A decision theory perspective on why women do or do not decide to have cancer screening: systematic review

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Abstract

Title. A decision theory perspective on why women do or do not decide to have cancer screening: systematic review.

Aim. This paper is a report of a review in which decision theory from economics and psychology was applied to understand why some women with access to care do not seek cancer screening.

Background. Mammography and cervical smear testing are effective modes of cancer screening, yet many women choose not to be screened. Nurses need to understand the reasons behind women’s choices to improve adherence.

Data sources. Research papers published between January 1994 and November 2008 were identified using the Cumulative Index to Nursing and Allied Health Literature, MEDLINE and PsycINFO data bases. The search was performed using the following terms: cervical cancer screening, breast cancer screening, decision, choice, adherence and framing. Forty-seven papers were identified and reviewed for relevance to the search criteria.

Methods. Nineteen papers met the search criteria. For each paper, reasons for obtaining or not obtaining cancer screening were recorded, and organized into four relevant decision theory principles: emotions, Prospect Theory, optimism bias and framing.

Findings. All women have fears and uncertainty, but the sources of their fears differ, producing two main decision scenarios. Non-adherence results when women fear medical examinations, providers, tests and procedures, do not have seek knowledge about risk and frame their current health as the status quo. Adherence is achieved when women fear cancer, but trust care providers, seek knowledge, understand risk and frame routine care as the status quo.

Conclusion. Nurses need to address proactively women’s perceptions and knowledge about screening by openly and uniformly discussing the importance and benefits.

Keywords: adherence, breast cancer screening, cervical cancer screening, decision theory, nursing, systematic review, women
Introduction

There are substantial health benefits for early cancer detection, but many women with access do not get screened. There are also many known socio-cultural barriers to cancer screening, e.g. lower socioeconomic status, race and lack of healthcare insurance, access to care or education [American Cancer Society (ACS) (2007), Centers for Disease Control and Prevention (CDC) (2007), Davis et al. 2005]. Therefore, to increase the rate of uptake, we need to determine internal factors for obtaining screening.

In the United States of America (USA), the benefits of early detection from screening for breast and cervical cancer are not fully realized and not shared equally by different segments of the population, resulting in unnecessary deaths that disproportionately affect poor and minority populations (ACS 2007). For example, the Centers for Disease Control and Prevention (2007) estimate that 25% of women aged 40 years and older have not obtained a mammogram within the previous 2 years, and 16% of women aged 18 years and older have not had a cervical smear test within the previous 3 years. Similarly, the National Cancer Institute (2007) estimates that there will be 182,460 new cases of breast cancer in 2008, with 40,460 deaths, and 11,070 cervical cancer cases, with 3870 deaths.

However, little is known about why some women who do have access to care do not obtain cancer screening. According to the American Cancer Society (2007), among women with insurance, 30% of women 40 years old and older had not obtained a mammogram within the previous 2 years and 18% of women 18 years old and older had not had a cervical smear test in the previous 3 years (Centers for Disease Control and Prevention 2007). Even in the United Kingdom (UK), where there is universal healthcare coverage, a substantial percentage still do not obtain routine screening: approximately 4-4 million women are ‘invited’ each year to be screened for cervical cancer, but in 2006 only 3-6 million had the test (Cancer Research UK 2007). Moreover, women in the UK die from breast cancer at similar rates to the USA (Cancer Research UK 2007), indicating influences other than availability (although many fewer women die from cervical cancer; Cancer Research UK 2002).

The review

Aim

The aim of the review was to apply decision theory from economics and psychology to understand why some women with access to care do not seek screening.

We hypothesized that fear of cancer and a frame of reference that assumes current health as the status quo is associated with non-adherence (the ‘current health’ status quo), while a fear of cancer and a frame of reference that assumes routine medical testing as the status quo is associated with adherence (the ‘preventative health’ status quo).

Design

To test this hypothesis, we performed a systematic review (Timmins & McCabe 2005) of existing research on breast and cervical cancer screening, creating a qualitative synthesis of the literature on why women do and do not decide to obtain cancer screening.

Search methods


To be included in the review, papers had to meet the following inclusion criteria: qualitative or quantitative research design; breast and/or cervical cancer screening was the primary health promoting behaviour; published January 1994 to November 2008.

