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Abstract

Colorectal cancer (CRC) is one of the most prevalent cancers worldwide, and an ideal target for early detection and prevention through cancer screening. Unfortunately, rates of participation in screening are less than adequate. In this study we explored why people who were offered a fecal immunochemical test for CRC decided to participate or not, and what influenced them to take action and complete the test. We conducted 4 focus groups and 30 telephone interviews with 63 people. The main reason for deciding to screen or not was “wanting to know” their CRC status, which operated on a continuum ranging from wanting to know, through varying degrees of ambivalence, to not wanting to know. The majority of participants expressed ambivalence with regard to CRC screening, and the main cue to action was the opportunity to screen without being too inconvenienced.

Key words

Cancer, screening and prevention; focus groups; interviews; qualitative analysis; risk, perceptions; self-care

Colorectal cancer (CRC) is a significant global health problem. It is one of the most prevalent cancers worldwide, and the third most commonly diagnosed cancer in men and the second in women in developed countries (Jemal et al., 2011). In Australia, CRC is the second most commonly diagnosed cancer in both men and women, although men have higher rates of incidence than women (Australian Institute of Health & Welfare, 2008). It is also the second most common cause of cancer-related death in Australia (Australian Institute of Health & Welfare, 2012). The incidence of CRC increases with age; around 93% of people diagnosed in Australia are aged 50 or older (Australian Institute of Health & Welfare, 2012).

Screening is an effective means of reducing the incidence of death from CRC (Australian Institute of Health & Welfare, 2012), and population-based bowel cancer screening has been introduced in a number of countries (Benson et al., 2008). In the Australian context, as in many countries, screening begins with testing a sample of feces for minute traces of blood, which is an indication of CRC risk but can be caused by other factors. The test does not detect CRC itself, and individuals returning a positive screen are then referred for diagnostic evaluation, usually by colonoscopy. The most recent Cochrane systematic review of CRC screening reported an overall reduction in mortality of approximately 25% (adjusting for nonattendance to screening), and a false-positive rate of approximately 80%, which can lead to adverse psychosocial and physiological consequences (Hewitson, Glasziou, Watson, Towler, & Irwig, 2008). The review included studies using fecal occult blood test (FOBT) technology for testing for CRC risk, and the authors conclude that the results “provide further support for the use of FOBT as a population-screening modality to reduce CRC mortality” (p. 1546).

In Australia, the National Bowel Cancer Screening Program (NBCSP) was introduced in 2006 with the aim of reducing the incidence of, and mortality due to, CRC. The program uses a

fecal immunochemical test (FIT) technology for detection of occult blood (Australian Institute of Health & Welfare, 2012). FIT is now the preferred FOBT technology because of its superior acceptability and capacity to detect cancer (Young, 2009). Currently the NBCSP sends FIT kits to people turning 50, 55, 60, 65, and 70 years, although at the time of the study kits were sent to those turning 50, 55 and 65. The test is completed at home and posted to a central pathology laboratory for analysis.

Screening participation rates through the NBCSP are lower than ideal, with the most recent figures reporting a participation rate over the period July 2008 to June 2011 (Phase 2) of 38.4% (Australian Institute of Health & Welfare, 2012). Issues with uptake have also been reported in other countries (Levin et al., 2011). It is important, therefore, to understand how people make the decision to participate or not participate in CRC screening, and what influences them to take action.

Literature Review

Previous research has explored people's knowledge, attitudes and beliefs about CRC, and facilitators and barriers to screening. Quantitative research in this area has identified a range of demographic characteristics associated with screening for CRC, including gender, age, socioeconomic status, and ethnicity (Javanparast et al., 2010; Vernon, 1997; Ward et al., 2010), in addition to knowledge about and attitudes toward CRC and screening (Gregory et al., 2011; Janz et al., 2007; Vernon, 1997). Health motivation has also been reported to be a significant influence on the decision to screen for CRC (Gregory et al., 2011; Vernon, 1997). In a review of the literature by Vernon (1997) the author identified that health motivation, or a preventative health orientation (illustrated in engagement in other forms of health promotion), was most consistently positively associated with screening and was also a differentiating factor between persistent compliance with screening and persistent refusal.

Risk perception has been found in some studies to influence the decision to screen for CRC (Vernon, 1997). For example, Lipkus et al. (2000) found that baseline absolute risk did not predict screening intentions whereas greater perceived absolute risk, comparative risk and concerns at follow-up were predictive of thinking about, or planning to get, an FOBT. Paradoxically, in the UK CRC Screening Pilot Evaluation Team's (2003) evaluation of the United Kingdom screening pilot, perceived susceptibility was not found to be associated with screening. Similar results have been reported in other studies (Madlensky, Gallinder, McLaughlin, & Goel, 2003). Other influential variables include knowing someone with cancer or CRC (Vernon, 1997), provider recommendation and family history of CRC (Costanza et al., 2005).

A number of barriers to CRC screening have also been identified, including individual barriers, provider barriers and system barriers (Walsh, 2005). Individual barriers include lack of knowledge about CRC and screening, and negative attitudes toward screening (Janz et al., 2007; Jones et al., 2010), procrastination (Janz et al., 2007; Vernon, 1997; Worthley et al., 2006), lack of perceived susceptibility (Vernon, 1997; Worthley et al., 2006), fear of having cancer or not wanting to know about health problems (Arveux et al, 1992; Vernon, 1997), and procedural barriers such as possible embarrassment, pain, discomfort and the perceived unpleasantness of the test (Cole et al, 2011; Janz et al., 2007; Jones et al., 2010; Vernon, 1997). Procedural barriers were identified in The UK CRC Screening Pilot Evaluation Team's (2003) report as the most significant factor affecting uptake of CRC screening. An Australian study of why people refuse screening for CRC also found individual barriers, including procrastination, unpleasantness of the test and lack of symptoms, to be significant barriers (Worthley et al., 2006).

Research from the United States has identified provider barriers, such as lack of recommendation or negative attitudes toward CRC screening by health care providers, and

system barriers such as lack of health care coverage for CRC screening, as major obstacles to the uptake of screening (Costanza et al., 2005; Jones et al., 2010). According to Vedel et al. (2011) in their systematic review of the literature (where most of the studies were conducted in North America and Europe) the most frequently reported barriers to CRC screening were lack of provider recommendation, embarrassment, fear and discomfort on behalf of the patient, and the lack of health care coverage for screening tests.

Qualitative research has generally supported the quantitative findings on the importance of individual, provider and system barriers and facilitators to CRC screening (Brouse et al., 2003; Chapple, Ziebland, Hewitson, & McPherson, 2008; Garcia et al., 2011; Green et al., 2008; Wackerbath, Peters, & Haist, 2005; Weitzman, Zapka, Estabrook, & Goins, 2001). Qualitative research has also revealed barriers to and facilitators of CRC screening not reported in the quantitative literature, by delving more deeply into people's experiences and perceptions, and exploring cultural and social aspects of the CRC screening experience. For example, trust (Jones, Devers, Kuzel, & Woolf, 2010; Lasser, Ayanian, Fletcher, & Good, 2008) and being a "good citizen" (Chapple et al., 2008) have been found to influence CRC screening.

The influence of culture and gender on screening participation have also been qualitatively explored (Javanparast et al, 2012; Severino et al., 2009). Misperceptions of CRC and CRC screening underpinned by participants' cultural background were found in Goldman, Diaz and Kim's (2009) study of perspectives on CRC risk and screening among Dominicans and Puerto Ricans in the United States. The authors report that the most commonly mentioned cause of CRC was anal sex, and barriers to screening included stigma, misperceptions, embarrassment and machismo. Molina-Barcelo, Salas Trejo, Peiro-Perez and Malaga Lopez (2011) found that Spanish women were motivated by the importance of self-care and early detection, with the aim of preventing personal and family suffering, whereas men were encouraged by their partners.

