

## **Cancer Survivorship: Advancing the concept in the context of colorectal cancer**

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## Abstract

**Purpose:** Previous conceptualizations of cancer survivorship have focused on heterogeneous cancer survivors, with little consideration of the validity of conclusions for homogeneous tumour groups. This paper aims to examine the concept of cancer survivorship in the context of colorectal cancer (CRC).

**Method:** Rodgers' (1989) Evolutionary Method of Concept Analysis guided this study. A systematic search of PUBMED, CINAHL, PsycINFO and The Cochrane Library was conducted in November 2016 to identify studies of CRC survivorship. The Braun and Clarke (2006) framework guided the analysis and interpretation of data extracted from eighty-five publications.

**Results:** Similar to general populations of cancer survivors, CRC survivors experience survivorship as an individual, life-changing process, punctuated by uncertainty and a duality of positive and negative outcomes affecting quality of life. However, CRC survivors experience specific concerns arising from the management of their disease. The concept of cancer survivorship has evolved over the past decade as the importance of navigating the healthcare system and its resources, and the constellation of met and unmet needs of cancer survivors are realised.

**Conclusions:** The results highlight core similarities between survivorship in the context of CRC and other tumour groups, but underlines issues specific to CRC survivorship. Communication and support are key issues in survivorship care which may detrimentally affect CRC survivors' well-being if they are inadequately addressed. Healthcare professionals (HCP's) therefore have a duty to ensure cancer survivors' health, information and supportive care needs are met in the aftermath of treatment.

**Key words:** Cancer Survivorship; Survivors; Neoplasms; Colorectal Neoplasms; Concept Analysis

## Highlights

- The traditional attributes of cancer survivorship remain applicable to CRC
- CRC survivors experience unique physical and psychosocial challenges
- Healthcare and resource navigation are central experiences of cancer survivorship
- CRC survivors have persistent healthcare, information and support needs

## Background

Colorectal Cancer (CRC) is the third most commonly diagnosed malignancy worldwide, affecting approximately 3.5 million people annually (International Agency for Research on Cancer, 2014). Significant improvements in survival have been achieved as a result of evolving treatment modalities and screening initiatives which promote earlier diagnosis. However, substantial increases in the incidence of CRC have been forecast. In Ireland alone, colon and rectal cancer incidence is expected to increase by between 77% and 156% between 2010 and 2040 (National Cancer Registry of Ireland, 2014). Thus CRC survivors account for one of the most rapidly growing groups living with and after cancer.

## Defining Cancer Survivorship

The term survivorship is used to denote recovery, or life with and beyond a plethora of conditions and circumstances, including cancer (Mullen, 1985), sexual abuse (Dallam, 2010), the atomic bomb (Preston et al., 2007) and the holocaust (Hursting and Forman, 2009). To add to this confusion, the definition of survivorship varies between and within contexts. In cancer survivorship, there is a glaring disparity in the definition of who constitutes a cancer survivor, with different regions and organisations advocating for definitions beginning 1) at diagnosis, 2) after the end of treatment, or 3) after a specified time has elapsed where the individual remains disease free (Khan et al., 2012; Leigh, 2007; Reuben, 2004; Rowland et al., 2013). Other considerations in the definition of cancer survivorship are the inclusion or exclusion of individuals who are terminally ill (Khan et al., 2012) and survivors' family members and friends (Feuerstein, 2007; Leigh, 2007). Furthermore, Hebdon et al. (2015) delineated a difference between cancer 'survivor' and 'survivorship'. The former describes the individual who has had a diagnosis of cancer, while the latter refers to the ongoing healthcare needs of the individual.

In his highly influential paper, *Seasons of Survival*, Fitzhugh Mullen (1985) divided cancer survivorship into three distinct 'seasons'; acute, extended and permanent. Acute Survival begins at diagnosis, characterized by diagnosis, treatment, fear, anxiety, and uncertainty about the future. Extended Survival begins at the end of treatment, or the point of remission. Extended survival is an individual experience, reliant on the individuals' adaptability and life situation. Watchful waiting, fear of recurrence, physical limitations and isolation from healthcare professionals (HCP's) are distinguishing elements of this phase. Finally, permanent survival is characterized by an evolving sense of being cured. However, the individual has been irrevocably affected by their experience of cancer physically, psychologically and socially.

Several concept analyses have examined survival in adulthood. However, these analyses focus on breast cancer survivorship among African-American women (Farmer and Smith, 2002), survivorship of chronic illness (Peck, 2008), cancer survivorship (Doyle, 2008) and cancer survivors (Hebdon et al., 2015) (Table

1). Little work has been undertaken to build upon the theories developed within these concept analyses, nor to examine the validity of these conceptual models among survivors with different types of cancer. Furthermore, much of the cancer survivorship literature has been influenced by North American perspectives, with publication in the field driven by the seminal works of Mullen (1985) and the Institute of Medicine (IOM) (2006). Cancer survivorship has only become a priority in Europe relatively recently, as survival rates have improved over the past twenty years (Organisation for Economic Co-operation and Development, 2015). The understanding of cancer survivorship will continue to evolve and mature as culturally diverse views of the concept emerge. Predicted increases in the rate of CRC survivorship will underpin continuing empirical attention to the experiences and outcomes of CRC survivors. It is therefore imperative that such pursuits are grounded in appropriate conceptual foundation. The core attributes of cancer survivorship proposed by Doyle (2008) remain salient, as cancer survivorship is indeed:

*“A dynamic, emerging concept pertinent to all cancer care and may be defined as a process beginning at diagnosis and involving uncertainty. It is a life-changing experience, with a duality of positive and negative aspects unique to the individual experience but with universality.”* (Doyle, 2008, p. 502)

However, it is necessary to revisit the concept of cancer survivorship to ensure that the antecedents, attributes, consequences and definition of cancer survivorship reflect the experiences of homogenous tumour groups, as well as cultural, clinical and political maturations of the concept. Therefore, this concept analysis intends to extend the conceptual framework of Doyle (2008), examining its application to the concept of cancer survivorship in the context of CRC.

### **Concept Analysis**

Concepts are the building blocks of theory (Rodgers, 2000b). However, problems arise when concepts are extensively used, as ambiguity arises in the definition and terminology describing the concept (Rodgers and Knafl, 2000). Without clear conceptual foundation, the quality of subsequent research and theory development is weakened (Weaver and Mitcham, 2008). Research on cancer survivorship issues has flourished over the past three decades. However, early interpretations of cancer survivorship may fail to fully encompass conceptual attributes as knowledge in the field develops (Walker and Avant, 1995). A PUBMED search of cancer survivorship terms (Fig. 1) yielded over one million results, with almost 300,000 papers published since Doyle (2008). Fig. 1 highlights the influential nature of seminal publications by Mullen (1985) and IOM (2006). Therefore Rodgers (1989) Evolutionary Method of Concept Analysis guides this paper, as it recognises the dynamic, interrelated nature of reality, and acknowledges that the use, application and significance of a concept may change over time.

## Methods

The Rodgers (1989) method of concept analysis comprises of eight cyclical stages which facilitates inductive inquiry using a rigorous analytical approach to clarify the concept within the bounds of a particular context (Fig. 2). Identification of the concept attributes is a fundamental step in concept analysis, as they compose a definition of the concept which permits appropriate and effective use. Conceptual clarity is fostered as the antecedents, consequences, surrogate terms, references, and model case are described (Rodgers, 1989).

## Data Sources

PUBMED, CINAHL, PsycINFO and the Cochrane library were systematically searched in November 2016 (Table 2). Searches were limited to English language literature, and studies which included participants aged 18 years or older. To be eligible for review, publications must have referred to individuals with a diagnosis of CRC. Literature published prior to the publication of IOM (2006) were excluded, as it is a seminal publication which has shaped the direction of cancer survivorship care and research. Furthermore, the concept analysis by Doyle (2008) encompassed literature published prior to 2006. The volume of international grey literature on the subject of cancer survivorship has increased exponentially over the past decade in print and electronic form, thanks to the accessibility of social media platforms and other methods of self-publication. Combined with natural language barriers, it would not be possible to obtain an internationally representative sample of grey literature, and therefore lay perspectives have been excluded from this concept analysis. Nevertheless, this concept analysis makes an important contribution to the body of nursing knowledge. Sources were managed in EndNote 7.0. Duplicate and irrelevant studies were excluded following a review of the titles and abstracts. This resulted in 170 unique publications (Fig. 3). Eighty-five were randomly selected for review, accounting for 50% of eligible papers, exceeding the 20% recommended by Rodgers (2000a).

## Data Analysis

Thematic analysis of the data was guided by Braun and Clarke (2006). All included sources were read to gain familiarity with the literature. Included papers were imported to NVIVO 10, initial codes were generated and categorized into attributes, antecedents, consequences and referents. The codes within each category were analysed separately to identify potential themes. Codes were organized and reorganized into themes within each category until comprehensive definitions were generated for each category. In keeping with the iterative approach to analysis advocated by Rodgers (1989), the themes were evaluated firstly against the coded extracts, and subsequently against the included sources to ensure thematic accuracy, and rule out oversight of any additional themes. Finally, the themes were compared to those of

Doyle (2008) to establish similarities and differences in the proposed conceptual framework. Annotation, memo and link functions in NVIVO 10 were used in conjunction with reflective journaling to ensure critical reflection on the process of data collection and analysis.

## **Results**

### ***Antecedents***

The primary antecedent of CRC survivorship is the staging and diagnosis of a new malignant growth within the tissues of the colon or rectum, which may or may not have a genetic origin. The diagnosis may be preceded by changed bowel habits, including constipation, diarrhoea, or bleeding from the rectum.

### ***Surrogate Terms***

Surrogate terms used to describe cancer survivorship include 'living beyond cancer', 'life after cancer' and 'living with cancer'. Terms which are related to cancer survivorship include 'cancer survival', 'cancer survivor' and 'remission'. Although these surrogate phrases were deemed suitable alternatives to cancer survivorship, they may fail to encompass survivors who have active disease. Nevertheless, the phrases 'living beyond', 'life after' and 'living with' cancer were used in situations where individuals did not wish to identify themselves as a cancer survivor (Chambers et al., 2012a).

### ***Attributes***

The attributes of cancer survivorship identified by Doyle (2008) were used as a framework to present the thematic analysis of the literature pertaining to CRC survivorship (Table 1). The framework is extended with the identification of a further attribute, Navigating Systems and Resources. Cancer survivorship in the context of CRC may be defined as a process which begins at diagnosis, paved with uncertainty, with positive, as well as negative outcomes. Ultimately, the life-changing experience of illness and recovery are highly individualized, with needs specific to the individual and the experience of CRC itself. As a result, survivors must become resourceful, learning to navigate the complexities of the healthcare system and the resources available to them.

### **The Process Beginning at Diagnosis**

Few published studies define cancer survivorship in the context of their research. Of those who do, most agree cancer survivorship begins at the point of diagnosis, persisting through periods of remission and end of life care (Appleton et al., 2013; Chambers et al., 2012a; McCaughan et al., 2012). However, there are considerable inconsistencies in the timeframe and disease stage inclusion criteria of research involving CRC survivors. Less than half of reviewed studies clearly reported including CRC survivors receiving treatment, or living with recurrent or metastatic disease (Fig. 4; Fig. 5).



Few authors explicitly acknowledge diagnosis as the starting point of cancer survivorship, representing the origin of cancer survivorship as a transcendence or transition from patient to survivor (Appleton et al., 2013; Bains et al., 2012; Gordon et al., 2008, 2012; McCaughan et al., 2012; Palmer et al., 2013; Salsman et al., 2011; Snyder et al., 2008b; Soerjomataram et al., 2012). Despite this, survivors themselves recognize the importance of diagnosis and treatment in the continuum of cancer survivorship, as CRC survivors relate the symptoms and difficulties of these periods to their experiences of cancer survivorship (Anderson et al., 2013; Appleton et al., 2013; McCaughan et al., 2012; Nikoletti et al., 2008; Palmer et al., 2013).

There is consensus that the experience of cancer impacts upon the individuals' remaining life. Survivorship is often described as a process incorporating diagnosis and treatment, progressing into an altered life punctuated by both positive and negative consequences of the disease and its treatment (Appleton et al., 2013; Chambers et al., 2012a; Palmer et al., 2013). The dynamic process of survivorship in CRC is characterized by multiple mechanisms. Decision-making processes take priority during the diagnosis and treatment phases (Lynch et al., 2008b). When treatment is complete, monitoring for recurrence becomes a priority for HCP's (Brawarsky et al., 2013; Carpentier et al., 2013; Cooper et al., 2008; Esplen et al., 2007; Hu et al., 2011; Salz et al., 2009). Meanwhile, the survivor becomes preoccupied with healing, recovery, adjustment, adaption and coping processes (Appleton et al., 2013; Chambers et al., 2012b; Di Fabio et al., 2008; Esplen et al., 2007; Grant et al., 2011; Loi, 2011; McCaughan et al., 2012; Nikoletti et al., 2008; Serpentine et al., 2011). The recovery process occurs in a manner and pace unique to each individual (Appleton et al., 2013). The survivor may engage in a period of post-traumatic growth, using techniques including goal setting, meaning making and benefit finding to return to, or reconceptualize 'normal' life (Appleton et al., 2013; Chambers et al., 2012a; Nikoletti et al., 2008; Palmer et al., 2013; Salsman et al., 2009; Soerjomataram et al., 2012).