Search outcomes

Forty-seven papers fulfilled these criteria and their titles and abstracts were reviewed. Twenty-eight were subsequently excluded because the study sample was healthcare providers, or the primary focus was not breast and/or cervical cancer screening. Of these, 19 papers met all inclusion criteria and were evaluated for common themes regarding decisions to seek breast and cervical cancer screening.

The discarded studies were excluded based on the assessment of their titles and abstracts by the primary author. Papers excluded were not relevant to the review based on the aim, and did not fulfil one or more of the inclusion criteria. Two papers whose titles and abstracts reflected the aim and key search terms for this review were read and later excluded because they did not evaluate why women personally do or do not obtain cancer screening (Davey et al. 2005, Vehab & Gastaldo 2003).

Quality appraisal

No formal appraisal of study quality was undertaken.
Data abstraction

Descriptive properties of the 19 included studies are provided in Table 1. The studies were quantitative and qualitative. Convenience sampling was the predominant method, with sample sizes ranging from seven to 1280, from a variety of sources. Participants were of different races and ethnicities, ranging in ages between 14 and 86 years, and residing in different geographical locations throughout the US, UK and Sweden. Theoretical or conceptual models were described in only 58% (11/19) of the studies.

Synthesis

Content analysis was conducted (Patton 2002) to discover recurring words and themes. Common themes of the studies were used as exemplars and connected to four components of decision theory expected to relate to screening decisions (effects of emotion, prospect theory, optimism bias and framing).

Results

We begin by reviewing four main components of decision theory, followed by the systematic review of the literature and the ways in which it reflected these themes, concluding with recommendations to improve screening based on these effects. The results combine studies from the USA and other countries because the reasons for obtaining or not obtaining routine cancer screening were very similar across these groups.

Decision theory

Effects of emotion on decision-making

Emotion has long been suspected to affect decision-making, but only recently has this relationship been empirically investigated. Fear, which is highly associated with uncertainty, adaptively causes individuals to be risk-averse by inhibiting action and causing them to make safer bets, avoiding uncertainty and potential threats (Dawes 1998, Lerner & Keltner 2000, 2001, Nabi 2002).

Applied to cancer screening, it would be expected that fear of cancer would produce risk aversion and motivate women to obtain screening. However, this is not the case for all women, even those with medical insurance or universal healthcare provision. One possibility is simply that these women do not fear cancer. Another possibility is that they are less focused on their fear of cancer than their fear of the medical establishment, testing procedures or the results (i.e. ‘ignorance is bliss’).

Prospect theory

The classical utility model assumes that decision-makers are rational and seek to maximize utility (von Neumann & Morgenstern 1944). However, behaviour consistently contradicts this assumption, leading Kahneman and Tversky (1979) to develop Prospect Theory. According to this theory, potential losses are weighed more heavily than gains. This means that people are more afraid to incur a loss than they are enthusiastic to obtain an equal gain, and thus generally behave in a risk-averse manner to avoid such losses (Figure 1). In addition, Prospect Theory assumes that probabilities are not weighted linearly in people's minds. They expect events with a very small probability (e.g. 0–20%) to be more likely to occur, causing them to buy lottery tickets and fear unlikely diseases. In contrast, people expect events with a very large probability (e.g. between 80% and 99%) to be much less likely to occur, causing them to fear medical procedures with a high but non-certain success rate yet be unwilling to wear a seat belt when travelling. Thus, breast and cervical cancer, which are expected to affect 182,460 and 11,070 women in the USA in 2008 (respectively; Centers for Disease Control and Prevention 2007), may fall in the shadow of less likely but more highly publicized diseases such as the West Nile virus or avian flu (affecting zero and 114 people respectively in USA in 2008, CDC 2008, World Health Organization 2008).

Optimism bias

According to the ‘optimism bias’, people behave as if the risk of bad things happening is greater for other people than for themselves (Weinstein 1982, 1987, Clarke et al. 2000). Thus, even if women fear cancer and understand the probability of getting disease, they may still underestimate their own personal risk of cancer and therefore not obtain screening.

Framing of alternative choices

According to Tversky and Kahneman (1981), an important variable in decision-making is the decision frame, which refers to:

the decision-maker’s conception of the acts, outcomes, and contingencies associated with a particular choice…controlled partly by the formulation of the problem and partly by the norms, habits, and personal characteristics of the decision-maker (p. 453).

