levels of fitness had returned in a relatively short period of time.

#### *Cancer related pain/loss of sensation*

Another common physical consequence of colorectal cancer reported across studies was the experience of cancer-related pain or a loss of physical sensation in parts of their body<sup>18-19,21,26,30,33,35,37</sup>. Pain may be experienced in direct relation to treatment for colorectal cancer, which may then require further treatment to rectify. Patients may also be left with neuropathy in certain areas of the body as a result of chemotherapy which can lead to either numbness or tingling or burning sensations. This can result in constant feelings of pain, limiting a patient's ability to lead a normal life, or can lead to a complete lack of sensation in the affected area which could result in repeated injuries. Even if the feelings of pain or neuropathy fade over time, the impact for the patient may be hyper-vigilance whereby any new instance of pain could lead to exacerbated feelings of fear of recurrence; *'but I still get pains and I've become a bit of a "bowelholic" so I worry about all of that'*<sup>18</sup>.

#### *Sexual Dysfunction*

As detailed above colostomy bags can have a specific impact on intimacy for patients. However, sexual dysfunction extends beyond stoma patients and was a common experience for many following treatment for colorectal cancer. This can be caused by either surgery or chemotherapy<sup>3,6,8-9,29,31-32,36,39</sup>. Whilst sexual desire, or ability to engage in sexual activity may have been diminished following treatment, a lot of patients came to terms with this, given the life-threatening nature of their illness.

However, as time went on there were feelings of guilt that they were depriving their partner or limiting their enjoyment of sex: *'When he knows it hurts, it's in the back of his mind constantly. I know that that makes it more difficult for him to have an orgasm, because he's worried about me'*<sup>32</sup>. The longer the problems persisted however, the more concerned patients became that they were never going to get back to the type of sex life they had had before their diagnosis.

Those patients who were single experienced different concerns, worried that the late effects of their treatment would scare off new partners. This can then prevent them from getting close to someone. Indeed, those who did meet people whom they developed feelings for discussed how their attitude suddenly changed when they discovered the impact of their treatment.

#### Impact on employment

A number of factors can impact on the ability of a CRC survivor to return to work following treatment for their cancer. Within included studies there was a discussion surrounding the

physical limitations of patients; psychological barriers which might be impacting return to work; as well as support from employers and colleagues which can help with getting back into employment.

#### *Physical aspects affecting return to work*

The physical and psychological impacts of colorectal cancer and its treatment can have a significant impact on a patient's ability to return to work following treatment, and it can take a long time before they felt ready. This theme was prevalent across seven included papers<sup>4,13,16,26,36-37,40</sup>. Some patients set themselves goals which if they achieve would be seen as a sign that they are ready to get back to work.

However, some were perhaps too keen to return to work and show they were capable of performing to the same levels as pre-diagnosis. This could then lead to more damage being done; *'Went back to work too soon, got hernia by lifting patients. Needed to do another surgery and change stoma to other side. Kept putting it off. You know, I guess, you know, let it be'*<sup>37</sup>. In other instances, returning to work may highlight limitations in what aspects of their role they can continue to carry out.

#### *Psychological barriers to returning to work*

Psychological barriers may also prevent people from returning to work, if for example they feel uncomfortable carrying out certain tasks whilst wearing a colostomy bag<sup>13,21,26,42</sup>. Furthermore, worries about the impact of having a stoma may cause patients anxiety about how they will get to work, especially if they have a long commute, or have to make use of public transport.

#### *Support in returning to work*

However, participants also discussed, in eight of the included papers, instances where they have felt supported in returning to work<sup>2,5,13,16,19,40-42</sup>. What was clear, was for those who did return to work the support of employers and co-workers was essential in allowing patients to feel accepted back into the work environment. This relied on a realistic awareness from patients, co-workers and employers that a change in role or expectations may be needed.

On the other hand, if co-workers or employers were not understanding this could create a hostile environment where the patients did not feel welcome. This could lead to a reluctance to engage in employment for fear of being judged as inadequate by one's co-workers; *'Sometimes, colleagues just think, oh, you got this disease so you will always bring bad luck. So, a cancer diagnosis becomes a death sentence. They just want to get rid of you as quickly as possible'*<sup>40</sup>.

#### **Psychosocial Adjustment**

A number of psychosocial adjustment strategies were identified outlining the steps people took to help them cope with the transition from a cancer patient to someone living with colorectal cancer as a chronic illness.

