Barriers to and facilitators of colorectal cancer screening in different population subgroups in Adelaide, South Australia

Colorectal cancer (CRC) is the second most common cancer and cause of cancer mortality in Australia.1 Up to 90% of CRC mortality may be preventable with early detection, indicating that the net benefit of screening is substantial.2 A National Bowel Cancer Screening Program (NBCSP) for early detection of CRC was adopted recently in Australia.3,4 Studies in Australia and overseas have shown disparity in CRC screening participation based on socioeconomic status,5–7 location,6,8 ethnicity,9–11 age and sex.12–14 Australian NBCSP reports found lower participation rates among men and socioeconomically disadvantaged, Indigenous and non-English-speaking populations.3,4,15–17 Although studies have investigated barriers to and enablers of screening participation, few have included different cultural groups that may be underserved. We aimed to identify and to describe how these might be shared or be distinct across these groups.

Methods

We conducted a qualitative study based on interviews with people from different cultural groups in South Australia2,1 between July 2009 and December 2010. We recruited participants aged 50–75 years (except for six Indigenous participants aged under 50 years) from five cultural groups: people who identified as Greek, Vietnamese or Iranian, through their response to community associations and advertisements on their local radio stations; native-English-speaking Anglo-Australians, through local newspapers; and Indigenous people from metropolitan Adelaide and rural and remote South Australia, through SA Health and the Aboriginal Health Council of SA.

Interviewers explored participants’ knowledge and experience of bowel cancer and screening, including barriers to and facilitators of screening. Interviews were audiorecorded and transcribed verbatim. Text was entered into NVivo, version 8 (QSR International, Southport, UK) for analysis. A coding structure was developed based on key concepts from the research questions. We also generated codes inductively to capture unexpected concepts. The same coding structure was applied across all groups to enable comparisons between groups.

Ethics committee approval was granted by the Social and Behavioural Research Ethics Committee of Flinders University and the Aboriginal Health Research and Ethics Committee of the Aboriginal Health Council of SA.

Results

We interviewed 121 men and women, 34 of whom had participated in the NBCSP (Box).
Facilitators and barriers

You are dealing with a dirty part of the body … it’s why many people don’t like to do it. (Greek woman, 58 years)

The offer of a faecal occult blood test (FOBT) kit without charge was considered to be a major facilitator of screening participation.

Common barriers to screening participation were lack of symptoms, no family history of cancer and doubt about test accuracy arising from sampling and mailing procedures.

Language barrier

Language barriers were a key problem for most non-English-speaking participants. Although people were willing to participate, they could not read the invitation or follow the instructions for sample collection. This delayed or prevented participation. No participants knew translations were supplied on the NBCSP website. Most participants relied on family members to assist, leading to embarrassment.

I read the instructions but it was not easy to understand. I decided to call the phone number that was provided but I did not feel comfortable either. (Iranian woman, 56 years)

English-speaking participants, in contrast, said the instructions were easy to follow.

… you read through and it’s all very logical, very simple and straightforward. In 2 days you stick it in the letterbox and get the letter back in a week’s time. (Anglo-Australian man, 62 years)

Fatalistic views about cancer

Most Anglo-Australians thought cancer was treatable, and that this had improved over time. However, participants from culturally and linguistically diverse (CALD) groups were more likely to avoid screening because of fear of cancer diagnosis, seeing cancer as unpreventable and fatal.

It’s the forbidden disease. In the Greek community when they hear this word, it is the end of the world for them. They don’t like to talk about it. (Greek woman, 69 years)

I know my grandma, for her the word “cancer” — her immediate thought would have been fear. She came from a generation that thought would have been fear. (Iranian woman, 56 years)

Privacy of doing the test

For most participants, the privacy of at-home testing was valued. However some Indigenous participants used the term “shame job” to describe the FOBT. They explained that they lacked privacy in their homes, neighbourhoods and communities. In remote areas, even postal workers had intimate personal knowledge, creating potential embarrassment from mailed FOBT kits and samples.

Indigenous participants and those from CALD backgrounds — but not Anglo-Australians — said they wanted health worker support to complete the test because of perceived low self-efficacy.

Doctor’s recommendation

Although all participants considered a doctor’s recommendation to be encouraging to some extent owing to trust in or personal obligation to their doctors, Anglo-Australians valued physician endorsement highly and said it strongly influenced their decision to undergo screening.

If my doctor asked me to do it I would do it because I’ve got a lot of respect for him and he’s looked after me wonderfully. (Anglo-Australian woman, 61 years)

Moral obligation

The Iranian group in particular discussed a moral obligation to participate: compliance was the morally acceptable response to free preventive services offered by a government to improve individual and population health.
that involving health care professionals in screening using an FOBT may benefit most Australians, for different reasons. For people from CALD groups, a health professional may help with several identified barriers: language, problems with self-efficacy and confidence, and fatalistic views about cancer. Anglo-Australians valued both privacy and medical recommendation and they may prefer to receive their clinician’s recommendation, then take the test home to use in private. For Indigenous Australians, testing as a “shame job” appeared to arise from the smallness and inter- connectedness of communities, and being screened by health workers in such a community may contribute to this embarrassment. Indigenous community-controlled research may be needed to identify possible solutions.

The diversity we observed across participant groups suggests that a one-size-fits-all bowel cancer screening program is not equitable. Tailored approaches need to be developed to ensure equitable participation across the population.

Discussion

We identified several culture-specific issues related to CRC screening among five culturally distinct groups in Adelaide. Further work is necessary to extend and replicate our findings; however, we propose several possible strategies that could be tested as means to achieving greater equity in the NBCSP.

The first is changes to public communication about cancer and screening. We found different understandings of the preventability of cancer in different groups. Media reporting of CRC in Australia has been shown to be relatively low,22222222 accurately reporting of preventability and screening efficacy, including social marketing about screening, could improve screening uptake. This would need to be culturally and linguistically appropriate. In this study, English speakers found testing straightforward, easy and private; non-English speakers were confused, felt uncomfortable and had to talk to a family member about their faces. Translated program documents on a website made no difference. If equitable access to screening is to be provided, language barriers must be overcome.

Our second strategy relates to the role of health professionals in screening. Consistent with many other studies,2323232324 we found a doctor’s endorse ment facilitated screening participation for all participants, and especially Anglo-Australians. We hypothesise

A few participants from Greek and Iranian groups suggested that personal preventive health care was less important than other family health priorities in their cultures.

Spiritual beliefs

Belief in a spiritual aetiology of cancer was also suggested as a potential barrier to screening participation among Greek and Vietnamese communities. Some participants expressed the belief that health and disease and life and death were in God’s hands, and so not preventable.

The Vietnamese people believe in karma, if I have got the disease that is the Gods’ will . . . (Vietnamese man, 58 years)

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