

The Occupational Impact of Surviving Bowel Cancer

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Abstract

This study explored and identified the impact of bowel cancer on daily occupations. Approximately 60% of survivors live with ongoing psychological and physical issues. New Zealand has one of the highest bowel cancer rates in the world, with over 3000 people diagnosed every year. Using interpretive description methodology, this research investigated the experiences of a group of survivors. Most cancer care focuses on the treatment or end of life stages of bowel cancer; however, this study involved the often overlooked survivorship phase. Moreover, bowel cancer literature often uses quantitative methods. In contrast, the constructivist approach of this study facilitated the co-construction of knowledge with bowel cancer survivors, thus furthering the existing and emerging body of evidence regarding the life experienced by this population.

The study was conducted over three phases which are reported across four manuscripts. The first of these manuscripts, phase one, presents a scoping review designed to gain an understanding of the current state of knowledge regarding bowel cancer and occupations. Six domains of occupation impacted by bowel cancer were identified: social activity, physical activity, sexual activity, employment and role functioning, physical functioning, and self-care. The review also reported on a lack of health professional support after completion of treatment.

Review findings informed the second phase, semi-structured interviews with 15 participants – made up of bowel cancer survivors and some partners – exploring the occupational impact of bowel cancer. Taking an occupational science view of survivors as occupational beings, the second manuscript reports on three themes: “I had to heal myself”, “Life’s too short”, and “The person I’ve become”.

The third phase involved a further round of interviews with three new participants and two involved in the first round. These interviews had a dual focus; 1) to ascertain whether the identified themes resonated with participants and captured their experiences, and 2), to generate participant guidance as to the information needs of

bowel cancer survivors. Findings of the second and third phases are reported in two additional manuscripts, the first of which addressed the potential role of occupational therapy, currently underrepresented in oncology. Four themes emphasised the occupational impact across multiple aspects of life: changes in eating habits, changes in toileting habits, changes in relationships, and rethinking occupational choices. Findings revealed a possible role for occupational therapists through focused assessments and self-management, making use of peers to provide a credible, relatable voice. The final manuscript explored considerations for content and delivery of information to bowel cancer survivors across four themes: using a variety of media, the importance of relatability, pressure to conform, and someone who knows.

Hearing accounts of the challenges to everyday life and the practical and attitudinal responses experienced by bowel cancer survivors highlights the significant impact of the disease. Whilst some pre-cancer occupations are surrendered or adapted, others are increased or introduced, with significant variation amongst participants. This information can help survivors prepare for life after treatment, and health professionals understand the unique challenges faced by this population and thus improve health and well-being.

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List of abbreviations

Abbreviation	Definition
A	Analysis
ACS/ACSM	American Cancer Society/American College of Sports Medicine
ADLs	Activities of daily living
APR	Abdominoperineal resection
AUT	Auckland University of Technology
BCNZ	Bowel Cancer New Zealand
BCSCS	Bowel cancer survivor core set
BF	Bowel function
CC	Colon cancer
CI	Confidence interval
CRC	Colorectal cancer
CS	Cancer survivor
CSCS	Cancer survivor core set
CTNZ	Cancer trials New Zealand
DHB	District Health Board
EMAS	Engagement in meaningful activities survey
EORTC – QLQ-CR29/30/38	European Organisation for Research and Treatment of Cancer – Quality of life of cancer patient questionnaires
FACT-C	Functional assessment of cancer therapy – colorectal cancer
FC	Functional capacity
GP	General population
HAR	High anterior resection
HRQL	Health related quality of life
ICF	International Classification of Functioning, Disability and Health
ID	Interpretive description
ITEA	Integrating theory, evidence, and action
LAR	Low anterior resection
M	Months
NED	No evidence of disease
NZ	New Zealand
OPHH-II	Occupational performance history interview – 2 nd version
PA	Physical activity
PF	Physical functioning
PS	Performance status
QoL	Quality of life
RC	Rectal cancer
RF	Role functioning
RTW	Return to work
SD	Standard deviation
SF	Social functioning
SF-36	RAND Short form survey instrument
SDHB	Southern District Health Board
TV	Television
UK	United Kingdom
US	United States
WHO	World Health Organization

Glossary of Māori

Te Reo Māori	English translation*
Hinengaro	Psychological
Kai	To eat; to drink; food or meal
Māori	Indigenous New Zealander, indigenous person of Aotearoa/New Zealand
Mauri	Life principle, life force, vital essence, special nature, a material symbol of a life principle, source of emotions - the essential quality and vitality of a being or entity.
Tangi	To cry, mourn, weep; rites for the dead, funeral - shortened form of tangihanga.
Te Ao Māori	Māori worldview
Te Reo Māori	Māori language
Te Whare Tapa Wha	Māori model of health ¹
Tinana	Torso; body, trunk (of a tree), the main part of anything.
Tupuna	Ancestors, grandparents - western dialect variation of tipuna; plural tūpuna/tīpuna.
Wairua	Spirit, soul - spirit of a person which exists beyond death. It is the non-physical spirit, distinct from the body and the mauri. To some, the wairua resides in the heart or mind of someone while others believe it is part of the whole person and is not located at any particular part of the body.
Whakama	To be ashamed, shy, bashful, embarrassed.
Whānau	Extended family, family group, a familiar term of address to a number of people - the primary economic unit of traditional Māori society.

*translation taken from Te Aka Māori dictionary unless otherwise stated: <https://maoridictionary.co.nz/>

¹<https://www.health.govt.nz/our-work/populations/maori-health/maori-health-models/maori-health-models-te-whare-tapa-wha>

Attestation of authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Elizabeth Martin

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Co-authored works 1

Candidate contribution to co-authored publications

Chapter Three

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

Martin – 85%, Hocking – 10%, Sandham – 5%

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Clare Hocking

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Chapter Six

The manuscript entitled “Sink or swim. Information needs for thriving when transitioning from bowel cancer patient to bowel cancer survivor” has been drafted for publication but not yet submitted.

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CHAPTER ONE: INTRODUCTION

Introduction

This purpose of this study was to examine and extend the current understanding of how bowel cancer impacts daily occupations and the health and well-being of those affected. Health was viewed beyond the traditional biomedical view, with consideration of the impact of everyday activities on overall health and well-being. The intention was to draw on the experiences of bowel cancer survivors to add to the knowledge base of occupational scientists, occupational therapists, and people with bowel cancer themselves. The focus was on understanding both how people's participation in occupation had been impacted since treatment conclusion and their current situation in terms of participation in occupation. This chapter introduces the study and presents my own positioning as researcher. It provides an outline of the context of the project including background information concerning the topic.

Situating myself as the researcher

Within my life I have many roles – the two with most relevance to this research being bowel cancer survivor and occupational therapy educator. It is within these areas that my interest in the impact of bowel cancer on occupations has developed. In November 2015 I was diagnosed with Stage 3B bowel cancer, resulting in bowel resection surgery and twelve cycles of chemotherapy. As a result, I have experienced, and heard about, a lack of acknowledgement of and support with managing the difficulties of returning to and maintaining day-to-day life following treatment conclusion. The insider perspective I was able to bring to this study is further explicated in Chapter Two. My personal experience of bowel cancer was extended as I attended Cancer Society meetings, chatted to other patients at chemotherapy sessions, participated in online forums, and acted as a consumer representative for Cancer Trials New Zealand.

In 2015 I also graduated as an occupational therapist. In my forties, as a UK immigrant, I had decided on a career change from my previous profession as a primary school and then kindergarten teacher. As a result of studying occupational therapy, I have developed an understanding of the connection of occupation to health, well-being, and identity. My intention in undertaking this study was to use my increasing understanding and passion for occupational engagement, combined with my experiences of bowel cancer, to examine how the everyday lives of fellow bowel cancer survivors continued to be impacted by the aftermath of the treatment they had received. I wished to highlight any support needs people may have with regards to reengaging/engaging in occupation, how these could be provided for, and by whom.

Background

This section firstly addresses what occupations are and their relationship to health and well-being, as this is at the heart of my study and the area I wanted to explore for those impacted by bowel cancer. Secondly, the International Classification of Functioning and Health (ICF) (World Health Organization [WHO], 2001) is introduced and its relevance to this study outlined. Thirdly, the pathophysiology of bowel cancer is described along with the processes used to stage the cancer and the pathways taken to treat the disease, and the associated sequelae which can challenge health and well-being. As this study was based in Aotearoa New Zealand, an overview of the context of bowel cancer treatment in this country is then provided. As the phrase ‘bowel cancer survivor’ is used throughout this thesis, an outline of the term is supplied. Finally, the research aims and questions, rationale, methodology choice, study design, and organisation of the thesis are all considered.

Occupations and their relationship with health and well-being

Within occupational therapy, the term ‘occupations’ is attributed to the “everyday activities that people do as individuals, in families and with communities to occupy time and bring meaning and purpose to life” (World Federation of Occupational Therapists, 2021, para. 2). As demonstrated by the above quote, ‘activity’ – a word close in meaning to occupation – is regularly used interchangeably with occupation (Wilcock & Hocking, 2015), as is the case, on occasion, in this thesis.

Before addressing the relationship of occupation to health and well-being, a brief overview of the concepts of ‘health’ and ‘well-being’ is provided. In 1948 the World Health Organization defined health as “a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity” (WHO, 2021). It is argued that this definition is no longer suitable due to the increasing prevalence of chronic conditions, with a move to viewing health in terms of the ability to adapt (Huber et al., 2011). The concept of health is regularly linked to that of well-being, with the use of the phrase ‘health and well-being’ commonplace within many health disciplines (Henderson et al., 2020; Meleis, 2007; Mulligan, 2011; Reitz et al., 2020).

According to the United States Department of Health and Human Services (2018), there is no agreement concerning a single definition of well-being, but it generally involves the presence of positive emotions, the absence of negative emotions, fulfilment, satisfaction with life, and positive functioning. When well-being is considered in terms of occupational therapy, it also involves satisfaction when participating in occupations that enhance quality of life (QoL) (Reitz et al., 2020). A literature review across occupational therapy journals, an occupational science journal, and profession

renowned mainstream monographs, critiqued how well-being was conceptualised within occupational therapy. The review revealed inconsistency regarding definitions and use of the term (Aldrich, 2011). Overall, it was reported that well-being includes elements of physical and psychological health, has objective and subjective aspects, and is dependent on environmental factors and opportunities to participate in various valued activities. The author of the review also commented that evaluations of well-being centred on satisfaction and QoL, and indicators included coherence, success, and control.

Occupations can be defined as the everyday activities people do to bring meaning and purpose to life, including things people need to, want to, and are expected to do (World Federation of Occupational Therapists, 2021). These occupations can encompass looking after self (self-care), enjoying life (leisure), and contributing to the social and economic fabric of the community (productivity) (Molineux, 2009); all so intrinsic to life that people “do occupation all their lives without ever knowing it” (Dickie, 2009, p. 15).

Occupations are part of the human condition and relate to health or illness of a physical, mental, spiritual, and social kind, meaning “occupation and health are intimately related” (Hocking, 2018, p. 114). Hocking (2009) identified that occupations contribute to health and well-being by enabling people to meet biological needs; providing physical activity, mental stimulation and social interaction to keep bodies, minds and communities in good health; and enabling self-expression, skills development, experiencing pleasure and achieving the things individuals believe to be important. Occupations also encompass the things people do to look after the well-being of the environment, with everyday occupations maintaining the life force (mauri) of the relationship between the physical and spiritual aspects of the natural environment (McNeill, 2020). Therefore, necessary and meaningful occupations are not only crucial to humans’ survival, but also fundamental for the creation and maintenance of health and well-being, QoL, and the life of the planet (Hitch et al., 2018; Molineux, 2009; Pizzi & Richards, 2017; Wilcock & Hocking, 2015).

Strong evidence of the positive impact of occupation on health was provided by research involving 11,637 individuals aged 15 and over from 15 European countries. The study found a positive correlation between physical activity (including leisure, domestic and work activities) and level of happiness (Richards et al., 2015). Further literature outlined how carrying out occupations with others strengthens relationships, enhances well-being, reduces the negative effects of stressful life events on health, and reduces mortality risk (Hammell, 2017; Sun, 2017; Thoits, 2010). Conversely, the inability to participate in meaningful occupations, namely those identified by an individual to have value or special meaning, can have a serious negative impact on

their health and well-being with an associated increase in stress (Kosma et al., 2013). This loss of occupational choice can occur due to life threatening illnesses, such as cancer (Hwang et al., 2015; Kosma et al., 2013). Nevertheless, the occupational perspective of health remains poorly understood, widely unappreciated (Kosma et al., 2013) and regularly overlooked by medicine (Wilcock & Hocking, 2015). As a result, an occupational approach to health is underutilised and under resourced (Wilcock, 2007).

The International Classification of Functioning, Disability, and Health (ICF)

The relationship between occupation and health is recognised in the ICF, an international biopsychosocial framework that broadly represents human functioning in a unified language (Geerse et al., 2017). The ICF was developed by the World Health Organization and provides a multi-disciplinary basis for understanding and studying health in two parts, each with two components (Hemmingsson & Jonsson, 2005; Larsson-Lund & Nyman, 2017). Part one (functioning and disability) includes the components: 1) body functions and structures, and 2) activities and participation. Part two (contextual factors) includes the components: 1) environmental factors, and 2) personal factors. Each component consists of domains, within which are categories containing units of classification (WHO, 2001). This structure provides a systematic framework for categorising occupations.

The activities and participation component covers the range of domains representing aspects of functioning from both an individual and a societal perspective (Kostanjsek, 2011) with activity defined as “the execution of a task or action,” and participation as “involvement in a life situation” (WHO, 2001, p. 14). Both concepts are understood as outcomes of interactions between a person’s health condition and the overall context in which they live (Rauch et al., 2010) and recognise the relationship between people’s daily lives and health (Hemmingsson & Jonsson, 2005). People with health conditions may experience limitations in activities and restrictions in participation due to the functional impact of their health condition, features of the environment, or both (Hemmingsson & Jonsson, 2005; Hwang et al., 2015; Rauch et al., 2010).

The ICF classification is accepted worldwide (Geerse et al., 2017), covering “most of the health and health-related domains that make up the human experience of functioning and disability, and the environmental factors that influence that experience of functioning and disability” (Cieza & Stucki, 2008, p. 303). It is, therefore, a comprehensive classification, that was used within this study due to its focus on how an individual’s function is impacted by their health condition, which, in the case of this study, is bowel cancer.

What is bowel cancer and how does it affect those diagnosed?

Bowel cancer is a malignant growth that develops inside the bowel, affecting the colon or rectum (Ministry of Health [MOH], 2021). At diagnosis, the cancer is staged to determine the location and amount of cancer in the body (Bowel Cancer New Zealand [BCNZ], 2020). The most widely used classification for bowel cancer is the T (tumour), N (nodes), and M (metastases) system (MOH, 2011). The T category refers to the primary tumour and considers size, how deeply it has grown into the organ, and whether it has invaded nearby tissues; N describes whether the cancer has spread to lymph nodes; M considers whether the cancer has metastasised (spread) to other parts of the body (BCNZ, 2020). This information is then used to stage the cancer across five levels from 0-4 (MOH, 2011). Stage 4 is the highest and indicates the cancer is more advanced than in the lower stages, that is, it has spread to other organs within the body (BCNZ, 2020). Stage of cancer determines the treatment administered, which commonly involves surgery, chemotherapy and/or radiotherapy. Sometimes an opening is surgically created in the abdomen, known as an ostomy, and the end of the bowel protrudes through the skin, known as a stoma. Bowel movements are then collected in a bag attached to the skin around the stoma (Bowel Cancer UK, 2019).

Bowel cancer treatment is associated with various sequelae. These include: fatigue (Cabilan & Hines, 2017; Hubbard et al., 2010; Sanoff et al., 2015; Shipp et al., 2015); altered bowel habits due to surgery and the resultant change in structure and function of the bowel, and/or the presence of an ostomy (D'Souza et al., 2016; Knowles et al., 2013; Schneider et al., 2007; Steginga et al., 2009); anxiety, depression and fear of recurrence (Denlinger & Barsevick, 2009; Ho et al., 2016; Hubbard et al., 2010; Worrall et al., 2021); peripheral neuropathy in hands and feet (Cabilan & Hines, 2017; Ho et al., 2016; Sanoff et al., 2015; Schneider et al., 2007); impaired memory and concentration (Denlinger & Barsevick, 2009; Shipp et al., 2015); sleep disruption (Bours et al., 2016; Denlinger & Barsevick, 2009); and sexual dysfunction (D'Souza et al., 2016; Sanoff et al., 2015; Saunders et al., 2021; Sun et al., 2016). These sequelae may continue years after treatment conclusion, or permanently (Beesley et al., 2017; Drury et al., 2017; Rodriguez et al., 2015). With such a variety of symptoms, and the previously highlighted link between occupation and health, impacts on participation in occupation can be reasonably expected.

Bowel cancer in New Zealand

Due to New Zealand's public health system, citizens and permanent residents are eligible to receive publicly funded treatment, including surgery, chemotherapy, radiotherapy, and ongoing screening if necessary (MOH, 2019a). Some may choose to receive treatment provided by health insurance, or self-fund. In addition, it is

recognised that “supportive and rehabilitation care should be available to all people with colorectal cancer” (MOH, 2011, p. ix). For those with a stoma, all supplies are provided and delivered without charge, with the contact details of stoma nurses for each District Health Board (DHB) freely available online (Ostomy New Zealand, n.d.).

People diagnosed with bowel cancer are covered by one of four regional cancer networks: the Northern, Southern, Midland, and Central Cancer Networks. Within these networks there are currently a number of DHBs that deliver health services to the local population. In an article analysing the characteristics and outcomes of patients with bowel cancer by cancer network, Blackmore et al. (2020) reported the health service provided in each region resulted in equitable outcomes. However, Bagshaw et al. (2021) reported inequalities, particularly regarding the Southern District Health Board (SDHB). The authors revealed three external reviews had reported delayed or denied colonoscopies to “numerous symptomatic patients, with adverse outcomes for some” (p. 99).

In order to address inequalities such as these, and beyond, the New Zealand Government commissioned the Health and Disability System Review (2020). As a result of the review, the New Zealand Health System is to be reformed to address current issues of inequity and inconsistency. This reform will see the disestablishment of the 20 existing DHBs and the merging of their functions into a new single entity, Health NZ, which will lead day-to-day running for the whole of the country (Department of the Prime Minister and Cabinet, 2021). Under this organisation, publicly funded services will be continued, meaning bowel cancer treatment is still available for those diagnosed.

What is a bowel cancer survivor?

Cancer has been traditionally viewed as an acute illness, however, earlier detection and advances in medical intervention have resulted in increasing numbers living longer after diagnosis (Ayyoubzadeh et al., 2020; Yang et al., 2020) meaning that it now falls into the category of a chronic condition (Hubbard et al., 2010; Newman & Hunter, 2020; Pereira, 2014). As a result, the term ‘survivor’ has become more commonly associated with the disease.

The term was first prominently discussed by Fitzhugh Mullan (1985) – a physician who had himself survived cancer – in his seminal paper, the “Seasons of Survival”. He categorised cancer survivorship into acute, extended, and permanent seasons. The acute stage is the period enveloping the initial diagnosis and treatment, the extended stage begins at treatment conclusion and includes possible remission, and the permanent stage represents a cure or long-term remission (Newman & Hunter, 2020).

Literature demonstrates inconsistency regarding when an individual becomes a 'cancer survivor', with definitions beginning at diagnosis, at the end of treatment or after a disease-free period of time (Drury et al., 2017). For the purposes of this study, the term 'survivor' is used to describe an individual who has completed primary treatment for bowel cancer, whether that involved surgery, chemotherapy, radiotherapy, or a combination.

Research aims and questions

The study has three aims: 1) To identify and describe the range of occupational outcomes people can experience after bowel cancer; (2) To identify the occupational needs of bowel cancer survivors and how the findings can be given practical application; (3) To identify the occupationally focused information needs of bowel cancer survivors and highlight pertinent considerations when providing information.

To achieve these aims, the following questions asked were:

- What is the occupational impact of having had bowel cancer?
- How do people manage the occupational impact of having had bowel cancer?

The aims and research questions were designed to gain a deeper understanding of the experiences from an occupational perspective, and to share this understanding with the overall intent of improving participation in occupation and the health and well-being of those living with the aftermath of bowel cancer treatment.

Rationale for the study

Bowel cancer is the third most diagnosed cancer in the world (Ayyoubzadeh et al., 2020), with nearly one million cases diagnosed worldwide each year (MOH, 2019a). New Zealand has one of the highest rates of bowel cancer in the world (Blackmore et al., 2020) with the 14th highest rate globally in 2018 (World Cancer Research Fund, n.d.). Therefore, it is not surprising that local studies have focused on epidemiology, incidence, prevalence, treatment, and survival rates (Jackson et al., 2015; Sharples et al., 2018). The same is true internationally, as demonstrated by the Healthy People 2030 Framework (U.S. Department of Health and Human Services, n.d.) where a search for "colorectal cancer" produced 11 results related to either screening, reducing death rates, genetic testing, or preventative medicine. The focus on saving lives is understandable, and indeed has contributed to an international increase in the number of people living beyond bowel cancer (Brouwer et al., 2018; Pereira, 2014). This trend is reflected in New Zealand where 1800 of the 3000 people diagnosed with bowel cancer every year survive beyond treatment (Robertson et al., 2017).

The focus on prevention, treatment and saving lives is reflected in the health professional input over the cancer continuum. Following intense specialist medical intervention during diagnosis and treatment, the level of health professional support diminishes greatly (Drury et al., 2017), with many survivors feeling neglected (Ho et al., 2016). There is a clear gap to be bridged as survivors resume responsibility for their own lives. Occupation can be a means of filling this gap and thus facilitating a return to a self-directed life. This study provides necessary knowledge regarding resuming occupations after bowel cancer treatment, including the challenges and what is achievable, to contribute towards filling this void.

In the literature, it is reported that bowel cancer survivors experience significant impact on their daily occupations and health and well-being (Ho et al., 2016; McMullen et al., 2017). Currently there is a paucity of empirical evidence addressing health-related outcomes for bowel cancer survivors and the flow-on effects on occupation. While the multidimensional concept of QoL has become an important outcome measure for cancer survivors (Arndt et al., 2004; Ganesh et al., 2016), within this concept, participation in occupation, a crucial outcome in determining the effects of cancer treatment, is not clearly conceptualised or measured (McMullen et al., 2017). This view was corroborated by van der Mei et al. (2011) in their analysis of the extent participation, as defined in the ICF, is represented in general cancer-specific health related QoL instruments. The study involved two coders who had knowledge of the ICF systematically linking items of outcome measures to the ICF. Results suggested the number of participation-related ICF codes covered in these measures is limited, with the proportion ranging from 3 to 35%.

My study will generate greater understanding of the relationship of surviving bowel cancer and people's daily occupations. By addressing the period following treatment, it focuses on an area often not prioritised in cancer care (Knowles et al., 2013). Drury et al. (2017) suggested health professionals have a duty to ensure bowel cancer survivors' health, information and support care needs are met after treatment conclusion; a duty potentially eased when armed with knowledge of likely impact on day-to-day life. Findings can be used to inform and improve open communication between health professionals and survivors, a key issue in improving well-being for survivors (Drury et al., 2017).

It is well recognised that understanding the unique challenges and issues of bowel cancer survivors is important to optimise patient support and minimise impact on daily life and better identify those who may be at greater risk of reduced functioning and, therefore, benefit from therapy/input (Denlinger & Barsevick, 2009; Knowles et al., 2013; Rodriguez et al., 2015). Moreover, Steginga et al. (2009) suggested interventions

to improve QoL after bowel cancer may be more effective if they used an integrated approach targeting psychosocial, symptom, and lifestyle variables.

The occupational focus of this study will specifically benefit the occupational therapy profession as it seeks an enhanced knowledge of occupational engagement for bowel cancer survivors, allowing therapists to view their clients as occupational beings and use occupation therapeutically (Hocking, 2009). As Pizzi and Richards (2017) commented, when therapists make connections for people about how participation in occupation improves health they have “the potential to transform lives” (p. 3), but currently the role of occupation in terms of physical, mental, and social health is poorly understood (Wilcock & Hocking, 2015). Occupational therapists have the education, skills, and knowledge to provide interventions for adults with cancer (Braveman et al., 2017). However, the profession is currently underutilised in oncology (Pergolotti et al., 2016), with a reported need for practice to be more occupation-focused (McGrath, 2013). This situation contrasts with other specialities such as orthopaedics, cardiology and stroke where occupational therapy has an established presence and rehabilitation role, addressing self-care, productivity, and leisure needs (Schiavi et al., 2018).

In conclusion, the number of bowel cancer survivors is continually increasing, but this is not reflected in research outputs. The needs of the after-treatment group are recognised but insufficiently addressed, with the disease receiving considerably less attention than the other two leading cancers (breast and prostate) from both the public and scholars (Olsen et al., 2019). This study provides an opportunity to shed light on the experiences and needs of this population.

Choice of methodology

As the purpose of this study was to capture the post-treatment bowel cancer experience for survivors and use it to add to the related body of knowledge, it was considered most suitable to apply a qualitative approach. Several methodologies were considered, including case study, grounded theory, and phenomenology, but interpretive description (ID) was decided upon.

There were several factors influencing my decision to use ID to guide the study. Firstly, I believed my own experiences of bowel cancer would have a strong bearing on how I conducted the research and could be used to enhance the process. Given ID explicitly recognises and capitalises on “the researcher as instrument” (Thorne, 2016, p. 70), I could use my experiences in a positive way, constantly reflecting and acknowledging how my personal circumstances were impacting the research process.

Secondly, I wanted my position as an occupational therapist to play a major role in shaping the research, ensuring it had an occupational focus. Interpretive description recognises the fundamental part disciplinary orientation plays in shaping a research project; indeed Thorne (2016) comments that “our disciplinary orientation is our epistemological positioning” (p. 75). I felt ID gave me permission to embrace my profession and unashamedly use this to scaffold the research.

Thirdly, I had personally felt the feeling of abandonment at the end of my cancer treatment as health professional support was withdrawn and, as an occupational therapist, could see areas where support regarding my daily occupations would have been beneficial. One of the major foci of ID is that analysis should be clinically applicable in the context of the practice field (Thorne, 2016), and I believed ID provided a clear way for my research to be applied into occupational therapy practice.

Finally, I wanted to capture what the bowel cancer survivor experience was like for others, to gain a true picture of how their everyday lives had been affected by the disease and treatment sequelae. Interpretive description recognises that researchers are not satisfied with mere description, but rather the patterns, relationships, and associations within a phenomenon (Thorne, 2016). The use of ID facilitated a rich description of the phenomenon of living after bowel cancer.

Design of the study

The study was carried out over three phases which are now briefly explained.

Phase one included a five-stage scoping review (Arksey & O'Malley, 2005) to locate, analyse, summarise and present literature and research findings (McKinstry et al., 2014) regarding bowel cancer and its impact on occupations. Findings produced by this “knowledge synthesis approach” (Tricco et al., 2017, p. 2) informed the subsequent phases.

Phase two included semi-structured interviews with 11 bowel cancer survivors, along with four partners, informed by ID methodology. Interviews focused on the range of occupational outcomes experienced after bowel cancer and ways found to manage them. Data were analysed thematically to determine common themes accurately representing the experiences of participants.

Phase three included a second round of interviews with two original and two new participants and one partner. Interviews were guided by the insights and themes identified in the first data set and provided participants with the opportunity to reflect on whether findings resonated with their experiences. A secondary focus of the interviews was to ascertain the views of bowel cancer survivors regarding the information they

believed would be beneficial in aiding recovery. Again, data were analysed thematically.

The phases represent a progression of knowledge. Firstly, existing knowledge which been largely developed in a medical context, often with a quantitative, observational focus has been identified. This has been augmented by insights of the phenomenological aspects of occupation generated by experiential accounts of living with the after-effects of bowel cancer in the everyday world. This knowledge is then translated into the theory base (Wright-St Clair & Hocking, 2019) and applied to the practice context.

Organisation of the thesis

I have chosen to format the findings of my doctoral research around four articles for publication. At the time of examination, three articles have been published in international journals and one is to be submitted for consideration to a peer reviewed journal. These articles form the basis of Chapters Three, Four, Five, and Six in this thesis.

One consequence of the decision to structure the thesis around the publications is that the initial ordering of chapters differs from a traditional thesis format, with the methodology and research design presented prior to the literature review. This is because the majority of literature was located, reviewed and synthesised within the scoping review undertaken in phase one of the study. Having the methods employed in this review presented before its overall findings means the thesis flows in a logical order. A brief overview of each of the chapters is now provided.

Chapter One presented the positioning of myself as researcher, background to the research topic including a New Zealand context, rationale for the study, methodology and research design, and how the thesis is organised.

Chapter Two outlines the methodology and research design. This information is presented as in a traditional thesis to provide clarity. However, some information is briefly reiterated in subsequent findings chapters where it forms part of published/submitted articles.

Chapter Three, as explained above, provides a review of the literature and represents the first of the published articles. It includes the scoping review methods, findings, and discussion of the occupational impact of having had bowel cancer gleaned from previous research. As a scoping review format was used, a variety of literature was considered including peer reviewed articles, theses, and publications produced by cancer-related non-government organisations.

Chapter Four presents the second published article. This chapter takes an occupational science perspective and considers phase two of the study in relation to the occupational concepts of doing, being, becoming, and belonging.

Chapter Five represents the third published article. This chapter considers findings in relation to the potential role of occupational therapy with bowel cancer survivors, including recommendations for taking a self-management approach.

Chapter Six represents the fourth article, to be submitted for consideration for publication. This chapter considers the educational material information needs of bowel cancer survivors, encompassing findings relevant beyond the fields of occupational science and occupational therapy.

Chapter Seven considers and discusses the key findings. Conclusions are reached and the limitations of the study acknowledged.

Appendices are referred to throughout the thesis. They are presented following the final chapter and references.

Conclusion

This chapter has presented my positioning as researcher, a brief outline of the key areas of the topic, and rationale for the study. An overview of the methodology and research design has been provided and the thesis format outlined, including chapter contents. The next chapter presents the methodology and methods used.

CHAPTER TWO: METHODOLOGY AND RESEARCH DESIGN

Introduction

This chapter outlines the methodology used to guide this study and the methods employed. Firstly, an outline of the preliminary work carried out prior to study commencement is presented. An overview of qualitative methodology is then provided, followed by an in-depth review of the specific qualitative methodology employed – interpretive description. A description of the research design is then given, addressing each of the three phases separately. Ethical considerations are discussed throughout the chapter where relevant.

Preliminary work

Prior to commencing the study, some preliminary work was carried out with the purpose of being as prepared as possible for the forthcoming research. This firstly consisted of reflecting on how my personal experiences of bowel cancer could influence the research, and secondly consulting with individuals who I thought could provide valuable insight into the research topic.

Reflexivity and considering the insider perspective

My initial preparatory work involved writing an honest reflection of my thoughts and feelings regarding starting the study, a sample of which is provided in Appendix A. This process enabled awareness of my feelings and emotions regarding my own bowel cancer experiences, and the impact this may have on the study processes. One of my original intentions in undertaking the research was to use my experience with bowel cancer to enhance and strengthen the study. I viewed the fact that I had had the disease as an advantage, providing insight into the experiences of the participants and facilitating the rapid building of rapport with them. While I believe this was the case, taking the time to write how I was feeling helped me to recognise and acknowledge the disadvantages having had personal experiences could pose. For example, I feel I remained very positive throughout my cancer journey, and indeed recognised many benefits of the whole experience. Writing these thoughts down, and sharing them with my supervisors, facilitated an appreciation that this would not necessarily be the case for others who had had bowel cancer. I became acutely aware of the possibility I could portray this outlook to participants who could then be inhibited and reluctant to share their true feelings for fear of expressing negative aspects of the cancer experience. My world view could be obvious in the interviews, validating or invalidating participant

responses. Due to this insight, I searched the topics of reflexivity and the insider perspective to gain a greater understanding and awareness of how I personally might influence the research, to ensure the study reflected participant experiences rather than my own.

Reflexivity was purported to be “central to qualitative research methodology” (p. 321) by Lambert et al. (2010) in their review of literature exploring the concept of reflexivity from a midwifery perspective. The reflexive process enhances awareness of preconceptions and expectations through the constant examination of personal thoughts, thus controlling subjectivity, and highlighting how these factors may have influenced the research process (Darawsheh, 2014; Williams, 2015). Reflexivity enables researchers to examine the “inevitable” (Terry et al., 2017, p. 25) impact they will have on data collection and analysis, as they consider their personal interest in the topic.

To improve rigour and validity, thus increasing the quality of research (Morse, 2015; Noble & Smith, 2015), reflexivity was employed throughout this study. A reflexive journal was kept, allowing the consideration and acknowledgement of how my experiences with bowel cancer could impact my reactions, attitudes, feelings, and perceptions (Foster, 2009; Moore, 2015), and ensuring the research was transparent and oriented toward participant experiences (Foster, 2009; Lambert et al., 2010; Merriam & Tisdell, 2016). The documentation of what was occurring subjectively and conceptually throughout the process became a core element informing the inductive data collection and analysis, allowing the appreciation of the implications of my own role in the process (Thorne, 2016).

The position of insider is someone who personally belongs to the group to which their participants also belong (Hayfield & Huxley, 2015), providing both advantages and disadvantages (Thorne, 2016). Regarding advantages of insider status, the experiential base and identity shared with participants may facilitate greater acceptance and openness and, therefore, generate richer data (Dwyer & Buckle, 2009; Hayfield & Huxley, 2015). Participants may be more prepared to reveal experiences due to an assumption of shared understanding (Dwyer & Buckle, 2009). Having personal knowledge of the research topic can enable deeper understanding, with Foster (2009) suggesting it is “a requirement of qualitative research” (p. 20). Foster came to this conclusion as a result of her exploration of family members’ experiences of rare cancer of a loved one, something she had personally experienced.

Regarding insider disadvantages, in their phenomenological and ethnographic study, Mortenson and Dyck (2006) reported that there is a possibility that the researcher can

be too close to, and familiar with, the topic, endangering authenticity (Mortenson & Dyck, 2006). Researcher perceptions could possibly be influenced by their own experiences, leading to data collection fashioned by the researcher's experience rather than the participants' (Dwyer & Buckle, 2009). There is also the risk of participants assuming their narrative is intrinsically understood by an insider interviewer, leading to their comments being misunderstood or misconstrued by the researcher, as identified by Hayfield and Huxley (2015) in their reflective piece discussing the advantages and disadvantages of the insider and outsider in qualitative research. Both authors had carried out research with lesbian and bisexual women, and reflected on their experiences, Hayfield as an insider bisexual woman, and Huxley as an outsider heterosexual woman.

When a researcher is an insider, there is the danger of participants assuming the interviewer has had similar experiences and, therefore, not explaining their own situation fully (Dwyer & Buckle, 2009). In addition, there is a danger of analysis focusing on shared researcher-participant aspects, with participant-only elements not emphasized, or the researcher taking content for granted and overlooking aspects of the data (Dwyer & Buckle, 2009; Hayfield & Huxley, 2015).

To view myself purely as an 'insider' oversimplifies my relationship with participants. As someone who has had bowel cancer I can be classed as an insider, and yet my life situation is very different to that of the participants in many ways such as life stage, gender, activity level, and social and living situations. In addition, many participants had experience with an ostomy, something I do not have, and radiotherapy, again something of which I have no experience. Therefore, on some level I could also be classed as an outsider, having not had identical experiences to participants (Foster, 2009; Hayfield & Huxley, 2015). When considering this matter, literature suggests researchers occupy "the space between" (Dwyer & Buckle, 2009, p. 54) insider and outsider, with the main consideration not being which group the researcher falls into, but rather integrity, a profound interest in participant experiences, a commitment to representing these experiences accurately, and maintaining high standards of research practice (Dwyer & Buckle, 2009; Foster, 2009).

Consultation

The second area of preliminary work involved consultation with several individuals to benefit from their knowledge and expertise. Firstly, the colorectal nurse specialist at Rotorua Hospital, Ann-Maree Murphy, was consulted regarding how she believed bowel cancer patients in general would feel about being involved in the research. She reported she believed many of her patients would be happy to be involved, and indeed might enjoy the opportunity to talk about their experiences.

Consultation also occurred to ensure I was behaving in a culturally appropriate manner when engaging with Māori participants. As the research was taking place in Aotearoa New Zealand, the principles of Te Tiriti o Waitangi (The Treaty of Waitangi, 1840) needed to be considered, as did the fact that I am an immigrant from England. I met with the Lakes DHB General Manager for Māori Health, Phyllis Tangitu, to increase understanding regarding cultural sensitivity. Phyllis stressed the importance of ensuring participants felt at ease and were under no pressure to answer questions which made them feel uncomfortable. Phyllis also explained how body parts associated with toileting and sexuality were considered sacred and very private and that participants may feel whakama (shame/embarrassment) when referring to these areas. She also commented that Māori participants may cover a wide range, from “staunch Māori” not wanting to discuss these areas at all, to “Māori village residents” used to communal bathing and more open to contributing to potentially embarrassing conversations. I therefore decided to particularly emphasise to Māori participants that there was no pressure to speak about anything they were not comfortable with. I also determined to be vigilant to body language suggesting discomfort with the topic and adapt my questioning accordingly.

Consultation also took place with the AUT Mātauranga Māori Committee who recommended having a Māori person to accompany me to interviews with Māori participants. This was to assist with liaising with the survivors and their whānau (in te reo Māori where appropriate) and helping them to feel more comfortable. They also suggested it would be beneficial to have a health professional available to provide advice if participants identified symptoms that may be medically concerning. In addition, the committee felt that the sharing of my own bowel cancer experiences would break down barriers and increase trust, and that my personal reason for doing this research would be appreciated and respected by participants and their whānau.

Following this consultation with the Mātauranga Māori Committee, Glenys Courtney-Strachan, who affiliates with Te Arawa/Ngāti Raukawa, Ngāti Tukorehe and Pamiti Uruuru, agreed to attend interviews with Māori participants if they requested it. In addition, Ann-Maree agreed to provide advice regarding appropriate action to take if participants identified potentially concerning medical symptoms.

Methodology: Interpretive Description (ID)

Interpretive description originates from the 1990s, when Sally Thorne and colleagues were searching for a methodology that would enable interpretive rather than descriptive analysis and which could facilitate a comprehensive understanding of people's subjective experiences and behaviour (Thorne, 2016). They also recognised the

"epistemological confusion" within the field of qualitative health research (Thorne, 2016, p. 231) and the necessity for a methodology which would produce knowledge readily transferrable to clinical practice, in contrast to the theoretically driven social science approaches prominent at the time (Thorne, 2011). Although ID was initially conceived for use in Thorne's profession, that of nursing, its benefits have since been recognised and used by other disciplines including physiotherapy (Miciak et al., 2018), social work (Craig et al., 2015), and occupational therapy (Hill et al., 2020).

Before describing what ID is, it is useful to determine what it is not. In contrast to other established methodologies, it does not provide a precise, ordered method with a series of steps to follow. Nor is it a completely unique or discrete approach, distinct from other established qualitative methodologies; rather it has evolved from these. Indeed, Thorne (2016) openly acknowledges and encourages borrowing from other research techniques as appropriate, as an alternative to adapting and, as a result, compromising the use of these conventional approaches. Interpretive description allows the researcher to move beyond the exact processes of other research methods, instead providing a "coherent organising framework" (Thorne, 2016, p. 82) with a focus on aligning with the epistemological underpinnings of the discipline for which it is being used.

Interpretive description offers an analytical, inductive approach, designed to facilitate an increased understanding of health with a focus on lived experience in relation to the clinical context (Teodoro et al., 2018; Thorne et al., 2004). The methodology allows the formation of knowledge with an exploratory, interpretive tone (Hunt, 2009; Thorne, 1997) which lies "somewhere between fact and conjecture" (Thorne, 2016, p. 17) – that is, between objective and subjective experiences – regarding a clinical phenomenon. Participants and researchers co-construct a narrative whereby patterns and associations are identified, with this new knowledge potentially generating a practice-related response (Teodoro et al., 2018). The new knowledge generated in my study was regarding the phenomenon of living beyond bowel cancer, with the potential practice-related response predominantly discussed in Chapter Five. The aim of ID is to affect clinical practice, a goal which differentiates it from other qualitative methodologies, such as grounded theory, with their focus on theorising (Thorne, 2016).

Scaffolding the study

Thorne (2016) suggests a vital stage of the research process is scaffolding, whereby a design plan is developed from an initial position. The first aspect of scaffolding is the **literature review** which provides an overview of what has been written about the topic of interest, allowing the researcher to become conversant with current knowledge and thinking. The importance of making a literature search as extensive as possible is

stressed within ID, for example including grey literature, theses, and reports alongside traditional published articles from a variety of disciplines. The scoping review carried out in phase one represents the literature review element in this study, presenting findings related to the occupational impact of surviving bowel cancer.

