

## REVIEW

## PERSPECTIVES OF ADULT SURVIVORS OF COLORECTAL CANCER WITH AN OSTOMY ON THEIR NEEDS: SYNTHESIS OF QUALITATIVE RESEARCH STUDIES

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## Abstract

**Aim:** Colorectal cancer survivors must address the challenges of living with their condition, while their primary needs change over time. The extent to which the needs of survivors are fulfilled is one of the key indicators of success throughout the illness. This study aimed to explore and expand understanding of the needs of adult survivors of CRC with ostomy, according to their own views and experiences. **Design:** A synthesis of qualitative research studies. **Methods:** Four electronic databases were used: Scopus, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Proquest, and Science Direct, published 2000–2016, and using PRISMA guidelines as search strategies. The Critical Appraisal Skills Programme qualitative research checklist was used to ensure the quality of the articles. A three-point system was used to estimate the average score for all articles. **Results:** Initial codes were employed by coding the primary study line-by-line. The codes were then structured into eight descriptive themes, and, finally, three new analytical themes were established, including information needs, experiences of having stoma, and surviving for a better life. **Conclusion:** Information related to the illness is pivotal for CRC survivors in dealing with their current and future conditions. In addition, support from those closest to them, family, and healthcare workers has a positive impact on the acceptance of the illness and the will to survive. Determining the subjective needs of adult CRC survivors with ostomies is crucial if they are to be helped to adapt successfully to conditions and to continue living normal lives.

**Keywords:** adult survivors, colorectal cancer, needs, qualitative synthesis, thematic synthesis.

## Introduction

Colorectal cancer (CRC) is one of the most commonly diagnosed cancers worldwide (Ferlay et al., 2013; Stewart, Wild, 2014; Siegel, Miller, Jemal, 2015). It has the third highest incidence of all types of cancer (Center et al., 2009; Ferlay et al., 2013). Around a tenth of all cancer incidence (Haggar, Boushey, 2009) for both men and women is usually detected in the age group > 50 years. CRC-related mortality rates in developed countries have been declining steadily over the past 20 years (Torre et al., 2015), and in the US, the relative survival rate at five years is currently around 64% (Sun et al., 2013). In contrast, CRC cases have been rising rapidly in developing countries and westernized Asian countries (Sung et al., 2005; Arnold et al., 2017), now accounting for almost 45% of the total number of cases (Favoriti et al., 2016). The increasing number of CRC cases has affected the expanding needs of CRC survivors. The term “cancer

survivors” refers to a broad range of patients, starting from those who have recently ended their active treatment cycle to patients who have had follow-up checks for years, and which will continue throughout their lives (Hoekstra, Heins, Korevaar, 2014). There are three distinct phases for CRC survivors: diagnosis of the illness, the first treatment, and the changeover from receiving treatment to being classed as extended survivors and long-term survivors (more than five years) (Chow, Ting, Su, 2014). CRC survivors will face the possibility of secondary cancers, side effects of the treatment, and comorbid condition (Denlinger, Engstrom, 2011). Commonly, CRC survivors only have basic information about their illness, in other words, they do not have a deep understanding of their condition (Salz et al., 2014), which presents an obstacle. Long-term follow-up, health support, and lifestyle modifications remain essential components of care of CRC survivors (Denlinger, Barsevick, 2009), with every patient having their own priority of needs.

A number of studies have reported the various challenges facing CRC survivors, including physical, psychological, sexual, and spiritual problems that can

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be complex and persistent, resulting from both the illness and the treatments (Mahjoubi et al., 2012; Kimura et al., 2014; Kimura et al., 2016). CRC survivors need to directly assess and identify their specific needs, as well as the perceived magnitude of them. In this current study, needs are understood as daily activities which have benefits in aiding survivors to achieve a normal life. It is important that nurses and healthcare providers are fully informed regarding the needs of cancer survivors in order to help them lead as normal a life as possible. Virginia Henderson's Nursing Need Theory emphasizes the role of nursing that supports individual independence whenever possible. Unfortunately, most qualitative syntheses discuss models of survivorship, the psychological, physical, and social problems faced by the survivors, and the supportive care needs of CRC survivors. Only a limited number of syntheses of qualitative research studies focus on the needs of adult CRC survivors with ostomies. While there are a growing number of studies of CRC survivors, a patient with an ostomy might face challenges if they have not been able to adapt successfully. Understanding the primary needs of CRC survivors can help them to survive and adapt successfully to their condition and situation. A synthesis of qualitative research studies aims to give a broader, deeper, and more comprehensive understanding, revealing details of particular phenomena – in this case, the needs of CRC survivors – which could provide valuable information. The aim of this current study is to explore the subjective needs of CRC survivors using a synthesis of qualitative research studies.

