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1 A Qualitative Study Exploring Health Perceptions and Factors
2 Influencing Participation in Health Behaviors in Colorectal Cancer
3 Survivors

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5
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24

Abstract

1
2 *Purpose:* The purpose of the study was to explore colorectal cancer survivors' health
3 perceptions following cessation of active treatment for cancer and to explore the factors
4 influencing participation in health-promoting behaviors that may help reduce cardiovascular
5 disease risk. *Methods:* Face-to-face interviews were conducted with participants that had
6 completed active treatment for cancer within the previous two years. Participants were
7 colorectal cancer survivors (N = 24, men =11, women = 13 *M* age = 69.38 years, SD = 4.19)
8 recruited from a private hospital in Perth, Australia on the basis that they had existing
9 morbidities that put them at increased risk of cardiovascular disease. Interview transcripts
10 were analysed using thematic analysis. *Results:* Five main themes emerged: *back to normal;*
11 *the pleasures in life: "is it worth it?"; beliefs about health behavior; scepticism of eating*
12 *guidelines; and lack of motivation.* The majority of participants felt they were in good health
13 and had made a full recovery. Participants questioned whether it was worth changing their
14 lifestyle given their life stage and referred to the desire to enjoy life. Lay health beliefs,
15 scepticism of eating guidelines, and a lack of motivation were barriers to change.
16 *Conclusions:* Interventions should target lay beliefs and scepticism in relation to health
17 behaviors in order to reinforce the importance and value of participating in health-related
18 behavior. *Implications for Cancer Survivors:* Findings may inform the development of
19 effective, patient-centered interventions that target lay health beliefs and build motivation for
20 health behavior change.

21
22 **Keywords:** cancer survivors, health behavior, motivation, psychology, cancer, oncology

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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 favourably with overall data with more than 60% of those diagnosed surviving beyond 5 years. However, compared to 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 [14, 7]. Fatalistic beliefs were often described as reasons for not making health behavior changes. Although some research suggests that survivors may be motivated for

1 The scoring ranges from 1-5 with an ASA of 1 indicating a normal healthy patient; a score of
2 2 indicating well controlled disease of one body system (i.e., controlled hypertension or
3 diabetes or mild obesity), and a score of 3 denoting controlled disease of more than one body
4 system (i.e., poorly controlled hypertension or morbid obesity) [21]. Patients classified as
5 ASA 1 were excluded on the basis that they were deemed healthy and not at increased risk of
6 cardiovascular disease and those with an ASA score of 4 or 5 were excluded on the basis that
7 they had severe systemic disease that is a constant threat to life or were not expected to
8 survive. The ASA tool has demonstrated validity as a marker of patient's preoperative health
9 status [22].

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

14 **Ethical Approval**

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

19 **Data Collection**

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

25 **Data Analysis**

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

17 **Results**

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

1 were more likely to score 2 ($\chi^2(1)=5.15, p=.023$). Full participant characteristics are
2 summarized in Table 1.

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

8 **Back to normal**

9 Most participants spoke of feeling in good health and referred to their colorectal
10 experiences in a past tense: "Well that's history now and I've been good ever since. My
11 bowel movements are back to normal and I've had no trouble at all... I've been normal,
12 yeah" (Peter, aged 76). Others referred to their health being unchanged since their
13 treatment: "I've felt just as healthy now as I did before the operation" (Patricia, aged 76).
14 However, a few participants expressed fear their cancer would return when asked about
15 their present health: "most days I'm really good but I still get pains and I've become a bit
16 of a 'bowelhollic' so I worry about all of that" (Mary, aged 65). Mary's use of the term
17 'bowelhollic' indicates that she has become fixated or 'obsessed' with the function of her
18 bowel. For others, concerns were related to symptoms and the need to be not far from a
19 toilet and these anxieties affected quality of life and social functioning:

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

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

1 **The pleasures in life: “Is it worth it?”**

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

13 **Beliefs about health behaviors**

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

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

20 Other participants justified their regular consumption of meat based on the longevity in his
21 family: “My grandfather lived to be 88 and my grandmother 92 and they ate more fat and
22 rubbish but it was good wholesome stuff you know bread and butter puddings...bread and
23 dripping” (Michael, aged 69). For Barbara, free range foods were considered healthy: “We
24 have free range eggs so they’re low fat anyway” (Barbara, aged 76).