The second aspect involves clarifying the **theoretical forestructure** by locating the researcher within the field and its associated theoretical world (Thorne, 2016). The researcher is viewed as an instrument, with the acknowledgment that their thinking and actions significantly impact the nature and outcome of the study, particularly so when they have insider knowledge of the topic under study. This is in contrast to some established methodologies, such as phenomenology where the researcher may endeavour to set aside any predetermined ideas to determine the true spirit of the phenomenon being investigated (Finlay, 2011). Three related elements contribute to the theoretical forestructure of ID: Locating theoretical allegiance on entering the study, locating yourself within the discipline, and locating your personal relationship to the ideas held (Thorne, 2016). Each of these areas will now be considered.

Theoretical allegiances

When using ID, researchers are asked to locate their theoretical allegiances. Once this knowledge is established, it can drive the research approach. In the early stages of this study, I considered which methodological approaches and paradigms I most identified with, and how these related to my goals for the study. As an aim of the research was to explore the subjective experiences of individuals who have had bowel cancer, I considered the use of a qualitative methodology appropriate as it explores human behaviour, motives, views, and barriers and opportunities (Neergaard et al., 2009), and gains the view or perspective of a sample group (Stanley & Nayar, 2014). I wanted the study to capture what life was like for people once they had completed bowel cancer treatment and felt the best way to do this was by talking with them, thereby providing the social interaction to allow individuals to construct knowledge and experiences (Constantino, 2008) and develop subjective meanings of their experiences (Cresswell, 2014). This aligns with the relativist ontology of the constructivist worldview where there is no single reality, but rather participant views of reality are elicited by the researcher (Teherani et al., 2015). I wanted the interactions with study participants to be open and honest and their accounts to be shaped around the major questions. As a result, I envisioned rich rather than superficial data would be elicited (Milne & Oberle, 2005; Neergaard et al., 2009) as participants were given time to describe experiences in the way that best suited them (Grattan et al., 2018). I expected participants to give a subjective account of what life was like for them now, and by comparing and

contrasting their experiences, to be able to develop a nuanced understanding of commonalities and variation within participant accounts.

The constructivist word view also recognizes that researchers' own backgrounds shape their interpretation as they position themselves within the study and researcher understanding is co-constructed with that of the participants (Hunt, 2009; Thorne et al., 2004). This process allows the researcher to make sense of the meaning others have about the world, using the data collected (Cresswell, 2014), and makes visible how assumptions and preconceptions may influence the research (Hunt, 2009). ID is underpinned by a constructivist worldview (Hunt, 2009), and given that its aim is to influence clinical practice in the field – something I strongly wanted my research to achieve – it was considered the methodology most closely aligned to my positioning.

Location within the discipline

Interpretive description considers disciplinary orientation to be a crucial factor in how successful a research study will be and, therefore, it is vital for a researcher to consider firstly what their disciplinary position is, and secondly how this can impact the whole research process. The value of recognising the impact disciplinary orientation has on a study is demonstrated in an “extensive and exhaustive” (p. 437) meta-analysis drawing on 292 qualitative research reports exploring the experiences of individuals with chronic illness (Thorne et al., 2002). The authors found that the profession of the researchers strongly influenced the study direction, even when the same methodology was employed. For instance, psychologists focused on the psychological effects of chronic illness, sociologists on social rules impacting behaviour, and anthropologists on the patterns associated with beliefs about health within the social and cultural context.

Thorne (2016) also made the point that each discipline has a burning question which binds the profession together and determines the lens through which the world is viewed. Occupational therapists look through an occupational lens, and so I consider the burning question for the profession to be, “How does health impact occupation?” This question has driven the focus of my research as I have endeavoured to discover the occupational impact of having had bowel cancer on the health and well-being of those affected. The very fact that I am an occupational therapist has driven my interest and enthusiasm for the topic of this study. I was previously a primary school teacher; if this were still the discipline I most associated with, it is highly unlikely I would have researched a topic with occupation at its heart.

When reflecting on the impact of my disciplinary orientation, I considered the philosophical framework of occupational therapy in terms of ontology and epistemology. **Ontology** is concerned with the nature of reality (Cresswell, 2014).

Within occupational therapy – and, therefore, within this study – the ontological positioning is, “Ever-changing humans, interconnected with ever changing environments, occupy time with ever changing occupations, and thereby transform – and are transformed by their actions, environments and states of health” (Hooper & Wood, 2018, p. 45). Occupational therapists, therefore, view humans as occupational beings, who require occupation to grow, survive, belong, and thrive whilst continually interacting with their environment (Hooper & Wood, 2018). This environment constitutes physical, social, cultural, and institutional aspects (Townsend & Polatajko, 2007). This knowledge influenced my research, as I considered the immense impact engaging in – or being unable to engage in – occupation had had on clients I have worked with as an occupational therapist, and the importance of considering the context of the multiple realities being studied (Lincoln & Guba, 1985).

Epistemology is concerned with the nature of knowledge (Thorne, 2016). Within occupational therapy and this study, the epistemological positioning is “knowledge about occupation is primary and serves as the key subject that integrates all other knowledge. Knowledge is pieced together in-for-and-with the ever-changing practice situation; therefore, the essence is fluid and contingent upon the arising practice moment” (Hooper & Wood, 2019, p. 45). Therefore, the principal concern of this study was focused on knowledge about occupation, considering the three integrated domains of social, biological, and psychological knowledge (Kielhofner, 1983).

On reflection I can see how my disciplinary orientation has influenced the initial course this study took. I have spent time in hospices with individuals who were approaching end of life due to cancer and observed family members in the same situation. I am aware how I viewed these experiences through an occupational lens as I was made acutely aware of the impact not being able to engage in preferred occupations had on those involved (Martin, 2015). When my brother was approaching end of life due to advanced cancer, I was able to witness the huge improvement in his well-being and sense of self when able to attend a cricket match, for instance. I feel going through these experiences as an occupational therapist added to my desire to focus my research on the impact on occupations rather than the huge array of other directions a study exploring bowel cancer could take. Also, occupational therapy is a very client centred profession where the client is often viewed as the family/whānau rather than an individual (American Occupational Therapy Association [AOTA], 2020a), which also influenced the study direction. Participants were offered the opportunity to have partners/family/friends present at the interviews, in keeping with the occupational therapy view that the client may be more than the individual, and that changes in one person’s occupations will likely impact the occupations of others.

In addition, my insider position should also be considered in terms of epistemology as it had a direct impact on the knowledge co-created by myself as researcher and my participants (Hayfield & Huxley, 2015).

Locating personal relationships

The third element of determining the theoretical forestructure involves recognising and locating the personal position of the researcher within the study (Thorne, 2016). A phenomenon is naturally viewed through the researcher's lens which has been moulded by personal and professional experiences (Moore, 2015). My role as an occupational therapist meant I naturally viewed the research in terms of occupations and how these were affected by having had bowel cancer. As previously acknowledged, I also anticipated that my own experiences as a bowel cancer survivor would significantly impact the research. As explained, my positioning at the commencement of the study was that this would be a positive factor, particularly in quickly building rapport with participants who recognised me as someone who may have had similar experiences. I also believed it would reduce apprehension and embarrassment regarding revealing issues with bowel dysfunction. After completing the research, I feel this was true in both cases.

Foundational underpinnings of ID

As mentioned earlier, ID does not provide a structured method, meaning that studies adopting this methodology differ in research design, with a variety of techniques employed for data collection and analysis. However, whichever design is followed, all ID studies are underpinned by several philosophical underpinnings (Hunt, 2009; Thorne, 2016), as listed below.

Studies following the ID methodology ought to:

- Be carried out in as naturalistic context as possible where the rights and comfort of the participants are respected.
- Appreciate and value both subjective and experiential knowledge as sources of insight.
- Capitalise on human commonalities as well as individual expressions of variance within a shared focus of interest.
- Reflect issues not bounded by time and context but attend to the time and context in which human expressions are enacted.
- Acknowledge a socially constructed element to human experience that cannot be meaningfully separated from its essential nature.
- Recognise that in the world of human experience, reality involves multiple constructed realities that may at times be contradictory, and
- Acknowledge an indivisible interaction between the knower and the known, meaning the researcher and what is being researched influence each other (Thorne, 2016).

The research design, guided by these principles, will now be outlined.

Research Study Design

As previously described, the study was conducted in three phases: a scoping review to establish the state of current knowledge, semi-structured interviews exploring participants' experience of everyday occupations after completion of treatment for bowel cancer, and a further round of interviews to confirm and expand on findings from Phase Two and seek information about bowel cancer survivors' preferences regarding information dissemination. The methods for each phase are detailed below, with links drawn to the manuscripts written to disseminate findings.

Phase One – Scoping review

A broad review of the literature to inform the study proposal was initially carried out, revealing a gap in knowledge regarding the occupational impacts following treatment completion for bowel cancer survivors. The limited literature that addressed this phase often explored cancer in general rather than specific cancers. While this literature is useful – as many cancer survivors experience common symptoms such as decreased levels of physical functioning and participation in social, work, and leisure activities (Hunter et al., 2017) – each cancer also produces unique challenges and situations. I wanted to be definitive about what had been produced specific to bowel cancer and, therefore, decided to complete a thorough review.

While undertaking a systematic review was considered, a scoping review format was chosen. Both formats provide transparent and rigorous methods to identify and analyse relevant publications related to a research question, however, the scoping review format was used as my initial review revealed that there was not a published body of research into the occupational impact of having had bowel cancer and scoping reviews are suitable when the topic has not been extensively reviewed, or there is limited published evidence (O'Brien et al., 2016; Pham et al., 2014; Sucharew & Macaluso, 2019). This type of review provided a means of identifying key characteristics and mapping the body of literature (Munn et al., 2018; O'Brien et al., 2016; Pham et al., 2014). In addition, following this format for review ensured the focus remained on providing an overview of the selected literature – regardless of quality – rather than the critical appraisal of individual studies that is possible when a coherent body of research exists (Peters et al., 2015; Pham et al., 2014; Sucharew & Macaluso, 2019). Both published and grey literature were included, making it ideal to inform both practice and further research (Arksey & O'Malley, 2005; Colquhoun et al., 2014; Levac et al., 2010; Westphaln et al., 2021). The informing of practice is, of course, a fundamental feature of ID, with the desire to integrate knowledge into the practice context (Thorne, 2016).

Arksey and O'Malley's (2005) framework was employed to provide a structured format for locating, analysing, and summarising literature (McKinstry et al., 2014). It involved five stages: (1) identifying the research question, (2) identifying relevant studies, (3) study selection, (4) charting the data, and (5) collating, summarising, and reporting the results. This process is iterative, with steps revisited as necessary. Full details regarding these five steps are reported in the next chapter. Thirty-three publications were included in the final review which identified six domains of occupation impacted by a bowel cancer diagnosis and treatment: Social activity, physical activity, sexual activity, employment and role functioning, physical functioning, and self-care. Findings from the scoping review were published in the British Journal of Occupational Therapy (Martin et al., 2020b) and helped inform the following exploratory qualitative phase utilising inductive reasoning (Thorne, 2016).

Phase Two

Phase Two of the study is now outlined, including preliminary work, participant selection criteria, description of the recruitment process, data collection via semi-structured interviews, and how the data were analysed. Prior to commencement of this phase, ethical approval was applied for and granted from Auckland University of Technology Ethics Committee (Appendix B) and Lakes DHB Research and Ethics Committee (Appendix C). Ethical considerations covered in these applications are discussed as applicable throughout the rest of this chapter.

Preliminary work prior to data collection

Prior to data collection commencement, I carried out some preliminary tasks to facilitate the richest possible data. Firstly, I journaled my expectations concerning how I believed the interviews would go. This piece of writing was based on the scoping review findings and my own experiences of bowel cancer. An excerpt can be seen in Appendix A.

In response to this exercise, I decided to make a concerted effort to allow participants to have time to think and reflect during the interviews. My aim with this strategy was to give participants the opportunity to truly consider any changes they had experienced – but had not initially identified – and I felt they needed unpressured time to achieve this. I also decided questions should be as open as possible to enable the full range and impact of experiences to be considered.

I also prepared an interview guide which I shared with my supervisors. After their feedback I altered the introduction to include a clearer outline of the aim of the research and what I hoped to hear from participants, that is, how having had bowel cancer had been, and was still, impacting their day-to-day lives (Appendix D). I also adapted the

questions, making some more open ended such as “What would other people notice or say about you now?” and “What advice would you give to someone diagnosed with bowel cancer about how to manage the after-effects?” In addition, I became more aware of how I used the term “occupation”. This word is generally only used regarding employment outside the field of occupational therapy; I wanted to hear how a variety of occupations had been impacted, not just paid work. I also added additional prompting questions designed to be used when clarification was needed or to further explore issues raised (Jeans et al., 2019).

I used my prepared guide during two pilot interviews with friends who had witnessed my bowel cancer journey happy to play the part of a bowel cancer survivor, a strategy which has previously been successfully utilised in health focused qualitative research (Kennedy, 2017). During the interviews I found my friends often naturally referred to information I had planned to cover in upcoming questions; I thus learned to be flexible and adapt the questions asked in response to the answers given. Following these pilot interviews, I began working towards data collection, as outlined in the following sections.

Participant selection

Individuals were eligible to participate in the study if they were living in New Zealand, had received a bowel cancer diagnosis, and finished treatment at least three months prior, or they were a significant other of the affected individual. The decision to welcome significant others to participate was taken to provide an opportunity to hear an alternate perspective of the impact bowel cancer had on the survivor’s occupations and potentially reveal contextual nuances and a richer understanding (Abma & Stake, 2014). This decision rested with the bowel cancer survivor. It was felt family and/or friends could provide multiple perspectives of the way having had bowel cancer changed the survivor’s occupational needs and routines and to elicit contextual nuances and a richer understanding (Abma & Stake, 2014). This intent was signalled through information on the flyer and information sheets indicating that people who were close to someone who had bowel cancer were welcome to take part. Once participants had agreed to be involved, I also reminded them that significant others were invited to contribute to interviews. The period of at least three months post-treatment was chosen to allow time for the immediate effects of radiotherapy and chemotherapy to have subsided, to be replaced by more long-term impacts. There was no upper time limit, as my intention was to capture the occupational impact across the whole term of survivorship.

My first intention was to recruit people knowledgeable with the phenomenon of surviving bowel cancer. My second intention – consistent with the constructivist

approach – was to select a broad sample of people with diverse experiences in order to generate practical knowledge applicable to bowel cancer survivors in general and of use to the health professionals who work with them. Purposive sampling was used, a process congruent with ID research (Grattan et al., 2018; Hunt, 2009) as it facilitates contact with individuals with experience of the phenomenon being investigated (Thorne, 2016). This sampling method involves the deliberate selection of participants based on predetermined criteria, who represent various features of the study population (Rapley, 2014; Thorne, 2016). Participants were required to be competent in conversational English.

No target or limit was placed on ethnicity. Māori have higher incidence rates than non-Māori for several cancers (MOH, 2017b, 2018), however this is not the case with bowel cancer where incidence rates amongst both male and female Māori are lower than for non-Māori (MOH, 2017b, 2018). Nonetheless, due to a rapidly increasing rate amongst Māori (Shah et al., 2012), active recruitment strategies were used to generate findings more representative of Aotearoa New Zealand. My contact at Lakes DHB, Ann-Maree Murphy, shared details of the study with Māori clients to invite them to participate.

In order to capture the full range of impacts on occupation, a number of selection criteria were considered to gain diversity across sampling (Thorne, 2016). Participants were selected to provide insights across six demographic parameters I anticipated would influence the range and intensity of occupations they engaged in:

1. Rural/urban dwellers: To explore the impact of location on occupations. Categorised as a) rural areas with moderate urban influence, b) rural areas with low urban influence, c) highly remote/ rural areas and d) independent urban communities (Sharples et al., 2018).
2. Active/sedentary: Including a) *Sedentary*: a lifestyle that includes only the light physical activity associated with typical day-to-day life, b) *Moderately active*: a lifestyle that includes at least 2 ½ hours of moderate or 1 ¼ hours of vigorous physical activity spread throughout the week, c) *Active*: a lifestyle that includes 5 hours of moderate or 2 ½ hours of vigorous physical activity spread throughout the week (MOH, 2020a).
3. Male/female: To explore impact of gender on occupations.
4. Tumour stages 1-4: To explore impact of stage at diagnosis. This criterion originally involved stage 1-3 as those with stage 4 cancer are often receiving palliative care. It was considered that this group would have very different occupational impacts and be out of the realms of this study's focus. However,

after consultation with Ann-Maree Murphy, it was decided to include participants diagnosed with stage 4 who were considered “cured” rather than palliative to give the perspective of those who had experienced advanced cancer. It was also considered that as I would be leading the interviews, I could ensure the focus remained on occupations impacted by bowel cancer, rather than where the cancer had metastasised to.

5. Variety of ages: Given that in New Zealand 90% of people who develop bowel cancer are over the age of 50 years (Health Navigator New Zealand, 2021), it was expected the majority of participants would be within this age range and reflective of this fact. However, the incidence of bowel cancer amongst younger people is increasing (Robertson et al., 2017) and, therefore, younger participants were also sought. The aim was to recruit participants across the following age groups:

- ≤ 50 years
- 51-64 years – working age
- 65-74 years – youngest-old
- 75-84 years – middle-old
- ≥85 years – oldest-old (Lee et al., 2018)

6. Stoma/no stoma: To explore the impact this has on occupations; there is no consensus in the literature as to whether bowel cancer survivors’ QoL is impacted more for those with a stoma than those without (Cotrim & Pereira, 2008; Hornbrook et al., 2017; Yau et al., 2009).

Participant recruitment

Although ID studies generally involve between five and 30 participants (Teodoro, 2018), Thorne (2016) does not specify an optimal sample size and stated that “interpretive description can be conducted on samples of almost any size” (p. 103). Instead, the emphasis is on being transparent about the reasons for sampling choices and reporting on what the sample is understood to reflect (Thorne, 2016). I set out to recruit a maximum of 25 participants, including significant others, across Phases Two and Three of the study. This was considered a large enough number to encompass variety within the selection criteria, and also a realistic number to recruit in terms of accessing volunteers. This original approximation of sample size assisted with recruitment planning (Malterud et al., 2016).

Participants were recruited via personal and professional networks including relatives of friends, relatives of AUT staff, individuals identified by fellow occupational therapists, and patients registered with Lakes DHB. Table 1 provides the numbers of participants generated via different recruitment strategies.

Table 1: Number of participants generated via different recruitment strategies

Recruitment strategy	Number of participants
Lakes DHB	8 (and 4 partners)
Relatives of friends	1
Professional networks	1
Relatives of AUT staff	1

Intermediaries – such as friends, university staff, and Ann-Maree Murphy at Rotorua Hospital – were provided with a flyer advertising the study (Appendix E), information sheets (Appendix F), and a consent form (Appendix G) to pass to potential participants. This information included my identity as researcher with reference to my own bowel cancer diagnosis to ensure transparency. Information about what involvement in the research would entail was included and it was made clear that participation was voluntary. Being provided with this information enabled participants to decide whether to volunteer to take part in the study and ensured the consent given was fully informed (Webster et al., 2012). I was able to recruit participants covering a variety of characteristics/occupational profiles by conducting recruitment over time and indicating to the intermediaries which characteristics I was looking for, for example, Māori, active, rural dweller, etc. As the individuals approached all met one of the desired aspects, everyone who expressed an interest was selected and so I was able to ensure diversity across parameters. While this diversity would contribute to breadth of knowledge, the small number of participants in relation to each demographic parameter limited the possible depth.

With the prospective participant's permission, the intermediaries passed the names and contact details of interested parties to me. I then made contact via email, text or phone call, depending on what contact details had been provided. During the ensuing conversations, I further explained the study, answered any questions, and ascertained if the interested party met the inclusion criteria for the study (which was the case for all who had expressed an interest). The participant was also asked for the demographic information discussed above, that is, rural/urban dwelling, activity levels, age, tumour stage, and whether they had a stoma, or had had one reversed. If the potential participant was still keen to be involved, an interview time and place was arranged at the end of the conversation, and I reminded participants of their right to withdraw at any stage without giving an explanation. In order to reduce burden, interviews were arranged at locations and times that suited participants. If the participant indicated their partner would like to be involved, they were emailed an additional information sheet (Appendix H). When participants involved both the bowel cancer survivor and their

significant others, they were given the option of being interviewed separately or together.

Data collection and analysis

Throughout Phase Two of the research, data collection and analysis were carried out concurrently, in keeping with an ID perspective (Thorne, 2016). The methods are described here as they occurred chronologically. This phase involved a total of 11 interviews with 15 participants (including four partners). When determining final sample size, the five areas within the concept of “information power”, as suggested by Malterud et al. (2016), were considered: (1) Study aim – the broad aims required a sample large enough to provide sufficient information power to cover the comprehensive phenomenon being researched, (2) Sample Specificity – involved ensuring participants were all bowel cancer survivors or partners who were knowledgeable about the impact of bowel cancer on occupations, but also exhibited some variation regarding demographics and, therefore, experiences, (3) Use of established theory – The study was grounded in occupational science and I had experience of the empirical matters being studied, (4) Quality of dialogue – I was familiar with the topic and comfortable discussing my own experiences to enhance quality of dialogue. Using pilot interviews also improved dialogue, (5) Analysis strategy – The exploratory cross-case analysis requires more participants to enable sufficient information power. In addition, analysis occurred alongside data gathering so that interview topics and questions could be refined over time and the extent to which insights were generated by subsequent participants could be monitored. All these factors were considered throughout the research process, and the sample number required was constantly revisited in terms of what was necessary to achieve the desired breadth to gain a thorough overview of the topic.

Semi-structured interviews were the chosen method for data collection and were used as they can “generate free-ranging conversations ... that are directed by what participants have to say” (Roulston & Choi, 2017, p. 233). This method of data collection aligned with the constructivist worldview whereby individuals construct knowledge and experiences through social interaction (Constantino, 2008; Cresswell, 2014). Semi-structured interviews provided a means of hearing the subjective experiences of individuals with first-hand knowledge of the phenomenon being explored as researcher understanding was co-constructed with that of the participants (Cresswell, 2014; Thorne, 2016). Researcher initiated interview questions promoted interactive dialogue which helped to develop understanding (Constantino, 2008).

Māori participants were given the option of having a Māori individual present during the interview, but this option was declined. The four partners who were involved chose to

be interviewed at the same time as the bowel cancer survivor, in agreement with the survivor. Interviews were carried out over the phone or face-to-face at the participant's home or at a mutually agreed location. The interviews conducted at participant homes caused potential risk and vulnerability for me as the interviewer. As a safety precaution, in advance of each face-to-face interview, I set up a person who knew where I would be visiting, along with the scheduled start and proposed finish time of the interview. This person was sent a text message immediately prior to entering the proposed venue and on exiting. Details can be found in the Researcher Safety Protocol (Appendix I).

Prior to the commencement of each interview, I gave the participant/s time to review the consent form they had received and ask any questions. The participant/s then signed the form, which I kept, and retained a second copy. At this time, participants were reminded they were free to choose which questions to answer, could say as little or as much as they wanted during the interview and could cease the interview or withdraw information from the research at any time, up until one week after the interview, without giving an explanation. Participants were reminded the session would be recorded and invited to withdraw if they are uncomfortable with this practice. They were also reminded of my status as a bowel cancer survivor, helping to reduce the possibility of a researcher/participant imbalance (Haigh, 2005) and break down barriers/embarrassment in relation to sharing details of personal functioning such as toileting. Participant responses during interviews suggest my insider status enhanced communication and helped some talk more freely about sensitive topics.

I began each interview with general chat to build rapport and then used the interview guide discussed earlier to direct the conversation towards the aims of the study. The first question was general and asked participants to outline what their life was like before cancer and how they perceived it to have changed since diagnosis and treatment. This overview of the participant's life provided information I could refer to during the interview and gave them an opportunity to share their story (Thorne, 2016). This was followed by the series of questions in the interview guide focussing on a variety of occupational domains and how engagement within these may have changed since their bowel cancer diagnosis. Having partners present provided additional insights as to how the life of the survivor had been impacted since diagnosis. Prior to the interview I had prepared an interview guide with questions for significant others (Appendix J), but found I did not need to refer to this as partners naturally gave their views in answer to the questions I asked the bowel cancer survivor participant. Audio from the interviews were digitally recorded, and copies stored on a password protected computer.

I transcribed verbatim the first three interviews, maintaining participant anonymity with the use of pseudonyms and the removal of any identifiable information, such as geographical area or health service (Punch, 2014). I felt the process of personally transcribing the initial interviews would be beneficial and an opportunity to slow my “attention to the nuances, words, phrases, and pauses, and to hear more deeply what the language contains” (Thorne, 2016, p. 158). I shared this transcript with my supervisors who provided feedback, pointing out areas where I had missed opportunities to follow up on participant comments and thus gain richer data. My early post-interview reflections helped me analyse my performance (Roulston et al., 2013) and highlighted my – or participants – assumptions that I automatically knew what experiences or actions they were referring to due to my similar experiences (Dwyer & Buckle, 2009). Consequently, I made a conscious effort to act as a naïve researcher, especially following participant comments such as, “You’ll understand from your own experiences”. Documenting what was happening to me conceptually and subjectively helped with understanding of the implications of my own role in the construction of data (Thorne, 2016).

After the fourth interview a professional transcriber was employed. Interviews continued to be transcribed verbatim to facilitate accuracy and ensure authenticity and scientific and ethical integrity (Noble & Smith, 2015). Prior to commencing this work, the transcriber signed a confidentiality agreement as in Appendix K. I checked the accuracy of each transcript, and made any necessary alterations, by listening to the interview recording while reading it.

I continued journaling my initial thoughts as soon as possible after each interview, reflecting on how the interview had flowed, my own performance as interviewer, and what I viewed as key content. This process provided a direction for upcoming interviews. I also began writing notes during the interviews. I had originally believed this might be distracting and negatively affect my ability to listen, but realised it was necessary to ensure I revisited points needing clarification/elaboration. However, rather than writing large amounts, I used the strategy of writing one or two words which was enough to remind me of areas to return to when the participant had finished speaking (Doody & Noonan, 2013). Participants were given the chance to review their interview transcript and make any comments they saw as relevant. Two participants took this opportunity but did not provide any additional feedback.

As each interview was transcribed, thematic analysis began, to enable early insights to be incorporated into future data collection (Grattan et al., 2018) and enable the concurrent data collection and analysis, constant comparative analysis, and iterative analysis recommended when using ID (Thorne, 2016). Transcripts were reread several

times, to increase familiarity and facilitate immersion in the data. On occasion, corresponding audio recordings were listened to again to monitor the participant's tone of voice, as this indicated the importance a participant was attaching to a comment, whether they were making light of something, or were uncomfortable discussing a particular topic.

Analysis within ID methodology can involve the utilisation of a variety of analysis methods and techniques (Hunt, 2009; Thorne, 2016). As ID facilitates the identification of patterns in the data, thematic analysis was employed. As a novice in terms of this form of analysis, for the first three transcripts I followed the steps suggested by Braun et al. (2018) which I learned at a two-day qualitative data analysis workshop facilitated by Gareth Terry, a researcher at AUT. I used line-by-line coding to establish initial codes, with the comments function within Microsoft Word used to manage the coding. Sections of the text were highlighted, and a potential code written in a corresponding comment box in the margin. Comment boxes were also used to record my thoughts and questions about the data. An example is provided in Appendix L. The document was then shared with my first supervisor, who added her codes and comments, enabling triangulation of researcher perspectives as initial coding was compared.

After analysing three or four transcripts, and becoming more familiar and confident with the analysis process, I began to focus less on line-by-line coding and more on the bigger picture characteristic of ID, thus ensuring I was not “derailed by excessive precision” (Thorne, 2016, p. 160). There became more of an emphasis on broad questions – such as “What is this telling me?” to ensure the contextual nature of the data was respected and an understanding of the whole picture was obtained (Hunt, 2009; Teodoro, 2018; Thorne et al., 2004). This breadth rather than precision approach permitted groups of data bearing similar characteristics to be examined and re-examined for a range of alternative meanings (Thorne et al., 2004). Consideration of my comments and reflections recorded after each interview added to and enhanced the analysis.

I also began to regularly brainstorm ideas about what the data were telling me. I wrote these ideas in different coloured pens on large sheets of paper, with arrows and lines connecting common threads. I also added questions that arose as I considered these ideas. This process allowed recurring ideas and thematic patterns to begin to appear on the page (Thorne, 2016). Text excerpts were also copied and pasted into documents with descriptive titles to temporarily combine potentially related ideas into subsets. These strategies ensured consistency with the emergent analytic, which ID stimulates (Thorne, 2016) and permitted groups of data bearing similar characteristics to be examined and re-examined for a range of alternative explanations (Thorne et al.,

2004). In this way, evolving themes and patterns founded on the subjective perceptions of participants were developed (Berterö, 2015). These unfolding themes were discussed at monthly sessions with both supervisors.

After the first seven interviews had taken place, additional questions relating to the recurring patterns and emerging themes were added to the guiding questions and incorporated into future interviews (Teodoro et al., 2018) (Appendix M). These questions were designed to enable participants to interpret what had been said by previous participants and add their own related experiences, thus enhancing the data. Iterative and concurrent data collection and analysis continued for the rest of Phase Two as I dwelt in the data “repeatedly and purposefully ... developing a relationship with it” (Thorne, 2016, p. 165). To ensure I remained ‘on track’ I repeatedly returned to my research question and relied on my occupational therapy disciplinary grounding to guide my analysis.

The first 11 interviews were carried out (with 15 participants) – ranging in duration from 30 to 100 minutes – over the period May to December 2019. After these had been completed, and data analysed, it was considered a meaningful clinical description of the phenomenon under investigation had been generated (Cuthbert et al., 2021). Thorne (2016) described a meaningful clinical description as one that makes sense to a clinician with knowledge of the phenomenon being researched. Therefore, data collection for this phase was complete.

Phase Three

Phase Three addressed the third study aim, which was to identify the occupationally focused information needs of bowel cancer survivors and highlight the factors for consideration when providing information. It involved four further interviews with a dual focus; firstly, to ascertain whether the themes identified in Phase Two resonated with participants and had captured the experience, and secondly, to generate participant guidance as to the information to provide to bowel cancer survivors. The use of a second round of interviews increased credibility of the findings of Phase Two by enabling interview strategies to be shaped by the evolving analysis (Thorne, 2016), and provided more opportunities to capture a truly insider perspective (Neergarde et al., 2009) as participants helped co-create the findings of the study (Hunt, 2009). Individual interviews were chosen, rather than an alternate method such as focus groups, as it was felt participants would be more open to discussing potentially embarrassing subjects on a one-to-one situation, rather than with a group of strangers.

Whether to re-interview participants from the previous phase or recruit new individuals who had not been involved in the study thus far was considered. Thorne (2016)

suggests repeat interviews provide the opportunity to share a synthesis of what had been learned from both the individual's comments and those of other participants and reflect the extent to which they resonate. The same author also proposes a similar form of confirmation or elaboration can be achieved with a small number of new participants. Therefore, the decision was taken to gain the perspective of both new and previously involved participants, as both presented benefits.

Participant recruitment

Two participants who had taken part in the second phase of the study and indicated willingness to participate in further studies were contacted via email and invited to take part in a second interview, which both agreed to. Two new participants were recruited through the contact at Lakes DHB, with Ann-Maree Murphy supplying them with the advertising flyers, information sheets, and consent forms. The partner of one new participant was also interviewed alongside her husband. Procedures regarding practical arrangements for carrying out the interviews were as in Phase Two. Over Phases Two and Three a total of 18 participants were involved.

Data collection and analysis

Three interviews were carried out face-to-face and one over the telephone between July and November 2020. Interviews varied in length from 60 to 80 minutes. The benefits of an established relationship were clear in the repeat interviews as rapport had already been developed and there were opportunities for additional information about areas discussed in earlier interviews to be added (Vincent, 2013). A new interview guide was employed, as seen in Appendix N. This guide had two sections, reflecting the dual focus of the interviews. The first section included the title of each of the themes from Phase Two and a bullet pointed synopsis; under each heading pertinent quotes relating to that theme were included. This information was not intended to be read word-for-word but instead provided a framework for the interview, with quotes shared when I felt they would enhance the conversation and understanding of the essence of the themes. Sometimes quotes had been provided by the current interviewee, sometimes from other participants. The process was very much an interactive conversation, where participants were encouraged to ask questions and make comments throughout. As each theme was discussed, participants naturally responded to what was being said. Sometimes this response was the nod of a head and a comment indicating their agreement with what had been shared, sometimes it involved further examples to demonstrate how the theme resonated with them, and sometimes it was a question asking for clarification as to what was encompassed within a theme.

The purpose of this sharing of themes was to go further than the conventional member checking aim of ascertaining whether everyone agrees with what is being reported – although this is beneficial and increases credibility of findings (Noble & Smith, 2015). Rather, this step was an opportunity to expand the evolving patterns and associations as the data were transformed into findings. The second interviews allowed reflection on what I knew so far and how I knew it and enabled me to challenge myself and “avoid stopping at the obvious” (Thorne, 2016, p. 177).

The second part of the interview was intended to capture participant views regarding the information they believed would be beneficial in aiding recovery as a whole. When participants agreed to take part in the third phase of the study, they were emailed a copy of a booklet entitled “Living beyond bowel cancer” to consider prior to their interview. This 23-page full colour electronic resource had been produced by BCNZ to offer support and advice to bowel cancer survivors as they “navigate the new terrain” (BCNZ, 2019, p. 5) after treatment conclusion. It contains a variety of generic information including medical follow-up care, and topics such as “exercise and staying active”, and “emotions and feelings” in “practical” and “personal” sections. Extensive text is included, along with images and featured tips/important considerations, such as becoming aware of available toilet locations before leaving the home. All participants had printed their own copy of the resource and referred to it during the interview.

Participants were given the opportunity to express their opinion as to whether they saw a need for such a publication, the overall usefulness of the resource, how they felt it could be improved, and their preferences regarding the medium for delivering such information. Being presented with the findings of Phase Two of this study, which were explicitly drawn from experiences of bowel cancer survivors residing in the same country, plus having access to the BCNZ resource, enabled participants to generalise beyond their own experience in considering the information needs of bowel cancer survivors – and the form in which such information might be delivered. Again, early insights were incorporated into future interviews (Clark et al., 2011; Grattan et al., 2018). For example, I communicated some of the views of earlier participants regarding the BCNZ resource in subsequent interviews to ascertain if these thoughts were shared by other bowel cancer survivors. The interviews were transcribed verbatim by the professional transcriber. Data collection and analysis again occurred concurrently, with the continued implementation of the breadth rather than precision focus developed in Phase Two.

Advancing credibility and rigour

Thorne (2016) identified four criteria to assess rigour and credibility in ID studies. These are epistemological integrity, representative credibility, analytic logic, and interpretive authority. Each is now discussed in relation to this doctoral study.

Epistemological integrity

To ensure research findings are credible, the research question, research design and strategies used should be consistent with the epistemological position stated (Thorne, 2016). Early sections of this chapter demonstrate how the methodology and methods used in this study are in accordance with the epistemological positioning. For example, I acknowledge my disciplinary and personal positioning and how this may have impacted the research process and describe how I was consistently self-reflexive and self-aware of my biases and perspective (Moore, 2015). The multiple realities and the co-construction of knowledge are demonstrated as the subjective experiences of participants, in combination with my position as enquirer, interacted and influenced each other.

Representative credibility

Representative credibility is enhanced when the sampling and data collection methods used reflect the findings and “the theoretical claims that the study purport(s)” (Thorne, 2016, p. 234). Representative credibility was enhanced in this study through the purposive sampling employed. Initially, interviews were with New Zealand European females. In order to gain diversity, and a mix of participants reflecting the populations of Aotearoa New Zealand, the point of contact at Lakes DHB was asked to locate potential participants covering the variety of criteria listed in the preliminary section earlier in this chapter. For example, Ann-Maree identified Māori and male participants, those with a stoma, those who lived rurally, and those who had been treated for stage 4 cancer. The use of semi-structured interviews enabled participants to freely share thoughts and views. This process, combined with the contribution of partners at both rounds of interviews, enabled a wider understanding of the occupational impact of having had bowel cancer.

Analytic Logic

Analytic logic involves the reasoning of the researcher being made explicit throughout the whole research process (Thorne, 2016). Evidence for the inductive reasoning process used within this study is provided by the description of the process of analysing data. Earlier in this chapter, I described how my initial line-by-line analysis developed into looking more broadly at the bigger picture and thinking more interpretively. This change occurred as I became more confident in my analytic skills,

and more familiar with the data. The research process is also made visible through provision of the interview question guide, additional questions added later, and an example of early coding in the appendices.

Interpretive authority

Thorne (2016) recognises that perspective influences all knowledge, and so it is fundamental to the credibility of a study that the researcher's interpretations are trustworthy and external to researcher bias. Throughout the whole research process, I kept a reflexive journal to facilitate deep reflection on my own thoughts and feelings and identify any potential bias. I was determined that findings would reflect participant experiences rather than my own and feel my engagement in reflexivity helped achieve this. In addition, I consistently consulted with Ann-Maree Murphy at Lakes DHB, as well as receiving feedback from three sets of anonymous referees after submitting article manuscripts for consideration for publication.

Chapter summary

This chapter has provided an outline of the three phases of this study. An overview of ID has been presented, including how it provided an analytical, inductive approach to facilitate an understanding of the occupational experience of individuals who had survived bowel cancer, which can be used to inform practice for people working with this population (Teodoro et al., 2018; Thorne, 2016). The strategies by which credibility was enhanced have also been addressed. What follows are four chapters accepted or submitted for publication. Each outlines a part of the story of this study, with all parts considered together as a whole in the final discussion chapter. The next chapter reports the methods and findings of the scoping review, which occurred in Phase One of the study.

CHAPTER THREE: THE IMPACT OF SURVIVING BOWEL CANCER ON OCCUPATION - A SCOPING REVIEW

Prelude to Manuscript One

The following chapter reports the literature review undertaken for Phase One of this study, to extend my understanding of the occupational impact of having had bowel cancer, thus reducing the risk of being limited by my personal experiences and perceptions. This ensured the questions and prompts used in the Phase Two interviews came from a broad base.

The chapter includes an enhanced version of an article published in the British Journal of Occupational Therapy (Martin et al., 2020b). Additions include consideration of the strengths and limitations of qualitative and quantitative research. It outlines the methods used in a scoping review, guided by Arksey and O'Malley's (2005) methodological framework, exploring knowledge contained in the literature regarding the impact of having had bowel cancer on occupations. The version of the article that appears here includes corrected search terms as provided in a corrigendum notice published by the British Journal of Occupational Therapy and added to the online version of the article.

Studies included in the review were selected using defined inclusion and exclusion criteria, following identification of the research question and relevant literature. Only one of the publications selected was written by an occupational therapist, with a variety of disciplines contributing to the other 32 pieces of literature including nursing, medicine, psychology, epidemiology, counselling, social work, anthropology, and physical therapy. The fact that so many professions contributed to the knowledge base indicates recognition of the wide-reaching impact on occupation, albeit without an occupational therapy focus. Several publications had occupation as the focus of the study, such as exercise, sexual activity, or employment, whereas for others, occupation was revealed as an aspect of the overall experience. For example, those with a QoL focus addressed areas such as functional limitations, changes in dietary choices, and sleep patterns.

Publications also varied in terms of methodology and research design, with an assortment of mixed methods, quantitative, qualitative, reviews, an opinion piece, and a report for a cancer charity. The number of participants in the 10 qualitative studies ranged from 4 to 33, with a mean of 18. Participant numbers in the 16 quantitative studies covered a large range from 42 to 1966. Methods used in these publications

also varied, for example, longitudinal studies, population-based cohort studies, correlation surveys, observational studies, and cross-sectional studies.

The publication dates of the literature included in the review suggests research addressing the topic area of bowel cancer and occupations is increasing. Only three publications were produced prior to 2010, with 30 published since this date, 10 of which were published in 2017.

Information considered key in the studies was extracted and charted into Table 4 presented in the chapter. Findings related to occupation were then analysed and constructed into themes to present a narrative account of what had been revealed. This analytic process involved a comprehensive consideration of any noted links to occupation, and the identification of six occupational domains impacted. Finally, results are discussed in relation to the potential role of occupational therapy with bowel cancer survivors. Literature published since completion of the scoping review is considered in subsequent chapters, where results of later phases of my study are reported, and in the discussion chapter where the overall findings are considered.