For example, a woman deciding to obtain or not obtain screening processes information within the frame of detecting and preventing illness, rather than that of treating an existing illness.
<table>
<thead>
<tr>
<th>References</th>
<th>Sample size</th>
<th>Race/Ethnicity</th>
<th>Age (years)</th>
<th>Theory</th>
<th>Sample</th>
<th>Location</th>
<th>Data Collection</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ackerson et al. (2008)</td>
<td>7</td>
<td>AA</td>
<td>21–37</td>
<td>Interaction Model of Client Health Behavior</td>
<td>Purposive</td>
<td>MI public health department</td>
<td>Face-to-face INT with and w/o routine PS</td>
</tr>
<tr>
<td>Adams et al. (2001)</td>
<td>164</td>
<td>AA</td>
<td>35–86</td>
<td>Health Belief</td>
<td>Convenience</td>
<td>TX concert, health fairs, churches, clinics, school of public health</td>
<td>CSS; 3 groups from different regions</td>
</tr>
<tr>
<td>Behbakh et al. (2004)</td>
<td>146 (39 H, 73 AA, 29 C, 5 other)</td>
<td>AA, C, H, other</td>
<td>Mean age 49</td>
<td>None</td>
<td>Convenience</td>
<td>Ill healthcare clinics</td>
<td>CSS; invasive CC with, w/o PS</td>
</tr>
<tr>
<td>Blomberg et al. (2008)</td>
<td>86</td>
<td>Not reported</td>
<td>Not reported</td>
<td>None</td>
<td>Purposive</td>
<td>Stockholm, Sweden health clinics</td>
<td>Telephone or Fax INT with open-ended QNNR</td>
</tr>
<tr>
<td>Canales and Geller (2004)</td>
<td>20</td>
<td>AI</td>
<td>39–75</td>
<td>Grounded</td>
<td>Convenience</td>
<td>VT personal homes</td>
<td>Focus group INT with open-ended QNNR</td>
</tr>
<tr>
<td>Carter et al. (2002)</td>
<td>1,280 (429 AA, 851 H)</td>
<td>AA, H</td>
<td>24–49</td>
<td>None</td>
<td>Convenience</td>
<td>NY healthcare clinic</td>
<td>CSS; self-report QNNR</td>
</tr>
<tr>
<td>Davis et al. (2005)</td>
<td>91</td>
<td>AA</td>
<td>40–84</td>
<td>None</td>
<td>Convenience</td>
<td>TN churches, housing projects, health fair</td>
<td>QNNR</td>
</tr>
<tr>
<td>Denberg et al. (2005)</td>
<td>24 (6 AA, 6 C-A, 6 C, 6 H)</td>
<td>AA, C-A, C, H</td>
<td>50–80</td>
<td>Grounded</td>
<td>Purposive</td>
<td>CA healthcare clinics</td>
<td>Face-to-face INT</td>
</tr>
<tr>
<td>Fowler (2006)</td>
<td>30</td>
<td>AA</td>
<td>52–72</td>
<td>Grounded</td>
<td>Convenience</td>
<td>OH Churches</td>
<td>Face-to-face INT with open-ended QNNR</td>
</tr>
<tr>
<td>Jennings (1997)</td>
<td>52 (32 AA, 20 L)</td>
<td>AA, L</td>
<td>14–39</td>
<td>Planned Behavior</td>
<td>Convenience</td>
<td>Mid-Atlantic state Learning centres</td>
<td>Focus group INT with open-ended QNNR</td>
</tr>
<tr>
<td>Nelson et al. (2002)</td>
<td>733 (95 AA, 88 A, 176 C, 374 L)</td>
<td>AA, A, C, L</td>
<td>18+</td>
<td>None</td>
<td>Convenience</td>
<td>CA medical centres</td>
<td>Mailed Survey with telephone follow-up</td>
</tr>
<tr>
<td>Phillips et al. (1999)</td>
<td>26</td>
<td>AA</td>
<td>40–65</td>
<td>Health Belief</td>
<td>Convenience</td>
<td>Urban area, location not indicated; community-based centre and local teacher's union</td>
<td>Focus group INT with open-ended QNNR</td>
</tr>
<tr>
<td>Rauscher et al. (2005)</td>
<td>650 (314 AA, 336 C)</td>
<td>AA, C</td>
<td>52–75+</td>
<td>Transtheoretical</td>
<td>Convenience</td>
<td>NC public health department</td>
<td>Longitudinal survey (7 years)</td>
</tr>
<tr>
<td>Saidi et al. (1998)</td>
<td>913</td>
<td>Not indicated</td>
<td>52–61</td>
<td>None</td>
<td>Convenience</td>
<td>South-East England GP practices</td>
<td>Mailed QNNR</td>
</tr>
<tr>
<td>Tessaro et al. (1994)</td>
<td>132</td>
<td>AA</td>
<td>35–60+</td>
<td>Lay Helping Conceptual</td>
<td>Convenience</td>
<td>Location not indicated; Churches and Community centres</td>
<td>Focus group INT with open-ended QNNR</td>
</tr>
<tr>
<td>Thomas et al. (2005)</td>
<td>135 (85 women; 50 men)</td>
<td>A, AC, AR, I, P, WA, G</td>
<td>20–75</td>
<td>Health Belief</td>
<td>Convenience</td>
<td>England community centers</td>
<td>Focus groups INT with open-ended QNNR</td>
</tr>
<tr>
<td>Whynes et al. (2007)</td>
<td>1388</td>
<td>Not reported</td>
<td>20–50+</td>
<td>None</td>
<td>Convenience</td>
<td>East–central England GP practices</td>
<td>Self-completed QNNR</td>
</tr>
<tr>
<td>Young et al. (2002)</td>
<td>94</td>
<td>AA</td>
<td>40–60+</td>
<td>None</td>
<td>Random</td>
<td>MI healthcare clinics</td>
<td>Experimental (half intervention, half none)</td>
</tr>
</tbody>
</table>

