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Original citation & hyperlink:
Newby, K, Cook, C, Meisel, SF, Webb, TL, Fisher, B & Fisher, A 2017, 'Young people’s beliefs about the risk of bowel cancer and its link with physical activity' *British Journal of Health Psychology*, vol 22, no. 3, pp. 449-462
http://dx.doi.org/10.1111/bjhp.12238/
ISSN 1359-107X
ESSN 2044-8287

Publisher: Wiley

Accepted by BJHP 09.03.2007

Young people's beliefs about the risk of bowel cancer and its link with physical activity

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Word count (exc. figures/tables): 5825/6000

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Acknowledgements

The authors would like to thank the young people who gave up their time to participate in the research, Gemma Pugh (GP) who conducted a number of the interviews, and the teachers at each of the participating schools for their support and assistance recruiting participants and organising the interviews, namely James Hodgson, David Webb, and Laura Harvey. This work was supported by Cancer Research UK [grant number C43975/A20816].

Abstract

Objectives: The primary objective was to explore young people's risk appraisals of bowel cancer, including whether they had a coherent understanding of the protective effects of physical activity (PA). A secondary objective was to examine whether the Illness Risk Representations (IRR) framework could be used to understand beliefs underlying bowel cancer risk appraisals.

Design: Qualitative.

Methods: Framework analysis of semi-structured interviews with 19 people aged 14-17 years.

Results: Participants judged their risk of getting bowel cancer as low. This was based on a lack of family history of cancer and their current lifestyle behaviours, which were viewed as having a protective effect, or because they planned on making change to their lifestyle in the future when disease risk became more relevant. Participants were not aware of, and struggled to understand, the link between PA and bowel cancer. They also lacked knowledge of the effects of, or treatments for, bowel cancer. Beliefs underlying judgements about the risk of bowel cancer fitted the IRR framework reasonably well.

Conclusions: The present research suggests that interventions designed to increase PA with a view to reducing the risk of bowel cancer should aim to make the future risk of bowel cancer feel more tangible, help young people to understand the full range of consequences, explain how and why preventative behaviours such as PA are effective in reducing risk, and emphasise that the typical late presentation of symptoms, and therefore investigation by healthcare services, reduces treatability.

Background

Bowel cancer (cancer of the colon and rectum) is the fourth most common cancer in the UK (Cancer Research UK, 2016b). Additionally, it is the second most common cause of cancer-related mortality accounting for 10% of all deaths from cancer (Cancer Research UK, 2016b). A family history of bowel cancer, some chronic illnesses, and lifestyle factors can all increase the risk of bowel cancer (Cancer Research UK, 2016a). One of these lifestyle factors is insufficient physical activity (PA).

Evidence suggests that to confer the greatest protective effect on bowel cancer, PA needs to occur throughout the lifespan (Lee, Paffenbarger Jr., & Hsieh, 1991). Furthermore, evidence indicates that PA in childhood tracks into adulthood (Strong et al., 2005). This means that people who are not physically active as children are also unlikely to be physically active as adults. Despite the importance of PA in early life, levels of PA in young people are low, and there is a substantial decrease in levels of PA from childhood to adolescence. For example, the Health Survey for England found that <10% of 12-15 year olds in the UK meet the UK Government guidelines of ≥60 minutes of at least moderate activity per day (Health Survey for England, 2012).

It is important therefore to find ways to promote PA among young people in order to reduce their risk of getting bowel cancer in the future. A number of theories of health behaviour identify risk appraisal as a primary motivator of protective action. According to Protection Motivation Theory (PMT; (Rogers & Prentice-Dunn, 1997)) for example, people will be motivated to perform a protective behaviour providing their risk and efficacy appraisals are sufficiently high. Risk appraisal is typically operationalised as judgements about the likelihood and severity of a threat (such as bowel cancer), and efficacy appraisal as the perceived effectiveness of an action (such as PA) in removing that threat, along with

perceived ability to perform that action. Recent meta-analyses indicate that there is a small effect of changing risk appraisal on behaviour, which can be enhanced if efficacy appraisals are also high or simultaneously increased (Sheeran, Harris, & Epton, 2014; Tannenbaum et al., 2015).

A small number of experimental studies have examined the effect of increasing risk and efficacy appraisals for colon cancer on PA intentions among adults (Courneya & Hellsten, 2001; Graham, Prapavessis, & Cameron, 2006; McGowan & Prapavessis, 2010). Collectively, these studies show that increasing risk and efficacy beliefs can increase adults' intentions to be more physically active. Notably, two of these studies were not able to manipulate perceived severity (Graham et al., 2006; McGowan & Prapavessis, 2010), possibly due to their adult sample already believing that cancer is severe leading to a ceiling effect. The manipulation may be more successful among younger people who may be less aware of the seriousness of cancer in general or of colon cancer specifically (Graham et al., 2006). Two of the studies also failed to manipulate perceived likelihood (Courneya & Hellsten, 2001; Graham et al., 2006). Courneya and colleagues (2001) argued that this may reflect optimistic bias among their young adult sample. Taken together, these studies suggest that while informing people about the threat of bowel cancer is a promising strategy for motivating PA, more needs to be understood about how to best alter appraisals of bowel cancer severity and likelihood.