Introduction

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

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

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

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

The vast majority of literature refers to those who have had cancer as “survivors.” However, there is inconsistency regarding when an individual becomes a “cancer survivor,” with definitions beginning at diagnosis, at the end of treatment, or after a disease-free period of time (Drury et al., 2017). This review focuses on the period

following treatment conclusion - when the immediate sequelae of surgery/chemotherapy/radiotherapy have subsided - to gain an understanding of the longer-term, and potentially variable, occupational impact of bowel cancer.

Methods

A scoping review format was selected to gain a comprehensive understanding and synthesis (Colquhoun et al., 2014) of the published literature addressing bowel cancer and occupations, regardless of study quality. Following this format ensured the richness of research findings was prioritised over the assessment of study vigour required in a systematic review (Armstrong et al., 2011; Peters et al., 2015). The scoping review approach allowed for the incorporation of both published and grey literature, making it ideal to inform both practice and further research (Arksey & O'Malley, 2005; Colquhoun et al., 2014; Levac et al., 2010; Peters et al., 2015). Arksey and O'Malley's (2005) framework was employed to provide a structured format for locating, analysing, and summarising literature (McKinstry et al., 2014), and involved five stages: (1) identifying the research question, (2) identifying relevant studies, (3) study selection, (4) charting the data, and (5) collating, summarising and reporting the results. This process is iterative, with steps revisited as necessary.

1. Identifying the research question

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

2. Identifying relevant studies

Initially CINAHL Complete and MEDLINE databases were searched to locate studies of the occupations of participants with bowel cancer, generating 924 results. To reduce the amount of irrelevant studies generated, studies focused on cancer screening or prevention were screened out using the Boolean operator "NOT". See Table 2 for the final search terms.

Table 2: Process for identifying and refining search terms

Final Search Terms	Boolean Command
"bowel cancer" or "colon cancer" or "rectal cancer" or "colorectal cancer" or "colorectal carcinoma" or "colorectal neoplasm"	AND
"occupation*" or "daily activit*" or "activities of daily living" or "ADLs" or "leisure" or "social activit*" or "return to work" or "employment"	AND
'Cancer N5 risk' OR 'epidemiology' OR 'cancer N5 screening' OR 'cancer N5 prevention' OR 'neoplasm N5 risk' OR 'cancer N5 mortality' OR 'cancer N5 incidence' OR 'pharma*' OR 'drug therapy' OR 'preoperative' OR 'pre-operative' OR 'pre-op' OR 'perioperative' OR 'peri operative' OR 'post operative' OR 'post-operative' OR 'postoperative' OR 'post surgery' OR 'molecul*' OR 'etiology' OR 'aetiology' OR 'etiological factor'	NOT

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

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

3. Study selection

Titles and abstracts of identified literature were screened by the first author (EM), with those appearing relevant to the research question retained. Secondly, two authors (EM and CH) screened full texts using initially agreed inclusion and exclusion criteria. As familiarity with the text increased, the two first authors discussed and refined the criteria. The final inclusion/exclusion criteria are presented in Table 3.

Table 3: Inclusion and exclusion criteria

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

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

** Criteria added during data charting process

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

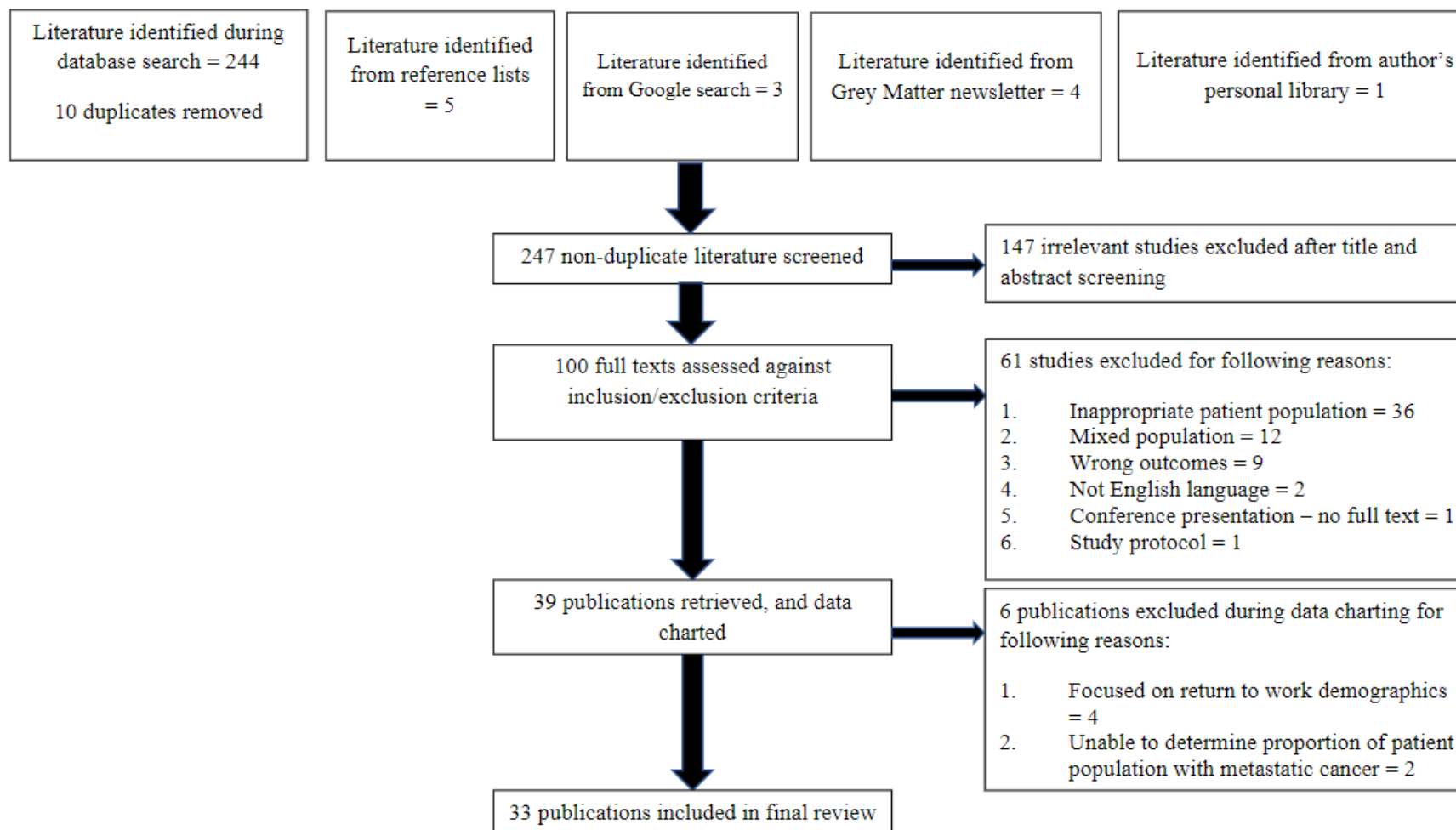


Figure 1: Study selection process

4. Charting the data

Data from each of the publications were extracted and charted under the following headings: Author/year, methodology/publication description, location, study population, and reported findings related to occupation, and are presented in Table 4. To ensure reliability and consistency, one author (EM) extracted the data, and another (CH) verified a 15% sample of publications selected to span the various research methodologies and large to small participant numbers. This process of sampling was employed due to second author time constraints and was in keeping with other published scoping review methods (Leppard et al., 2018; Seida et al., 2018). The charting process was iterative with continual extraction and updating of the table (Levac et al., 2010). During this process the decision was taken to exclude four studies predominantly addressing return to work (RTW) demographics. This ensured the focus remained on the research question addressing how occupations (in this case work occupations) were impacted rather than whether or not people returned to work. An additional two studies were excluded as they combined numbers of survivors diagnosed with stages three and four cancer making it impossible to determine the proportion with metastatic disease. In total 33 articles were included as presented in Table 4.

5. Collating, summarizing, and reporting the results

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

Findings

Characteristics of data

The majority of publications originated in Australia (N=9), followed by the US (N=7) and the UK (N=5). Sixteen studies employed quantitative methods, ten qualitative methods, two were mixed method, and three were systematic/literature reviews. The majority (N=19) were published in oncology/cancer journals (including those specialising in nursing, geriatrics, and psychology), three in colorectal disease journals, and three in medical journals. Most studies had study populations combining colon and rectal cancer survivors (N=26) with 6 including only rectal cancer participants.

The review revealed a significant degree of cataloguing of negatively impacted occupations with links made to the symptoms contributing to interruptions to occupational engagement. Such cataloguing is to be expected considering the prominence of quantitative studies with their aim of investigating concrete elements that can be observed and quantified. While such methodologies provided valuable

insights into the impact of surviving bowel cancer, they did not report on the subjective experiences and meaning present in the qualitative studies. This consideration highlights the strengths and limitations of both methodologies, which are now examined.

One of the most obvious advantages of qualitative research is the potential to generate rich, deep data through the exploration of concepts, rather than being limited by a set of pre-determined questions (Crinson et al., 2016; Taylor, 2007). As researchers interact with participants during broad, open-ended inquiry, detailed descriptions of the feelings, experiences, and opinions of participants can be interpreted (Choy, 2014; Rahman, 2017). Using semi-structured interviews – the “gold standard alternative for questionnaires” (Theofanidis & Fountouki, 2019, p. 159) – enables a holistic understanding of the human experience and can assist with “humanizing health care” a factor “easily lost in a sea of numbers” common in quantitative research (Morse, 2012, p. 68).

Nonetheless, the subjective nature of qualitative research can also be viewed as a weakness, as data can be misinterpreted, particularly if a robust methodology is not adhered to (Crinson, et al., 2016). In addition, the nature of qualitative research necessitates smaller sample sizes, raising concerns with generalizability to the whole study population (Rahman, 2017). This is demonstrated in the Shipp et al. (2015) study with its sample size of four males. Rich data were reported in the study, but the issue is raised whether this could be applied to the wider bowel cancer survivor population with such a limited sample.

In contrast, data from quantitative research can be converted into mathematical expressions such as percentages, which can then be more accurately generalized to a larger population, especially given the generally large, randomly selected sample size (Rahman, 2017). However, quantitative studies do exist with smaller sample sizes, such as the Tomruk et al. (2015) correlation study with 42 participants, raising questions regarding the generalisability of such studies.

As quantitative research deals with numbers and produces quantified data, it is often viewed as scientific fact and, therefore, more valuable than the narrative data produced by qualitative studies (Taylor, 2007). With quantitative research, the research design is directed by set rules and guidance (Morse, 2012). This results in the possibility of the test and results being replicated, making the data less open to dispute.

However, the underlying positivist paradigm of quantitative research does not consider the shaping of social reality or people’s interpretations of actions; this can result in a lack of identification of deeper explanations and meanings (Choy, 2014; Rahman,

2017). For example, several publications in my review included the use of surveys, a method that lacks any direct interaction between the researcher and participant (Rahman, 2017). The questionnaires commonly used often include closed questions, providing little opportunity for explanation or expansion and thus limited description of experiences (Choy, 2014).

Themes

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

Social activity

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

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

Significant impact was also reported due to the resulting bowel dysfunction experienced by survivors without an ostomy who described how unpredictability of bowel movements, urgency, and diarrhoea necessitated closeness to toilet facilities, intensifying anxiety and fear and leading to the subsequent avoidance of social activities away from home (Arndt et al., 2004; Hardcastle et al., 2017; Landers et al., 2011; McMullen et al., 2017; Ruakere, 2016; Vironen et al., 2006). Locations with

unfamiliar toilet facilities were avoided as were time periods when the bowels were not quiescent (Hardcastle et al., 2017; Wilson et al., 2010) with one survivor explaining, "It's the bowel, the uncertainty of it that keeps me in" (Wilson et al., 2010, p. 765).

Survivors explained how friends eventually stopped inviting them to social engagements due to continual refusal and the embarrassment felt when talking about the bowel problems being experienced (Hardcastle et al., 2017; Landers et al., 2011).

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

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

Physical activity

Bowel dysfunction - including frequency, looseness, constipation, and poor reactions to certain foods - provided a significant impediment to physical activity, as did the presence of an ostomy (Arndt et al., 2004; Cengiz & Bahar, 2017; Dennis et al., 2013; Grant et al., 2011; Knowles et al., 2013; Krouse et al., 2017; Shipp et al., 2015; Wilson et al., 2010). Additional barriers included fatigue (a greater reported obstacle for women than men), pain, somatization, neuropathy, poor balance, low level of fitness, poor health, and lack of motivation (Chambers et al., 2012; Kang et al., 2014; Krouse et al., 2017; McMullen et al., 2017; Shipp et al., 2015; Tomruk et al., 2015), with the receipt of radiation therapy associated with less physical activity (McMullen et al., 2017). Negative associations were found between the sedentary occupation of

television viewing and functional and physical well-being, especially in less active survivors, with a gradual increase in TV watching time from 12 to 36 months post diagnosis for those viewing 3-4 hours per day (Lynch et al., 2011). In contrast, studies addressing bowel cancer survivors as a homogenous group - rather than according to their prior activity levels - report some survivors decreased passive activities, such as reading and watching TV, replacing them with more active pastimes such as sport as the length of time since diagnosis increased (Chambers et al., 2012; Dennis et al., 2013; Shipp et al., 2015). The benefits of an increase in physical activity included improved energy levels, improved functional capacity, the confidence to carry out ADLs and RTW, and a sense of well-being (Dennis et al., 2013; Krouse et al., 2017; Spence et al., 2011; Tomruk et al., 2015). In addition, physical activity - particularly walking - was found to improve bowel function for females with and without ostomies; in contrast, bowel function for male ostomates worsened with increasing activity and did not change or only slightly improved for those without ostomies (Krouse et al., 2017).

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

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

Sexual activity

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

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

Employment and role functioning

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

Studies utilising QoL measures also considered employment combined with other forms of occupation. Findings identified the presence of role limitations, particularly for those who had received adjuvant chemotherapy or radiotherapy, rectal cancer survivors, and as a result of a decline in emotional health in women (Arndt et al., 2004;

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

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

Physical functioning

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

al., 2011; Kunitake et al., 2017). In addition, poor physical functioning is associated with poor emotional and mental health in women (Domati et al., 2011).

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

Self-care

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

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

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

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

Table 4: Data extracted from publications

Author/s, year	Method Publication description	Origin/ Location	Study population (M/yrs post diagnosis/treatment)	Reported findings related to occupation
Appleton et al., 2013	Qualitative Oncology nursing journal	UK	13 CRC CS, 5M – 5 yrs post-treatment. Mean age=67 yrs	<p>Enabler of transition back to normal roles – making jokes about having cancer, welcoming social attitudes as work/hobbies resumed</p> <p>Incremental increase in occupation (walk on golf course/pick up golf balls/ play 9 holes; walk further each day)</p> <p>Accept requests to talk to other CRC patients/attend support groups/participate in research</p> <p>Develop strategies to adapt to changes e.g., adjust to loss of status with retirement, stop carrying things up/down stairs, use pads/wet wipes (faecal incontinence); not eat as much</p> <p>Maintain routines and normality (not doing anything different)</p>
Arndt et al., 2004	Quantitative (population- based cohort study) Cancer journal	Germany	<p>309 CRC CS 1- and 3- yrs post diagnosis</p> <p>186 CC (12 with ostomy), 119 RC (47 with ostomy)</p> <p>Mean age=66 yrs (SD 9.2 yrs)</p> <p>241 alive at 3 yr follow up</p> <p>Response rate 82% at 1 yr and 92% at 3 yrs</p>	<p><i>Functioning: CS vs GP at 3 yrs (EORTC QLQ-C30 mean scores, 95% CI)</i></p> <p>SF: 72.8 vs 86.8; PF: 78.7 vs 81.0; RF: 78.1 vs 79.9</p> <p>Absolute prevalence of functional limitations higher in elderly</p> <p><i>RF: 1 to 3 yrs (EORTC QLQ-C30 and QLQ-CR38 mean scores)</i></p> <p>Ostomy vs non-ostomy: 69.1 vs 78.8 at 1 yr; 76.5 vs 78.8 (p=0.04) at 3 yrs</p> <p><i>Attributes to decline in RF and SF:</i></p> <p>Adjuvant chemo- and/or radiotherapy</p> <p><i>Sexual activity: 1 to 3 yrs (EORTC QLQ-CR38 mean scores)</i></p>

				38.3 to 30.8 (p=<0.01)
Beesley et al., 2017	Quantitative (prospective registry-based study) Psycho-oncology journal	Australia	148 CRC CS in paid workforce 12M post diagnosis Mean age=56.3 yrs (range=45-64)	Physical well-being significantly worse CS (SF12: 44.8 mean) than GP (52.0 mean) (p=0.001). CS who maintained/increased work had similar physical and mental well-being to GP Functional well-being improved significantly more over time in CS who maintained or increased work
Cabilan and Hines, 2017	Systematic review Systematic review database	Australia	CRC CS ≤12M from end of treatment (date of surgery or last dose of adjuvant treatment)	<i>Maintenance of functional independence</i> Declined from 69.8% to 57% (1 study); decreased from 84% to 26.7% at 3M, 29.7% at 6M and 24.4% at 12M (1 study); declined by 12.8% (not statistically significant) (1 study) Declined by 57.3% at 3M, 54.4% at 6M, 57.2% at 9M, and 59.6% at 12M (1 study – elderly nursing home patients) <i>Functional QoL (mean difference from baseline)</i> Within 3M —8.98 (95% CI —18.13, 0.18) (3 studies); at 6M —3.79 (95% CI —8.67, 1.10) (4 studies); 12M 15.31 (95% CI —8.08, 38.70) (2 studies) <i>Social QoL (mean difference from baseline)</i> Within 3M —1.52 (95% CI —4.18, 1.14) (3 studies); 6M 0.55 (95% CI —1.50, 2.60) (4 studies); 12M 8.69 (95% CI 1.10, 16.27) (2 studies) <i>Attributes to decline in physical and functional QoL</i> Ageing, poor functional status, comorbidities, advanced stage cancer and adjuvant therapy (3 studies) <i>Dressing and clothing choice:</i> Loose clothes to hide ostomy and pouching system; some clothing created pressure against the ostomy <i>Bathing:</i> Only on days when changed pouching system; cover ostomy
Cengiz and Bahar,	Qualitative Nursing journal	Turkey	12 individuals with ostomy, 9 CRC CS Mean age=54.41 yrs	

2017

(SD=19.14)

with a thin film dressing

Muslim religious practices: Reluctance to attend prayers with faeces in bag; ablution before every prayer

Sleep: Inability to fall asleep, remain asleep, or sleep in a favoured position due to fear of damaging ostomy; need to wake up to evacuate pouch

Sexual activity impairment: Concern partner disturbed by physical changes in body; loss of libido, retrograde/no ejaculation

Daily PA: Reluctance to go out or go for a walk

Social life: Avoidance of social activities, keep ostomy secret

Positive impact of support from family/friends

Ostomy management, e.g. leakage/flatulence – teacher not drinking water during day for fear of leakage

Chambers et al., 2012

Quantitative
(prospective correlational survey)

Clinical oncology journal

Australia

1,966 CRC CS at 5, 12, 24, and 36M postdiagnosis

Age categories at 36M: 20-49yrs (7.7%), 50-59 (19.1%), 60-69 (35.7%), 70+ (37.4%)

Strength: population based, large cohort

Limitation: low response rate (29% of eligible respondents at 36 months)

Increased PA over time

Higher levels of somatization and anxiety associated with lower levels of PA, with further decline if distress increases (but association with PA did not hold for depression or threat appraisal)

Fatigued CS 50% more likely to be inactive or insufficiently active

Positive threat appraisal corresponds to higher PA level

Cotrim

Quantitative

Portugal

153 CRC CS, 6-8M

Function scales (EORTC QLQ-CR 30) ostomy vs non-ostomy:

and Pereira, 2008	(descriptive cross-sectional study with a correlational design) Oncology nursing journal		post-surgery (47 rectal, 106 colon, 46 with ostomy). Mean age=64.64 yrs (SD =10.74; range = 27–88) 96 informal caregivers	PF: 61.1 vs 70.78 (p=0.009) RF: 19.57 vs 45.95 (p<0.001) SF: 27.90 vs 43.93 (p=0.007) Sexual function: 16.29 vs 30.67 (p=0.005)
Dennis et al., 2013	Mixed method cross sectional survey Oncology journal	Canada	CRC CS: pre-treatment (n = 54), undergoing treatment (n = 62), finished treatment <6M (n=67) or >6M (n = 178) Mean age=69 yrs (range: 36–91 yrs)	75% moderately active ≥4 times per week (gardening, climbing stairs, walking, housework), 17.5% 1–3 times, 5.3% <1 time 42.4% vigorously active < 1 time per week (less than normal controls), 29.6% 1–3, 18.0% ≥4 times Bowel issues provided barrier to increasing activity 39.3% made dietary changes, 21.1% increased PA, 39.1% wanted to increase PA Lack of support to make lifestyle changes
Domati et al., 2011	Quantitative (observational retrospective study) Medical journal	Italy	220 CRC CS ≥5 yrs post-surgery Mean age=66.6 yrs (range 43–81) 79.9% CC, 20.1% rectal 10% with permanent ostomy	<i>SF-36 average value scoring:</i> ♂ CS 18 points lower than ♂ GP; ♀ CS 31 points lower than GP; ♀ CS 20 points lower than ♂ CS (p <0.05) <i>RF due to emotional health:</i> ♀ CS 10 points lower than GP ♀; ♀ CS 17 points lower than ♂ CS (p <0.05) <i>Lifestyle aspects</i> Social relations: 14.1% improved, 79.1% unchanged, 2.8% worsened Cultural relations: 10% improved, 80% unchanged, 5% worsened Physical interests: 12.7% improved, 80.9% unchanged, 3.8% worsened Activity: 11.8% improved, 66.4% unchanged, 14.5% worsened Sexual activity: 4.4% improved, 60.9% unchanged, 31.3% worsened

Grant et al., 2011	Qualitative Oncology nursing journal	US	33 CRC CS with ostomies ≥5 yrs post diagnosis Mean age=69.75 yrs	<p>Religious aspects: 15.9% improved, 75.9% unchanged, 5.5% worsened</p> <p>Work activity: 3.7% improved, 64.5% unchanged, 31.9% worsened</p> <p><i>Eating:</i> Discover which foods to eat to avoid gas and rapid transit through gastrointestinal tract, limit food to control output, grazing rather than big meals, chew food slowly, not drinking before eating</p> <p><i>Impact on PA:</i> Change from running to walking; inability to lift heavy weights; ceasing of some activities; resumption of hiking, bowling, gardening after adapting to ostomy</p> <p><i>Employ strategies to avoid offending others:</i> Swim early in the morning, not revealing presence of ostomy</p> <p><i>Changes in sleep:</i> Sleep on back to avoid pouch bursting, restlessness at night</p> <p><i>Modify clothing</i> to protect ostomy from excess pressure and/or wear loose clothes so pouch not seen, self-acceptance and reveal colostomy to clothing sale staff</p> <p><i>Sexual activity.</i> Reluctance to take off clothes due to partner's reaction, inability to have sex</p> <p><i>Adapting to travel:</i> Preparation of extra supplies such as clothes, wipes, ostomy supplies, stay at hotel rather than with friends/relatives,</p>
Hamaker et al., 2015	Systematic review Geriatric oncology journal	The Netherlands	CRC CS	<p>Embarrassment when having faecal accidents at work</p> <p><i>Reduction in PF after treatment for RC:</i> Mean score 7% lower than baseline at 6 months, 5% lower at 12 months using QLQ-C30 or SF-36/SF-12 (16 studies).</p> <p>– 4% / –10% respectively using SF-36 (1 study of CC only); –23% / –7% respectively using SF-36 (1 study of CRC)</p> <p><i>Reduction in RF after colorectal surgery</i> (SF-36 or QLQ-C30, 16 studies): 8% lower at 6M (range -23% - +6%), 5% lower at 12M (range -</p>

				<p>17% - +10%); values returned to baseline at 1 yr (1 study of CC); mean – 46% at 6 months, –10% at 1 yr (1 study of CC and RC)</p> <p>Elderly patients experience the greatest and most persistent decline in self-care capacity (up to 61% reduction in IADL at 1-yr post diagnosis, 2 studies)</p> <p>1 yr post diagnosis not resumed housework (40%), driving (23%), shopping (50%) (1 study)</p> <p><i>Factors associated with delayed / greater loss of physical or role functioning:</i> Pre-op radiotherapy, older age, being single or 🏠 (6 studies)</p>
Hardcastle et al., 2017	Qualitative Psycho-oncology journal	Australia	<p>24 CRC CS completed treatment within past 2 yrs</p> <p>Mean age=69.38 yrs (SD = 4.19)</p>	<p>Developing fixation with bowel function</p> <p>Need for easy access to toilet facilities affecting social life</p>
Hewes and Graney, 2014	Opinion piece Rehabilitation counselling journal	US	Author CRC survivor	<p>Adaptations to job role suggested, e.g., Reduce weight lifting requirements, assignment to alternative tasks</p> <p>Extended bathroom time/privacy issue concerns on RTW</p> <p>Changed experience of showering due to difficulty observing stool in pouch</p>
Ho et al., 2016	Qualitative Psycho-oncology journal	Canada	<p>30 CRC CS completed treatment</p> <p>Median age=60 yrs (range 41-75)</p> <p>57% CC, 43% RC.</p>	<p>Difficulty transitioning from active cancer patient to survivor; calming anxiety over time to return to normal life</p> <p>Developing interest in talking about CRC to raise its public profile; support advocacy and recently diagnosed CS</p> <p>Realisation toileting is changed dramatically</p>
Hornbrook	Quantitative	US	577 (60.5% response rate) RC CS ≥5 yrs post	🏠 reported substantially higher frequency of soilage of undergarments

et al., 2017	survey Medical journal		diagnosis Mean age=73.1 yrs	CS with anastomoses more likely to be productive than those with permanent ostomies
Kang et al., 2014	Quantitative (cross sectional study) Cancer journal	Korea	427 CRC CS - different stages and medical status 47.1% <60 yrs	<i>Greatest perceived exercise barriers post-treatment</i> (mean values using adapted Exercise Barrier Questionnaire for Older Adults 5-point Likert scale; higher mean value indicates greater barrier) Fatigue: 2.58 (SD=0.08 p=0.767) Low level of physical fitness: 2.36 (SD=0.08 p=0.163) Poor health: 2.24 (SD=0.08 p=0.005) Tumour location (colon vs rectal), cancer stage (I-II vs III-IV), surgery (Yes vs No), and ostomy (Yes vs No) not significant factors that could affect exercise barriers Need to educate CS on the positive effects of exercise
Knowles et al., 2013	Quantitative (cross sectional survey) Oncology nursing journal	Scotland	381 CRC CS (138 rectal, 243 colon) ≥2 yrs post-surgery (median time interval 4.4 yrs) Median age=67.3 yrs (interquartile range 60.1, 74.3) 57% response rate	8% of RC survivors documented problems with stool leakage 'always', and 8% 'most of the time' vs 1% and 3% of CC survivors. Protective pad 'always' required by 17% of RC survivors vs 5% of CC survivors 9% of RC survivors 'always' had to alter activities due to bowel function vs 1% of CC survivors Dietary modification to control bowel movements reported by 30% of RC vs 15% of CC survivors <i>EORTC QLQ-C30 and EORTC QLQ-CR38 scores:</i> Reduced RF and SF in RC vs CC In ♀, greater sexual dysfunction in RC vs CC (median 66.67 vs. 50.00 P=0.009) <i>Within RC group, receipt of pre-operative radiotherapy vs no radiotherapy:</i> increased defecation problems (median 23.81 vs. 19.05

Krouse et al., 2017	Quantitative (cross sectional survey) Quality of life journal	US	557 RC survivors ≥5 yrs post diagnosis Mean age=72.6 yrs Mean yrs since surgery=12.9 Response rate 60.5%	<p>P=0 .005), reduced SF (median 83.33 vs. 100 P=0 .048), and greater financial difficulties (13% 'quite a bit; 4% 'very much' P=0.049).</p> <p>Of CS who reported PA helped with BF, walking most common (76%), followed by cycling (7%), gardening (6%), swimming (6%)</p> <p><i>Increases in function (using SF12) correlates with PA levels.</i> Adjusted mean "non-active" to "meeting guidelines" adjusted mean scores: PF: 40.6 to 48.0 SF: 46.0 to 51.4 RF: 42.2 to 46.8</p> <p>♂ with ostomies had consistently worsening scores on all BF scales with increasing PA; ♂ without ostomies had no change or slightly improved scores on all BF scales with increasing PA. Women with or without ostomies had consistently higher scores on all BF scales with PA.</p> <p><i>Barriers to PA:</i> Hernia, skin problems, fistula, neuropathy, pain, fear of stool leakage, having an ostomy, and persistent fatigue</p>
Kunitake et al., 2017	Quantitative (cross sectional survey) Cancer journal	US	708 CRC CS ≥5 yrs post diagnosis Mean age=66.19 (SD=10.63) Median survival time since surgery 8.2 yrs (range 5–19.5 yrs) 96% CC, 4% RC	<p>CS had higher overall HRQL and functional capacity compared with age-group-matched non-cancer controls</p> <p>Good functional capacity: 98 % able to perform all IADL activities</p>
Landers et al., 2011	Literature review Oncology nursing journal	Ireland	RC CS following sphincter-saving surgery (also includes individuals with chronic	<p><i>Dietary modifications to manage bowel symptoms:</i> Increase or decrease vegetable intake (2 studies); decrease of red meat, salt, and sugar (1 study); diets high in fibre and low in fat content (1 study)</p>

			bowel disease)	<p>53% of participants wore absorbent pads to manage faecal incontinence (1 study)</p> <p>Use of barrier cream and moist wipes to reduce anal soreness due to frequency of bowel movements (1 study)</p> <p>Location and availability of a bathroom key considerations when outside the home (2 studies)</p> <p>Threat of faecal incontinence led to fear of social engagements (1 study)</p> <p>Meticulousness in choosing strategies to avoid embarrassment and humiliation when away from home (2 studies)</p>
Lynch et al., 2011	Quantitative (longitudinal cross-sectional study) Cancer journal	Australia	<p>1,966 CRC CS at 5, 12, 24, and 36M post-diagnosis</p> <p>1266 completed all time frame interviews</p> <p>Age category at 6 months post diagnosis (%): 20-49 (8.5), 50-59 (19.4), 60-69 (33.7), 70+ (38.4).</p>	<p><i>Interactions between TV viewing time and PA (FACT-C)</i></p> <p><i>Physical well-being score</i></p> <p>Inactive CS with up to 5 h TV/day vs ≤ 2 h TV/day were 21% lower (95% CI: 13%, 27%)</p> <p>Sufficiently active CS with up to 5 h TV/per day vs ≤ 2 h TV/day - no significant difference</p> <p><i>Functional well-being score</i></p> <p>Inactive CS - 30% difference between top and bottom television viewing categories (95% CI: 22%, 36%)</p> <p>Sufficiently active CS with up to 5 h TV/per day vs ≤ 2 h TV/day - 16% (95% CI: 5%, 26%) lower</p>
Lynch et al., 2016	Quantitative (prospective, population-based study) Cancer journal	Australia	<p>239 middle aged (45–64 yrs) CRC CS (in paid workforce at diagnosis) at 6 and 12M post-diagnosis</p> <p>Median age (25th, 75th percentile) =57 yrs (52,</p>	<p>Individuals sleeping ≥ 9 h/ day 2.69 times more likely to reduce work time or retire (relative to those sleeping the recommended 7 to 9 hours) (95 % CI 1.06, 6.87; $p=0.038$)</p> <p>Individuals who have received chemotherapy and/or radiotherapy 3.06 times more likely to reduce work or retire (95 % CI 1.61, 5.80; $p<0.01$)</p>

			61)	
			Response rate 34%	
Macmillan Cancer Support, 2017	Report Publication for CS	UK	General CS completed treatment	Benefit of support provided by attending cancer groups Lack of support to get life “back on track”
McGrath et al., 2017	Mixed method (including prospective population-based study) Cancer nursing journal	Australia	171 middle-aged (45-64 yrs) CRC CS at 6M and 12M post diagnosis Median age= 56 yrs (range 51-60) (25th and 75th percentiles)	<i>Reasons for leaving work:</i> Difficulties with bowel function, having ostomy (difficulty bending and lifting heavy weights), reduced strength, neuropathy (limited use of hands and feet), medication adverse effects, and cognitive difficulties <i>Benefits of RTW:</i> Social support, increased sense of worth, structured routine, distraction from illness, financial benefit, return to normality Importance of effective communication and a cooperative and adaptable workplace Cancer experience changing perception of the importance of work
McMullen et al., 2017	Quantitative (observational study with longitudinal and cross-sectional components) Medical journal	US	567 RC CS ≥ 5 yrs post diagnosis Mean age=72.5 yrs 61% response rate	Participation in activities strongest predictor of QoL <i>Association of surgery type with activity participation</i> (mean scores - 0=worst, 5=best): Sphincter-sparing surgery 2.9, ostomy 2.0, temporary ostomy 2.9 (p <0.0001) For CS with sphincter sparing surgery, participation in activities associated with soilage (p <0.0001; 2.1 and 4.1 in those with the most vs least soilage, respectively) and radiation therapy (p = 0.0006; 2.6 and 3.2 in those with and without radiation therapy, respectively) <i>Barriers to participation (similar across surgery types):</i> RTW - Bowel dysfunction, depression, fatigue, pain <i>Social activities away from home</i> - Need to control diet, access to bathrooms, ostomy self-care routines, unpredictability of severe

Ramirez et al., 2009	Qualitative Women and health journal	US	30 ♀ CRC CS with ostomies ≥ 5 yrs post diagnosis. Mean age=70 yrs (range 44 to 93 yrs)	<p>constipation or diarrhoea</p> <p><i>Sexual or intimate contact</i> - Pain, impotence, embarrassment, partner's reactions after surgery</p> <p>PA - Neuropathy, weakness, poor balance</p> <p><i>Group 1: No Long-Term Sexual Difficulties (N = 11)</i></p> <p>Minor modifications to intercourse</p> <p>Ostomy management techniques, e.g., New or empty pouch in place before sex; covering of pouch to keep stable and hidden.</p> <p>Importance of supportive spouse</p> <p><i>Group 2: Long-Term Sexual Difficulties (N =7)</i></p> <p>Painful intercourse; inability to have intercourse due to vaginal changes following treatment; feeling undesirable due to pouch</p> <p>Retrospective desire for more information prior to surgery about potential long-term effects on intimacy</p> <p>Masturbation in place of intercourse</p> <p><i>Group 3: Life course, age-related changes in sexuality (N=3)</i></p> <p>Intercourse no longer important to maintain harmonious marital relationship – attributed to growing older</p> <p>Engagement in non-sexual acts of intimacy and love, e.g., Picking flowers for partner</p> <p><i>Group 4: No sexual experience post-surgery (participants with no partner) (N=9)</i></p> <p>Barriers to having sexual partner: perceived smell of ostomy; apprehension of potential partner's reaction</p> <p>Increased time spent on personal hygiene due to increased bowel</p>
Ruakere,	Qualitative	New	10 Māori CRC CS	

2016	Doctoral thesis	Zealand	Mean age=52.5 yrs	<p>movements; changing of undergarments due to soilage</p> <p>Preparations (e.g., extra clothes) when leaving the home</p> <p>Replace toilet paper with baby wipes after bowel motion to reduce chaffing</p> <p>Disrupted sleep due to bowel movements at night</p> <p>Try different foods & drinks to improve bowel function, e.g., reduce red meat</p> <p>Reluctance to manage personal ostomy care due to cultural issue (ostomy perceived as dirty and normal process of excreting waste from body has been altered)</p>
Shipp et al., 2015	Qualitative Occupational therapy journal	Australia	4 🏴󠁧󠁢󠁥󠁮󠁧󠁿 CRC CS >40 yrs Mean age=58 yrs	<p><i>Barriers to leisure participation:</i> Fatigue, cognitive decline, lack of motivation, body changes, environmental factors, need for close proximity of bathroom</p> <p><i>Enablers to leisure participation:</i> Positive attitude, social support</p> <p>Replacing PA (golf) with sedentary activities (reading and watching movies); gradual return to physically demanding activities following treatment</p>
Spence et al., 2011	Qualitative Cancer journal	Australia	<p>10 CRC CS completed adjuvant chemotherapy treatment within past 4 weeks.</p> <p>Mean age=57.8 yrs</p> <p>6 CC, 4 RC</p>	<p>Structured exercise programme contributed to</p> <p>Increased confidence to exercise, do ADLs, and RTW</p> <p>Increased fitness and reduced fatigue</p> <p>Improved flexibility</p> <p>Greater sense of health/well-being/control</p> <p>Increased self-esteem and positive outlook</p> <p>Development of healthy lifestyle habits, e.g., planning to maintain exercise schedule</p>

				Knowledge of importance of exercise and training techniques
				Enjoyment of regular social contact with trainer
				Importance of benefits of maintaining routine recognised
Tomruk et al., 2015	Quantitative (correlation study) Cancer journal	Turkey	42 CRC CS \geq 6 months post-treatment Mean age=60.58 (SD=9.02)	PS significant predictor of FC FC significantly correlated with QoL, PS, impact of fatigue on daily functioning, and age
Vironen et al., 2006	Quantitative (cross sectional) Colorectal disease journal	Finland	82 RC CS \geq 1 yr post curative surgery Mean age=68 yrs Median follow up time: 21M	<i>SF-36 mean scores (GP vs RC survivors):</i> PF: 74.8 vs 73.9 (p=0.79). CS 65–79 yrs 59.8 vs 71.3 (p=0.01); No differences between CS 40–64 yrs and GP. SF: 79.9 vs 68.9 (p=0.002) Comparison of surgery types (HAR – High anterior resection; LAR – Low anterior resection; APR - abdominoperineal resection) RAND 36 mean scores: PF: HAR 72.1; LAR 74.6; APR 66.0 (p=0.06) PP: HAR 46.4; LAR 57.1; APR 55.8 (p=0.8) RE: HAR 54.8; LAR 65.7; APR 59.0 (p=0.4) SF: HAR 70.6; LAR 68.9; APR 67.5 (p=0.5) Major bowel dysfunction impaired SF significantly (P = 0.05) for those who had undergone HAR and LAR compared with those without bowel dysfunction. Incontinence (p=0.02) and urgency (p=0.01) impaired SF (P = 0.01). Individuals with urinary dysfunction worse SF than patients with no urinary dysfunction

				<p>♂ <i>sexual activity:</i></p> <p>Changes in sexual function in 63% sexually active pre-surgery</p> <p>Sexual dysfunction more common after APR (87%) than after LAR or HAR (50%) (P=0.01)</p> <p>Preoperative radiation had no statistically significant effect on incidence of sexual dysfunction (P = 0.08) in ♂</p> <p>♀ <i>sexual activity:</i></p> <p>Changes in sexual function in 33% sexually active pre-surgery</p> <p>Social networks developed with other CS</p> <p>Outside activities restricted to places with familiar toilet facilities</p> <p>Permanent ostomates returning to normality through establishing and modifying daily routines; temporary ostomates putting lives on hold until reversal</p> <p>Use of pattern recognition, experimentation, manipulation of environment (e.g., keeping record of effects of foods and medication on bowel function)</p>
Wilson et al., 2010	Qualitative Colorectal disease journal	UK	<p>20 postoperative CRC CS</p> <p>Mean age=62 yrs</p> <p>9 with ostomy (6 reversed)</p>	
Yau et al., 2009	Quantitative (longitudinal study) Colorectal disease journal	UK	<p>186 RC survivors at 1- and 3-yrs post adjuvant chemotherapy completion</p> <p>93 with ostomy (46 temporary, 47 permanent) (median age=61 yrs, range 38-78)</p> <p>93 non-ostomy (median age=62 yrs, range 32-</p>	<p>EORTC SF scores at 3 yrs (permanent ostomy vs prior temporary ostomy vs no ostomy) 87 vs 87 vs 97 (P=0.009); no significant difference in other EORTC functioning domains</p>

79)

85% completed
questionnaires at 3 yrs

Key: ACS/ACSM - The American Cancer Society (ACS) and the American College of Sports Medicine (ACSM); BF -Bowel function; CC – Colon cancer; CI – Confidence Interval; CRC – Colorectal cancer; CS - Cancer survivor; EORTC – QLQ-CR30 – European Organisation for Research and Treatment of Cancer – Quality of life of cancer patients questionnaire; EORTC QLQ-CR38 - European Organisation for Research and Treatment of Cancer – Quality of life questionnaire, Colorectal cancer module; FACT-C – Functional Assessment of Cancer Therapy – Colorectal Cancer; FC - Functional capacity; GP – General population; HRQL – Health related quality of life; M – Months; PA – Physical activity; PF – Physical functioning; PS – Performance status; QoL – Quality of Life; RC – Rectal cancer; RF – Role functioning; RTW – Return to work; SD - Standard Deviation; SF – Social functioning; SF-12 – RAND 12-item Short Form Survey Instrument; SF-36 – RAND 36-item Short Form Survey Instrument; ♀ - Female; ♂ - Male

Discussion and implications for occupational therapy

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

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

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

Firstly, occupational therapy input could be initiated as soon as a bowel cancer diagnosis is received, facilitating the building of early therapeutic relationships which can be continued throughout treatment and beyond (Buckland & Mackenzie, 2017). An already developed rapport and continuing support from a trusted occupational therapist could reduce feelings of vulnerability and abandonment at the conclusion of treatment

and contribute to open communication – a key issue in improving well-being for survivors (Drury et al., 2017). In addition, occupational performance issues can be identified and addressed immediately, potentially reducing functional decline and the resultant impact on occupational participation (Buckland & Mackenzie, 2017; Cabilan & Hines, 2017). Review findings highlight the unique challenges and issues of bowel cancer survivors, knowledge which when combined with early and effective occupational therapy input can optimise patient support, minimise impact on daily life, and better identify those who may be at greater risk of reduced functioning and, therefore, benefit from therapy.

