Older women’s illness representations of cancer: a qualitative study

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Abstract

This paper investigates the role of illness representations in older women’s utilization of cancer screening. Older women’s own beliefs, or illness representations, of cancer and cancer screening in relation to breast cancer and cervical cancer were explored using relatively unstructured, face-to-face interviews. Twenty women aged between 45 and 70 were interviewed, half of whom were regular screeners and half under-screeners. A comparison of the illness representations of the screeners with the under-screeners indicates some differences regarding cancer in general, and substantial differences regarding the treatment and cure of cancer. The screeners expressed less concern about cancer and gave more positive examples of the successful treatment of cancer. The under-screeners were more likely to express cynicism about the medical profession, to indicate that a person would have symptoms if they had cancer, that they would not want most of the treatment available for cancer, that screening is more important for younger women and that the use of alternative therapies negates the need for cancer screening. Few differences emerged between the two groups regarding the causes of cancer.

Introduction

Breast cancer

After skin cancer, breast cancer is the most prevalent cancer in women in Australia with about 2400 women dying as a result of it each year (Jelfs et al., 1994). The chance of a woman in Victoria contracting breast cancer in her lifetime is 1:13 (Karlik et al., 1996). The National Program for the Early Detection of Breast Cancer, which uses screening mammography, was initiated in Australia in early 1991. It is recommended that women aged between 50 and 69 have a free screening mammogram every 2 years (National Advisory Committee for the Early Detection of Breast Cancer, 1992), while free screening mammograms are also available to women over 40.

Cervical cancer

This is less common, with about 340 women dying from cervical cancer each year in Australia and a woman having a 1:95 chance of being diagnosed with cervical cancer before she reaches the age of 75 (Jelfs, 1995). The concern with cervical cancer is that it is substantially preventable if detected in the pre-cancerous stage (Mitchell and Medley, 1990). Pap smear testing has been promoted to women in Australia for over 20 years. In Australia, all women who have ever been sexually active and who have not had a hysterectomy are recommended to have a Pap smear test every 2 years (Jelfs, 1995).

The under-utilization of screening for breast cancer and cervical cancer

There is evidence that both screening mammograms and Pap smear tests are being under-utilized.
In the period between July 1991 and December 1994 only 41% of women aged over 40 had obtained a screening mammogram (Abraham et al., 1995). Data from the Victorian Cytology Service indicate that 70% of women aged 50–59 and 45% of women aged 60–69 obtained a Pap test in 1994 or 1995 (Mitchell and Higgins, 1996). The under-utilization of mammography and Pap smears by older women is particularly problematic as the risk of breast cancer increases with age. A 35-year-old woman has a 1:110 risk of developing breast cancer in the next 10 years and a 55-year-old woman a 1:48 risk (Karlick et al., 1996), while 50% of all diagnoses of cervical cancer are made in women over 50 (Jelfs, 1995). In order to be successful, any screening program relies on a large proportion of the targeted population being screened (IARC Working Group on Evaluation of Cervical Cancer Screening Programmes, 1986).

Previous research in breast cancer and cervical cancer screening

When studies have a theoretical basis, the theoretical models most frequently used are the Health Belief Model (HBM) (Rosenstock, 1974; Janz and Becker, 1984) and the Theory of Reasoned Action (TRA) (Ajzen and Fishbein, 1980). Both screening mammography and Pap smear intentions or behaviours have been associated with a number of variables from the models: perceived susceptibility (Hill et al., 1985; Champion, 1991; Cockburn et al., 1991; Stein et al., 1992; Seow et al., 1995), perceived benefits of the screening test (Cockburn et al., 1991, 1992; Aiken et al., 1994; Seow et al., 1995) and social influence (Hill et al., 1985; Champion, 1991; Montano and Taplin, 1991), in particular the important role played by the woman’s medical practitioner (Cockburn et al., 1990; Clover et al., 1992; Stein et al., 1992; Aiken et al., 1994; Shelley et al., 1994). Screening mammography has been associated with the barriers of cost (overseas but not relevant in Australia, Bastani et al., 1991; Stein et al., 1992; Aiken et al., 1994), concerns about radiation (Bastani et al., 1991; Aiken et al., 1994) and embarrassment (Stein et al., 1992). Pap smears have been associated with the barriers of embarrassment (Hill et al., 1985; Peters et al., 1989; Cockburn et al., 1992), finding a smear uncomfortable (Hill et al., 1985), painful or anxiety provoking, or forgetting (Australian Health Ministers’ Advisory Council. Cervical Cancer Screening Evaluation Committee, 1991) and being too busy or believing there is no need for a smear if you are healthy (Cockburn et al., 1992).

Other variables associated with both mammography and Pap smears include women’s knowledge of the recommended interval between these screening tests (Peters et al., 1989; Bastani et al., 1991; Glanz et al., 1992), socioeconomic status and age (Cockburn et al., 1991, 1992; Adelson et al., 1992; Shelley et al., 1994). Mammographic screening is associated with concern about breast cancer (McCaul et al., 1996; Savage and Clarke, 1996), prior behaviour (Stein et al., 1992; Savage and Clarke, 1996) and ease of access to mammography programs (Cockburn et al., 1991).