### Adopting a positive outlook on life

Adopting a positive outlook on life appeared to be an important factor in helping people make psychosocial adjustments to their life following cancer. Many patients, across included papers discussed their view of cancer not being a death sentence<sup>5,19,24,30</sup>; or that they felt lucky to be alive<sup>4,12,18-19,26,38-39</sup>.

#### *Cancer not a death sentence*

Patients expressed an awareness that cancer is a chronic, rather than a terminal illness and that because of this they needed to stay positive. Whilst it may be a normal reaction to initially dwell on the cancer diagnosis, in the long-term this may be counterproductive. However, there was also an acknowledgement that the journey back to 'normal' may be a long one which required taking small steps and continuing to look after their health to ensure they kept on top of any symptoms; *'I just come back for my check-ups. . .I am determined, and usually if I'm determined to do something, I do it'*<sup>30</sup>. Those who were able to adapt to their new life post-cancer could be left feeling that if they could beat cancer then there was nothing really that they could not achieve.

#### *Lucky to be alive*

In contrast to the sub-theme focusing on cancer not being a death sentence, some saw their colorectal cancer diagnosis as a reminder that they were not invincible and that they were lucky to still be here following their diagnosis; *'The message comes home to you, you're not here forever, you know, and it can, I think, give an incentive to maybe make the most of this life'*<sup>4</sup>. This led them to view survivorship as a second chance and therefore make changes to how they lived, to ensure that they made the most of their lives. However, it could take patients some time to come to terms with their illness and treatment before they reached the stage where they were ready to embrace life as a colorectal cancer survivor<sup>39</sup>.

### The recovery process

Participants discussed a wide range of psychosocial factors contributing to the recovery process from the acute phase of cancer. Many participants described setting themselves recovery goals<sup>5,21,26,29-30,33,36</sup>; receiving support in the recovery process<sup>11,15,31-32</sup>; and adapting to a new normal<sup>4-5,11-12,16,18,21-22,30-31,33,36-37</sup>.

#### *Setting recovery goals*

The setting of recovery goals served as a way of participants measuring their recovery and often involved setting small, realistic goals, which would give them an indication that they were getting back to some form of their pre-cancer self. Upon successful completion of these

recovery goals participants would often set themselves new goals which increased in intensity until they achieved their ultimate goal which symbolised the end of the recovery process for them.

### *Support with the recovery process*

There was an acknowledgement from participants across the included papers that it was difficult to complete the recovery process on their own, and many praised the efforts of clinical staff in implementing survivorship care plans. This was especially important if and when participants changed doctors or consultants, as it ensured a smooth transition in their cancer journey; *'Good to have (an SCP)<sup>1</sup> if you change doctors or are referred to a different doctor for a consult'*<sup>15</sup>. They also allowed participants to monitor their own recovery and encouraged them to be more involved in their care.

Furthermore, the presence of a supportive partner could also help patients overcome some of the psychological issues described above. For example, having a partner who made the effort to make one feel attractive with a colostomy bag could go a long way to helping participants overcome body image concerns.

### *Adapting to a new normal*

An important aspect of the recovery process was a striving for normality which would indicate that participants had returned to some semblance of their pre-cancer selves. This could be in the form of adjusting their understanding of what was normal through normalisation of their post-cancer life. Adapting to a new normal could also involve accepting that some lifestyle changes needed to be made, as it was not physically possible to fully return to their pre-cancer life; *'It took me a while to adjust to the loss of status but now that I have retired I feel much stronger, work is no longer my life, I am happier and no worse off'*<sup>5</sup>.

Alternatively, it could be in the form of striving to return as closely as possible to the person they were before their diagnosis. This could be in the form of activities which would have been taken for granted in the past, such as being physically active. However, there were some issues with striving for normality which could impact on psychosocial adjustment as some participants seemed reluctant to make any changes to their lives following treatment. This may indicate a level of denial of how life changing a cancer diagnosis and its treatment can be.

### Meaning of cancer and survivorship

The meaning of cancer survivorship is a concept that only appeared in five of the included papers and related to the tendency of some participants to view their illness as a journey. Whilst some identified with the term cancer survivor<sup>23,35</sup>; others were uncomfortable associating with this schema<sup>6,22-23,26,35</sup>.

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<sup>1</sup> SCP – Survivorship Care Plan



### *Identifying with the term cancer survivor*

Participants related how having colorectal cancer was a life changing ordeal and it is therefore important to acknowledge a change in status from patient to survivor. For some there was a key point in their journey which marked the transition to survivorship. Others already identified with themselves as survivors, with cancer just another issue they had had to deal with; *'Well, you survive lots of things, don't you...? I'm just a survivor, you know. Had a rotten first husband, survived that'*<sup>23</sup>.