A body of work initiated by Cameron (Cameron, 2003; Cameron, 2008) aims to specify the beliefs upon which risk appraisals are based and may therefore offer a useful theoretical framework for improving our understanding of how people assess their risk of getting bowel cancer. This is important because if we are to successfully manipulate risk appraisals, we first need to understand the beliefs on which they are based. These beliefs,

organised within the Illness Risk Representations (IRR) framework, are based on the Common Sense Model (CSM; (Leventhal, Brissette, & Leventhal, 2003) which has typically been used to understand how people appraise and cope with an illness (Hagger & Orbell, 2003). Applied in this new way, the IRR framework can be used to understand how healthy populations appraise the risk of health threats.

Cameron (Cameron, 2003; 2008) proposed that illness risk representations for any illness threat are formed as a result of matching characteristics of the self with relevant illness risk representation components. For example, in the case of bowel cancer, illness risk representations about the cause of disease (e.g. 'being physically inactive puts me at risk of bowel cancer') are based on matching beliefs about the cause of bowel cancer (e.g. 'bowel cancer is caused by being physically inactive') with self-characteristics (e.g. 'I am physically inactive'). The components include identity (the label given to the illness and its symptoms), cause (factors responsible for the occurrence of the illness), timeline (time of onset and course of illness), consequences (expected pain, psychosocial effects, and death) and control (control over illness progression). The identity, cause, timeline and control (over prevention) components are proposed to serve as the basis for perceived likelihood estimates, and the consequences and control (over treatment/cure) components to serve as the basis for perceived severity estimates.

Evidence in support of the IRR framework has been provided by a number of studies that have examined peoples' behaviour in response to threats such as skin cancer (Cameron, 2008), cardiovascular disease (Classen, Henneman, Kindt, Marteau, & Timmermans, 2010), and sexually transmitted infection (Newby, French, Brown, & Wallace, 2013). However, whether the IRR framework could be useful in explaining how people appraise and respond to the risk of bowel cancer is yet to be determined.

According to the CSM, people will only perform health behaviours that are consistent with their understanding of the threat to their health (Leventhal et al., 1997). That is, common-sense representations of an illness shape beliefs about risk and therefore what, if any, behaviours are selected and performed in order to reduce the threat. For example, if young people do not believe that physical inactivity causes bowel cancer then they are unlikely to increase their levels of PA in order to reduce that threat. Instead, other behaviours for which there is a more intuitive link to the illness may be selected instead. These could include for example changes to their diet. Here the link between the behaviour and the part of the body that is affected is direct and logical given that food comes into contact with the bowel. In support of the importance of providing a coherent model of the behaviour, Bishop and colleagues (Bishop, Marteau, Hall, Kitchener, & Hajek, 2005) found that explaining the link between smoking and cervical cancer increased intentions to stop smoking among women receiving abnormal cervical screening results.

The Present Research

The primary objective of the present study was to explore young people's bowel cancer risk appraisals, including whether they have a coherent understanding of the preventative relationship between PA and bowel cancer. A secondary objective was to examine whether the IRR Framework could help to understand beliefs underlying bowel cancer risk appraisals. As far as we are aware, this is the first study that seeks to understand how young people appraise their risk of bowel cancer and to explore people's beliefs about the relationship between preventative behaviour and this disease. It is also the first qualitative study to examine how well the IRR framework reflects the way in which assessments of illness risk are made.

Method

Participants

To be eligible for participation, individuals had to be aged between 13-18 years old and to have not been diagnosed with cancer themselves. In total, 19 young people aged 14-17 years old participated in this study (8 males and 11 females). The ethnicity of participants was as follows: 13 White British, two Indian, two of mixed ethnicity, one Black Caribbean, and one Asian other. Ten of the participants had known someone with cancer. In two cases this was a parent; in all other cases this was a more distant family member or friend or a friend's parent. Six of the participants only engaged in PA at school (approximately 2-3 hours a week). The remaining participants reported that in addition to PA at school, they also played sport, or took part in exercise classes or recreational activities such as walking. Participants were recruited from three secondary schools located in Liverpool (n = 5), Birmingham (n = 3) and London (n = 11). Two of the schools were comprehensive and one was a boy's grammar. Sample size was determined pragmatically and aimed to include as many participants as was feasible within time and financial constraints.

Materials and procedure

The study received institutional ethics approval prior to commencement. The head teacher at each school provided their consent to allow teachers to provide eligible pupils with an information sheet about the study. Pupils provided informed consent before participating. Parental consent was obtained for those aged under 16 years (n=9).

A semi-structured interview schedule was developed by the research team to guide the interviews. Some questions were designed to specifically elicit beliefs relating to each of the five IRR components. Further questions were included to enable additional beliefs to be explored. The schedule was structured to ensure that questions exploring participants

understanding of the physiological link between PA and bowel cancer were asked after all questions exploring beliefs about the likelihood of illness. This was done to ensure, that should participants not be aware of this link, that this new information did not influence the appraisals of likelihood captured by this research. The schedule was piloted with six young people recruited through family and work colleagues of the authors. Minor amendments were subsequently made. The finalised schedule is presented in supplementary file one.