Limitations of theoretical models

Research using the HBM and the TRA usually explains only about 20–40% of the variance in screening behaviours or intentions to have a screening mammogram or a Pap test (e.g. Cockburn et al., 1991; Montano and Taplin, 1991). These are essentially cognitive rational models which share underlying assumptions about the importance of health and the desire to avoid negative health outcomes (Weinstein, 1993). The use of these models restricts the research to an examination of variables which are consistent with these underlying assumptions and offers limited scope to explore alternative sources of influence in health behaviour. A reliance on a quantitative methodology also inhibits the identification of new or unexpected variables, a limitation overcome by the use of a qualitative approach (Waxler-Morrison et al., 1995).

There is evidence in the literature that women have beliefs about cancer and cancer screening which are not consistently included in these models: that screening is not necessary if you do not have any symptoms (Lane et al., 1992), that worrying about cancer can bring it on (Verres,
that a person would ‘know’ if they had cancer (Salazar and Carter, 1994; Salazar and de Moor, 1995) or that they would rather not know if they had cancer (Calnan, 1984; Elkind et al., 1989; Gregg and Curry, 1994). Sometimes these beliefs are included in quantitative studies, often they are not. When they are included, they are not always defined as the same component of the model. It could be argued that if the protocol of the TRA as described by Ajzen and Fishbein (1980) was followed, then any unusual beliefs held by the relevant population should be identified. However, when researchers have developed questionnaires by first conducting qualitative interviews with the relevant population, their questions have tended to relate only to the behaviour in question. For example, a study of mammography asked about positive and negative outcomes of having a mammogram, relevant people who might influence the woman, and environmental factors that might influence having a mammogram (Montano and Taplin, 1991). Similarly, a study of Pap tests asked about the positive and negative outcomes of having a Pap test, social referents, and perceived barriers to performance (Hill et al., 1985). Other views regarding cancer and cancer screening would not be elicited.

Illness representations

The present study utilizes the framework of illness representations to investigate commonsense beliefs and their role in screening decisions. Howard Leventhal and colleagues (Leventhal et al., 1980; Leventhal and Nerenz, 1982) proposed that people have representations of illness which influence their health behaviour. They described four components of illness representations: identity (the disease label and its symptoms), cause (what causes the illness), consequences (the physical, emotional, economic and social consequences of the illness) and time line (expectations about the course of the illness, e.g. is it acute, cyclic or chronic). A fifth component, cure, which relates to perceptions of the curability of the illness, was added by Lau and Hartmann (1983). The model suggests that people are active processors of information. Illness representations are derived from a number of sources, i.e. bodily experiences, past experiences with illness and information gathered from the social environment (Leventhal et al., 1984). These illness representations play a part in the process of health-related behaviour by guiding entry into medical treatment, the use of medical treatment and coping with illness (Skelton and Croyle, 1991). Such representations can be highly idiosyncratic and very different to the medical view of an illness. They affect people’s behaviour regarding adherence to medical treatment (Meyer et al., 1985) and decisions to engage in screening behaviours (Payne, 1990). These representations are constantly updated by the individual and are thus open to intervention; however, first, it is necessary to understand them (Leventhal et al., 1984).

The identity, cause and cure components of illness representations are of most interest in screening for breast and cervical cancer. The identity element of women’s representations may be influential in screening decisions, e.g. women report having no symptoms of cancer as a reason for not being screened (Elkind et al., 1989; Lane et al., 1992). In relation to cause, a woman who believes that cancer is caused by stress may perceive that she does not need to be screened if she is not under any stress. Similarly cure may be pertinent, as the rationale for screening is that early detection will lead to more successful treatment of an illness. The consequences and time-line components, which relate to the physical, social and economic consequences of a condition, and the duration of an illness (Leventhal et al., 1984), will not be directly investigated as they are more relevant to individuals with an illness, rather than to healthy individuals contemplating screening.

Some of the illness representations components are similar to the variables included in the HBM and the TRA. The consequences, time-line and cure components of illness representations are conceptually similar to the perceived severity variable in the HBM, although the latter variable has been of limited value in screening research (e.g. Hill et al., 1985; Aiken et al., 1994). The cure component may be similar to perceived benefits,
when benefits are operationalized as the curability of the health threat in question. As an illness representation, however, the cure component relates more to the idea of the cure of a disease in general, rather than to the success of any particular health action. There may also be some relationship between the cause component of illness representations and the perceived susceptibility variable, as perceptions of some causes of an illness may suggest to an individual that they are not personally susceptible to that illness. This is an aspect of perceived susceptibility which is not generally included in the literature.

The aim of the present study was to identify and describe older women’s illness representations of cancer and cancer screening, particularly for breast and cervical cancer, and to explore any differences in the illness representations held by screeners and under-screeners.

