Elder women's decision-making in breast cancer care: An Israeli study

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ABSTRACT

Purpose: Much research has examined women's decision-making behaviour in breast cancer care. Patient age has shaped preferences, values, decision style and participation in treatment decisions. The aim of this study was to test the validity of the Michigan Assessment of Decision Style (MADS) (Pierce, 1995) in an older cohort and provide information on decision styles to identify areas of tailored decision support necessary for Israeli women.

Methods: This study examined the decision-making styles of older Israeli women receiving routine mammography screening. Fifty two women over 65 years of age, attending a routine mammography screening, were administered a questionnaire containing demographic information and the MADS to determine hypothetical treatment decision-making. The MADS is a 16-item questionnaire assessing decision-making behaviour by characterizing four factors: avoiding, deferring, information-seeking and deliberation.

Results: Age, family history of breast cancer, and having a current mammography were not significantly associated with any of the four MADS factors. Deliberation and Deferring had the highest mean scores, followed closely by Information-Seeking and Avoidance. Correlations among the factors indicate a significant, positive correlation between Deliberation and Information-Seeking and a significant negative correlation between Deliberation and Deferring, consistent with previous studies.

Conclusions: These findings indicate that older Israeli women's decision style is characterized by information seeking and deliberation reflecting a disposition towards engagement. The findings contribute to clinicians' understanding of women's preferences by countering the traditionally accepted stereotype that older women will employ a passive role when faced with an important health care decision.

Introduction

Medical decision-making in breast cancer care has been the paradigm of patient participation for about two decades. Since the well known study that established the possibility of breast conservative treatment for women with early stage breast cancer (Fish et al., 1985), women are more commonly given the choice between having a mastectomy or a lumpectomy followed by radiation therapy. However, the choice between these two surgical options is not the only decision women may have to make for their breast cancer treatment. Other choices may include the decision whether to have breast reconstruction, if a mastectomy was chosen, whether to have adjuvant chemotherapy to reduce the risk that the cancer will recur, whether to join a research protocol, the decision about taking hormonal treatment, and even the newly developed issue of Herceptin as adjuvant treatment for women with Her-2 Neu positive tumours. As well as the numerous medical decisions women face, there are more personally relevant decisions they struggle with such as disclosure to family members, whether or not to continue work, where to go for social support, and the many choices that ultimately shape a woman's quality of life following treatment.

Much research has been done to examine the concept of women's decision-making in breast cancer care (Beaver et al., 1996; Budden et al., 2003; Katz et al., 2005; Pierce, 1993; Romanek et al., 2005). The issues surrounding personal decision-making are complex and multi-faceted (Pierce and Hicks, 2001). There is growing evidence that demonstrates the psychological benefit of

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being involved in the decision-making process regarding treatment (Fallowfield et al., 1994). Women have different preferences regarding their participation in the decision-making process and the role they desire in collaborating with their physician (Beaver et al., 1996; Degner et al., 1997). To enable quality decision-making, several studies have documented individual preferences for the type and amount of information women seek to make an informed choice (Degner et al., 1997; Bildeau and Degner, 1996; Hughes, 1993). More recent studies are linking decision behaviour with quality of life following treatment (Hack et al., 2005; Pierce, 1996).

Preferences for participation in decision-making

Decision-making preferences with respect to the level of desired participation is important because it involves the patient—provider relationship, information seeking, and the expression of personal values and preferences. In a large study of 1012 patients with breast cancer (Degner et al., 1997), women were asked about their preference regarding their levels of participation in treatment decision-making, as well as their understanding of how much they actually achieved their preference. Preference was measured by using a card-sorting technique with selections ranging from the active role (where the patient selects her own treatment) through the collaborative, to the more passive role where the women wants the physician to decide for her. Only a small number of women wanted to select their treatment alone (22%). Forty percent of the women wanted to select their treatment in collaboration with their physician, and 32% wanted the physician to decide for them. Interestingly, however, only 42% of women reported that they have achieved their preferred level of control in the decision-making process regarding their treatment. It seems that when facing a life-threatening disease, taking charge and a proactive role is still very difficult and demanding for many women. With respect to informational needs, it was found that women wanted information concerning their chances for a cure and the possibility of the disease spreading or recurring. Younger women (under 50) ranked information about physical and sexual attractiveness as also important, opposed to older women that needed mainly information about their ability to remain independent and care for herself. Understanding the differences in decision behaviour, including differences in preferences, between younger and older women, helps clinicians tailor interventions that are more likely to meet the woman’s personal needs and will presumably lead to greater satisfaction with the outcomes of their decisions.