## **Uncertainty**

Cancer survivors live with a sense of uncertainty from the moment of diagnosis. Bowel dysfunction arising from CRC treatment is a constant reminder of potential recurrence, as symptoms resemble those experienced prior to diagnosis (Custers et al., 2016; Desnoo and Faithfull, 2006; McCaughan et al., 2012). Fear of recurrence may be heightened by inadequate support structures, perceptions of 'abandonment' by HCP's following treatment, and unexplained deviations from the plan of follow-up care or surveillance (McCaughan et al., 2012; Tofthagen, 2010). Survivors may be confronted by the fragility of their survival when a peer experiences recurrence (McCaughan et al., 2012). However, the impact of fear of recurrence could be moderated through adoption of a 'que sera sera' or 'that's life' attitude and use of survivorship care plans (Anderson et al., 2013; Faul et al., 2012; McCaughan et al., 2012; McMullen et al., 2008).

For those who require an ostomy, it may impact on physical, functional, psychological and social aspects of life (Caravati- Jouvenceaux et al., 2011; Mols et al., 2014). Following ostomy formation there was a period of trial and error for CRC survivors as they learned to cope with altered digestive function and identify appropriate ostomy equipment (Desnoo and Faithfull, 2006; Grant et al., 2011; McMullen et al., 2008; Palmer et al., 2013). Survivors spoke of unpredictability when describing the loss of control over the body that came about as a result of the ostomy. Ostomy function varied daily, causing embarrassment and loss of confidence as leakage, incontinence or flatulence from the ostomy were anticipated (Desnoo and Faithfull, 2006; Grant et al., 2011; McMullen et al., 2008; Ramirez et al., 2009). Living with an ostomy and the chronic effects of CRC becomes a careful balancing act between competing priorities for survivors, as they attempt to resolve the joy of having survived with the sadness of living with the unpredictable, sometimes humiliating consequences of CRC (McMullen et al., 2008).

Survivors' may find themselves in a position where they are no longer able to engage in the work or activities they enjoyed prior to diagnosis due to the physical consequences of CRC (Anderson et al., 2013; Domati et al., 2011; Gordon et al., 2008; Grant et al., 2011; Hanly et al., 2013; McCaughan et al., 2012; Sisler et al., 2012; Thong et al., 2011a; Tofthagen, 2010). The precarious nature of employment caused survivors financial distress, in turn contributing to poorer psychological well-being (Baravelli et al., 2009; Gordon et al., 2008; Grant et al., 2011; Lundy et al., 2009). Furthermore, employment insecurity may result in some CRC survivors concealing the extent of their disease and risk of recurrence from employers and insurers. More than two-thirds of survivors indicate they would not inform their employer or health insurance company if they were diagnosed with a hereditary form of CRC (Esplen et al., 2007).

Up to two-thirds of CRC survivors wish to undergo genetic screening, as they believe it may assist them in planning for their future healthcare, family planning and life enjoyment (Cragun et al., 2012).

However, the prospect of having a hereditary form of CRC caused clinically significant symptoms of anxiety and depression in almost two-fifths of CRC survivors (Esplen et al., 2007). Furthermore, survivors revealed difficulties disseminating information about genetic risk to family members, as they struggled with guilt and worry about the risk of cancer for their offspring (Esplen et al., 2007).

The process of survivorship occurs parallel to the normal aging process (McCaughan et al., 2012; Phipps et al., 2008; Ramirez et al., 2009). Up to four-fifths of CRC survivors experience co-morbid health conditions, which may be more limiting than living with an ostomy or CRC in some circumstances (Anderson et al., 2013; McMullen et al., 2008; Palmer et al., 2013; Phipps et al., 2008; Soerjomataram et al., 2012). As a result, some CRC survivors describe difficulties attributing physical and psychosocial



symptoms to the experience of cancer, rather blaming age or comorbidity (McCaughan et al., 2012; Ramirez et al., 2009).

### **Life-Changing Experience**

CRC survivors' quality of life (QOL) may be negatively influenced by the presence of an ostomy, level of physical activity and the experience of chronic symptoms including pain, fatigue, anxiety, changes in bowel habit and sexual dysfunction, with some variation in these effects between genders (Chambers et al., 2012b; Di Fabio et al., 2008; Domati et al., 2011; Krouse et al., 2009; Lynch et al., 2007b, 2008a, 2011; Milbury et al., 2013; Peddle et al., 2008a; Ristvedt and Trinkaus, 2009; Sun et al., 2015; Thraen-Borowski et al., 2013). Despite this, survivors' rate their health and QOL positively, in some cases improving over time, with long-term survivors reporting QOL levels comparable to normative populations (Caravati-Jouvencaux et al., 2011; Chambers et al., 2012a, 2012b; Di Fabio et al., 2008; Jansen et al., 2011; Phipps et al., 2008; Ristvedt and Trinkaus, 2009; Serpentine et al., 2011; Soerjomataram et al., 2012; Steginga et al., 2009; Thong et al., 2011a, 2011b). Several authors suggest positive ratings of QOL are a consequence of response shift, or positive reframing. Although some survivors struggle to come to terms with bodily changes and chronic treatment effects, many are capable of remarkable resilience, reframing the experience of symptoms or presence of an ostomy over time (McCaughan et al., 2012; McMullen et al., 2008; Palmer et al., 2013). Survivors may identify positive consequences of cancer, including appreciation for life, gratitude, strengthening of relationships, changing priorities and hope for the future (Appleton et al., 2013; Grant et al., 2011; McMullen et al., 2008; Nikoletti et al., 2008; Ramirez et al., 2009). For many, the new normal of the body and bodily function were things to adapt to and live with, and were better than possible alternatives to their situation, such as more aggressive types of cancer, treatment, or death (Appleton et al., 2013; Desnoo and Faithfull, 2006; McCaughan et al., 2012; McMullen et al., 2008; Ramirez et al., 2009).

The diagnosis of CRC and the implications of treatment were a considerable upheaval in an individual's life (Appleton et al., 2013; Palmer et al., 2013). As survivors overcome the diagnosis and treatment periods, the perceived threat on life reduces, and the individuals' identity transcends that of patient. The individual may either adopt the identity of survivor, or avoid an illness-related identity entirely, instead conceptualizing themselves as a person who had cancer (Chambers et al., 2012a). The transition in self-identity is unique to each individual, occurring within a dichotomy of positive and negative experiences (Appleton et al., 2013). As CRC survivors begin to re-evaluate their lives in the aftermath of a life-threatening event, they may appreciate life more than a person who did not have such a life experience, feel psychologically stronger for having endured illness and have an altruistic desire to 'give back' through peer-support, advising HCP's, and engaging in research (Appleton et al., 2013; Baravelli et al.,

2009; Grant et al., 2011; Ho et al., 2015; Loi, 2011; McCaughan et al., 2012; Palmer et al., 2013; Serpentine et al., 2011; Tofthagen, 2010).

### **Duality of Positive and Negative Aspects**

Adjusting to the period of cancer survivorship is fraught with challenges arising from the complications and long-term effects of CRC and its treatment, and required CRC survivors to make changes in their lives. Changes in lifestyle are positive and necessary to regain health, enhance life and reduce stress (Anderson et al., 2013; Palmer et al., 2013; Pullar et al., 2012). However, where a CRC survivor believed they had led a relatively healthy life prior to diagnosis, lifestyle changes are not considered a helpful behaviour (Anderson et al., 2013; Mols et al., 2012). Thus, changes in lifestyle are made with a degree of uncertainty, accompanied by conflicting or confusing information (Anderson et al., 2013; Haggstrom et al., 2009; McMullen et al., 2008; Nikoletti et al., 2008).

Although heavy smoking or alcohol intake among CRC survivors is infrequent, many survivors fail to meet physical activity, body mass index and fruit and vegetable intake recommendations (Chambers et al., 2012a, 2012b; Grimmer et al., 2011; Hawkes et al., 2008; James et al., 2006; Johnson et al., 2009; Lynch et al., 2007a, 2008c; McGowan et al., 2013; Peddle et al., 2008a, 2008b; Pullar et al., 2012; Speed-Andrews et al., 2012, 2013; Thraen-Borowski et al., 2013; Wijndaele et al., 2009). Achieving recommended levels of physical activity may be difficult if the survivor is experiencing chronic effects of CRC, treatment or co-morbidities (Anderson et al., 2013; Chambers et al., 2009; Hawkes et al., 2008; Lynch et al., 2007a, 2008c; Palmer et al., 2013). Changes in diet are as much to do with attaining a sense of control over bowel function or ostomy output, as it is to control the disease trajectory, and prevent recurrence (Anderson et al., 2013; Esplen et al., 2007; Grant et al., 2011; McMullen et al., 2008; Nikoletti et al., 2008; Palmer et al., 2013; Pullar et al., 2012; Sun et al., 2015). Bowel control is a significant challenge for CRC survivors, and a systematic regime of medication, dietary management and self-devised management strategies are developed by survivors to manage bowel dysfunction (Desnoo and Faithfull, 2006; Grant et al., 2012; Nikoletti et al., 2008; Sun et al., 2015).

Survivors may outgrow the identity of cancer patient, but continue to have difficulties re-integrating to normal life (McCaughan et al., 2012; Palmer et al., 2013). Returning to normal was a major goal for many CRC survivors, but unfortunately it was not always possible due to changes in bodily function (Desnoo and Faithfull, 2006; McCaughan et al., 2012; Palmer et al., 2013). Rather, survivors described an evolving 'new normal' from the limbo experienced at the end of treatment, becoming accustomed to persistent side-effects or formation of an ostomy. This new normal required CRC survivors to take a steep learning curve and develop new coping strategies (McCaughan et al., 2012; McMullen et al., 2008).

Gendered differences in adjustment and need for support were identified by Grant et al. (2011) and McCaughan et al. (2012). However, the specific effect of gender remains debatable. Males tend to downplay symptom effects, support needs and challenges with adjustment, while females admit difficulties with adjustment, but develop strategies to manage symptoms and minimize their impact (Grant et al., 2011; McCaughan et al., 2012). Despite qualitative studies suggesting male survivors adopt more stoic attitudes to physical and psychosocial issues, quantitative research indicates males may in fact suffer greater distress, have poorer coping skills and experience worse social well-being than their female counterparts (Au et al., 2012; Goldzweig et al., 2009; Ristvedt and Trinkaus, 2009).

The societal de-stigmatization of cancer assists survivors to return to a conventional daily life within the constraints of their new normality. Individuals felt the increased awareness of cancer and greater opportunity to openly discuss cancer fostered hope (Appleton et al., 2013). Yet, CRC remains a taboo subject, not just because it is perceived as a disease of lifestyle (Anderson et al., 2013), but because there is a societal aversion to faeces (Ramirez et al., 2009). Survivors feel it is inappropriate to discuss the consequences of the disease openly, instead using euphemisms to describe their cancer, its treatment, and side-effects (Desnoo and Faithfull, 2006). This stigma is heavily intertwined with the theme of hiding away. Aside from dietary changes, CRC survivors felt the presence of an ostomy impacted upon their ability to engage in physical and social activities, and significantly impacted upon their body image (Grant et al., 2011; Loi, 2011; McCaughan et al., 2012; McMullen et al., 2008; Mols et al., 2014). Hiding away involved a process of concealing the ostomy or avoiding situations where their ostomy may be seen by others (McMullen et al., 2008; Ramirez et al., 2009).

The theme of hiding away extended to include CRC survivors who experienced difficulties with bowel dysfunction. Such survivors spoke about the isolation and avoidance of social activities which resulted from erratic changes to bowel patterns and loss of bowel control (Desnoo and Faithfull, 2006; Grant et al., 2011). Hiding away impacted upon survivors' relationships with spouses, family members and friends. Furthermore, the need to be close to toilet facilities to avoid accidents and embarrassment limited the survivors' ability to travel and engage in daily activities (Desnoo and Faithfull, 2006; Grant et al., 2011; Krouse et al., 2009; Loi, 2011; McCaughan et al., 2012; Nikoletti et al., 2008).

The frequency of sexual activity declined for over one-third of CRC survivors, a consequence of sexual dysfunction and negative body image (Domati et al., 2011; Ellis et al., 2010; Ramirez et al., 2009). Those who experienced difficulties with body image and sexuality sought to hide away by withdrawing from, avoiding or altering approaches to sexual intimacy, thus circumventing perceived embarrassment or vulnerability (Altschuler et al., 2009; Grant et al., 2011; McMullen et al., 2008; Ramirez et al., 2009). Such strategies contributed to a sense of loss for CRC survivors. However, this loss could be mediated in

some circumstances by identifying alternative self-management strategies, being grateful for life and having a supportive family or spouse (Au et al., 2012; Chambers et al., 2012b; McMullen et al., 2008; Nikolett et al., 2008; Ramirez et al., 2009). Indeed, having an empathetic, supportive spouse was crucial to CRC survivors' psychosocial adjustment to having an ostomy (Altschuler et al., 2009; Goldzweig et al., 2009).