**Method**

**Rationale for the selection of the method**

Relatively unstructured individual face-to-face interviews were selected as the most appropriate way to explore the illness representations of a sample of older women. Individual interviews rather than focus groups were chosen to enable women to freely express their views, unhindered by the dynamics present in a group situation (Kitzinger, 1995). Open-ended questions allow participants to respond freely within their own framework and to introduce issues which are salient to them (Britten, 1995). Closed questions prohibit this type of response and impose the researcher’s framework on the respondents. Open-ended questioning is recommended in the early stage of research to avoid investigating what is of interest to the researcher rather than to the participant (Leventhal and Nerenz, 1985). In-depth interviews also permit an exploration of each participant’s views about cancer and cancer screening in general, rather than focussing on specific aspects of the topic. Quantitative methods can then be used to establish the generality of the findings.

**Pilot study**

Pilot interviews were conducted with two women in the appropriate age group who were known to the researcher. Some alterations to the order of questions were made after consultation with the interviewees.

**Recruitment of participants**

Participants were recruited by word of mouth using purposive sampling. Women aged 45–70 years known to the interviewer were informed of the study and invited to participate. These women were also asked to invite other women to participate. An attempt was made to include women from a broad cross-section of the community, and equal numbers of screeners and under-screeners. The researcher spoke personally to each woman prior to the interview, explained the nature and purpose of the study, and invited her to participate. No woman spoken to by the researcher refused to be involved, although several women spoken to by other women declined to be interviewed.

**Procedure**

Interviews were conducted at a time and place which was convenient for the interviewees. All interviews were conducted by the first researcher and were tape recorded to ensure a complete record of the interview was available (Britten, 1995). All questions on the interview schedule were asked, unless the participant had previously provided an answer. Unclear statements, very brief answers or unusual ideas were explored. The interviews took between 18 and 45 min. The tape recordings of the interviews were transcribed.

**Interview schedule**

The interview schedule contained items on the possibility of people having cancer without knowing it, the woman’s own views about the cause of cancer, whether the woman felt she was different to other women regarding cancer, any experiences the woman had had with breast or cervical cancer, and the woman’s thoughts on the potential cure or treatment of breast and cervical cancer. A number of items related to screening: what the woman
thought about the idea of screening for cancer, what she thought is the purpose of screening for cancer, her response to the idea of having a mammogram; her experiences of having a mammogram; her response to the idea of having a Pap smear; her experiences of having a Pap smear and her reasons for having or not having a Pap smear. Participants were also asked for their age, their highest education level and their main occupation. The first items were questions which could be easily answered by participants to assist them to settle into the interview (Britten, 1995). Items relating to the woman’s views and behaviour regarding screening were asked late in the interview. The general items about screening were placed before the more specific items in order to minimize socially desirable responses.

Analysis

The analysis of the interview transcripts was performed manually. An initial list of categories was developed from the themes which emerged. This list was expanded during the analysis process. The interview transcripts were coded into 72 categories, grouped under the broad headings of: cancer in general, causes of cancer, diagnosis, treatment, cure, screening in general, mammography, Pap tests, symptoms of cancer, influence of other people and evidence of acquiring illness representations or of changing beliefs. Comments made by participants were assigned to the appropriate category. Comments which were clearly irrelevant to the topic were not categorized. Each participant was classified as a screener or under-screener. Summaries of each category were made, differentiating screeners from under-screeners. In reporting the results of the interviews, the focus is on information gathered which relates to the three illness representations (identity, cause and cure), information relating to screening behaviours which has not been reported in the literature, and information on acquiring illness representations. Quotes from the participants are used as illustrations. After each quote the status of that individual as a screener (S) or under-screener (U-S) is indicated.

Results

Participants

Twenty women aged between 46 and 69 (mean = 56.4) years were interviewed. Their education level ranged from grade 6 to Master of Arts. Their occupations were: home duties/mother (n = 4), farmer (n = 2), secretarial (n = 2), home duties/bookkeeper (n = 1), teacher (n = 1), retired teacher/writer (n = 1), retired medical technician (n = 1), student (n = 1), sales assistant (n = 1), shop owner (n = 1), sports trainer (n = 1), natural therapist (n = 1), retired nurse (n = 1), taxi driver (n = 1) and retired lecturer (n = 1). Only one of the women had never been married.

Screening status of participants

The women were divided into screeners and under-screeners. The screeners were defined as women who had previously obtained a screening mammogram. Previous mammography behaviour rather than Pap smear behaviour was used as the criterion of screening status because mammograms require initiation on the part of the woman, whereas having a Pap smear may be controlled more by the woman’s doctor (Clarke et al., 1997). Free screening mammograms have been available to women in the Geelong area since late 1993. The woman who was less than 50 years old who had tried to obtain a mammogram but was told by her doctor she could not have one (this information is incorrect, as BreastScreen, the screening mammography service, offers free mammograms to women aged over 40, but only actively promotes them to women aged 50–69) was included in this category as her stated intention was clearly to be screened. Two other women aged less than 50 had obtained a mammogram and one did not intend to ever obtain one.