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## Methods

### Design

A synthesis of qualitative research studies was chosen for this review since this approach can expose the broader dimensions of healthcare by exploring the phenomena through primary qualitative research (Ring, Jepson, Ritchie, 2011). The purpose of a synthesis of qualitative research studies is to show that the results of research can be more effective, efficient and applicable in the field by integrating inter-related qualitative research (Edwards, Kaimal, 2016). The thematic synthesis by Thomas and Harden (2008) was used in the study, beginning with line-by-line coding of the primary studies, followed by

construction of descriptive themes, and, finally, the development of analytical themes.

### Eligibility criteria

The inclusion criteria for articles were: 1) primary studies; 2) studies covering the population with colorectal cancer (defined as individuals aged 18 years or over when diagnosed); 3) and those having undergone surgery and colostomy or ileostomy. Conversely, articles on surgical technique, or the treatment process (chemotherapy or radiotherapy), articles without a specific focus on colorectal cancer, and thesis studies were excluded, especially those measuring instrument validity, case studies, editorials, and commentaries. The current study was limited to English language, full text, peer-reviewed journals to guarantee quality.

### Search Strategy

The search strategies systematically used the PRISMA guideline to assess the needs of CRC survivors (Moher et al., 2009). Searches were conducted manually in order to locate articles that matched the inclusion criteria for relevant articles. In this study, the reviewers used four electronic databases: Scopus, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Proquest, and Science Direct, from 2000 to 2016, providing a good number of relevant papers. Search terms or keywords were divided into three concepts: needs, or difficulties, or barriers, or care needs, or healthcare needs, or demands, or challenges, or unmet needs, or met needs; AND colorectal cancer, or colon cancer, or rectal cancer, or bowel cancer, or survivors, or survival, or survivorship; AND ostomy, or ostomies, or ostomates, or colostomy, or ileostomy, or stoma.

### Study Selection

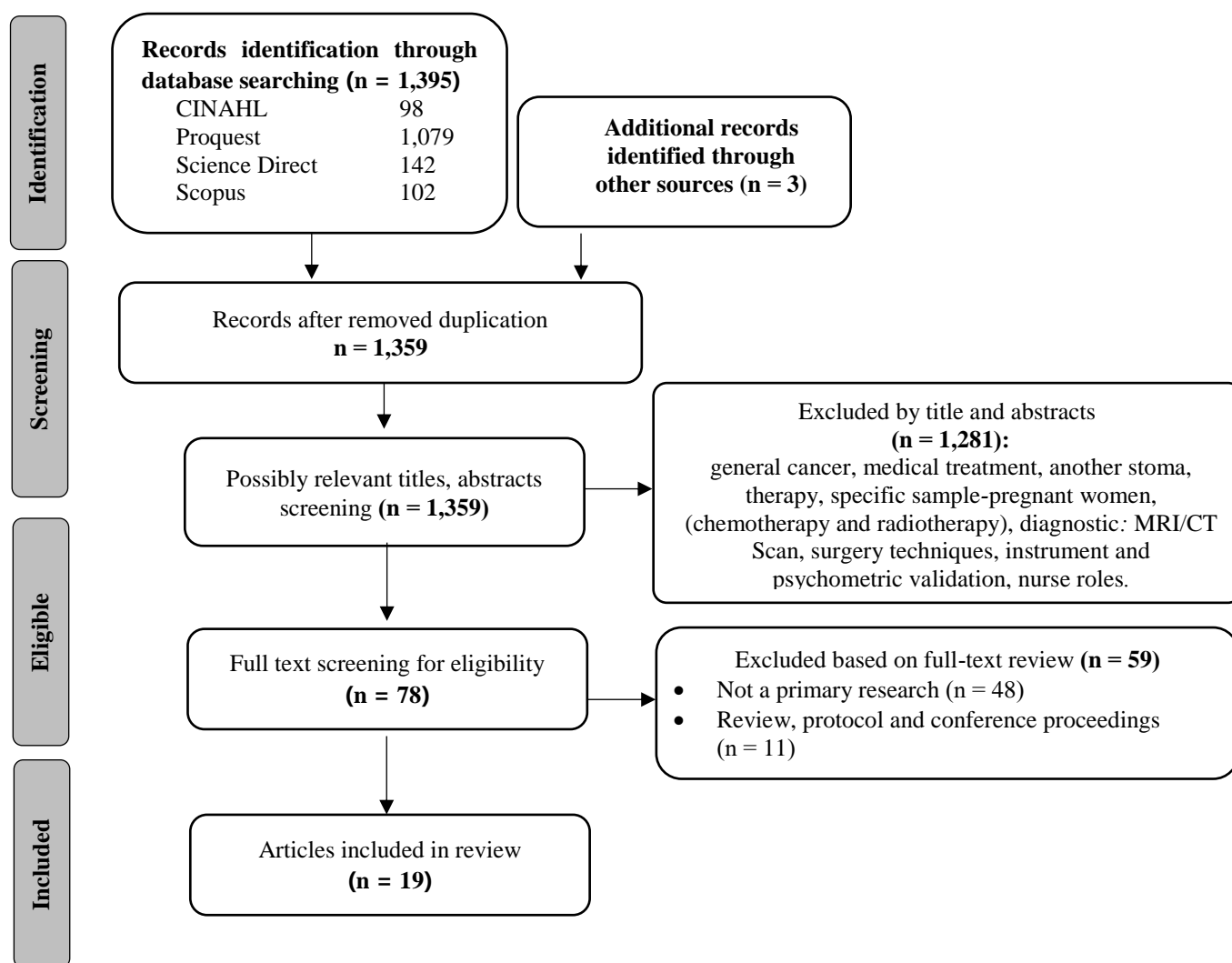
The first step in the selection process was to identify articles in the four databases using specific search terms or keywords. The reviewers independently screened all records using the inclusion and exclusion criteria, after removing duplicates, titles, and abstracts. Three additional records were excluded due to duplication. A total of 1,359 articles were screened by titles and abstracts by the two reviewers (YT, CS), who worked independently by reading the details of titles and abstracts. The next selection was based on the following criteria: full articles, peer-reviewed, between 2000 and 2016, English language, academic journals, colostomy and ileostomy. In this step, 1,281 articles were excluded for failing to match the inclusion criteria: general cancer, medical treatment, a different stoma, therapy, specific sample of pregnant women, chemotherapy and radiotherapy, diagnostic:

MRI/CT scan, surgery techniques, instrument and psychometric validation, and nurse roles. The next stage was the screening of the full papers of 78 articles, 59 of which were excluded for being ineligible for this study: quantitative research and mixed method research, not primary research, review, protocol, and conference proceedings. The authors screened all the articles before reaching consensus on the selected articles. Finally, 19 articles were deemed eligible for use in this study (Figure 1).

### Evaluation of quality articles

To measure the quality of the articles, the two authors (YT, CS) used the Critical Appraisal Skills Programme (CASP) qualitative research checklist, consisting of ten questions and eight subcategories: research design, recruitment, data collection, researcher-participant relationship, ethical issues, data analysis, findings, and the value of the research

(Critical Appraisal Skills Programme, 2016). The aim of the first two questions is to screen the suitability of articles to being subjected to rigorous study. A three-point system was used in this study to estimate the average score for all articles relating to the eight subcategories (1 = weak; 2 = moderate; 3 = strong) (Coffey et al., 2016). The scores for this paper ranged between 8 to 24, while overall scores were calculated from the sum of each paper. When there were differences of opinion between the two reviewers (YT, CS), a third reviewer (PS or BS) was consulted to reach an agreement. This quality review was conducted to aid readers' critical acceptance of the credibility of the included papers' findings, and thus papers were not excluded for their scores. The final result of the full-stage review was decided by consensus among all the authors (YT, PS, BS, and CS).



**Figure 1** Flow diagram of article study selection

### Data Extraction

Currently, there is no single agreement on classification of different types of qualitative syntheses, and different authors adopt varying frameworks (Campbell et al., 2011). The authors extracted data independently from all the included studies, and discrepancies were resolved through discussion (Table 1). The data synthesis of thematic synthesis was performed in three phases as developed by Thomas and Harden (2008). The first stage, quotations from the primary studies, involved the researchers (YT, CS) reading and coding line-by-line to produce the initial codes. The two researchers read

and re-read the articles, with reference to earlier published articles, and then created a table of quotations to produce the initial codes. Next, they searched the codes for pre-existing meanings, and new concepts were created when deemed necessary from the initial codes at the earlier stages. In the second stage, the codes were structured into descriptive themes to describe the developing themes from the previous stages. Lastly, the descriptive themes were developed into analytical themes. This process resulted in three analytical themes, all of which were confirmed by PS, BS.

