

# A qualitative study exploring health perceptions and factors influencing participation in health behaviors in colorectal cancer survivors

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## Abstract

**Purpose:** The purpose of the study was to explore colorectal cancer survivors' health perceptions following cessation of active treatment for cancer and to explore the factors influencing participation in health-promoting behaviors that may help reduce cardiovascular disease risk.

**Methods:** Face-to-face interviews were conducted with participants that had completed active treatment for cancer within the previous 2 years. Participants were colorectal cancer survivors ( $N=24$ , men = 11, women = 13, M age = 69.38 years,  $SD=4.19$ ) recruited from a private hospital in Perth, Australia on the basis that they had existing morbidities that put them at increased risk of cardiovascular disease. Interview transcripts were analyzed using thematic analysis.

**Results:** Five main themes emerged: *back to normal; the pleasures in life: 'is it worth it?'; beliefs about health behavior; skepticism of eating guidelines; and lack of motivation.* The majority of participants felt they were in good health and had made a full recovery. Participants questioned whether it was worth changing their lifestyle given their life stage and referred to the desire to enjoy life. Lay health beliefs, skepticism of eating guidelines, and a lack of motivation were barriers to change.

**Conclusions:** Interventions should target lay beliefs and skepticism in relation to health behaviors in order to reinforce the importance and value of participating in health-related behavior.

**Implications for Cancer Survivors:** Findings may inform the development of effective, patient-centered interventions that target lay health beliefs and build motivation for health behavior change. Copyright © 2016 John Wiley & Sons, Ltd.

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## Background

Improved early detection and treatment of cancer has led to increases in the number of people surviving cancer [1]. Colorectal cancer (CRC) survival rates compare favorably with overall data with more than 60% of those diagnosed surviving beyond 5 years. However, compared with non-cancer controls, CRC survivors are more likely to be insufficiently active or inactive, and high-risk drinkers [2] and the majority fail to meet the public health guidelines for lifestyle variables [3,4]. For example, CRC survivors have been found to have the lowest rates of exercise of any cancer group [5], and high levels of obesity [5], hypercholesterolemia, and hypertension [6]. These lifestyle behaviors put CRC survivors at an elevated risk of other chronic conditions like cardiovascular disease and diabetes [7]. Adoption and maintenance of health-related behaviors such as exercise may promote better health and reduced risk of chronic disease among CRC survivors [8]. Despite these potential benefits, a significant

proportion of CRC survivors do not adhere to health behavior guidelines, including maintaining a healthy weight, engaging in regular exercise, eating five portions of fruit and vegetables per day, limiting alcohol consumption, and refraining from smoking [1].

Based on this research, cancer survivors are an at-risk population that would benefit from behavioral interventions to promote health-related behaviors. Such interventions need to be based on evidence that identifies the psychological and behavioral factors linked to health-related behaviors in this population [9–11]. However, few studies have explored perceptions of health or the influences on health behaviors in cancer survivors and those that have tended to be in relation to breast cancer [12] or cancer survivors in general [13]. Research has revealed that CRC survivors commonly attribute their illness to genetics, divine control or fate, and questioned how much control they had over developing cancer or any chronic disease [7,14]. Fatalistic beliefs were often described as reasons for not making health behavior changes. Although

some research suggests that survivors may be motivated for change or already making health behavior changes [15,16], other studies have found little evidence to suggest that cancer survivors as a cohort are adopting healthier lifestyles [17]. Surveys in Australia and the US revealed that cancer survivors were overweight, consumed insufficient fruit, vegetables, and fiber, and were not sufficiently active [3]. Further, a population-based survey in the UK found lower levels of exercise among cancer survivors than the general population [18]. Regardless of motivational readiness, the influences on health behavior change among colorectal cancer survivors are understudied.

Given the paucity of research on CRC survivors' health behaviors to date, the present study aimed to explore how CRC survivors perceive their health having made a successful recovery and explore the main influences that impact on lifestyle behavior change. The current study adopted a qualitative approach to address the need for rich, in-depth experiential data on cancer survivors' views of health behaviors. As a consequence, we do not pose specific hypotheses, rather we expect to build a detailed picture of the beliefs and perceptions of CRC survivors toward health-promoting behaviors through an inductive, 'bottom up' approach.