Table I presents the screening status of the participants. As it shows, six of the women had obtained both a mammogram and a Pap smear in the last 2 years, and two women had obtained a mammogram, but Pap tests were no longer applicable to them. Only one woman had never had either a mammogram or a Pap test.
Table I. Screening status of participants

<table>
<thead>
<tr>
<th>Screening status</th>
<th>No. of women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Screeners</td>
<td></td>
</tr>
<tr>
<td>had obtained both a mammogram and a Pap test in last 2 years</td>
<td>6</td>
</tr>
<tr>
<td>had obtained a mammogram in last 2 years, Pap test not applicable (would have if</td>
<td>2</td>
</tr>
<tr>
<td>it was)</td>
<td></td>
</tr>
<tr>
<td>had obtained a mammogram in last 2 years, overdue for Pap test (2-4 years since</td>
<td>1</td>
</tr>
<tr>
<td>last)</td>
<td></td>
</tr>
<tr>
<td>tried to obtain mammogram (aged less than 50, doctor said can’t have one), had</td>
<td>1</td>
</tr>
<tr>
<td>Pap test in last 2 years</td>
<td></td>
</tr>
<tr>
<td>Under-screeners</td>
<td></td>
</tr>
<tr>
<td>had Pap test in last 2 years, not had mammogram</td>
<td>2</td>
</tr>
<tr>
<td>overdue for Pap test (more than 2 years since last), not had mammogram</td>
<td>6</td>
</tr>
<tr>
<td>Pap test not applicable (wouldn’t have if was), not had mammogram</td>
<td>1</td>
</tr>
<tr>
<td>never had Pap test or mammogram</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
</tr>
</tbody>
</table>

Identity—the label and symptoms of cancer

The identity component of a person’s illness representation relates to the label and symptoms of the illness in question. The interviews indicated clear differences in the identity of cancer for the screeners and under-screeners (see Table II).

Identity was classified into general comments about cancer (i.e. not being afraid of cancer or expressing concern about it), and comments about the relationship between the presence of symptoms and cancer. The screeners were more likely than the under-screeners to say they were not afraid of cancer and knew of people who had cancer with no symptoms. The under-screeners were more likely to express concern about cancer or to comment that you would have symptoms if you had cancer.

Cancer in general

During the course of the interviews, many women made a general type of comment about cancer, e.g. whether it worried them or how often they thought about it. Screeners were less concerned or anxious about cancer than were the under-screeners. Screeners suggested:

I’m not frightened of cancer at all. I believe I would cope pretty well. (S)

I don’t think I have fears so much about cancer. (S)

I don’t worry about cancer for myself. (S)

Three of the under-screeners expressed fears about cancer:

I don’t want to know about it really because it’s a frightening thing. (U-S)

They say the big ‘C’ word is a death sentence when you get it and those sort of quotes don’t come out of nothing. (U-S)

Examples of people having cancer with no symptoms

Only screeners gave clear examples of people they had known who had had cancer with no symptoms:

I’ve had friends say that they had absolutely no idea, crash, they are hit with this diagnosis when they didn’t even feel unwell. (S)

My husband had cancer before he knew it because at the time he was diagnosed he already had secondaries. (S)

Would need symptoms before getting screened

Some of the women who were under-screeners clearly associated having cancer with having some symptoms or signs of a problem. They would only consider having a mammogram or Pap test if there was something wrong. Speaking about mammograms:
## Table II. Illness representations of cancer for screeners and under-screeners

<table>
<thead>
<tr>
<th>Identity of cancer</th>
<th>Screeners (n = 10)</th>
<th>Under-screeners (n = 10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>not afraid of cancer</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>concerned about cancer</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>having cancer with no symptoms</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>would need symptoms</td>
<td>0</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Causes of cancer</th>
<th>Screeners (n = 10)</th>
<th>Under-screeners (n = 10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>lifestyle factors</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>heredity</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>stress</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>latent in everyone</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>environment</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>bump/knock</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>random</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>hygiene/infection</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>hormones</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Treatment/cure of cancer</th>
<th>Screeners (n = 10)</th>
<th>Under-screeners (n = 10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>positive examples of treatment</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td>negative examples of treatment</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>wouldn’t want treatment</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>cynical about doctors</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>concern about air</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>might go on its own</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>mastectomy—pragmatic</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>mastectomy—horrific</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>mastectomy—physical concerns</td>
<td>1</td>
<td>4</td>
</tr>
</tbody>
</table>

*Women gave more than one response.*

If I get sick, well, then I’ll start to think about it, but in the meantime I’m just not interested. (U-S)

No, I haven’t had one. If I had any worries that I feel require it, I will do so. (U-S)

If it gets to the stage where I think there is something there I might wander off and have one. (U-S)

Similarly for Pap smears:

If I felt that it was necessary. If I found that there were any irregularities at all—change of mucous lining or anything that might be strange or unusual... If there is anything that is worrying me, otherwise I think that I should be OK. (U-S)

I just haven’t worried about it... I just don’t feel the need for it... I think I would know if there was something haywire. (U-S)

Clearly these women’s beliefs about cancer having symptoms are affecting their lack of screening.