A = African, AA = African American, AC = African Caribbean, AI = American Indian, AR = Arabic, AS = Asian, C-A = Chinese American, C = Caucasian, G = Greek, H = Hispanic, I = Indian (Gujarati), L = Latina, P = Pakistani, WA = West African; States (US) are abbreviated with their traditional postal abbreviation. BC, breast cancer; CC, cervical cancer; GP, General Practitioner; MAMM, mammography; N, sample size; PS, pap smear; SCR, screening; CSS, Cross-Sectional Survey; QNNR, questionnaire; INT, interview.
How a decision is framed can be affected by how the information is presented, which in turn affects choices. In a seminal study, Tversky and Kahneman (1981) presented two groups of students with alternative options to combat an outbreak of an Asian disease expected to kill 600 people. The first group was given two choices with a positive frame: Program A where ‘200 people will be saved’, or Program B where ‘there is a 1/3 probability that all 600 people will be saved, and 2/3 probability that no people will be saved’. The second group was given two similar choices, with a negative frame: Program C where ‘400 people will die’, or Program D where ‘there is 1/3 probability that nobody will die, and 2/3 probability that 600 people will die’ (p. 453). Seventy-two per cent of students in the positive frame group selected Program A (risk-averse and certain), whereas 78% of the students in the negative frame group selected Program D (risk prone and uncertain). Thus, the framing of the problem changed decisions from risk-averse to risk-prone, even though the options had equivalent mathematical utilities.

Applied to cancer screening, perhaps women who do not obtain cancer screening either do not believe that they will die, or are not impressed by the reduction in probability from early detection and treatment.

Another important aspect of framing is the decider’s status quo (Dawes 1998). For example, parents who obtain routine vaccinations for their children probably assume that vaccinations are just something one does – a ‘preventive health’ status quo. Because vaccinations are expected, an active choice is needed only to avoid vaccination (Dawes 1998). Applying this logic to cancer screening, women may view this as a way to preserve the status quo, maintaining their health and keeping up with routine appointments. Alternatively, other women may view screening as a threat to their status quo of good health and routine behaviour because it is an uncommon event that entails the previously unconsidered possibility of having cancer. This latter status quo is more likely for women with low socioeconomic status or educational level, for whom preventative health care is unlikely the status quo. These women assume that they are healthy and associate healthcare providers with illness – a threat to their ‘current health’ status quo. In this case, going to the doctor is considered risky, even though non-adherence ‘would not be considered risk-averse if the expected values of that choice are calculated’ (Lerner & Keltner 2001, p. 148). Due to lack of knowledge, these women do not perceive themselves as at risk for breast or cervical cancer, but rather focus on the inherent costs of screening, such as time, money, embarrassment and discomfort.