## Method

The current study conformed to suggested guidelines by Clark [19] in terms of relevance of study question, appropriateness of method, transparency of procedures, and soundness of approach (RATS). A RATS checklist is provided as an online supplemental table (Appendix A).

### Participant recruitment

Participants were recruited on the basis that they had existing morbidities that put them at increased cardiovascular risk. Participants were deemed to have cardiovascular risk factors if they had an American Society of Anesthesiologists (ASA) physical status score of at least 2 or 3. ASA is a global score that assesses the physical status of patients before surgery [20]. The scoring ranges from 1–5 with an ASA of 1 indicating a normal healthy patient; a score of 2 indicating well-controlled disease of one body system (i.e., controlled hypertension or diabetes or mild obesity), and a score of 3 denoting controlled disease of more than one body system (i.e., poorly controlled hypertension or morbid obesity) [21]. Patients classified as ASA 1 were excluded on the basis that they were deemed healthy and not at increased risk of cardiovascular disease and those with an ASA score of 4 or 5 were excluded on the basis that they had severe systemic disease that is a constant threat to life or were not expected to survive. The ASA tool has demonstrated validity as a marker of patient's preoperative health status [22].

Patients meeting study inclusion criteria ( $N=126$ ) received a letter from their colorectal consultant ( $N=4$ ) inviting them to participate in the study. Patients indicated willingness to participate to their oncologist and were subsequently contacted by a researcher at to arrange an interview.

### Ethical approval

Ethical approval was obtained from the St John of God Human Research Ethics Committee prior to data collection. Participants signed an informed consent form prior to interview. Participants were informed that pseudonyms would be used in any reporting of the data to protect their identity.

### Data collection

Semi-structured interviews lasting up to 2 hours were conducted. An interview guide (Appendix B, online supplemental materials) was used with questions concerning perceptions of health, attitudes toward health behaviors, and influences on exercise and healthy eating. Interviews were digitally recorded and transcribed verbatim. Data collection ceased at the point when data saturation was reached [23].

### Data analysis

Data were analyzed using inductive thematic analysis [24]. The analysis involved several steps. The first step involved *immersion* in which interview transcripts are read several times to identify participants' meanings and experiences. The second step involved attaching codes to salient text segments. The third step examining whether codes may be combined to form broad-level themes. During these processes, inductive analysis was used to identify themes that emerge directly from the data linked to attitudes toward, and experiences of, participation in health behaviors. Consistent with the qualitative approach, we recognize and acknowledge that data interpretation was likely influenced by the researcher's prior knowledge. At the same time, there was an attempt to be open to new findings that may conflict with existing theories and previous findings [24–26]. The final step involved reviewing themes, cross-checking for overlap, and defining and naming themes. To broaden data interpretation, a second researcher read the transcripts and offered further insight into the emerging themes. The analysis offered is one interpretation of the interviewees' experiences. Nevertheless, we aimed to offer a credible interpretation that captured participants' perceptions and experiences. This was done through 'thick description' derived from participants' quotations so that readers can judge the interpretation for themselves [26].

## Results

Twenty-four participants agreed to participate in the study. In terms of annual household income, the majority of participants (65%) were in the lower income categories. These income categories are approximately equivalent or below the average annual household income in Australia of AU\$50,128 (approximately US\$35,087) [27]. Response bias analyses indicated that there were no significant differences in the age ( $t(124)=1.53, p=.294$ ) and gender distribution ( $\chi^2(1)=1.63, p=.202$ ) of participants that agreed to participate compared with those who declined ( $N=102$ ). We did find that participants were more likely to have an ASA score 3 relative to non-participants who were more likely to score 2 ( $\chi^2(1)=5.15, p=.023$ ). Full participant characteristics are summarized in Table 1.

Data analysis identified five main themes relating to participants' perceived influences on health behavior change: *back to normal, the pleasures in life: 'is it worth it?', beliefs about health behaviors, skepticism of eating guidelines, and lack of motivation*. A summary of the emergent themes with example quotes is provided in Appendix C (as online Supporting Information).