Survivors gained confidence by learning to manage bowel dysfunction and other symptoms over time and regaining some aspects of their normal life prior to cancer (Desnoo and Faithfull, 2006; McCaughan et al., 2012). Building confidence entailed identifying patterns in bowel function, making changes in lifestyle, and seeking information (McCaughan et al., 2012). Goal setting was integral to this process of rebuilding and regaining, bringing survivors a sense of hope, and allowing them to evaluate their progress toward their goals (Anderson et al., 2013; Appleton et al., 2013; Palmer et al., 2013).

### **Individual Experience of Illness and Recovery**

Each individual experiences the process of diagnosis, treatment and recovery uniquely, depending on their coping mechanisms and support structures (McCaughan et al., 2012). The transition from life during treatment to life after treatment brings various challenges for each cancer survivor, and the rate at which each individual recovers from and adjusts to these challenges is variable (Appleton et al., 2013; McCaughan et al., 2012). The idea of 'normality' after cancer treatment varied substantially, ranging from a desire to return to prior form or devise a new normality. Factors influencing normality are diverse and heavily influence the survivors' confidence and growth. These factors include the type and severity of symptoms experienced, and the success and acceptability of self-management strategies employed to regain control of bodily functions (Bains et al., 2012; Desnoo and Faithfull, 2006; Grant et al., 2011).

CRC survivors may experience disparity in care and outcomes of cancer treatment due to ethnicity, age, and access to health insurance, adding a further facet to the individual experience of CRC survivorship (Chambers et al., 2012b; Haggstrom et al., 2009; Schneider et al., 2007; Steginga et al., 2009). Similar to other groups of cancer survivors, the timing, need and ability to process cancer-related information is highly individualized, yet HCP's do not always tailor responses to survivors' circumstances (Anderson et al., 2013; Baravelli et al., 2009). Despite these challenges, resilience and the ability to re-appraise life allows CRC survivors' to appreciate life, in some cases to a greater degree than one who had not experienced cancer (Serpentini et al., 2011).

### **Navigating Systems and Resources**

Upon diagnosis of CRC, survivors must learn how to navigate the healthcare system. The multitude of healthcare providers, variance in models of care provision, and fragmentation of healthcare meant this

could be a protracted and complex experience (Baravelli et al., 2009; Gordon et al., 2012; Haggstrom et al., 2009; Sisler et al., 2012; Snyder et al., 2008a, b). Survivors may attend multiple physicians for follow-up care, including a medical oncologist, a radiation oncologist, a surgeon, a gastroenterologist and a primary care practitioner, each with different objectives for survivorship care (Baravelli et al., 2009; Haggstrom et al., 2009). The complexity of the process means that some CRC survivors fall through the cracks of follow-up; as many as one-quarter do not believe they are receiving cancer-related follow-up care (Haggstrom et al., 2009). The difficulty experienced by CRC survivors in managing and navigating follow-up is further highlighted by Gordon et al. (2012), as more than half had difficulty accurately recalling medical appointments over the past six months.

There is a substantial risk that surveillance for cancer recurrence may be prioritized above the management of chronic effects and provision of information and support to survivors (Di Fabio et al., 2008; Phipps et al., 2008; Tofthagen, 2010). Haggstrom et al. (2009) reports that just seven percent of CRC survivors attended a medical professional for management of side-effects, compared to eighty-five percent who attend for follow-up tests. Inadequate support and symptom management by HCP's result in survivors experiencing confusion (Tofthagen, 2010). Where support from HCP's is inadequate, CRC survivors believe they must be responsible for their health at the end of treatment, and try to devise self-management strategies and self-sufficiency in the absence of medical support (Desnoo and Faithfull, 2006; Grant et al., 2011; McMullen et al., 2008; Palmer et al., 2013). On the other hand, egalitarian relationships between HCP's and the survivor eased the complexity of managing residual effects, developing self-management strategies and navigating follow-up care (Appleton et al., 2013; Palmer et al., 2013). Egalitarian relationships were characterized by ease of access to information and open communication between the survivor and HCP (Appleton et al., 2013).

A significant theme in the period following treatment is the met and unmet needs of CRC survivors'. Survivors experienced a broad range of health, information and support needs arising from CRC. Specific support and information needs for CRC survivors pertain to the management of the ostomy and altered bowel function. Diet and lifestyle advice were particularly prominent needs within the reviewed literature, as survivors express frustration about conflicting or confusing information and the trial and error approach to symptom management advocated by HCP's (Anderson et al., 2013; Haggstrom et al., 2009; Ho et al., 2015; McMullen et al., 2008; Nikoletti et al., 2008; Pullar et al., 2012; Sanoff et al., 2015). The general needs of CRC survivors reflect those of the heterogeneous population of cancer survivors, and relate to the psychological and social consequences of cancer. Few CRC survivors' are explicitly asked about their emotional well-being in the aftermath of treatment, though most find such enquiry useful (Baravelli et al., 2009). Furthermore, CRC survivors highlight difficulties accessing specialist



psychological support for both themselves and their family members (Anderson et al., 2013; Grant et al., 2011). The timing of support and information is crucial, but the point at which the survivor is ready to process such information is highly individualized (Anderson et al., 2013; Haggstrom et al., 2009; Nikoletti et al., 2008).

As CRC survivors enter the post-treatment period the frequency of contact with HCP's reduces, thus the level of support diminishes (McCaughan et al., 2012; Tofthagen, 2010). Unfortunately, some survivors may not benefit from, or desire to be involved in cancer support groups, due to difficulty discussing bowel-related concerns in a general cancer support forum because of embarrassment or lack of sensitivity from others (Baravelli et al., 2009; McCaughan et al., 2012; McMullen et al., 2008). Despite these issues, CRC survivors demonstrate particular resourcefulness in securing information and support outside the hospital environment, using telephone helplines, information booklets, internet resources, cancer peer-support, counselling, complementary/alternative medicine, and family support (Anderson et al., 2013; Appleton et al., 2013; Lawsin et al., 2007; McCaughan et al., 2012; McMullen et al., 2008; Nikoletti et al., 2008; Ramirez et al., 2009; Stein et al., 2009; Tofthagen, 2010).

### **Consequences**

In keeping with the framework of Doyle (2008), the consequences of CRC survivorship are presented in relation to physical, psychological, social and spiritual health, and an additional theme, the constellation of met and unmet survivorship needs. QOL is a central concept to the consequences of CRC survivorship. Although QOL and the burden of chronic symptoms may improve over time, it remains that survivors continue to experience significant challenges in the years following diagnosis and treatment.

### **Physical Health**

CRC survivors experience an abundance of physical effects as a direct result of cancer and its treatment. Those who survive CRC live with particular physical symptoms arising from chemotherapy, bowel surgery, and pelvic radiotherapy. Like other tumour groups, CRC survivors may experience pain, sleep disturbance and fatigue (Anderson et al., 2013; Domati et al., 2011; Grant et al., 2011; Grimmer et al., 2011; Jansen et al., 2011; McCaughan et al., 2012; Peddle et al., 2008a; Phipps et al., 2008; Schneider et al., 2007; Shun et al., 2011; Sisler et al., 2012; Stein et al., 2009; Thong et al., 2011b, 2013). However, side-effects particular to CRC survivors include weight changes; sexual dysfunction (erectile problems, vaginal dryness, dyspareunia), upper gastrointestinal disturbances (food intolerance, nausea, vomiting, loss of appetite), and bowel dysfunction (constipation, diarrhoea, abdominal cramping, flatulence, incontinence, urgency, frequency) (Anderson et al., 2013; Bailey et al., 2015; Caravati-Jouvencaux et al., 2011; Den Ouden et al., 2012; Di Fabio et al., 2008; Ellis et al., 2010; Grant et al., 2011; Grimmer et



al., 2011; Jansen et al., 2011; Lynch et al., 2008b; McMullen et al., 2008; Milbury et al., 2013; Nikoletti et al., 2008; Phipps et al., 2008; Ramirez et al., 2009; Ristvedt and Trinkaus, 2009; Sanoff et al., 2015; Schneider et al., 2007; Serpentine et al., 2011; Sisler et al., 2012; Thong et al., 2011a, 2011b; Verhaar et al., 2015).

CRC survivors report difficulties with peripheral neuropathy, an irreversible effect of chemotherapy, which causes pain, paraesthesia and cramping of the hands and feet, affecting survivors' mobility and daily activities (Ho et al., 2015; Padman et al., 2015; Palmer et al., 2013; Sanoff et al., 2015; Tofthagen, 2010). In addition, those who lived with an ostomy as a consequence of cancer survival were more likely to experience hernia and skin care issues at the ostomy site (pain, irritation, rash and fungal infection) (Hornbrook et al., 2011; Lynch et al., 2008b; McMullen et al., 2008).

### **Psychological Health**

The psychological aspect of cancer survivorship is significant. Fear of recurrence, depression, anxiety and distress are enduring issues for some survivors, heightened around the time of clinical appointments (Appleton et al., 2013; Chambers et al., 2012b; Dunn et al., 2013; Espen et al., 2007; Faul et al., 2012; Krouse et al., 2009; Laws et al., 2007; Loi, 2011; Lynch et al., 2008c; McCaughan et al., 2012; Milbury et al., 2013; Nikoletti et al., 2008; Phipps et al., 2008; Ristvedt and Trinkaus, 2009; Schneider et al., 2007; Shun et al., 2011; Stein et al., 2009; Thong et al., 2013). The physical effects of CRC treatment, including bowel dysfunction and peripheral neuropathy had significant negative effects on CRC survivors' psychological well-being, body image, and adaption to survivorship (Bailey et al., 2015; Desnoo and Faithfull, 2006; Ho et al., 2015; McMullen et al., 2008; Padman et al., 2015; Palmer et al., 2013; Phipps et al., 2008; Schneider et al., 2007; Serpentine et al., 2011; Thong et al., 2011b; Tofthagen, 2010). Despite these consequences, some survivors undergo post-traumatic growth. Many learn to cope with the effects of cancer therapy to the extent where they may no longer consider them major problems, eventually becoming more comfortable with their body image, and deriving strength and resilience from the experience of cancer (Appleton et al., 2013; McCaughan et al., 2012; Thong et al., 2011b).

### **Social Health**

The themes of isolation and hiding away were particularly salient to social well-being. CRC survivors may experience poorer social well-being, particularly in the first five years following treatment, worsened by changes in employment, financial concerns, inadequate support, symptom distress, and the presence of an ostomy or bowel dysfunction (Anderson et al., 2013; Baravelli et al., 2009; Caravati-Jouvenaux et al., 2011; Domati et al., 2011; Gordon et al., 2008; Grant et al., 2011; Hanly et al., 2013; Jansen et al., 2011; Krouse et al., 2009; McCaughan et al., 2012; Ristvedt and Trinkaus, 2009; Shun et al., 2011;

Steginga et al., 2009; Thong et al., 2011a; Tofthagen, 2010). As a consequence of the physical effects of CRC, many survivors reduced their social activities to avoid potential embarrassment and inconvenience in public places (Loi, 2011; McCaughan et al., 2012; McMullen et al., 2008). Attending social events requires careful preparation, therefore toilet mapping and menu planning were important behaviours undertaken to avoid accidents and embarrassment (Desnoo and Faithfull, 2006; Nikoletti et al., 2008). The physical and psychological effects of treatment impacted upon sexual relationships, particularly for females, as some avoided intimacy due to pain, and fear of reaction from their partner (Grant et al., 2011; Krouse et al., 2009; McMullen et al., 2008; Milbury et al., 2013; Ramirez et al., 2009). However, this was not a problem for all survivors, as they expressed gratitude for being alive and having a supportive family or spouse (Chambers et al., 2012b; Nikoletti et al., 2008; Ramirez et al., 2009).

### **Spiritual Health**

As a consequence of the uncertainty brought about by CRC survivorship, the experience has a unique effect on the survivors' spirituality. Religiosity assists some survivors' to cope with the process of survivorship and is associated with more positive QOL (Loi, 2011; Salsman et al., 2011). As survivors come to terms with a new normal, they have an opportunity to reappraise their lives, finding new meaning and benefits in survivorship (Appleton et al., 2013; Desnoo and Faithfull, 2006; Domati et al., 2011; McMullen et al., 2008; Ramirez et al., 2009). Survivors may develop a desire to give back to the healthcare services by providing peer support and assisting HCP's in research (Appleton et al., 2013; Grant et al., 2011; Loi, 2011; McCaughan et al., 2012; Palmer et al., 2013; Tofthagen, 2010).

### **The Constellation of Met and Unmet Survivorship Needs**

Survivors' develop a constellation of health, information and support needs as a result of the experience of CRC. Survivors face new challenges specific to the nature of their disease, encompassing bowel management, ostomy care, health promotion, diet and lifestyle advice, requiring significant practical and psychological support to facilitate adjustment (Anderson et al., 2013; Haggstrom et al., 2009; Ho et al., 2015; McGowan et al., 2013; McMullen et al., 2008; Nikoletti et al., 2008; Pullar et al., 2012). Other unmet information and healthcare needs were similar to those of survivors of other forms of cancer, and included information about diagnosis, investigations, treatments, prognosis, medication management, surveillance, follow-up care, genetic risk, management of chronic side-effects, return to work, financial concerns and who to contact should cancer-related problems arise (Bains et al., 2012; Baravelli et al., 2009; Esplen et al., 2007; Faul et al., 2012; Nikoletti et al., 2008; Sisler et al., 2012; Tofthagen, 2010; Vadaparampil et al., 2010).