The interviews were conducted in summer 2015 by five researchers (KN, TLW, AF, SM, GP), all with experience of interviewing on sensitive subjects. Interviews were carried out in a private room and lasted between 45 and 60 minutes. All interviews were recorded and transcribed prior to analysis.

Analysis

The data were analysed using a deductive version of Framework Analysis in accordance with Gale and colleagues (2013). An initial set of codes representing IRR beliefs was developed. For example, for the component 'consequences', three codes to capture beliefs about death, pain and the psychosocial consequences of cancer were formed. Three researchers (KN, CC, and SM) independently coded three interview transcripts using the initial set of codes. Additional codes were added if the content of the interview could not be captured by the predetermined codes. The three researchers then met to discuss the initial coding. A few minor changes were made at this point and an agreed set of codes was created. This set of codes, known as the 'analytical framework', was then used by the team to code all of the remaining interviews.

A framework matrix was created in Microsoft Excel. Participants' responses were summarised within relevant cells of the matrix and illustrative quotes were entered for each cell. Two researchers (KN and AF) then independently interpreted the data, examining the

codes in detail across participants to identify themes. Following discussion, KN and AF came to a shared interpretation of the findings which is presented below. Quotes are provided to illustrate the themes and each quotation is followed by a code which represents the participants' gender and participant number.

Detailed information about bowel cancer is provided in supplementary file two to enable the reader to make comparisons to participants' responses.

Findings

Most but not all of the participants had heard of bowel cancer. Participants were however vague about details of the disease and the language that they used indicated a degree of uncertainty and guess work based on their existing understanding of the human body, personal experiences, and messages from the media. In the section that follows, we present participants beliefs with respect to the components of the IRR framework.

Identity

None of the participants reflected on personal characteristics that they felt put them at increased risk of bowel cancer. Two participants (one male, one female) said that they thought the disease was more likely to affect men than women; neither related this to their own risk of bowel cancer.

Cause

The majority of participants knew that those with a family history of cancer were at increased risk of cancer themselves. Almost all reported no cancer in their immediate family; a fact that they used in part to explain their relatively low level of perceived vulnerability:

> *And I don't know anyone in my family who's had cancer or bowel cancer, so I don't think I've got that much of a chance that I'll get it* (2M)

Participants identified a number of behaviours that they believed increased or reduced the risk of bowel cancer. In the former category was poor diet (e.g., eating too much sugar or salt, over-eating, eating processed food/meat, fatty foods, acidic foods, or citric acid), smoking, drinking alcohol, having a sedentary lifestyle, pollution, radiation, and chemicals (e.g. in water or sanitary products). Behaviours deemed likely to reduce the risk of bowel cancer included healthy eating (e.g. eating fibre) and drinking water. Once again, participants reflected on their own lifestyle behaviour as evidence of their reduced risk:

> *Also I think being vegetarian I'm not eating a lot of red meat... overall I do take care of my body. I try and drink a lot of water, and things. ... I'd say unlikely* (11F)

> *I'd like to think I have more control, because I do put myself in a position where I'm less susceptible to developing it, by staying fit and healthy, yeah* (8F)

A few participants when discussing lifestyle risks noted 'exceptions to the rule' such as having a '*Grandma who smoked 60 cigarettes a day*' who had '*nothing wrong with her'*, and contrasted this with others who were young or lived an apparently healthy lifestyle but still got cancer. This appeared to discredit messages about the efficacy of lifestyle changes. Some participants talked about cancer being '*bad luck'*, '*chance*', or a '*random event*':

> *It's just your cells doing something weird* (3M)

> *With this mutation thing it can be anyone* (8M)

Overall, participants estimated that about 40-50% of incidences of bowel cancer were due to hereditary factors or chance and 50-60% were due to lifestyle factors.

Participants were asked directly how they thought lifestyle behaviours were linked to bowel cancer. Most found this question difficult to answer. Some participants suggested that the cause might be to do with ingesting certain foods, particularly processed products:

I'm tempted to say if it's stemmed from chemicals that are in certain processed foods, things like that. Probably something to do with what we take in, because that's how I see the only way it could affect the inside (7F)

Some mentioned specifically that a lack of fibre may be responsible:

So fibre is supposed to keep everything moving. So it prevents things building up and causing cancer, bad things happening. So I guess that sort of diet (4F)

Other explanations included alcohol causing mutations, trauma to the bowel area, a blockage in the bowel, or fat clogging up the veins that supply the bowel. Levels of PA did not feature in any of the participants' accounts of how bowel cancer occurred.