### *Not identifying with the cancer survivor schema*

A number of participants actively rejected the term cancer survivor as they did not see this as part of their identity and did not want to be defined by their illness. Others felt they had to put their cancer behind them to help other people move on; *'didn't want to upset my mam and dad too much cause [sic] they've got enough on their plate being 70-year-old and looking after me sister'*<sup>26</sup>. Some participants actively rejected the term as they felt that there was an inherent negativity in the word survivor.

### Behaviour Change

An important aspect of the psychosocial adjustment to living with colorectal cancer as a chronic illness appeared to be the adoption, or non-adoption, of behaviour change strategies. Within included papers patients spoke about their motivations to change their behaviour<sup>10,25,30</sup>; successful behaviour change<sup>10,17-18,25,30,33,37,43</sup> and barriers preventing them from changing their behaviour<sup>17-18,25</sup>.

### *Motivation to change behaviour*

Some participants were aware of the need to change certain aspects of their behaviour and were willing to do so but had not managed to achieve this yet. These lifestyle changes seemed to be associated with factors such as weight, healthy eating, and exercise; *'I think I'd like to get more handle on my weight and my exercise issues'*<sup>30</sup>. For example, a number of participants displayed an awareness that certain aspects of their behaviour, prior to their cancer diagnosis, needed to change and that this could have a positive aspect on their adjustment. For those who had already adopted some forms of healthy behaviour change, such as engaging in physical activity, there was an acknowledgement that more could still be done.

### *Successful behaviour change*

Several studies detailed participants who described how they had already made changes to their diet not only out of necessity from having a stoma, as well as being a way of controlling their weight. Other participants discussed changes to alcohol consumption, although this may be in order to spend more time with family rather than specifically as a way of protecting

one's health; *'I mean I don't drink as much now as I used to cause I used to be a well seven days a week. . . but only two or three pints but now I'm only going once a week'*<sup>26</sup>. Furthermore, participants displayed an understanding that there may be many different aspects of their lifestyle which needed to change following cancer but saw this as a potentially positive step towards protecting their health.

### *Barriers to behaviour change*

Participants discussed several barriers potentially preventing them from changing their behaviour in an attempt to adjust to living with colorectal cancer as a chronic illness. This could be due to a lack of motivation to engage in healthy activities such as physical activity; or a lack of awareness of lifestyle choices which could impact on their recovery from cancer. For instance, participants may not understand why they need to change their diet, in order to allow them to change their behaviour, and instead draw on anecdotal evidence to support the status quo; *'A lot of people have gone through many years of having a high fat diet and have lived to many years'*<sup>18</sup>.

Participants may also have received insufficient health information to allow them to distinguish between the natural impact of getting older compared to late effects of cancer. This could prevent them from engaging in physical activity if they felt it was pointless and they would never regain previous levels of energy. For those who did have an understanding of the need to make adaptations to their behaviour, a further barrier could be a lack of motivation to change.<sup>17</sup>.

## **Discussion**

The aim of this systematic review and qualitative synthesis was to collate and synthesise evidence on the experiences of living with colorectal cancer as a chronic illness. A further aim was to inform new interventions aimed at improving supportive care patients living with this illness. Following our synthesis, we identified three higher order concepts which related to supportive care needs of patients; common physical and psychological late effect of cancer; and methods of psychosocial adjustment to living with and beyond colorectal cancer.

Our findings are consistent with previously reported research in that certain aspects of living with and beyond colorectal cancer seem to be prevalent across studies and countries. For example, supportive care from clinical staff (Browne et al., 2011; Kent et al., 2012) and social support have been consistently reported in the literature as important factors in coping with colorectal cancer after treatment has finished (Haviland et al., 2017). Furthermore, whilst previous literature has highlighted that there is a high prevalence of unmet health information needs within this population (Playdon et al., 2016), this synthesis illustrates that this is true across multiple countries, with several unmet needs. For examples, a lack of information in relation to diet and nutrition was noted in studies conducted in the UK (Anderson et al., 2013; Beaver et al., 2010; Brown et al., 2016); Australia (Hardcastle et al., 2018), the Netherlands (Hoedjes et al., 2017) and the USA (Sterba et al., 2015). A lack of

information with regards stoma care was found in studies conducted in the USA (Sun et al., 2013; Sun et al., 2014), the UK (Beaver et al., 2010; Boulton et al., 2015), and the Netherlands (den Bakker et al., 2018). We also noted a need to carefully tailor the timing of health information provision to ensure that patients are taking this information on board. For example whilst there will be individual differences in the level of information and time of delivery there was a sense that patients were bombarded with too much information whilst still coming to terms with their diagnosis (Boulton et al., 2015; Brown et al., 2016; Ho et al., 2016; Stuhlfauth et al., 2018; Wang et al., 2016). It may be appropriate in some cases to time delivery of information on late effects of treatment and advice for minimising recurrence for after primary treatment has finished (Boulton et al., 2015; Stuhlfauth et al., 2018).