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

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

Further research

Occupational therapy can undoubtedly benefit bowel cancer survivors, but current input is limited. This is possibly due to a lack of research into the disease's impact on occupations and specific strategies to manage those impacts, thus resulting in occupational therapists being ill-equipped to gain a role in this field. The fact that this review generated 33 publications, only one of which was authored by occupational

therapists (Shipp et al., 2015) highlights this discrepancy. Further research could focus specifically on occupational impacts for bowel cancer survivors. Enhanced knowledge of occupational engagement for bowel cancer survivors would enable therapists to view their clients as occupational beings and use occupation therapeutically (Hocking, 2009). Findings could help define the role of occupational therapy within bowel cancer survivorship and recommend potential interventions to improve participation.

Limitations

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

Conclusion

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

Key findings

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

What the study has added

This review identified six domains of occupation that are impacted by bowel cancer (social activity, physical activity, sexual activity, employment and role functioning, physical functioning, and self-care) but survivors report a distinct lack of health professional support after completion of medical treatment and being left to devise self-

management strategies to accommodate the long-term effects of their cancer. The sequelae of bowel cancer can have a significant impact on occupational participation. There is scope for increasing and improving occupational therapy input to assist people with cancer-related loss of function to re-engage in valued occupations and improve well-being

CHAPTER FOUR: DOING, BEING, BECOMING, AND BELONGING: EXPERIENCES TRANSITIONING FROM BOWEL CANCER PATIENT TO SURVIVOR

Prelude to Manuscript Two

The previous chapter outlined the current knowledge regarding the impact of bowel cancer on occupations. This information was used to inform Phase Two of the study, which involved analysis of data collected during interviews with bowel cancer survivors, and is presented in the following chapter largely consisting of an article published in the Journal of Occupational Science (Martin et al., 2020a). The manuscript version that appears here includes additional critique of the cited literature.

The scoping review findings helped inform Phase Two by filling my knowledge gaps and enabling movement beyond my own experiences and preconceptions. For example, I had no experience of living with an ostomy, or the faecal incontinence commonplace amongst many bowel cancer survivors. In addition, the decline in functioning reported for a significant period post-treatment, correlated with advancing age, emphasised the relevance of being diagnosed at the relatively young age of 46. I would consider I was back to my pre-cancer levels of function within months of treatment conclusion, and the review highlighted how this was not the case for many others, particularly those at a later stage of life. Other findings reinforced my understanding with the reporting of aspects that I personally experienced. For example, when travelling, I always like to have access to my own bathroom, a situation similarly reported in the literature. Both the qualitative and quantitative research aided in expanding my understanding, with participant quotes in the qualitative studies emphasising the personal impact of bowel cancer and the statistics quoted in the quantitative studies spotlighting the extent of the identified issues.

This new knowledge was used when developing the questions in the interview guide used in Phase Two. For example, a theme identified in the scoping review recognised changes in 'social activity,' which was addressed specifically as a general question using this term, and additionally one related to relationships. Furthermore, the scoping review identified adaptations in how occupations were carried out. This area was included in the interview questions when participants were asked if they do things differently to accommodate ongoing effects.

The findings presented in this chapter are discussed in terms of occupational transitions, the relevance of which to bowel cancer survivors became apparent during

data collection and analysis. Participants talked of negotiating the change from the health professional regulated treatment period to the independently managed post-treatment phase and articulated how they negotiated this transition. Alignment to the occupational science concepts of doing, being, becoming, and belonging is also discussed. As I talked with participants and analysed their words, I recognised the prominence of these four dimensions within both their actions and thoughts. On further reading, I was able to make more connections and extend my thinking regarding the interweaving of these concepts within the lives of my participants. This approach enabled in-depth consideration of what bowel cancer survivorship looked and felt like for my participants when considered as occupational beings.

Introduction

Occupational transitions involve movement from one life phase, condition, or status to another (Scalzo et al., 2016). They are a normal part of life (Christiansen & Townsend, 2010), affecting people's identity and life course (Walder & Molineux, 2017), and are thus worthy of study. Bowel cancer is the fourth most common cancer worldwide (Rawla et al., 2019) and increasing survivorship (Hawkins et al., 2015; Husson et al., 2015; Lee et al., 2015) offers an opportunity to study sudden and unexpected transitions associated with life threatening illness and the associated changes in body structures and functions. This article explores the occupational impact of transitioning from bowel cancer patient to survivor. There is disparity concerning when an individual becomes a survivor, with definitions beginning at diagnosis, end of treatment, or after a disease-free period (Drury et al., 2017); in this study the term refers to those who have completed cancer treatment.

There is evidence to support the idea that there is a significant occupational impact on people who transition from bowel cancer patient to survivor. A scoping review exploring how people's occupations were affected by that transition revealed social occupations, physical activity levels and physical capacity to engage in occupation, sexual activity, self-care, employment, and role functioning were all impacted (Martin et al., 2020b). As indicated by these examples, much emphasis in literature and the media is given to the 'doing' of survival, including the 'battle' to carry on living. However, little literature addresses the impact on a person's being, their sense of belonging, and who they can become as a consequence of those shifts in occupational engagement.

These concepts of doing, being, becoming, and belonging were first introduced by Ann Wilcock (1998, 2006). Since their inception, they have consistently been referred to and included in occupational science and occupational therapy literature, as demonstrated by the review of their use (Hitch et al., 2014a). In their critical analysis exploring the four concepts, the authors utilised the Integrating Theory, Evidence, and Action (ITEA) method in order to embrace theoretical constructs, a diverse range of evidence, and practice. One hundred and six sources were located – including 80 peer reviewed journal articles, 16 theses, eight books, and two other documents – which were considered to contribute to the understanding of doing, being, becoming, and belonging. Some of the sources included in Hitch et al.'s analysis (2014a) relate to specific conditions, including cancer. For example, Palmadottir (2010) identified a sense of belonging to a rehabilitation centre for Icelandic breast cancer survivors, and La Cour (2008) identified how experiencing new challenges was vital to becoming for people with advanced cancer. Other sources cited by Hitch et al. (2014a) relate to occupational transitions. For example, Lala and Kinsella, (2011) discussed the

importance of transitions over time to becoming, Pickens et al. (2010) highlighted the continuous reaction and adjustment involved in becoming, with Schwartzman et al. (2006) commenting how these transitions can be both healthy and unhealthy.

Doing, being, becoming, and belonging have been interpreted to be continuously interlinking concepts that reside within each individual (Hitch, 2017) and occur through occupation (Taff et al., 2018). **Doing** has been described as the way people engage in personally meaningful occupations (Hitch et al., 2014a). It is often associated with action and behaviour and considers the participation in, and performance of, an occupation (Hitch et al., 2018; Hitch & Pépin, 2020). Doing can be visible or tacit (Hitch et al., 2014a; Taff et al., 2018), impacted by external factors (Kay & Brewis, 2017), and adapted to accommodate personal circumstances (Hitch, 2017).

Feelings individuals experience through their doing inform their sense of self and identity and, therefore, their **being** (Gallagher et al., 2015; Kay & Brewis, 2017). This dimension of occupation involves the state of existing and is determined by the interests and needs of individuals (Wilcock & Hocking, 2015). Being is conveyed through an individual's creativity and roles (Hitch, 2017; Taff et al., 2018), and although associated with agency, choices are not always possible (Hitch, 2017). In addition, being allows people to recognize their uniqueness, and as a result be true to themselves (Gallagher et al., 2015). Closely aligned to being is spirituality, a concept credited with enabling well-being through providing a sense of purpose and meaning (Hitch & Pépin, 2020).

The concept of **becoming** adds a future perspective to the notions of doing, being and belonging (Wilcock & Hocking, 2015) and refers to the continual development and growth of an individual as they change and progress during a lifetime (Hitch, 2017; Kay & Brewis, 2017). This growth is driven by goals and ambitions that may alter and be revisited over time, emerge through both choice or necessity, and be inspired by new circumstances and challenges (Hitch, 2017). A person's becoming is unique and synonymous with their occupational potential, as they strive to become the person they have the potential to be (Wicks, 2005). For each individual, personal and environmental factors influence the route their occupational potential takes, making it an unpredictable "fluid phenomenon" (Asaba & Wicks, 2010, p. 122).

Belonging pertains to the development of relationships with family, friends, organisations, or communities as people engage in occupations alongside – or for the benefit of – others (Wilcock & Hocking, 2015). As a result, individuals experience a sense of connection to places, people, communities, cultures, and times (Hitch, 2017). Relationships with these elements can take place simultaneously, be experienced

positively or negatively, and involve a sense of reciprocity and contributing to others (Hitch, 2017; Kay & Brewis, 2017). Belonging contributes to a person's own identity within a group of other people. As relationships are formed, shared identity and sense of purpose can be developed, as individuals establish a sense of who they are through interactions with others.

Doing, being, becoming, and belonging are interrelated and constantly interacting (Hitch et al., 2014b; Wilcock & Hocking, 2015). However, the influence of each dimension is not equal at any one time and varies depending on occupational characteristics, personal meaning, and environmental factors (Hitch, 2017). This dynamic interaction has a significant effect on health, and consequently where an individual is positioned on a well-being continuum at a certain point of their life (Gallagher et al., 2015; Hitch, 2017; Hitch & Pépin, 2020). Hitch and Pépin (2020) suggested this continuum covers a range from ill-being to well-being and represents the perceived outcome from occupational engagement. Individuals travel towards the negative end of the continuum when there is dysfunction or disruption in occupational domains. The present study considered where bowel cancer survivors saw themselves on this continuum and the impact their experiences had on that positioning. The aim of the study was to explore the subjective experience of surviving bowel cancer, with the goal of generating new knowledge of the occupational impacts of this transition. The research question addressed was: How does surviving bowel cancer affect people's occupations?

Methodology

Qualitative research explores human behaviour, motives, views, and barriers (Neergaard et al., 2009), and gains the view or perspective of a sample group (Stanley & Nayar, 2014); in this case people whose everyday lives have been affected by bowel cancer. We used an interpretive description, qualitative methodology (Thorne, 2016), an inductive analytic approach that explores phenomena from participants' viewpoint, combined with a contextual inquiry (McQuestion & Fitch, 2016), to generate a thematic description of a phenomenon (Thorne, 2016). Rather than offering a discrete method, ID provides a methodology that allows the researcher room to interpret or explain, capturing themes and patterns determined by the subjective views of the researchers (Thorne et al., 2004). Qualitative description methodology is underpinned by a constructivist worldview (Hunt, 2009), whereby individuals construct knowledge and experiences through social interaction (Constantino, 2008) and subjective meanings of experiences are developed (Cresswell, 2014). The constructivist worldview also recognizes that the researchers' own backgrounds shape their interpretation, as they

position themselves within the study. As a result, researcher understanding is co-constructed with that of the participants (Hunt, 2009; Thorne et al., 2004), as assumptions and preconceptions that may influence the research are made visible (Hunt, 2009). This transparency was particularly relevant given the first author (EM) has a personal experience of treatment for bowel cancer and its impact on occupations. Reflexivity was employed throughout this research, allowing her to consider and acknowledge how those experiences might impact her reactions, attitudes, feelings, and perceptions (Foster, 2009; Moore, 2015). This process reduced the potential for bias due to preconceived ideas, and ensured the research was oriented toward participants' experiences (Foster, 2009; Merriam & Tisdell, 2016).

Research Design

Ethical considerations

Ethical approval was received from the Auckland University of Technology Ethics Committee (Reference 18/411) and the first author's local, publicly funded hospital – where she has been a patient and employee – that agreed to be a recruitment site.

Participant recruitment and data gathering

Adult New Zealanders who had completed treatment for bowel cancer more than three months prior were recruited through the authors' personal and professional networks, which included local hospital staff. A flyer advertising the research was emailed, posted, or delivered by hand to potential participants. The flyer alerted participants to EM's status as a bowel cancer survivor. Those expressing an interest in taking part were then provided with an information sheet explaining the research in full.

Participants were offered the opportunity to have partners and/or family members contribute to the interview. This was designed to hear multiple perspectives of the diagnosed individual and those likely to be impacted by changed occupational needs and routines and reveal contextual nuances and a richer understanding (Abma & Stake, 2014). A consent form was signed by all participants prior to collecting data from them.

Participants were offered the option of an interview face-to-face in a mutually agreed upon location, or a telephone or video call. Interviews were semi-structured, ranged from 30 to 100 minutes in duration, and used open ended questions following a topical interview guide (Hunt, 2009) (Appendix D). Prior to interview commencement, the interviewer (EM) reminded participants of her insider status. This helped develop rapport and aided with balancing the power differential, which can be present in researcher/participant interactions (Moore, 2015). This experiential base and identity shared with participants helped to facilitate greater acceptance and openness and

may, therefore, generate richer data (Dwyer & Buckle, 2009; Hayfield & Huxley, 2015). Participants may have been more prepared to reveal experiences due to an assumption of shared understanding (Dwyer & Buckle, 2009).

Data management and analysis

Audio recorded interview data were transcribed verbatim to facilitate accuracy and ensure authenticity and scientific and ethical integrity (Noble & Smith, 2015).

Participant names were changed to pseudonyms at the transcription stage to ensure anonymity. Analysis was based on three strategies: Concurrent data collection and analysis, constant comparative analysis, and iterative analysis (Thorne, 2016).

Following these approaches ensured data collection and analysis informed each other, and that the shape and direction of the inquiry evolved as new possibilities arose and were considered.

Analysis of transcripts was initiated as the transcription of each interview was completed, to allow insights developed during interviews to be incorporated into the ongoing data collection (Grattan et al., 2018; Hunt, 2009). Thematic analysis was employed to identify common themes and patterns within the subjective perceptions of the participants (Berterö, 2015; Hunt, 2009; Thorne et al., 2004). Triangulation of author perspectives was achieved by comparing the initial coding of the first two authors. Emerging codes were then discussed by all authors in repeated meetings where potential themes were identified. Analysis focused on broad questions – such as “What is going on here?” or “What am I learning about this?” (Hunt, 2009), to ensure the contextual nature of the data was respected (Thorne et al., 2004) and an understanding of the whole picture was obtained. This breadth, rather than line-by-line, approach permitted groups of data bearing similar characteristics to be examined and re-examined for a range of alternatives (Thorne et al., 2004). Throughout data analysis a reflexive journal was kept by the first author. The documentation of what was occurring subjectively and conceptually became a core element, informing the inductive data collection and analysis, and enabling an appreciation of the implications of her role in the process (Thorne, 2016).

Following analysis of the initial seven transcripts, recruitment was paused and preliminary themes identified. To enrich the data, these themes formed the focus of the final four interviews to enable new participants to interpret what had been previously said, as well as adding their own experiences. This process is in keeping with the iterative nature of ID.

Results

Fifteen participants were recruited (including four spouses), varying in age from 42 to 92 years. They covered a range of dwelling types, activity levels, and tumour stages. Both female and male survivors were recruited, some with a stoma and some without. Table 5 illustrates participant demographics. Following data analysis, three themes were identified – “I had to heal myself”, “Life’s too short”, and “The person I’ve become”. Each theme is discussed below.

Table 5: Demographics of participants

Pseudonym	Sex	Age	Bowel cancer stage	Time since treatment conclusion	Ostomy status	Activity level*	Rural°/urban#
Julie	Female	92	1	20+ years	None	a	Urban
June	Female	68	3	13 years	Reversed	b	Urban
Sarah	Female	42	3	4 years	Reversed	c	Urban
Stella	Female	67	3	1 year	Permanent	c	Urban
Cecilia	Female	57	4	2 years	None	a	Rural
Andrew (and wife, Kathryn)	Male	63	2	9 months	None	b	Rural
James (and wife, Donna)	Male	58	3	4 months	None	b	Urban
Ray	Male	66	3	18 months	Reversed	c	Rural
Will (and wife, Mary)	Male	43	1	3 months	Reversed	b	Urban
Merina (and husband, Robert).	Female	80	3	2 years	Permanent	a	Urban
Maia	Female	61	3	2 years	Permanent	a	Urban

* Active/sedentary – a) Sedentary: a lifestyle that includes only the light physical activity associated with typical day-to-day life, b) Moderately active: a lifestyle that includes at least 2 ½ hours of moderate or 1 ¼ hours of vigorous physical activity spread throughout the week, c) Active: a lifestyle that includes 5 hours of moderate or 2 ½ hours of vigorous physical activity spread throughout the week

° Rural areas with moderate urban influence

Independent urban communities

Themes

“I had to heal myself”

With the stepping back of health professional involvement, participants acknowledged and acted on a sense of self-determination in their recovery: *“Once I left the hospital, I knew I had to heal myself”* (Maia). This healing involved both existential and practical aspects. Participants learned individually significant lessons from their cancer journey, which they made use of as they *“got on”* with the business of their new lives.

Participants often, independent from health professionals, used a trial-and-error process to heal themselves, particularly regarding food, noting that *“the dietary thing's huge”* (June). They moved away from foods they self-identified as cancer causing and towards a diet they felt may bolster health, consuming *“a lot more vegetables and stuff like that”* (Donna) and *“virtually cutting out sugar”* (Andrew). In addition, reducing meat was seen as critical to a continued recovery as *“that's what a lot of people have said you should do”* (Donna), *“some people talk about a link between cancer and meat”* (Andrew), and *“pork is causing bowel cancer”* (Maia).

In addition, exercise engagement was seen as health promoting for both mental and physical reasons, being identified as *“so good for the head”* and *“a real form of therapy”* (Stella). Exercise was seen as a metaphor for cancer survivorship and coping with future uncertainty: *“If I can keep pushing forward, I might run faster than the cancer can come back”* (Sarah). In addition, June found exercise beneficial when dealing with her sense of abandonment at the end of treatment: *“The thing I've found the most helpful is exercise.”*

Some participants found that they were assisted on their path of self-healing by helping others. For June and Sarah this involved taking on a new role of consumer representative for cancer research organisations. They described how the role entailed sitting on various committees and looking at *“all those silly questions about treatment that clinicians and researchers don't think about”* (Sarah). Sarah explained her reasons for taking on the role:

It's a way of me giving back. I'm not going to cure it, and I'm not going to save the world ... but if I can make a change for someone ... then it hasn't been all in vain ... there needs to be something coming out of it.

Both consumer representatives acknowledged the personal benefit and enjoyment they experienced from helping others with Sarah expressing, *“I really enjoy it”*, and June admitting, *“I became a cancer consumer rep for my own benefit, as well as trying to benefit other people”* adding, *“it gave me confidence, dealing at a higher level of people on the Cancer Society, the doctors and people”*.

An important aspect of healing was to minimise the emotional and physical impact of cancer pulling participants away from desirable and enjoyable occupations, with self-reliance and self-determination used to demonstrate a sense of strength: *“If I couldn’t do it, then I’d just have to do it”* (Julie); *“You just have to manage ... you learn to cope and get by”* (June); *“[I] carried on”* (Cecilia, Julie, Stella, Donna, Merina, Robert); *“I tried to maintain life”* (Stella) *“as best you can”* (June, Stella). The need to carry on was reinforced by spousal and society expectations: *“He had a cancer. It’s been taken out. It’s time to carry on”* (Donna). Expectations were also internal, with a sense of personal responsibility to make the best of their life, especially when others did not survive: *“If I sat back and did nothing, then I’m wasting what I’ve been given”* (Sarah). This was sometimes taken to the extreme, with Sarah training for a 72km ultramarathon, proudly declaring, *“if I have to drag my butt round and do it, I will”*. In addition, James planned to complete an 84km cycle ride acknowledging, *“that’s something that we probably wouldn’t normally do”*.

A heightened sense of spirituality was also evident from participants, with some viewing cancer as *“a messenger”* (Cecilia) or teacher for their own or others’ spiritual well-being. This outlook is illustrated by Cecilia’s response when her cancer returned: *“By the time it came back, grrr... I thought, ‘What lessons have I not learned?’”* For Stella, a bowel cancer diagnosis followed an earlier metastatic melanoma, prompting her to ask, *“So, getting this cancer it was ‘Why now? What’s this all about? What’s the purpose involved in this?’”* Maia also found reason in her cancer, *“I look on it like I was meant to go through this,”* adding *“In a way I guess that’s why my tūpuna [Māori ancestors] made me slow down and getting this [cancer] in a funny way ... it did help to really slow me down to really, really think about things”*. Observing others’ experiences with cancer was also viewed through a spiritual lens. When speaking of her relationship with a fellow bowel cancer patient Cecilia reported:

Matt, he had his last relapse, and I’d go and visit him, and honestly, I don’t know whether you want to call it a guardian angel, or you want to call it the Holy Spirit, or a spirit guide. Whatever you want to call it, they were speaking so strongly to me, ‘You learn the lessons, or this is how you’re going to go’.

“Life’s too short”

After treatment, participants re-evaluated what was important to them and expressed a new belief that life was *“too short”* (James, Sarah) to spend time on things which did not enhance their lives. Instead, they thought *“carefully about where you are in life”* (Andrew) and made the decision to *“make the most of what you’ve got”* (Ray) because *“there’s things that you don’t want to miss out on”* (James).

The threat of a potentially foreshortened future made participants selective of their time, often putting their needs and wants ahead of others: *"If I want to do something, I'll go and do it. If I don't want to do something, I'm not going to do it for the sake of making everyone else happy"* (Sarah). The importance of self-prioritisation meant that participants would tolerate a sense of discomfort: *"If somebody wants my help, then they have to ask for it. And I find that really hard to accept ... because I like to be there for other people"* (Cecilia). Maia also found it hard to take a step back from helping other people: *"It [cancer] did help to really slow me down to really, really think about things, prioritising myself"*.

With their newfound realisation that life could be cut short at any time, participants devoted more quality time to family, with Will recognising *"we do a lot with the kids now.... You want to show them the country and spend a bit of time with them."* Merina articulated that *"for me, it's my family. That's my priority."* She verbalised her gratitude at still being around to gain pleasure from her extended family: *"I can still enjoy my great-grandchildren, and my grandchildren, however naughty they might be."*

The quality of interpersonal relationships was also evident in the changes participants reported in their friendship groups. They exhibited a desire to move towards things that gave life value, such as expending energy on fostering deep friendships, and distancing from superficial or energy draining relationships. June's bowel cancer experience had *"made [her] put up a few walls"*, with only a select group of people retained. Participants had a conflicted relationship with having fellow survivors as friends after finishing their treatment:

I knew some of them were going to die and if I allowed myself to get down because of them, it could affect my health and I chose not to keep in touch with them at that time because you have to look after yourselfthere are other things you need to prioritise. (Maia)

Conversely, Sarah found insider understanding and friendship from another cancer patient she met online: *"She was three months ahead of me. We both had this, 'Right, we're going to do this'. We egged each other through the last three months of chemo. We chortled each other along"; "So, we had these things that normal people would think were a bit mad, but that was good to see that"*. The shared understanding between survivors meant that Sarah did not have to expend energy explaining what it was like to receive chemotherapy, or defend actions possibly viewed by non-survivors as extreme or inappropriate.

Furthermore, participants felt they had defeated death and were hugely appreciative of the chance to *"have another go at life"* (Merina), when others had not: *"I'm very aware of how my mother was, and four of my brothers, who died of cancerous conditions, and*

how lucky I am" (Merina). Although Ray struggled with the after-effects of his treatment, he admitted that these difficulties paled in comparison with losing his life: *"It could be better, but it could be a lot worse too, eh. I could be dead."* This belief endured with Julie who, more than 20 years since her cancer, commented, *"I still think I'm fortunate"*.

"The person I've become"

Participants felt different to their pre-cancer self. They related pronounced changes in their behaviour when compared to their pre-cancer character, such as their reactions to everyday situations. These were often considered permanent, with some regarded as unwelcome, and others positive. Participants pushed away sympathy, rejecting the feeling of being unwell, *"sick"* or vulnerable and in need of additional protection. They vehemently expressed how they did not want people feeling sorry for them or to use cancer as an excuse for not carrying out their chosen occupations:

I didn't need the sympathy card. I did not want anything like that.... It doesn't stop you doing anything. I don't really use it as a lever for anything, or something that I can't do. (Stella)

I've got no excuse not to do anything. (Sarah)

Rejection of sympathy was particularly discussed in relation to well-meaning family and friends. Ray described how some friends had *"become like mother hens and ... a bit annoying sometimes"* as they fussed over what food he could eat. *"It's embarrassing really because there's no need for it. I mean, if they didn't know I was sick they wouldn't do it."* Disassociating from the sick role, Ray proclaimed *"I'm not sick really. I'm just not normal"*.

Participants wanted to engage in meaningful occupations without being treated differently by others. For this reason, Stella chose to initially not reveal her cancer diagnosis to her work colleagues: *"So many people hear about bowel cancer and immediately you've got the funeral dress ready and all the rest of it, and I just thought I don't need it and I don't need it to be dramatized"*. Stella further expanded on her desire to be distanced from the sick role: *"I wanted my life to carry on as normal. I didn't want my time off work to be associated with illness."* June also expressed pride in working throughout the time when she was receiving chemotherapy, *"I'd managed to get through 12 weeks of chemo and was one day off work"*. Participants did not want their cancer to shape them and instead chose to see themselves as strong and able to continue with their life without playing *"the cancer card"* (Sarah); *"I wasn't trying to be a superhero or anything like that, I just didn't need illness to define me. It is what it is, isn't it?"* (Stella).

Participants observed the internal pressure from a cancer diagnosis to put on a brave face, along with the external pressure to be positive. June reported, *"People are constantly telling you to not be negative"* and admitted, *"you try and be strong for other people, not necessarily for yourself."* Any visible let up in the fight, through perceived weakness, could be viewed as losing the battle and letting the cancer win. This 'carrying on' had its drawbacks, with Stella describing the resultant emotional impact:

It wasn't until Christmas time when we had some time off, I was just sitting talking with my sister about everything and nothing and we were both recapping about the year and what it had been like and I was in tears. And I said, 'Oh my gosh, I think it's all just caught up with me'. So, I think it was more about I had been – not in denial – but I had just carried on and absorbed it and tried to maintain life as best I can.

This emotional response illustrates how cancer had indeed affected her, something she had not recognised previously. In addition, participants revealed a reluctance to acknowledge the emotional impact of a cancer diagnosis and subsequent treatment, for fear of being viewed as vulnerable, weak, or unable to cope:

I'm pretty good at being able to put the face on and just go and do it, and then on the inside be falling to pieces, and sit in the car and have a really good cry. (Sarah)

[My daughter] used to say to me, 'how are you feeling?' and I used to think 'I can't be bothered talking about feelings'. (Stella)

Participants were also constantly alert to the possibility of cancer recurrence, which generated a relentless, underlying sense of danger, leaving them far more vigilant to how their body was functioning. Even a minor *"little niggle"* (Julie) could prompt a rapid and intense anxiety response with the overwhelming thought *"Oh my god, is it back?"* (June). Andrew went so far to admit that he was *"terrified"* of recurrence, adding *"I'm very, very alive to the possibility that we've been there, and it can come back again"*. June described the resultant state of mind as *"existential angst"*, a feeling epitomised by James who continually asked himself *"Have they got it all out? Did they get it all?"* James' wife, Donna, described how *"If he got sick, I think he'd worry. If you've got a sore stomach, I think you worry"*.

Living with constant uneasiness meant that previously inconsequential matters took on increased significance than they had pre-cancer, with anxiety triggered by *"little things"* (Donna) and *"weird things, silly things, not just the woes of the world"* (Sarah). Sarah further acknowledged *"I never would have thought that, previously. I'd just keep going, and just go and do stuff ... This is ridiculous. I'm [normally] quite a confident, ballsy person"*.

Moreover, participants spoke of a change in their interpersonal style in everyday life, with direct and forthright communication, and a lowered tolerance for perceived trivial matters being common: *“I am more straight up now ... I definitely carry a bit of attitude”* (Cecilia); *“My filter’s broken ... I don’t have a filter now ... I’m not rude, I just don’t put up with bullshit”* (Will). Participants described lower empathy towards other people’s worries that were perceived as minor in comparison to their own experiences of cancer treatment: *“If I’ve spent the whole day faffing around with someone crying because they’ve lost their teabag, or they’ve gained a kilo of weight, that’s going to piss me off”* (Sarah). This annoyance with others resulted in heightened irritability as participants could now get *“annoyed real quick”* (James) and *“really, really angry”* (Maia), resulting in them being *“really, really nasty”* (Maia). The change in persona experienced is summed up by Cecilia who admitted she *“rather liked the person [she] was before”*, adding *“I haven’t grown enough to like the person that I have become”*.

Discussion

Participants in this study found themselves at various points on the well-being continuum as they transitioned to bowel cancer survivor. Their positioning was firstly influenced by the dynamic, interlinking relationship of their doing, being, becoming, and belonging (Wilcock, 1998, 2006), with these dimensions particularly shaping the existential aspects of emotional and mental well-being. This is especially relevant considering the study was based in bicultural Aotearoa/ New Zealand where emotional, mental, spiritual, and social well-being are deemed equally as important as physical health (MOH, 2017a). Secondly, they correspond with the experiences of others whose occupational transitions have been influenced by life changing illness or injury (Scalzo, 2016; Walder & Molineux, 2017).

Doing

The dimension of doing is often characterised as “active”, with actions frequently outwardly visible (Hitch et al., 2014a; Taff et al., 2018). Outwardly noticeable doing was evidenced in this study through the lifestyle changes participants made. Their diet and exercise adjustments were both in keeping with guidelines promoted by governments (MOH, 2020a) and the World Health Organization (2004) and influenced by the abundance of information in the media extolling the benefits of a healthy lifestyle. The advantages of being physically active and avoiding perceived cancer-inducing foods were ardently acclaimed by participants, with huge advantages identified in regulating both body and mind. Dealing with a cancer diagnosis – along with the subsequent treatment and ongoing recovery – brings with it a myriad of emotional and mental

struggles. Engagement in physical activity provided one pathway for facing and overcoming these difficulties.

Doing can also be tacit and include mental and spiritual aspects (Hitch et al., 2014a; Taff et al., 2018). In this study tacit doing included worrying about recurrence, contributing to increased anxiety. This is a common feature of the transition following illness or injury as people adjust to living with future uncertainty (Hack & Degner, 2004; Scalzo et al., 2016). Tacit doing also included the rejection of sympathy and the perception of being vulnerable and in need of help. In keeping with prevailing societal messages about taking personal responsibility for health, participants instead wanted to be viewed as strong and independent. By carrying on with their everyday round of occupations, no matter what they were up against, they were conforming to the commonly recognised persona of a battling cancer survivor not allowing cancer to win.

A common goal was to resume previous role performance through independently managing household tasks despite the debilitating effects of illness. Such behaviour can help develop self-esteem and a sense of purpose (Scalzo et al., 2016). Combined with finding new occupations, this doing contributed to self-discovery (Walder & Molineux, 2017) and participants' sense of being, and aided transitions (Scalzo et al., 2016).

Existential and cultural factors also influenced doing for health. Within New Zealand the holistic Māori model of health, Te Whare Tapa Whā, uses the analogy of four walls of a house to illustrate the four dimensions of well-being – whānau (family health), tinana (physical health), hinengaro (mental health) and wairua (spiritual health) (MOH, 2017a). All four areas are clearly represented in the findings, capturing the existential aspect of both doing and the associated dimension of being.

Being

Being allows individuals to plan and envision a future, but being diagnosed with bowel cancer unexpectedly put participants' dreams and plans on hold as they became acutely aware of their own mortality and the possibility that their future may be foreshortened. Being also incorporates the reflective aspect of occupation, enabling people to become keenly aware of their thoughts and feelings. This was clear for participants who reflected on their current life in terms of how they spent their time, what they wanted to do in the future, and who they wanted to become. A re-evaluation of values and what was important enabled participants to put what had happened to them into perspective, affecting the occupations they chose to engage in (Walder & Molineux, 2017). Being also enhances a sense of self, on occasion exhibited by a sense of self-discovery (Lyons et al., 2002), demonstrated by participants' realisation

and acknowledgment of the changes in their persona, i.e., the person they had now become.

The fact participants acknowledged changes in their attitudes and behaviour suggests they were remaining faithful to their true selves (Hitch et al., 2014a). However, the question arises whether they are genuinely faithful to themselves when spurning sympathy and being determined to carry on independently. Rather, is this behaviour influenced by the image of the strong cancer survivor beating the disease that is propagated by Western society? The individualistic viewpoint also contrasts with the spiritual view some participants had of their lives, with their cancer beyond their control. They made sense of what had happened to them in terms of a wider context of life (Jim et al., 2006; Maley et al., 2016), finding a rationale for their cancer and believing it had occurred for a reason. This in turn helped them develop the confidence to engage in new occupations (Walder & Molineux, 2017).

For some participants, this belief gave them a sense of peace and reduced the fear associated with cancer; they were able to justify why they had developed bowel cancer and rationalise its occurrence. Despite peace being a distinct facet of being (Wilcock & Hocking, 2015), this was not something experienced by all participants as they came to terms with these changes. They found themselves to be easily irritated, short tempered, fearful, and with heightened anxiety, all unwelcome emotions which can decelerate the transition process (Scalzo et al., 2016).

In addition, people are ideally able to exercise choice in their expression of being, but this is not always possible. This is demonstrated by participants' admission that they at times covered up how they were feeling, a coping strategy reportedly employed by older New Zealanders when faced with negative emotions (Andrew & Dulin, 2007). This reluctance to reveal emotions could contribute, perhaps subconsciously, to the attitude that sympathy and excessive compassion are neither desired nor encouraged due to the possibility of bringing to light uncomfortable emotions such as vulnerability, fear, and despair. Moreover, participants sometimes did not realise their true feelings until they were exposed through communication with loved ones. With the exposure of these emotions came the realisation and acceptance that cancer has indeed impacted and changed them. Participants were, therefore, still working towards establishing emotional stability following their cancer, an important step towards engagement in occupations (Walder & Molineux, 2017).

Wilcock (1998) suggested "a dynamic balance between doing and being is central to healthy living and wellness, and how becoming whatever a person, or a community, is best fitted to become is dependent on both" (p. 248). This study's findings demonstrate

the impact when this balance is affected by illness. When this is the case, doing and being can change quickly, as can hopes and aspirations for the future (Hitch et al., 2014b). The result is a negative impact on well-being, with survivors consequently becoming something they did not envisage or welcome.

Becoming

The interaction between being and becoming can fluctuate greatly, as demonstrated by the coexistence of the diverse emotions participants experienced. They spoke with pride of their strength, but also expressed embarrassment at their perceived weakness and increased anxiety; they suppressed fears but were also hypervigilant of recurrence; they hid their emotions from others, and yet on other occasions were openly irritated and straight talking. These emotions resulted in participants becoming someone different, as evidenced by the unfavourable ways they described themselves as angry, annoyed, abrupt, and nasty. In contrast, when the relationship between being and becoming is positive it can be “the site of powerful human experiences, which draw together who people are and who they can be” (Hitch et al., 2014b, p. 252). This is evident in the feelings of self-efficacy experienced by participants when they recognised their inner strength and conquered fears to engage/reengage in their favoured occupations. They were empowered and saw themselves as resilient enough to conquer challenges and barriers (Walder & Molineux, 2017) and, therefore, more likely to realise their occupational potential (Wicks, 2005).

The fluctuating being of participants illustrates how becoming is an ongoing process across a lifetime as people are constantly becoming different (Wilcock & Hocking, 2015). Occupational goals are continually formed and changed. For those experiencing illness or injury, unexpected and unimagined goals may be thrust upon them, influencing their being and subsequently the person they become. Participants in this study did not choose bowel cancer but had to rapidly change their lives to accommodate it, which in the process changed who they became. Wilcock (1998) spoke of how becoming aims for the best outcome and highest potential. Individuals who can travel a steady pathway while striving to achieve this potential are more likely to feel helpful feelings (Wilcock & Hocking, 2015). Participants in this study were knocked off their pathway by bowel cancer, contributing to the unwelcome feelings and personality traits they reported. Suddenly a distinct gap had developed between occupational goals and achievements (Hitch et al., 2014a).

However, the process of becoming involves growth as well as decline (Wilcock & Hocking, 2015). Occupations that demonstrate growth – with positive actions and goals – were also evident in participant accounts. Learning and engaging in new occupations helps individuals change and become different (Lyons et al., 2002). Participants

exhibited a drive towards more challenging occupations, demonstrating a desire to make use of the time they had and not let life's experiences pass them by. They had had a major severance in their life story but were looking forward and exploring new ideas and possibilities. They had reflected on their values and set priorities for occupations that mattered most (Hammell, 2004; Wright-St Clair, 2003), in a determined effort to regain direction in their lives and attempt to overcome negative feelings (Scalzo et al., 2016). The ability to think in a future-oriented way enhanced the desire and capability to explore new occupations and limited the negative effects of the illness (Scalzo et al., 2016; Walder & Molineux, 2017). This is evidenced by participants seeing themselves as more fortunate than others and recognising the benefits gained from their cancer experience. As a result, they saw it as an opportunity for learning and growth (Jim, 2006; Walder & Molineux, 2017). Their priorities about what to do with their lives had changed. For example, they found they no longer wanted to dedicate their lives to their work or to pleasing other people. Instead, other occupations – such as helping others in a similar situation or participating in more extreme physical challenges – took on new importance. These occupations had not previously been an element of who they were, and through engaging in them participants made deliberate choices about becoming someone quite different.

Belonging

Participants had also developed their sense of belonging, with their identity now including that of cancer survivor. Some manifested a distinct connectedness to the bowel cancer community through their engagement in new occupations designed to help others affected by the same disease, and relationships were fostered with others in a similar situation. Helping and being helped by others in this way provided structure for developing meaning in their lives. Having a desire to belong and contribute or help others also provided a sense of purpose and motivation for occupational engagement (Walder & Molineux, 2017).

Belonging was also interlinked with doing, being, and becoming in terms of the social environment which had a marked impact on how participants transitioned. The importance of social support was evident in the strengthening of social relationships with family. Feeling a sense of connection and acceptance with peers particularly influenced being and becoming as social networks changed with some new friends arriving whilst other, older friends did not join participants on their transition and faded from their lives. Reasons for these friendship losses were on occasion due to friends being unable to deal with the mortality implications of cancer, but were also sometimes a result of a deliberate survivor decisions to sacrifice them. For the sake of their well-being – and simply to make life happier and more fulfilled – participants made

purposeful, deliberate decisions as to who remained in their post-cancer world. Being and belonging came together in relationships as participants reflected on themselves and identified the person they were now or hoped to become in the future.

Limitations

All participants resided in the North Island of New Zealand; recruitment from a wider geographical area may have yielded different results. The first author has personal experience of bowel cancer and, as a result, her personal experiences may have influenced data collection and analysis. To address this issue reflexivity was a feature of the research. In addition, having two co-authors who have no personal experience of the disease added balance and rigour to the analysis.

Conclusion

Participants in this study had transitioned from bowel cancer patient to survivor, and, as a result, aspects of their doing, being, becoming, and belonging had changed. While literature has described the impact on doing for those in transition following life changing illness or injury, the repercussions on the four interrelated areas of doing, being, becoming, and belonging – and the finding of becoming something you do not entirely welcome – has not been previously reported in the occupational science literature. Becoming more irritable, impatient, self-centred and self-focused are not perceived as positive changes by society. More research around the “dark side of occupation” (Twinley, 2013, p. 229) and a person’s subjective experiences following cancer treatment would increase understanding in this area. There is also scope to research whether an unexpected change in identity is a feature of occupational transitions amongst other populations. There are additional implications for further research in occupational science concerning the transitions of other groups who have experienced sudden changes in health and occupations. Possibilities include exploring how transition may be hindered by unfavourable occupations (Scalzo et al., 2016).