### Causes of cancer

Women were asked for their own views on the causes of cancer. Ideas about the cause of cancer were also mentioned in response to a question about any differences between the participant and other women in her age group regarding cancer. In general there were few differences between the screeners and the under-screeners in terms of their perception of the causes of cancer (see Table II).

### Lifestyle factors

A total of 15 women mentioned some type of lifestyle factor as a cause of cancer, e.g. diet.
smoking or drugs. Diet was the most frequently mentioned cause with six screeners and six under-screeners suggesting it. Five of the screeners and three of the under-screeners mentioned smoking.

Family history
Family history, genes or heredity was mentioned by 14 women. The lack of a history of cancer was specifically mentioned by eight women—four screeners and four under-screeners. Family history was not directly referred to as a cause of cancer by one woman whose sister has breast cancer. There were no clear differences between the screeners and under-screeners.

Stress
Various types of stress, for example financial, or emotional stress, were frequently cited. This was mentioned by six of the screeners and six of the under-screeners. Two of the under-screeners, who are involved with alternative therapies, placed particular emphasis on stress as the cause of cancer:

For me, it means repressed emotions... I would rather tell people how I feel, no matter how hurtful it’s going to be to them and for me consequently, rather than suffer the consequences of cancer. (U-S)

It’s usually a grief that has happened. Usually you’ll find that some major loss has happened within the last 2 years. It may be either a death of someone close or it could be something like retirement, relationships split-up. Anything where the person has not been able to grieve properly or resolve, go through, the process. (U-S)

Latent in everyone
Nine women suggested that cancer is latent in everyone and is triggered by something. Comments of this type were made by four of the screeners and five of the under-screeners.

Well we all have it in our system and something usually triggers it off. (U-S)

Environment
Another cause of cancer related to environmental agents, such as pollution and insecticides. Slightly more screeners than under-screeners raised this issue as a cause of cancer.

Maybe they can be caused by environmental whatever, like pollution, like chemicals in the air. (S)

Bump/knock
Five of the women, three screeners and two under-screeners, mentioned a bump or a knock as causing cancer. Some had examples to support this belief:

Another friend of mine was in a car accident and she was very badly bruised and then about 3 months later a lump came up in the breast exactly where the bruise was and she maintains that it was the blow. (S)

I do know a fellow who had a testicle cancer and he had a fall on his surfboard and then they discovered that he had it in his testicle. (U-S)

Other causal factors
Some of the women, equally screeners and under-screeners, suggested that the occurrence of cancer was a random event:

...it seems to manifest itself at any time. It doesn’t seem to have a lot of rhyme or reason to it. (U-S)

Only two of the women commented that hygiene or infection may be involved in the cause of cancer and one woman suggested that hormones, specifically hormone replacement therapy, was a cause of cancer.

Treatment/cure of cancer
Women were asked for their thoughts on the treatment and potential cure of breast cancer and cervical cancer (see Table II). They also spoke about people they had known with any type of cancer. The screeners mentioned more people who had been cured, while the under-screeners spoke about not having treatment if they had cancer and
expressed cynicism about doctors. The screeners and under-screeners were not differentiated on their overall response to the idea of having a breast removed, although the under-screeners were more likely to mention physical concerns related to the operation.

There was little difference between the screeners and the under-screeners in the number of people they mentioned who were not cured of cancer. However, there was a large difference in the number of positive examples cited. Only two of the under-screeners cited positive examples, or stories of people being cured, compared with eight of the screeners.

**Positive examples**

Examples of positive outcomes of treatment included:

- I guess you’d say her operation was successful at the time because she must have worked for nearly 10 years after that. (S)

- One of my husband’s aunts, who was 82 when she died of cancer, she had her breast removed when she was 30, she had 52 years with no flare up. (S)

**Negative examples**

Some of the negative examples women offered were:

- You do hear about the occasional people who say that they got over it, but perhaps when you look back you know that there are perhaps a lot more people that you know didn’t and are now dead. (U-S)

- She had the breast removed and that was fine, but then it might have been 18 months later, she developed another sort of cancer—lymphoma—and she was 2 months from the time she found it until the time she died. (U-S)

**Would not want treatment**

Five of the 10 under-screeners stated that if they were diagnosed with cancer, they would not have most of the treatment available. They were not asked about that specifically, it was something they volunteered. For some this was a fatalistic approach to illness:

- Maybe because I have other problems and I think if this is going to take me out, well, that’s the way I’m going to go and just use up the quality I had. (U-S)

Others had more definite concerns about the treatment of cancer:

- It really makes you wonder whether sometimes you are better off just ignoring the problem rather than putting up with a cure that is worse than a complaint and not always effective. (U-S)

**Cynical about doctors**

One aspect of women’s thoughts on the treatment of cancer, particularly for the under-screeners, reflected a cynical view of doctors:

- I just wonder whether doctors are too ready to cut, and to experiment and to use people for their research. (S)

- ...the medical profession are more happy to cut you up inside and show everybody because you are just another learning tool... I have a cynical attitude about the medical profession. (U-S)

Two other under-screeners expressed distrust of doctors in general:

- Like doctors have convinced us that we’re at their mercy, for their machines to be used on us, that we don’t have control over our lives. (U-S)

- I get a little bit upset with the medical profession, even though I have been on that side, because it all seems to be the almighty dollar... It all seems to be a big con—maybe I’m a bit biased. (U-S)

**Might just go on its own**

One of the under-screeners was concerned that doctors act too quickly to treat suspected cancer:
Concerns about air/surgery
There were other aspects of the treatment of cancer which some of the women volunteered opinions about. For example, two of the under-screeners expressed concerns about air getting to the cancer during surgery:

You hear stories of when they open them up and the air gets to them, well I don’t know medically whether that is right or wrong. (U-S)

I mean, everybody says, ‘Don’t have the operation. As soon as the operation’s on, the air gets to it and it [the cancer] travels’. (U-S)

Mastectomy
The women were more familiar with the treatment of breast cancer than with that of cervical cancer, and offered a range of responses to the idea of having a breast removed. They were categorized into those viewing a mastectomy as a horrific experience and those who were more pragmatic in their response. Some of the women also spoke about the physical consequences of a mastectomy. Interestingly, there was no difference between the screeners and the under-screeners in regard to expressing horrific or pragmatic views about having a breast removed. However, the under-screeners referred more to physical concerns related to having a mastectomy. An example of a pragmatic response:

Oh, if I had breast cancer I would have it off. It wouldn’t worry me. I have no worries about vanity or anything like that. I would be more inclined to think of my life. (S)

A horrific response:

I think it would be exceptionally traumatic. I think women that go through it must go through an awful lot. Yeah, I think it would be very much part of them, almost in some ways worse than losing an arm. (S)

Physical concerns about a mastectomy:

... I know this woman...who had a breast removed... She had to actually have physiotherapy and be actually taught how to be able to lift her arm. And the pain, the pain of having to hang out the washing and things like that was very traumatic, apart from what she’d gone through. (U-S)

Screening
All participants were asked what they thought about the idea of screening for cancer. Most women responded with fairly predictable answers, with the screeners being generally more positive in their replies. For example, nine screeners and five under-screeners responded with comments about finding a problem as early as possible, two screeners and one under-screener suggested that you would be foolish not to have the tests that are available, one screener that it saves money by saving lives and one screener that screening programs may make a difference to an individual’s life span. Four under-screeners made negative comments about screening in general, suggesting that the money could be better spent elsewhere, that women should be encouraged to be more aware of their own bodies and deal with their own problems or that problems are picked up too early. One screener had philosophical doubts about the money spent on such things while in other countries there are people starving.

Screening is more important for young women
Four women made comments about screening being most important for young people. Interestingly, three of these women were under-screeners who said they would not have treatment if they had cancer. It seems that for these women their age and the fact that their children had grown up, was an important factor (they were aged 48, 56 and 61). They were not necessarily against the idea of screening. Indeed, they supported it—for younger women. They stressed a woman’s role as a mother:
I think, actually, to have a Pap smear when you're young is important... Because if they have got families, I think the most important role for a mother is to survive as long as you can for your children while they are young. (U-S)

Well, if it helps the young ones, because they've got a young family. I mean my children have grown up. (U-S)

Maybe if I was younger and had a young family coming on I might think about it more seriously. (U-S)

Another woman, who was a regular screener, was concerned about young people not having access to mammograms:

I think it should extend to any young person, not necessarily even a mother, but I don't think that it should go necessarily only to an older person. (S)

It is important to note that this is an idea these women volunteered. They were not asked about age, but it clearly is important to some women.

Reasons for not having a mammogram

Ten women who had not obtained a mammogram, and were classified as under-screeners, were asked for any reasons why they were not screened. These will be summarized briefly as some of the reasons women gave have been described in detail in the section on illness representations. Four women said that they would only have a mammogram if they felt there was a problem. Two women commented about concerns related to the process, either about machines interfering with their health or exposure to radiation. These were the women using alternative therapies, one of whom commented that she did not feel a need for a mammogram because she was dealing with the underlying problems. Two women said they had not had time to have a mammogram, one gave apathy as her reason, and one stated that she practised breast self-examination regularly, had regular clinical breast examinations and did not feel at risk.