Gender differences in reasons for nonparticipation were also found; women found the test unpleasant and feared the results while men “showed carelessness and lack of concern” (p. 669).

Despite the growing body of qualitative research in this area, there remains a gap in understanding the reasons why some people appear to be able to surmount what seem to be significant barriers to screening. Another gap in the literature is an understanding of why some people who agree to screen for CRC fail to take action, while others follow through on their intentions. Furthermore, much of the existing research is based in the United States, with relatively few Australian studies found. This is a significant gap in the literature because of major differences in health care systems between countries, and the impact these systems have on screening participation. In particular, financial concerns have been shown to be a major barrier to screening in the American studies, whereas Australia’s public health care system means that this barrier is unlikely to be significant. There are also differences in the nature of the screening programs offered in different countries.

Our Australian study aimed to build on existing literature on the decision to screen for CRC and address the gaps identified above. In particular, we explored why people who were offered a FIT decided to screen or not to screen, and what influenced some of them to take action and complete the test despite the barriers widely documented as impacting participation. We explored the decision to screen and screening behavior separately based on research suggesting that there is often a gap between intention and behavior (Webb & Sheeran, 2006), with intentions explaining on average only 28% of the variance in future behavior (Sheeran, 2002).

Methods

The analysis reported here formed the qualitative aspect of a randomized controlled trial. The trial tested whether personalized and online decision support, tailored on psychological variables, resulted in better participation in CRC screening than non-tailored online and traditional paper

based resources (Authors, 2010). The participants (n=3408) were recruited from a randomly selected sample of men and women identified from the Australian electoral roll, and randomized to tailored, non-tailored and control groups. All trial participants completed a baseline survey exploring variables from the Preventive Health Model as well as decision “stage” using the Precaution Adoption Process Model. Participants allocated to the tailored group were also given online feedback tailored to their responses. Trial participants were invited to screen for CRC and sent a FIT by post, accompanied by either paper-based bowel cancer information (control group), or access to information via the online tool. They were asked to complete the FIT within a specified time frame and send it to a laboratory (using a pre-paid postage pack) for analysis. Eligibility criteria for the randomized controlled trial included: aged between 50 and 75 years; access to the internet at some location (because the decision support system was internet based); and having not undertaken FIT screening in the preceding 12 months. The age range was selected to reflect the target population for CRC screening.

In order to explore decision-making around CRC screening, we conducted focus groups and interviews with 63 participants from the randomized controlled trial who had been sent a FIT, including 43 screeners and 20 nonscreeners. We use the term “screeners” to describe those participants who participated in CRC screening by returning their completed FIT, and “nonscreeners” to describe those participants who failed to return the completed kit within the specified time frame (12 weeks). The term “participant” refers to participants in the interviews and focus groups. Ethics approval for the trial, including the qualitative component, was sought and granted by the relevant ethics committee. Participants were assured of their confidentiality and that no identifying information would be presented in any outcomes of the study.

Recruitment and Sampling Framework

Interview and focus group participants were purposively recruited from participants in the

randomized controlled, and sampled using a maximum-variability sampling framework (Grbich, 1999). Interview participants were chosen based on a selection matrix of: completion of FIT, gender, and age group. These factors were chosen to ensure that the views of both screeners and nonscreeners were included, and that the sample was heterogeneous with regards to age and gender. Participants were selected with a view to meeting the recruitment goal of 30 participants. Focus group participants were recruited to explore their perceptions of the usability and acceptability of the decision support tool (these data are not reported here), and participants were chosen based on a selection matrix of: randomization; completion of FIT; gender; and age group. Participants were selected with a view to meeting the recruitment goal of 30 participants. We anticipated that we would recruit more screeners than nonscreeners for the interviews and focus groups given that there were fewer nonscreeners in the overall sample of participants in the randomized controlled trial.

Using a list of all participants in the randomized controlled trail, potential participants were telephoned by one of the authors and invited to participate in a focus group or telephone interview. As each selection criterion was met, the list was scanned for the next person who fulfilled an unmet criterion. Sixty-three (63) people agreed to participate (43 screeners and 20 nonscreeners), 30 in the telephone interviews and 33 in the focus groups. Sixty-five (n=65) people refused to participate, of which 27 (41.5%) were nonscreeners. The main reasons given for refusal were: too busy with work and other commitments, illness, and not interested in being involved. Thirty-five (n=35) men and 28 women agreed to participate. The majority of the participants were aged between 55 and 64 (56%), with 19% aged 50-55 and 25% aged 65-70+. The participants were mainly employed, either full-time (37%) or part-time (16%), with 43% retired.

Data Collection

We conducted 4 focus groups and 30 telephone interviews. Telephone interviews were conducted with 16 screeners and 14 nonscreeners, and 27 screeners and 6 nonscreeners participated in the focus groups. Semistructured interview guides for the telephone and focus group interviews were developed with the aim of exploring the decision to screen or not to screen for CRC. The interview guides focused on the reasons for the decision, and the influence of others on their decision. Particular issues were explored within these domains. These were based on the facilitators and barriers identified in previous research including; the perceived efficacy of screening, possible concerns about the test results, procedural barriers with regard to the FIT, health perceptions, thoughts on cancer, and participants' perceived risk of cancer. Participants were also asked to discuss any other issues relating to CRC, screening and their decision-making, and the open-ended nature of the interview guide encouraged the participants to express their own views and experiences.

Six pilot telephone interviews were conducted to refine the interview guide, and a few minor changes were made before proceeding with the data collection. The pilot interviews were included in the analysis. The telephone interviews were conducted between May and June 2011, and the average duration of the interviews was approximately 30 minutes. The interviews were conducted by one of the authors who worked as a project officer on the randomized controlled trial.

A different interview guide was developed for the focus groups because we wanted to explore in detail the participants' perceptions of the usability and acceptability of the decision support tool (this analysis will be published separately); however the focus group guide also incorporated the questions used in the telephone interviews and these data were included in the analysis presented here. There were 8 participants in focus group 1, 10 in focus group 2, 8 in focus group 3, and 7 in focus group 4. The focus groups were conducted by a research consultant

not connected with the study in a consumer testing laboratory at a local research organization. Participants were encouraged to discuss issues freely and express divergent views. Issues raised that were outside of the interview guide were pursued. All participants were invited to enter into the discussions. The focus groups took place in September 2011 and were around 2 hours in duration. The focus group participants were compensated for their time and travel (\$50).

Data Analysis

The interviews and focus groups were audio-taped and transcribed verbatim. We used a framework analysis approach to analyze the data. Framework analysis is a qualitative method of analysis that is specifically suited to applied research that has specific questions, a limited timeframe, a predesigned sample, and a priori issues that are to be explored, such as those identified in existing literature (Strivastava & Thomson, 2009). Framework analysis does, however, provide the additional capacity to identify and examine emergent themes and ideas (Strivastava & Thomson, 2009; Lipstein et al., 2010).

Framework analysis has been used previously to explore CRC screening (Green et al., 2008), and the analytic processes are similar to other forms of thematic analysis commonly used in qualitative research in this area (Weitzman et al., 2004). Framework analysis involves a 5-step process: familiarization with the interviews and transcripts to gain an overview of the data and note any key ideas and recurrent themes; identifying a thematic framework, using both a priori and new themes arising from the data; indexing, where portions or sections of the data that correspond to a particular theme are identified; charting, where indexed pieces of data are arranged in charts of the themes; and mapping and interpretation, which involves analysis of the key characteristics as laid out in the charts (Strivastava & Thomson, 2009).