Framing is a particularly powerful concept, because it can explain why all women may have fear, and all fear produces risk aversion, but in some cases this results in screening and in other cases avoidance. Those who fear the uncertainty and loss of control associated with healthcare providers, medical procedures and test results are avoiding risk by avoiding screening, while those who fear cancer are avoiding risk by obtaining screening. The screening literature is reviewed below to determine if these suppositions are supported by studies examining why women do or do not obtain cancer screening.

Previous researchers have investigated the role of framing on screening, particularly whether loss-framed (e.g. ‘you will get cancer’) or gain-framed (e.g. ‘stay healthy’) interventions are more effective. The results are inconsistent. Consistent with Prospect Theory, loss-framed messages generally promoted screening behaviour better than gain-framed messages (Banks et al. 1995, Edwards et al. 2001, Schneider et al. 2001, Abood et al. 2005), but one study showed the opposite (Sarfati et al. 1998). Finney and Iannotti (2002) found that reminder letters including either a loss- or a gain-framed message did not statistically significantly increase screening compared to a standard letter.

A systematic review has also been conducted of 11 different randomized controlled trials of screening tests (including breast and cervical cancer) by Jepson et al. (2000); however, this was not aimed at understanding the decision process per se. Informed decision-making was not included as one of the review inclusion criteria (‘to determine whether the intervention was aimed at informed uptake, rather than just increasing uptake’ p. 27), but only one of the 190 studies evaluated the effect of an intervention on the screening decision (for antenatal screening) and decision theory was not used in the review to interpret the results. Importantly, this paper concluded that future research was needed on the decision process. An additional systematic
review of interventions to promote cervical screening considered 'message framing', but none of the 35 studies from the US and UK examined the effects of message framing on the uptake of pap smear testing (Forbes et al. 2002).

Common themes in the literature

Women fear different things

Supporting the 'current health' status quo, fear was found across studies to prohibit preventive health care. Women did not obtain mammography screening (Tessaro et al. 1994, Phillips et al. 1999, Adams et al. 2001, Young et al. 2002, Canales & Geller 2004, Thomas et al. 2005, Fowler 2006) or cervical cancer screening (Jennings 1997, Nelson et al. 2002, Behbakht et al. 2004, Thomas et al. 2005, Whynes et al. 2007) because they feared that the screening would reveal cancer and they preferred not knowing. Even if women acknowledged that cancer screening was important to their health, fear influenced their decision not to have regular breast and cervical cancer screening (Carter et al. 2002, Young et al. 2002). Fear related to treatments for breast cancer was also a barrier (Tessaro et al. 1994, Young et al. 2002, Canales & Geller 2004), with fear of radiation treatment for breast cancer being the greatest, present in 61% of women (Young et al. 2002). Thus, while healthcare providers perceive women who do not obtain routine screening as behaving in risky manner, these women see the test itself as risky, thereby decreasing risk by not obtaining screening (Slovic 1987).

Despite this consistency, fear does not have a monotonic effect on screening. Supporting the 'preventive health' status quo, fear was also found to motivate routine screening (Tessaro et al. 1994, Jennings 1997, Saidi et al. 1998, Canales & Geller 2004, Whynes et al. 2007). As much as women disliked screening, fear of cancer and its inherent uncertainty was the driving force motivating 15% of African American and 10% of Latina women to obtain screening in a study by Jennings (1997). Saidi et al. (1998) reported that 31% of women in their study obtained breast cancer screening because they feared cancer and would rather know. Contributing to fear was the belief that their risk was higher than that of other women the same age (the reverse of the optimism bias), according to Saidi et al. (1998). Whynes et al. (2007) found that 28.5% of the women obtaining routine cervical screening feared testing, but their fear was 'overridden' by their personal motivation and provider recommendation. This group may have believed that their risk was higher than other women because they also had the highest degree of smokers, and personal or family history of cancer.