Reasons for not having a Pap test

Women who were overdue for a Pap test, or had never had one, were asked why they had not had a test and they gave a variety of responses. Their reasons included: did not feel a need because they did not have any symptoms \( (n = 2 \ U-S) \), had simply never got around to it \( (n = 1 \ U-S) \), having difficulty finding a woman doctor \( (n = 1 \ U-S) \), felt less at risk because she was no longer sexually active \( (n = 1 \ U-S) \), concern that she may have a prolapse which would be discovered during a Pap test and may lead to surgery \( (n = 1 \ S) \), had decided not to have Pap tests any more, particularly as she was no longer on the pill \( (n = 1 \ U-S) \), and sorting any problems out herself \( (n = 1 \ U-S) \). The latter two women were both using alternative therapies.

The experience of having a mammogram or Pap test

When women were asked about the experience of having these screening tests, they tended to respond with negative aspects of the procedures. This was particularly the case for Pap smears, as the following quotes from regular screeners demonstrate:

Well, they always reckoned it didn’t hurt, but I thought it was uncomfortable. I felt sore, I could always feel where they had scraped those cells. (S)

Oh, it's just uncomfortable and embarrassing basically. It’s mostly embarrassing I guess. (S)

Pretty revolting. Well, it is uncomfortable, undignified, an invasion. But it is for your own good my dear. (S)

Oh, I don’t like anything like that. I hate going for all those internal examinations and that, but I just pretend that it is not me. (S)

Acquiring illness representations

In the course of the interviews, several women described how they had drawn conclusions about cancer or changed their beliefs as a result of
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experiences they had or information they gathered from their social environment:

I used to think that people’s attitude and their mind over matter...but since it happened to my husband and I know how healthy and fit he was and seemed to do everything right and still developed the cancer, I realise that ‘mind over matter’ isn’t everything. (S)

I was really surprised to learn how many young girls, and...my doctor said to me that he had actually treated...girls in their late teens/early 20s, for cancer and that made me think very deeply because I thought it would occur in middle age/older women and that is why I encouraged my daughter to have one...(Pap test) (S)

I, as a child, don’t remember people getting it as prevalently as they do now. So I assume that it is this age and all the strange things that we eat and drink and the environment. (S)

My Dad was a heavy smoker, Mum was a heavy smoker. But she didn’t die of cancer. So it’s the individual, isn’t it? (U-S)

Discussion

These interviews clearly demonstrated that some Australian women do have their own ideas, or illness representations, about cancer and cancer screening, which are different from those of the medical profession and are not addressed by the theoretical models frequently utilized. The views expressed in these interviews, particularly by the under-screeners, relate to cancer in general rather than to any specific type of cancer. It could be argued that these are generic responses to cancer which would affect the individual’s response to the idea of screening for cancer. Sufficiently negative illness representations of cancer may mean that the individual does not arrive at the stage of considering the value of any particular screening test for cancer. This is a key difference between these illness representations and the beliefs included in studies utilizing the HBM or the TRA, which relate more specifically to aspects of a specific health action.

Several of the themes which emerged are potentially important factors in women’s decisions regarding screening for breast cancer and cervical cancer. These themes emerged in a small sample of women and their generalizability must be tested using a larger sample. A subsequent telephone interview survey with a sample of 1200 women has demonstrated the relevance of many of these views in a more representative group (Savage and Clarke, unpublished manuscript).

Theoretical implications

Identity component of illness representations

The view that cancer involves obvious symptoms and that screening is not necessary in the absence of symptoms indicates a representation of cancer and of screening which is contrary to the utilization of screening. Such views have been described in the literature (Elkind et al., 1989; Peters et al., 1989; Zapka et al., 1989) but in an ad hoc fashion. They have not been measured consistently in either the HBM or the TRA in previous breast cancer or cervical cancer research. Their presence in the representations of these women suggests their importance in an Australian sample of older women.

Cause component of illness representations

In general the participants’ views on the cause of cancer are similar to those found in other studies (Fallowfield and Clark, 1991; Clarke et al., 1993) and include some views not accepted by the medical profession, e.g. the roles played by stress or by knocks or bumps being attributed as a cause of cancer. One exception to this similarity was the emphasis placed on the role of a particular type of stress by the two women who are involved in alternative therapies. These women are interesting because their strong views about repressed emotions causing cancer has ramifications for their screening behaviour. Neither felt the need for screening because they were doing things to pre-
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vent themselves from getting cancer. The role of alternative therapies as an alternative to cancer screening is a concept which is not included in the literature and is not accommodated by the HBM or the TRA.

The emphasis on family history as a cause of cancer expressed by the participants in this study echoes a trend found in the literature. This emphasis may lead some women to have a false sense of security, if there is no cancer in their family. The protective role of having no family history of cancer, or of using alternative therapies, may underlie responses to items measuring perceived susceptibility. However, neither of these views has been addressed by the popular theoretical models.