Charting is one aspect of framework analysis that is different to other forms of thematic analysis, and offers important advantages. It involves presenting the data in tables with the

themes on the vertical axis and participants on the horizontal axis. Quotes from the interviews are presented for participants under each theme. Charting provides a visual display of the data to facilitate comparisons between participants and the exploration of negative cases, and ensures that the analysis is based firmly in participants' views. It also provides a transparent means of sharing the data with other researchers for group discussion. The charts form a basis for the final stage of mapping and interpretation, the aim of which is to define concepts, explore and map the range of phenomena, create typologies, find associations, provide explanations and develop strategies, all of which are grounded in the data and reflective of the attitudes, beliefs and values of the participants (Strivastava & Thomson, 2009).

We used the online qualitative data analysis software, Dedoose (Version 4.3.86, 2012) to assist the data analysis process. Dedoose was chosen over other qualitative analysis software, such as NVivo, as the online format allowed all of the researchers to work on the analysis using the same data set. We began by developing codes and grouping similar codes into themes. Themes were identified on the basis of patterned responses or meaning within the data set that “capture[d] something important about the data in relation to the research question” (Braun & Clark, 2006, p. 82). Thus patterned responses in relation to participants' discussions about why they decided to screen or not to screen, and what influenced screeners to take action and complete the test, were collated. The analysis initially focused on a priori issues based on the interview guides (such as “risk perception” and “influence of others”). After further exploration we identified a number of emergent themes (such as “wanting to know”, “ambiguity” and “self care”), which were incorporated into the thematic framework. The development of the initial codes and themes was carried out by one of the authors who was not involved in the randomized controlled trial, and who had no previous knowledge or experience with CRC or screening. Once the thematic framework was identified, indexing of the codes was undertaken.

At this stage the decision was made to test the reliability of the coding framework using the multi-rater Kappa measure of agreement through the facilities made available by Dedoose. We recognize that the concept of inter-rater reliability is a controversial one in qualitative research (Pope, Ziebland, and Mays, 2000), particularly with regard to concerns that a reliability assessment of a predefined list of themes will limit the inductive nature of data analysis by closing the process to additional induction once a coding framework is confirmed (Cook, 2011). However, we felt that it was useful to check that we all understood what the initial codes were representing, and that there was consistency across the ways in which we interpreted the participants' comments. To test for inter-rater reliability, four interviews were indexed using the coding framework, and the same interviews were then independently indexed by two others using the same coding framework. Kappa scores of 0.96 and 0.98 were achieved, showing good inter-rater reliability. Differences were discussed and any issues with the coding resolved before the rest of the transcripts were coded. We were mindful of the importance of the induction process continuing throughout the analysis, and the codes were refined and reorganized as the analysis process continued.

Once the interview transcripts were coded we charted the themes and undertook the final stage of mapping and interpretation. All of the authors were involved in the analysis and meetings were held to discuss the themes and resolve issues, using the charts as a visual display of participants' views. To help with the final stage of the analysis, we followed Braun and Clarke's (2006) suggestion of asking a number of questions of the data, such as: What does this theme mean? What assumptions underpin it? What are the implications of this theme? What conditions might have given rise to it? Why do people talk about this thing in this particular way (as opposed to other ways)? What is the overall story the different themes reveal about the topic? (p. 94).

Rigor

A number of processes were used to ensure analytic rigor (Shenton, 2004). These included the use of both interview and focus group methods of data collection, negative case analysis, frequent debriefing sessions to discuss the analysis, and ensuring the involvement of researchers with no previous knowledge and experience with CRC and screening. We included both screeners and nonscreeners in the research in order to ensure a variety of perspectives on decision making around screening. We have described the context of the research and detailed the methods of data collection and analysis. In what follows we present a rich description of the analysis using multiple examples from the interview transcripts and ensuring that the views of all participants are represented.

Results

Nearly all of the participants (98%) had decided to screen for CRC in response to the invitation to participate in the randomized controlled trial, although not all of the participants (32% nonscreeners) followed through on this decision. We begin with a discussion of the decision to screen for CRC, followed by an exploration of what motivated the screeners to follow through on their decision. Only information on participants' screening status is included alongside quotations to maintain their anonymity.

The Decision to Screen for CRC

The participants discussed a range of reasons for making the decision to screen for CRC. Underlying these we found a central thread running through the discussions, namely "Wanting to Know" their CRC status. We begin with a discussion of the concept of "wanting to know", where we present respondents' views of why they agreed to be sent the FIT and screen for CRC. We then explore the notion of ambivalence, where we propose that while the participants expressed a desire to know their CRC status, ambivalence was evident in the strength of their conviction and

the relative importance of screening.

Wanting to know. Both screeners and nonscreeners discussed the value of screening in terms of providing them with knowledge of their CRC status. More specifically, while the participants generally understood that the FIT was only the first step in the process to diagnosis, they described the FIT as a means by which to find out whether or not they had bowel cancer. As one of the focus group participants commented with regard to why he had done the FIT, “. . . it was for my own wanting to know if I’ve got it [CRC]” (Screener). Screening with the FIT was described as a “safety check” (Screener), a way of checking on their health status while they still felt healthy and in the absence of symptoms, “. . . my health is pretty good at the moment. As I say it just helps you to know what’s going on with your body” (Screener).

Wanting to know their CRC status extended to participants’ thoughts about how they might respond to the results. Although many participants discussed feeling concerned or anxious about the results (one of the barriers to screening identified in the research literature), the majority reported that they would rather know than not know, irrespective of whether the results were positive or negative. Wanting to know was also described as overcoming concerns about the test itself, which involves taking a sample of feces. Some participants were concerned about doing the FIT because they found the test “gross” (Nonscreener) or did not like the idea of “playing with poo” (Nonscreener) - another reported barrier to screening. However, for the most part, the participants were able to overcome their discomfort because they wanted to know their CRC status.

The participants outlined two advantages of knowing their CRC status. First, if the results were negative for blood, the FIT was seen to offer reassurance by indicating that they did not have CRC, for example, “It’s nice to know I’m clear for a few years anyway” (Screener). Second, if the result was positive for blood, the FIT was described as providing early detection to improve

participants' chances of survival if they did have CRC. As one participant put it, "No-one wants to know they've got cancer but I think most of us would want to know as soon as possible so something if possible can be done" (Screener).

Not wanting to know. The participants also discussed "not wanting to know" in relation to CRC. In most cases they were hypothesizing about why other people might decide not to screen. For example, in response to the discussion of a friend who chose not to engage in any form of cancer screening, a participant stated: "It's difficult because that's her right. It's her right not to know" (Nonscreener). Another participant discussed her feeling that some people wish to remain oblivious to their cancer status: "And the disadvantage [of screening], for some people, not for me, but for some people is that they really don't want to know" (Nonscreener).

There were only two nonscreeners who identified that they, personally, would rather not know their CRC status, and that this was the primary reason for the decision not to complete the FIT. Their main concern was in relation to what might happen in the aftermath of finding out they have CRC, particularly with regard to treatment. For one nonscreener, her decision not to know related to her experience of watching her mother die of cervical cancer:

I don't participate in any type of screening. . . . I watched my mother die an absolutely horrible death as a result of all the treatment she had for cervical cancer and I vowed and declared at that time that I would rather not know about it, thank you very much.
(Nonscreener)

The other participant expressed similar concerns about negative effects of cancer treatment.

These two nonscreeners were unusual in their discussion of not wanting to know their CRC status; the majority of participants, including nonscreeners, wanted to know and made the decision to do the FIT. Given the centrality of wanting to know as expressed by the participants,

this raises the question of what it is that underpins this desire. In our analysis we found that wanting to know was underpinned by notions of self-care and the importance of taking personal responsibility for one's health.