**Table 1** Overview of characteristics of the included studies (Part 1)

Author (year)	Aim (objectives)	Method	Participants	Data collection	Data analysis
Andersson, Engström, Söderberg (2010)	to describe the experience of women living with a colostomy as a result of rectal cancer	qualitative study	5 women	interviews	thematic content analysis
Hall et al. (2012)	to explore the experiences and support needs of people with colorectal cancer	qualitative study	30 (17 men; 13 women), aged 37–85 years	semi-structured interview	analytical method
Sahay, Gray, Fitch (2000)	to learn about the experiences of persons with colorectal cancer, about their perceptions of their illness, and the meaning they attribute to their situation	qualitative descriptive study	20, aged 48–87 years	interviewed over the telephone	coding categories
Beaver et al. (2010)	to explore patient perceptions of their experiences of follow-up care after treatment for colorectal cancer	exploratory qualitative study	27 (14 men; 13 women), aged 59–86 years	interviews	thematic analysis
Landers, McCarthy, Savage (2012)	to explore the bowel symptom experiences and symptom management strategies following sphincter saving surgery for rectal cancer	qualitative analysis	123	semi-structured interview	deductive content analysis
Sun et al. (2014)	to describes the health-care-related experiences of long-term CRC survivors with ostomies who participated in a community-based study with focus groups	qualitative study	33 (17 men; 16 women), aged 63–76 years	focus group discussion	thematic analysis
Grant et al. (2011)	to describe how gender shapes the concerns and adaptations of long-term (i.e., more than five years) CRC survivors with ostomies	qualitative study	33 (17 men; 16 women)	focus group discussion	content analysis
Brown, Greenfield, Thompson (2016)	to describe patient knowledge and awareness of long-term and late onset treatment consequences amongst CRC survivors	qualitative study	19 (11 men; 8 women), aged 37–84 years	semi-structured interviews	framework analysis
Danielsen et al. (2013)	to explore the impact of a permanent intestinal ostomy on everyday life, and to gain further knowledge of patients' educational needs	phenomeno-logical and hermeneutic technique	15	focus group interviews	content analysis

**Table 1** Overview of characteristics of the included studies (Part 2)

Author (year)	Aim (objectives)	Method	Participants	Data collection	Data analysis
Anderson, Steele, Coyle (2013)	to explore patient needs for advice on diet, activity and lifestyle; patient beliefs about the role of diet, activity and lifestyle for reducing disease risk; and preferred formats, timings and routes of delivery for such guidance	qualitative study	40 (6 groups; 20 men; 20 women) aged 27–84 years	focus group discussion (face-to-face interview)	framework analysis
Taylor (2001)	to increase understanding of the experiences of a sample of colorectal cancer patients	hermeneutical phenomenological study	8	semi-structured, in-depth, face-to-face interviews	thematic Analysis
Appleton et al. (2013)	to explore in-depth, the lived experience of survivors of colorectal cancer	cross sectional qualitative study	13 (8 men; 5 women) aged 45–84 years	semi-structured, face-to-face interviews	interpretative phenomenological analysis
Taylor, Richardson, Cowley (2010)	to understand how individuals recover following colorectal cancer surgery	grounded theory	16	in-depth interviews (face-to-face interviews and telephone interviews)	constant comparative analysis
Taylor, Rischardson, Cowley (2011)	to examine the difficulties experienced during different phases of recovery from surgery over time	grounded theory	16	semi-structured interviews	constant comparative analysis
Sun et al. (2013)	describes persistent ostomy-specific concerns and adaptations of long-term (5 years) CRC survivors	qualitative study	33 (17 men; 16 women)	focus groups discussion	thematic analysis
Palmer et al. (2013)	to identify and describe the health goals of CRC survivors who have completed cancer treatment	qualitative study	41	semi-structured qualitative interviews	content analysis
Broughton, Bailey, Linney (2004)	to investigate the care of large bowel cancer from patients' and carers' perspectives	qualitative study	49 (aged 37–92 years)	semi-structured interviews	framework analysis
Sjövall et al. (2011)	to investigate how life situation of persons with advanced colorectal cancer and their partners is affected by living with the disease and its treatment	descriptive qualitative study	21 (12 survivors; 9 partners)	interviews	content analysis
McMullen et al. (2011)	family caregiving; explores how long-term CRC survivors manage their ostomy care	ethnography	31 (15 received no help with ostomy care; 11 received help with ostomy care and other activities; 5 received only ostomy care assistance, with no other form of informal or paid caregiving)	interviews, field notes	thematic analysis

## Results

Synthesis of the eligible articles resulted (Table 2) in three analytical themes were: 1) information needs (information regarding everyday life, and choosing the right foods); 2) experiences of having stoma (challenge of having stoma, stoma complications, and coping process); and 3) surviving towards a better life (moving forwards, support networks, and opportunities for discussion).

### Information needs

#### Information regarding daily activities

For CRC survivors, detailed and comprehensive information about the illness is fundamental to dealing with and living with the impact of the illness. Initial information in comprehensible language is needed by the survivors to help them know more about their situation (Sahay, Gray, Fitch, 2000; Sun et al., 2014), including complications that might occur in the future

(Andersson, Engström, Söderberg, 2010; Beaver et al., 2010; Hall et al., 2012). Another issue is informing the patients about how the illness could affect their sexual life, particularly for survivors of productive ages (Hall et al., 2012). Male CRC survivors usually suffer from erectile dysfunction (Brown, Greenfield, Thompson, 2016), which could influence their sexual activity (Grant et al., 2011). Furthermore, interaction with the community also plays a pivotal role for CRC survivors in increasing their confidence and acceptance of their condition. When going out into the community, they choose the most convenient and comfortable clothes to wear (Andersson, Engström, Söderberg, 2010; Beaver et al., 2010). Female survivors have more issues than male survivors due to limited opportunities to wear jeans or anything close-fitting. They also face difficulties wearing a bikini while swimming, since the stoma can be seen (Grant et al., 2011; Sun et al., 2013).