Therefore, depending on the source of the fear, women could either be shown to avoid (when fearing the test or the results) or to seek (when fearing cancer itself) screening; in both cases, they acted to reduce the risk that was salient to them. Thus, consistent with decision theory, fear caused women to avoid risk, but the way in which they framed the risk, or the source of their fear, created opposing effects on behaviour.

It will not happen to me

Supporting the weighting function of Prospect Theory and the optimism bias, we found consistent evidence that women did not obtain screening because of misperceptions of their risk of cancer and the benefits of screening. This is striking evidence of the optimism bias. Eiser and Cole (2002) found that the participants overall believed that their risk of cervical cancer were well below average among women their same age, regardless of their knowledge of risk factors. In another study, 36% of the African American women had never had a mammogram (well below the nationwide average of 15.9%; Centers for Disease Control and Prevention 2007), due to a mistaken belief that they were not at risk for breast cancer (Davis et al. 2005). Thomas et al. (2005) found that women in their mid-50s believed that they no longer needed breast and cervical cancer screening, perhaps based on the age limit for screening. Some women believe their risk for cervical cancer is dependent upon sexual behaviour, reducing their perceived risk when they are not in a sexual relationship (Blomberg et al. 2008). Although some individuals may be at reduced risk for breast and/or cervical cancer, reduced risk does not mean that there is no risk, thus, breast and cervical cancer may be further examples of the optimism bias producing unhealthy choices (Weinstein 1982).

Problems attributable to underestimating one's risk for cancer are particularly pronounced when women do not have a family history of the disease. Those without a family history did not perceive themselves as at risk and, thus, did not think they needed to obtain mammography or cervical smear testing, in studies by several researchers (Tessaro et al. 1994, Saidi et al. 1998, Adams et al. 2001, Carter et al. 2002, Denberg et al. 2005, Fowler 2006, Ackerson et al. 2008). Although having a family history of breast cancer is associated with an increase in risk (ACS 2007), some women have been found to believe that if there is no family history of cervical cancer, there is no risk (Carter et al. 2002, Ackerson et al. 2008). This is a misperception, because cervical cancer is not associated with a family history of that particular form of cancer. Therefore, women who do not understand the risks/causes of cancer believe that they are not at risk, assume that they are healthy and do not perceive ‘routine exams’ as
part of the status quo (Denberg et al. 2005, Ackerson et al. 2008).

Therefore, beyond biases that may influence how a person processes information, many women simply do not have accurate information about cancer and screening. Cervical cancer screening seems particularly to suffer from a lack of knowledge. One study showed that 83% of the 1280 participants reported an understanding of breast cancer, but only 53% reported an understanding of cervical cancer; in addition, African American women had statistically significantly less knowledge than Hispanic women (Carter et al. 2002). These findings were similar in women diagnosed with cervical cancer, where 25% of 146 women diagnosed with cervical cancer believed that it was not possible to get cancer of the cervix; these women either obtained the cervical smear test irregularly or had never been tested (Behbakht et al. 2004). Across studies, a common, incorrect belief has been found among women not obtaining screening that cervical cancer was not a possibility for them or that there was little they could do to prevent or reduce the risk (Carter et al. 2002, Eiser & Cole 2002, Nelson et al. 2002, Behbakht et al. 2004, Denberg et al. 2005, Ackerson et al. 2008).

There also seems to be a misperception about the extent to which people can ‘feel’ or ‘detect’ cancer in their own bodies, as many women think that routine screening is unnecessary because they take good care of themselves and do not experience symptoms (Canales & Geller 2004, Davis et al. 2005, Blomberg et al. 2008). Some American Indian women do not obtain routine mammography because they believe that they are ‘in touch with their bodies and tending to bodily changes’, which means that they do not need screening and breast cancer will not happen to them (Canales & Geller 2004). Similarly, Swedish women who did not obtain screening felt that they took good care of themselves and were ‘in tune’ with their bodies which protected them from cervical cancer, according to Blomberg et al. (2008).