Screening as self care. Both screeners and nonscreeners described CRC screening as a form of self-care, and the participants viewed themselves as being health conscious individuals who take care of their health: “. . . it's taking care of your health really” (Screener). Screening for CRC and other cancers also allowed the participants to take personal responsibility for their health: “. . . you've got to take a bit of responsibility for your own health” (Screener). The importance of taking personal responsibility for their health was reinforced by the insistence that the decision to test for CRC was a personal decision, an “individual thing” (Screener), rather than relying on the expectations of others, such as family or peers. The view that other people have no influence on the decision to screen for CRC was expressed quite strongly by nearly all of the participants.

Contrary to the research literature, health professionals, too, were not considered a major influence on the participants' decision to screen. Participants discussed how they had made the decision despite the fact their doctors had not suggested that they do the FIT, emphasizing that the decision to screen is a personal one: “. . . I haven't spoken to a health person at all, I've just put a decision on myself for whatever reason to say yes [I will do the FIT]” (Screener). In fact, some participants stated that they had done the FIT despite their doctors suggesting that they should not do the test:

I asked my doctor [if I should screen for CRC], she said ‘no you haven't got a history’ blah, blah, blah; however you know I heard around of friends having . . . bowel cancer and I wanted to do it, so it was really my decision. (Screener)

In this section we have explored “wanting to know” as underpinning the decision to

screen for CRC, and the importance of self-care and personal responsibility in participants' wanting to know their CRC status. In the following section we discuss ambivalence about the screening decision, the impact of ambivalence on procrastination and the ability of participants to ultimately follow through on their decision to screen for CRC, and the role of risk perception in ambivalence. We use the term "ambivalent" to mean a lack of conviction or certainty with regard to the desire to know (or not to know) their CRC status.

Ambivalence about the screening decision. As discussed earlier, nearly all of the participants made the decision to receive a FIT to screen for CRC because they wanted to know their CRC status. However, we found that in most cases the desire to know was not expressed as an important or urgent desire. Only a few participants expressed a strong conviction about wanting to know whether or not they had CRC, such as: ". . . not knowing, is not . . . really an option in my opinion . . ." (Screener). Similarly, not wanting to know was a desire strongly expressed by only two nonscreeners. As one of these participants stated: "I would rather not know about it, thank you very much" (Nonscreener).

For the majority of participants, both screeners and nonscreeners, the decision to do the test was expressed in more ambivalent terms such as "why not?" (Screener), "there's no real reason not to" (Screener), and "it doesn't hurt to screen" (Screener). One nonscreener explained her decision to do the FIT in similarly ambivalent terms: "I just thought it would be nice to know that you haven't got a problem down in your bowels" (Nonscreener). These participants can be described as wanting to know their CRC status, yet ambivalence can be seen in the apparent lack of conviction or certainty regarding the importance of screening.

It appears, therefore, that "wanting to know" did not function simply on an "either-or" basis, with screeners wanting to know and nonscreeners not wanting to know their CRC status. Instead, we propose that "wanting to know" operated on a continuum based on the strength of

participants' conviction. This continuum ranged from a strong conviction about "wanting to know" (it was extremely important to find out their CRC status), through a more ambivalent position (being prepared to engage in screening but not necessarily considering it to be important), to a strong conviction about not wanting to know at the other end of the continuum. For those participants with a strong desire to know, following through on the decision to screen was relatively easy, while for those who expressed varying degrees of ambivalence the ability to follow intention with action was more difficult.

Ambivalence and procrastination. Ambivalence in the screening decision was reflected in procrastination about following through on the decision to screen. Although a small number of nonscreeners were unable to do the test because of significant life events (such as caring for a dying relative), or having to have a colonoscopy (negating the need for the FIT), procrastination was the main reason given by nonscreeners for not taking action despite making the decision to screen. For example, one nonscreener who had been overseas periodically during the period of the randomized controlled trial initially gave this as his reason for not doing the FIT, but then went on to state: "It should have been a matter of urgency. I must have a degree of procrastination in me not to seize the moment in between those trips and get this done" (Nonscreener). Similarly, one of the focus group participants initially stated that her reason for not following through on her decision to screen was that she was caring for a friend who subsequently died of CRC, and that she was then busy and sick, but went on to say: "Actually that's probably not true. It's probably due to that 'come on you know you're supposed to have had one', so yeah" (Nonscreener).

Procrastination was an issue for screeners as well. In fact, taking immediate action following the decision to screen was a straightforward process for only a few of the screeners whose desire to know their CRC status was strong enough for them to make screening a priority.

For the majority, though, there was a degree of procrastination involved before they were able to prioritize the test and get it done:

No I didn't do it quickly. I put it on the side and thought I'd do it later and then I think I got a reminder that I hadn't done it and so then I did it. (Screener)

Some screeners had procrastinated on testing in the past, describing how they still had unused FOBTs in their cupboards that had been given to them by their doctors.

Ambivalence and risk perception. Risk perception played an important role in the participants' level of conviction about wanting to know their CRC status. Risk was discussed in terms of age, having a family history of bowel cancer, and having a personal history of other forms of cancer. Some participants saw themselves as being at risk of CRC: "Yeah, I'm in that sort of age group that's more likely than not [to get CRC] . . ." (Screener). Some expressed ambivalence with regard to whether or not they were at risk. For example, discussing an absence of risk factors and stating ". . . but you never know" (Screener), or "... but that doesn't mean anything I suppose" (Nonscreener). Others did not see themselves as being at risk, or described mitigating factors that lessened their perceived risk, such as leading a healthy lifestyle, eating well and having a positive attitude. One participant expressed this belief as: "Well I'm certainly more aware of [CRC] and I take care of myself in a better way. I look after my diet, I keep myself relatively healthy . . ." (Screener).

A lack of perceived risk or ambivalence about risk reduced the importance of screening for participants despite agreeing to do the FIT: "I guess if I was worried about my health that would motivate me to move it [doing the FIT] up my list of jobs to do. But that's not really a big factor" (Nonscreener). Yet even for those who viewed themselves to be at risk, ambivalence was still evident. For example, a woman whose sister died of CRC explained her decision to screen as

follows:

Oh I think [screening is] very advantageous, because as I said there's so many cancers going around and you never know what you've got. My sister died of colon cancer, so you think "Well cancer's in the family, it doesn't hurt [to screen]". (Screener)

Here we see a lack of conviction or certainty in the decision despite having a family history of CRC, evident by the phrase "it doesn't hurt [to screen]". A nonscreener described the importance of screening due to her family history, yet still did not follow through on the decision to screen: "Because I am a cancer sufferer . . . I was very interested in completing this bowel cancer screening because my mother actually died of bowel cancer" (Nonscreener). This suggests that awareness of risk factors might not be enough of a motivator to overcome ambivalence to screening and move some people from intention to action.

Overall, what was interesting about participants' discussions about risk was that while there was an awareness of the risk factors associated with CRC, particularly in terms of age, diet and family history, these were not necessarily seen as personally relevant. This can be seen in the example of a screener who perceived her risks of CRC as being "similar to all women . . . I don't really worry about it, it doesn't stress me on a day to day basis" (screener), despite having a family history of CRC. Age was another risk factor that was not necessarily viewed as personally relevant. For example, in one of the focus groups the discussion turned to a question in the questionnaire of perceived risk (the questionnaire was filled out as part of the randomized controlled trial), and how the participants rate their risk of CRC:

I have to say I answered no to one of those [questions]. I think it was the question "Do you think you're in a high risk group from getting bowel cancer?" No, other than being

over 50, and I mean that's the whole world that's over 50 so that's not a high risk group that's everybody, so my answer was no. (Nonscreener)

This lack of personal relevance in relation to risk may have played a role in participants' ambivalence about screening.