### Back to normal

Most participants spoke of feeling in good health and referred to their colorectal experiences in a past tense: 'Well that's history now and I've been good ever since. My bowel movements are back to normal and I've had no trouble at all... I've been normal, yeah' (Peter, aged 76). Others referred to their health being unchanged since their

treatment: 'I've felt just as healthy now as I did before the operation' (Patricia, aged 76). However, a few participants expressed fear their cancer would return when asked about their present health: 'most days I'm really good but I still get pains and I've become a bit of a "bowelholic" so I worry about all of that' (Mary, aged 65). Mary's use of the term 'bowelholic' indicates that she has become fixated or 'obsessed' with the function of her bowel. For others, concerns were related to symptoms and the need to be not far from a toilet and these anxieties affected quality of life and social functioning:

I take knickers in the car, I take a decent toilet roll...it's an awful way to live and there's no stopping it...I don't see friends anymore...they just stopped asking to go out for lunch (Carol, aged 68)

Other participants experienced anxieties that affected their quality of life and social outings: '(I) used to like the football and things like that but I can't go now because of big crowds. I can't take the risk to go to the toilet I can't wait'.

### The pleasures in life: 'Is it worth it?'

One of the key themes that emerged was the desire to enjoy life and not having to constantly monitor what you eat: 'Life is too short to not eat what you want anyway' (Cheryl, aged 68). Often enjoyment of life was linked to 'worth it' beliefs with several questioning whether it was worth changing their lifestyle given their life stage: 'I'm quite happy...I suppose I see giving up the pleasures in life may not be worth it at this stage' (Stuart, aged 68). Another participant had such 'is it worth it' reinforced by his doctor: 'As my doctor said when you're 73 years old, it will be very hard to change and is it really worthwhile?' (Barry, aged, 73). Another diabetic participant talked about feeling depressed when he measures his blood sugar: 'I get really upset when I see the high reading ... I sometimes wonder is it really worthwhile worrying about it at my time in life' (Paul, aged 65).

### Beliefs about health behaviors

Another dominant theme concerned lay perceptions of health and foods classified as healthy. During the interviews it became apparent that several participants consumed a diet high in meat and some justified eating a lot of meat in their diet:

I wouldn't give up meat...I like meat and I feel as though you need the iron. Most people that I see that are non-meat eaters look pretty anemic...they don't seem really healthy. They don't seem like they've got muscles on them (Barry, aged 73)

Other participants justified their regular consumption of meat based on the longevity in his family: 'My

**Table 1.** Self-reported sample characteristics

Age (years)	
Mean	69.38
SD	4.19
Range	63–77
Marital status	
Married/living together	16
Divorced	4
Not married	0
Widowed	0
Highest completed education	
Primary	2
Secondary/high school	10
Post-school vocational	6
University	2
Annual household income	
<AUS\$ 30,000	6
AUS\$ 30,000–AUS\$ 52,000	7
AUS\$ 52,000–AUS\$ 104,000	3
AUS\$ 104,000–AUS\$ 156,000	3
AUS\$ 156,000–AUS\$ 208,000	0
AUS\$ 208,000–AUS\$ 260,000	1

Four participants did not report their marital status, highest completion education, and annual household income. One AUS\$ = approximately US\$0.70.

grandfather lived to be 88 and my grandmother 92 and they ate more fat and rubbish but it was good wholesome stuff you know bread and butter puddings...bread and dripping' (Michael, aged 69). For Barbara, free range foods were considered healthy: 'We have free range eggs so they're low fat anyway' (Barbara, aged 76).

There were also lay perceptions regarding sufficiency of exercise. When asked about the guidelines, Annie said 'Well they say about 15 min a day don't they?' Annie went on to say 'I do about a kilometer a day...I'm doing enough as far as I'm concerned' (Annie, aged 69). Others felt that they did not need to exercise either because their health was under surveillance by their physician: 'I don't know there's anything that would encourage me to change my lifestyle...I saw my cardiologist last week, he's happy with me...I'm quite happy with the way my health' (Pauline, aged 68).