CRC survivors may feel that information and support needs are not adequately met by HCP's due to reduced contact with healthcare staff following treatment (Grant et al., 2011; Haggstrom et al., 2009; McCaughan et al., 2012; Palmer et al., 2013; Phipps et al., 2008; Sisler et al., 2012; Tofthagen, 2010). The psychological needs of the survivor may be overlooked due to prioritization of cancer surveillance activities (Baravelli et al., 2009; Di Fabio et al., 2008). As a result, survivors become resourceful, identifying alternative sources of support and information outside the healthcare environment (Anderson et al., 2013; Nikoletti et al., 2008). Though the quality of these resources may be questionable, survivors may feel they are left with little option but to pursue such resources, particularly if they are encouraged to follow trial and error approaches to symptom management (Anderson et al., 2013; Desnoo and Faithfull, 2006; Grant et al., 2011; McMullen et al., 2008; Palmer et al., 2013).

### ***References***

CRC survivorship may be used to describe the experiences of any individual who has received a diagnosis of CRC, whether cured or living with a terminal diagnosis. Survivorship affects the individual, their families, friends and the HCP's responsible for diagnosis, treatment, disease surveillance and management of cancer-related issues.

### ***Related Concepts***

QOL remains one of the most commonly used related concepts within the cancer survivorship literature. However, other concepts used in relation to CRC survivorship include health behaviour, illness perception, symptom burden, survivor identity, psychological distress, post-traumatic stress, coping, adaption, adjustment, continuity of care, and unmet need. Although each of these concepts reflect attributes of CRC survivorship, they fail to fully encompass the diverse, individual and dynamic nature of the experience.

### ***Model Case***

Where a model case possessing all attributes of the concept is identified rather than constructed, the clarification of the concept is enriched. However, selecting a model case in the context of CRC may introduce potential bias, as it would require the selection of an individual with colon or rectal cancer, thereby failing to fully embody the concept.

### ***Discussion***

Historically, cancer survivorship was considered the timeframe one could expect to live after cancer. As oncology professionals sought to increase survival rates, the management of survivorship issues was not prioritized. As cancer survival rates have improved over the past two decades, cancer survivorship has

evolved to become more than a measure of time. High profile reports from Reuben (2004) and IOM (2006) facilitated an expansion in the focus of cancer survivorship research, encompassing the survivor, their QOL, and their needs in the aftermath of treatment as well as epidemiological concerns of survival rates, morbidity and mortality.

This study has demonstrated that the attributes and consequences of cancer survivorship within the context of CRC are ultimately a fine balance between positive and negative effects. Like general populations of cancer survivors, CRC survivors also experience survivorship as an individualized, life-changing process beginning at diagnosis, paved with uncertainty and a duality of positive and negative outcomes impacting upon physical, psychological, social and spiritual domains of well-being (Doyle, 2008; Farmer and Smith, 2002). However, within these attributes, there are an abundance of experiences specific to CRC, due to the site of disease and the consequences of its treatment. Unlike Farmer and Smith (2002) and Doyle (2008), fertility issues were not a significant concern in CRC survivorship, due to age-related factors. However, CRC survivors must adjust to the distinct challenges presented within the themes of loss of control and hiding away which result from bowel dysfunction and ostomy formation. Survivors experience an array of needs to understand their newfound situation as CRC survivors, and may eventually experience an altruistic drive to share their experiences and management strategies for the benefit of other survivors and the HCP's who care for them.

This study is limited by the exclusion of anecdotal and lay literature and non-English publications. Furthermore, much of the literature reports European, Australian and North American perspectives, therefore the generalizability of these findings may be limited. However, this is the first concept analysis which situates the concept of cancer survivorship in the context of CRC. This study highlights the evolution of cancer survivorship, extending the concept to include the attribute navigation of systems and resources, and the consequence, the constellation of met and unmet needs (Fig. 6).

QOL remains an important consequence of cancer survivorship, yet there is a dearth of empirical research considering the effect of healthcare experience on QOL and health-related outcomes in the context of CRC survivorship. The Contextual Model of Health- Related QOL (Ashing-Giwa, 2005) may be used to situate this concept, as it allows the evaluation of QOL with due consideration of the demographic, economic, cultural and healthcare contexts which may influence health and illness.

Becoming self-sufficient in managing the after-effects of CRC and regaining a sense of normality are important goals of CRC survivors' recovery. However, unmet health and information needs are substantial barriers to these goals. It is imperative that HCP's endeavour to meet CRC survivors' information and healthcare needs in an individualized manner. This may be achieved through a variety of interventions,

including personalized survivorship care plans, treatment summaries, or a consultation at the conclusion of treatment, to provide information about survivorship issues and facilitate healthcare navigation in survivorship.

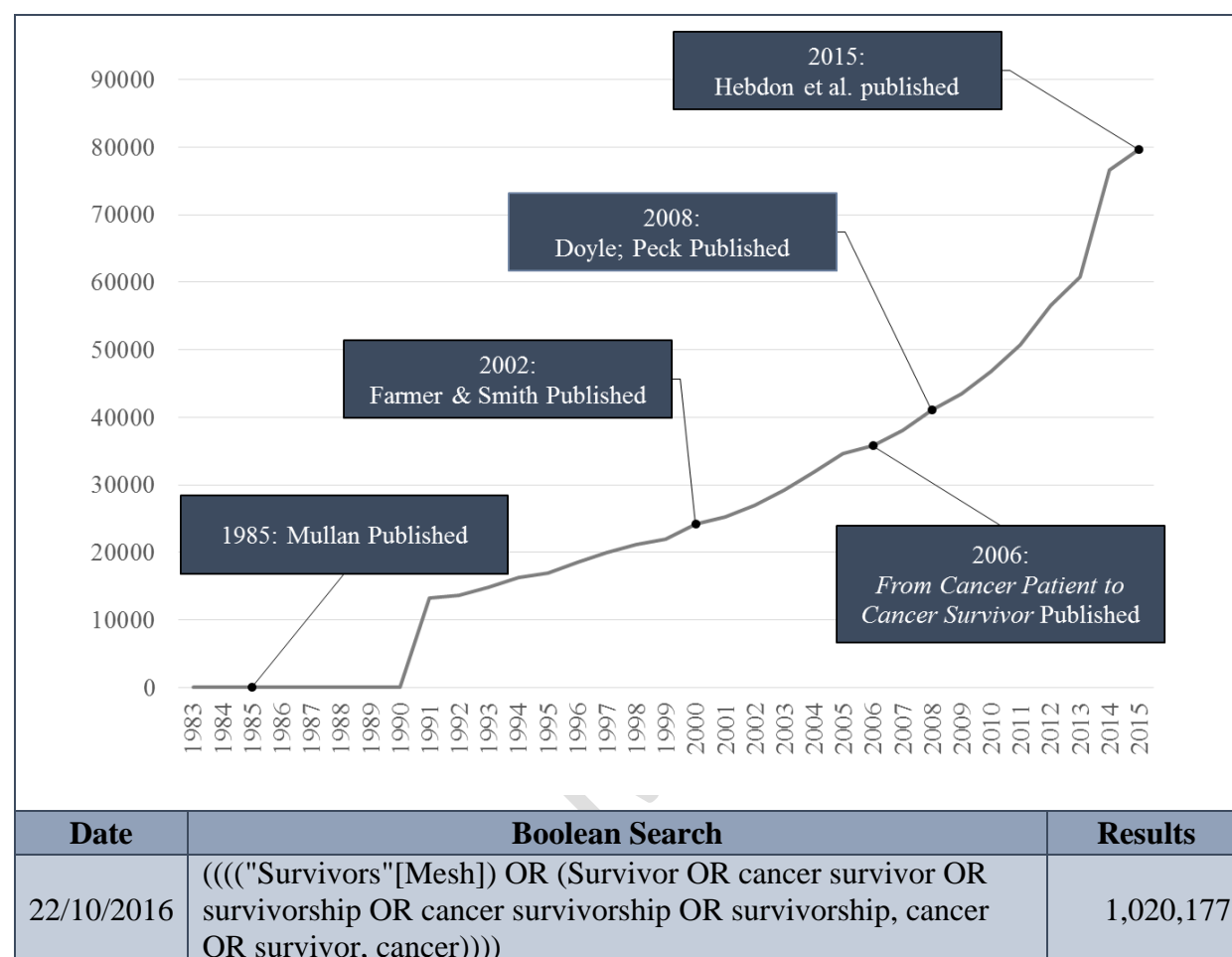
### **Conflict of Interest**

The authors report no conflict of interest. The authors alone are responsible for the content and writing of this paper.

### **Funding**

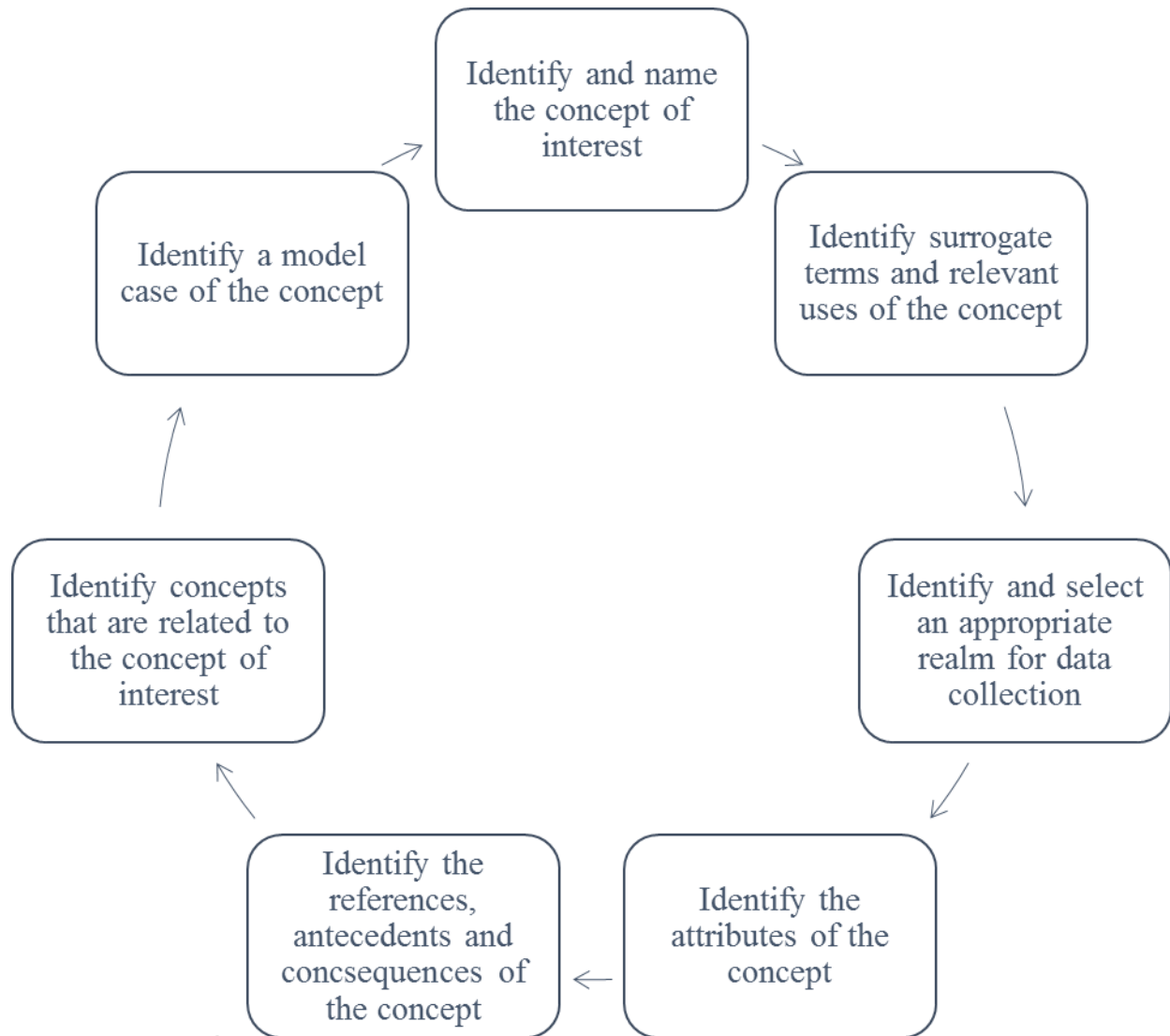
This research is supported by funding from the Health Research Board of Ireland, grant number HPF.2014.715.