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

8 **Scepticism of eating guidelines**

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

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

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

25 **Lack of motivation to change**

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

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

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

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

14 In relation to eating, Stuart also didn’t perceive a need to change: “I honestly don’t feel
15 that I do eat terribly unhealthy foods I’m sorry I just don’t feel the need to do it terribly
16 much”. However, Stuart recognises that he is overweight and expresses low confidence in
17 losing weight and maintaining weight loss:

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

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

1 For others, motivation was underpinned by ambivalence and dissonance. Like Stuart,
2 Cheryl indicated that she was very conscious of calories and would like to lose some weight,
3 but did not feel a sufficiently strong desire to change her diet and exercise level for her health
4 and she enjoyed eating and drinking: “I’m not particularly interested in changing my
5 lifestyle...I think about it (calories) all the time but it’s whether I do anything about it or
6 not...because I like food, I like chocolate, I like alcohol” (Cheryl, aged 68). Other participants
7 did not see a need to change their lifestyle because they were under the regular surveillance of
8 doctors : “As I say the GP keeps a check on me regularly, because of the conditions I have, so
9 I’m quite happy with her care, rather than to go to something other” (Pauline, aged 68) and “I
10 feel with my vigilant doctor, that he won’t let me get away with not going for tests...he’s
11 always looking to see if I need blood tests, blood pressure and things like that” (Patricia, aged
12 76).

13 Discussion

14 The current study found that most participants considered themselves to be in good health
15 and referred to their CRC experiences in a past tense. However, a few participants reported
16 experiencing persistent, unpredictable bowel problems that adversely affected their quality of
17 life. Similar findings have been reported elsewhere [28]. For example, Beaver et al. [28]
18 found that patients who did not have a stoma were particularly vulnerable to altered bowel
19 function. Previous research has also documented fears concerning food choice among
20 colorectal cancer survivors and mixed messages and confusion regarding appropriate nutrition
21 [29]. Furthermore, consistent with theories of health threat and coping [30], most participants
22 did not perceive their cancer as a health threat any longer and that their recovery had removed
23 any threat. Many did not perceive themselves at risk of chronic disease and felt no need to
24 engage in preventive behaviors as there was no threat to address. Several participants felt
25 medical surveillance was sufficient and did not see a need to take further action. These are

1 new findings and they are inconsistent with some previous research reporting that survivors
2 are either motivated to change [15] or have actively made health behavior changes including
3 diet, weight loss and exercise [16]. Nevertheless, our findings are consistent with research in
4 indicating that those with a cancer diagnosis were less likely to be physically active following
5 treatment [31]. Williams et al. [31] also found little evidence that a cancer diagnosis
6 motivated patients to make health-protective changes.

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

20 Participants perceived themselves to engage in sufficient exercise. This is consistent with
21 previous research in CRC survivors and older adults which found that one of the main barriers
22 to exercise was beliefs that they were sufficiently active even though few met recommended
23 levels [4, 33]. In addition, research has indicated that a minority of colorectal cancer survivors
24 believed that exercise would actually increase cancer risk by weakening the immune system
25 [29]. The rich qualitative data from the present study suggests that colorectal cancer survivors

1 tend to over-estimate their level of exercise engagement. The findings in the current study
2 concerning lay perceptions of exercise and healthy eating, the ‘is it worth it’ beliefs, and
3 perceived protection from medical surveillance underscore the important role that medical
4 professionals have in providing information and encouraging health behavior change in
5 patients. Physician recommendations have been shown to be instrumental in facilitating
6 health behavior change in cancer survivors [34]. Further, older cancer survivors may be more
7 receptive to physician advice concerning health matters [35]. Despite positive attitudes of
8 health professionals towards the provision of lifestyle advice [36], the extent to which they
9 actually administer such advice in practice appears to be modest [37]. Further research is
10 needed to explore oncologists’ attitudes and barriers toward the provision of lifestyle advice
11 to their patients and to find ways in which such advice could be routinely provided.

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

20 **Strengths and Limitations**

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

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

11 **Conclusion**

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

20

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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

Note. Four participants did not report their marital status, highest completion education, and annual household income. 1 AUS\$ = approximately 0.70 US\$.