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Doing, being, becoming, and belonging: Experiences transitioning from bowel cancer patient to survivor

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ABSTRACT

Transitions are a normal part of life, affecting people's identity and life course. Evidence supports the idea that there is a significant occupational impact on people who experience sudden and unexpected transitions associated with life threatening illness. This interpretive description study explored the occupational impact of transitioning from bowel cancer patient to survivor for individuals living in Aotearoa/New Zealand. Qualitative interviews were conducted with 11 individuals who had completed treatment for bowel cancer. Data were thematically analysed and three key themes identified: I had to heal myself, Life's too short, and The person I've become. Themes are discussed in relation to the occupational concepts of doing, being, becoming, and belonging; with the finding of becoming something not entirely welcome, not previously reported in the occupational science literature. Further research is needed to ascertain whether an unexpected change in identity is a feature of occupational transitions amongst alternative population groups.

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KEYWORDS

Occupational science; Bowel cancer; Transition; Occupation; Doing, being, becoming, belonging; Survivor

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., 2020). 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.

Wilcock's (2006) concepts of 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 recognise 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 which may alter and be revisited over time, emerge through both choice and 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, 2014b, 2020; 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. This study considered where bowel cancer survivors saw themselves on such a 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 descriptive qualitative methodology (Thorne, 2016), an inductive analytic approach which 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, interpretive description 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 recognises 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 which may influence the research are made visible (Hunt, 2009). This transparency was particularly relevant given the first author 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—which 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 the first author'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 so as to hear multiple perspectives of the diagnosed individual and those likely to be impacted by changed occupational needs and routines; thereby revealing contextual nuances and a richer understanding (Abma & Stake, 2014). All participants signed a consent form prior to collecting data.

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 30-100 minutes in duration, and used open ended questions following a topical interview guide (Hunt, 2009) (See Appendix A). Prior to interview commencement, the first author, who conducted the interviews, 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, potentially generating 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.

Analysis was initiated as the transcription of each interview was completed, thus allowing 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 (Bertero, 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 (Yardley, 2015). 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 alternative meanings (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 interpretive description.

Results

Eleven participants were recruited (four male and seven female), varying in age from 42 to 92 years. They covered a range of dwelling types, activity levels, and tumour stage, some with a stoma and some without. See Table 1 for participant demographics. In four cases the spouses of participants chose to be involved with data collection. Following data analysis, three themes were identified: 1) I had to heal myself, 2) Life’s too short, and 3) The person I’ve become. Each theme is discussed below.

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

Table 1. Participant Demographics

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	Male	63	2	9 months	None	b	Rural
James	Male	58	3	4 months	None	b	Urban
Ray	Male	66	3	18 months	Reversed	c	Rural
Will	Male	43	1	3 months	Reversed	b	Urban
Merina	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

to heal myself" (Maia). 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 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). 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 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). 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 were assisted on their path of self-healing by helping others. June and Sarah took on a new role of consumer representative for cancer research organisations and 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. Using self-reliance and self-determination, participants demonstrated 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 72 km ultramarathon, proudly declaring, *"if I have to drag my butt round and do it, I will"*. James planned to complete an 84 km cycle ride acknowledging, *"that's something that we probably wouldn't normally do"*.

A heightened sense of spirituality was also evident, with some participants 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 tipuna¹ 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 took 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 new found realisation that life could be cut short at any time, participants devoted more quality time to family. Will recognised "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" and 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 which gave life value,

such as 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 yourself ... there 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 3 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 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 dramatised”. 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 the fact that they had had 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 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 as 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 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 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 (Ministry of Health, 2017). Secondly, they correspond with the experiences of others whose occupational transitions have been influenced by life changing illness or injury.

Doing

The dimension of doing is often characterised as 'active', with actions often 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 (Ministry of Health, 2015) 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 acclaimed by participants, with advantages identified in regulating both body and mind. Dealing with a cancer diagnosis—along with the subsequent treatment and ongoing recovery—brings a myriad of emotional and mental struggles. Engagement in physical activity provided one pathway for 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. In 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), hīnengaro (mental health), and wairua (spiritual health) (Ministry of Health, 2017). 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 in which they chose to engage (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, which 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), it was not something experienced by all participants. Some 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).

People are, ideally, able to exercise choice in their expression of being, but this is not always possible as 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). 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; then 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). When this balance is affected by illness, study findings revealed 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, as demonstrated by the coexistence of participants’ diverse emotions. They spoke with pride of their strength, yet expressed embarrassment at their perceived weakness and increased anxiety; they suppressed fears, and were hyper vigilant of recurrence; they hid their emotions from others, but on occasion 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 more likely to realise their occupational potential (Wicks, 2005).

The fluctuating being of participants illustrates how becoming is an ongoing process across a lifetime (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 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 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 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, including opportunities for learning and growth gained from their cancer experience (Jim, 2006; Walder & Molineux, 2017). Their priorities about what to do with their lives had changed. They no longer wanted to dedicate their lives to their work or to pleasing other people. Instead, new occupations such as helping others in a similar situation or participating in more extreme physical challenges took on importance. Through engaging

in these occupations, participants made deliberate choices about becoming someone quite different.

Belonging

Participants 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 provided structure for developing meaning in their lives. Having a desire to belong and contribute provided a sense of purpose and motivation for occupational engagement (Walder & Molineux, 2017).

Belonging was 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 new friends arriving and other, older friends fading 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 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 Aotearoa/New Zealand; recruitment from a wider geographical area may have yielded different results. The first author's personal experiences of bowel cancer may have influenced data collection and analysis. To

address this issue reflexivity was a feature of the research; and having two co-authors with no personal experience of the disease added balance and rigour to the analysis.

Conclusion

Study participants 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 inter-related 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. Further research in occupational science concerning the transitions of other groups who have experienced sudden changes in health and occupations includes exploring how transition may be hindered by unfavourable occupations (Scalzo et al., 2016).

Note

1. Tipuna is te reo (Māori language) for ancestors.

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Appendix A. Interview guide

1. Could you please introduce yourself by telling me about you and your life. E.g. 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? e.g.
 - Fatigue
 - Thinking
6. Have you found ways to manage these effects 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. What would other people notice or say about you now?
9. Are there times when you do what you want despite the consequences?
10. Thinking about your employment specifically, has there been any change? In what ways?
11. Do you think the ongoing effects have affected your relationships? In what ways?
 - Intimate
 - Family
 - Social
 - Work related
12. What advice would you give to someone diagnosed with bowel cancer about how to manage the after-effects?
13. Is there anything else you'd like to add regarding how bowel cancer has impacted your life?