Participants were then told by each interviewer that there was a link between PA and bowel cancer and asked why this may be. All of the participants found it difficult to answer this question. Some participants believed that exercise might keep the body in optimal condition, making cancer less likely:

It might obviously keep the cells healthy as well, and stop a mutation occurring (2M)

Similarly some participants felt that a healthy body was more able to fight off cancerous cells once formed:

I think if you exercise and have a healthy lifestyle then your immune system is more likely to be better and more equipped and it can deal with those cells more and that sort of thing (8M)

It would probably help reduce it because obviously it keeps your cells healthy and active. So if you've got a healthy body your cells keep regenerating... so that might make it easier to fight it off and kill those cells that are mutated (1M)

Participants also suggested that physical activity might improve digestion:

Maybe to do with digestion again, just helping it all (2F)

Finally, some participants thought that excess fat and obesity might account for the relationship between PA and cancer risk:

> *If you don't do enough exercise then, again, that's going to clog up your arteries because you're eating too much and not burning off the fat* (11F)

Timeline

All participants believed that people got bowel cancer from late middle age (40-50 years) onwards. This was put down to ageing cells which were '*deteriorating*' and '*more likely to do something stupid*'. As such bowel cancer was seen as a problem for the future and not something that young people would give much consideration to:

> *I just feel like it affects older people more. So I don't have to worry now, but when I'm older I might do* (5F)
>
> *Once you get past about 40-ish, then that's when you should start concentrating on it, thinking about it* (4M)

Some participants viewed other cancers, such as breast cancer, as more of a concern for young people as these seemed to affect people throughout the adult lifespan. Despite the participants believing that bowel cancer was a condition that mostly affects older people, many could see the benefit of adopting a healthy lifestyle for cancer prevention from a young age. Sometimes this related to putting good habits in place early, which would then benefit them later:

> *I don't think what I do now will affect my chance of getting cancer too much, but I do think it will play a factor, because if you don't participate in much sport now, the chances are you're not going to participate in sport when you're older (5M)*

> *It's important to stay fit as a child because it will set you up, and it will obviously reduce risks for the future.... If you exercise as a child more, then you have a stronger body, which you can maintain more easily as an adult* (2M)

Other comments suggested that participants believed that behaviours have a cumulative effect on the body:

> *Just because we are younger doesn't really mean that what we do isn't going to affect us. It isn't like a sudden age where it's like okay, everything you do from now is going to affect you; it's kind of like a gradual thing* (3F)

Some participants however, felt that preventative behaviours could be postponed until later in life:

> *Well, hopefully, I will make sure that when I get to whatever age it is, that it starts being more of a risk, I will hopefully have already started to take better care of my diet or exercise* (10F)
>
> *Yes [what I do now affects my health in the future], like a bit, but I don't think it's majorly important. Probably when you are 20 [It starts to become important]. Because when you get to that age, you've stopped growing and everything, haven't you, so that's when you have to start looking after yourself properly* (5F)

Frequency of occurrence

A number of participants made judgements about the likelihood of getting bowel cancer based on beliefs about the prevalence of the disease. Participants judged the overall likelihood of getting bowel cancer as low due to it receiving relatively little media attention and because they had not heard of anyone with the disease:

It [bowel cancer] wasn't, like, the first cancer that comes to-mind ...breast cancer because it's so talked about and how often people have said that they don't expect to get it and they do. I think that might be my biggest concern (11F)

I don't think that there's much, not publicity, but awareness about it [bowel cancer]. I don't think I know anyone with it. Maybe it's less common. Or it might not be but I just haven't heard about it much (3F)

Consequences

The majority of participants knew that bowel cancer, like all cancers, could be fatal:

I think that [death] is what's going to happen if it doesn't get relieved or cured (7M)

Participants mentioned a number of symptoms including discomfort, or a change in bowel habits and blood in stools:

I know the symptoms of it are blood in your faeces and unusual bowel behaviour so more diarrhoea or constipation (2M)

The emotional impact of cancer was identified by many of the participants:

I think obviously it would impact on people around me as well because they'd be obviously very sad and stuff like that. And it would probably make life a lot harder for them as well, dealing with somebody who has got cancer, probably a lot more stressful, I can imagine (2M)

Well, it would, obviously, be a real strain, especially if it was quite difficult to treat, or whatever, because obviously there isn't a cure, so they could die. So it would be a massive strain on your family and friends (6F)

One participant identified the potential for bowel cancer to affect mental health:

I think you'd become, obviously, quite depressed, and rightly so. Quite depressed, withdrawn, that would obviously affect your social life and your interaction with others (8F)

A number of participants also identified the financial implications of cancer:

I suppose, and also financially, if I'm supporting a family when I'm older, then yes, that's also a negative effect. I won't be able to support them anymore. ...Cancer in general doesn't just affect the person with cancer (3M)

Control over Cure/Treatment

Similarly to perceptions of likelihood, there was some indication that the relatively low media and public profile of bowel cancer also affected participants' beliefs about whether bowel cancer is treatable:

Bowel cancer is just something I don't really hear of commonly. I mean, I don't really know exactly how it affects your body in any way, so probably not as serious (8F)

When asked how bowel cancer would be treated, participants frequently listed surgery, chemotherapy, and radiation. However, participants were not sure about the extent to which bowel cancer could be treated and many commented that it would depend on how early the cancer was identified.