CHAPTER FIVE: THE OCCUPATIONAL IMPACT OF BOWEL CANCER: SURVIVORS' VOICES AND ADVANCING THE ROLE OF OCCUPATIONAL THERAPY ASSESSMENT AND INTERVENTION

Prelude to Manuscript Three

This chapter reports methods and brings together findings from Phases Two and Three of the study. Incorporating findings from the second round of interviews (Phase Three) enabled their synthesis with initial findings to enrich data and provide further insights. Participants added their thoughts as to whether identified themes were applicable and captured their experiences of having had bowel cancer.

Whilst the previous chapter took a theoretical, occupational science view of findings, this chapter takes a clinician-based perspective with findings viewed in relation to their relevance to occupational therapy practice. Continuing to look through an occupational lens, two major areas of practice – assessment and intervention – are focused on. In this way, the aim of ID methodology to be clinically applicable is addressed as the findings are specifically relevant to occupational therapy practice. This manuscript has been published in the Australian Occupational Therapy Journal (Martin et al., 2021). The version that appears here includes an enhanced review of literature with critique and additional details provided for the sources used.

Introduction

Necessary and meaningful occupations are fundamental to the creation and maintenance of health, well-being, and quality of life (Wilcock & Hocking, 2015). These benefits are attenuated, and stress increased, when occupational choice is limited and participation restricted, as after bowel cancer treatment (Martin et al., 2020b). Bowel cancer is one of the most diagnosed cancer worldwide (Arnold et al., 2017) and recent improvements to survival rate have resulted in it being considered a chronic rather than acute condition (Grimmett et al., 2017). Many bowel cancer survivors experience ongoing impacts in multiple areas including psychological (Martin et al., 2020a), cognitive (Martin et al., 2020a), social, physical (Breedveld-Peters et al., 2020), sexual (Martin et al., 2020b), self-care, employment and role functioning (Beesley et al., 2017; Martin et al., 2020b).

Despite the reported impact from bowel cancer treatment, post-treatment clients are not prioritised in cancer care (Lee et al., 2015). Support for the provision of rehabilitation services stems from the acknowledgment that cancer survivorship is a significant public health issue (Risendal et al., 2014). However, efforts to improve rehabilitation care often do not focus on cancer survivors (Sleight & Stein Duker, 2016). Consequently, survivors feel abandoned as they transition from cancer patient to survivor (Drury et al., 2017; Martin et al., 2020a) due to the implicit expectation from clinicians that the survivor will actively manage their own care (Jansen et al., 2015). Shipp et al. (2015) explored the impact of having had bowel cancer on leisure participation, however, little is generally known about the experiences of survivors as they make this transition and the occupational impact of having had bowel cancer. Furthermore, the uptake and potential role of occupational therapy is not clearly described in relation to cancer care (Wallis et al., 2020). Consequently, survivors have unmet occupational performance needs (Rijpkema et al., 2020).

The profession of occupational therapy's focus on function makes it appropriate for this population, especially considering bowel cancer survivors with good physical and emotional role functioning are considerably more likely to be satisfied with their participation levels (Breedveld-Peters et al., 2020). Moreover, positive results for occupational therapists' input with cancer survivors are reported by Rijpkema et al. (2020), in their historical cohort study analysing data from 181 adults who had been treated for non-metastatic cancer. Although participants had received treatment for a variety of cancers – rather than just bowel – the findings are relevant to the present study given the focus on occupational therapy consultation and treatment within cancer rehabilitation. The authors reported client improvement in both performance and satisfaction, highlighting benefits of occupational therapy input for cancer survivors

generally. However, as each cancer produces its own challenges and areas of need, it is valuable to consider the specific needs of those affected by different cancer types. Utilising the strength-based approach common within the occupational therapy profession, the goal of intervention would be to help people live “their own version of a satisfying life” (Dunn, 2017, p. 395).

Despite the potential benefits, occupational therapy is underrepresented in cancer care. In their review of literature evaluating the needs for occupational therapy, Pergolotti et al. (2016) concluded that despite many adult cancer survivors reporting limitations in daily activities, the profession is insufficiently used. The lack of development of services is possibly due to time and financial constraints (Boland et al., 2018; Buckland & Mackenzie, 2017). The present research is part of a broader study, which aimed to contribute to the current understanding of the ways having had bowel cancer impacts daily occupations and the health and well-being of those affected. The intention was to draw on the experiences of bowel cancer survivors to add to the knowledge base of occupational scientists, occupational therapists, and those of other disciplines working with people who have had bowel cancer. This study aims to first describe experiences of the occupational impacts after completing treatment and second, consider the practice implications for occupational therapy in terms of specific areas for assessment and intervention with bowel cancer survivors.

Methods

Ethical approval for this study was received from Auckland University of Technology Ethics Committee (reference number 18/411).

Research team

The research was carried out as part of the first author’s doctoral study. She is an occupational therapist and bowel cancer survivor, and took the lead on participant recruitment, data collection and analysis. The second and third authors are experienced researchers who provided academic supervision. The second author is an occupational therapist and occupational scientist.

Methodology and methods

An ID qualitative methodology was chosen for its inductive, analytic approach (Thorne, 2016), enabling understanding of the experiences of bowel cancer from a participant perspective alongside a contextual inquiry from the researchers’ perspective as occupational therapists and researchers. ID considers disciplinary orientation to be a crucial factor in how successful a research study will be and legitimises alignment of the researchers’ occupational perspective and practice concerns with the aim of the

study. The chosen methodology recognises how researchers' backgrounds affect their interpretation of data and how understanding evolves in conjunction with participants (Thorne, 2016). As the first author had treatment for bowel cancer in 2016, reflexivity was consistently utilized to increase awareness of how her personal experiences may influence perceptions, emotions, and responses (Foster, 2009). The reflexive process included the keeping of a reflexive journal, thus ensuring transparency and increasing validity as the possibility of bias due to preconceived ideas was reduced (Foster, 2009). The documentation of what was occurring subjectively and conceptually throughout the process became a core element informing the inductive data collection and analysis, allowing the appreciation of the implications of the first author's role in the process (Thorne, 2016).

Participants and recruitment

Purposive sampling (Grattan et al., 2018) was used to identify New Zealand participants who had completed treatment for bowel cancer at least three months previously. Participants were given the option of having partners and/or family members take part in the interview. To capture the diverse range of impacts on occupation, participants were targeted covering a range of ages, activity levels, rural/urban locations, tumour stages, and stoma/non stoma presence, thus enhancing representative credibility (Thorne, 2016). Participants were recruited via the first author's professional and personal networks including staff at her local hospital where she had been previously treated for bowel cancer and was employed as an occupational therapist. A flyer advertising the research and giving details of the first author's status as a bowel cancer survivor was hand delivered or emailed to prospective participants. Those expressing interest were provided with an information sheet outlining the research.

Data collection

Data collection involved two rounds of face-to-face or telephone semi-structured interviews at a jointly agreed location and time. Prior to each interview a consent form was signed by participants. The first round of interviews used an interview guide informed by the results of a scoping review (Martin et al., 2020b). The interview guide included questions such as "Have you done things – or plan to do things – you wouldn't have done before diagnosis?" and "Do you think the ongoing effects have affected your relationships? In what ways?" The full script has been included in a previous publication related to this research (Martin et al., 2020a) and is attached as Appendix D. Before each interview, the first author reminded participants of her experiences with bowel cancer to help reduce any power imbalance and encourage open discussion (Dwyer & Buckle, 2009). Eleven initial interviews were carried out, ranging in length

from 30 to 100 minutes, with contributions from four partners. Partner contributions were considered within the data analysis as these provided multiple perspectives of the impact on changes in occupational needs and routines and enriched the data.

A second, more contained, round of interviews was carried out with two of the original and two newly recruited participants, with one partner, to garner feedback on the veracity of the findings. The two original participants had indicated interest in participating in further studies. The two new participants were recruited via staff at the first author's local hospital, with parameters given for one participant from each sex. Thorne (2016) suggested repeat interviews provide the opportunity to share a synthesis of what had been learned from both the individual's comments and those of other participants and to reflect on the extent to which they resonate. The same author also proposes a similar form of confirmation or elaboration can be achieved with a small number of new participants. Therefore, the decision was taken to gain the perspective of both new and previously involved participants, as both presented benefits. Interviews were guided by the insights and themes that emerged in the first data set and provided participants with the opportunity to reflect on whether findings and the manner in which they were presented resonated with their experiences (Thorne, 2016). During the interviews identified themes – including quotes from the first round of interviews – were shared with participants who responded with their own thoughts. The use of a second round of interviews increased credibility of the findings by enabling interview strategies to be shaped by the evolving analysis (Thorne, 2016).

Data analysis

Immediately after each interview, recordings were transcribed verbatim; the first four by the first author and the remainder by a professional transcriber. Participants were offered the transcript of their interview and an opportunity to comment on accuracy and/or make any other comments they felt relevant. Two participants requested this but did not give any additional feedback.

Various analysis methods and techniques are acceptable within ID (Hunt, 2009; Thorne, 2016). As the methodology facilitates the identification of patterns in the data, analysis involved concurrent data collection and thematic analysis of verbatim interview transcripts to enable early insights to be incorporated into future data collection (Grattan et al., 2018). The first author immersed herself in the data by highlighting with colours and adding marginal comments to transcripts, with an emphasis on broad analytic questions (such as “what is this telling me?”) to ensure the contextual nature of the data was respected (Thorne et al., 2004) and an understanding of the whole picture obtained. Text excerpts were copied and pasted into documents with descriptive titles to temporarily combine potentially related ideas into subsets, in order to construct

evolving themes and patterns founded on the experiences of participants. The constant comparative analysis and iterative analysis methods utilised ensured consistency with the emergent analytic which ID stimulates (Thorne, 2016) and permitted groups of data bearing similar characteristics to be examined and re-examined for a range of alternative explanations (Thorne et al., 2004). As an experienced researcher, the second author also coded initial transcripts. Emerging patterns were discussed by all authors via email and in meetings where potential themes were identified. New insights were considered in light of participant data and earlier analysis, with open discussion until consensus was reached. Figure 2 illustrates the qualitative process and order of interviews.

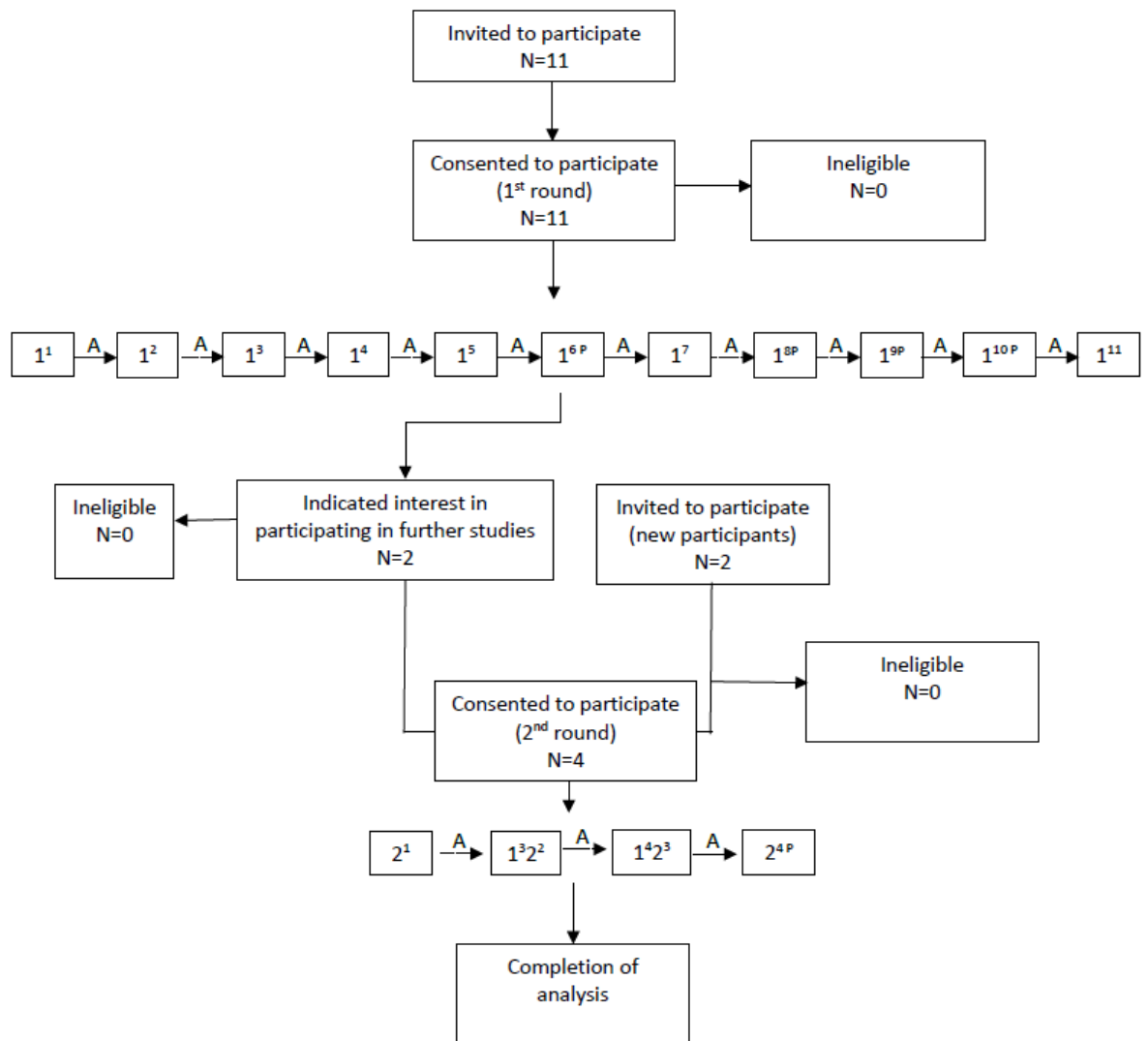


Figure 2: Qualitative process and order of interviews

Note: A=Analysis; ^P denotes participation of the interviewee's partner.

Findings

Across both rounds of interviews, 12 female and six male participants varying in age from 42 to 92 years were recruited, none of whom reported input from an occupational therapist post-treatment. Table 6 presents participant demographics.

Table 6: Participant demographics (n=18)

	Bowel cancer survivors	Number/%	Partners
Sex	Male	5 (38%)	1 (20%)
	Female	8 (62%)	4 (80%)
Age in years	< 50	2 (15.5%)	
	51-64	5 (38.5%)	
	65-74	4 (31%)	
	75-84	1 (7.5%)	
	≥85	1 (7.5%)	
Cancer stage	One	2 (15%)	
	Two	1 (8%)	
	Three	8 (62%)	
	Four	2 (15%)	
Time since treatment conclusion	<2 years	5 (38%)	
	2-5 years	6 (46%)	
	6-10 years	0 (0%)	
	>10 years	2 (15%)	
Ostomy status	None	4 (31%)	
	Reversed	6 (46%)	
	Permanent	3 (23%)	

Four themes relating to the occupational disruptions experienced by participants are reported here. As the aim of the study was to generate information to inform practice across the diverse occupational impacts of having had bowel cancer, differences related to gender, age and other demographic characteristics were not analysed. Additional findings are reported elsewhere (Martin et al., 2020a). Participant pseudonyms are used throughout the findings. Pseudonyms are coded to indicate where participants were in the order of interviews, and whether they were a bowel cancer survivor or partner. For example, 1⁶ indicates the sixth interviewee in the first round of interview, 2³ indicates the third interviewee in the second round of interviews, 1^{9P} indicates the partner of the ninth interviewee in the first round of interviews, and 1³²² indicates the participant took part in both rounds of interviews.

Changes in eating habits

Strategies

For some participants, eating habits were restricted. Some considered why they had contracted cancer, changing their diet to move away from foods identified as causes:

You have a change of thought of everything you're eating, and what you've eaten before and the things you've got to eat again ... processed food and all that, they've all got cancer. So, it throws your mind and what to bloody eat. (Maia 1⁵)

Maia's own research had revealed foods she considered bowel cancer causing and wanted to avoid. She yearned for food she felt comfortable and safe with: *"I was thinking of the Māori kai[food] of the old days and how I wished I still had those to eat ... Māori kai, seafood, bush kai"* (1⁵). She considered unprocessed food to be risk free, but without regular access to it she developed a reluctance to consume anything: *"I had to put this block around me not to eat, because I didn't know what to eat"*. However, recognising the importance of eating to her health and recovery, she chose to use marijuana to stimulate her appetite: *"I have a bit of a puff before I eat just to get the munchies."*

Some dietary adjustments occurred out of necessity. Ostomate participants talked about certain foods *"rush[ing] through"* and *"fill[ing] up the stoma very quickly"* (Merina 1¹⁰), making the bag contents too *"runny"* (Will 1⁶, Maia 1⁵, Merina 1¹⁰). These foods varied but frequently included those with a high fibre content. Despite this common ground, a fine line had to be walked when making dietary choices, as too much starch produced an alternate problem: *"When I eat bread or something that's got starch in it ... it gets too thick ... and then it pops"* (Maia 1⁵). Also, participants talked of odour radiating from the ostomy bag after eating certain foods, such as fish, placing them off the menu.

Those without an ostomy also *"struggled with food"* (June 1^{3 22}), making dietary changes to accommodate increased bowel movements, urgency and/or flatulence, often reducing fibre intake: *"Things like onions I just can't touch. They just go straight through within a matter of an hour. Leafy greens ... I've got to stay away from. ... Most fruits upset my stomach as well"* (Ray 1¹¹). Consequently, food eaten was sometimes *"completely counter-intuitive to what you would think would be a normal healthy diet"* (June 1^{3 22}).

These enforced changes caused obvious distress: *"Oh avocados, fancy saying I can't eat avocado. I just hang out for them"* (Merina 1¹⁰); *"I can't eat some things and I love them ... Good steaks and roast meat I really miss"* (Ray 1¹¹). Sometimes the pull of these favoured foods was too strong to resist, but after consumption the consequences

had to be faced: *"I'm no good for the next two days"* (Ray 1¹¹). Consequently, participants often avoided preferred foods. For instance, Sarah (1²) generally abstained from junk food in favour of something more *"substantially nutritious, just to not make things pay horrifically the next few days after."* Ray (1¹¹) too had replaced many of his favourite foods, with oat bran and yogurt his new *"go to thing."* Similarly, Merina (1¹⁰) had discovered that she could still eat one of her favourite foods – cabbage – if she ate it raw and *"very finely chopped."* She explained how she needed *"to have something like that, otherwise potato, kumara, carrots, parsnips, pumpkins, they're very good for you, I suppose, but they're very boring."*

A trial-and-error approach towards eating was adopted: *"I do randomly try something, give it a try again. Most times it's an abject fail"* (June 1^{3 22}). Ray (1¹¹) too, 20 months after his stoma reversal, was still finding it difficult to ascertain which foods triggered increased bowel movements: *"You know you have the odd hamburger and it'll play up and you think well was it the lettuce? Was it the tomato? Was it the meat?"*

Social considerations

Limitations experienced due to food choices also impacted social gatherings. For example, June (1^{3 22})'s abstinence from alcohol because she was *"scared of the effect on [her] gut"* put *"the kibosh on [her] social life"* as *"going out for a glass of water doesn't have the same appeal as going out for a glass of wine."* She also had issues regarding people's reactions to the food restrictions she faced:

It's annoying dealing with people when you're out, saying, 'I can't eat this, I can't eat that'. It's like you're just doing it to be a pain, you're being difficult, or you're on some wacko diet. I've kind of stopped going out for that reason.

Other participants drastically reduced their eating when away from home. When invited to social gatherings, Sam (2⁴) either went straight home after eating or chose not to eat at all as *"within half an hour of eating he's on the toilet"* (Lynne 2^{4P}). Lynne expressed their attitude regarding their situation, commenting, *"you can either feel sorry for yourself and not go out, and not do anything, or you just have to plan."* Sam (2⁴) employed the same food avoidance strategy when on long-haul flights because he was *"worried about what might happen."*

Changes in toileting habits

Strategies

In addition to the impact dietary choices had on the content of ostomy bags and frequency of bowel motions, managing changes in toileting habits was also problematic. Stella (1⁴²³) described how challenging she found the first encounter with her stoma bag: *"The stoma nurse she came in ... I'm busy looking away ... and she*

said ‘Stella, it’s perfectly natural.’ And I said, ‘No it’s not. My nose has never been so close to my bum.’” Participants also had to adjust to a change in appearance: “I was having trouble looking at myself in the mirror with that stoma bag” (June 1³ 2²). Will (1⁶) “always tried to hide” his ostomy pouch and as a result would “avoid situations where it would become obvious”. The burden of dealing with the ostomy was accentuated by fear of leakage, with strategies employed such as wrapping it in a plastic bag before sleeping.

After ostomy reversal surgery, participants faced the new challenge of adapting to their “unpredictable and erratic” (June 1³ 2²) bowel: “I can spend nights ... doing ten or eleven trips ... to the bathroom” (Sarah 1²). Will (1⁶) explained how he would sleep in the lounge to be closer to the toilet, but still “didn’t make it half a dozen times” causing him to think, “Shit, is this life now?”

Social considerations

Fear of negative social reaction to bowel dysfunction was also a concern: “I try really hard to try and make that less noticeable” (Sarah 1²). She further explained her concerns about personal odours:

I fart heaps ... It's like, does my car smell like this? Is it just permanently embedded in my clothing? I also get a little paranoid that as much as I clean myself up after a bowel motion, it might just keep coming ... there's days where it's just like this sloppy mess.

Embarrassment was felt regarding the impact of bowel dysfunction on others, with Sarah (1²) admitting “I hate it when someone else has got to go to the bathroom after me”, and Sam (2⁴) using his campervan toilet when visitors were staying, despite having a two-bathroom house.

Changes in bowel function also influenced engagement in social occupations, with Sarah (1²) commenting, “it decides when it wants to not be social”. She often chose to stay home and eat takeaway food rather than face multiple trips to the bathroom in a restaurant. Participants were also reluctant to have people stay at their homes due to the extra time needed for toileting: “We can’t have [family] like we used to ... because ... we’ve only got one bathroom” (Robert 1^{10P}). They also faced obstacles when meeting up with people away from home due to “eruptions in the stoma area” or because of the need for numerous toilet stops. The inconvenience meant overnight visits had ceased altogether for some. However, some participants were still able to enjoy staying with friends by being prepared:

On my very first weekend away ... there's no way I wanted anything to run out and so I had a pouch in my suitcase, but I also had a spare bag

in the back of the car because I was paranoid about not having supplies with me. (Stella 1⁴2³)

Preparedness was also employed when going out socially. For example, arriving early to the cinema to ensure seating with easy access to the toilet, or taking medication to reduce bowel movements.

Changes in relationships

Attending social functions

Surviving bowel cancer also impacted relationships. Maia (1⁵)’s ability to attend social functions where several people would be present was impacted by feeling emotionally “vulnerable”:

I can’t really go to any of the tangi [Māori funeral]. I know I’ll pick up everybody’s feelings and it’s just whoosh. And then it gets me down and then I have to come home and clear myself ... I have to be very, very careful where I go because I pick up anything.

This fear of taking on the feelings of others affected Maia (1⁵) to such an extent that she conceded, “*I hardly go out*”, a huge loss both on a cultural and social level.

Sexual relationships

Sexual relations were also impacted, with June (1³ 2²) revealing this area of life with her husband had been affected “*totally, absolutely*” and Will (1⁶) declaring “*I didn’t like it, the feel of it [ostomy] ... and that affected things quite a bit.*” After surgery, Ray (1¹¹) experienced erectile dysfunction and explained how “*I used to enjoy sex but it’s not the end of the world.*” Over time, he had come to terms with his condition: “*You haven’t got it, it doesn’t work so yeah, we’ll get over it.*” Maia (1⁵) admitted that after her stoma forming surgery “*it took me ages to allow my husband to touch me again*” as she faced the fear of her pouch bursting.

Changes in friendships

Cancer was also responsible for the loss of friendships. In some instances, this was because people did not know how to cope with, or be around, someone with cancer: “*They didn’t quite know what to say or do*” (June 1³ 2²); “*They didn’t want to be near me, and I guess what I put it down to was they were scared they might catch it*” (Maia 1⁵). For Sam (2⁴), his pre-cancer time with friends had been predominantly spent at the pub. As his wife reasoned, “*if Sam’s not at the pub drinking, what’s the relationship now? We don’t really have one.*” Others could not deal with the additional support someone with cancer required, leading survivors to find out “*who good friends were and who weren’t*” (Sarah 1²).

Wanting someone to talk to

Participants would have liked more opportunity to talk to other bowel cancer survivors. They did not want to burden family and friends – often feeling pressure to put on a brave face – but would have appreciated the chance to be totally honest with someone who had had similar experiences as *“they really understand”* (Beth 2¹). They believed that unless someone had had bowel cancer, they could not comprehend what it was like, as illustrated by Beth’s (2¹) response to someone belittling the impact of having a colostomy bag: *“How the hell do you know what a colostomy feels like? You don’t.”* Participants also did not feel comfortable discussing areas such as bowel dysfunction as *“nobody wants to talk about their poo”* (Beth 2¹). This need for someone to communicate honestly with extended to affected family members, with Lynne (2^{4P}) acknowledging that *“a bit of support for me would have been nice”* and June (1^{3 22}) commenting *“I find it amazing there aren’t support groups.”*

Rethinking occupational choices

The impact of having had bowel cancer caused some participants to rethink their occupational choices.

Leisure occupations

The presence of an ostomy impacted water-based occupations due to the visibility of the pouch through swimwear, and fear of its response when submerged in water: *“The very first time [swimming] I was absolutely petrified there was going to be Code Brown”* (Stella 1⁴²³). While Stella (1⁴²³) overcame this trepidation and returned to regular swimming, others did not adapt so well, significantly reducing occupations such as fishing and beach sports.

After stoma reversal surgery, leisure occupations continued to be affected due to increased bowel movements: *“I was too scared to go out walking, because I thought I would need to go to the toilet”* (June 1^{3 22}). However, in time, survivors learned strategies to overcome these issues, including developing a knowledge of toilet location in the local area: *“I know where all the public toilets are if I’m out walking, including McDonald’s. All those places you can whip into on your way past, the BP [petrol] station”* (June 1^{3 22}), and being prepared: *“If I’m out in the bush I always make sure I’ve got wet wipes with me, or loperamide [medication to reduce bowel movements]”* (Sarah 1²).

As well as bowel dysfunction, physical occupations were impacted by reduced abdominal strength: *“It’s quite scary riding a bike when you haven’t got any abdominal control”* (Sarah 1²). A very keen cyclist before her cancer, Sarah (1²) admitted, *“I’ve lost my cycling mojo”*. More sedentary leisure occupations were also affected due to

“chemo brain” and the “fog thing that you have when you’re on chemo and radiation... it doesn’t leave you” (June 1³ 2²). Consequently, June would “lose track of things when reading”, and so now read “more lightweight things, that I don’t have to think quite so much about.”

Employment

Work occupations were reconsidered, with two participants attributing the decision to give up full time employment to having had cancer. Ray (1¹¹) explained his decision was because *“I don’t think it’s fair on the employer, not when you get up in the morning wondering how you’d feel and whether you had to stay by the toilet all day.”* Other participants were considering early retirement. James (1⁸) confessed, *“I’m certainly not enjoying my work as much as I did.”* When asked if he would consider leaving or changing his job, his answer was an unequivocal *“Oh yeah, too right!”* Andrew (1⁹) exhibited a similar mindset, admitting he was far less emotionally invested in his job and *“seriously looking at pulling the plug.”*

Discussion

The purpose of this study was to describe the experiences of bowel cancer survivors post-treatment with respect to their occupations, and to identify the implications for occupational therapy practice in terms of assessment and intervention. The survivors interviewed for this study described a variety of ways in which their engagement in occupation had been affected as a consequence of having had bowel cancer. While definitive recommendations for practice cannot be drawn from the study, therapists can nonetheless learn from those with lived experience of managing everyday occupations after active medical intervention is completed. The impacts reported spanned psychological, physical, and quality of life domains indicating a variety of areas where occupational therapy input might potentially be beneficial, particularly in terms of preparing for independent management of their condition.

Assessment

Occupational therapy assessment focuses on occupational performance issues and has an essential role in identifying areas for intervention. The present study identified significant occupational impacts of having had bowel cancer, across several domains, highlighting the opportunity for occupational therapy to improve outcomes.

Furthermore, the survivors and their partners interviewed attested the need for tailored advice, rather than one size fits all. To identify the range of needs reported by the survivors in the present study, multidimensional occupational therapy assessment is needed to provide information on a baseline level of functioning and areas of strengths and weaknesses across multiple aspects of everyday life.

Structured assessment measures provide clinicians with an objective, measurable, and specific assessment of strengths and difficulties in areas of occupational performance and functioning. They enable domains to be covered systematically, reducing the potential for essential areas to be overlooked, and support the evaluation of progress with adjustments to intervention plans made accordingly. Presently, there is no bowel-cancer specific assessment tool available for use in occupational therapy, necessitating the adoption of existing measures. A number of these measures could be considered; two illustrative possibilities are discussed below.

Performance history assessment

The Occupational Performance History Interview (OPHI-II) is a semi-structured interview assessment designed to encompass work, play and self-care using a rating scale and open-ended questions (Taylor, 2017), thus providing an overall picture of a survivor's occupational identity, occupational competence, and the impact of the environment. We consider it suitable for use with this population, given Rijpkema et al.'s (2020) report that cancer survivors predominantly consult an occupational therapist about concerns with work ability, leisure and daily routines. Moreover, the nature of the semi structured interview enables the opportunity to delve deeper into areas of particular importance to the client. The three scales from the OPHI-II have been found to be valid across diagnosis, culture, language, and age (Taylor, 2017). The OPHI-II might be supplemented with further measures, such as an interest checklist, if reengagement in previous occupations is no longer desired or appropriate (Taylor, 2017).

Cognitive assessment

The generally accepted view that cancer treatment can contribute to cognitive issues – corroborated by the present study's findings – suggest an additional place for an assessment specifically focused on this area. The Perceive, Recall, Plan, and Perform (PRPP) System of Task Analysis is a cognitive assessment tool that focuses on everyday home and work tasks, enabling therapists to identify issues with cognitive strategies and the impact on routines and roles. The PRPP uses three data collection methods – observation of tasks, a questionnaire, and an interview – all of which have demonstrated validity and reliability (Lewis et al., 2016). The PRPP has been identified as a potentially beneficial measurement and interview tool with breast cancer survivors, suggesting it may also be valuable to use with other types of cancer survivors (Lewis et al., 2016).

While the potential use of both assessments would provide valuable information when treating bowel cancer survivors, a measure addressing the specific needs of this

population would provide a more thorough means of addressing all the identified domains.

Intervention

The role of occupational therapy in supporting recovery for bowel cancer survivors may take a variety of forms including traditional individualised intervention. As occupational therapists are not always in a position to deliver this, one possible solution is the use of group-based self-management programmes. For the purposes of this paper, self-management refers to “an individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent with living with a chronic condition” (Barlow et al., 2002, p. 178). Although there are variations in the conceptualisations of self-management and the delivery of self-management programmes (Lennon et al., 2013), the commonly accepted aim is to empower clients living with a chronic illness to attain optimal health and well-being (Cuthbert et al., 2019) by actively managing their condition to enhance quality of life (Lennon et al., 2013), thus maintaining their autonomy. Some participants in the present study independently sought solutions to problems they encountered, suggesting support for a self-management approach engendering a sense of control over one’s own care (Jansen et al., 2015).

Occupational therapists have a role in supporting the use of self-management, acknowledged as a vital component of chronic disease management (Grimmett et al., 2017) and an area of need for cancer survivors (Sleight & Stein Duker, 2016). They are skilled in both group facilitation and education (Sleight & Stein Duker, 2016), and so would be ideally suited to leading self-management groups. The occupational perspective provided by the therapist would ensure group content could effectively focus on relevant personal, leisure, and productive occupations (Boland et al., 2018; Udovicich et al., 2020). As participants in the present study identified the opportunity to talk to fellow bowel cancer survivors as an area of need, the use of group interaction with peers, described as “beacons of information” (Drury et al., 2020, p. 7), would provide a credible, trustworthy voice, with fellow cancer survivors providing examples of real people living and managing their lives post bowel cancer. As with breast cancer survivors, group sessions would be most effective if made up of individuals who have survived the same type of cancer (Schmidt et al., 2020), particularly as bowel dysfunction or ostomy management are taboo topics (Chelvanayagam, 2014). A group made up entirely of bowel cancer survivors is more likely to provide a non-stigmatising environment for open discussions.

One goal of self-management interventions for bowel-cancer survivors would be reengagement in previously enjoyed occupations, supported by peers sharing adaptive

strategies such as mapping out locations of public toilets, managing social situations by being fully prepared with ostomy supplies, or priming a dinner party host regarding food choices. Discussions might broach alternate occupations that still hold the core aspect of previously valued occupations, such as Sam's social bonding through drinking beer with friends. Specific occupational therapy input might encompass sources of adapted clothing for participants withdrawing from occupations due to fear of their ostomy bag being visible, or crafting and adjusting clothing for one-off situations. Participants could also be alerted to protective equipment available – such as a stoma guard to prevent leakage when involved in strenuous occupations – or assisted to create their own individually tailored equipment. Return to employment – a key component in increasing self-worth – could be supported through work environment and duty adaptations, and negotiations with employers for extended/flexible toilet breaks to address the barrier created by altered bowel function (Buckland & Mackenzie, 2017; McMullen et al., 2017).

Strengths and limitations of the study

Having personal experiences of bowel cancer can be viewed as both a researcher strength, enhancing rapport with participants, and a limitation influencing data collection and analysis. Consistent use of reflexivity reduced this possibility, as did regular meetings with co-authors to discuss research design, methods, and analysis. All participants lived in the North Island of New Zealand. Recruitment of a greater number of participants over a wider geographical area may have yielded different results and would have lent greater certainty to the occupational therapy role outlined.

Key Points

- Having had bowel cancer can significantly impact occupational participation
- Findings suggest occupational therapists have a role in assessment and intervention planning with this population
- Self-management group interventions provide a potential approach to support occupational reengagement

CHAPTER SIX: SINK OR SWIM. INFORMATION NEEDS FOR THRIVING WHEN TRANSITIONING FROM BOWEL CANCER PATIENT TO BOWEL CANCER SURVIVOR

Prelude to Manuscript Four

This chapter focuses on the narrative views of bowel cancer survivors in relation to considerations they see as important regarding content and delivery of information to best inform preparation for life post-treatment. Insights are predominantly drawn from Phase Three of the study but results from Phase Two are also incorporated where appropriate to provide additional context and perspectives on the topic. Whereas the two preceding manuscripts had a distinctly occupational science and therapy focus, this chapter considers the wider scope of the needs of bowel cancer survivors and is relevant to a variety of general health services involved in the post-treatment phase of this group. This manuscript is being prepared for consideration for a journal with a cancer focus, thus appealing to readers from a variety of disciplines, rather than solely occupational therapy.

Preparing this manuscript prompted an entrance into the health literacy literature to canvas advice from knowledge translation experts, providing a wealth of information. One way of initially locating relevant sources within this vast field was to concentrate on literature that addressed health literacy specifically within the cancer field, rather than generally. After consideration of my findings, I then focused on locating health literacy literature related to other areas identified by participants, which resulted in the use of publications addressing conditions other than cancer.

Similarities regarding what bowel cancer survivors want and the advice previously provided to those designing resources for this population are identified. The need for multiple, flexible resources with a more relatable and occupational focus is then discussed.

Introduction

People who receive treatment for bowel cancer often live with ongoing effects. Changes in bowel functioning (D'Souza et al., 2016), diet (Beesley et al., 2017), and employment (Beesley et al., 2017) are all reported, along with increased anxiety (Worrall et al., 2021), impaired memory and concentration (Shipp et al., 2015), sleep disruption (Bours et al., 2016), and sexual dysfunction (Saunders et al., 2021). Often the full extent of the health, vocational, psychological, and social effects of these and other sequelae do not become apparent until treatment conclusion (Drury et al., 2020); or months later (Sodergren et al., 2019).

These sequelae suggest an ongoing need for support (Chan et al., 2020; Russell et al., 2015), a topic considered by Wieldraaijer et al. (2019) in their cohort study involving completion of three identical surveys over a six-month period by 259 bowel cancer survivors within five years post-surgery. A quarter of their participants consulted a health care provider for information, clearly indicating a desire for information post-treatment. One potential way this need can be met is through the provision of high quality, clear information matching individual need. Having this need met has been described as “one of the most important factors of supportive cancer care across the whole cancer continuum” (Husson et al., 2011, p. 761) and vital for positive outcomes.

Good quality information has been found to positively influence quality of life, with lower incidence of anxiety and depression also reported amongst well-informed cancer survivors able to feel a sense of control over their disease (Husson et al., 2011; Wieldraaijer et al., 2019). In contrast, when information provision is unsatisfactory, this can contribute to anxiety and depressive symptoms, as reported by Beekers et al. (2015) in their 3080-participant population survey where the survivors involved covered a variety of cancer types, including bowel. However, individually tailored input from clinicians is not always practical due to time and financial constraints (Boland et al., 2018; Buckland & Mackenzie, 2017) and the need for information on the after-effects of treatment has largely gone unmet (Geller et al., 2014), even though cancer survivors in general have been reported to be keen to educate themselves (Choudhury et al., 2020).

Pamphlets or booklets have been reported to be a favoured mode of information dissemination because they are easily carried, information can be accessed selectively, and learning is self-paced (Wilson et al., 2012). While this finding dates from nearly a decade ago when the internet was not the feature of life it is today, it could be argued that these advantages carry over to written information available online, particularly with the prevalence of smart phones enabling on demand access to

written information. Whether written information is in a digital or paper form, a degree of reading skill is involved, disadvantaging those with lower levels of health literacy (Hart et al., 2015), and thus contributing to worse clinical outcomes and poorer physical health (Busch et al., 2015; Hart et al., 2015; Papadakos et al., 2018).

Video or audio formats disseminated via the internet are alternatives for conveying information (Bağrıaçık Altıntaş & Vural, 2018) and remove the reliance on reading (Wilson et al., 2012). Wilson et al.'s (2012) structured literature review of 30 studies comparing print and multimedia health materials found they performed equally well. The findings of the review focused on whether materials helped individuals comprehend and retain information presented to them. They did not, however, consider that multi-media materials have some form of presenter, in a way that written material does not; an important consideration given the expansion of, and variety of mixed media available.

Although bowel cancer survivors are generally well informed as to their disease and treatment, research has found that they have limited knowledge about improvements in lifestyle, nutrition, bowel system management, return to work and the availability of support groups (Drury et al., 2020; Wieldraaijer et al., 2019). For example, 69% of bowel cancer survivors in the United Kingdom reported not being provided with any advice about nutrition (Matsell et al., 2020), despite the effectiveness of dietary advice and education in improving quality of life for this population (Ravasco et al., 2012). In addition, the majority of publications focusing on the information needs of cancer survivors address a variety of cancers. Studies that solely focus on information needs of bowel cancer have been generally quantitative in nature.

This study aimed to investigate the particular information needs of bowel cancer survivors and identify considerations in terms of content and method of delivery when providing information for this population. The research question addressed was: What do individuals who have completed treatment for bowel cancer identify as important considerations for content and delivery of information to best inform preparation for life after treatment?

Methods

Research design

This paper presents selected findings from a larger research project utilising interpretive description (ID) methodology (Thorne, 2016) to explore the impact of having had bowel cancer on occupations (daily activities). In the first round of interviews, 11 bowel cancer survivors (and four partners) who had completed treatment

at least three months prior were asked about their experiences. The methods and results are reported elsewhere (Martin et al., 2020a, 2020b). The second round of interviews focused on the views of bowel cancer survivors regarding the information they believed would be beneficial in aiding recovery. Although the majority of the data reported here resulted from the second round of interviews, the first round also produced some insights relevant to the research question. Therefore, contributions from five participants (including one partner) in the earlier interviews are also reported within this paper to provide additional context and perspectives on the topic.