### Skepticism of eating guidelines

Several participants expressed skepticism concerning the links between eating and health, and this theme is linked with the previous theme of lay health perceptions. Cheryl attested to this: 'A lot of people have gone through many years of having a high fat diet and have lived to many years' (Cheryl, aged 68). Other participants considered that eating 'healthy' food is no protection against cancer:

My husband eats good food, doesn't eat rubbish, never has done. Yet he'd had prostate cancer, cancer on the lip...I'm the one that eats like crap and yet I'm 69...two different individuals, one eats fantastic, the other doesn't both have had cancer, work that one out (Annie, aged 69)

Annie's perception is that eating behavior *per se* does not affect likelihood of getting cancer. Several participants also rejected the recommendations to reduce consumption of meat, particularly red meat. For example, Brian justified his meat-based diet on longevity in the family: 'we eat a lot of meat probably more than we should according to some theories...still her (wife) parents lived to an average age of 90 and ate the same sort of diet' (Brian, aged 74). The testimonies of these participants show awareness of the recommendations but also skepticism or at times a rejection of the guidelines.

### Lack of motivation to change

Many participants expressed a lack of motivation to change diet or increase exercise levels. Underlying the lack of motivation were often failed attempts to change health behaviors. For Janice, her lack of motivation was partly linked to her perception of no obvious health benefits:

I don't think I'll be any healthier for doing it...because I've done it and that didn't alter anything much at all as far as my diabetes when I was walking it didn't make a blind bit of difference to what my blood sugar was like at all so consequently it's too easy to give it up (Pauline, aged 68)

For Lynda, lack of motivation to exercise was tied to both the effort required to participate and confidence in her capability to perform the exercises:

I watch those Biggest Losers sort of things and wished I had the motivation to do the exercises...It's up here, you can't do it, when you can do it, you know it's just a matter of sort of putting the effort in (Lynda, aged 63)

In relation to eating, Stuart also did not perceive a need to change: 'I honestly don't feel that I do eat terribly unhealthy foods I'm sorry I just don't feel the need to do it terribly much'. However, Stuart recognizes that he is overweight and expresses low confidence in losing weight and maintaining weight loss:

I know that I am carrying too much weight but I cannot get rid of it... I've made attempts to get rid of it and I can get down to around 111, 112 kg and then I go on holiday... My weight just goes up (Stuart, aged 68)

Several participants also referred to motivation or self-discipline as a personality trait: 'I suppose it's in your make up whether you actually can discipline yourself to exercise or do certain routine things' (Stuart) and 'I wish I was one of those strong will-powered persons but I'm not' (Elaine, aged 66).

For others, motivation was underpinned by ambivalence and dissonance. Like Stuart, Cheryl indicated that she was very conscious of calories and would like to lose some weight, but did not feel a sufficiently strong desire to change her diet and exercise level for her health, and she enjoyed eating and drinking:

I'm not particularly interested in changing my lifestyle...I think about it (calories) all the time but it's whether I do anything about it or not...because I like food, I like chocolate, I like alcohol (Cheryl, aged 68).

Other participants did not see a need to change their lifestyle because they were under the regular surveillance of doctors:

As I say the GP keeps a check on me regularly, because of the conditions I have, so I'm quite happy with her care, rather than to go to something other (Pauline, aged 68)

and

I feel with my vigilant doctor, that he won't let me get away with not going for tests...he's always looking to see if I need blood tests, blood pressure and things like that (Patricia, aged 76).

## Discussion

The current study found that most participants considered themselves to be in good health and referred to their CRC experiences in a past tense. However, a few participants reported experiencing persistent, unpredictable bowel problems that adversely affected their quality of life. Similar findings have been reported elsewhere [28]. For example, Beaver *et al.* [28] found that patients who did not have a stoma were particularly vulnerable to altered bowel function. Previous research has also documented fears concerning food choice among colorectal cancer survivors and mixed messages and confusion regarding appropriate nutrition [29]. Furthermore, consistent with theories of health threat and coping [30], most participants did not perceive their cancer as a health threat any longer and that their recovery had removed any threat. Many did not perceive themselves at risk of chronic disease and felt no need to engage in preventive behaviors as there was no threat to address. Several participants felt medical surveillance was sufficient and did not see a need to take further action. These are new findings and they are inconsistent with some previous research reporting that survivors are either motivated to change [15] or have actively made health behavior changes including diet, weight loss, and exercise [16]. Nevertheless, our findings are consistent with research in indicating that those with a cancer diagnosis were less likely to be physically active following treatment [31]. Williams *et al.* [31] also found little evidence that a cancer diagnosis motivated patients to make health-protective changes.