In another study (Beaver et al., 1996) of patients’ preferences for participation in decision-making, it was also found that the majority of the newly diagnosed women preferred to play a more passive, deferring role when making decisions regarding their surgical treatment. In this study 150 women with a new diagnosis of breast cancer were interviewed regarding their preference for participating in treatment decision-making, and 200 women with benign breast disease served as a comparison group. Unlike the women diagnosed with breast cancer, the benign group preferred a more collaborative role in decision-making regarding their care. This finding demonstrated again that when actually confronting a life-threatening disease, women’s role in decision-making shifts towards a more passive role, most likely a result of the sometimes overwhelming psychological burden of a cancer diagnosis as the cognitive burden of complex and emotionally charged health care decisions.

One of the early studies describing decision-making in breast cancer care was conducted by Pierce (1993). In her qualitative study of 48 women diagnosed with breast cancer, women were interviewed while actively engaged in making a treatment decision. A qualitative analysis of the interview data revealed three major decision-making styles termed Deferrers, Delayers and Deliberators. Categorically Deferrers appeared to be influenced by the salience of a particular alternative, which allowed them to make quick, conflict free decisions by deferring the responsibility of making a choice to a family member or physician. They frequently selected the alternative recommended by the physician without further information seeking or deliberation of the possible alternatives. Delayers, in contrast, appeared to structure the decision problem in a way that allowed consideration of at least two options. Their deliberation between the two alternatives was, however, random and superficial, and they appeared to jump from consideration of one option to another without a systematic process. This style can only make a decision when one of the options become more salient for some reason related to an immediate appeal. Delayers typically experience more conflict and distress than Deferrers, presumably because they either do not know how to go about making a decision, or cannot distinguish aspects of the various options that would lead to a preference. Deliberators, in contrast, expressed a personal responsibility for making a quality decision and became engaged in the decision-making process in a manner that was more deliberative and purposeful than either the Deferrers or the Delayers. These women were characterized by: 1) the use of a strategy or plan 2) an explicit consideration of risk 3) an expressed confidence in their decision-making process and 4) recognition of a time in the future when they might regret their choice. It is interesting to note that only 15% of the participants were characterized by the more demanding deliberative decision-making style (Pierce, 1993). Yet, this is the deliberative process that normative models of decision behaviour predict will lead to a quality decision (Bell et al., 1988). Linkages between actual decision behaviour and post-treatment well-being and emotional adjustment highlight the importance of choosing a systematic evaluation of individual decision styles.

Fallowfield et al. (1994) studied 269 women diagnosed with breast cancer. Women were given measures of anxiety and depression before treatment and at 3, 12, 24 and 30 months later. For 28% of the women, at three years, irrespective of the surgeon’s preferred approach to treatment or the surgery performed, anxiety and depression were at a remarkable level well beyond intervention. Forty-one women younger and older women, helps clinicians tailor interventions that are more likely to meet the woman’s personal needs and will presumably lead to greater satisfaction with the outcomes of their decisions.

In a succession of instrument development studies, Pierce (1995) identified and tested a series of instruments for each of the three qualitatively derived decision styles resulting in the 16-item Michigan Assessment of Decision Style (MADS). Analysis of the instrument yielded four factors: avoiding, deferring, information seeking and deliberation. The characterization of decision styles is consistent with the initial qualitative findings with the much needed benefit of providing a psychometrically reliable measure. Since the instrument was developed using samples of American, primarily Caucasian women seeking mammography screening, there was a need to evaluate the measure within different cultures. In a study of Australian women, Budden et al. (2003) replicated procedures used in the development of the MADS by selecting a comparable sample of women’s seeking mammography to assess their pre-diagnostic decision-making styles related to treatment choices for early breast cancer. The selection of a sample of women
seeking mammography in the development of the measure is to provide a close proxy to the stressful environment in which women have an actual diagnosis of breast cancer. 

Consistent with Pierce's studies, women were given the questionnaires at a mammography clinic, asking them to respond to the questions as if they were placed in the position of making a treatment decision for breast cancer. Of the 366 participants, 90% were categorized by a predominant deferring score; less than one percent endorsed avoidance; 33% identified information seeking as their predominant factor and 63% could be characterized by the deliberation factor. The high level of deliberation expressed by women in this study may be related to the fact that they were responding to a hypothetical situation and not on an actual diagnosis, which is clearly related to higher levels of anxiety and stress (Keller et al., 2004). The important finding is that the MADS discriminated women's decision style into the same factors as previous studies although with different levels. It must be noted, however, that the study involved primarily educated Caucasian women and no translation of the instrument was required.