Another factor in the relationship between ambivalence and risk perception is that instead of focusing on their risk of CRC specifically, the participants more often expressed their risk in terms of a generalized risk of cancer. For example, in the discussions of age as a risk factor, the participants discussed the need to test for lots of diseases as you get older, with bowel screening another one to add to the list. When discussing their cancer risks the participants expressed the view that cancer is "all a part of our history and biology of the human body" (Nonscreener), "it is so common nowadays" (Screener), cancer "is a part of life" (Screener) and "I think probably everybody is aware that cancer can happen to anybody" (Screener). For some this perception of cancer being prevalent worked to foster a desire to know their CRC status, but had the opposite effect on two nonscreeners who expressed a more fatalistic view about their risk of cancer:

The world is full of chances; you have to take chances as they come. . . . It might happen to you, it might not. You don't know, it's just like winning Lotto [Lottery], isn't it?

(Nonscreener)

I never give [my risk of cancer] a great deal of consideration. I just think it won't happen to me and if it does then it was meant to be and let's just hope it's fast and sharp and, a fatalistic view, I guess. (Nonscreener)

The above discussion highlights the complexity of risk perception in participants' decisions about

whether or not to screen for CRC, and the lack of a sense of urgency or importance in relation to CRC risk and screening.

The participants discussed a number of influences on their perception of risk for CRC and the personal relevance of risk factors. The most common was knowing personally or hearing about someone who had bowel cancer, which was described as highlighting the importance of screening for CRC and thus decreasing ambivalence. The media also influenced participants' risk perception, as can be seen in the following extract: “. . . my doctor's never suggested I have [a FIT] either, so if it's not coming from the general media, newspaper, TV or radio then . . . the awareness isn't there” (Screener). The media was even influential in persuading the participant who stated that she did not want to know her CRC status (because of her experience of watching her mother die of cancer) to do the FIT: “In hindsight it was the wrong decision to make. When I read the follow up data on the TV and newspaper I felt that it was very remiss of me not to have done [the FIT]” (Nonscreener). Thus in this case the media portrayal of the importance of screening for CRC moved the participant towards the “wanting to know” end of the end continuum.

In this section we have proposed that ambivalence about screening is one possible explanation for why it was that although both screeners and nonscreeners had decided to screen, not everyone followed through and did the FIT – in other words, screening for CRC was not considered important or relevant enough to make it a priority. This raises the question of what is required for participants to follow through on their decision to screen and take action, particularly because there is evidence that a medium-to-large change in intention leads only to a small-to-medium change in behavior (Webb & Sheeran, 2006). Research certainly identifies cues to action - stimuli that help bridge the gap between intention and behavior - as critical to the transformation of intention to action (Flight, Wilson, & McGillivray, 2012). In what follows we

address the second focus of our analysis, namely an exploration of what motivated the screeners to follow through on their decision to screen for CRC, despite their apparent ambivalence toward screening.

Taking Action

We identified three cues to action in participants' discussions that motivated the screeners to follow through on their decision to screen, namely convenience, opportunistic screening, and making a commitment to follow through on the decision to screen. These cues appeared to be effective because they supported participants to undergo screening despite a lack of conviction about wanting to know their CRC status.

Convenience and opportunistic screening. For the participants who followed through with the FIT, despite expressing ambivalence about screening, an important cue to action was being provided the chance to screen in a way that caused them the least inconvenience:

. . . it was free and it was being done for me so I didn't kind of have to head off to the doctor or anything like that and it was actually being set up for me. (Screener)

The importance of the FIT being free and sent to people's homes, rather than having to go to a doctor or pharmacy to get a test, was also discussed at some length in the focus groups.

Being provided the opportunity to screen through participation in a screening program or research study was another cue to action for the participants. Some participants spoke of wanting to do the FIT prior to the invitation to participate in the randomized controlled trial, but not following through and getting the kit themselves. Being invited to participate in the study was therefore a good opportunity for them to do the FIT:

. . . I seized the opportunity when I got it because . . . I was hoping that I would get one [through the national screening program], but I didn't actually go to my doctor and say 'I think I should have a test at my age because I've never had one'. (Screener)

I heard that [the Australian government were] going to stop the testing and so I thought this was an opportunity to get tested before they stop. Just the opportunity was there so I decided to take it. (Screener)

In other words, while the participants might have wanted to know their CRC status, the desire to know was not strong enough for them to seek out a screening test, and they would rather wait for the opportunity to present itself. The importance of being given the opportunity to screen through the participation in a screening program or research study, rather than actively seeking a screening test, was also discussed by a nonscreener who still wanted to do the test. He stated: "Given the opportunity to do it again I think I wouldn't have any hesitation to do it now" (Nonscreener). In fact nearly all of the nonscreeners expressed the desire to do the test, but were noncommittal when told they could get a test from their doctor or pharmacy rather than wait for another opportunity to come their way.

The emphasis on convenience and opportunistic screening was evident even when participants perceived themselves to be at risk and viewed screening as an important part of taking responsibility for their health. Similarly, those participants who had previously screened for CRC (generally through the Australian government's screening program) and wanted to participate in ongoing screening viewed being sent the FIT as a useful reminder of the need to continue to screen:

I mean it's the second time I've done it, I got one for my 55th birthday, bowel testing, thank you very much . . . And thank you for giving me a nudge to do it again. (Screener)

This same participant discussed how “ease of access” (by being sent a screening test through a government funded screening program) helps people in “getting over the hurdle of actually getting yourself a kit, working out how to do it and doing it” (Screener).

All participants had been provided a convenient opportunity to screen by being sent a free FIT through participation in the randomized controlled trial, however not all of the participants followed through on their decision to screen. We propose that because of ambivalence toward CRC screening it might take time for screening for CRC to become a priority in people's lives, highlighting the importance of being provided the opportunity to screen in an ongoing manner. This is also supported by the fact that some participants had been provided with screening tests by their doctors but had not used the tests: “I had received a kit before and never used it, I just left it in the cupboard but when this came along I thought yes I'll do it” (Screener).

Making the commitment to screen. The final cue that helped transform participants' intentions into action was making a commitment to do the FIT through participation in the randomized controlled trial. This came up particularly in the focus groups, where the participants discussed the impact of going through the questionnaire on the study's website, which had to be completed prior to the FIT being sent to them. It appears that taking the time to engage with the website acted to both reinforce the decision to screen (which they described as having been made as soon as they received the invitation to participate in the study) and bring the test itself closer to the top of their priority list:

I think [the website] pushed us into doing something about it . . . so probably I think with regard to the actual website it sort of perhaps brought it to mind and made you more conscious of it to yes, go ahead and do something about it. (Screener)

Engaging with the website was described as making a commitment to follow through and complete the test: “Well I made a commitment, I’ll go ahead with it” (Screener). The value of the website as a cue to action is also supported by some of the results of the randomized controlled trial (which will be reported elsewhere), where those participants who were allocated to the web-based version of the questionnaires and information sheets were more likely to do the FIT than those who participated in a paper-based version.