Participants were asked which cancers they felt were most serious and where bowel cancer fitted into that order. Pancreatic cancer was mentioned a number of times as being the most serious because of the low chances of survival. Some cancers were identified as being more serious than others because they affected a vital organ (e.g. the brain or lungs). For some, the bowel was considered part of that group but others felt that the bowel was less vital and that parts of the bowel could be fairly easily accessed and removed:

It's because it's kind of… it's where all foods end up and that's where a lot of things happen. I think it's probably quite a vital organ to your body. So it would be quite bad (8M)

I feel like surgery would work better, especially because... the way I say this might sound a bit weird, it's in quite a reachable place as well. It's not like too deep into the body that you can't find the tumour. So I feel like it would work well (11F)

The majority of participants felt that the only way to treat cancer was with conventional medicine, and that without this, the disease would progress. A small number of participants suggested that there was a chance that someone could get better without treatment:

I think it's possible [that people with cancer can get better without treatment], but I think the likelihood of survival is quite slim… I just think there's a chance because, before this treatment ever happened, people must have died quite a lot from cancer, but I'm guessing some people may have survived (2M)

None of the participants felt that alternative medicine or a healthy lifestyle could change the course of bowel cancer once it was present. However, some participants did feel that these could be beneficial in terms of managing the symptoms:

I think if it was the early stages of the diagnosis and the stages of the cancer then possibly [you could manage the symptoms with lifestyle behaviours], but if you are talking about critical stages, no (6F)

I think it would probably work [to alleviate cancer symptoms], but it would probably make it a bit easier to deal with, like eating healthily and physical activity. But overall, I don't think you could deal with it [cancer] that way, it would be quite hard to, yes (8M)

Discussion

The present research found that young people consistently judged their risk of getting bowel cancer to be low. This seemed to be based on their lack of a family history of cancer and their current lifestyle behaviours (e.g., good diet, relatively high levels of PA), which were viewed as being protective, or because they planned to change their lifestyle in the future when disease risk became more relevant. While cancer was viewed as a serious and potentially fatal illness, participants lacked knowledge about the effects of bowel cancer and it was not considered distinct from other cancers in terms of severity. Furthermore, the success of treatment for bowel cancer was unknown. Participants struggled to explain how levels of PA contribute to bowel cancer risk, finding it easier to imagine harm occurring through direct contact with a substance (e.g. unhealthy food).

Beliefs underlying judgements about the risk of bowel cancer fitted the IRR framework reasonably well. The beliefs expressed, and used to make assertions about personal risk, were largely captured by the five illness risk representation components. In particular, appraisals of likelihood were underpinned by beliefs about the 'Cause' of illness, and appraisals of severity were underpinned by beliefs about illness 'Consequences'. Of interest, however, and not captured by the framework, the relatively low media and public profile of bowel cancer unhelpfully influenced participants' appraisals of their risk of getting bowel cancer, it's lack of prominence led young people to conclude that bowel cancer cannot be that common or serious.

The present research represents one of the first studies to try to understand the beliefs underlying young people's appraisals of the risk of bowel cancer. IRR was used as a framework for organising these beliefs, but we were also open to the possibility that additional beliefs could influence judgments. The interview schedule was carefully prepared

and piloted with six young people prior to administration, and participants were drawn from cities in south, central and northern England. Data were coded by three researchers, and interpreted by two researchers, thus increasing the reliability and trustworthiness of the data and the breadth of interpretation.

The findings should however be interpreted in the context of a number of potential limitations. First, caution should be taken in generalising the findings given that the sample was drawn from urban and sub-urban areas only. Second, interviewer effects may have influenced responses. For example, many participants reported seeing the benefit of adopting a healthy lifestyle for cancer prevention. However, this was in the context of the interviewer having just explained that PA can help to reduce the risk of bowel cancer; and participants may have felt uncomfortable disagreeing with this idea. It should also be acknowledged there is the potential for information provided to participants during the interview on the link between PA and bowel cancer to have altered their beliefs about the risk of illness. Whilst the structure of the interview schedule ensured that the provision of this new information would not have influenced participants' beliefs about the likelihood of bowel cancer, there is the potential for it to have influenced severity appraisals. Whilst we did not identify any direct evidence of this, there is for example the possibility that this new information could have led to defensive processing, and consequently for individuals who did not meet recommended levels of PA to downplay the severity of the illness. Finally, the sample is limited to 19 participants. Data collection ceased on pragmatic grounds rather than when no new information appeared to be obtained (i.e. saturation point). As such, care should be taken not to overstate the findings. Whilst the themes from the initial interviews seemed to be replicated in the later interviews, further interviews may have identified additional themes or provided more nuanced explanations.