# Figures:

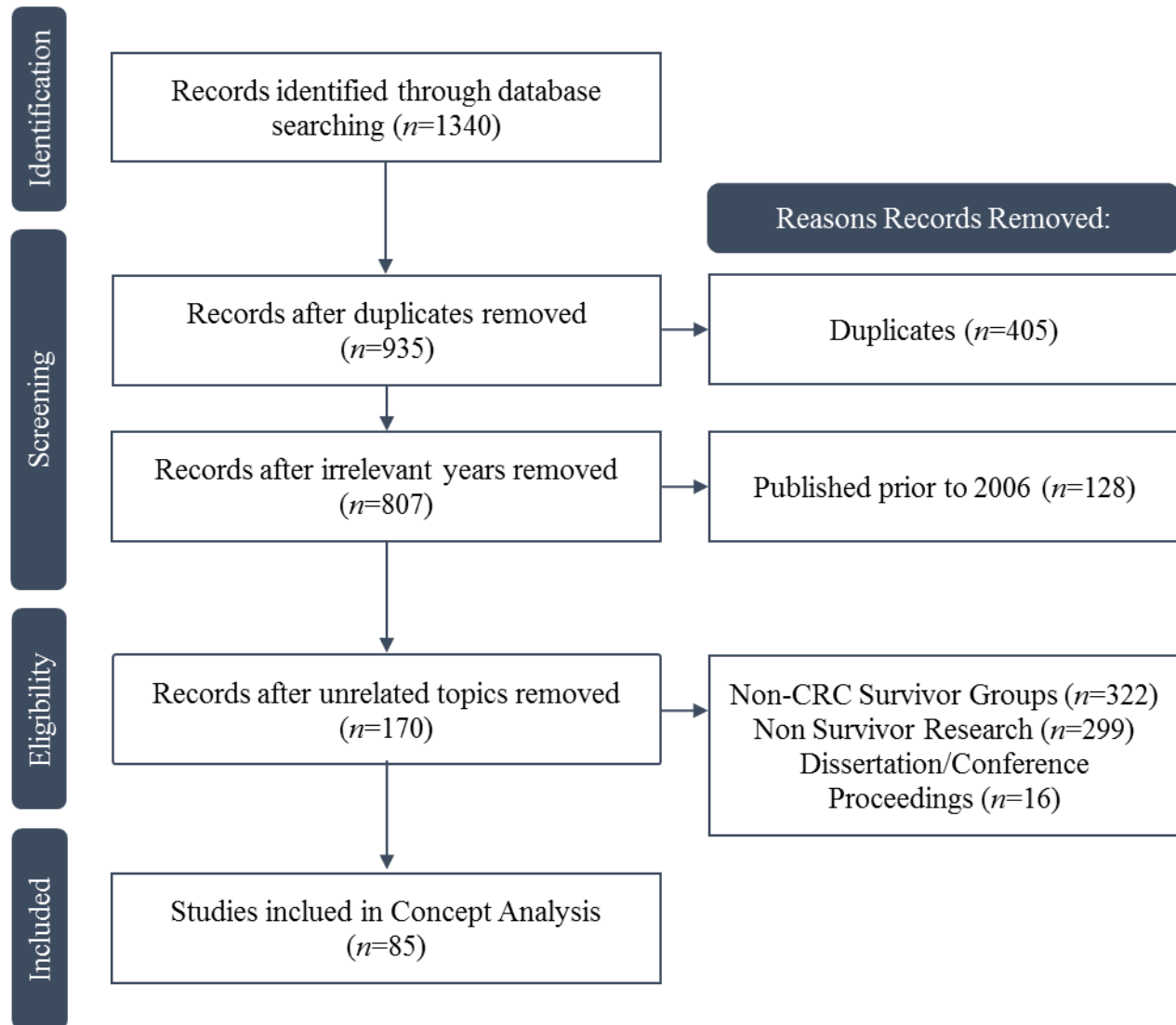


**Figure 1: Cancer survivorship publications search of PUBMED database, 1983-2015.**

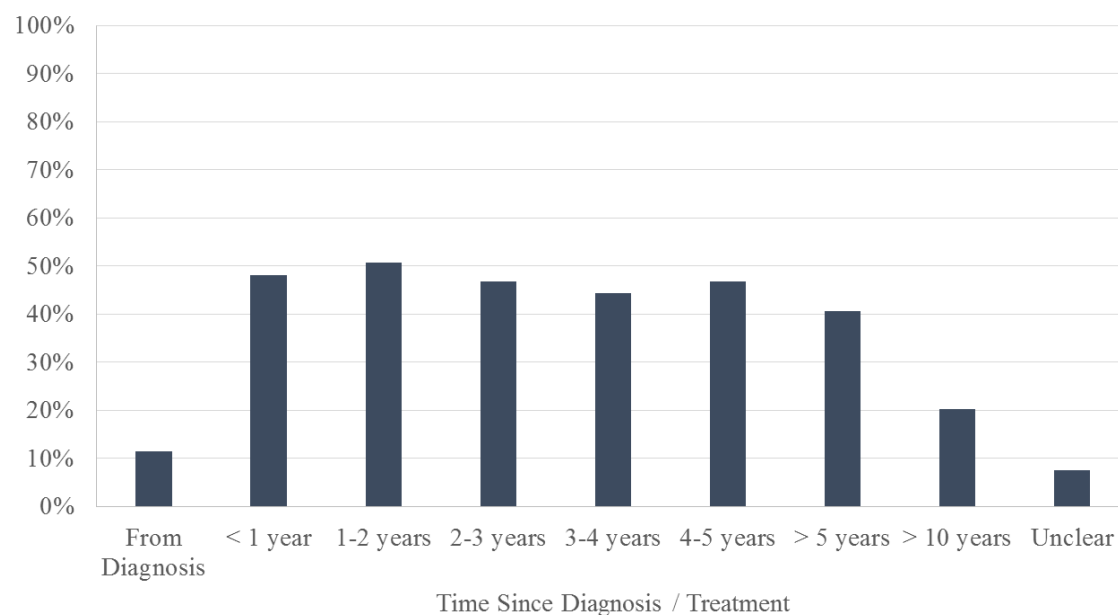




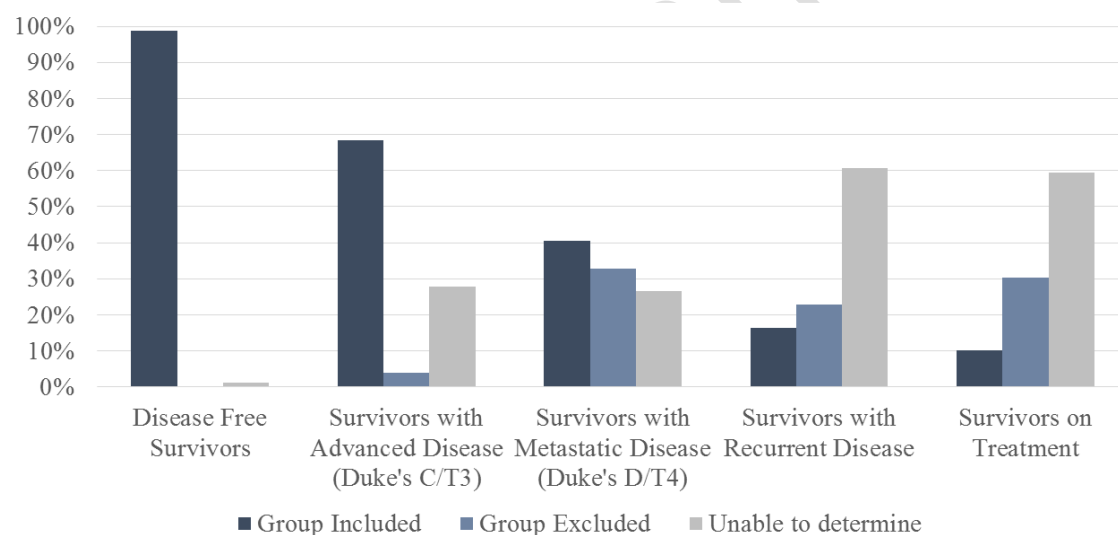
**Figure 2: Rodgers evolutionary method of concept analysis**



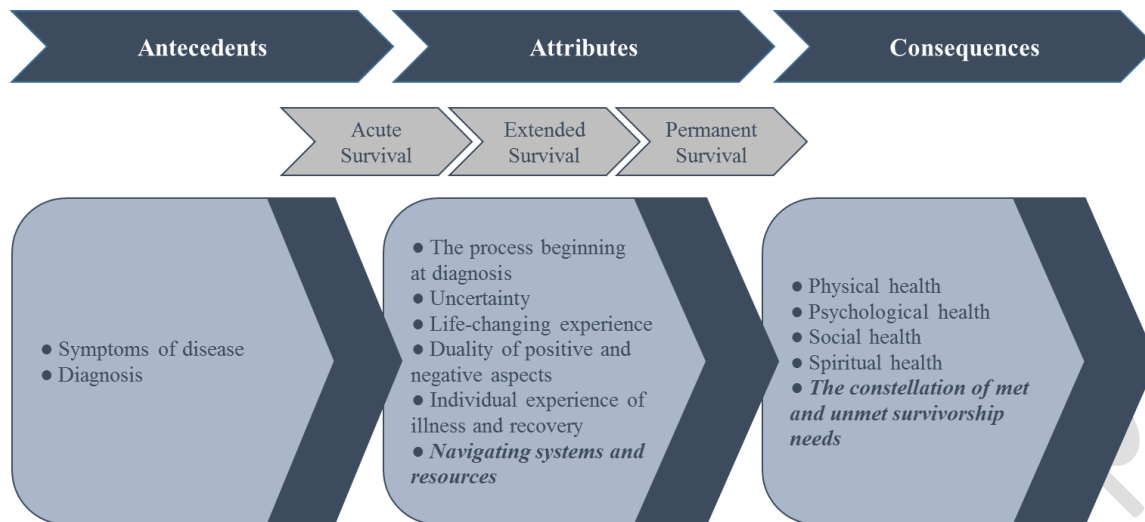
**Figure 3: Concept analysis PRISMA flow diagram**



**Figure 4: Proportions of studies using selected timeframes of survivorship**



**Figure 5: Proportions of studies including colorectal cancer survivors with selected stages of disease**



**Figure 6: Proposed antecedents, attributes and consequences of cancer survivorship in the context of colorectal cancer.**

Authors	Farmer & Smith (2002)	Peck (2008)	Doyle (2008)	Hebdon et al (2015)
<b>Concept</b>	Breast Cancer Survivorship for African-American Women	Survivorship	Cancer Survivorship	Survivor in the context of cancer
<b>Model</b>	Rodgers	Walker and Avant	Rodgers	Walker and Avant
<b>Antecedents</b>	<ul style="list-style-type: none"> <li>• Cancer diagnosis</li> </ul>	<ul style="list-style-type: none"> <li>• Person with established future memories</li> <li>• Baseline or stable quality of life</li> <li>• Event / disease / trauma which leads to suffering and forces one to face his / her mortality</li> </ul>	<ul style="list-style-type: none"> <li>• Cancer diagnosis</li> </ul>	<ul style="list-style-type: none"> <li>• Diagnosis of cancer</li> <li>• Treatment of cancer</li> <li>• Being alive</li> </ul>
<b>Attributes</b>	<ul style="list-style-type: none"> <li>• Complex</li> <li>• Individualised</li> <li>• Process</li> <li>• Unique</li> <li>• Relational</li> <li>• Dynamic</li> </ul>	<ul style="list-style-type: none"> <li>• Acceptance of current and past life circumstances</li> <li>• Altered self-image and self-identity which fully incorporates past events</li> <li>• Modified future memories which incorporate new life circumstances</li> </ul>	<ul style="list-style-type: none"> <li>• The process beginning at diagnosis</li> <li>• Uncertainty</li> <li>• Life-changing experience</li> <li>• Duality of positive and negative aspects</li> <li>• Individual experience with universality</li> </ul>	<p>An individual:</p> <ul style="list-style-type: none"> <li>• who is living with a history of malignancy,</li> <li>• who has lived through a difficult experience such as cancer treatment,</li> <li>• has been impacted in positive and negative ways by the experience, and</li> <li>• whose experience is personal and contextual</li> </ul>
<b>Consequences</b>	<ul style="list-style-type: none"> <li>• Physical</li> <li>• Psychosocial</li> <li>• Spiritual</li> <li>• Socioeconomic</li> </ul>	<ul style="list-style-type: none"> <li>• Quality of life improved or returned to baseline</li> <li>• Ability to live in harmony with ramifications</li> <li>• Fewer exacerbations secondary to accommodating lifestyle to fit new future memories</li> <li>• Complete biopsychosocial adaption</li> <li>• Ability to find meaning in experience, be it spiritual, meaning, logical meaning or both</li> <li>• Continued vulnerability, be it positive or negative</li> </ul>	<ul style="list-style-type: none"> <li>• Physical health</li> <li>• Psychological health</li> <li>• Social health</li> <li>• Spiritual health</li> </ul>	<ul style="list-style-type: none"> <li>• The individual does not survive unaffected</li> <li>• Experiences physical, emotional, financial and social challenges</li> <li>• Needs support from external sources</li> <li>• Positive outcomes including improved self-advocacy, a sense of well-being, and victory of overcoming a challenge.</li> </ul>

**Table 1: Antecedents, Attributes and Consequences of Survivorship and Cancer Survivorship reported in Previous Concept Analyses**