Discussion

We identified the main reason for participants deciding to screen for CRC as “wanting to know” their CRC status. Previous research on the decision to screen for cancer has also identified the importance of wanting to know, or not wanting to know, in this decision. For example, in their survey of the factors that influence screening compliance, Arveux et al. (1992) found that the main reason for not participating in CRC screening was “not wanting to know more about their health status” (p. 574). At the other end of the spectrum, Richardson et al. (2002) found in their qualitative study of women’s understanding and experience of DEXA scanning for osteoporosis that knowing one’s risk status was “central to participants’ reasoning about DEXA scans” (p. 122). Self-care and taking personal responsibility for health were important considerations in relation to the decision to screen. This has been found in previous research on CRC screening (Chapple et al., 2008; Lipworth et al., 2010; Molina-Barcelo et al., 2011), and is consistent with social theories related to late modernity, where self management and individualization of responsibility have been recognized as central concepts in western industrialized societies

(Crawford, 2006; Crawshaw, 2012). However, our research has identified that wanting to know one's cancer status might not necessarily be a simple "yes or no" decision, but rather functions on a continuum ranging from wanting to know, through varying degrees of ambivalence, to not wanting to know.

Only a few of the participants in our study expressed strong views on wanting to know or not wanting to know their CRC status, with the majority demonstrating an overall ambivalence with regard to CRC screening, despite an awareness of CRC risk factors. Ambivalence was seen in the participants' lack of conviction about the importance of screening (using terminology such as "why not" and "it doesn't hurt to screen") and in their procrastination once the decision was made. Ambivalence in the decision to screen for cancer has been reported in other studies (Knops-Dullens, N. de Vries, & A. de Vries, 2007; Lipkus & Klein, 2006; Polzer, Mercer, & Goel, 2002). For example, Halabi et al. (2000) found that women who were off-schedule for a mammography were more likely to be ambivalent about screening mammography. The women in Willis' (2008) Swedish study of mammography screening also expressed ambivalence in the decision to attend a mammography. The ambivalence expressed by our participants might result from the Australian political and cultural context in which CRC screening is not given a high enough priority by government or health professionals (in fact, some of our participants reported that their doctors had told them that they do not need to screen for CRC). It may also be a result of the two-step screening process adopted in Australia, where individuals test for CRC risk using a FIT, followed by colonoscopy. Additional research is needed to explore this insight.

Our participants indicated ambivalence in both the decision to screen for CRC, and also their risk perception with regard to CRC. Similarly, in Willis' (2008) study of women's participation in mammography screening, where women expressed ambivalence in the decision to screen, ambivalence in risk perception was also reported where women expressed low risk but

went on to make statements such as “but you never know” (p. 142). Researchers and commentators have in fact pointed to the important part played by ambivalence in the individual’s response to risk in general (Beck, 2006; Lupton & Tullock, 2002). For example, Lupton and Tullock (2002) explored risk epistemologies of a group of Australians, and found that contradiction, ambivalence and complexity were apparent in their participants’ accounts of their understandings and experiences of risk. Beck (2006) goes so far as to state “Risk is ambivalence” (p. 331). Our study adds support to the relationship between risk perception and ambivalence.

An important issue in relation to risk and ambivalence is the extent to which people view risk information as personally relevant (Lipworth et al., 2010). For example, in Mesters, Ausems and de Vries’ (2005) study of the general public’s knowledge, interest and information needs related to genetic cancer, the authors found that “[n]ot being able to estimate the personal relevance of genetic information created feelings of ambivalence, which left most people undecided regarding exposing themselves to genetic information” (p. 72). According to Craddock Lee (2010), “risk information is rarely taken up as value-neutral objective truth, but . . . is deeply subjective, interiorized against a preexisting sense of self” (p. 6). He views this translation of risk information as central to understanding ambivalence toward public health efforts like screening.

The ambivalence expressed by participants might explain why not all of them followed through on their decision and did the FIT. Similarly, Constanza et al. (2009) suggest that the intention to screen when not coupled with action (in the form of scheduling a mammography in their research) “belies an underlying ambivalence or persistent procrastination” (p. 347). This suggests that ambivalence might play a role in moderating the relationship between intention and behavior, where participants who were more certain about wanting to know their CRC status were more likely to follow through on their intention to screen, and vice versa. Research on the relationship between ambivalence, attitudes, intention and screening behavior has demonstrated a

similar effect. For example, Connor et al. (2002) found that attitudes toward healthy eating were more predictive of healthy eating behaviors when ambivalence was lower. Dormandy, Hankins, and Marteau (2006) explored the moderating role of ambivalence in the attitude to and uptake of a prenatal screening test for Down Syndrome, and concluded that ambivalence might undermine the making of informed choices about screening.

Previous research on barriers to CRC screening has identified a range of barriers, but ambivalence has not been specifically discussed. It is possible that ambivalence underpins these barriers, as in our study. Potential barriers, such as finding the test unpleasant or fear of the results, were overcome by a strong desire to know their CRC status, but a more ambivalent attitude resulted in procrastination, which was identified as the main reason for not completing the FIT. Previous research has also identified procrastination as a major barrier to CRC screening (Janz et al., 2007; McCaffery et al., 2001; Vernon, 1997; Worthley et al., 2006). This relationship between ambivalence and procrastination in CRC screening should be explored further.

Previous research has identified that changing behavioral intentions does not necessarily engender behavior change (Webb & Sheeran, 2006), and highlighted the importance of exploring and understanding cues to action. Given their ambivalence regarding wanting to know their CRC status and procrastination in following through on the decision to screen, the main cue to action for our participants was the opportunity to screen without being too inconvenienced (i.e. receiving a free FIT kit, delivered to their homes). Similarly, calling women to mammography screening and ease of attendance was identified in Willis' (2008) study as important in overcoming women's ambivalence about screening without being coercive. These findings highlight the importance of providing convenient (and free) screening opportunities for target populations in an ongoing manner. It may also be that the results are a reflection of the Australian health care system, which provides free access to screening for a range of cancers. This may lead

to the expectation that screening should be free and initiated by the government. Another cue to action was making a commitment to do the FIT through engagement with the website as part of their involvement in the randomized controlled trial. The role of personal commitment, and commitment to others, has been identified as an important factor in moving people from intention to action (Ajzen, Czasch, & Flood, 2009). For example, Elley, Dean and Kerse (2009) found that personal commitment and a commitment to others through participation in a physical activity intervention motivated people to engage in physical activity.

In our study the participants were keen to emphasize that the decision to screen with the FIT was their decision and not influenced by others, including their health professionals. This contrasts with previous research that has highlighted the importance of recommendations from health professions in the decision to screen for CRC (Costanza et al., 2005; Holt et al., 2009; Jones et al., 2010; Vedel et al., 2011; Zajac et al, 2010). However, the participants did identify indirect influences on their decision to screen, such as knowing others with CRC and media reports on the topic. This suggests opportunities to noncoercively influence people's decisions around CRC screening in terms of indirect influences such as the media.

Conclusion

Our Australian study builds on existing literature on the decision to screen for CRC by exploring why people who were offered the FIT decided to screen or not to screen, and what influenced them to take action and complete the test. The study highlights the complex relationship between risk perception and screening behavior, demonstrating ambivalence to screening among both screeners and nonscreeners. This suggests that unless individuals have a sense of personal risk for CRC, screening opportunities will need to be as accessible and convenient as possible.

Limitations

This is a qualitative, exploratory study and as such is limited in terms of generalizability. More

screeners than nonscreeners participated in the study, and it is possible that people who felt strongly about not participating in CRC screening might not have wanted to be interviewed. Furthermore, the fact that the participants were selected from participants in a randomized controlled trial evaluating a decision support tool for CRC screening could have created a bias towards “wanting to know” their CRC status. Additional research needs to be done exploring the extent to which these findings are applicable more generally, and in particular in other countries given the differences in health systems and approaches to screening.

References

Authors. (2010)

Arveux, P., Durand, G., Milan, C., Bedenne, L., Levy, D., Ha Doan, B. D., & Faivre, J. (1992).