Recruitment

The second round of interviews included five participants. Two of these had participated in the earlier interviews and indicated willingness to participate in further studies, two were new to the study, and one was the wife of one of the new participants. The two participants involved in the first round of interviews had given consent at that time to contribute to the second round. The new participants were recruited through flyers advertising the research that were distributed to the first author's personal and professional networks and disclosed the first author's bowel cancer survivor status. Interested potential participants were given an information sheet and informed that the interview would involve commenting on both the findings from the first round of interviews and an online booklet, which they were asked to consider from the perspective of all bowel cancer survivors in New Zealand. The 23-page booklet, emailed to participants, is entitled "Living beyond bowel cancer". It was produced by Bowel Cancer New Zealand [BCNZ] (2019a) to offer support and advice to bowel cancer survivors as they "navigate the new terrain" (p. 5) after treatment conclusion. It contains extensive generic information and images addressing medical follow-up care and various topics such as "exercise and staying active" and "emotions and feelings" in "practical" and "personal" sections. It also features tips/important considerations such as locating toilets ahead of time when planning an outing. The resource was chosen as a stimulus for participant views and preferences as it is specific to the bowel cancer survivorship period and produced within New Zealand by the country's largest bowel cancer charity. Because it is readily available as a pdf document in the resources section of the BCNZ website, it was easy to provide to participants via email or post.

Data collection

Participants signed a consent form prior to commencing their 60-80 minute interview, which was conducted by telephone or face-to-face at a mutually agreed location. After confirming they had received the BCNZ booklet, which all had printed and referred to during the interview, themes and supporting participant quotes from the first round of interviews were shared using a prepared interview guide (Appendix N). Sometimes the

quotes were their own from the first interview, sometimes they were those of others. In considering the findings, participants were encouraged to engage in conversation, ask questions and make comments. Drawing on both the reported findings and the print resource they had been provided with, participants were then invited to share their thoughts regarding the most effective way to meet bowel cancer survivors' information needs.

Data analysis

Following verbatim transcription, data were analysed thematically using concurrent data collection and analysis, constant comparative analysis, and iterative analysis – in line with ID methodology (Thorne, 2016). The first author familiarised herself with the data by reading and rereading transcripts while listening to the interview recordings (Braun & Clarke, 2014; Noble & Smith, 2015). Early insights were incorporated into subsequent interviews (Grattan et al., 2018), for instance by asking participants whether they agreed or had varying viewpoints. All authors discussed emerging patterns relating to the research question in several meetings and potential themes were established. Reflexivity was used throughout data collection and analysis; the first author kept a reflexive journal to allow consideration and acknowledgement of how her experiences with bowel cancer could impact her reactions, attitudes, feelings, and perceptions (Foster, 2009; Moore, 2015). The potential for bias due to preconceived ideas was, therefore, reduced, ensuring the research was transparent and oriented toward participant experiences (Merriam & Tisdell, 2016).

Findings

Two male and eight female participants (including partners), varying in age from 42 to 80 years, informed the findings reported here. See Table 7 for details.

Table 7: Participant demographics

Pseudonym	Sex	Age	Time since treatment conclusion	Rural/urban
Sarah*	Female	42	4 years	Urban
Cecilia*	Female	57	2 years	Rural
Merina* (and partner, Robert)	Female	80	2 years	Urban
Maia*	Female	61	2 years	Urban
Sam** (and partner, Lynne)	Male	64	1 year	Urban
Beth**	Female	59	1 year	Urban
June***	Female	68	13 years	Urban
Stella***	Female	67	1 year	Urban

* Participated in first round of interviews **Participated in second round of interviews

***Participated in both rounds of interviews

Participants agreed that although sufficient information about bowel cancer and its treatment was received at diagnosis and during treatment, they would also have appreciated “*some sort of follow-up thing*” (Beth) at treatment conclusion. They agreed that information post-treatment would be valuable as “*having knowledge gives me strength ... if I understand what's happening, I can deal with it*” (June). Additionally, information was deemed as beneficial in addressing areas survivors had not even considered because “*you can't ask for what you want if you don't know*” (Lynne). Who participants wanted this information from, what they did and did not want, and in what format, are addressed within the following four themes.

Using a variety of media

Participants expressed varying views as to the best format to disseminate information at treatment conclusion, with June bemoaning, “*There's no little discharge pack or anything when you leave, saying, 'This may not happen, but if you get this [particular symptom], this is what it could be'*”. Participants also suggested phone apps may “*give the resources to navigate your way through the whole system – before, during and after*” (June), with links to relevant material.

Online videos were suggested as a resource that could support bowel cancer survivors across several domains of need. Firstly, to enable bowel cancer survivors to hear the experiences of others who had had the disease, to provide both motivation and comfort that what they were experiencing was common and ‘normal’. Secondly, videos were recommended as a practical means of demonstration, for example how to manage a

stoma: *"I would have liked to have seen a video of how to put the stoma on, how to put the actual bag on"* (Lynne); *"A little clip where ... instead of putting it square, you can put it on the diagonal. Just little wee tricks like that"* (Stella). However, it was important to remember that *"if people are older, they might not necessarily be internet savvy"* and *"when there's something on-line, people don't necessarily go to it"* (Stella). As an alternative, Stella felt *"if you've got a pamphlet or a little booklet, you're prone to pick it up and put it down. And you dip into it"*. There was advice for written information to be *"bullet-pointed"* (Lynne) to ensure it was not too *"wordy"* (Stella), and that *"jargon"* was avoided to ensure *"we talk to people in their language"* (Stella). Finally, participants felt information should be *"strength-based"* to help survivors understand that *"life doesn't stop, and it [bowel cancer] doesn't need to define you"* (Stella). This finding was also clear in participant responses to the initial themes identified in the first round of interviews.

Sam's wife, Lynne, felt that survivor gender also played a part in which information format was most suitable:

The men don't read anything ... I'm not saying that all men are like that, but the majority of the men are. Whereas women, I think we read everything, and we like to understand, we like to feel a bit more in control.

Although most participants emphasised that they would like to have received some form of information regarding managing life at treatment conclusion, Lynne acknowledged that at that stage *"your brain is still processing a lot of stuff, so when you got given something like that it might get filed away for a little while"* and then referred to at a later date.

Regarding timing of information provision, Sam reflected that he would have liked to have been told *"the bloody truth the whole way through, because we were given it in steps"*. He did however acknowledge that *"somebody who might not have been strong enough to cope maybe needs to have little drip feeds"*. June epitomised this view when describing how she was given information at the beginning of treatment setting out what lay ahead:

At the time, I didn't want to look at it. I didn't want to read it. I threw it in the drawer and slammed the drawer shut. But the number of times I pulled that information out and looked at it and thought, 'Right, that's what's going to happen next. Okay. I can deal with that.'

Beth suggested information could be provided at regular intervals, for example one month after treatment conclusion, six months, one year, etc. She felt that this would allow survivors to *"reflect on it and think 'Yeah, that is how I feel'. Just comparing it to*

that.” She acknowledged that while some people *“will just put it in the rubbish, they’re not interested, other people, like myself, would have read it.”* Beth’s comment again highlights the variation in participant views about what constituted valuable information, with no consensus as to the most effective way to provide it.

The importance of relatability

Receiving information that was personally relevant was deemed important by all participants. In particular, they felt strongly that the photographs in various materials they saw needed to be of people they could relate to. Sarah, aged 42 years old, explained how she was given a brochure at treatment conclusion where *“the youngest person in the whole thing was a 73-year-old hanging out her washing, it looked like”*. June, who was 55 when her treatment ended, was also given printed information and commented *“I remember being shown this brochure, and saying, ‘For goodness sake, lose the old people’* (June).

Thirteen years post-treatment, June believed the photographs used in more recently produced materials had gone to the other extreme; referring to the BCNZ publication she observed, *“Oh my god, they’ve lost the old people and replaced it with young people ... lose the young people”*. June rationalised that *“it doesn’t matter what sort of people you put in there, there’s going to be a whole lot of people who can’t identify with those photos”*, instead suggesting *“maybe just don’t have people in the brochure. Maybe just stick with watermarks on the page of lakes, rivers, New Zealand bush”* rather than *“polarising photos of people that you totally can’t identify with”*.

Participants agreed that one way to improve relatability was to intersperse quotes and/or stories from bowel cancer survivors outlining their experiences – *“because it makes it personable, and they’re not embarrassed to talk about poos”* (Beth). It was suggested this might take the form of *“a quote from somebody and then a link, where you could read their story”* (June). Such information could be encouraging: *“I remember I read ... about a guy who had just cycled the length of the South Island with a stoma. And I thought, ‘Oh, isn’t that cool’. I guess it was the inspirational stories that triggered me”* (Stella). Participants felt the quotes resulting from the first round of interviews would be beneficial for other survivors to hear by providing both inspiration and the knowledge that what they were experiencing was in keeping with that felt by others who had had the same disease.

In relation to the BCNZ resource, Stella commented that although she considered it *“an excellent resource”* due to its coverage of several relevant topics, she pondered *“but is it the gospel? Does it remove people being individual about it?... I don’t know”*.

The pressure to conform

Participants felt that information and imagery could generate pressure to abide by certain lifestyle behaviours following treatment. This perceived demand prompted the comment: *"There's just a lot of preachy words in there [the BCNZ resource] about changing your lifestyle. I'm so sick of this preaching"* (June). Relating this to the previously discussed photographs, June observed people *"had all the designer gear on"* and how *"it makes you feel inadequate actually, if you're not grinning like a Cheshire cat, parading around in your gym gear."*

Participants also felt pressure to conform to healthy eating guidelines that were not always financially possible: *"For Sam, if he was told, 'You have to eat salmon', he'd be like, 'No, it's too bloody expensive'"* (Lynne). Dietary information was also confusing for participants who received contrasting messages about the 'right' foods to eat:

I run the menu; I was very confused about what he was allowed ... We sort of got told ... 'Yeah, do whatever you like, Sam. Just eat and drink and keep going'...it was like everything, what I know to eat healthy, went out the door with this (Lynne).

Maia received similar contrasting messages:

When I was in hospital and the doctors were telling me that I had to eat food, and then I was reading all the information about what to be aware of and what not to eat after the bowel cancer and all this and everything that was on my menu was everything that I wasn't allowed to eat.

There was also a belief that information suggesting lifestyle changes could cause survivors to feel in some way responsible for their cancer diagnosis and in turn increase the severity of a condition identified as common in the first round of interviews, that of anxiety:

There's a lot of blame out there now. A lot of perception that if you get bowel cancer, it's your own fault, because you've either been eating too many sausages, too much ham and red meat, and not exercising properly ... That could be upsetting. You could beat yourself up for not doing something right (June).

If people are really concerned that their cancer's going to come back, would they look at this [BCNZ resource] and say, 'Oh look, I've had a couple of alcoholic drinks and I don't drink enough water and eat regular small, lighter meals'. That sense of self-evaluation all the time could be quite problematic for people ... especially if they're watching and being hyper-vigilant ... about whether they're doing the right thing, or the wrong thing (Stella).

In contrast, when presented with findings from the first round of interviews from the present study, participants generally responded positively. Rather than feeling pressure

to behave in a certain way, they reported comfort in hearing the words of other bowel cancer survivors, which corresponded to their own experiences. Their response suggests the advantages of hearing insights derived solely from people who have had bowel cancer without a professional voice making generalised claims.

Someone who knows

Woven throughout the participants' narratives – in response to both the findings of the present study and the BCNZ resource – was the potential value of connecting with the experiences of other bowel cancer survivors throughout their cancer journey, but particularly after treatment conclusion as *"it's a tumultuous time, particularly at the end of everything"* when *"you feel very, very alone"* (June). June commented how, in terms of support, *"there was literally nothing"* and how she *"thought about trying to start a support group"* but *"didn't have the energy"*. Sarah would have liked to *"talk to people of my age group,"* particularly those who were getting on with life rather than having a *"woe is me"* attitude; *"someone who's actually gone out there and done something"*.

Some participants reported that their interview for this study was the first time they had shared experiences with someone who had also had bowel cancer. Beth articulated the benefits of such an opportunity, remarking how *"you can be really honest with someone, and they really do understand"*. Moreover, when responding to the quotes shared from the first round of interviews for the present study, June added that it was *"reinforcing"* to hear *"other people saying the same things"*, suggesting more benefit in hearing the words of 'real' people as opposed to information in a generic resource. Participants expressed preference in hearing the quotes shared in the present study's findings rather than the generic information shared in the BCNZ resource. It was felt that unless someone had had bowel cancer, they could not comprehend what it was like, as illustrated by Beth's response to someone invalidating the experience of having a colostomy bag: *"How the hell do you know what a colostomy feels like? You don't. You've never had a colostomy"*. She also commented that another barrier to talking about bowel cancer was that *"nobody wants to talk about their poo,"* with Cecilia adding that she would not talk to someone unless *"you know somebody else knows, and somebody else can share that humiliation, if you're a proud person"*. June also made the point that *"every cancer is unique ... somebody who's had breast cancer won't be experiencing the same symptoms as somebody who's had bowel cancer"*.

Participants also felt that they would enjoy the opportunity to help other bowel cancer survivors: *"If somebody was in the same position as I have been, I would love to go and listen to them, and talk to them, and help support them"* (Beth). When asked the best way to arrange and manage this contact with other survivors, Beth's reply was *"maybe you could have people to ring. And people that volunteer. They could leave*

their name, and if you would like to talk to somebody, you could give these people a ring and arrange something." Beth articulated how her views correlated with those of the first round of interview participants regarding how helping others could assist with self-healing.

Several reasons for the emphasis placed on access to fellow survivors were apparent: as an outlet, and to help relieve internal pressure to put on a brave face and conceal concerns from loved ones, for fear of adding to their stresses:

Most of the time there's stuff going on, and you won't let anyone know (Sarah).

It's not because you haven't got family who care, or anything, it's just that you try and be strong for other people, not necessarily for yourself. You try and keep yourself afloat, plug up the holes, keep floating along, for everyone else. Because it makes everyone else feel better, that you're doing okay (June).

Participants particularly related to a theme identified after the first round of interviews regarding changing as a person and the need to mask true feelings, agreeing that this was a common feature of their behaviour post diagnosis. Although present in the BCNZ resource, these experiences are addressed less directly in regard to the possible pressure to be positive and get on with life. Participants warmed more to the voice of other bowel cancer survivors in the present studies findings, rather than that in the text of the published resource.

Although the desire to talk to others who had had bowel cancer came through strongly, this did not appeal to all participants, particularly regarding group situations. When referring to the possibility of attending a group with other survivors, Sam acknowledged that it was *"just not me"*. Other participants specified their reasons for not considering support group attendance were to avoid concentrating thoughts on their cancer, or because they did not feel comfortable sharing their difficulties with stoma management: *"I don't want to be in a group where we talk about cancer or that's the focus"* (Stella); *"I can't talk publicly about my condition"* (Merina).

Discussion

Relatable people

After treatment conclusion, individuals commonly do not exhibit physical indicators of their disease; this can contribute to feelings of isolation as others surmise that the survivor has returned to their pre-cancer self and, therefore, no longer requires support (Drury et al., 2020). Fellow bowel cancer survivors understand that this is often not the case, and so hearing from and/or communicating with them can provide an optimal way

to receive information. In the present study this was particularly evident when a participant commented that they had appreciated the opportunity to talk about their experiences with a fellow bowel cancer survivor during the interview process. As peers based their comments on a shared identity and experience, they have more impact than generic information provision (Embuldeniya et al., 2013) and can be provided face-to-face, either one-to-one or in a group situation. Such direct peer support provides an opportunity for bowel cancer survivors to share concerns openly with someone who may have had similar experiences and potentially receive advice as to how to deal with such difficulties. Findings from the present study suggest hearing the voice of a recognisable and relatable person - either via them speaking on a video, quotes from a named person, or someone they can link up with – has benefits that outweigh being told information by a health practitioner or organisation.

Evidence reported in the literature supports the use of such a personally relatable strategy, as opposed to information presented as universal and applying to everyone, with personal stories suggested as a means of building health literacy (Sentell et al., 2020). In addition, self-management literature emphasises the value of sharing information about people's lives. A pilot randomised trial involving participants referred for diabetes education found that a group involving informal stories told by a peer, as opposed to expert or standardised narratives, resulted in 79% attendance compared to 35% in the control group, and significantly higher participant enablement (Greenhalgh et al., 2011). Verification that their perceptions of unique and isolating experiences were relatively common amongst survivors could be comforting and beneficial (Wilson, 2017). Another advantage of hearing the conversational voices of peers is that individuals are not inhibited from gaining information due to a lower level of health literacy, which may be the case with written materials. Low health literacy means some published materials are inappropriate for some cancer survivors (Hart et al., 2015; Wilson et al., 2012).

In addition, participants in the present study anticipated several benefits of discussing experiences with peers, including helping to overcome the barrier of talking about embarrassing subjects such as bowel dysfunction. This topic in Western culture is often viewed as taboo, with discussion concerning it deemed inappropriate or discouraged and, as a result, those affected may avoid sharing their experiences for fear of offending (Chelvanayagam, 2014).

Relatable experiences

A further consideration with regards to relatability, pertains to not only being able to relate to other people, but also the activities portrayed in resources. For example, physical activity is generally represented as some form of exercise, as demonstrated

by the pictures of people in sports attire which some of the present study's participants found objectionable. This narrow interpretation of physical activity does not encompass the wider range of physically active occupations such as the lifting or carrying that may be involved as part of work, or domestic tasks around the house (WHO, 2018). These day-to-day activities may be far more relatable to bowel cancer survivors than attending a gym.

Considering the findings of the present study, combined with evidence reported in the literature, raises the question of whether what is missing from information to people after bowel cancer is a lack of consideration of the impact on people's lives in terms of their sense of self and identity, relationships to people, places, communities, and cultures, and/or their development and growth over time. These are all factors considered within the field of occupational therapy in relation to the concepts of doing, being, becoming, and belonging (Wilcock, 1998, 2006). The consideration of these interrelated factors suggests the emphasis in information provision should not only include relatable people, but also relatable experiences. As reported by Martin et al. (2020a), bowel cancer survivors have a desire to make the most of life and live it to the fullest, suggesting they would benefit from hearing examples from people who are still managing to carry out their favoured activities despite the issues now faced. For example, survivor quotes recounting how they had overcome their fear of swimming with a stoma pouch could provide inspiration to others with the same concerns (Martin et al., 2020a). Similarly, a participant voice explaining how they were still utilising trial and error when making food choices could normalise this for others with similar issues.

Moreover, comparing experiences with other survivors could help improve relationships with loved ones by releasing them from engaging in uncomfortable conversations such as the possibility of recurrence (Choudhury et al., 2020; Martin et al., 2020a; Ussher et al., 2006). Likewise, discussing cancer related events and feelings with peers has been found to lead to improvements in psychosocial well-being and healthy behaviour as experiences are validated and normalised (Daniels et al., 2021; Embuldeniya et al., 2013; Ussher et al., 2006). Post-traumatic growth can also be cultivated, often resulting in positive lifestyle changes (Whiteley et al., 2019).

Mode of delivery

The need for information to be about relatable experiences delivered by a relatable person points to the need for material in multiple formats within a flexible information source. This is particularly relevant as the participants in the present study did not have a consensus as to the 'best' way to deliver information. A flexible resource would enable survivors to focus on the content and media they most relate to. Online delivery could potentially support such a resource, firstly in terms of facilitating direct peer

support and, secondly, regarding accessing the 'voices' of bowel cancer survivors in written and video forms. In contrast, brochures, by their very nature, present a limited range of information and the same information to every reader.

The BCNZ brochure is just such an example, containing a range of images which produced contrasting responses from participants. Some viewed images of people in sportswear as merely representing the variety of people who have had bowel cancer and a means of providing advice regarding lifestyle changes. They acknowledged the need to live a 'healthy' life following their cancer treatment, indicating a need for information promoting increased activity levels and outlining the benefits of such (Goodwin et al., 2020). However, other participants viewed the same images with resentment and felt pressure to live up to what they perceived the picture suggested, for example being engaged in regular exercise.

The varied response of participants to this perceived pressure indicates a fine line between providing information which encourages beneficial lifestyle habits, and that which induces feelings of not behaving in the 'right' way to promote best recovery. Bowel cancer is often perceived as a disease caused by poor lifestyle choices (Drury et al., 2017) which can add to this pressure. These feelings can be reinforced by publications suggesting change, such as to diet, and providing pictures of 'healthy' foods. There is no one picture of an individual that every bowel cancer survivor will relate to, suggesting this is due to how people personally 'read' the pictures.

The benefit of an online source of information is that people could identify and access personally relevant material. An online smorgasbord could enable survivors to hear the voices of other survivors, either in written or video format. This may appeal to individuals who find it easier to read about or watch videos of people talking about issues, especially if they are uncomfortable discussing potentially embarrassing issues, such as with bowel or sexual dysfunction. Such an online site with options regarding what content people select to view would put the control back into the survivor's hands. Thus, the possibility of not relating to images/videos of people due to differences in age or attitudes would be reduced (Hart et al., 2015).

Several examples of survivor voices are currently available online, for example that provided by Bowel Cancer New Zealand (n.d.). However, these tend to focus on stories recounting diagnosis and treatment rather than how people are coping with day-to-day life after treatment conclusion, suggesting a gap in information currently available.

The internet can also be used to promote personal support, for example in the informal peer-to-peer support scheme offered online by Bowel Cancer Australia (2020). Members are provided with the contact details of other bowel cancer survivors to

enable them to contact each other at a mutual time, either on the phone, by email or face-to-face. Ensuring survivors are matched as appropriately as possible is important, as lack of similarity with others can thwart rapport (Embuldeniya et al., 2013). To address this issue, the Bowel Cancer Australia network – supported by bowel cancer nurses and a nutritionist – considers age, region, gender, treatment, and stage of cancer when connecting survivors (Bowel Cancer Australia, 2020). An alternative form of peer support is offered by Bowel Cancer New Zealand via a private Facebook Support Group (Bowel Cancer NZ patient and whanau support group, n.d.). Despite the benefits of peer support, participants in the present study reported difficulty locating and accessing it, aligning with literature that has reported bowel cancer survivors may either not be aware of support groups, or unable to access them (Drury et al., 2020). On occasion, the knowledge as to where and how these services are available may be sufficient to meet survivor needs.

A final point to consider is the timing of information provision. Providing all information at the conclusion of treatment may be overwhelming for some survivors, contributing to confusion and frustration (Arora et al., 2008). Moreover, valuable information can be missed and therefore not taken on board which can negatively impact decision making (Peters et al., 2007). Secondly, survivors may need to hear information more than once for it to be completely understood. Therefore, a system is required to ensure those involved across the care continuum remind survivors of existing information sources.

Strengths and Limitations

The first author's disclosure of her status as a bowel cancer survivor may have enhanced rapport with participants and contributed to data richness. However, this disclosure may have also influenced data collection and analysis as her perceptions were conceivably influenced by her own experiences (Dwyer & Buckle, 2009).

Reflexivity and discussions with co-authors were undertaken throughout the research process to address this issue.

All participants lived in the North Island of New Zealand. Recruitment over a wider geographical area may have yielded different results, especially considering the North Island is considerably more densely populated than the South Island (World Population Review, 2021). To reduce the possible impact of this disparity, participants were recruited from both urban and rural settings. However, most who contributed to this part of the study were from urban areas. Further research is needed from outside of New Zealand to ascertain if the findings are transferable to other geographical areas.

A printed document formed the basis of questions regarding information needs. This was valuable in stimulating discussion beyond participants' individual experiences of

bowel cancer and their perception of information provision regarding life after treatment. However, the use of other forms of information – such as the viewing of videos prior to or during interviews – could have facilitated the gathering of more varied data regarding other mediums of presentation. A further limitation is that four of the five second round participants were female (including one partner). A more even mix of male/female participants may have produced different results.

Conclusion

The findings of the present study concur with previous research findings relating to bowel cancer which found that one form of information can not universally meet the needs of all survivors (Salz et al., 2014; Saunders et al., 2021); there is no one truth that applies to everyone. Each survivor's cancer journey was very personal and individualised but reflecting this reality in a generic resource aimed at bowel cancer survivors in general is challenging. Online resources allowing survivors to choose information they can personally relate to would go some way to addressing this need. The gap between the information provided and survivors' lives needs to be as narrow as possible, with opportunities to hear the voices of others who are living their lives after treatment conclusion an important consideration. Delivery in multiple formats giving access to the voices of bowel cancer survivors – either in person, via videos, or direct quotes in written resources – provides a way of meeting the variable needs of those impacted by bowel cancer.

CHAPTER SEVEN: DISCUSSION

Introduction

This chapter provides a synthesis of the thesis outlining the impact of having had bowel cancer on occupations. The findings from this study – as presented in published and to be submitted articles – are reviewed in terms of what is congruent with the current literature and new insights revealed. Thoughts on how findings could inform future practice and be given practical application are presented. Strengths and limitations of the study are considered, followed by recommendations for future research. The chapter concludes with a personal reflection of my journey towards completing this thesis and my thoughts regarding my onward journey.

It is more than ‘doing’

The scoping review findings reported in Chapter Three indicated that once treatment for bowel cancer was complete, life did not automatically return to ‘normal’ and continue as it was pre-cancer. Rather, six wide reaching occupational domains affected were identified. These included physical functioning, social activity, physical activity, sexual activity, employment and role functioning, and self-care. These domains convey an objective or impartial perspective to the impact of having had bowel cancer. The themes were predominantly associated with participation in, and performance of, occupations, i.e., the doing aspect of Wilcock’s (1998) concepts, rather than the being, becoming, or belonging dimensions. As discussed in Chapter Four, *being* addresses an individual’s sense of self and identity (Gallagher et al., 2015; Hitch et al., 2018; Hitch & Pépin, 2020; Kay & Brewis, 2017), *becoming*, pertains to development and growth over a lifetime, while *belonging* refers to relationships and connection to places, people, communities, cultures, and times (Hitch, 2017; Wilcock & Hocking, 2015).

My findings likewise contained a large *doing* component, but – through analysis of the subjective experiences of bowel cancer survivors – also revealed the occupational impact in terms of their sense of being, their relationships (belonging), and the person they felt they had become. These interlinked dimensions particularly shaped the existential aspects of participant emotional and mental well-being. Recently published work has also identified such dimensions, albeit without using the recognised occupational science terms of being, becoming and belonging (Wilcock, 1998, 2006). For example, Rutherford et al. (2020) and Lim et al. (2021) – along with identifying the doing aspects mentioned earlier – reported on changes in body image and perception of self, and the associated distress. Saunders et al. (2021) also commented on survivor

issues with identity and self-confidence as they struggled to “rectify the people they were before rectal cancer and surgery, with their postsurgical selves” (p. 4). The same authors also referenced participant distress at having to miss out on attending family functions, with the associated impact on sense of belonging and purpose in the world evident.

The occupational focus used throughout my study provides insight into the nature of these and other challenges experienced by survivors. Thus, analysing the meaning of what people do in addition to the practicalities of what to do and how to manage situations has benefits. The examination of the benefits of self-management groups in Chapter Five sheds further light on this. While the sharing of ideas as to how to manage issues such as bowel dysfunction were viewed as beneficial, a focus on belonging is also clear with survivors united by similar experiences (Drury et al., 2020). Some participants in my study yearned for the opportunity to share their own experiences and thus strengthen their sense of belonging to the bowel cancer survivor community. They were happy to acknowledge how the disease had shaped the person they had become and identified themselves as a cancer survivor. In contrast, others, while being happy to share their experiences with me as a fellow bowel cancer survivor, did not wish to do the same with others. This was partly because they did not want their identity and sense of being to be tied up in their condition, articulating how cancer did not define them. Literature reports similar findings as survivors “feared being labelled or defined by their disease” (Drury et al., 2020, p. 7) and admitted “it’s defining me in a way ... I don’t want to be defined” (Saunders et al., 2021, p. 4).

These examples highlight the benefits of qualitative research, as also considered in Chapter Three. While the quantitative studies identified in my scoping review reported statistics and tables and were valuable in giving a broad overview of the impact of having had bowel cancer, it is the qualitative studies (including my study) that delved deeper and provided richer, more personal data. This enabled the findings to go beyond the doing and recognise the other aspects of the occupational impact, encompassing being, becoming, and belonging. The analysed data in my study also identified how people manage the occupational impact of bowel cancer, a thread throughout the four articles presented in previous chapters. Practical strategies referred to included taking extra provisions such as ostomy supplies when travelling, being aware of the location of public toilets, and altering diet to reduce negative impacts such as excessive bowel motions. Strategies to manage the emotional aspect of having had bowel cancer are also common within the articles, such as increasing exercise to relieve stress, and sharing experiences with other bowel cancer survivors.

Negative and positive changes

The literature reviewed in Chapter Three primarily catalogued occupations that were negatively impacted, making links to ongoing symptoms that interrupted engagement in those occupations. Literature published since the scoping review was carried out has continued to report along similar lines. For example, Loh et al. (2020) reported on limitations related to employment, volunteer, leisure, and social activities, and instrumental activities of daily living. In their meta-synthesis of qualitative studies describing bowel cancer survivors' experiences, Rutherford et al. (2020) identified themes such as physical functioning, social functioning, physical symptoms, sexual functioning, and employment. Lim et al. (2021) also reported on functional limitations and how physical symptoms hindered return to employment in a systematic review of qualitative studies.

My findings likewise identified negative adjustments, with participants significantly impacted physically, mentally, and spiritually. However, rather than merely categorising these impacts, the qualitative design of my study enabled the co-construction of accounts of related participant experiences. This provided knowledge as to *how* participants experienced these impacts, as well as *what* they experienced. For example, they expressed their frustration at having to accept limits regarding what they were now able to achieve, reducing their participation in some occupations, and having to force themselves to do things, such as eating/not eating certain foods – or indeed eating altogether. They also conveyed anger about not having financial access to a suggested diet, the pressure to exercise, having to reach compromises with sexual partners, and the feeling of being judged for getting bowel cancer in the first place.

Alongside this negative view, many of the same participants paradoxically talked of the positive impact of having had bowel cancer more in keeping with the 'Do-Live-Well' message encompassed by Moll et al. (2015). The authors are occupational therapy researchers who have created a 'Do-Live-Well' framework based on evidence related to the links between people's everyday occupations and their health and well-being (<http://dolivewell.ca>). When considering the dimensions of experience referred to in their framework, several links can be seen with my participant experiences and views of life. Examples are presented in Table 8.

Table 8: Findings examples related to dimensions of experience

Dimension of experience (Moll et al., 2015)	Example from my findings
Activating your body, mind, and senses	Engaging in physical activities not considered prior to cancer, such as running an ultra-marathon and cycling around New Zealand
Contributing to community and society	Acting as consumer representatives for cancer organisations
Taking care of yourself	Improving eating habits, such as reducing sugar intake
Experiencing pleasure and joy	Prioritising pleasurable occupations over paid employment

This positive view of the impact of having had cancer is recognised within the concept of post-traumatic growth where people who have experienced a traumatic event find meaning in and positively reinterpret the event (Marziliano et al., 2020). This concept has also been identified within the bowel cancer survivor literature. For example, Occhipinti et al. (2015) conducted a longitudinal study where the post traumatic growth of 1966 bowel cancer survivors was tracked from just after diagnosis to five years, and Jansen et al. (2011) explored the concept five years post diagnosis in 483 bowel cancer survivors. Both studies reported the presence of post traumatic growth in their populations, with the latter authors stating moderate to high levels in 46% of participants.

Whilst Jansen et al. (2011) provided results across three scales (spiritual change, appreciation of life, and new possibilities) that were correlated with QoL, Occhipinti et al. (2015) utilised a five-point scale measure with three sub-scales (personal growth, interpersonal relationships, and acceptance of life's imperfections). Results for both studies were quantified using means and percentages. Whilst such quantitative data has value in providing information regarding the magnitude of post-traumatic growth experienced, it does not provide qualitative knowledge regarding *how* this growth was experienced. The scales listed above appear to naturally link to Wilcock's concepts, for example spiritual change and personal growth can relate to being and becoming, and interpersonal relationships to belonging. Considering these aspects, a qualitative study could explore the significance of this growth. Examples can be found in my study regarding the positive identity some participants felt as they viewed themselves as strong enough to cope with the challenges cancer had presented them with. Additionally, some made lifestyle changes to live a healthier life, such as increasing exercise and improving dietary choices.

The identification and verbalisation of the overall experience of having had cancer within my participants – and literature – suggest value in considering how health is viewed within this population.

Participant view of health

Rather than seeing health as merely the “absence of disease” (WHO, 2021, para 1) and in biomedical terms, my participants readily talked about health in the well-being sense of doing things that were important to them. From this ‘doing well’ perspective, they were taking action to restore their social, emotional, and spiritual well-being, along with physical health, with the aim of leading a life which was personally meaningful to them. This was particularly evident in the “Life’s too short” theme discussed in Chapter Four, which highlighted the sense of making the most of their anticipated lifespan. Participants had experienced a serious health scare that had made them aware of their mortality and conscious of how their life could be limited.

They also recognised the importance of engaging in certain physical occupations to assist with improving mental health, talked of the importance of maintaining relationships with friends and family and associated social activities, acknowledged the emotional impact of having had bowel cancer and how that influenced occupational choices and routines, and considered spiritual well-being in terms of cultural practices and the lessons that could be learned from the cancer experience. Through their occupations they felt connected to family and friends, the natural world, and cultural traditions, all contributing to their sense of being, the person they were becoming, and their sense of belonging to people, their environment, and their identified culture. Through these connections they were able to meet the need to experience a positive identity and a sense of self-worth (Hammell, 2017).

Within this multi-dimensional view of health, participants also had a medical focus, as demonstrated by their fear of recurrence and lingering side effects such as peripheral neuropathy, results also reported by Lim et al. (2021). The portrayal of health in the media also tends to be biologically focused, with emphasis on people being ‘cured’ of cancer in terms of having no evidence of the disease in their body (known as NED or remission), aligned with a strong emphasis on screening and treatment. This view of health is demonstrated in Healthy People 2030, a framework produced by the US Department of Health and Human Services (n.d.). This framework has the aim of improving “health and well-being over the next decade”, and yet its clear focus on occurrence, screening, and treatment discounts the wider aspects of health and well-being identified as important by the participants in my study.

When considering health in relation to those who have had bowel cancer, it is valuable to remember that “health and illness are not mutually exclusive” (Wilcock & Hocking, 2015, p. 7). Studies relating to bowel cancer corroborate this view, with Cuthbert et al. (2021) reporting survivors’ views of health altered throughout their cancer journey and former views of the meaning of health were challenged. An editorial also supports the view that “health is not a fixed entity” (The Lancet, 2009, p. 781), but rather is dependent on circumstances, varying for each person and defined according to their individual functional needs. Huber et al. (2011) proposed a shift in emphasis from the WHO definition of health towards viewing it as “the ability to adapt and to self-manage” (p. 2). Valid as this updated definition is, it does not give any indication as to the nature of the adaptation. Based on the findings from my study, I would argue that this is implicitly occupational. On numerous occasions participants related examples of adapting their daily activities in an attempt to improve their health and well-being. Examples include reducing work hours to spend more time on personally fulfilling occupations and changing a main form of exercise from cycling to running due to the physical challenges of manoeuvring a bicycle.

Participants in my study demonstrated this ability to adapt in the way they went about their lives but did not find this easy. They expressed distress at having to go through this process alone, due to not only the lack of available professional support, but also the absence of knowledge regarding the occupational challenges to be faced as a result of their changing health status. Their health and well-being were threatened due to the lack of this knowledge, as they used trial and error – often including a lot of error – when struggling to make sense of how to live and who they could be in their post-cancer world. The valuable understandings of how to live and adjust to changed circumstances provided by the findings of my study hold promise for improving health and well-being for bowel cancer survivors.

A sense of abandonment

Participants identified an abrupt shift from receiving intense health professional support during treatment, to minimal input at its conclusion. They expressed feelings of abandonment and frustration at having to fend for themselves when accommodating the long-term effects of their cancer. Having health services dramatically reduced is clearly not working for many bowel cancer survivors (Drury et al., 2017; Ho et al., 2016; Knowles et al., 2013). This is a situation common for cancer survivors generally (Newman & Hunter, 2020), despite the WHO (2020) recommendation that “survivorship care should be adapted to the needs, preferences and resources of each patient ... and be delivered after completion of treatment” (p. 96).

The feeling of being deserted, allied to the variety of ways people are affected, suggests a need for increased health professional input after the acute phase of treatment is completed. Treatment provided by general practitioners is not able to meet all the needs that participants identified, because their expertise lies in medicine and the challenges experienced by survivors are predominantly occupational and existential. As suggested in Chapter Five, the areas impacted, such as reduced capacity or will to return to work, reduced physical function, and reduced engagement in physical activities, all point to a place for occupational therapy due to the profession's unique role in facilitating occupation (Pergolotti et al., 2019; Rijpkema et al., 2020; Wallis et al., 2020). However, no participants in my study reported any input from an occupational therapist post-treatment. Although the small sample size of my study indicates this may not be representative of all bowel cancer survivors in New Zealand, a scoping review highlighted the limitations of literature exploring the occupational role in cancer care in general (Wallis et al., 2020) and suggests this may be the case generally. The review considered 89 papers, including a range of research studies, grey literature, reviews, practice analyses, and an editorial. The authors reported a diverse ranges of occupational therapy roles, but these were predominantly descriptive, with sparse evidence regarding treatment outcomes. They concluded a lack of research and discourse within the occupational therapy profession across the cancer continuum.

The case for occupational therapy input

My findings also highlight the reciprocal relationship between participation and body structures and function as outlined in the ICF (WHO, 2001). It is to be expected that disruption to body structures and functions will impact participation, however, disruption to participation can also disrupt body structures and functions. This is demonstrated when participants no longer engaged in previously enjoyed physical activities due to the effects of their cancer, which negatively affected them psychologically. This finding is reflected in other studies where a positive correlation has been found to exist between depression and the need for meaningful occupation (Eakman, 2015). Engagement in chosen occupations supports both mental and physical health (AOTA, 2020b), is essential to human well-being (Hammell, 2017), and can build the foundation for life satisfaction (Goldberg et al., 2002). The significant impact on the occupations of my participants, aligns with results reported in the literature. This highlights the harm to health of *not* receiving clear and personalised guidance about occupational choices and routines. Utilising “the power of occupation” (AOTA, 2020b, p. 10) can promote well-being.

In Chapter One I referred to the suggestion from Drury et al. (2017) that health professionals have a duty to ensure bowel cancer survivors' needs are met after treatment conclusion. In order to do this, areas of strength and need should be identified, understood, and assessed thoroughly. With its focus on occupation, occupational therapy is a profession uniquely positioned to meet this duty and help to prevent the occupational impacts and consequent negative impact on health. As Lyons (2020) proclaimed, participation in meaningful occupation is occupational therapy's fundamental therapeutic modality. However, the form occupational therapy input should take is unclear, given the diversity of experiences reported by my participants. For example, some were intensely focused on the food they consumed and sought dietary advice, whereas others vehemently rejected guidance they felt was unattainable to the average person; some were planning to carry out extreme activities – such as an ultra-marathon – whilst others were reticent to even walk around their local neighbourhood; some wanted fellow bowel cancer survivors to talk to, and others rejected the idea of any form of peer support. This finding aligns with the guiding ID principle recognising that within human experiences, reality involves many realities that can be contradictory (Thorne, 2016), also reflected in the findings discussed in Chapter Four. Saunders et al. (2021) also reported variations amongst the experiences of rectal cancer survivors, particularly in terms of lifestyle and attitudes. As the experiences of participants varied so considerably, it follows that effective assessment is required to determine individual areas of need. The potential approaches to the form this assessment could take were discussed in Chapter Five and further considered later in this chapter.

Links between adaptation, self-management, and occupational therapy

Earlier in this chapter I referred to a shift away from the WHO definition of health towards the ability to adapt and self-manage suggested by Huber et al. (2011). This shift is reflected in Chapter Five with the suggestion that occupational therapy's role with cancer survivors may involve developing self-management strategies. Self-management is already a practice used within occupational therapy, with a theoretical approach of behaviour change focused on fatigue and stress management reported (Richardson et al. 2014). In addition, making decisions, solving problems, and performing actions are encompassed within self-management in occupational therapy (Stern, 2019).

Self-management refers to an individual's capacity to monitor their condition, and manage behavioural, cognitive, and emotional responses (Barlow et al., 2002). Self-management offers individuals the opportunity to move towards a point where they are

empowered to take control of their lives, using strategies to reconstruct their lifestyle, and improving overall QoL (Lemoignan et al., 2010). Input with such a focus could potentially help people adjust to the psychological and physical changes experienced post-treatment (Boland et al., 2018; Yang et al., 2020). Yet the time required to enable life changes to be put into place to promote well-being is often not provided by health services (Wilcock & Hocking, 2015). This is illustrated by the very limited health professional input after bowel cancer treatment conclusion. If clients were introduced to the idea of self-management and encouraged to implement it via initial occupational therapy input, they may be able to continue implementing strategies independently once health professional input concludes.