Database	Search Terms	Search Options	Results	Search Date
PUBMED	(((((("Colorectal Neoplasms"[Mesh] OR "Colonic Neoplasms"[Mesh] OR "Rectal Neoplasms"[Mesh]))) OR (((neoplasm OR neoplasms OR cancer OR cancers OR carcinoma OR carcinomas OR tumour OR tumours OR tumor OR tumors[Title/Abstract]))) AND ((colonic OR colon OR rectal OR rectum OR colorectal OR anal OR anus[Title/Abstract]))) AND (("Survivors"[Mesh]) AND ((Survivor OR cancer survivor OR survivorship OR cancer survivorship OR survivorship, cancer OR survivor, cancer[Title/Abstract])))	<b>Filter:</b> Humans Adult: 19+ years	576	24/11/2016
CINAHL	(TI (colonic OR colon OR rectal OR rectum OR colorectal OR anal or anus) OR AB (colonic OR colon OR rectal OR rectum OR colorectal OR anal or anus)) AND (TI (neoplasm OR neoplasms OR cancer OR cancers OR carcinoma OR carcinomas OR tumour OR tumours OR tumor OR tumors) OR AB (neoplasm OR neoplasms OR cancer OR cancers OR carcinoma OR carcinomas OR tumour OR tumours OR tumor OR tumors)) AND (TI (Survivor OR cancer survivor OR survivorship OR cancer survivorship OR survivorship, cancer OR survivor, cancer) OR AB (Survivor OR cancer survivor OR survivorship OR cancer survivorship OR survivorship, cancer OR survivor, cancer))	<b>Search modes:</b> Boolean/Phrase	309	24/11/2016
PsycINFO	(TI (neoplasm OR neoplasms OR cancer OR cancers OR carcinoma OR carcinomas OR tumour OR tumours OR tumor OR tumors) OR AB (neoplasm OR neoplasms OR cancer OR cancers OR carcinoma OR carcinomas OR tumour OR tumours OR tumor OR tumors)) AND (TI (colonic OR colon OR rectal OR rectum OR colorectal OR anal OR anus) OR AB (colonic OR colon OR rectal OR rectum OR colorectal OR anal OR anus)) AND (TI (Survivor OR cancer survivor OR survivorship OR cancer survivorship OR survivorship, cancer OR survivor, cancer) OR AB (Survivor OR cancer survivor OR survivorship OR cancer survivorship OR survivorship, cancer OR survivor, cancer))	<b>Search modes:</b> Boolean/Phrase	288	24/11/2016
The Cochrane Library	((((colonic OR colon OR rectal OR rectum OR colorectal OR anal or anus: ti,ab) AND (neoplasm OR neoplasms OR cancer OR cancers OR carcinoma OR carcinomas OR tumour OR tumours OR tumor OR tumors: ti,ab)) AND (Survivor OR cancer survivor OR survivorship OR cancer survivorship OR survivorship, cancer OR survivor, cancer))		98	24/11/2016

**Table 2 Colorectal Cancer Survivorship Database Search Strategies**



## References

- Altschuler, A., Ramirez, M., Grant, M., Wendel, C., Hornbrook, M.C., Herrinton, L., Krouse, R.S., 2009. The influence of husbands' or male partners' support on women's psychosocial adjustment to having an ostomy resulting from colorectal cancer. *Journal of Wound, Ostomy & Continence Nursing* 36, 299-305. DOI: <http://dx.doi.org/10.1097/WON.0b013e3181a1a1dc>.
- Anderson, A.S., Steele, R., Coyle, J., 2013. Lifestyle issues for colorectal cancer survivors--perceived needs, beliefs and opportunities. *Supportive Care in Cancer* 21, 35-42. DOI: <http://dx.doi.org/10.1007/s00520-012-1487-7>.
- Appleton, L., Goodlad, S., Irvine, F., Poole, H., Wall, C., 2013. Patients' experiences of living beyond colorectal cancer: a qualitative study. *European Journal of Oncology Nursing* 17, 610-617. DOI: <http://dx.doi.org/10.1016/j.ejon.2013.01.002>.
- Ashing-Giwa, K.T., 2005. The contextual model of HRQoL: A paradigm for expanding the HRQoL framework. *Quality of Life Research* 14, 297-307. DOI: <http://dx.doi.org/10.1007/s11136-004-0729-7>.
- Au, T.Y., Zauszniewski, J.A., King, T.M., 2012. Health-seeking behaviors and sexuality in rectal cancer survivors in Taiwan: associations with spirituality and resourcefulness. *Oncology Nursing Forum* 39, E390-397. DOI: <http://dx.doi.org/10.1188/12.ONF.E390-E397>.
- Bailey, C.E., Tran Cao, H.S., Hu, C.Y., Chang, G.J., Feig, B.W., Rodriguez-Bigas, M.A., Nguyen, S.T., Skibber, J.M., You, Y.N., 2015. Functional deficits and symptoms of long-term survivors of colorectal cancer treated by multimodality therapy differ by age at diagnosis. *Journal of Gastrointestinal Surgery* 19, 180-188. DOI: <http://dx.doi.org/10.1007/s11605-014-2645-7>.
- Bains, M., Yarker, J., Amir, Z., Wynn, P., Munir, F., 2012. Helping cancer survivors return to work: what providers tell us about the challenges in assisting cancer patients with work questions. *Journal of Occupational Rehabilitation* 22, 71-77. DOI: <http://dx.doi.org/10.1007/s10926-011-9330-4>.
- Baravelli, C., Krishnasamy, M., Pezaro, C., Schofield, P., Lotfi-Jam, K., Rogers, M., Milne, D., Aranda, S., King, D., Shaw, B., Grogan, S., Jefford, M., 2009. The views of bowel cancer survivors and health care professionals regarding survivorship care plans and post treatment follow up. *J Cancer Surviv* 3, 99-108. DOI: <http://dx.doi.org/10.1007/s11764-009-0086-1>.
- Braun, V., Clarke, V., 2006. Using thematic analysis in psychology. *Qualitative research in psychology* 3, 77-101. DOI: <http://dx.doi.org/10.1191/1478088706qp063oa>.
- Brawarsky, P., Neville, B.A., Fitzmaurice, G.M., Earle, C., Haas, J.S., 2013. Surveillance after resection for colorectal cancer. *Cancer* 119, 1235-1242. DOI: <http://dx.doi.org/10.1002/cncr.27852>.
- Caravati-Jouvenaux, A., Launoy, G., Klein, D., Henry-Amar, M., Abeilard, E., Danzon, A., Pozet, A., Velten, M., Mercier, M., 2011. Health-related quality of life among long-term survivors of colorectal cancer: a population-based study. *The Oncologist* 16, 1626-1636. DOI: <http://dx.doi.org/10.1634/theoncologist.2011-0036>.
- Carpentier, M.Y., Vernon, S.W., Bartholomew, L.K., Murphy, C.C., Bluethmann, S.M., 2013. Receipt of recommended surveillance among colorectal cancer survivors: A systematic review. *J Cancer Surviv* 7, 464-483. DOI: <http://dx.doi.org/10.1007/s11764-013-0290-x>.
- Chambers, S.K., Baade, P., Meng, X., Youl, P., Aitken, J., Dunn, J., 2012a. Survivor identity after colorectal cancer: antecedents, prevalence and outcomes. *Psycho-Oncology* 21, 962-969. DOI: <http://dx.doi.org/10.1002/pon.1991>.
- Chambers, S.K., Lynch, B.M., Aitken, J., Baade, P., 2009. Relationship over time between psychological distress and physical activity in colorectal cancer survivors. *Journal of Clinical Oncology* 27, 1600-1606. DOI: <http://dx.doi.org/10.1200/jco.2008.18.5157>.

- Chambers, S.K., Meng, X., Youl, P., Aitken, J., Dunn, J., Baade, P., 2012b. A five-year prospective study of quality of life after colorectal cancer. *Quality of Life Research* 21, 1551-1564. DOI: <http://dx.doi.org/10.1007/s11136-011-0067-5>.
- Cooper, G.S., Kou, T.D., Reynolds, H.L., Jr., 2008. Receipt of guideline-recommended follow-up in older colorectal cancer survivors : a population-based analysis. *Cancer* 113, 2029-2037. DOI: <http://dx.doi.org/10.1002/cncr.23823>.
- Cragun, D., Malo, T.L., Pal, T., Shibata, D., Vadaparampil, S.T., 2012. Colorectal cancer survivors' interest in genetic testing for hereditary cancer: implications for universal tumor screening. *Genetic Testing and Molecular Biomarkers* 16, 493-499. DOI: <http://dx.doi.org/10.1089/gtmb.2011.0247>.
- Custers, J.A., Gielissen, M.F., Janssen, S.H., de Wilt, J.H., Prins, J.B., 2016. Fear of cancer recurrence in colorectal cancer survivors. *Supportive Care in Cancer* 24, 555-562. DOI: <http://dx.doi.org/10.1007/s00520-015-2808-4>.
- Dallam, S.J., 2010. A model of the retraumatization process: A meta-synthesis of childhood sexual abuse survivors' experiences in healthcare. Doctoral Dissertation, University of Kansas. No DOI available.
- Den Oudsten, B.L., Traa, M.J., Thong, M.S., Martijn, H., De Hingh, I.H., Bosscha, K., van de Poll-Franse, L.V., 2012. Higher prevalence of sexual dysfunction in colon and rectal cancer survivors compared with the normative population: a population-based study. *European Journal of Cancer* 48, 3161-3170. DOI: <http://dx.doi.org/10.1016/j.ejca.2012.04.004>.
- Desnoo, L., Faithfull, S., 2006. A qualitative study of anterior resection syndrome: the experiences of cancer survivors who have undergone resection surgery. *European Journal of Cancer Care* 15, 244-251. DOI: <http://dx.doi.org/10.1111/j.1365-2354.2005.00647.x>.
- Di Fabio, F., Koller, M., Nascimbeni, R., Talarico, C., Salerni, B., 2008. Long-term outcome after colorectal cancer resection. Patients' self-reported quality of life, sexual dysfunction and surgeons' awareness of patients' needs. *Tumori* 94, 30-35. No DOI Available.
- Domati, F., Rossi, G., Benatti, P., Roncucci, L., Cirilli, C., Ponz de Leon, M., 2011. Long-term survey of patients with curable colorectal cancer with specific reference to the quality of life. *Internal and Emergency Medicine* 6, 529-535. DOI: <http://dx.doi.org/10.1007/s11739-011-0590-y>.
- Doyle, N., 2008. Cancer survivorship: evolutionary concept analysis. *Journal of Advanced Nursing* 62, 499-509. DOI: <http://dx.doi.org/10.1111/j.1365-2648.2008.04617.x>.
- Dunn, J., Ng, S.K., Holland, J., Aitken, J., Youl, P., Baade, P.D., Chambers, S.K., 2013. Trajectories of psychological distress after colorectal cancer. *Psycho-Oncology* 22, 1759-1765. DOI: <http://dx.doi.org/10.1002/pon.3210>.
- Ellis, R., Smith, A., Wilson, S., Warmington, S., Ismail, T., 2010. The prevalence of erectile dysfunction in post-treatment colorectal cancer patients and their interests in seeking treatment: A cross-sectional survey in the West-Midlands. *Journal of Sexual Medicine* 7, 1488-1496. DOI: <http://dx.doi.org/10.1111/j.1743-6109.2009.01461.x>.
- Esplen, M.J., Madlensky, L., Aronson, M., Rothenmund, H., Gallinger, S., Butler, K., Toner, B., Wong, J., Manno, M., McLaughlin, J., 2007. Colorectal cancer survivors undergoing genetic testing for hereditary non-polyposis colorectal cancer: motivational factors and psychosocial functioning. *Clinical Genetics* 72, 394-401. DOI: <http://dx.doi.org/10.1111/j.1399-0004.2007.00893.x>.
- Farmer, B.J., Smith, E.D., 2002. Breast cancer survivorship: are African American women considered? A concept analysis. *Oncology Nursing Forum* 29, 779-787. DOI: <http://dx.doi.org/10.1188/02.ONF.779-787>.
- Faul, L.A., Rivers, B., Shibata, D., Townsend, I., Cabrera, P., Quinn, G.P., Jacobsen, P.B., 2012. Survivorship care planning in colorectal cancer: feedback from survivors & providers. *Journal of Psychosocial Oncology* 30, 198-216. DOI: <http://dx.doi.org/10.1080/07347332.2011.651260>.

Feuerstein, M., 2007. Defining cancer survivorship. *J Cancer Surviv* 1, 5-7. DOI: <http://dx.doi.org/10.1007/s11764-006-0002-x>.

Goldzweig, G., Andritsch, E., Hubert, A., Walach, N., Perry, S., Brenner, B., Baider, L., 2009. How relevant is marital status and gender variables in coping with colorectal cancer? A sample of middle-aged and older cancer survivors. *Psycho-Oncology* 18, 866-874. DOI: <http://dx.doi.org/10.1002/pon.1499>.

Gordon, L., Lynch, B.M., Newman, B., 2008. Transitions in work participation after a diagnosis of colorectal cancer. *Australian and New Zealand Journal of Public Health* 32, 569-574. DOI: <http://dx.doi.org/10.1111/j.1753-6405.2008.00312.x>.

Gordon, L.G., Patrao, T., Hawkes, A.L., 2012. Can colorectal cancer survivors recall their medications and doctor visits reliably? *BMC Health Services Research* 12, 440. DOI: <http://dx.doi.org/10.1186/1472-6963-12-440>.

Grant, M., McMullen, C.K., Altschuler, A., Hornbrook, M.C., Herrinton, L.J., Wendel, C.S., Baldwin, C.M., Krouse, R.S., 2012. Irrigation practices in long-term survivors of colorectal cancer with colostomies. *Clinical Journal of Oncology Nursing* 16, 514-519. DOI: <http://dx.doi.org/10.1188/12.cjon.514-519>.