**Table 2** Perspectives' of colorectal cancer on needs: overview of analytical, descriptive and subtheme

Subtheme	Descriptive themes	Analytical themes
information using appropriate media	daily activities information	information needs
toileting information		
obstacles to having sex		
wearing comfortable clothing		
additional insurance needed		
early diet information	choosing the right food	
paying attention while eating		
awareness of food reactions		
toileting frequently	challenges of having stoma	experiences of having stoma
self-control of bowel movement		
uncontrolled flatulence		
challenge of diarrhea	stoma complication	
difficulty dealing with constipation		
painful ostomy wound		
stoma side effects		
risk of leakage		
feeling hopeless about illness	coping process	
feeling discouraged		
having stoma is annoying and embarrassing		
acceptance and planning for future		
enhancing colorectal cancer and stoma risk reduction	keep moving forwards	survival for a better life
learning attributes of the stoma		
return to or leaving work		
familial and spousal support	support network	
support by healthcare providers		
discussion with ostomy groups		
lack of support from healthcare provider		
having somebody as a good listener	time for discussion	
healthcare provider always has time		
having trust in the treatment		

### *Choosing the right food*

In the early stages, dietary information from a dietician and information in various easy to understand formats, such as leaflets, might have a positive impact (Broughton, Bailey, Linney, 2004; Beaver et al., 2010; Appleton et al., 2013). Survivors need goals to help them to achieve a normal life, with adherence to diet and regular exercise (Anderson, Steele, Coyle, 2013). The first step is controlling the size of diet, eating small amounts frequently, and choosing a healthy diet (Anderson, Steele, Coyle, 2013; Appleton et al., 2013; Palmer et al., 2013; Brown, Greenfield, Thompson, 2016). Not all kinds of food can be consumed by CRC survivors. They need to pay more attention to what they eat (Grant et al., 2011; Palmer et al., 2013; Sun, et al., 2013), otherwise, their diet will fail (Taylor, Richardson, Cowley, 2011). Nevertheless, some patients do not adhere to their dietary instructions. They test foods to see what will happen. In other words, they experiment (Beaver et al., 2010; Landers, McCarthy, Savage, 2012), since they do not fully believe the information they are given on diet (Anderson, Steele, Coyle, 2013). Over the years, the survivors gain more knowledge of diet, especially of restricted foods such as corn, spicy foods, sugary foods, and raw vegetables (Andersson, Engström, Söderberg, 2010; Sun et al., 2014). If they choose inappropriate foods, the results are unpredictable and can lead to increased gas and cause unpleasant odours (Grant et al., 2011; Landers, McCarthy, Savage, 2012).

### *Experiences of having a stoma*

#### *Challenge of having a stoma*

Toileting is one of the major difficulties experienced by CRC survivors with an ostomy, due to lack of control over defecation. Constantly going to the toilet is a nuisance and an embarrassment. Patients sometimes feel unsatisfied after toileting, and sleep patterns can be affected (Landers, McCarthy, Savage, 2012) as unpleasant odours from the stoma repeatedly wake them at night (Sun et al., 2013). There are several ways to control this situation, such as avoiding breakfast, scheduled toileting (Landers, McCarthy, Savage, 2012), and eating and chewing slowly to regulate bowel movements (Grant et al., 2011; Sun et al., 2013). In addition, CRC patients who sleep in a supine position minimize stoma bag dispatch. Preparation before sleeping is essential to avoid or minimize the risk of leakage (Andersson, Engström, Söderberg, 2010).

#### *Stoma complication*

Diarrhea may occur about once a fortnight as an allergic reaction to some foods (Beaver et al., 2010).

Consequently, CRC survivors need to learn how to minimize such reactions, for instance, by avoiding sweet foods and using medication (Landers, McCarthy, Savage, 2012). The weight of CRC survivors with stoma will decrease slightly since many vitamins are lost from the body through defecation and disruptions in absorption and distribution by the body. Clear understanding of diet and food information can help them retain their normal weight (Hall et al., 2012; Anderson, Steele, Coyle, 2013; Palmer et al., 2013). On the other hand, constipation is another of the adverse effects that commonly occur when CRC survivors lack information about diet. When it happens, they can experience inconvenience or pain when toileting. Dietary fiber can help to manage and control bowel movements (Landers, McCarthy, Savage, 2012), as can limiting consumption of fizzy drinks. Medication can help minimize symptoms of uncontrolled flatulence. Another common problem with having a stoma is the unpleasant odour that escapes from the ostomy (Grant et al., 2011; Sun et al., 2013), which can, however, be controlled with bowel irrigation (Broughton, Bailey, Linney, 2004; Landers, McCarthy, Savage, 2012; Brown, Greenfield, Thompson, 2016).