In a Canadian study, Hack et al. (2005) reported a study on 205 women diagnosed with breast cancer who completed the Decisional Role Preference Scale (the card-sorting technique described earlier on, (Degner et al., 1997) at baseline (time of surgical treatment) and at three years follow-up). At follow-up, they also completed a quality of life questionnaire (EORTC QLC C30). Results demonstrated that women who indicated at baseline that they were active involved in choosing their surgical treatment had significantly higher overall quality of life at follow-up than women who indicated passive involvement. These actively involved women had also significantly higher physical and social functioning than women who reported a more passive role. Higher quality of life was therefore related to reports of experiencing involvement in treatment decision-making.

Consideration of age in decision-making behaviour

Studies have shown that age can be an important factor regarding women's preference to take part in the decision-making process, as well as their actual behaviour when facing a cancer diagnosis (Johnson et al., 1996; Perets et al., 1997). From a clinical perspective, it is well known that younger women are more commonly playing an active and assertive role just as they do in their everyday lives. It is much less common for the "older generation" to question the doctor, to look for a second opinion, to seek for more information and to make their own choice regarding their care.

Several studies have found that when women are diagnosed with breast cancer, their preferences shift from an active role to one that is more passive and dependent on others, a finding that is more robust among older women (Bilodeau and Degner, 1996; Romanek et al., 2005). Although these studies have noted differences among young and older women, few included women age 65 and older and none have identified the factors that account for these differences. Without an elaborated and systematic understanding of the decision behaviour of older women, we cannot provide decision support that is tailored to meet their needs and preferences.

Given the existing evidence of the role of participation in these decisions, it is important to assess patient's disposition regarding their involvement to better meet their style at the time decisions are made. This association is particularly important [relevant] give the emerging literature indicating that the decision-making process is linked to long term outcomes and age.

Andersen et al. (2000) examined the relationship between women's perception of regarding their involvement in their treatment decision-making and long term health related quality of life (HRQOL). They interviewed women 2.5 and 10 years post-diagnosis about their health related quality of life, and their perceived involvement in the decision-making regarding their care. What they found was that perceived involvement in decision-making about breast cancer treatment and about follow-up care is associated with better HRQOL for survivors 2.5, and 10 years post-diagnosis. A major problem with this study is in the bias of retrospective recall; however women are reporting their perception that their involvement was instrumental in their long-term well being.

All these studies of decision-making styles, preferences (hypothesetical and actual) and potential benefits to long term psychological morbidity and quality of life were done, by large, on Western populations. To date, we do not have relevant measures or findings to guide decision support interventions for Israeli women. Moreover, the issue of psychosocial concerns in older women with breast cancer has received little attention in the past, but does receive more and more attention in recent years as the population in both countries is reaching advanced age e.g., (Figueiredo et al., 2004; Ganz et al., 2003; Heidrich et al., 2006; Maly et al., 2005).

It is therefore the purpose of this proposed study to examine older (65 years of age and older) Israeli women seeking mammography to evaluate the utility of the MADS in characterizing their decision-making style in a hypothetical situation, which is a first step in the exploration of decision behaviour in this understudied demographic cohort.

Methods

Sample and data collection procedure

A cross-sectional design was employed in the study. A convenience sample of fifty-two women over 65 years of age attending a routine screening mammography at a screening centre were given a survey including demographic and screening information and the 16-item MADS (Pierce, 1995). All respondents were literate in Hebrew and given the questionnaire before attending screening when the possibility of a cancer diagnosis was most salient and emotionally available. It was explained to the respondents that the survey was intended to learn about how women might go about making a decision if they were diagnosed with breast cancer and that the questions were hypothetical and were in no way connected with the results of her test. The study was given ethical approval by the Institutions' Ethics Committees.

Measurement

The Michigan Assessment of Decision Style (MADS) is a 16 item instrument on a 5-point Likert scale to measure four pre-decision behaviours. For MADS the scale ranges from "strongly disagree" to "strongly agree" (score 1 to 5, respectively). The approach to decision-making is identified by four factors: Avoidance, Deferring Information-Seeking and Deliberation. Two factors, Avoidance ($\alpha = 0.68$), consisting of four items and Deferring Responsibility ($\alpha = 0.76$), consisting of three items, indicate a tendency or preference to minimize personal involvement in the decision and defer the responsibility to another. The two remaining factors, Information Seeking ($\alpha = 0.85$) consisted of five items indicating an inclination for being involved in the decision-making process and seeking information and Deliberation reflecting the structuring of information into a systematic plan for making a decision. The tool has been tested for validity and reliability in a variety of settings including breast cancer (Budden et al., 2003).
It takes between 5 and 10 min to complete the MADS questionnaire. The tool was translated to Hebrew and back translated to English for validation.

Data analysis

Validation of the MADS
Reliability analyses were performed using Cronbach’s alpha to estimate the internal consistency of the factors of the MADS. Pearson’s correlations were used to determine the magnitude and direction of association among the factors, as a test of predictive validity (see Table 2).