Previous literature has also considered psychophysiological late effects of colorectal cancer which can impact on adjustment to living with the condition as a chronic illness. For example, fear of cancer recurrence is a commonly cited consequence of living with cancer in general (Savard, 2013; Shay et al., 2016) as well as colorectal cancer more specifically (Custers et al., 2016) and is considered to be consistently experienced over time (Koch et al., 2012). However, we did not find this to be a particularly prominent theme in the articles included in this review. Whilst some studies did discuss it, this tended to be a specific reaction to symptomology or as part of a process of overall lifestyle changes to limit the possibility of recurrence rather than an omnipresent source of anxiety (McGeechan et al., 2018). Further to this, previous literature has demonstrated that return to work following colorectal cancer can be challenging (Bains et al., 2011), something which was supported by the papers included in this review. Specifically, we highlighted that there were several physiological barriers to returning to work such as physical limitations (Wang et al., 2016) and a loss of stamina (Sun et al., 2013), in addition to psychological barriers such as anxiety related to odours and smells emanating from colostomy bags (McGeechan et al., 2018). However, in some instances these can be overcome by supportive colleagues and employers (Appleton et al., 2013; Zamanzadeh et al., 2018) and a recognition that physical limitations may necessitate a reevaluation of what is feasibly possible for them to carry out (Chow et al., 2014).

The findings of this systematic review have provided evidence for factors affecting psychosocial adjustment to colorectal cancer. Previous research has highlighted that those participants with an internal locus of control can adjust better to living with colorectal cancer as a chronic illness (Mititelu, 2016; Wilson, 2017). However, our results indicate that both internal locus of control and external locus of control can help with adjustment. For example, some participants felt that they were lucky to be alive following their treatment (Anderson et al., 2013; DeSnoo & Faithfull, 2006; Hardcastle et al., 2017; Ho et al., 2016; McGeechan et al., 2018; Sun et al., 2014; Urquhart et al., 2012), and the need for support from others in the recovery process was also highlighted (den Bakker et al., 2018; Faul et al., 2012; Ramirez et al., 2014). However, most studies included in this systematic review discussed aspects of internal locus of control in terms of setting goals for recovery (Appleton et al., 2013; Jakobsson et al., 2017; McGeechan et al., 2018; Muntlin Athlin et al., 2018; Palmer et al., 2013;

Saunders & Brunet, 2019; Stuhlfauth et al., 2018), and adapting to a new normal as someone who is living with and beyond colorectal cancer (Anderson et al., 2013; Appleton et al., 2013; den Bakker et al., 2018; Gruß et al., 2019; Ramirez et al., 2014; Stuhlfauth et al., 2018) supporting previously reported evidence.

### *Future research*

A number of theoretical approaches have been proposed previously to describe the experience of living with colorectal cancer as a chronic illness. However, whilst elements of biographical disruption (Bury, 1982), sense of self (Charmaz, 1983), and liminality (Turner, 1969) are relevant to this population the results of this systematic review have highlighted that there are a myriad of late effects and adjustment strategies which can impact on how patients come to terms with this illness. None of the previously reported theories capture all of these elements and therefore there is a need to conceptualise a new theoretical approach which encapsulates all of the themes identified above. A more robust theory will be essential for informing interventions in the future which can help patients to adapt to life following curative treatment for colorectal cancer.

### *Conclusion*

To the best of our knowledge this is the first systematic review and qualitative synthesis of studies reporting the experience of living with colorectal cancer as a chronic illness. We followed a rigorous search strategy and have reported our findings in line with the COREQ guidelines. In order to reduce publication bias we have searched for literature not published in traditional journals, and have reported on a wide range of studies from countries across the globe, with no language restrictions. We have reported on the experiences of over 600 participants from a range of ethnic backgrounds with a roughly even split of men and women. Furthermore, we have considered our results in the context of existing theoretical approaches to chronic illness and argue that they do not fully encapsulate the experience of living with colorectal cancer as a chronic illness.

### **Declaration of competing interests**

GJM authored one of the papers included in this review. Steps outlined above were taken to reduce bias.

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