Having a stoma can be uncomfortable and painful (Taylor, Richardson, Cowley, 2010). Pain and symptoms should be minimized to the point where they are close to “normal” (Landers, McCarthy, Savage, 2012). CRC survivors also worry that the wound will burst open (Taylor, Richardson, Cowley, 2010; Sjövall et al., 2011). A hernia and prolapse are significant complications of stoma (Sun et al., 2013). To prevent further complications, CRC survivors must avoid heavy lifting (Grant et al., 2011), be vigilant for every emerging symptom, and follow risk reduction strategies.

#### *Coping process*

Most people are shocked when diagnosed with CRC (Broughton, Bailey, Linney, 2004). At first, patients with CRC are frightened to look at the stoma (McMullen et al., 2011; Danielsen et al., 2013). They feel embarrassed about having a stoma, which leads to a loss of self-confidence (Grant et al., 2011; Palmer et al., 2013). Male CRC survivors are often mocked and bullied by girls (Beaver et al., 2010). Rejection has a negative impact on their psychological condition and situation (van Mossel et al., 2014). Often, they are in a state of disbelief and are anxious about the future (Sahay, Gray, Fitch, 2000). Therefore, they avoid talking about cancer as a way to ease their minds. Since some find talking about their illness embarrassing, they hide the fact that they are CRC survivors, while those who are especially sensitive



about having the illness might be provoked by the subject, and can become aggressive and angry about it (Grant et al., 2011). For others, cancer is not a taboo topic (Appleton et al., 2013).

Being a CRC survivor means living with the condition and receiving long-term care from treatment until completion (Sun et al., 2013). People with CRC suffer when they have a stoma. It also changes the lives and perspectives of their spouses and family (Sjövall et al., 2011). Hence, support is needed to change their lives and attitudes (Hall et al., 2012). Trying to accept their condition can help CRC patients to adapt successfully. They do not have any expectations before the results of diagnostic testing (Broughton, Bailey, Linney, 2004). Later, they face the choice of suffering from the illness or dealing with it positively (Sahay, Gray, Fitch, 2000). Over time, most CRC survivors try to accept their illness without complaint (Grant et al., 2011).

Each CRC survivor may have a different response to their illness. Some may become depressed that their life has changed (Landers, McCarthy, Savage, 2012). They may despair of getting through each day when life is so hard and they have no interest in it (Hall et al., 2012; Landers, McCarthy, Savage, 2012). Unable to do anything, they feel that they are of no use to others. This results in an inability to cope with their situation (Taylor, 2001; Sjövall et al., 2011; Hall et al., 2012). Death can occur suddenly and the condition will get worse over time. Patients with CRC fear dying when in the middle of life (Sjövall et al., 2011). However, if they survive they must also face the fact that their condition will not return to normal, and they must worry about their future (Sahay, Gray, Fitch, 2000; Taylor, 2001).

### ***Surviving for a better life***

#### ***Keep moving forwards***

To accept their illness, CRC patients must have a good knowledge and understanding of the illness (Beaver et al., 2010; Danielsen et al., 2013). They must have a positive mindset about the illness, which can strengthen their coping mechanism for dealing with it. Additionally, learning to live with the illness and trying to lead a normal life can help them get through the situation (Grant et al., 2011). Enjoying life by doing all former activities as before can help them get through it (Sjövall et al., 2011; Palmer et al., 2013). They should foster an attitude of “counting their blessings” since other people might be even worse off than themselves (Sahay, Gray, Fitch, 2000; McMullen et al., 2011).

CRC survivors need to recognize the signs of a healthy stoma. The stoma should be reddish around the outside

and the peristomal skin area should be clean (McMullen et al., 2011). It is essential to be prepared for a leakage, since leakages can occur at any time (Hall et al., 2012). In order to keep the stoma in good condition, CRC survivors need to know how to change the ostomy bag independently. Firstly they are shown how to do it, and then they are given the chance to practice handling it (Danielsen et al., 2013; Sun et al., 2014). An ostomy pouch is essential for collecting faeces. Families and friends should also be informed about the kind of ostomy pouches that are most effective and efficient to use (Sun et al., 2014).