The beliefs that emerged reflect elements of the IRR framework as described by Cameron (2003). In terms of likelihood, participants largely judged risk on the basis of their beliefs about the Causes of bowel cancer. Beliefs about control over prevention were closely linked with beliefs about cause. When talking about cause, participants reflected on lifestyle behaviours that they believed reduced their likelihood of getting bowel cancer in the future. The IRR component of Identity had little influence on likelihood appraisals. This is likely because the features of individuals that increase the likelihood of bowel cancer, such as being male or having conditions such as diabetes or ulcerative colitis, are not well known. In terms of Timeline, whilst the age at which most people were affected by bowel cancer was an important consideration for young people in this study, it did not affect perceptions of likelihood per se but rather the relevance of the illness to the participants now as teenagers. Of importance however, the distal nature of the illness led a number of participants to believe that prevention efforts could be postponed until middle age and as such unfavourably influenced judgements about control over prevention. In terms of judgements of severity, beliefs about the consequences of bowel cancer seemed to be taken into consideration although these representations were not particularly rich and were largely based on hypotheses and ideas rather than any lived experience. Control of cancer through its treatment or cure, was deemed relevant to judgements of severity, but participants' knowledge of treatments was relatively poor, thus undermining its potential influence. Participants also seemed to judge the likelihood and severity of bowel cancer based on the (relatively low) public and media profile of the disease. This suggests that appraisals are not solely made by matching characteristics of the self with risk representation components.

The findings suggest a number of ways in which beliefs underlying young people's appraisals of bowel cancer risk could be changed in order to motivate them to engage in

preventative behaviour. Previous attempts to manipulate appraisals of the likelihood of getting bowel cancer have at times been unsuccessful (Courneya & Hellsten, 2001; Graham et al., 2006) and have led to the conclusion that young people may be overly optimistic about the likelihood of getting bowel cancer. Consistent with this idea, the present study found that participants largely judged their likelihood of getting future bowel cancer to be low, and this was rationalised in part by their engagement in preventative behaviour including PA. While participants believed that their levels of PA were good and therefore protected them against the risk of bowel cancer, when they were asked specifically about activities that they did in a typical day or week, whilst this was not assessed using standardized measures, it was clear that this fell short of the recommended levels for many. Whether this reflects a degree of optimistic bias or simply a lack of knowledge about the amount or intensity of PA required to offer protection is unclear but either way making this shortfall apparent to young people might be advantageous. Previous studies have also struggled to manipulate perceptions of the severity of bowel cancer (Graham et al., 2006; McGowan & Prapavessis, 2010). This has been attributed to a ceiling effect whereby those reaching adulthood are likely to have experiences of cancer to draw upon and thereby judge severity as high. The present research supports that. Participants' beliefs about the consequences of cancer in general and bowel cancer specifically were not rich and did not reflect an appreciation of the full range of psychosocial consequences and ramifications and this may be due to their age and consequently more limited life experience. Helping young people to put themselves 'in the shoes' of an older person diagnosed with bowel cancer may, therefore, be an effective strategy for enhancing appraisals of severity.

There are a number of other implications for practice evident from the findings. As discussed above, the age relevance of the illness appears to be important in motivating action.

Strategies which enable young people to visualise a future self and to perceive the benefits of preventative behaviour now in reducing future risk would be beneficial. In addition, encouraging individuals to reflect on the likelihood that they will begin or significantly increase levels of PA in later life, and conveying that this would not fully compensate for lack of PA in earlier life, would also be beneficial. There was some evidence that perceptions of likelihood were undermined by knowledge of 'exceptions to the rule', such as those who had smoked all their life but not got cancer. Providing young people with a clear explanation of how factors relating to genetics, lifestyle and chance interplay to determine cancer risk may help to prevent individuals refuting the contribution of lifestyle behaviour both in contributing to and preventing cancer. It was clear from the findings that young people struggled to understand how PA may relate to bowel cancer risk. The work of Bishop and colleagues (2005) who studied women's understanding of the link between smoking and cervical cancer, suggests that providing a coherent and common sense explanation of this relationship could be important for motivating PA.

In order to increase perceptions of the severity of bowel cancer, it may be important to highlight that treatment for bowel cancer is more effective when presentation is early, than for more advanced disease (see supplementary file two). Key to this is also explaining that it is in the advanced stages when most people notice symptoms and therefore engage with health care services. It may also be helpful to emphasise the essential role that the bowel plays in normal human functioning and the daily consequences faced by those whose bowel is diseased or has been removed.

Conclusions

The present research provides evidence that young people may underestimate their risk of getting bowel cancer in the future. This finding suggests that interventions that manipulate

young adults' beliefs about the risk of bowel cancer may be successful in motivating protective behaviour, such as promoting PA. The findings also attest to the importance of providing young people with a coherent and logical explanation of how protective behaviours such as PA work to reduce risk. The way in which young people in this study made judgments about the risk of bowel cancer reflected elements of illness risk representations described by Cameron (2003), providing support for the idea that this theoretical framework could be useful in developing future interventions. Given the study sample size, additional qualitative work of this nature is required to support and increase confidence in these conclusions.

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Accepted by BJHP 09.03.2007

Risk of bowel cancer and its link with physical activity

Appendix S1 – Interview Schedule

Section 1: Informed consent and demographics (10 mins)

- **Read information sheet, check they understand, respond to any questions, and seek consent**
- **Check eligibility**
  - Aged between 13-17 years
  - Have not personally had cancer
- **Record demographics (on Data Collection Sheet)**
  - Age
  - Ethnicity
  - Gender

Section 2: Physical activity (10 minutes)

Purpose of this section is to understand what their life priorities are at the moment and where physical activity fits into this, as well as their current levels of physical activity. It is also an opportunity to build rapport.