Cure component of illness representations

The views expressed by the participants regarding the cure or treatment of cancer in general included some of the most illuminating comments. The notion of not wanting treatment if one was diagnosed with cancer was expressed by five of the women, all of them under-screeners. This view of cancer is not represented in the breast cancer or cervical cancer literature. It suggests a different approach to health than that assumed by the models, but is clearly an important factor in these women’s decisions regarding cancer screening. Another interesting characteristic is the paucity of positive examples of the treatment of cancer volunteered by the under-screeners. These women may not be aware of as many successful stories of cancer treatment as the screeners—perhaps these women avoid the topic of cancer and therefore do not hear of successful treatments or they may only attend to the negative stories. Their views in some ways resemble those expressed by a group of African-American women who gave similarly negative responses to the treatment of cancer (Gregg and Curry, 1994). Their responses reflect a generally pessimistic view regarding cancer which only became apparent because of the general nature of the questions asked. When speaking about a more specific aspect of the treatment of breast cancer, such as having a breast removed, screeners and under-screeners were almost equally represented in the horrific or pragmatic types of responses. Although concerns about having a breast removed has frequently been included in previous studies, the present interviews suggest that this measure may not differentiate between screeners and under-screeners.

Four of the women, mostly under-screeners, suggested that screening is more important for younger women, especially those with young children. These women seemed to imply that their lives were less important because their role as a mother was largely over. This is an important point which has not been investigated in the literature and may affect screening behaviours in a larger sample. This view is inconsistent with the underlying importance of health assumed in most theoretical models. It is related to the concept of health motivation in general which has occasionally been measured, and has been associated with mammography compliance (Fischera and Frank, 1994) and Pap test intentions (Hennig and Knowles, 1990). The view that one’s health is less important after your children have grown up may underlie responses to items on health motivation in general.

Perceived barriers

While the women were quite articulate about the negative aspects of the experience of having these screening tests, particularly Pap smears, none cited these aspects as reasons for not having the tests. The fact that the regular screeners made so many comments about what they disliked about Pap tests, while continuing to have them, questions the importance of the barriers component of the HBM and may assist in explaining the findings of some research, where high scores on the barriers items have correlated with positive screening behaviours (e.g. Hyman et al., 1994).

Validation of the concept of illness representations

The concept of illness representations was validated by the women’s active involvement in forming their own beliefs about cancer and cancer screening. Women’s beliefs changed over time. Information from their social environment played a key role in the development of these beliefs. The interviews suggest that the HBM and the TRA are not comprehensive enough to capture the full range of factors that influence women's decisions regarding cancer screening.
role in this process. In speaking of cancer and cancer screening the women focused on information they had gathered from people they had known with cancer, and rarely mentioned medical professionals as sources of knowledge. The idiosyncratic nature of some of the responses suggests that this methodology was successful in obtaining information about the women’s own illness representations, rather than the accepted view of cancer and cancer screening. Although Leventhal and Nerenz (1985) warn that what is salient to the person at the time of the interview may be of only temporary significance to the individual, an exploration of illness representations creates an expanded range of potentially influential factors which can be verified in future research.

Conclusions

- This study identified some beliefs, or illness representations, which are inconsistent with the assumptions made by the theoretical models frequently utilized in the area of cancer screening. In particular the assumption that health is all-important and that the aim of avoiding negative health outcomes determines health behaviours is incompatible with some of the ideas held by the women interviewed.
- Several important differences were found in the representations of cancer and cancer screening expressed by the screeners and the under-screeners. This suggests that these beliefs may contribute to explaining the difference in their screening behaviours. The screeners gave more positive examples of the successful treatment of cancer and expressed less concern about cancer. The under-screeners were more likely to express cynicism about the medical profession, to indicate that a person would have symptoms if they had cancer, that they would not want most of the treatment available for cancer, that screening is more important for younger women and that the use of alternative therapies negates the need for cancer screening.
- While the generalizability of these findings must be tested in a larger sample of women, this study identified several new areas to be incorporated in future research.

Practical Implications

Many of the views expressed in these interviews have practical implications.

- The promotion of cancer screening tests needs to stress that cancer is often asymptomatic, as people retain the view that if one has cancer one would know it.
- The belief that the use of alternative therapies precludes the need for cancer screening has important implications for the promotion of screening. The growth in the popularity of alternative approaches to health (MacLennan et al., 1996) suggests that the types of views held by some of these women may become influential and may need to be taken into consideration when designing promotional materials.
- Further education on the role of genetics in breast and cervical cancer may be indicated to counter the false belief that no family history of cancer greatly reduces one’s susceptibility to it.
- The comments made by some women that screening is more important for younger women suggest an unexplored avenue in the promotion of screening tests, given that mammograms are targeted only to women over 50.
- The negative views about the treatment or cure of cancer expressed by many under-screeners may indicate a need for the use of more positive examples of successful cancer treatment outcomes in promotional materials.

Acknowledgments

The authors gratefully acknowledge the contribution of the 20 women who were interviewed for this study and Rosemary Clarke for her careful transcriptions.

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Received on April 14, 1997; accepted on October 5, 1997