No one told me that I should
Why are so many women misinformed about their personal risk of cancer and their ability to detect it? An unanticipated and disturbing theme in the literature was the fact that many reported that they were not told by their healthcare provider that they needed to obtain screening, or were not told of the benefits and risks. In a longitudinal study involving 650 women, 42% of the women said that they did not receive a recommendation or referral from their provider for mammography, even though provider recommendation is one of the strongest predictors of initiation and maintenance of regular mammography, in a study by Rauscher et al. (2005). Women who were already obtaining routine screening before the study continued to do so throughout the 7-year study, although not all of them had received a recommendation from their provider during that time. Thus, healthcare provider recommendation may be less necessary for women who have already adopted the ‘preventative health’ status quo. Those who still had not begun routine screening by the end of the study had more negative attitudes towards screening and less healthcare provider contact (Rauscher et al. 2005). In another study, 33% of women who had never obtained a mammogram reported that this had never been suggested by their physician (Davis et al. 2005). In a study by Tessaro et al. (1994), women who only saw healthcare providers when there was a specific problem said that they had not received a recommendation for mammography because the provider was focusing on the health concern, not on preventive health. This is particularly striking for two reasons: (1) it suggests that healthcare providers are partially responsible for the ‘current health’ status quo, and, (2) it makes it less likely that women will change from the ‘current health’ to the ‘preventative health’ status quo, given that the most women place the provider in control (Young et al. 2002).

Even when healthcare providers do recommend screening, sometimes women still do not obtain the test because they are uncertain about the provider’s motives, particularly when the provider did not inform them of the benefits of screening (Fowler 2006, Jennings 1997, Phillips et al. 1999, Thomas et al. 2005, Whynes et al. 2007). Providers’ advice about cervical screening was thought to be important, but not important enough to motivate adherence, according to Whynes et al. (2007). Providers who dismissed women’s feelings and gave ‘mixed messages’ about the importance of screening are viewed as unhelpful, and reduce the desire to screen (Thomas et al. 2005).

One possible reason for lack of information transfer between healthcare provider and patient is that providers underestimate how much information patients actually need, wrongly assuming that they would ask for information if they needed it; in contrast, some patients put all of their control into the provider’s hands and assume that the provider would tell them if they needed an exam (Rimal & Real 2003). To combat this problem, providers must openly discuss patients’ personal risks for cancer and the effectiveness of preventive measures in order to stimulate knowledge and the motivation towards screening (Rimal & Real 2003). This is particularly true for women in the ‘current health’ status quo.

Two types of deciders with a different status quo
Use of the concept of framing is a particularly powerful way to synthesize the literature on decisions to obtain screening for breast and cervical cancer. Women from lower socioeconomic
groups and minorities are much less likely to have access to quality health care, more likely to fear and mistrust healthcare providers, and do not feel empowered to seek out information. As a result, they do not believe that they are at risk for cancer and/or do not understand the effectiveness of early detection and treatment. These factors co-occur and reinforce each other, producing a ‘current health’ status quo whereby women assume that they are healthy and do not go to a healthcare provider unless they feel very ill.

In contrast, women from higher socioeconomic backgrounds, with more traditional education, often have access to high-quality health care, are given the time and attention of their healthcare providers, whom they trust and heed, and are empowered to obtain information. As a result, they are more likely to see themselves as at risk for cancer and understand the effectiveness of early detection and treatment. These factors also dynamically co-occur to produce an entirely different ‘preventive health’ status quo, whereby women rely on their healthcare providers and on routine medical care for good health.

Discussion

Limitations of the review

We acknowledge that there are limitations to this review, in which we used a systematic yet subjective process to synthesize the literature. In addition, no appraisal of study quality was undertaken. In using a decision framework, while we did find many striking themes that suggest ways to improve screening, we may have missed other themes. Further, because framing has not been extensively studied with respect to screening adherence, the papers we reviewed were not directly focused on this process and thus all our interpretations were indirect. However, this novel approach yielded multiple important lessons that can be followed up in future research.

Strengths of the review

Adherence is usually studied by looking at risk tendencies with respect to single variables such as patient characteristics (race, gender and ethnicity), the framing of the message or family history of disease. Using the decision theory framework, particularly the effects of framing and the status quo, we were able to determine how fear can explain women’s motivations both to seek and to avoid screening. We were also able to combine variables that are typically studied in isolation into two stable, dynamic states that are mutually reinforcing and affect perception and motivation. This framework is more powerful and useful because it is much easier to change one’s frame of reference regarding health care than one’s race, ethnicity or socioeconomic status.