- LIFE PRIORITIES EXERCISE: I'm going to show you a list of things that I want you to prioritise in terms of how important they are to you at the moment.

  Interviewer to have these 'life priorities' printed out on cards and to ask the participant to put them in order of importance.

  - Looking physically attractive
  - Learning a new skill
  - Doing well at school
  - Staying fit and healthy
  - Making new friends
  - Having fun and enjoying yourself
  - Saving money
  - Getting the latest technology

- Are there other things, not on this list, that are priorities for you at the moment? If so, please add to list so that they can be included in your ranking exercise.

- Why have you put them in this order? [PROBE: highest/lowest priorities]

- Which ones do you think will become more important to you over the next few years? Why do you say this?

- What other things are priorities for you at the moment not on this list?

- Generally speaking, how important is staying fit and healthy to you at the moment?
    - What are the benefits to you of being fit and healthy?
    - What things do you do to stay fit and healthy? [PROBE: diet, physical activity]

- Where do you get advice and information about how to stay fit and healthy?
    - PROBE: friends, family, teachers, media, healthcare professionals

- In a typical week, what types of physical activity do you do? Explore what (including frequency and intensity)

- In a typical day, how many hours do you spend sitting down (e.g. lessons, TV viewing time, games console playing, internet surfing, phone chats etc.)?

- How easy/difficult is it for you to be physically active? Identify the barriers and facilitators of exercise
    - What could you do to be less *in*active? Is this likely/possible? What would get in the way or put you off?
    - What kind of activities do you enjoy? Could you do these more?
    - Is there anything you would like to do/try? What's stopping you?

Section 3: Understanding of cancer (30-40 minutes)

This section is intended to elicit beliefs about bowel cancer risk including those relating to the Illness Risk Representations (IRR) framework. Where a question is intended to elicit beliefs relating to a component of the IRR, the relevant component is identified alongside in bold font and square brackets.

Opening questions

This subsection is intended to build the participants comfort talking about cancer and to begin eliciting knowledge and beliefs about cancer.

- What do you think or feel when you hear the word 'cancer'?
    - What are the first thoughts that come into your mind?

  - Do you have any particular images in your mind?
- Do you feel that you have in any way been affected by cancer? (For example, friends or family developing the disease).
- What types of cancer have you heard of? [E.g. lung, breast, bowel etc.]
- Please can you tell me what, if anything, you know about bowel cancer?
  - Discuss initial thoughts and images again (if they know what bowel cancer is)
  - NB this is just an opening question, understanding will be further prompted below; if they struggle ask them what they know about cancer in general then:
    - Make sure before moving on that they know what the bowel is - show image in CRUK debriefing leaflet and make sure that they know that bowel refers to the large colon and rectum; briefly explain digestive system and how bowel fits within that – wording on leaflet if needed

Beliefs about likelihood

This subsection largely explores beliefs relating to likelihood of bowel cancer

- What do you think causes bowel cancer? **[Cause & Identity]**
  - [PROBE: diet, smoking, alcohol, genetics, environment]
  - How do you think these different things cause cancer? What do you think they do to the human body that causes cancer?
    - EXPLORE e.g. if they say 'diet', ask them in what way they think that would cause cancer i.e. what is their understanding of the physiological link;
    - EXPLORE to identify any misperceptions about cause - if identify, see if they can explain what they think the mechanism of action is.

- How much control do you think people have over whether or not they get cancer? **[Cause & Control]**
  - Is bowel cancer sometimes caused by things we have no control over? i.e. our genes.
  - How much do you think the risk of getting bowel cancer is down to what we do (our lifestyle) versus things we have no control over (our genetics)? Why do you day that?

- What do you think people can do to reduce their risk of getting bowel cancer (e.g. not smoking, drinking etc. but also PA)? **[Cause & Control]**
  - EXPLORE to tease out understanding of physiological link; Again probe for misperceptions about how cancer can be prevented.
  - How effective do you think these things are at reducing the risk of getting cancer? Which do you think is most/least effective?

- Do you think that things you do now affect your chances of getting bowel cancer in the future? **[Cause & Timeline]**

- What makes you think/believe this?
- EXPLORE at what age (if any) they think that what they do will start to have an effect.

- Who do you think is most at risk of getting bowel cancer? **[Identity & Timeline]**
  - Why do you say this?
  - At what age do you think people are most likely to get bowel cancer? Why is this?

- How likely do you think you are to get bowel cancer at some point in your life?
  - EXPLORE reasoning: family history, lifestyle? Is this view based on current lifestyle or on basis of future (intended) lifestyle? Ask them about both.

This subsection ends with a few questions relating specifically to exploring participants understand of the link between bowel cancer and PA.