Views of a general population on mass screening for colorectal cancer: the Burgundy Study. *Preventive Medicine, 21*, 574-581.

Australian Institute of Health & Welfare. (2008). *Cancer in Australia: an overview, 2008* (Cat.

No. CAN 42). Canberra, Australia: Australian Institute of Health & Welfare.

Australian Institute of Health & Welfare. (2012). *National bowel cancer screening program:*

monitoring report, Phase 2, July 2008-June 2011 (Cat. No. CAN 61). Canberra, Australia: Australian Institute of Health & Welfare.

Ajzen, I., Czach, C., & Flood, M. G. (2009). From intentions to behavior: implementation

intention, commitment, and conscientiousness. *Journal of Applied Social Psychology, 39*(6), 1356-1372.

Beck, U. (2006). Living in the world risk society. *Economy and Society, 35*(3), 329-345. doi:

10.1080/03085140600844902

Benson, V. S., Patncik, J., Davies, A. K., Nadel, M. R., Smith, R. A., & Atkin, W. S. (2008).

Colorectal cancer screening: a comparison of 35 initiatives in 17 countries. *International Journal of Cancer, 122*, 1357-1367. doi:10.1002/ijc.23273

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in*

Psychology, 3, 77-101.

Brouse, C. H., Basch, C. E., Wolf, R. L., Shmukler, C., Neugut, A. I., & Shea, S. (2003). Barriers

to colorectal cancer screening with fecal occult blood testing in a predominantly minority urban population: a qualitative study. *American Journal of Public Health, 93*(8), 1268-1271.

- Chapple, A., Ziebland, S., Hewitson, P., & McPherson, A. (2008). What affects the uptake of screening for bowel cancer using the faecal occult blood test (FOBT): a qualitative study. *Social Science and Medicine*, *66*, 2425-2435. doi:10.1016/j.socscimed.2008.02.009
- Cole, S. R., Zajac, I., Gregory, T., Mehaffey, S., Roosa, N., Turnbull, D., Esterman, A., & Young, G. (2011) Psychosocial variables associated with colorectal cancer screening in South Australia. *International Journal of Behavioral Medicine*, *18*, 302-309. doi:10.1007/s12529-010-9101-1
- Connor, M., Sparks, P., Povey, R., James, R., Shepher, R., & Armitage, C. J. (2002). Moderator effects of attitudinal ambivalence on attitude-behaviour relationships. *European Journal of Social Psychology*, *32*, 705-718. doi:10.1002/ejsp.117
- Cook, K. E. (2011). Reliability assessments in qualitative health promotion research. *Health Promotion International*. Advance access published May 10, 2011, retrieved from <http://heapro.oxfordjournals.org/>. doi:10.1093/heapro/dar027
- Costanza, M. E., Luckman, R., Stoddard, A. M., Avrunin, J. S., White, M. J., Stark, J. R., Clemow, L. ... Rosal, M. C. (2005). Applying a stage model of behavior to cancer screening. *Preventive Medicine*, *41*, 707-719. doi:10.1016/j.ypmed.2004.12.013
- Costanza, M. E., Luckman, R., White, M. J., Rosal, M. C., LaPelle, N., & Cranos, C. (2009). Moving mammogram-reluctant women to screening: a pilot study. *Annals of Behavioral Medicine*, *37*, 343-349. doi:10.1007/s12160-009-9107-6
- Craddock Lee, S. J. (2010). Uncertain futures: individual risk and social context in decision-making in cancer screening. *Health, Risk and Society*, *12*(2), 101-117. doi:10.1080/13698571003637048
- Crawford, R. (2006). Health as a meaningful social practice. *Health*, *10*, 401-420. doi:10.1177/1363459306067310

- Crawshaw, P. (2012). Governing at a distance: social marketing and the (bio) politics of responsibility. *Social Science and Medicine*, 75, 200-207.
doi:10.1016/j.socscimed.2012.02.040
- Dedoose (2012). *Web application for managing, analyzing, and presenting qualitative and mixed method data, Version 4.3.86*. Los Angeles, CA: SocioCultural Research Consultants, LLC. Retrieved from <http://www.dedoose.com>
- Dormandy, E., Hankins, M., & Marteau, T. M. (2006). Attitudes and uptake of a screening test: the moderating role of ambivalence. *Psychology and Health*, 21(4), 499-511.
doi:10.1080/14768320500380956
- Elley, C. R., Dean, S., & Kerse, N. (2009). Physical activity promotion in general practice: patient attitudes. *Australian Family Physician*, 36(12), 1061-1064.
- Flight, I., Wilson, C., & McGillivray, J. (2012). Turning intention into behavior: the effect of providing cues to action on participation rates for colorectal cancer screening. In R. Ettarh (Ed.), *Colorectal cancer – from prevention to patient care* (pp. 68-86). Retrieved from <http://www.intechopen.com/books/colorectal-cancer-from-prevention-to-patient-care/>
- Goldman, R. E., Diaz, J. A., & Kim, I. (2009). Perspectives of colorectal cancer risk and screening among Dominicans and Puerto Ricans: stigma and misperceptions. *Qualitative Health Research*, 19(11), 1559-1568. doi:10.1177/1049732309349359
- Grbich, C. (1999). *Qualitative research in health: an introduction*. New South Wales, Australia: Allen and Unwin.
- Green, A., Peters-Lewis, A., Percac-Lima, S., Betancourt, J. R., Richter, J. M., Janairo, M. R., Gamba, G. B., & Atlas, S. J. (2008). Barriers to screening colonoscopy for low-income Latino and white patients in an urban community health center. *Journal of General Internal Medicine*, 23(6), 834-840. doi:10.1007/s11606-008-0572-6

- Gregory, T. A., Wilson, C., Duncan, A., Turnbull, D., Cole, S. R., & Young, G. (2011). Demographic, social cognitive and social ecological predictors of intention and participation in screening for colorectal cancer. *BMC Public Health, 11*, 38-47. Retrieved from <http://www.biomedcentral.com/1471-2458/11/38>
- Hewitson, P., Glasziou, P., Watson, E., Towler, B., & Irwig, L. (2008). Cochrane systematic review of colorectal cancer screening using the fecal occult blood test (Hemoccult): an update. *American Journal of Gastroenterology, 103*, 1541-1549. doi:10.1111/j.1572-0241.2008.01875.x
- Janz, N. K., Lakhani, I., Vijan, S., Hawley, S. T., Chung, L. K., & Katz, S. J. (2007). Determinants of colorectal cancer screening use, attempts, and non-use. *Preventive Medicine, 44*, 452-458. doi:10.1016/j.ypmed.2006.04.004
- Javanparast, S., Ward, P., Carter, S., & Wilson, C. (In Press). Barriers to and facilitators of colorectal cancer screening in different population subgroups in Adelaide, South Australia. *Medical Journal of Australia*.
- Javanparast, S., Ward, P., Young, G., Wilson, C., Carter, S., Misan, G., Cole, S., ...Matt, M. A. (2010). . How equitable are colorectal cancer screening programs which include FOBTs? A review of qualitative and quantitative studies. *Preventive Medicine, 50*, 165-172. doi:10.1016/j.ypmed.2010.02.003
- Jemal, A., Bray, F., Center, M. M., Ferlay, J., Ward, E., & Forman, D. (2011). Global cancer statistics. *CA – A Cancer Journal for Clinicians, 61*, 69-90.
- Jones, R. M., Devers, K. J., Kuzel, A. J., & Woolf, S. H. (2010). Patient-reported barriers to colorectal cancer screening: a mixed methods analysis. *American Journal of Preventive Medicine, 38*(5), 508-516. doi:10.1016/j.amepre.2010.01.021
- Jones, R. M., Woolf, S. H., Cunningham, T. D., Johnson, R. E., Krist, A. H., Rothenich, S. F., &