Self-management can also be facilitated through information provision, as suggested in Chapter Six. The development of a flexible source, providing information in various forms, could enable bowel cancer survivors to live their best life, particularly when attention is given to the concepts of doing, being, becoming, and belonging. An application of these interrelated concepts within resources would encourage an emphasis on both relatable people and experiences, both identified as important considerations from my findings.

The role of assessment

Findings from the study as presented in Chapters Three to Six have raised areas to consider that will now be discussed, beginning with links to the ICF (WHO, 2001). Given this global framework's acknowledgement of the connection between occupation and health, and because my findings identified several ICF domains of both body functioning and activities and participation impacted, it is worth considering in relation to my research.

The potential of an ICF Bowel Cancer Survivor Core Set

Several subsets of ICF categories have been developed containing lists of the categories considered most relevant for certain health conditions (Karlsson & Gustafsson, 2012; Selb & Cieza, 2021a). These 'core sets' are developed using a standardised process. The goal is to provide tools for assessing and reporting the functioning of an individual with that health condition, with the aim of making the ICF practical for regular use (Selb & Cieza, 2021a).

Selb and Cieza (2020b) asserted that the core of any assessment should include information regarding a person's functioning, suggesting that ICF core sets would have value when assessing the needs of individuals who have had bowel cancer. While a core set for bowel cancer has not been created, one for cancer in general has been

proposed (Geerse et al., 2017). This initial Cancer Survivor Core Set (CSCS) was developed using both a Delphi and validation study, and consists of 19 ICF categories, five from the body functions and structures component, eight from the activities and participation component, and six from the environmental factors component. These are presented in Table 9.

To assess if the CSCS contained content sufficient to include the needs of bowel cancer survivors, I aligned the CSCS with the narratives of my participants (as demonstrated in Tables 10, 11 and 12) to gain insight as to how it could be customised for bowel cancer and thus contribute to a proposed Bowel Cancer Survivor Core Set (BCSCS). The categories listed in the third column of Table 9 are those I identified in my study. These were determined by examining each interview transcript and making explicit links to related areas.

Table 9: Categories and domains identified in the CSCS and my findings

ICF Component	Domains and categories identified in proposed Cancer Survivor Core Set (Geerse et al., 2017)	Domains and categories aligning with my findings
Body functions and structures	<i>Mental functions</i>	<i>Mental functions</i>
	B130 – Energy and drive functions	B130 – Energy and drive functions*
	B140 – Attention functions	B140 – Attention functions*
	B152 – Emotional functions	B152 – Emotional functions
	<i>Sensory Functions and Pain</i>	<i>Sensory Functions and Pain</i>
	B280 – Sensation of pain	B280 – Sensation of pain*
		<i>Functions of the digestive, metabolic and endocrine systems</i>
		B515 – Digestive functions
		B525 – Defecation functions*
		B535 – Sensations associated with the digestive system
Activities and Participation	<i>Genitourinary and Reproductive Functions</i>	<i>Genitourinary and reproductive functions</i>
	B640 – Sexual functions	B640 – Sexual functions*
		<i>Muscle functions</i>
		B730 – Muscle power functions*
	<i>Learning and Applying Knowledge</i>	<i>Learning and Applying Knowledge</i>
	D166 – Reading	D166 – Reading*
	D177 – Making decisions	D177 – Making decisions*
	<i>General tasks and demands</i>	<i>General tasks and demands</i>
	D240 – Handling stress and other psychological demands	D240 – Handling stress and other psychological demands*

Mobility

D475 – Driving

Self-Care

D570 – Looking after one's health

Interpersonal interactions and relationships

D710 – Basic interpersonal interactions

D720 – Complex interpersonal interactions

Major life areas

D870 – Economic self-sufficiency

Self-Care

D530 – Toileting*

D570 – Looking after one's health*

Interpersonal interactions and relationships

D710 – Basic interpersonal interactions

D720 – Complex interpersonal interactions

**Environmental
Factors**

Support and relationships

E310 – Immediate family

E320 – Friends

E355 – Health professionals

Attitudes

E410 – Individual attitudes of immediate family members

Services, systems and policies

E570 – Social security series, systems, and policies

E580 – Health services, systems, and policies

Support and relationships

E310 – Immediate family

E320 – Friends

E355 – Health professionals

Attitudes

E410 – Individual attitudes of immediate family members

E420 – Individual attitudes of friends

E425 – Individual attitudes of acquaintances

E460 – Societal attitudes

Services, systems, and policies

E580 – Health services, systems, and policies

Note: * Categories that may trigger a referral to occupational therapy

Some of the categories identified in the CSCS are not included in the third column (those identified in my findings). This does not indicate that these categories do not apply to bowel cancer survivors, merely that they were not specifically identified within the data I collected. For example, I did not seek data regarding economic self-sufficiency, and it is possible the category of social security series, systems, and policies was not evident due to the availability of universal health care in New Zealand and because my focus was on health rather than aspects such as income and housing. More categories may also have been identified if a larger sample size had been used.

It is envisaged that a BCSCS could be utilised by health professionals from several disciplines. Areas of need, which could be addressed by clinicians from other professions could be highlighted, triggering a referral to a more appropriate service. For example, a number of the categories identified by my participants indicate occupational therapy could be beneficial. These are denoted with an asterisk in Table 9. Tables 10, 11, and 12 now presented include participant quotes to illustrate links to the identified ICF domains and categories.

Table 10: Participant quotes illustrating domains and categories identified in my findings: Body functions and structures

Body functions and structures	
Mental functions	Illustrative participant quotes
B130 – Energy and drive Functions	The sheer and utter exhaustion (June)
B140 – Attention functions	I lose track of things when I'm reading (June) There are times where I'll forget people's names, or I'll forget words (Sarah) I used to be very, very sharp in my mind and it's slowed it down a bit. I've forgotten some things (Maia)
B152 – Emotional functions	I find, since I've had treatment, I get anxious about weird things. Silly things, not just the woes of the world (Sarah) I know when the stoma's not working well, like at the moment, things like that, my anxiety does go higher. I have that sense of it's something that's not able to be managed and I'm not in control (Stella) I'm terrified of that (recurrence) (Andrew) I'm probably more ignorant and arrogant than I ever was (Cecilia) You do tend to worry about little things a lot more (James) If he got sick, I think he'd worry. If you've got a sore stomach, I think you worry (Donna - partner) I know if I get angry, I can get really, really angry and really, really nasty (Maia)
Sensory functions and pain	Illustrative participant quotes
B280 – Sensation of pain	I've got permanent neuropathy in my feet ... I'm on permanent medication until the end of my life, and that's to stop either the horrifically horrible hot, burning sensations, feeling like my toenails are being peeled off, the pins and needles, or the weird numbness. I don't sleep for about three or four days, being kept awake with pain (Sarah)

I was sore all night. So, I get on my back and rock backwards and forwards and tried to get rid of this and got up and had some Panadol and Codeine and Loperamide ... I hate getting all these cramps (Merina)

Functions of the digestive, metabolic and endocrine systems

Illustrative participant quotes

B515 – Digestive functions

My ability to absorb fluids is dramatically reduced, so I can get really dehydrated really quickly (Sarah)

I've got to make sure I drink lots and lots of fluid. Because I noticed the first couple of times I went, and I didn't drink, the stoma was really dry, and it was pancaking (Stella)

Things like onions I just can't touch. They just go straight through within a matter of an hour ... I'm losing weight now which has got them a bit worried (Ray)

B525 – Defecation functions

The main impact and it's a huge impact, is bowel function ... there is no normal anymore (June)

Because I've got no storage vessel, it just keeps coming out. So, it might not be over in a couple of minutes. It might feel like it's over in a couple of minutes, and I'll get up, leave the bathroom, and have to come back in again. And it'll just basically be a constant cycle for maybe about four or five hours. It will just rotate around (Sarah)

I have a different bowel movement from pebbles to 32 feet of it (Julie)

I'm almost faecal incontinent ... it's got a mind of its own (Ray)

I slept in the lounge closer to the toilet and I didn't make it half a dozen times so that was hard. 2 o'clock in the morning and shit all down the back of your legs (Will)

I have eruptions in the stoma area (Merina)

B535 – Sensations associated with the digestive system

Gassy foods are the other thing. Absolute no go – beans and things like that. Absolute no, no, no (June)

I fart heaps. I can do days when it's just normal. And there's other days where I'm just this toxic cloud (Sarah)

**Genitourinary and
reproductive
Functions**

B640 – Sexual
functions

Illustrative participant quotes

Because of with the catheter, it's caused that problem and I ended up with ED [erectile dysfunction] ... you haven't got it ... it's like something you have and you own and it doesn't work (Ray)

It took me ages to allow my husband to touch me again. I'm worried saying "oh my bag, watch out, watch out, don't forget to watch out for my bag. Don't forget it's got shit in there!" So, things like that, you worry about the bag and the pressure and the man (Maia)

Muscle functions

B730 – Muscle
power functions

Illustrative participant quotes

I do have difficulty with my abdominal muscles ... it's quite scary riding a bike when you haven't got any abdominal control (Sarah)

Table 11: Participant quotes illustrating domains and categories identified in my findings: Activities and participation

Activities and participation	
Learning and applying knowledge	Illustrative participant quotes
D166 – Reading	I don't read in depth. I read more lightweight things, that I don't have to think quite so much about now (June)
General tasks and demands	Illustrative participant quotes
D240 – Handling stress and other psychological demands	<p>Things can tip you over the edge pretty easily. ... if I've spent the whole day faffing around with someone crying because they've lost their teabag, or they've gained a kilo of weight, that's going to piss me off (Sarah)</p> <p>Initially, when you found out you had bowel cancer, though, you actually were a very changed person. You became quite needy, which was lovely. It was really nice. Your softer side came out. You felt vulnerable, obviously (Kathryn - partner)</p>
Self-care	Illustrative participant quotes
D530 – Toileting	<p>Every now and again something goes dramatically wrong, and it's a day or two of just horrendous-ness (June)</p> <p>So, we've got quite good at working out which public bathrooms are open, when, and where. (Sarah)</p> <p>I can spend certain nights sitting in the bathroom or doing ten or eleven trips backwards and forwards to the bathroom. I lost all my rectum, so I have no storage compartments. So, when stuff needs to come out, it kind of needs to come out. There's nowhere to sit and wait. I always get a little paranoid that as much as I clean myself up after a bowel motion, it might just keep coming. So, it's not that you can just wipe and it's gone. since the surgery, have used perfume a little bit more. I have also invested in wet wipe toilet wipe things. (Sarah)</p>
D570 – Looking after one's health	<p>The thing I've found the most helpful is exercise ... I walk as much as I can every day (June)</p> <p>I can't eat high fibre. My diet is completely counter-intuitive to what you would think would be a normal healthy diet.</p>

It's the complete opposite. It's low fibre, high carb pretty much. (June)

I'm going to do the full Ring of Fire [ultra-marathon]. I've got 20 hours to do 72 km (Sarah)

I go to the gym probably at least three times a week and it might be four. I emphasised in my article about how important it was to maintain exercise all throughout. If there was anything I wanted to get over, it was that message, to continue doing exercise. It's so good for the head. (Stella)

I've virtually cut out sugar, with the exception I like a bit chocolate. But sugar in my teas and coffees and that, no I never take sugar (Andrew)

We're eating better and getting back into exercise. We get our fruit from Brown Owl so that's organic food and we're eating less red meat (Will)

Interpersonal interactions and relationships

D710 – Basic interpersonal interactions

Illustrative participant quotes

I've got a little bit less tolerance for people's fluffiness (Sarah)

My filter's broken so I find people really inconsiderate, and I can see it (Will)

He's got a quicker temper now (Mary - partner)

It's probably made me put up a few walls, I think. My personal space is a lot smaller than it was (June)

D720 – Complex interpersonal interactions

I'm less tolerant, definitely less tolerant ... I do let these things get to me way, way more than they should (Andrew)

Table 12: Participant quotes illustrating domains and categories identified in my findings: Environmental factors

Environmental factors	
Support and relationships	Illustrative participant quotes
E310 – Immediate family	<p>But I think it probably makes you closer. I think we're much more appreciative of each other. You talk more and be more open with each other (Mary -partner)</p> <p>It's easier being me than being a loved one having to watch it. So, make sure your loved ones are cared for (Will)</p> <p>My Mum was the most amazing help for me (June)</p> <p>The girls are very attentive (Stella)</p> <p>I think for me it has, it's definitely changed it for me a little bit, that relationship, because I do value that more (Andrew)</p> <p>It's brought us closer together (Andrew)</p> <p>It's been hard on the kids. The relationship with the kids. I don't know how many times the kids tell me they love me every day now. They never used to (Will)</p>
E320 – Friends	<p>When I became a person that needed someone to do that (offer support), I lost quite a few, particularly some really good friendships. But I've gained people that were either acquaintances or we knew of them, and they've become really close in our friendship circle. I think I found out who were my good friends, and who weren't (Sarah)</p> <p>I've got a couple of dear friends who are forever asking after me, personally (Merina)</p>
E355 – Health professionals	<p>The lymphedema physio was just amazing, and she said she'd encountered another woman ... who had exactly the same thing – bowel cancer lymphedema. She'd been told by her GP that she was just fat and needed to lose some weight. I did refer myself to a dietician, but that was not very useful, so I stopped that.</p> <p>I had a public health nurse, a district nurse, coming to help me when I came home. She was coming every day to change my stoma bag. And it was a different nurse every flipping day. There was no consistency, so you had to go through this whole thing with someone different every day (June)</p> <p>My stoma nurse was probably the one that got me through more than anything. She kept in touch for quite a few</p>

months after I had my reversal, just to touch base (Sarah)

That doctors don't know everything. That there are people who should be doctors, and there are people who shouldn't be doctors (Cecilia)

For a while I was really frustrated with the medical side. They don't tell you what to expect (Ray)

Attitudes

Illustrative participant quotes

E410 – Individual attitudes of immediate family members

The way we see it, he had a cancer, it's been taken out, it's time to carry on. I wouldn't actually call James a cancer victim, or anything like that (Donna - partner)

He used to feel like he was being a burden to me. Just be kind to yourself. You've bloody had cancer and it is hard work and it is all of those things, so if you feel like shit or if you've got a short temper and stuff it's fine (Mary - partner)

I just say I'm doing my bit and making it easier for her (Robert - partner)

E420 Individual attitudes of friends

It's annoying dealing with people when you're out, saying, "I can't eat this, I can't eat that". It's like you're just doing it to be a pain, you're being difficult, or you're on some wacko diet (June)

I had a few mates here. When I told them I had cancer they didn't want to be near me, and they were like this [turns away]? And a lot of them didn't want to be near me and I guess what I put it down to was they were scared they might catch it (Maia)

E425 Individual attitudes of acquaintances

There were some people who were visibly different, and almost like you were contagious. They didn't quite know what to say or do, so they kind of kept away (June)

Some of my work mates were very, "Oh, she's going to die" (Sarah)

E460 – Societal attitudes

People are constantly telling you not to be negative (June)

So many people hear about bowel cancer and immediately you've got the funeral dress ready (Stella)

I don't believe I eat meat as much as I used to, because I know that some people talk about a link between cancer and meat as well (Andrew)

Services, systems, and policies

E580 – Health services, systems and policies

Illustrative participant quotes

There's just a dearth out there. Maybe it's changed in the last ten years or so, but once you've finished your treatment, that was it. I was out the door, gone (June)

I never got given any form of support when I was in hospital. I am embarrassed to say that I had an OT and physio come and look at me, but because I could walk up stairs, I was all good. And that is pretty much all I got, no support whatsoever. I would get all the support – everyone would jump out of the woodwork when I had cancer. The moment I got discharged from oncology because I no longer had cancer, nothing (Sarah)

Once you've finished your surgery the hospital don't want to know (Ray)

You're entitled to 12 sessions with lymphedema physios. So off I went, organised all that for myself, got a referral from oncology to the lymphedema physio, and have never looked back. But that took months of me beavering away, asking people, badgering people (June)

I almost have the wrong type of cancer. If I'd had breast cancer there's all this support out there (June)

As illustrated in Table 9, although the CSCS corresponds with several categories identified in my findings, there are also a number which are not recognised, including the areas of toileting and digestion. The relevance of the CSCS to bowel cancer survivors is, therefore, corroborated by my findings, but also missing important elements as demonstrated by the illustrative quotes in Tables 10-12. For example, participants commented on changes in defecation and digestive functions, and digestive system sensations. The lack of these components is possibly due to the heterogenous nature of cancer sequelae, and consequently using a global cancer core set highlights the likelihood of overlooking important differences between cancers.

The associated societal stigma towards bowel function (Chelvanayagam, 2014) adds an extra layer to the occupational impact of bowel cancer and justifies a more explicit tool for assessing client need than the many occupational therapy assessments currently available. A BCSCS would provide a checklist of key areas to guide practitioners as to the areas to broach with bowel cancer survivors and ensure that all important topics of conversation are opened. This is important as my findings highlighted how every bowel cancer survivor's experience was unique and personal. Although there were common themes, distinct differences were apparent; for example, some talked about how their sexual activities had been impacted, whereas for many this was not reported as a significant issue. A BCSCS would enable practitioners to identify areas of need for individuals, rather than assuming these would be consistent for everyone in the bowel cancer survivor population. Such a checklist would also direct clinicians to ask about the potentially embarrassing and difficult areas such as sexual or bowel function, areas which may not be raised due to embarrassment on the part of the client or clinician. Avoiding this 'conspiracy of silence' (Lemus-Riscanevo et al., 2019) would address the desire stated in Chapter One that open communication is enhanced between survivors and health professionals, as individual need, function, and progress would all be evaluated (Grill et al., 2011; Tschiesner et al., 2007).

Core sets can take two forms – comprehensive and brief (Selb & Cieza 2020a). The brevity of the latter version makes it more beneficial in clinical settings (Karlsson & Gustafsson, 2021), indicating its value for health professionals when engaging with bowel cancer survivors and maintaining consistency with ID methodology. A proposed BCSCS could potentially be used in two ways, firstly to contribute to an occupationally focused outcome measure for cancer, and secondly, to assess the content validity of measures currently in use. Both are now considered.

An occupationally focused outcome measure for bowel cancer

The previous section has demonstrated that there is a unique set of domains and categories that were reported by bowel cancer survivors that are not represented in the

CSCS. The absence of these areas relates to the concept of validity and whether a measure assesses the construct it is intended to measure (Polit & Yang, 2016; Steiner & Norman, 2008). Content validity is the extent to which the content of an instrument (items or questions) adequately reflects the construct to be measured and is often viewed as the most important measurement property of an outcome measure (Terwee et al., 2018). It is important that all items included should be relevant for the construct being considered (Terwee et al., 2018). Construct validity determines whether the assessment measures the construct adequately and the content covers all the necessary domains to represent the construct of interest (Aktas et al., 2015). In relation to my study, the construct of interest is bowel cancer and occupations, with findings indicating bowel cancer survivors experience issues in addition to those common amongst the general cancer survivor group.

While there are cancer specific patient reported outcome measures with bowel cancer as a subset such as the European Organisation for Research and Treatment of Cancer (EORTC) QLQ-CR29, and the Functional Assessment of Cancer Therapy-Colorectal (FACT-C) (Smith & Cocks, 2015), neither have a specific focus on occupation. This absence of a clearly defined occupational perspective is problematic, potentially resulting in some of the issues specifically affecting QoL for bowel cancer survivors not being addressed. The present risk from the CSCS is construct underrepresentation for bowel cancer, whereby there are areas of content missing that do not allow for the necessary experiences of bowel cancer survivors to be accurately assessed. This in turn negatively impacts construct validity.

Construct validity should be the main consideration with the development of a new outcome measure for bowel cancer survivors. From first understanding the nature of the construct of interest, the necessary content to include in a valid measure could be determined. The categories listed in the third column of Table 9 go some way to pinpointing the important content to be included in such a measure. An effective outcome measure needs to represent matters of importance identified by those affected (Marshall et al., 2006). As the categories identified by my findings have directly emanated from the experiences of bowel cancer survivors, a measure based on them would have good validity. As Cuthbert et al. (2021) identified, a key goal when working with bowel cancer survivors – and within the healthcare environment in general – is to understand the client experience to facilitate more client-centred care. An outcome measure based on client experiences would go some way towards achieving this. As Pizzi and Richards (2017) claimed, it is vital to evaluate health from the client's perspective, as only the client can determine whether well-being has been achieved.

A BCSCS could be used to develop an occupationally focused outcome measure, providing domains to establish an item pool (Selb et al., 2015), and providing the foundation for instrument development (Karlsson & Gustafsson, 2021). However, the benefits of such an assessment would be impacted by the reliability and validity of the outcome measure; unless these are sound, the outcome measure may be limited in assessing the needs of bowel cancer survivors. When this is the case the measure will have low validity, for example in terms of underrepresentation of constructs (Brown, 2010). This could be the case if only the categories identified in the CSCS were used to develop constructs for a measure to be used with bowel cancer survivors. It is essential for measures to have good validity, not only to ensure they are effective for use with clients, but also because of the potential overall impact on evidence-based practice. As Brown (2010) reports, if researching occupational therapists use assessments with low construct validity to generate data and findings, then the conclusions resulting from such studies will not be sound.

Given the overarching view of health illustrated by the varied experiences of my participants, the dimensions of doing, being, becoming, and belonging would also be valuable to consider within such a measure, and ensure an occupational focus to support adaptation after completion of active treatment. The doing of occupations is the visible, easily recognisable form and, therefore, potentially easier for both clients and health professionals to identify as an area of concern. For example, individuals may be identified as doing things, such as returning to work, indicating that they have reengaged in life. However, occupational therapists look beyond this and consider not just *what* someone is doing, but *how* they are doing. For example, when we consider Stella's experience of swimming for the first time following her stoma forming surgery, other disciplines, such as nursing and medicine, might consider how this is beneficial for her health and well-being, but not how it is enabling her sense of identity as a swimmer, or sense of belonging to the pool environment where she has spent so much time prior to her cancer diagnosis. For Stella, swimming provided meaning to her life. Considering how occupation contributes to living a meaningful life, and the resultant focus on meaningful occupations is what separates occupational therapy from other professions (Hammell, 2004). It enables a focus on QoL enhancement through enablement of meaningful occupation with the understanding that time spent in meaningful occupation contributes to a sense of purpose and value to life (Hammell, 2004). In addition, Eakman (2015) highlighted the distinct relationship between meaningful occupation and meaning in life. These are all relevant areas when considering the health of those who have had bowel cancer, given the reported links between health, well-being, and occupations.

An occupation focused measure would include elements of identity and belonging alongside the functional aspects. Including this as a part of the multidimensional nature of the assessment would increase its validity, enhancing the meaningfulness of the assessment. In turn, the ability of practitioners to undertake a strong assessment and, therefore, improve client outcomes would be strengthened.

Participant narratives in my study went beyond the carrying out of tasks, focusing on how they felt and what they were becoming – whether this was perceived negatively or positively. When occupational therapists consider everyday occupations as experiences rather than merely tasks, it enables them to regard occupations as perceived by our senses, and, therefore, as they are lived (Hasselkus & Dickie, 2021). When the way someone feels when engaged in an occupation is prioritised above the occupation's purpose or outcome, occupational therapists are able to consider occupations that are meaningful to them and support well-being.

Assessment of the content validity of established outcome measures

Secondly, a BCSCS could be used to assess the content validity of already developed outcome measure instruments (Selb et al., 2015; Sengers et al., 2021), such as the Engagement in Meaningful Activities Survey (EMAS) (Goldberg et al., 2002). The EMAS was originally developed to test the hypothesis that there was a relationship between engagement in meaningful activities and QoL, with the survey's first reported application focusing on a population of individuals with severe and persistent mental health illness (Goldberg et al., 2002). Its use has since extended to older adults, with reports the measure had good internal consistency ($\alpha = .89$) and moderate test–retest reliability ($r = .56$) and was valid to use with this age group (Eakman et al., 2010b). Although carried out in the greater Los Angeles area of the US – suggesting differences in culture to Aotearoa New Zealand – Eakman et al.'s (2010b) study does provide preliminary evidence that the tool may be appropriate in the New Zealand bowel cancer survivor population, given that 90% of bowel cancer survivors in New Zealand are over 50 years of age (Health Navigator NZ, 2021). Further evidence for the effectiveness of the EMAS is that it was successfully used to evaluate the effects of occupational therapy on QoL and engagement in meaningful activities among women with breast cancer (Petruseviciene et al., 2018).

Each of the 12 items within the EMAS begin with the phrase “The activities I do...” and are self-rated on a five-point Likert scale. Generally, the scale reflects an individual's belief that their daily activities provide congruence with their needs and values, provide evidence of competence, and are valued within the individual's social or cultural group (Eakman et al., 2010a). The EMAS can be related to the dimensions of doing, being, becoming, and belonging. Table 13 illustrates areas where I believe there are links.

Table 13: Links between EMAS items and doing, being, becoming, belonging

EMAS item	Link to doing, being, becoming, or belonging
The activities I do help me take care of myself (e.g., keep clean, budget my money).	Doing, Becoming
The activities I do reflect the kind of person I am.	Doing, Being
The activities I do express my creativity.	Doing, Being
The activities I do help me achieve something which gives me a sense of accomplishment.	Doing, Being, Becoming
The activities I do contribute to feeling competent.	Doing, Being, Becoming
The activities I do are valued by other people.	Doing, Belonging
The activities I do help other people	Doing, Belonging
The activities I do give me pleasure.	Doing, Being
The activities I do give me a feeling of control	Doing, Being
The activities I do help me express my personal values.	Doing, Being
The activities I do give me a sense of satisfaction.	Doing, Being
The activities I do have just the right amount of challenge	Doing, Being, Becoming

Using an assessment such as the EMAS or a newly developed measure with links to doing, being, becoming, and belonging would encourage a focus firmly based on occupational impact. The incorporation of multiple aspects of the client's doing, being, becoming, and belonging could facilitate collection of data to direct work with survivors. Health professionals do not treat what they have not measured; an appropriate assessment has the power to direct subsequent interventions. Participants in my study reported a desire to be in control of their own lives, a situation common for people whose lives have been disrupted by illness (Cuthbert et al., 2021; Hammell, 2004). An assessment identifying aspects of life which could potentially be improved through interventions where clients manage their own health would support interventions with this focus. This is particularly relevant as post-treatment is a key time for promoting self-management strategies (Cuthbert et al., 2021).

In conclusion, a new measure based on the identified categories suggested above for a BCSCS could provide a valid means of assessing the occupational needs of bowel cancer survivors, ensuring the focus is on their specific areas of need. A focus on the identified needs specific to this population would ensure the constructs and content being assessed are relevant, thereby enhancing both validity and positive outcomes for clients. Moreover, the same information could be used to ascertain whether an outcome measure such as the EMAS is valuable to use with this population.

Strengths of this study

A major strength of this study was the openness with which participants spoke of their experiences and concerns, facilitating rich findings. I believe my adherence to the ID principles contributed to their willingness to share their cancer journey. For example, participants chose the environment where their interview would be carried out and I endeavoured to make them feel as comfortable and relaxed as possible. I feel this was particularly apparent in the relationships I built with the Māori participants. As a British immigrant, the consultation I carried out prior to the interviews helped greatly and ensured that when I entered the home of my Māori participants I behaved in a culturally appropriate manner, putting them at ease and ensuring they did not feel pressured to discuss anything they were not comfortable with. I feel this contributed to them being particularly open and forthcoming. The fact that I too had had bowel cancer enabled a strong connection between myself and participants, as demonstrated by their comments such as “You’ll understand because you’ve been there”, when talking about a particular experience. Acknowledging that the researcher and what is being researched influenced each other in this way contributed to the depth of data.

An additional strength of the study is that participants included both New Zealand European and Māori participants, covered a range of additional criteria such as variations in activity level and rural/urban dwelling, and covered a wide span of ages, from early 40s to early 90s, with the majority of participants over 60. The proportion of participants within the various age ranges generally reflected the demographic within New Zealand where incidence increases with age (Robertson et al., 2017). To mirror the current situation in New Zealand more fully, more participants over the age of 70 could have been included.

The design of the study over three phases was also a strength, with each phase informing the next. The scoping review allowed an understanding of the current state of knowledge regarding bowel cancer and occupations. Completing this process meant the participant interviews could be informed by present thinking around the topic. The second round of interviews allowed the confirmation and expansion of findings from the first round. In addition, the study design and findings have been subjected to peer review through the publication process. This procedure facilitated the refinement and improvement of their reporting.

Limitations of this study

Although my personal bowel cancer experience enhanced the study, I also feel this could have been a limitation. I mentioned how participants commented on how I would

understand what they were referring to as I had had bowel cancer myself. In the earlier interviews I believe this was a disadvantage; because I *did* understand, on occasion I did not follow up on participant comments, thus potentially missing out on more valuable data. However, this possibility was addressed in a supervision session, after which I made a concerted effort to serve as a naïve researcher and ask more probing questions.

A further limitation is that the mix of male to female participants does not accurately represent the current situation in New Zealand. In 2018 the number of registrations for bowel cancer were 1710 males and 1479 females (MOH, 2020b), whereas my participants (excluding partners) consisted of eight females and five males. A mix that more accurately represented the gender split may have produced different results.

The current situation in New Zealand is also not reflected in the ages of my bowel cancer survivor participants. In 2019 the majority (1317) of people diagnosed with bowel cancer were in the 75+ age group (MOH, 2019b), but only 15% of my participants were in this bracket. In contrast, most of my participants were in the 51-64 (38.5%) and 65-74 (31%) age groups which may have influenced findings. For example, those in the oldest age bracket are less likely to have had concerns regarding unemployment, and more comorbid health conditions impacting their occupations.

My performance as researcher may also have impacted the richness of data regarding any changes in sexual activity. I asked all participants if this area of life had been impacted, receiving a variety of responses as reported in Chapter Five. However, if I had probed this area to a greater extent, participants may have been more forthcoming in describing their experiences, and richer data gained as a result. This reticence may have been a combination of neither my participants nor myself feeling particularly comfortable discussing this aspect of life. This situation is reflected in practice, with sexual dysfunction rarely discussed among patients and their health care providers, with barriers such as feelings of embarrassment or inappropriateness identified (Averyt & Nishimoto, 2014; Traa et al., 2014). After reflecting on my own performance as a researcher I also realised I automatically assumed sexual dysfunction would be more of a concern for the younger participants. This view is corroborated in literature with sexuality considered to be less important for older individuals with health care providers making stereotypical assumptions (Averyt & Nishimoto, 2014; Traa et al., 2013).

Finally, while the large number of participant characteristics contributed to the desired breadth, it limited the achievable depth of knowledge for all the different demographic areas of interest. To achieve depth in a broad sample of participants, greater numbers would be required.

Recommendations for further research

Chapter Six included recommendations to increase peer support for bowel cancer survivors, in keeping with the study by Worrall et al. (2021) who identified psychosocial support as the number one area of need for this population. This finding also corresponds with the initial consultation comment from Ann-Maree Murphy (colorectal cancer nurse specialist) that many of her patients would appreciate the opportunity to talk about their experiences. Further research could explore various aspects of peer support currently in place: Does this deliver what is needed? Is it most effective in a group or one-to-one situation? What are the advantages and disadvantages of face-to-face or online/telephone communication? Participants shared that they wanted to talk to someone relatable. Further research could investigate how this might work in practice and whether talking to other bowel cancer survivors makes a difference. In addition, in Chapter Five I suggested an intervention could include group based self-management programmes. Further research could explore the benefits and feasibility of such groups being initially led by health professionals, who in turn train lay members to take over the leadership role. Research could also explore whether self-management group members are more inclined to discuss deeply personal or embarrassing issues with a health professional or fellow survivor leading could be explored.

Also, further research could focus on the effectiveness of self-management interventions within the field of occupational therapy to determine its potential use with bowel cancer survivors. The use of self-management strategies was suggested in Chapter Five, but additional studies could explore whether this is indeed a viable and beneficial option to be used.

Finally, the scoping review findings reported in Chapter Three highlighted a distinct correlation between QoL and participation in occupations. Quality of life is commonly used as an outcome measure with cancer survivors (Arndt et al, 2004; Ganesh et al., 2016). However, within the instruments currently available, there is no clear conceptualisation or measurement of participation in occupation (McMullen et al., 2017; van der Mei et al., 2011). Findings from my study could be used to investigate what QoL outcome measures for cancer survivors should encompass to capture the participation in occupation aspect.

Recommendations for practice

Due to the diversity of experiences reported by participants, effective assessment is vital to ensure identification of occupational needs specific to the individual. The

potential forms this assessment could take include the use of a Bowel Cancer Survivor Core Set based on the identified domain and categories of the ICF relevant to my participants. Additionally, the links made to doing, being, becoming, and belonging suggest assessment based on these concepts would be beneficial in ensuring assessment retained an occupational focus.

The findings suggest a clear role for occupational therapy. However, making specific recommendations for clinicians from this study is problematic due to the small sample size and diversity of participant experience. Nonetheless, findings suggest occupational therapy led self-management provides a potential means of meeting the occupational needs of bowel cancer survivors.

Bowel cancer survivors would benefit from being informed of the potential impact on their occupations and how others have managed this impact. This may consist of adapting their regular occupations or developing new ones. Findings suggest this information would have most value if provided by fellow bowel cancer survivors, either physically or via published material. For maximum effectiveness, published material should contain individuals and experiences that bowel cancer survivors are personally able to relate to.

Finally, educating interprofessional health teams on the impact of bowel cancer on occupations could increase understanding of how bowel cancer survivors' daily lives could be affected. This in turn would raise awareness of the correlation between occupation and health and well-being.

My reflection on this study and my place within it

As stated in Chapter One, my intention when embarking on this study was to make use of my experiences as a bowel cancer survivor and occupational therapist/educator. I wanted to explore the impact of having had bowel cancer on people's everyday lives and highlight their continuing occupational needs and ways in which these could be met. As I reach the end of my study, I feel I have achieved these aims, with a huge amount of learning along the way. Part way through my study, I changed role from a practicing occupational therapist within a DHB, to an occupational therapy lecturer, greatly increasing my knowledge of occupation and enhancing the occupational focus of my work. I am grateful for work colleagues who willingly shared their occupational science and therapy knowledge with me.

I am also conscious that my position as insider influenced the study. I feel writing down my thoughts concerning my own experiences and how these might affect data collection and analysis was valuable in highlighting my own feelings and emotions

before commencing the process. Once I began carrying out interviews, I found it impossible not to relate what the participants said to my own life. However, rather than trying to eliminate this, I acknowledged it and – due to the continual use of reflexivity – was able to keep my focus on participant experiences, rather than myself. I was, therefore, able to represent their experiences and views accurately.

Regarding the methodology, I have grown from being unsure and lacking in confidence at my abilities to use it well, to fully embracing it and recommending ID to work colleagues. Initially, I was looking for more structure from the methodology, but realised over time that this was due to my lack of confidence as a researcher. Over the course of the study, I have appreciated the flexibility offered by ID, as opposed to the more structured approaches of some other methodologies. I also feel it allowed me to embrace my position as insider and integrate this into the research and kept me focussed on how findings could be integrated into practice.

One area where I feel I could have improved the study was to report on the differences in impact dependent on where the cancer was specifically located. Although rectal and colon cancers are both classed as 'bowel cancer', they can have very differing effects on people, which is not reported on in my study. This is another potential area for further research. Information regarding tumour site would potentially need to be collected from a health professional or patient records, as some participants in my study were not aware which part of their bowel had been affected.

A lack of consideration of tumour location may also have impacted the data collected regarding changes in sexual functioning. Literature reports sexual functioning can be impacted for both rectal and colon cancer survivors, but this is more significant in the former. For example, erectile problems were reported in 54% of rectal and 25% of colon cancer survivors; dry vagina in 35% rectal and 28% colon cancer survivors; and pain during intercourse in 30% rectal and 9% colon cancer survivors (Den Ouden et al., 2012). As I did not have information regarding tumour site, I was unable to determine whether any of these findings were reflected in my participants.

My onward journey

As mentioned earlier in this chapter, the development of an ICF core set for bowel cancer survivors could have many benefits and is something I would seek to contribute to in the future. I feel such a core set would provide a means of highlighting the range of areas which can be affected for bowel cancer survivors and would go some way to ensuring the important topics of conversation for each individual are opened, thus identifying all the potentially relevant areas of need. The development of an ICF Core Set involves several steps as part of a multimethod scientific process (Selb & Cieza,

2020a). The first stage involves four preparatory studies: An empirical multicentre study, a systematic literature review, a qualitative study, and an expert survey. The empirical multicentre study applies the ICF checklist to a target group of individuals to identify the problems most experienced. The systematic literature review summarises the literature on the health condition group. The expert survey identifies problems of the target group considered relevant by the experts and professionals who commonly treat them. The qualitative study reflects the view of individuals living with the health conditions. Following this stage, the results are used to form the basis of a structured decision-making and consensus process at an international conference, leading to the production of the first version of a core set. This is then tested and validated (Selb & Cieza, 2020a).

The development of an ICF core set would be a major project, involving the collaboration of many researchers. However, I feel that my experience completing this study would mean I have the skills to contribute to the qualitative study of stage one. The number of conditions addressed by ICF core sets is continually increasing, with seven subcategories including cancer which has core sets for breast, and head and neck cancers (ICF Research Branch, 2017). Noten et al. (2021) have recently published a study outlining the development of a core set for cerebral palsy, indicating the work is ongoing and has value. Contributing to the development of a BCSCS would also enable me to move from a sole researcher to working with research partners. I am now employed as an occupational therapy lecturer which offers possibilities for collaborations; I am in close contact with academics with diverse health backgrounds, many of whom have research experience and whom I would be looking to form research partnerships with.

I envisage using information identified in my findings as the foundation for developing a new outcome measure for bowel cancer survivors. Earlier in this chapter, I discussed how I had identified the constructs that could be used within such a measure. In the future I would like to further develop these by breaking them down into core constructs and then potential items. If this information was published, it could attract others who have an interest in bowel cancer and occupations and lead to a co-developed project.

As explored in Chapter Six, the resources currently available were not meeting the information needs of bowel cancer survivors. A participatory action research study could involve service users in developing resources designed for groups who do not relate well to what is currently available. Such a co-designed study would harness the combined knowledge and experiences of service users (bowel cancer survivors) and researchers, thus benefitting service users, researchers, practitioners, research processes and research outcomes (Slattery et al., 2020). As such, produced resources

are more likely to be valid and acceptable to the people they are aimed at (Jessup et al., 2018). One population group who could be involved in such a project are Māori, due to the well documented health disparities between Māori and non-Māori (Pitama et al., 2014). Although registration rates of bowel cancer are lower amongst both male and female Māori than for non-Māori (MOH, 2017, 2018), there is a rapidly increasing incident rate amongst Māori (Shah et al, 2012), who are younger at diagnosis (Robertson et al., 2017). Moreover, the median age at diagnosis needs to be considered in regard to Māori incidence rates. In the period 2007-2008 the median age of diagnosis for bowel cancer was 73 years (Sharples, et al., 2018). The average age of death for Māori males generally is 73, and females 77 (Stats NZ, 2021), which would naturally impact the number of Māori who develop bowel cancer. In my study, participants commented on the perceived expensive foods and exercise clothes presented in the BCNZ information booklet shared with them. Considering the working age Māori population receive on average \$140 less per person, per week than non-Māori (Schulze & Green, 2017), the development of a resource containing more realistic advice and information could be of benefit to this population.

A further consideration is that while publication in journals and presentations at conferences can be an effective mechanism for portraying findings to health professionals, this is not appropriate to reach bowel cancer survivors. My participants clearly indicated interest in being able to access information directly from relatable people, suggesting my findings are not presented in the best format for them to make use of the insights generated. This indicates a need to consider more accessible dissemination strategies for this population, particularly as the written format of the BCNZ resource was not preferred by all participants. I will, therefore, consider alternate, and more effective, means of disseminating my findings to bowel cancer survivors.

I would also like to use my knowledge as an insider researcher to submit a reflective autoethnographic piece for consideration for publication in a journal. I have learnt a substantial amount throughout the course of this research, particularly regarding the benefits and pitfalls of having had similar experiences to my participants. I was initially nervous and felt the weight of doing justice to them and their experiences but found this was lifted somewhat as soon as I began my interviews. I felt a bond with my participants that I did not expect to feel with complete strangers. This was manifested through the feeling of being in the same 'club', which others who had not had the disease could not join and would not understand. This had huge advantages in quickly building rapport and enabling participants to be honest and open, safe in the

knowledge that they were talking to someone who could understand and would not be shocked or disgusted at comments regarding bowel dysfunction, for instance.