- Did you know that being physically active can reduce your risk of getting bowel cancer? *NB this is at least half an hour of moderate PA 5 times a week, although the more the better*
  - Why do you think this might be?
  - Encourage them to suggest causal explanations. **[Cause & Control]**

- How likely do you think you would be to get bowel cancer at some point in the future if you: **[Control]**
  - Did all the things that doctors recommend to prevent it (i.e. healthy diet, exercise, didn't smoke, had little/no alcohol, kept at a healthy weight)?
  - Did all of these recommended things but you still didn't do any exercise?
  - Didn't do any of the things that doctors recommend (i.e. had an unhealthy diet, didn't exercise, smoked, drank alcohol, and were overweight)?

Beliefs about Severity

This subsection largely explores beliefs relating to severity of bowel cancer

- Which cancers do you think are the most serious?
- How serious do you think bowel cancer is?
  - What do you think the symptoms would be? **[Identity & Consequences]**
  - How much pain/discomfort do you think people experience when they have bowel cancer? What is the nature of this pain? i.e. where is it, and does it come and go or is it there all the time? **[Consequences]**

- Do you think bowel cancer be cured (e.g. radiotherapy, chemotherapy). How well do you think this works? **[Control]**
- Do you think the pain can be controlled? How well do you think this works? **[Control]**
- What do you think is the worst thing that could happen if someone got bowel cancer? What's the likelihood of this happening? **[Consequences]**

- What do you think the consequences of cancer could be for you and your family? **[Consequences]**
  - PROBE: for non-health related (as well as health related) consequences e.g. for study, work, stress, finances, emotions

- If you developed bowel cancer but had no medical treatment for it, what do you think would happen? **[Consequences & Control]**
  - Do you think you could get better by yourself? Could your body 'fight it off'?
  - Is there anything you could do/take (e.g. unconventional medicines) that would make you better?
  - How long do you think you would be ill for?

- If you did get treatment, what do you think would happen? **[Consequences & Control]**
  - What course would things take?
  - Can you put a time against these things i.e. how long would take?

This section ends with a few questions to explore emotional responses relating to risk

- Are you worried about getting bowel cancer? Why/why not?
  - EXPLORE whether they think these levels of worry might change as they get older

- If you developed cancer in the future, do you think that you might look back at choices you made about your lifestyle? What do you think your thoughts might be?
  - How might this make you feel?
  - Explore different scenarios i.e. if they had lived a very healthy life, and a less healthy life. Ask for each, 'do you think you might wish you had done things differently?'

Section 4: Reflections (5 minutes)

Purpose of this section is to reflect on the issues discussed and bring the interview to a close.

- What do you think is the biggest challenge in motivating young people to do more physical activity?

- What do you think would most motivate you to make lifestyle changes that will help reduce the risk of getting cancer when you are older?

- What advice would you give to us about how we should communicate the risks of cancer to young people?

Debriefing

Give them CRUK leaflet

Ask them if they have any questions and try and answer (but explain limits: we are not experts in (bowel) cancer)

Refer them to CRUK website and helpline (details on leaflet) if needed

Appendix S1

Detailed information about bowel cancer

Bowel cancer is the second most common cause of cancer-related mortality accounting for 10% of all deaths from this disease (Cancer Research UK, 2016e). Whilst 5-year survival rates are good for people diagnosed at an early stage of cancer (stage one), only 15% of people are typically diagnosed at this time (Cancer Research UK, 2016d). Approximately 20-25% of people are diagnosed at each of the remaining three stages, with 5-year survival decreasing markedly with increasing stage such that diagnosis at stage four has a five year survival rate of 7% for men and 8% for women (Cancer Research UK, 2016d). Symptoms of bowel cancer include a change in normal bowel habits, bleeding from the rectum or blood in stools, and pain in abdomen or back passage (Cancer Research UK, 2016a). The main treatments for bowel cancer are surgery, radiotherapy and chemotherapy. Long-term effects of treatment include needing to have a colostomy or illeostomy bag, stools that are softer, looser or liquid, constipation, bloating, wind, and faecal and urinary incontinence.

There are a number of factors which can increase the likelihood of bowel cancer. These include a strong family history of bowel cancer, having ulcerative colitis or crohn's disease, and having conditions which affect the production of insulin or growth hormones such as diabetes (Cancer Research UK, 2016c). Incidence is also higher amongst males and increases with age; lifetime risk of bowel cancer is approximately 1 in 14 in males and 1 in 19 for females, with the majority of diagnoses in patients $\geq$65 years (Cancer Research UK, 2016e). Those who are overweight or obese are also at increased risk. There is also evidence of lifestyle factors including smoking, drinking alcohol, eating red and processed meat, and insufficient PA

(Cancer Research UK, 2016b). Evidence suggests that there is a direct link between PA and bowel cancer, irrespective of obesity. Mechanisms of action include, a reduction in circulating hormones and growth factors that stimulate growth of epithelial cells of the colon (such as insulin and insulin-like growth factors IGF-1), a reduction in inflammatory markers, improved immunity and an increase in gut motility (reducing exposure of the colonic epithelium to carcinogens in food and gastric bile) (Wolin, Yan, Colditz, & Lee, 2009).

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