- Vernon, S. W. (2010). The relative importance of patient-reported barriers to colorectal cancer screening. *American Journal of Preventive Medicine, 38*(5), 499-507.
doi:10.1016/j.amepre.2010.01.020
- Knops-Dullens, T., de Vries, N., & de Vries, H. (2007). Reasons for non-attendance in cervical cancer screening programmes: an application of the Integrated Model for Behavioral Change. *European Journal of Cancer Prevention, 16*, 436-445.
- Lasser, K. E., Ayanian, J. Z., Fletcher, R. H., & DelVecchio Good, M. (2008). Barriers to colorectal cancer screening in community health centers: a qualitative study. *BMC Family Practice, 9*, 15-22. doi:10.1186/1471-2296-9-15
- Levin, T. R., Jamieson, L., Burley, D. A., Reyes, J., Oehrli, M., & Caldwell, C. (2011). Organized colorectal cancer screening in integrated health care systems. *Epidemiologic Reviews, 33*, 101-110. doi:10.1093/epirev/mxr007
- Lipkus, I. M., & Klein, W. M. P. (2006). Effects of communicating social comparison information on risk perceptions for colorectal cancer. *Journal of Health Communication, 11*(4), 391-407. doi:10.1080/10810730600671870
- Lipkus, I. M., Lyna, P. R., & Rimer, B. K., (2000). Colorectal cancer risk perceptions and screening intentions in a minority population. *Journal of the National Medical Association, 92*, 492-500.
- Lipstein, E. A., Nabi, E., Perrin, J. M., Luff, D., Browning, M. F., & Kuhlthau, K. A. (2010). Parents' decision-making in newborn screening: opinions, choices, and information needs. *Pediatrics, 126*(4), 696-794. doi:10.1542/peds.2010-0217
- Lipworth, W. L., Davey, H. M., Carter, S. M., Hooker, C., & Hu, W. (2010). Beliefs and beyond: what can we learn from qualitative studies of lay people's understandings of cancer risk? *Health Expectations, 13*, 113-124. doi:10.1111/j.1369-7625.2010.00601.x

- Lupton, D., & Tulloch, J. (2002). "Risk is part of your life": risk epistemologies among a group of Australians. *Sociology*, 36(2), 317-334.
- Madlensky, L., Espfen, M. J., Gallinger, S., McLaughlin, J. R., & Goel, V. (2003). Relatives of colorectal cancer patients: factors associated with screening behavior. *American Journal of Preventive Medicine*, 25(3), 187-194. doi:10.1016/S0749-3797(03)00202-2
- Mesters, I., Ausems, A., & de Vries, H. (2005). General public's knowledge, interest and information needs related to genetic cancer: an exploratory study. *European Journal of Cancer Prevention*, 14, 69-75.
- Molina-Barcelo, A., Salas Trejo, D., Peiro-Perez, R., & Malaga Lopez, A. (2011). To participate or not? Giving voice to gender and socio-economic differences in colorectal cancer screening programmes. *European Journal of Cancer Care*, 20, 669-678.
doi:10.1111/j.1365-2354.2011.01263.x
- Polzer, J., Mercer, S. L., & Goel, V. (2002). Blood is thicker than water: genetic testing as citizenship through familial obligation and the management of risk. *Critical Public Health*, 12(2), 153-168. doi:10.1080/09581590210127389
- Pope, C., Ziebland, S., & Mays, N. (2000). Qualitative research in health care: analyzing qualitative data. *BMJ*, 320, 114-116
- Richardson, J. C., Hassell, A. B., Hay, E. M., & Thomas, E. (2002). "I'd rather go and know": women's understanding and experience of DEXA scanning for osteoporosis. *Health Expectations*, 5, 114-126.
- Severino, G., Wilson, C., Turnbull, D., Duncan, A., & Gregory, T. (2009). Attitudes towards and beliefs about colorectal cancer and screening using the Faecal Occult Blood Test within the Italian-Australian Community. *Asian Pacific Journal of Cancer Prevention*, 10, 387-394.

- Sheeran, P. (2002). Intention-behavior relations: a conceptual and empirical review. *European Review of Social Psychology*, 12(1), 1-36. Retrieved from <http://dx.doi.org/10.1080/14792772143000003>
- Shenton, A. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, 22, 63-75.
- Strivastava, A., & Thomson, S. B. (2009). Framework analysis: a qualitative methodology for applied policy research. *Journal of Administration and Governance*, 4(2), 72-79.
- The UK CRC Screening Pilot Evaluation Team. (2003). *Evaluation of the UK colorectal cancer screening pilot, final report*. Edinburgh, UK: Department of Community Health Sciences, University of Edinburgh.
- Vedel, I., Puts, M. T. E., Monette, M., Monette, J., & Bergman, H. (2011). Barriers and facilitators to breast and colorectal cancer screening of older adults in primary care: a systematic review. *Journal of Geriatric Oncology*, 2, 85-98.
doi:10.1016/j.jgo.2010.11.003
- Vernon, S. W. (1997). Participation in colorectal cancer screening: a review. *Journal of the National Cancer Institute*, 89(19), 1406-1422.
- Wackerbarth, S. B., Peters, J. C., & Haist, S. A. (2005). "Do we really need all that equipment?": factors influencing colorectal cancer screening decisions. *Qualitative Health Research*, 15, 539-554. doi:10.1177/1049732304273759
- Walsh, J. (2005). Colorectal cancer screening: the time is now! *Journal of General Internal Medicine*, 20(11), 1068-1070. doi:10.1111/j.1525-1497.2005.00246.x
- Ward, P. R., Javanparast, S., Matt, M. A., Martini, A., Tsourtos, G., Cole, S., Gill, T., ... Young, G. (2010). Equity of colorectal cancer screening: cross-sectional analysis of National Bowel Cancer Screening Program data for South Australia. *Australian and New Zealand*

Journal of Public Health, 35(1), 61-65. doi:10.1111/j.1753-6405.2010.00637.x

Webb, T., & Sheeran, P. (2006). Does changing behavioral intentions engender behavior change?

A meta-analysis of the experimental evidence. *Psychological Bulletin*, 132(2), 249-268.

doi:10.1037/0033-2909.132.2.249

Weitzman, E. R., Zapka, J., Estabrook, B., & Goins, K. V. (2001). Risk and reluctance:

understanding impediments to colorectal cancer screening. *Preventive Medicine*, 32, 502-

513. doi:10.1006/pmed.2001.0838

Willis, K. (2008). "I come because I am called": recruitment and participation in mammography

screening in Uppsala, Sweden. *Health Care for Women International*, 29, 135-150.

doi:10.1080/07399330701738143

Worthley, D. L., Cole, S. R., Esterman, A., Mehaffey, S., Roosa, N. M., Smith, A., Turnbull, D.,

& Young, G. P. (2006). Screening for colorectal cancer by faecal occult blood test: why

people choose to refuse. *Internal Medicine Journal*, 36, 607-610. doi:10.1111/j.1445-

5994.2006.01155.x

Young, G. P. (2009). Population-based screening for colorectal cancer: Australian research and

implementation. *Journal of Gastroenterology and Hepatology*, 24(S3), S33-S42.

doi:10.1111/j.1440-1746.2009.06069.x

Zajac, I. T., Whibley, A. H., Byrne, D., Guy, J., Morcom, J., & Youth, G. P. (2010). Endorsement

by the primary care practitioner consistently improves participation in screening for

colorectal cancer: a longitudinal analysis. *Journal of Medical Screening*, 17, 19-24.

doi:10.1258/jms.2010.009101