Redefining the future is another way to accept the illness (Sun et al., 2013). CRC survivors should think positively about returning to a normal life and doing daily activities as usual (Anderson, Steele, Coyle, 2013). Patients with CRC need to organize their lives very well (Appleton et al., 2013). The cancer can act as a reminder to them (Landers, McCarthy, Savage, 2012) that anything can happen at any time in life. (Hall et al., 2012). As a result, CRC patients may appreciate life much more (Taylor, Richardson, Cowley, 2010). They are obliged to change their lifestyle and behavior to stay healthy (Palmer et al., 2013). All in all, by trying to become a different person they can actually create a better life for themselves (Anderson, Steele, Coyle, 2013). Returning to work or leaving are dilemmas for CRC survivors. A number of patients look forward to returning to work, and plan to work fulltime (Andersson, Engström, Söderberg, 2010; Landers, McCarthy, Savage, 2012). While they may want to return to work, they will need to convince their workplace that they are able to do so (Broughton, Bailey, Linney, 2004). On the other hand, some survivors chose to give up working, since work no longer has meaning in their life (Appleton et al., 2013).

#### ***Support network***

Information about cancer charity networks is also needed by ostomates (Appleton et al., 2013). One reason is that the cost of treatment is expensive, and covered by out-of-pocket financing. With the high cost of treatment and lack of financial support, it is beneficial if patients have insurance to cover the cost.

Life partners/spouses are one of the most important sources of support for CRC survivors. Therefore they need to be involved in the healthcare process (Sjövall et al., 2011). Having the support of a partner can help CRC survivors to adapt to their situation (Grant et al., 2011). When the condition of patients worsens, it is beneficial to mobilize all family members in raising their spirits (Grant et al., 2011; Sjövall et al., 2011; Hall et al., 2012). Relatives and those close to survivors can provide them with positive energy



(Sjövall et al., 2011). Their encouragement helps CRC survivors to learn to live with cancer (Sun et al., 2013), and they provide the various kinds of support needed by the patients (Hall et al., 2012). However, families in particular are anxious and frightened of the illness. They must know all about stoma to have a better understanding of the illness (Danielsen et al., 2013). Groups of other survivors give crucial support to CRC survivors with an ostomy. Being part of an ostomy group is empowering and has a positive impact on new CRC survivors (Anderson, Steele, Coyle, 2013; Sun et al., 2014). They can share experiences with other CRC survivors who have learned to enjoy life after having a stoma, and thus increase their understanding of how to survive through the illness and their enthusiasm to do so (Sun et al., 2013).

#### *Time for discussion*

Feeling miserable and depressed is a normal reaction to having a stoma. In order to minimize negative reactions, CRC survivors need to talk with someone who can ease their stress (Grant et al., 2011; Sjövall et al., 2011), since family often do not understand what they are going through. Humor is one of many ways to reduce the stress and suffering of survivors (Sun et al., 2013). In addition, having a good listener who survivors can talk to and share experiences with is important (Grant et al., 2011; Sjövall et al., 2011; Hall et al., 2012). Family members who act as healthcare providers can play an essential role in providing information and discussing health developments (Andersson, Engström, Söderberg, 2010).

Healthcare providers make maximum efforts to treat the illness or reduce the emerging symptoms. They directly control and manage interventions and are involved in taking care of CRC survivors (Sjövall et al., 2011). Healthcare providers should be kind and supportive, giving positive advice and visiting patients to check up on their current physical symptoms (Sun et al., 2014). They also make home visits once a week, inquiring about CRC survivors' health conditions and the development of their illness (Hall et al., 2012). Healthcare providers immerse themselves in the lives of patients and family, providing information clearly, in simple terms (Broughton, Bailey, Linney, 2004; Beaver et al., 2010). When information is shared with the family and patients, it gives them the opportunity to ask about anything related to the illness (Sun et al., 2013). Healthcare providers are good listeners who provide information in a comprehensible way to CRC survivors and family (Broughton, Bailey, Linney, 2004). They also play a crucial spiritual role for CRC survivors with ostomies (Hall et al., 2012; Sun et al., 2014). As a result, CRC survivors feel grateful for the services provided (Sun et al., 2013). However, in some

areas, healthcare providers have limited time in which to talk to and support CRC survivors (Sahay, Gray, Fitch, 2000; Hall et al., 2012).

## **Discussion**

The results of this study summarize the literature on the needs of adult survivors of CRC with ostomies. The themes of the synthesis relate to the needs of adult CRC survivors: information needs (daily information, choosing the right food), experiences of having stoma (challenge of having stoma, stoma complication, coping process) and surviving towards a better life (keep moving forwards, support networks, sharing experiences with other survivors). On the other hand, the study also found several issues that are commonly raised by survivors, such as difficulties in finding a suitable stoma bag for everyday use and for travelling. Sex was another issue for survivors. Understanding CRC survivors' needs can help us to provide precisely the support they require to continue their daily activities.