Grant, M., McMullen, C.K., Altschuler, A., Mohler, M.J., Hornbrook, M.C., Herrinton, L.J., Wendel, C.S., Baldwin, C.M., Krouse, R.S., 2011. Gender differences in quality of life among long-term colorectal cancer survivors with ostomies. *Oncolgy Nursing Forum* 38, 587-596. DOI: <http://dx.doi.org/10.1188/11.onf.587-596>.

Grimmett, C., Bridgewater, J., Steptoe, A., Wardle, J., 2011. Lifestyle and quality of life in colorectal cancer survivors. *Quality of Life Research* 20, 1237-1245. DOI: <http://dx.doi.org/10.1007/s11136-011-9855-1>.

Haggstrom, D.A., Arora, N.K., Helft, P., Clayman, M.L., Oakley-Girvan, I., 2009. Follow-up care delivery among colorectal cancer survivors most often seen by primary and subspecialty care physicians. *Journal of General Internal Medicine* 24, S472-479. DOI: <http://dx.doi.org/10.1007/s11606-009-1017-6>.

Hanly, P., Walsh, P.M., A, O.C., Skally, M., Staines, A., Kapur, K., Fitzpatrick, P., Sharp, L., 2013. Work-related productivity losses in an era of ageing populations: the case of colorectal cancer. *Journal of Occupational and Environmental Medicine* 55, 128-134. DOI: <http://dx.doi.org/10.1097/JOM.0b013e3182820553>.

Hawkes, A.L., Lynch, B.M., Youlden, D.R., Owen, N., Aitken, J.F., 2008. Health behaviors of Australian colorectal cancer survivors, compared with noncancer population controls. *Supportive Care in Cancer* 16, 1097-1104. DOI: <http://dx.doi.org/10.1007/s00520-008-0421-5>.

Hebdon, M., Foli, K., McComb, S., 2015. Survivor in the cancer context: a concept analysis. *J Adv Nurs* 71, 1774-1786. DOI: <http://dx.doi.org/10.1111/jan.12646>.

Ho, M.Y., McBride, M.L., Gotay, C., Grunfeld, E., Earle, C.C., Relova, S., Tsonis, M., Ruan, J.Y., Chang, J.T., Cheung, W.Y., 2015. A qualitative focus group study to identify the needs of survivors of stage ii and iii colorectal cancer. *Psycho-Oncology* 25, 1470-1476. DOI: <http://dx.doi.org/10.1002/pon.3988>.

Hornbrook, M.C., Wendel, C.S., Coons, S.J., Grant, M., Herrinton, L.J., Mohler, M.J., Baldwin, C.M., McMullen, C.K., Green, S.B., Altschuler, A., Rawl, S.M., Krouse, R.S., 2011. Complications among colorectal cancer survivors: SF-6D preference-weighted quality of life scores. *Medical Care* 49, 321-326. DOI: <http://dx.doi.org/10.1097/MLR.0b013e31820194c8>.

Hu, C.Y., Delclos, G.L., Chan, W., Du, X.L., 2011. Post-treatment surveillance in a large cohort of patients with colon cancer. *The American Journal of Managed Care* 17, 329-336. PMID: <https://www.ncbi.nlm.nih.gov/pubmed/21718080>.

Hursting, S.D., Forman, M.R., 2009. Cancer risk from extreme stressors: lessons from European Jewish survivors of World War II. *Journal of the National Cancer Institute* 101, 1436-1437. DOI: <http://dx.doi.org/10.1093/jnci/djp357>.

Institute of Medicine, 2006. From Cancer Patient to Cancer Survivor: Lost in Transition, in: Hewitt, M., Greenfield, S., Stovall, E. (Eds.). The National Academies Press, Washington. DOI: <https://doi.org/10.17226/11468>.

International Agency for Research on Cancer 2014. World Cancer Report 2014, in: Stewart, B.W., Wild, C.P. (Eds.). International Agency for Research on Cancer, Lyon. DOI: <http://dx.doi.org/10.3945/an.116.012211>.

James, A.S., Campbell, M.K., DeVellis, B., Reedy, J., Carr, C., Sandler, R.S., 2006. Health behavior correlates among colon cancer survivors: NC STRIDES baseline results. *American Journal of Health Behavior* 30, 720-730. DOI: <http://dx.doi.org/10.5555/ajhb.2006.30.6.720>.

Jansen, L., Herrmann, A., Stegmaier, C., Singer, S., Brenner, H., Arndt, V., 2011. Health-related quality of life during the 10 years after diagnosis of colorectal cancer: a population-based study. *Journal of Clinical Oncology* 29, 3263-3269. DOI: <http://dx.doi.org/10.1200/jco.2010.31.4013>.

Johnson, B.L., Trentham-Dietz, A., Koltyn, K.F., Colbert, L.H., 2009. Physical activity and function in older, long-term colorectal cancer survivors. *Cancer Causes & Control* 20, 775-784. DOI: <http://dx.doi.org/10.1007/s10552-008-9292-9>.

Khan, N.F., Rose, P.W., Evans, J., 2012. Defining cancer survivorship: a more transparent approach is needed. *J Cancer Surviv* 6, 33-36. DOI: <http://dx.doi.org/10.1007/s11764-011-0194-6>.

Krouse, R.S., Herrinton, L.J., Grant, M., Wendel, C.S., Green, S.B., Mohler, M.J., Baldwin, C.M., McMullen, C.K., Rawl, S.M., Matayoshi, E., Coons, S.J., Hornbrook, M.C., 2009. Health-related quality of life among long-term rectal cancer survivors with an ostomy: manifestations by sex. *Journal of Clinical Oncology* 27, 4664-4670. DOI: <http://dx.doi.org/10.1200/jco.2008.20.9502>.

Lawsin, C., DuHamel, K., Itzkowitz, S.H., Brown, K., Lim, H., Thelemaque, L., Jandorf, L., 2007. Demographic, medical, and psychosocial correlates to CAM use among survivors of colorectal cancer. *Supportive Care in Cancer* 15, 557-564. DOI: <http://dx.doi.org/10.1007/s00520-006-0198-3>.

Leigh, S., 2007. Cancer survivorship: A nursing perspective, *Cancer Survivorship*. Springer, pp. 8-13. DOI: [http://dx.doi.org/10.1007%2F978-0-387-68265-5\\_2](http://dx.doi.org/10.1007%2F978-0-387-68265-5_2).

Loi, C., 2011. An analysis of artwork representing the experiences of colorectal cancer survivors. *Singapore Nursing Journal* 38, 5-9. No DOI Available.

Lundy, J.J., Coons, S.J., Wendel, C., Hornbrook, M.C., Herrinton, L., Grant, M., Krouse, R.S., 2009. Exploring household income as a predictor of psychological well-being among long-term colorectal cancer survivors. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation* 18, 157-161. DOI: <http://dx.doi.org/10.1007/s11136-008-9432-4>.

Lynch, B.M., Cerin, E., Newman, B., Owen, N., 2007a. Physical activity, activity change, and their correlates in a population-based sample of colorectal cancer survivors. *Annals of Behavioral Medicine* 34, 135-143. DOI: <http://dx.doi.org/10.1080/08836610701564147>.

Lynch, B.M., Cerin, E., Owen, N., Aitken, J.F., 2007b. Associations of leisure-time physical activity with quality of life in a large, population-based sample of colorectal cancer survivors. *Cancer Causes & Control* 18, 735-742. DOI: <http://dx.doi.org/10.1007/s10552-007-9016-6>.

Lynch, B.M., Cerin, E., Owen, N., Hawkes, A.L., Aitken, J.F., 2008a. Prospective relationships of physical activity with quality of life among colorectal cancer survivors. *Journal of Clinical Oncology* 26, 4480-4487. DOI: <http://dx.doi.org/10.1200/jco.2007.15.7917>.

Lynch, B.M., Cerin, E., Owen, N., Hawkes, A.L., Aitken, J.F., 2011. Television viewing time of colorectal cancer survivors is associated prospectively with quality of life. *Cancer Causes & Control* 22, 1111-1120. DOI: <http://dx.doi.org/10.1007/s10552-011-9786-8>.



- Lynch, B.M., Hawkes, A.L., Steginga, S.K., Leggett, B., Aitken, J.F., 2008b. Stoma surgery for colorectal cancer: a population-based study of patient concerns. *Journal of Wound, Ostomy & Continence Nursing* 35, 424-428. PMID: <https://www.ncbi.nlm.nih.gov/pubmed/18635994>.
- Lynch, B.M., Steginga, S.K., Hawkes, A.L., Pakenham, K.I., Dunn, J., 2008c. Describing and predicting psychological distress after colorectal cancer. *Cancer* 112, 1363-1370. DOI: <http://dx.doi.org/10.1002/cncr.23300>.
- McCaughan, E., Prue, G., Parahoo, K., McIlfatrick, S., McKenna, H., 2012. Exploring and comparing the experience and coping behaviour of men and women with colorectal cancer after chemotherapy treatment: a qualitative longitudinal study. *Psycho-Oncology* 21, 64-71. DOI: <http://dx.doi.org/10.1002/pon.1871>.
- McGowan, E.L., Speed-Andrews, A.E., Blanchard, C.M., Rhodes, R.E., Friedenreich, C.M., Culos-Reed, S.N., Courneya, K.S., 2013. Physical activity preferences among a population-based sample of colorectal cancer survivors. *Oncology Nursing Forum* 40, 44-52. DOI: <http://dx.doi.org/10.1188/13.onf.44-52>.
- McMullen, C.K., Hornbrook, M.C., Grant, M., Baldwin, C.M., Wendel, C.S., Mohler, M.J., Altschuler, A., Ramirez, M., Krouse, R.S., 2008. The greatest challenges reported by long-term colorectal cancer survivors with stomas. *The Journal of Supportive Oncology* 6, 175-182. PMID: <https://www.ncbi.nlm.nih.gov/pubmed/18491686>.
- Milbury, K., Cohen, L., Jenkins, R., Skibber, J.M., Schover, L.R., 2013. The association between psychosocial and medical factors with long-term sexual dysfunction after treatment for colorectal cancer. *Supportive Care in Cancer* 21, 793-802. DOI: <http://dx.doi.org/10.1007/s00520-012-1582-9>.
- Mols, F., Denollet, J., Kaptein, A.A., Reemst, P.H., Thong, M.S., 2012. The association between Type D personality and illness perceptions in colorectal cancer survivors: a study from the population-based PROFILES registry. *Journal of Psychosomatic Research* 73, 232-239. DOI: <http://dx.doi.org/10.1016/j.jpsychores.2012.07.004>.
- Mols, F., Lemmens, V., Bosscha, K., van den Broek, W., Thong, M.S., 2014. Living with the physical and mental consequences of an ostomy: a study among 1-10-year rectal cancer survivors from the population-based PROFILES registry. *Psycho-Oncology* 23, 998-1004. DOI: <http://dx.doi.org/10.1002/pon.3517>.
- Mullen, F., 1985. Seasons of Survivorship: Reflections of A Physician with Cancer. *The New England Journal of Medicine* 313, 270-273. PMID: <https://www.ncbi.nlm.nih.gov/pubmed/4010738>.
- National Cancer Registry of Ireland 2014. Cancer projections for Ireland 2015-2040. National Cancer Registry, Cork, Ireland. URL: <http://www.ncri.ie/sites/ncri/files/pubs/Cancer%20projections%20for%20Ireland%202015%20-%202040.pdf>.
- Nikoletti, S., Young, J., Levitt, M., King, M., Chidlow, C., Hollingsworth, S., 2008. Bowel problems, self-care practices, and information needs of colorectal cancer survivors at 6 to 24 months after sphincter-saving surgery. *Cancer Nursing* 31, 389-398. DOI: <http://dx.doi.org/10.1097/01.NCC.0000305759.04357.1b>.
- Organisation for Economic Co-operation and Development 2015. Health at a Glance 2015. OECD Publishing. DOI: [http://dx.doi.org/10.1787/health\\_glance-2015-en](http://dx.doi.org/10.1787/health_glance-2015-en).
- Padman, S., Lee, J., Kumar, R., Slee, M., Hakendorf, P., Richards, A., Koczwara, B., Kichenadasse, G., Sukumaran, S., Roy, A., Vatandoust, S., Karapetis, C.S., 2015. Late effects of oxaliplatin-induced peripheral neuropathy (LEON)--cross-sectional cohort study of patients with colorectal cancer surviving at least 2 years. *Supportive Care in Cancer* 23, 861-869. DOI: <http://dx.doi.org/10.1007/s00520-014-2423-9>.