Implications for patients

A majority of information about mammography and cervical smear testing has been directed at white women, who have a different cultural context from women of colour (Schneider et al. 2001). However, the need to redress the status quo of ‘current health’ is particularly striking for women in at-risk populations, such as those with a lower socioeconomic status, lower educational level and minorities – particularly Hispanic and Asian women who currently have the lowest rates of adherence for breast and cervical cancer screening in the USA (CDC 2007). Tailored messages about cancer screening that address the unique characteristics of the target group are effective in increasing adherence (Schneider et al. 2001, Champion et al. 2003), and if used more widely can increase screening and long-term adherence.

Implications for healthcare providers

Healthcare providers need to focus on moving women from the ‘current health’ to the ‘preventive health’ status quo. This can be done by clearly explaining cancer risk, the benefits of screening, and the procedures involved, being careful to consider fear of the unknown. This is not a simple task for two reasons. First, patients who come to a clinic are more likely to have already adopted the ‘preventive health’ status quo. Thus, instruction may be targeted at the wrong population, which could in turn discourage providers. To address this, providers need to educate women when they visit for acute conditions or temporary needs, such as viruses or repeated prescriptions. Second, women who fear cancer or the screening process may paradoxically avoid the information needed to reduce their fear, meaning that even when the information is presented, it may be ignored, again discouraging providers. Thus, information about screening needs to be consistent, offered even when patients come for unrelated reasons, and presented in an active manner that encourages dialogue, rather than a passive one that is easily ignored (e.g. a pamphlet). With their holistic approach to health care and high patient contact, nurses are in a particularly good position to enact such changes in clinic settings.

Implications for public policy

Because public health messages have the potential to reach individuals beyond the clinic, they can better target women...
who do have health care, but fail to use it. Such messages need to move women from the ‘current health’ to the ‘preventative health’ status quo by explaining to them the appropriate probabilities, addressing their fear and associating health with routine screening (Aaker & Lee 2001).

What this paper adds

- Emotions associated with screening (particularly fear) can produce two opposing decisions: to screen and not to screen.
- Healthcare providers underestimate how much information patients actually need and wrongly assume that patients ask for information when they need it.

Implications for practice and/or policy

- Nurses should promote screening by educating patients about the benefits and risks of breast and cervical cancer screening, even when they do not ask for information.
- Efforts directed at increasing adherence need particularly to address women’s fears associated with the procedures or a possible positive result.
- Public health messages need to target specifically the segments of the population that do have access to health care, yet fail to undergo routine screening.

What is already known about this topic

- Mammography and cervical smear testing are well-established screening tests that can detect cell changes and cancer when treatment is most effective.
- Certain external barriers exist that contribute to cancer screening practices, i.e. lack of healthcare insurance, lack of access to care, lower socioeconomic status and lack of education.
- Emotion affects decision-making but the relationship is not predictive: fear is associated with uncertainty and risk aversion, but women can use fear both to obtain or avoid screening.

Conclusion

The ultimate goal in cancer screening is to detect cancer. Very few women appear to understand that cervical smear testing aims to identify abnormal cells before transformation to malignancy, and that mammography can detect cancer in early stages when treatment is most effective. Nurses, whom people trust, need to avail themselves of the opportunity to address women’s fears and lack of knowledge, which produce uninformed decisions. The goal is to help women understand both the risks and benefits of screening, so that they can make informed decisions about whether or not they want to obtain the tests.

Currently, research does not directly focus on the decision process of patients and the frames therein which guide women’s healthcare choices. Future research should include studies that attempt to measure and alter women’s status quo, possibly using reframing techniques to help women ‘recontextualize’ the way they view medical care and cancer screening.

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Conflict of interest

No conflict of interest has been declared by the authors.

Author contributions

KA and SDP were responsible for the study conception and design, and made critical revisions to the paper for important intellectual content. KA performed the data collection, data analysis and was responsible for the drafting of the manuscript.

References


Sarfati D., Howden-Chapman P., Woodward A. & Salmon C. (1998) Does the frame affect the picture? A study into how attitudes to screening for cancer are affected by the way benefits are expressed. *Journal of Medical Screening* 5(3), 137–140.


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