CRC survivors are faced with adapting to various changes in their daily life due to the illness (Kimura, Kamada, Guilhem, 2016), and they need accurate information to deal with it. Information is needed on how to treat stoma, the process of stoma wound healing, complications that can occur in the stoma and the skin around the stoma, as well as advice on preventative measures that can be taken, and the types of food and beverages that must be consumed or avoided by CRC survivors. This information should be provided gradually and continuously until CRC survivors fully know and understand it. When information is not conveyed properly, it can have a negative impact on their condition. In addition, information regarding daily activities can help them accept their condition and prepare ways to overcome the difficult situations they will face. As a trusted and recommended source of information, healthcare workers need to share information clearly and understandably, taking into account several issues such as culture, language, and others (van Mossel et al., 2014). Using social media to share information may give survivors more opportunity to communicate, increase understanding of their conditions (Pellino et al., 2017), and enhancing their health literacy (Aoki, Inoue, 2017). On the other hand, information from social media often lacks validation (Sajid, Shakir, Baig, 2011).

Trauma and stress commonly occur in survivors' first year as cancer survivors (Graça Pereira, Figueiredo, Fincham, 2012). Stress can be triggered by financial problems, lack of knowledge, limited information, lack of support (Wang et al., 2016), recovery time,

adverse effects of treatment, and anxiety about how they can continue their lives (Hoekstra, Heins, Korevaar, 2014). In addition, stoma creation can make it difficult for CRC survivors to adapt to their new lives, and as a result, they need information from professional healthcare workers about ostomies (Danielsen et al., 2013). The majority of survivors do not take care of their own stoma even though training is given in hospital (Kelly et al., 2016). During their first year as survivors, patients commonly complain of stoma complications and suffer from conditions that affect their psychological health. In addition, CRC survivors with ostomies face a range of difficulties: sexual and psychological problems, issues related to clothing, complications when going on vacation, and others (Vonk-Klaassen et al., 2016). Sexual difficulties are common among CRC survivors, particularly among ostomy patients (Donovan, Thompson, Hoffe, 2010; Reese et al., 2014). The severity of sexual problems depends on the current condition and treatment procedures of the survivors (Averyt, Nishimoto, 2014), which are linked to demographic, medical and psychosocial factors (Milbury et al., 2013). Assessing sexual dysfunction, and providing information, support and treatment options can help survivors to function sexually (Traa et al., 2012). However, only a few survivors willingly answer and discuss sexual dysfunction (Averyt, Nishimoto, 2014), due to feelings of shame (Oskay, Can, Basgol, 2014). Another crucial need of CRC survivors is to choose the most appropriate food, and they must focus carefully on dietary information (Beeken et al., 2016). Some foods produce unpredictable reactions, and survivors need to pay attention to what they consume and be aware of the effects of various foods.

Returning to work is also a challenge for survivors. It is affected by several factors such as environment, personality, work demands, ability to work, health status, and financial status of survivors and family (Chow, Ting, Su, 2014). A third of survivors stop working within a year of surgery (Bhalla et al., 2014). Empowering survivors to accept and live their lives is crucial to improving their quality of life, achieving a fast recovery, and returning to work. A positive mind-set and support from relatives, friends, the community, and healthcare providers will increase understanding and acceptance in CRC survivors. Provision of adequate information on how to survive CRC, and family support have a huge impact on the chances of CRC survivors successfully recovering from cancer and setting goals for the future. In addition, CRC survivors need friends and someone to exchange thoughts and opinions with in order to have quality of life.

### **Limitation of study**

Despite some limitations, we have described the needs of CRC survivors. We used a large number of search terms to discover as many as possible. However, it is possible the authors missed further relevant articles relating to the terms. The review focused on published journals rather than other possible sources, such as grey literature, and the primary research for this study used only English publications, meaning the results of the study are not necessarily appropriate to non-English speaking countries. In further research, combining the qualitative study could give strong descriptions, explanations, and interpretations from diverse settings rather than an individual primary study. Future work should be undertaken to investigate needs based on length of time as CRC survivors, e.g., < 1 year, 1–3 years, and long-term survivors, and the needs of both survivors of productive age and old age, relating to their situations and cultural practices associated with the illness.

### **Conclusion**

The study indicated that there is important information that should be conveyed to CRC survivors such as advice on toileting, sex, wearing comfortable clothing, and how to choose the diet most appropriate for them. Moreover, they require information regarding the stoma and peristomal complications (e.g., the challenges of having a stoma, control of flatulence and constipation, and how to minimize the risk of stoma and peristomal complications). Despite their need of support, CRC survivors with ostomies also complain that they feel uncared for/neglected by their family, friends, and health professionals. Hence, support and communication from spouses, family, and health workers as a support system will increase their acceptance of their illness and health condition, and having the opportunity to relate their experiences to a sympathetic listener can improve the quality of life of CRC survivors.

### **Ethical aspects and conflict of interest**

The authors declare no conflicts of interest for the research, authorship and publication of this article.

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## Author contributions

Conception and design (YT, PS, BS), data analysis and interpretation (YT, PS, BS, CS), manuscript draft (YT), critical revision of the manuscript (YT, PS, BS, CS), final approval of the manuscript (YT).

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