Characteristics of decision style
Descriptive statistics on the four MADS factors provide information about the decision-style characteristics of this sample. To determine whether decision style was associated with individual characteristics (age, family history of breast cancer, and current mammography), we estimated associations among the four MADS factors and individuals characteristics using Pearson’s correlations for continuous measures of individual characteristics, and one-way analysis of variance (ANOVA) for categorical measures.

Results
Fifty-two women completed the questionnaires. The average age of the respondents was 71.3 years (SD = 4.8, range: 65–86). Most of the women in the sample were married (58.5%), followed by widowed (28.3%) and divorced (11.3%). Israel was the country of birth of 45 percent of the respondents. Most of the respondents (86.8%) indicated they had regular mammography exams, 40.4% referred themselves to the current mammography and 59.6% were referred by their doctor. Fewer than half of the respondents (43.4%) had a family member with breast cancer.

It is interesting to note that 18 women (25.3%) who were approached to answer the questionnaire and take part in the study, refused to do so. Their reasons for refusal are given in Table 1.

Table 2
MADS summary statistics and reliability (N = 52).

<table>
<thead>
<tr>
<th>Cronbach’s alpha</th>
<th>Range</th>
<th>Mean (SD)</th>
<th>Defer</th>
<th>Information-seeking</th>
<th>Deliberation</th>
<th>Avoidance</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.67</td>
<td>1–5</td>
<td>4.02 (1.1)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0.74</td>
<td>1–5</td>
<td>3.86 (1.2)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0.73</td>
<td>1–5</td>
<td>4.40 (0.8)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0.32</td>
<td>1–4.75</td>
<td>2.01 (0.92)</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

Discussion
This study represents a first attempt to examine the decision-making behaviour that older Israeli women may employ when making a hypothetical decision regarding their treatment for breast cancer care. Women attending a routine mammogram, before even having the test, were asked to complete a measure of their personal decision style as if they were in the position of making a decision for the treatment of breast cancer. It is interesting to note that 18 women declined to participate in the study even though it was anonymous, low risk, and requiring only a short period of time. The reasons they provided for declining participation in the study reflect suspicion or distrust (not wanting to sign forms), heightened distress (“stressed out from life”), or psychological avoidance (“don’t want to think about things like this”). Future studies may benefit from measuring psychological states like anxiety and mood to gain a clearer understanding of the ways in which personal dispositions may influence decision behaviour among different cultures and contexts.

The study of decision-making has grown to a large extent in the last few decades, and decision-making in breast cancer care has
been in some respects a paradigmatic model for the study of decision making in health care situations. It is not uncommon, in studies in this area, in order to try and understand this phenomenon, to examine it in a hypothetical situation, which means looking at the decision-making situation if we would have to face it, and not in the real time. Examining decision-making in a hypothetical situation may help also to understand women's preferences related to taking part in decision-making when it comes to the time of having to make decisions regarding their care.

Describing decision-making behaviour of elderly Israeli women was the focus of this study by providing a reliable measure of their decision-making style to better identify potentially problematic areas where structured decision support may be useful. It is commonly assumed that older women usually adopt a more traditional way of being involved in the decisions regarding their care, taking a less active part in the process, relaying more on the professional advice of their physician. However, in our study it was found that older Israeli women, in general, were information seekers and expressed a deliberative approach, at least when asked about a hypothetical, yet possible decision. This is an important finding that must be employed into the clinical setting, where older women are at times not even given the choice or the opportunity to take an active role when making decisions, with the medical stuff assuming that since they are older they will wish to employ a more traditional passive role.

Limitations

The main limitation of the study was the relatively small sample size and the fact that decision-making behaviour was addressed in a hypothetical situation, which is a common approach in preliminary studies.

Significance and implications for nursing

The significance of this study to the nursing body of knowledge is that it addresses a significant gap in our understanding of elderly Israeli women's experience of making breast cancer treatment decisions. That is, we know very little about how older women approach this problem, what their needs are, and most importantly, we do not know how to provide decisional support at this critical juncture of their treatment. The study enabled us to learn more about older Israeli women's decision-making styles to allow us to tailor a structured nursing intervention to assist older women when making decisions regarding their care. It is established that younger women find it easier to practise a more collaborative role when facing such decisions. In order to provide psychosocial aid and support to older women to adjust to this relatively new medical paradigm, it was important to first understand their decision-making behaviour in a relevant though less stressful scenario. The development of future decisional aids for this group of women is the interest of this project. This study is a preliminary study with an attempt to continue a larger research protocol on women's decision-making in a cross-cultural context and in all age groups. This finding indicates that this sample demonstrated that we should not use age or other demographic factors in predicting how women might make their decisions (e.g., countering stereotypes).

Conflict of interest statement

None declared.

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