Despite the benefits of having had the same disease, I was grateful that I had done some pre-reading regarding insider research before embarking on my data gathering. This emphasised the importance of constant self-reflection to ensure I avoided the common pitfalls such as focusing on my own experiences rather than my participants'. I found it a huge privilege to spend the time with my participants and am proud of what has been achieved. I would be keen to share my thoughts on my journey to assist others considering research from an insider perspective. Whilst some disciplines such as social work (Chammas, 2020) and psychology have considered this perspective (Breen, 2007), and some occupational therapy focused publications refer to using the concept (Mortenson & Dyck, 2006), I was not able to find any literature which has a specific focus on the experience and impact of being an insider within occupational therapy specific research. I therefore feel it would be a valuable area to consider for potential publication.

I also intend to continue to use the knowledge I have gained from this study and apply this to the role I hold as consumer representative for Cancer Trials New Zealand (CTNZ). When I began the role, I only had my own experiences to draw on, but now have greatly expanded my knowledge through listening to the views of thirteen other bowel cancer survivors and some of their partners. I hope to be influential in terms of being informed by my own research to assist with other studies directed by CTNZ.

Finally, in using the BCNZ resource with my participants, I have an understanding of how the publication is viewed by some individuals who have had bowel cancer. Therefore, I am uniquely placed to provide the organisation with feedback, which is something I will consider.

Conclusion

This study has generated greater understanding of the relationship of surviving bowel cancer and people's daily occupations, demonstrating that when treatment for the disease has been completed, life does not automatically return to 'normal' for those affected. Rather, attempts are made to manage the ongoing effects in the post-cancer world, to varying degrees of success. While this finding is not completely new, this research expands understanding of how these ongoing effects impact people from an occupational perspective. Looking through this occupational lens has highlighted how survivors adapted favoured occupations, or indeed relinquished them altogether. In some cases, significant losses in occupational satisfaction were reported, as previously enjoyed occupations were no longer possible, certainly not to the same degree.

The findings provide important information to health professionals; end of treatment does not signal the end of the bowel cancer experience and it is crucial that clinicians are alerted to this knowledge. Survivors have needs that are not currently acknowledged or met, many of which are related to limitations in participation in occupation. This suggests an obvious place for occupational therapy, but the profession is currently a predominantly underused source of support for this population. This study has highlighted a potential means of increasing occupational therapy input through the use of group-led self-management. This taps into the identified desire for increased contact with others who have had the same disease, whilst also providing a more cost-effective form than traditional one-on-one therapy (Hay et al., 2002; Lamb et al., 2010). This would afford a way for survivors to be supported to live the life they want, rather than a life determined by bowel cancer.

This study has demonstrated how experiences of doing, being, becoming, and belonging are affected for bowel cancer survivors. While the impact on doing is to be largely expected – due to bowel cancer’s well documented impact on bowel function for example – the finding that some people become someone/something they would not have wished for is more surprising. Survivors recognised this change but were struggling to accept it. The new knowledge generated by this study has not been reported in the literature, particularly that focused on occupational science. This suggests a challenge to occupational therapy and occupational science communities to consider these established concepts in other areas of research.

The co-constructed findings of this study have identified the main occupational areas impacted by having had bowel cancer. The ICF, a proposed cancer survivor core set, and an occupation focused assessment have been utilised to systematise this information. New knowledge regarding the construct of bowel cancer survivorship from an occupational perspective has been described and has potential application to developing a bowel cancer specific outcome measure. A number of outcome measures are currently used in cancer care, but there is a deficit of items addressing participation in occupation. My study provides the information required to develop such a measure.

Final Comments

At the heart of this study was a desire to identify and highlight the occupational impact of having survived one of the most commonly diagnosed cancers in New Zealand. My experiences had made this goal very personal and provided the motivation to begin the research once my own treatment was complete. As a recently graduated occupational therapist at the time, I was beginning to see the benefits occupational therapy could have. At the completion of my thesis my knowledge of this area has been greatly

increased, both generally and in relation to those who have had bowel cancer. I have learnt how experiencing a medical condition can impact occupations, the effect this can have physically, mentally, and spiritually, and potential assessments and interventions suitable for bowel cancer survivors.

Working on this thesis has facilitated the development of my research skills while generating new knowledge on a topic very dear to my heart. This combination has inspired me to take my research journey forward as a voice for not only the 18 participants who so willingly shared their experiences with me, but all those whose everyday lives are impacted by bowel cancer.

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Yau, T., Watkins, D., Cunningham, D., Barbachano, Y., Chau, I., & Chong, G. (2009). Longitudinal assessment of quality of life in rectal cancer patients with or without stomas following primary resection. *Diseases of the Colon and Rectum*, 52(4), 669–677. <https://doi.org/10.1007/DCR.0b013e31819eb970>

APPENDIX A: Excerpt copied from reflexive journal

I am in the process of working on my research proposal and feeling a mixture of excitement and nervousness that the study I have been considering for so long is really happening. I feel a responsibility to do justice to the many other people who have had bowel cancer and sincerely want to use my own experiences for good throughout the research process. I appreciate I am extremely fortunate to be in the position I am in and am particularly looking forward to meeting with other bowel cancer survivors and hearing about their journey.

I am expecting the participants' experiences to be very varied. I think some will have a lot to say and have been impacted a lot, whereas others will feel they haven't been that affected. I feel these participants may have been impacted more than they realise and hope the interview questions will tease out this information. If someone had asked me a year ago how my life had been impacted by bowel cancer, I think I would have replied with something along the lines of, "Not that much really". However, after reading a lot and automatically relating this to my own experiences, I feel my answer now would be quite different. I have realised my occupations have been impacted but as this has happened over time, the changes are not so easy to initially identify as if they had happened overnight for instance. It has been a gradual change through surgery, chemo, getting back to work etc.

Preparing for this research has meant my head has been consumed with bowel cancer. I have found myself reliving my own experiences of diagnosis, treatment, and life since completion many times over. Although I do not think this is necessarily a bad thing, I know it's something I need to be very aware of throughout the next few years, both for my own well-being and the success of the research. An overfocus on myself could potentially lead to the study being about myself, rather than my participants, something I am very keen to avoid.

30 March 2018

APPENDIX B: Auckland University of Technology Ethics Committee Approval

20 February 2019

Clare Hocking
Faculty of Health and Environmental Sciences

Dear Clare

Re Ethics Application: **18/411 Exploring the range of occupational outcomes that can be experienced after bowel cancer, and the ways individuals have found to adaptively manage them**

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 20 February 2022.

Standard Conditions of Approval

1. A progress report is due annually on the anniversary of the approval date, using form EA2, which is available online through <http://www.aut.ac.nz/research/researchethics>.
2. A final report is due at the expiration of the approval period, or, upon completion of project, using form EA3, which is available online through <http://www.aut.ac.nz/research/researchethics>.
3. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form: <http://www.aut.ac.nz/research/researchethics>.
4. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
5. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.

Please quote the application number and title on all future correspondence related to this project.

AUTEC grants ethical approval only. If you require management approval for access for your research from another institution or organisation then you are responsible for obtaining it. You are reminded that it is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard.

For any enquiries, please contact ethics@aut.ac.nz

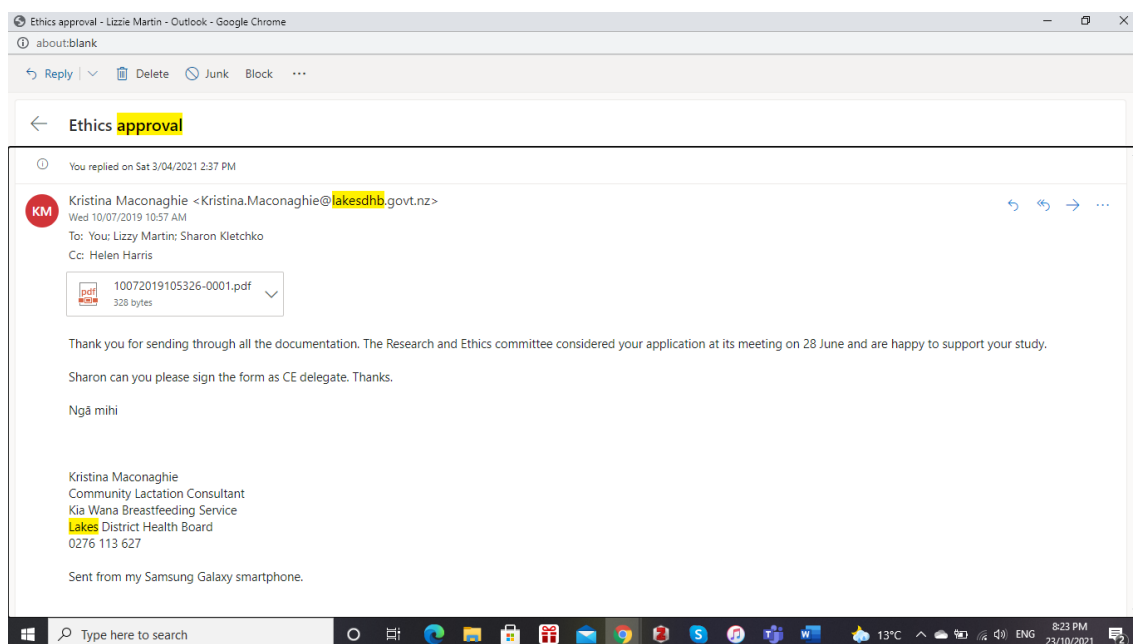
Yours sincerely,



Kate O'Connor
Executive Manager
Auckland University of Technology Ethics Committee

Cc: liz-martin@hotmail.com; Margaret Sandham

APPENDIX C: Email from Lakes DHB Research and Ethics Committee



APPENDIX D: Initial interview guide

Thank you very much for giving up your time to talk to me today. It's much appreciated.

Before we get going, I'll just run through the purpose of the interview and explain what my research is all about. The aim is to help other bowel cancer survivors by increasing their knowledge of the potential effects on their daily activities, and possible ways to deal with these. I'm finding out how bowel cancer has impacted people's lives, so I'd like to hear about your experiences of living after a bowel cancer...what life has been like for YOU.

I'd like to get an idea of your daily activities...the nitty gritty of daily life...the things you *like to* do...the things you do for fun...the things you *need to* do to get through the day...how things might have changed...or maybe not changed at all...both positive and negative things. There are no right or wrong answers, and although I had bowel cancer myself that doesn't necessarily mean that my experiences will be the same as yours.

Because of the nature of bowel cancer – it obviously affects the bowel – I might broach topics you're not comfortable with. If you're prepared to answer that would be really helpful, but you don't need to answer or talk about anything you're embarrassed about or not comfortable with. You are free to say as little or as much as they want during the interview. You can just say *I don't want to answer that can we move on*. You can also stop the interview at any time.

Just a reminder that your comments will all be anonymous. The only people who will know who you are, are myself and my two supervisors in Auckland. Any publications or presentations will use pseudonyms, so nobody reading it will know it's your words.

Interview questions

1. To begin with could you please introduce yourself. Tell me about you and about your life - so things like what your living situation is, how long ago your cancer was, what was going on in your life before diagnosis and how things may have changed since then
2. What impact – if any – has bowel cancer had on the things you do now?
 - Self-care
 - Domestic tasks
 - Social activities
 - Sport/exercise
 - Leisure
 - Spiritual
 - Hobbies
3. Have these things changed over the time since treatment finished?

4. Have you done things – or plan to do things -you wouldn't have done before the diagnosis?
5. You have talked about some of the ongoing effects you experience. Are there others?
 - Bowel management
 - Food intake
 - Fatigue
 - Thinking
6. Have you found ways to manage these things so you can still do the things you want or need to do? Can you share what you do?
7. Are there things you do differently to accommodate ongoing effects? Please explain.
8. Are there times when you do what you want despite the consequences?
9. Thinking about your employment specifically, has there been any change? In what ways?
10. Do you think the ongoing effects have affected your relationships? In what ways?
 - Intimate
 - Family
 - Social
 - Work related
11. When you think about your life overall, has your view of how to live changed at all? Has what's important to you changed? Has what gives life meaning changed?
12. What advice would you give to someone just diagnosed with bowel cancer?
13. Is there anything else you'd like to add regarding how bowel cancer has impacted your life?

APPENDIX E: Flyer advertising the research



Have you had bowel cancer or are you the family member/friend of someone who has?

Would you like to take part in research designed to help others diagnosed with bowel cancer?

If so you are warmly invited to take part in my study.

My name is Lizzie Martin. I am an occupational therapist and am studying towards a PhD with Auckland University of Technology (AUT). I had treatment for bowel cancer myself in 2016.

What will your participation involve? You will take part in one or two online or face to face interviews. Interviews with members/friends can be held separately or at the same time as those who have had bowel cancer.

What will the interviews be about? The interviews will focus on whether/how bowel cancer has impacted your daily activities – and how your life may have changed since your diagnosis.

Does it matter when I had bowel cancer? Anyone who has finished treatment for bowel cancer at least three months before the interview is eligible to take part.

If you are interested in taking part, or have any questions, please contact me on 0272624346 or email tth8191@aut.ac.nz

Many thanks

Lizzie Martin

The research is supervised by Professor Clare Hocking and Dr Margaret Sandham from AUT.

APPENDIX F: Participant information sheet



22 October 2018

Exploring the range of occupational outcomes that can be experienced after bowel cancer, and the ways individuals have found to adaptively manage them

My name is Lizzie Martin. I am a student at Auckland University of Technology (AUT) and an occupational therapist. I periodically work at Rotorua Hospital.

You are invited to take part in a study investigating the effects of surviving bowel cancer on daily activities. The study will help me towards my PhD degree.

What is the purpose of this research?

- The purpose of the research is to explore the impact of bowel cancer on people's daily activities after they have finished treatment. This information will be used to:
 1. Assist people diagnosed with bowel cancer in the future by suggesting strategies to deal with the effects on activities.
 2. Improve the practice of health professionals when treating these clients by increasing their knowledge and understanding of the potential impact on day to day activities
- It is anticipated guidelines will be produced to be used by both people newly diagnosed with bowel cancer and health professionals. Results from the research will be published in occupational therapy or cancer journals and presented at health professional conferences.

How was I identified and why am I being invited to participate in this research?

- You have been invited to take part in the research because you have had bowel cancer and expressed an interest in sharing your experiences.
- In order to capture the range of impacts on activities, participants will be selected including as many of the following areas as possible: rural/urban dwellers, active/sedentary lifestyles, male/female, with/without an ostomy, tumour stages 1-4, and across all adult age ranges.
- A family member or friend is also invited to join the study. Their perspective will help us understand more about how bowel cancer has affected your activities. If no one from your family wants to join the study, you can still join in.



How do I agree to participate in this research?

- You will need to complete a Consent Form to agree to participate in this research which will be posted or emailed to you.
- Your participation in this research is voluntary (it is your choice) and whether or not you choose to participate will neither advantage nor disadvantage you. You are able to withdraw from the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

What will happen in this research?

- I will carry out an interview with you, either face-to-face at your home or online/over the phone. It is anticipated the interviews will take approximately 90 minutes. You will be asked some questions about your daily activities and how having bowel cancer has impacted them.
- The interviews will be audiotaped and then typed. You will be offered a written copy of your interview and an opportunity to comment on accuracy and a chance to make any other comments you feel relevant.
- It is possible you may be asked to take part in a follow up interview at a later date. This might be to clarify/follow up things you mentioned in the first interview, or to give feedback on the draft findings and how useful they might be to others.
- If during the interview you demonstrate a technique or object which you use to help you participate in your activities, I may request a photograph or video recording. If you choose to agree to this, you will be asked to sign an additional consent form.
- You are welcome to have a support person present at the interview/s.
- You have the option of having a Māori support person present at the interviews, who will be provided if you would like this.

What are the discomforts and risks?

It is possible that talking about your experiences during the interviews may make you feel embarrassed, frustrated or dissatisfied if you are not able to take part in the activities you enjoyed prior to your diagnosis.

How will these discomforts and risks be alleviated?

You do not need to answer a question if you do not wish to and can stop the interview at any time.

If you feel distressed and in need of support, the Cancer Society provide a free information service and helpline on 0800 226237 Monday to Friday 8.30 am to 5 pm.

What are the benefits?

- You may find it interesting to talk about your daily experiences.
- You will be helping us learn more about the impact of bowel cancer on daily activities. This information may help other people in the future.
- You will be helping me complete my thesis and PhD degree.

How will my privacy be protected?

- We won't share your information with anyone else without your consent.
- We won't use your name in the report and will remove any information that might identify you.
- Only my supervisors and I can access the research information.
- All the research data will be stored safely and protected with a password at AUT.

What are the costs of participating in this research?

- This research won't cost you any money.
- However, you will spend your time with me, likely approximately 90 minutes for the interview, and possibly an additional 90 minutes if you are asked to take part in a follow up interview.
- Reading through the interview summary and providing any extra information you feel appropriate may involve an additional 30-60 minutes of your time.

What opportunity do I have to consider this invitation?

You will have at least a week to think about whether or not you would like to take part in the study.



Will I receive feedback on the results of this research?

You will be provided with a final summary of the research findings.

What do I do if I have concerns about this research?

- Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Professor Clare Hocking, clare.hocking@aut.ac.nz, 09 921 9162.
- Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTC, Kate O'Connor, ethics@aut.ac.nz, 921 9999 ext 6038.

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

- **Researcher Contact Details:**
Lizzie Martin - Email: tth8191@autuni.ac.nz, Phone: 0272624346
- **Project Supervisor Contact Details:**
Professor Clare Hocking - Email: clare.hocking@aut.ac.nz, Phone: 09 921 9162

Approved by the Auckland University of Technology Ethics Committee on 20 February 2019, AUTC Reference number 18/411.

APPENDIX G: Consent form



Project title: **Exploring the range of occupational outcomes that can be experienced after bowel cancer, and the ways individuals have found to adaptively manage them.**

Project Supervisor: **Professor Clare Hocking**

Researcher: **Elizabeth Martin**

- I have read and understood the information provided about this research project in the Information Sheet dated 22 October 2018.
- I have had an opportunity to ask questions and to have them answered.
- I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.
- I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.
- I agree to take part in this research.
- I agree to take part in a second interview if requested (please tick one): Yes ☐ No ☐
- I wish to receive a summary of the research findings (please tick one): Yes ☐ No ☐

Participant's signature:

Participant's name:

Participant's Contact Details (if appropriate):

.....
.....

Date:

Approved by the Auckland University of Technology Ethics Committee on 20 February 2019, Reference number 18/411

APPENDIX H: Significant other information sheet



12 March 2019

Exploring the range of occupational outcomes that can be experienced after bowel cancer, and the ways individuals have found to adaptively manage them

My name is Lizzie Martin. I am a student at Auckland University of Technology (AUT) and an occupational therapist. I periodically work at Rotorua Hospital.

You are invited to take part in a study investigating the effects of surviving bowel cancer on daily activities. The study will help me towards my PhD degree.

What is the purpose of this research?

- The purpose of the research is to explore the impact of bowel cancer on people's daily activities after they have finished treatment. This information will be used to:
 1. Assist people diagnosed with bowel cancer in the future by suggesting strategies to deal with the effects on activities.
 2. Improve the practice of health professionals when treating these clients by increasing their knowledge and understanding of the potential impact on day to day activities
- It is anticipated guidelines will be produced to be used by both people newly diagnosed with bowel cancer and health professionals. Results from the research will be published in occupational therapy or cancer journals and presented at health professional conferences.

How was I identified and why am I being invited to participate in this research?

- You have been invited to take part in the research because you are close to someone who has had bowel cancer and expressed an interest in sharing your perspective of how bowel cancer has impacted their daily activities.

How do I agree to participate in this research?

- You will need to complete a Consent Form to agree to participate in this research which will be posted or emailed to you.
- Your participation in this research is voluntary (it is your choice) and whether or not you choose to participate will neither advantage nor disadvantage you. You are able to withdraw from the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as

- belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

What will happen in this research?

- I will carry out an interview with you, either face-to-face at your home or online/over the phone. It is anticipated the interviews will take approximately 90 minutes. You will be asked some questions about your friend/relative/partner's experiences of everyday living.
- You are welcome to have a support person present at the interview/s.
- You have the option of having a Māori support person present at the interviews, who will be provided if you would like this.
- The interviews will be audiotaped and then typed.
- You will be offered a written synopsis of your interview and an opportunity to comment on accuracy and a chance to make any other comments you feel relevant.
- It is possible you may be asked to take part in a follow up interview at a later date.

What are the discomforts and risks?

It is possible that talking about your relative/friend's experiences during the interviews may make you feel distressed if they are not able to take part in the activities they enjoyed prior to their diagnosis.

How will these discomforts and risks be alleviated?

- You do not need to answer a question if you do not wish to and can stop the interview at any time.
- If you feel distressed and in need of support, the Cancer Society provide a free information service and helpline on 0800 226237 Monday to Friday 8.30 am to 5 pm.

What are the benefits?

- You will be helping us learn more about the impact of bowel cancer on daily activities. This information may help other people in the future.
- You will be helping me complete my thesis and PhD degree.

How will my privacy be protected?

- We won't share your information with anyone else without your consent.
- We won't use your name in the report and will remove any information that might identify you.

- Only my supervisors and I can access the research information.
- All the research data will be stored safely and protected with a password at AUT.

What are the costs of participating in this research?

- This research won't cost you any money.
- However, you will spend your time with me, likely approximately 90 minutes for the interview, and possibly an additional 90 minutes if you are asked to take part in a follow up interview.
- Reading through the interview summary and providing any extra information you feel appropriate may involve an extra 30-60 minutes of your time.

What opportunity do I have to consider this invitation?

You will have at least a week to think about whether or not you would like to take part in the study.

Will I receive feedback on the results of this research?

You will be provided with a final summary of the research findings.

What do I do if I have concerns about this research?

- Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Professor Clare Hocking, clare.hocking@aut.ac.nz, 09 921 9162.
- Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTC, Kate O'Connor, ethics@aut.ac.nz, 921 9999 ext 6038.

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

- **Researcher Contact Details:**
Lizzie Martin
tth8191@autuni.ac.nz
0272624346
- **Project Supervisor Contact Details:**
Professor Clare Hocking
clare.hocking@aut.ac.nz
09 921 9162

Approved by the Auckland University of Technology Ethics Committee on 20 February 2019, AUTC Reference number 18/411.

APPENDIX I: Researcher safety protocol



Project title

Exploring the range of occupational outcomes that can be experienced after bowel cancer, and the ways individuals have found to adaptively manage them.

Description

This research aims to generate new knowledge for bowel cancer survivors (i.e. any individual living with a cancer diagnosis from the time of diagnosis to the end of life), and health professionals who care for them, regarding the impact of surviving bowel cancer on daily activities and the ways individuals have found to manage them. Two rounds of semi-structured interviews will take place with bowel cancer survivors, along with their significant others, to a maximum of 25 participants. The first round of interviews will include 15-20 participants with a focus on the range of occupational outcomes experienced after bowel cancer and ways found to manage them. The second round will be with 5-10 participants and guided by the insights and themes which emerged in the first round, with participants given the opportunity to reflect on the extent to which findings resonate with their own experiences. Recruitment will be via several organisations, and the primary researcher's personal and professional networks. The same recruitment strategy will be used for both rounds of interviews. An interpretive description methodology will be used implementing concurrent data collection and thematic analysis. Research outputs will include the production of patient and practitioner resources and guidelines regarding the occupational impact of bowel cancer and possible strategies for managing them. The study enacts an ethos of enabling health care recipients to make informed decisions about treatment options and resume responsibility for their everyday lives, will better equip health professionals to support that outcome, and aligns with World Health Organisation imperative to attend to the participation outcomes of healthcare.

Applicant

Professor Clare Hocking

Primary Researcher

Elizabeth Martin

Research Location

The research interviews will take place in participant homes or online/over the phone. Elizabeth will be present at the location. If the participant is Māori , a designated Māori support person will also be present. Participant family members/friends may be present. Elizabeth will receive consent from the applicant to enter the property.

Elizabeth will consult online maps and guides to become familiar with the location prior to each interview. Elizabeth will use her own vehicle to attend North Island location interviews. She will use public transport to attend South Island interviews and will become familiar with services offered prior to each interview.

Data collection and interaction with participants

If the Māori support person is attending the interviews she will be travelling with Elizabeth. Elizabeth's supervisors will be aware of their attendance and the time and location of each interview.

Social/cultural context of the research

Elizabeth has worked with people of all ages, from all walks of life, of many nationalities, and from different social situations in the UK and New Zealand. She has lived in Rotorua for the past 11 years, increasing her familiarity with the Māori culture and developing strong relationships with friends/colleagues who identify with this culture. In addition, she has experience as a bowel cancer survivor herself.

Elizabeth has consulted with her two supervisors, the AUT Mātauranga Māori Committee, and Phyllis Tangitu (Lakes DHB General Manager for Māori Health).

The designated Māori support person is familiar with te reo Māori and will provide language support if necessary.

Safety of researcher activities

The researcher will not be undertaking any activities which are hazardous in nature.

Emergency plans

As a safety precaution, in advance of each face-to-face contact/interview, Elizabeth will set up a person who knows where she is visiting along with the scheduled start of the interview and the proposed finish time. This person will be sent a text message immediately prior to entering the proposed venue and on exiting the venue. Elizabeth's supervisors will also be aware of the time and location of each interview and notified at the completion of each one.

APPENDIX J: Significant other interview guide

Thank you for agreeing to join us for the interview. I'm really interested to hear your perspective regarding how ...'s life may have been impacted by their bowel cancer. I'd like to hear how *you* feel things may have changed for ... and for you as a couple.

The reason it's great to have people close to the person involved too is that you might be able to give another perspective. You might have noticed changes that ... hasn't. Please just chip in at any time even if I haven't asked you a question directly.

Interview questions

1. Can you tell me about your relationship with ...
2. What impact – if any – has bowel cancer had on the things he/she does now? The things you do as a couple?
 - Self-care
 - Domestic tasks
 - Social activities
 - Sport/exercise
 - Leisure
 - Spiritual
 - Hobbies
3. Have these things changed over the time since treatment finished?
4. Have you noticed ... does things he/she wouldn't have done before their diagnosis?
5. talked about some of the ongoing effects he/she experiences. Have you noticed any others?
 - Bowel management
 - Food intake
 - Fatigue
 - Thinking
6. Have you seen any ways in which has managed these things so he/she can still do the things they want or need to do?
7. Have you noticed ... doing any things differently to accommodate ongoing effects? Please explain.
8. Have you noticed any times when ... does what they want despite the consequences?

9. Do you think the ongoing effects have affected your relationship? In what ways?
10. Have you noticed any changes in the way ... views life since their cancer diagnosis? Has what's important to him/her changed?
11. What advice would you give to the family members/friends/whanau of someone just diagnosed with bowel cancer?
12. Is there anything else you'd like to add regarding how bowel cancer has impacted your life together?

APPENDIX K: Transcriber confidentiality agreement



Confidentiality Agreement

Project title: *Exploring the range of occupational outcomes that can be experienced after bowel cancer, and the ways individuals have found to adaptively manage them.*

Project Supervisor: Professor Clare Hocking

Researcher: Elizabeth Martin

- ☐ I understand that all the material I will be asked to transcribe is confidential.
- ☐ I understand that the contents of the tapes or recordings can only be discussed with the researchers.
- ☐ I will not make or keep any copies of the transcripts nor allow third parties access to them.

Transcriber's signature:

[Redacted signature]

Transcriber's name:BRENDA LIDDIARD.....

Transcriber's Contact Details:

.....[Redacted contact details].....

.....[Redacted contact details].....

Date: 21 June 2019

Project Supervisor's Contact Details:

Professor Clare Hocking

Email: clare.hocking@aut.ac.nz

Telephone: 09 921 9162

Approved by the Auckland University of Technology Ethics Committee on 20 February 2019, AUTEK Reference number 18/411.

APPENDIX L: Example of coding and using comment boxes for own thoughts and questions

The screenshot shows a Microsoft Word document with a comment thread on the right side. The document text is as follows:

I guess the other one is that if I can keep pushing forward I might run faster than the cancer can come back. But my chemo buddy who's no longer with us, she passed away three years ago this weekend, she was running marathons and things six weeks before she got diagnosed with Stage 4 bowel cancer. So, we met at my first IV treatment, and it was her second, and she was only three years older than I am. So her husband and my husband, we all sat there and gave each other the eyeball, and like, "That could have been us". So, I've got no excuse not to do anything. If I sat back and did nothing, then I'm wasting what I've been given.

Interviewer: You mentioned earlier that you're going to do an ultra-marathon next year. Can you just explain a bit about how you came to that decision?

Interviewee: I needed some way to celebrate being five years cancer free, which then becomes normal population again. My friends think it's hilarious, because 'normal' is never a term that's ever been put beside my name. Randomly it popped up. The reason why I run is because I got told I really shouldn't be running because my feet are so bad. I don't like being told I can't do things, so I'm going to go and do that. If I have to drag my butt round and do it, I will. I happened to just randomly see this thing advertised for what's called 'The Ring of Fire', which I thought was aptly named, would suit bowel cancer quite well. I did a third of it this year, and decided I loved it. It's a really, really beautiful place. There was spirituality there, not that I'm a spiritual person. But actually it just felt right. So I'm going to do the full Ring of Fire. I've got 20 hours to do 72 km, starting from the Chateau Tongariro, right around to the Chateau again. And I think that's because I don't have any excuses not to do it. Is that kind of a good answer?

Interviewer: Yes, that's really interesting. Thank you. You talked about that you have some bowel

The comment thread on the right side of the document is as follows:

- Lizzie Martin**
Pushing self will keep cancer away...acknowledgment of fear of recurrence
I wonder if this is the case for others? I'm aware I personally do not fear recurrence. Does that make me very unusual? Need more reflection
- Lizzie Martin**
Wanting to make best of life...given second chance and not wanting to waste opportunities.
- Lizzie Martin**
Celebrating surviving. Does others view this as a significant milestone?
- Lizzie Martin**
Determined, strong willed
- Lizzie Martin**
Driven, resilience when facing difficult situations. I wonder if cancer brings this out in people? Can it work the other way...people lose confidence and become weaker mentally?
- Lizzie Martin**
Tuning into what feels right
- Lizzie Martin**
Not using cancer as an excuse. Follow up if others have this "no excuses" attitude

The bottom of the screenshot shows the Word status bar with the following information: Page 3 of 20, 10439 words, English (New Zealand), Accessibility: Unavailable, Focus, and a zoom level of 100%.

APPENDIX M: Enhanced interview guide used after first seven interviews

Thank you very much for giving up your time to talk to me today. It's much appreciated.

Before we get going, I'll just run through the purpose of the interview and explain what my research is all about. The aim is to help other bowel cancer survivors by increasing their knowledge of the potential effects on their daily activities, and possible ways to deal with these. I'm finding out how bowel cancer has impacted people's lives, so I'd like to hear about your experiences of living after a bowel cancer...what life has been like for YOU.

I'd like to get an idea of your daily activities...the nitty gritty of daily life...the things you like to do...the things you do for fun...the things you need to do to get through the day...how things might have changed...or maybe not changed at all...both positive and negative things. There are no right or wrong answers, and although I had bowel cancer myself that doesn't necessarily mean that my experiences will be the same as yours.

Because of the nature of bowel cancer – it obviously affects the bowel – I might broach topics you're not comfortable with. If you're prepared to answer that would be really helpful, but you don't need to answer or talk about anything you're embarrassed about or not comfortable with. You are free to say as little or as much as they want during the interview. You can just say I don't want to answer that can we move on. You can also stop the interview at any time.

Just a reminder that your comments will all be anonymous. The only people who will know who you are, are myself and my two supervisors in Auckland. Any publications or presentations will use pseudonyms, so nobody reading it will know it's your words.

I've carried out about 7 interviews so far so I'll also ask you about some things others have said so I can get your interpretation

Interview questions

1. To begin with could you please introduce yourself. Tell me about you and about your life - so things like what your living situation is, how long ago your cancer was, what was going on in your life before diagnosis and how things may have changed since then.

2. What impact – if any – has bowel cancer had on the things you do now?

- Self-care
- Domestic tasks
- Social activities
- Sport/exercise
- Leisure
- Spiritual
- Hobbies

3. Have these things changed over the time since treatment finished?

4. Other people I have interviewed say the way they now respond to other people and things that happen is different. Has that been your experience?

5. What would other people notice or say about you now?

6. Some participants mentioned that they're very aware of cancer recurrence. Have you found that to be the case? How has that impacted you?

7. Some people have talked about how they didn't want sympathy (and still don't) and pushed it away. Was that the case for you at all? Could you provide any examples?

8. People also talked about not wanting to play the cancer card. What do you think playing the cancer card means? How do you feel about that?

9. The people that I've talked to have all told me something different about what they're eating and how they're managing food and eating. I'm interested in how people have found their own way to manage bowel function. What has been your experience?

- Do you manage your food intake yourself or does someone else help with that?
- Did you receive much guidance regarding any dietary changes?

10. Have you done things – or plan to do things -you wouldn't have done before the diagnosis?

11. Do you think the ongoing effects have affected your relationships? In what ways?

- Intimate

- Family
- Social
- Work related

12. Are there times when you do what you want despite the consequences?

13. When you think about your life overall, has your view of how to live changed at all? Has what's important to you changed? Has what gives life meaning changed? Sense of place in world? Sense of self?

14. What advice would you give to someone diagnosed with bowel cancer about how to manage the aftereffects?

15. Is there anything else you'd like to add regarding how bowel cancer has impacted your life?

APPENDIX N: Second round of interviews guide

Welcome and overview of research in general (as in first round of interviews).

I've carried out 11 interviews with people who have all had bowel cancer, all of different ages, male and female, some had ostomy, some without. After the interviews had been transcribed and I analysed all the information some common themes became clear.

Now I'm carrying out a few more interviews with people, including you, to see if the themes reflect your experiences and if there's anything more you'd like to add.

There are three main themes identified – they have titles using participant quotes:

"The person I've become",

"I had to heal myself"

"Life's too short"

I'll go through the themes and would like you to tell me about your views on them. You can interrupt at any time and add any thoughts you have. I'll also share some quotes that people said.

1. *"The person I've become"*

People found themselves to be different to their pre-cancer selves, they talked about how their behaviour had changed and how they now sometimes reacted differently to everyday situations.

"I rather liked the person I was before ... I haven't grown enough to like the person that I have become".

The changes talked about included:

Increased anxiety:

- A constant alertness to the possibility of cancer recurrence
- Increased tension and uncertainty

"Oh my god, is it back?"

Increased irritability and intolerance:

- Smaller, previously unimportant matters took on increased significance... they now got angrier and annoyed more quickly than before

"I am more straight up now"

"I definitely carry a bit of attitude".

"I am probably more ignorant and arrogant than ever before."

"My filter's broken ... I don't have a filter now".

Not wanting sympathy:

- Not disclosing how hard things sometimes can be.
- Not wanting to be viewed as a sick person.
- Not wanting cancer to define or shape their personality.
- Choosing to see themselves as strong and able to continue with life without playing the cancer card.
- Needing to feel useful and contribute to society.

"I wasn't trying to be a superhero or anything like that, I just didn't need illness to define me. It is what it is, isn't it?"

Putting the face one:

- *Internal* pressure to put on a brave face, along with the *external* pressure to be positive

"People are constantly telling you to not be negative"

"You try and be strong for other people, not necessarily for yourself."

- They were reluctant to acknowledge unwelcome emotions considered 'weak' such as increased anxiety and feeling weepy

"I think anybody that's been through cancer is the best liar or actor you could ever come across, because most of the time there's stuff going on, and you won't let anyone know. ...I don't want people feeling sorry for me."

"I generally don't tell anyone about it, because I feel silly about it"

2. "I had to heal myself"

People felt a need to continue to 'heal'. One of the ways they did this was by "carrying on"

- They were determined to minimise the impact of cancer and not use it as an excuse for not continuing with life as much as possible.

"I didn't need the sympathy card. I did not want anything like that.... It doesn't stop you doing anything. I don't really use it as a lever for anything, or something that I can't do."

- Felt a responsibility to make the most of life.

"If I sat back and did nothing, then I'm wasting what I've been given".

- Also, they talked about how a lack of health professional support prompted the need to manage for themselves.

“There's no help out there ... there was literally nothing”

“I likened it to being shipped out to sea in a leaky boat. And it's a weird thing ... but no matter how hideous the treatment is, somebody's doing something”

Benefits of exercise:

- People began taking part in exercise they'd enjoyed before or introduced new ones to help both physically and mentally... exercise was seen as a form of therapy.

“It clears my mind”

- People demonstrated a lot strength to overcome challenges in order to exercise, e.g. inconsistent bowel habits, presence of an ostomy, effects of peripheral neuropathy.

“I was too scared to go out walking, because I thought I would need to go to the toilet. So, I joined a gym, so that I could be right by a toilet”.

“The very first time ... I was absolutely petrified there was going to be Code Brown called on me”.

Adapting diet:

- Moving away from potentially cancer-causing foods and developing a healthier diet.
- Making dietary changes to accommodate changes in bowel function or an ostomy; trial and error to determine which foods were most manageable

Helping others:

- Using the cancer experience to help others, which in turn had personal benefits...being bowel cancer representatives, encouraging others to go to doctor if have symptoms...

3. “Life's too short”

Prioritising friendships:

- A move away from superficial friendships and towards deep friendships.
- Cancer testing friendships; finding out who true friends are.
- Losing old friends and gaining new ones or strengthening existing friendships.

"There were some people who were visibly different, and almost like you were contagious. They didn't quite know what to say or do, so they kind of kept away"

"My personal space is a lot smaller than it was."

"It made me put up a few walls,"

"I knew some of them were going to die and if I allowed myself to get down because of them, it could affect my health and I chose not to keep in touch with them at that time because you have to look after yourself."

It makes you closer:

- Being closer to, and more appreciative of, family members.
- Talking and being more open with family.

"At the end of the day it probably makes everyone a bit closer" because "there's nothing like that feeling of not having somebody."

Appreciating what you've got:

- Feeling lucky to still be alive.
- Appreciating things previously taken for granted.

"It could be better, but it could be a lot worse too, eh. I could be dead."

Being more selective with time:

- Wanting to take pleasure from life and not miss out on things.
- Putting own needs and desires above those of others.

"I think I'm now a bit more precious with my time. If I want to do something, I'll go and do it. If I don't want to do something, I'm not going to do it for the sake of making everyone else happy".

"If somebody wants my help, then they have to ask for it. And I find that really hard to accept, because I like to be there for other people."

"You need to look after yourself before you look after other people".

- Ceasing or cutting back on paid work. Re-evaluation of feelings towards work.

"That's what we're realising. If we're not enjoying something, we can change it ... you don't have to put up with it".

- Life becoming either simpler or much busier.

Learning lessons:

- People rationalised how current difficulties and limitations paled in comparison to previous symptoms, and to others who have had bowel cancer.

“Nothing can be as hard as doing treatment and surgery and stuff, so stop your whinging and move forward”.

- Learning to say ‘no’ when asked to do things by others.

“I’m trying to have a self-care plan that says, ‘Say no when you’re tired’.”

- Believing there is a reason for having had cancer.

“By the time it came back, grrr... I thought, ‘What lessons have I not learned?’”

“I look on it like I was meant to go through this.”

“...what I need for me to grow ... I just think the saddest thing is if people don’t use it as an experience to grow”.

Information provision focus

So that’s what I’ve identified so far. Now I’d like to I’m to find out what it would be useful for people to know when they are diagnosed with bowel cancer, or at any stage throughout their cancer journey. That’s why I am thinking about the BCNZ resource and sent it though to you, to find your thoughts regarding whether receiving information in this way is useful.

Sample questions:

- Had you seen this resource before?
- Have you received or seen any information about how to manage post-treatment?
- Would you have liked to receive anything?
- Do you think there’s a need for information post-treatment?
- Do you think if you had been provided with this sort of information when you were diagnosed it would have helped? In what way? Would it be useful to receive at the end of treatment? Or now?
- Do you think any areas would be more important to know than others?
- The BCNZ resource mentioned about increased anxiety and other emotional changes and that also came out very strongly in my findings. Do you think it’s important to inform people about these potential changes when they are

diagnosed? Or later in the journey? During treatment? Or at the end? Or not at all?

- Do you think resources like this are the most effective way for people to receive information? Is there a better way to receive information rather than having something to read? Can you think of any alternate ways of providing information which would be beneficial?
- Can you suggest any ways a resource like this could be improved?
- For other medical conditions such as depression, there are websites containing stories of people's experiences of diagnosis and treatment. Have you seen anything like that? Do you think something along those lines might be beneficial for those who have had bowel cancer?
- How do you feel about hearing quotes from other bowel cancer survivors, such as the ones I shared earlier?
- What things have resonated with you in terms of health education in the past? Anything in the media?
- Which delivery modes do you feel are most effective?
- What public health messages have you seen before? What did you find helpful?