Uncertainty over the future, beliefs in the 'need to enjoy life', and questions as to whether engaging health lifestyle behaviors were 'worth it at my age' were common responses. A lack of control over health and doubts concerning the value of health behavior change reflected fatalistic beliefs. This finding is consistent with previous studies that revealed individuals with fatalistic beliefs are less likely to engage in health-promoting behaviors such as exercise, fruit and vegetable intake, and smoking cessation [32]. Reedy *et al.* [7] also found that CRC survivors were concerned about the level of control they had over developing cancer or other chronic diseases in future. A study on African-American CRC survivors, Harper *et al.* [14] found that fatalism and medical mistrust may be influential in the adoption and maintenance of health behaviors in CRC survivors. Mistrust or skepticism over health guidelines was evident in the present study. One example of such mistrust or skepticism was related to a high-meat

diet with several referring to previous generations that had the same diet and lived to an old age.

Participants perceived themselves to engage in sufficient exercise. This is consistent with previous research in CRC survivors and older adults, which found that one of the main barriers to exercise was beliefs that they were sufficiently active even though few met recommended levels [4,33]. In addition, research has indicated that a minority of colorectal cancer survivors believed that exercise would actually increase cancer risk by weakening the immune system [29]. The rich qualitative data from the present study suggests that colorectal cancer survivors tend to over-estimate their level of exercise engagement. The findings in the current study concerning lay perceptions of exercise and healthy eating, the 'is it worth it' beliefs, and perceived protection from medical surveillance underscore the important role that medical professionals have in providing information and encouraging health behavior change in patients. Physician recommendations have been shown to be instrumental in facilitating health behavior change in cancer survivors [34]. Further, older cancer survivors may be more receptive to physician advice concerning health matters [35]. Despite positive attitudes of health professionals toward the provision of lifestyle advice [36], the extent to which they actually administer such advice in practice appears to be modest [37]. Further research is needed to explore oncologists' attitudes and barriers toward the provision of lifestyle advice to their patients and to find ways in which such advice could be routinely provided.

Lack of motivation was the final theme that influenced health behavior change and was underpinned by failed attempts to change and low self-efficacy; low outcome expectancies or lack of need to change. Lack of motivation has been found to be the dominant psychological barrier to exercise participation among prostate and breast cancer patients [12,38]. The present study adds to this literature by demonstrating that CRC survivors also lack motivation to adopt health-promoting behaviors. Future interventions with cancer survivors will need to find ways to address this lack of motivation. Suggestions for motivating individuals with low motivation have recently been suggested and may have utility in this population [39,40].

## Strengths and limitations

A particular strength of the current study is that we recruited those with comorbidities and therefore those most at risk to cardiovascular disease and as such, those that would benefit the most from making health behavioral changes. Furthermore, almost half the final sample comprised men who are an underrepresented group in studies on CRC survivors. The high male representation is important because men are reportedly more likely to have a poor diet and less likely to initiate health behavior change or

participate in such interventions [15]. We also recruited a high proportion of participants from more socially deprived backgrounds, evidenced by household income and educational attainment. Limitations of the current research should also be acknowledged. First, the response rate was low at 19%. However, response bias analysis found that participants had a higher ASA score compared with non-participants. That is, those who agreed to take part in the study had greater comorbidities as evidenced by a greater proportion having a higher ASA score. There were no significant differences in age and gender distribution between participants and those who declined participation. Second, our sample was drawn from CRC survivors from one hospital and the findings may not be transferable to other settings and participants.

## Conclusion

Present findings highlight that lay health beliefs and the perceived value of health behavior change are factors that likely influence low participation in health behaviors in CRC survivors. Findings from the present study suggest that developers of health behavior interventions in cancer survivors would do well to present evidence to actively dispel myths and lay beliefs concerning health behaviors. Discussions regarding health behavior change in this population could be improved by providing specific and detailed information about how to improve behaviors such as diet and exercise, including information on the current benefits and a rationale for doing so.

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