- Palmer, N.R., Bartholomew, L.K., McCurdy, S.A., Basen-Engquist, K.M., Naik, A.D., 2013. Transitioning from active treatment: colorectal cancer survivors' health promotion goals. *Palliative & Supportive Care* 11, 101-109. DOI: <http://dx.doi.org/10.1017/s1478951512000788>.
- Peck, S., 2008. Survivorship: a concept analysis. *Nursing Forum* 43, 91-102. DOI: <http://dx.doi.org/10.1111/j.1744-6198.2008.00100.x>.
- Peddle, C.J., Au, H.J., Courneya, K.S., 2008a. Associations between exercise, quality of life, and fatigue in colorectal cancer survivors. *Diseases of the Colon and Rectum* 51, 1242-1248. DOI: <http://dx.doi.org/10.1007/s10350-008-9324-2>.
- Peddle, C.J., Plotnikoff, R.C., Wild, T.C., Au, H.J., Courneya, K.S., 2008b. Medical, demographic, and psychosocial correlates of exercise in colorectal cancer survivors: an application of self-determination theory. *Supportive Care in Cancer* 16, 9-17. DOI: <http://dx.doi.org/10.1007/s00520-007-0272-5>.
- Phipps, E., Braitman, L.E., Stites, S., Leighton, J.C., 2008. Quality of life and symptom attribution in long-term colon cancer survivors. *Journal of Evaluation in Clinical Practice* 14, 254-258. DOI: <http://dx.doi.org/10.1111/j.1365-2753.2007.00842.x>.
- Preston, D.L., Ron, E., Tokuoka, S., Funamoto, S., Nishi, N., Soda, M., Mabuchi, K., Kodama, K., 2007. Solid cancer incidence in atomic bomb survivors: 1958-1998. *Radiation Research* 168, 1-64. DOI: <http://dx.doi.org/10.1667/rr0763.1>.
- Pullar, J.M., Chisholm, A., Jackson, C., 2012. Dietary information for colorectal cancer survivors: an unmet need. *The New Zealand Medical Journal* 125, 27-37. PMID: <https://www.ncbi.nlm.nih.gov/pubmed/22729056>.
- Ramirez, M., McMullen, C., Grant, M., Altschuler, A., Hornbrook, M.C., Krouse, R.S., 2009. Figuring out sex in a reconfigured body: experiences of female colorectal cancer survivors with ostomies. *Women & Health* 49, 608-624. DOI: <http://dx.doi.org/10.1080/03630240903496093>.
- Reuben, S.H., 2004. Living Beyond Cancer: Finding a New Balance. President's Cancer Panel 2003-2004 Annual Report, in: Services, U.S.D.o.H.a.H., Health, N.I.o., Institute, N.C. (Eds.). The President's Cancer Panel, Bethesda. URL: <https://pubs.cancer.gov/ncipl/detail.aspx?prodid=P986>.
- Ristvedt, S.L., Trinkaus, K.M., 2009. Trait anxiety as an independent predictor of poor health-related quality of life and post-traumatic stress symptoms in rectal cancer. *British Journal of Health Psychology* 14, 701-715. DOI: <http://dx.doi.org/10.1348/135910708x400462>.
- Rodgers, B.L., 1989. Concepts, Analysis and the Development of Nursing Knowledge: The Evolutionary Cycle. *Journal of Advanced Nursing* 14, 330-335. PMID: <https://www.ncbi.nlm.nih.gov/pubmed/2661622>.
- Rodgers, B.L., 2000a. Concept analysis: an evolutionary view, in: Rodgers, B., Knafl, K. (Eds.), *Concept development in nursing: foundations, techniques, and applications*, 2nd ed. W.B. Saunders, Philadelphia, Pa., pp. 77-102. No DOI Available.
- Rodgers, B.L., 2000b. Philosophical Foundations of Concept Development, in: Rodgers, B.L., Knafl, K.A. (Eds.), *Concept Development in Nursing: Foundations, Techniques, and Applications*, 2nd ed. Saunders, Philadelphia, pp. 7-37. No DOI Available.
- Rodgers, B.L., Knafl, K.A., 2000. Introduction to Concept Development in Nursing, in: Rodgers, B.L., Knafl, K.A. (Eds.), *Concept Development in Nursing: Foundations, Techniques, and Applications*, 2nd ed. Saunders, Philadelphia, pp. 1-6. No DOI Available.
- Rowland, J.H., Kent, E.E., Forsythe, L.P., Loge, J.H., Hjorth, L., Glaser, A., Mattioli, V., Fosså, S.D., 2013. Cancer Survivorship Research in Europe and the United States: Where have we been, where are we going, and what can we learn from each other? *Cancer* 119, 2094-2108. DOI: <http://dx.doi.org/10.1002/cncr.28060>.
- Salsman, J.M., Segerstrom, S.C., Brechting, E.H., Carlson, C.R., Andrykowski, M.A., 2009. Posttraumatic growth and PTSD symptomatology among colorectal cancer survivors: a 3-month



longitudinal examination of cognitive processing. *Psycho-Oncology* 18, 30-41. DOI: <http://dx.doi.org/10.1002/pon.1367>.

Salsman, J.M., Yost, K.J., West, D.W., Cella, D., 2011. Spiritual well-being and health-related quality of life in colorectal cancer: a multi-site examination of the role of personal meaning. *Supportive Care in Cancer* 19, 757-764. DOI: <http://dx.doi.org/10.1007/s00520-010-0871-4>.

Salz, T., Brewer, N.T., Sandler, R.S., Weiner, B.J., Martin, C.F., Weinberger, M., 2009. Association of health beliefs and colonoscopy use among survivors of colorectal cancer. *J Cancer Surviv* 3, 193-201. DOI: <http://dx.doi.org/10.1007/s11764-009-0095-0>.

Sanoff, H.K., Morris, W.L., Mitcheltree, A.-L., Wilson, S., Lund, J.L., 2015. Lack of Support and Information Regarding Long-Term Negative Effects in Survivors of Rectal Cancer. *Clinical Journal of Oncology Nursing* 19, 444-448. DOI: <http://dx.doi.org/10.1188/15.CJON.444-448>.

Schneider, E.C., Malin, J.L., Kahn, K.L., Ko, C.Y., Adams, J., Epstein, A.M., 2007. Surviving colorectal cancer : patient-reported symptoms 4 years after diagnosis. *Cancer* 110, 2075-2082. DOI: <http://dx.doi.org/10.1002/cncr.23021>.

Serpentini, S., Del Bianco, P., Alducci, E., Toppan, P., Ferretti, F., Folin, M., De Salvo, G.L., Nitti, D., Pucciarelli, S., 2011. Psychological well-being outcomes in disease-free survivors of mid-low rectal cancer following curative surgery. *Psycho-Oncology* 20, 706-714. DOI: <http://dx.doi.org/10.1002/pon.1763>.

Shun, S.C., Hsiao, F.H., Lai, Y.H., Liang, J.T., Yeh, K.H., Huang, J., 2011. Personality trait and quality of life in colorectal cancer survivors. *Oncology Nursing Forum* 38, E221-228. DOI: <http://dx.doi.org/10.1188/11.onf.e221-e228>.

Sisler, J.J., Taylor-Brown, J., Nugent, Z., Bell, D., Khawaja, M., Czaykowski, P., Wirtzfeld, D., Park, J., Ahmed, S., 2012. Continuity of care of colorectal cancer survivors at the end of treatment: the oncology-primary care interface. *J Cancer Surviv* 6, 468-475. DOI: <http://dx.doi.org/10.1007/s11764-012-0235-9>.

Snyder, C.F., Earle, C.C., Herbert, R.J., Neville, B.A., Blackford, A.L., Frick, K.D., 2008a. Preventive care for colorectal cancer survivors: a 5-year longitudinal study. *Journal of Clinical Oncology* 26, 1073-1079. DOI: <http://dx.doi.org/10.1200/jco.2007.11.9859>.

Snyder, C.F., Earle, C.C., Herbert, R.J., Neville, B.A., Blackford, A.L., Frick, K.D., 2008b. Trends in follow-up and preventive care for colorectal cancer survivors. *Journal of General Internal Medicine* 23, 254-259. DOI: <http://dx.doi.org/10.1007/s11606-007-0497-5>.

Soerjomataram, I., Thong, M.S., Ezzati, M., Lamont, E.B., Nusselder, W.J., van de Poll-Franse, L.V., 2012. Most colorectal cancer survivors live a large proportion of their remaining life in good health. *Cancer Causes & Control* 23, 1421-1428. DOI: <http://dx.doi.org/10.1007/s10552-012-0010-2>.

Speed-Andrews, A.E., McGowan, E.L., Rhodes, R.E., Blanchard, C.M., Culos-Reed, S.N., Friedenreich, C.M., Courneya, K.S., 2013. Correlates of strength exercise in colorectal cancer survivors. *American Journal of Health Behavior* 37, 162-170. DOI: <http://dx.doi.org/10.5993/ajhb.37.2.3>.

Speed-Andrews, A.E., Rhodes, R.E., Blanchard, C.M., Culos-Reed, S.N., Friedenreich, C.M., Belanger, L.J., Courneya, K.S., 2012. Medical, demographic and social cognitive correlates of physical activity in a population-based sample of colorectal cancer survivors. *European Journal of Cancer Care* 21, 187-196. DOI: <http://dx.doi.org/10.1111/j.1365-2354.2011.01290.x>.

Steginga, S.K., Lynch, B.M., Hawkes, A., Dunn, J., Aitken, J., 2009. Antecedents of domain-specific quality of life after colorectal cancer. *Psycho-Oncology* 18, 216-220. DOI: <http://dx.doi.org/10.1002/pon.1388>.

Stein, K.D., Kaw, C., Crammer, C., Gansler, T., 2009. The role of psychological functioning in the use of complementary and alternative methods among disease-free colorectal cancer survivors: a

report from the American Cancer Society's studies of cancer survivors. *Cancer* 115, 4397-4408. DOI: <http://dx.doi.org/10.1002/cncr.24591>.

Sun, V., Grant, M., Wendel, C.S., McMullen, C.K., Bulkley, J.E., Altschuler, A., Ramirez, M., Baldwin, C.M., Herrinton, L.J., Hornbrook, M.C., Krouse, R.S., 2015. Dietary and Behavioral Adjustments to Manage Bowel Dysfunction After Surgery in Long-Term Colorectal Cancer Survivors. *Annals of Surgical Oncology* 22, 4317-4324. DOI: <http://dx.doi.org/10.1245/s10434-015-4731-9>.

Thong, M.S., Mols, F., Lemmens, V.E., Creemers, G.J., Slooter, G.D., van de Poll-Franse, L.V., 2011a. Impact of chemotherapy on health status and symptom burden of colon cancer survivors: a population-based study. *European Journal of Cancer* 47, 1798-1807. DOI: <http://dx.doi.org/10.1016/j.ejca.2011.02.006>.

Thong, M.S., Mols, F., Lemmens, V.E., Rutten, H.J., Roukema, J.A., Martijn, H., van de Poll-Franse, L.V., 2011b. Impact of preoperative radiotherapy on general and disease-specific health status of rectal cancer survivors: a population-based study. *International Journal of Radiation Oncology, Biology, Physics* 81, 49-58. DOI: <http://dx.doi.org/10.1016/j.ijrobp.2010.12.030>.

Thong, M.S., Mols, F., Wang, X.S., Lemmens, V.E., Smilde, T.J., van de Poll-Franse, L.V., 2013. Quantifying fatigue in (long-term) colorectal cancer survivors: a study from the population-based patient reported outcomes following initial treatment and long term evaluation of survivorship registry. *European Journal of Cancer* 49, 1957-1966. DOI: <http://dx.doi.org/10.1016/j.ejca.2013.01.012>.

Thraen-Borowski, K.M., Trentham-Dietz, A., Edwards, D.F., Koltyn, K.F., Colbert, L.H., 2013. Dose-response relationships between physical activity, social participation, and health-related quality of life in colorectal cancer survivors. *J Cancer Surviv* 7, 369-378. DOI: <http://dx.doi.org/10.1007/s11764-013-0277-7>.

Toftagen, C., 2010. Surviving chemotherapy for colon cancer and living with the consequences. *Journal of Palliative Medicine* 13, 1389-1391. DOI: <http://dx.doi.org/10.1089/jpm.2010.0124>.

Vadaparampil, S.T., Quinn, G., Malo, T.L., Alvarez, A., Miree, C.A., Shibata, D., 2010. Knowledge about hereditary colorectal cancer among colorectal cancer survivors. *Genetic Testing and Molecular Biomarkers* 14, 603-609. DOI: <http://dx.doi.org/10.1089/gtmb.2010.0004>.

Verhaar, S., Vissers, P.A., Maas, H., van de Poll-Franse, L.V., van Erning, F.N., Mols, F., 2015. Treatment-related differences in health related quality of life and disease specific symptoms among colon cancer survivors: results from the population-based PROFILES registry. *European Journal of Cancer* 51, 1263-1273. DOI: <http://dx.doi.org/10.1016/j.ejca.2015.04.004>.

Walker, L., Avant, K., 1995. *Strategies for Theory Construction in Nursing*. Appleton and Lange, Norwalk, CT. No DOI Available.

Weaver, K., Mitcham, C., 2008. Nursing concept analysis in North America: state of the art. *Nursing Philosophy* 9, 180-194. DOI: <http://dx.doi.org/10.1111/j.1466-769X.2008.00359.x>.

Wijndaele, K., Lynch, B.M., Owen, N., Dunstan, D.W., Sharp, S., Aitken, J.F., 2009. Television viewing time and weight gain in colorectal cancer survivors: a prospective population-based study. *Cancer Causes & Control* 20, 1355-1362. DOI: <http://dx.doi.org/10.1007/s10552-009-9356-5>.