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Family decision-making processes about early stage breast cancer treatment

By B. Ann Hilton

Abstract

What role patients and their families should assume in making decisions about their care has stimulated much debate. What role they assume and want to assume and how they go about making decisions has received little study. This paper will present data on family decision-making about breast cancer treatment from a large longitudinal study of family adjustment to early stage breast cancer. Family interviews were done at the time of diagnosis and three weeks, three months, eight months and 12 months after diagnosis. Grounded theory methods were used to analyze the qualitative data. Fifty-five women, both partnered and not partnered, as well as their partners and children, participated. Four patterns of family decision-making were identified: "Defer to Physician", "Minimal Exploration", "Joint Participation" and "Extensive Deliberative Examination". The patterns reflected varying degrees and nature of patient, family and physician participation. Particular factors influenced how families made these decisions, the nature of the process and the outcomes. Facilitating strategies for family decision-making which nurses might use in their practice are described.

Every day, patients with breast cancer, their families and physicians face the task of making decisions about treatments which entail different probabilities of recurrence reduction, substantial risk of unpleasant effects or potential impact on body image. Important decisions must be made about the surgical procedures, adjuvant treatment such as hormonal therapy, chemotherapy and radiation therapy, and for some whether prophylactic mastectomy and/or reconstruction might be appropriate.

How are these decisions made? Who makes them? How are families involved in the process? What factors influence the process? A better understanding of how decisions are made would help health professionals to clarify ways of facilitating the process and identify those at risk for problems. Decisions made and how they are made can have far-reaching implications for family well-being.

The literature describes aspects of treatment decision-making for individuals. Those studies have generally found that most people prefer to defer to their doctor's authority (Blanchard, et al, 1988; Degner & Sloan, 1992; Pierce, 1993). The studies, however, shed

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little light on family involvement in such decisions. Although Degner and Sloan asked about family involvement, it was related to decisions if the patient were too ill to participate. In that case, 51% wanted the physician and family to share the decision-making with only 10% wanting their family to dominate.

It was suggested, based on a review of the literature, that family and friends are often excluded from the decision-making process because of the personal nature of the disease and because physicians often urge that decisions be made rapidly, making wide consultation difficult (Valani & Rumpler, 1985). Involvement of the spouse, on the other hand, was observed to be quite important, since the exclusion of the sexual partner from the decision-making process may cause friction in the relationship. Apparently, husbands, if left out, feel that the physicians are doing things to their partner, rather than for their partner.

Though most studies agree that the doctor's recommendation is most influential in the patient's decision-making process, the patient's involvement is still believed beneficial, for instance in helping to build the patient's sense of personal control (England & Evans, 1992). Cassileth et al (1980) found that those seeking as much information as possible were more hopeful. Patients and their husbands who had been encouraged to participate in the decision-making process together recovered normalcy much faster and to a greater extent than families which did not act together in the decision-making process (Morris & Ingham, 1988). A greater number of those offered a choice of surgery than those not offered a choice showed a normal ability to undertake work, had positive attitudes about the future, were confident in their ability to cope, functioned normally both physically and psychologically and enjoyed a return to their pre-diagnosis sex drive. These data were collected prior to surgery and at two-month intervals for 10 to 12 months post-surgery. They concluded that participation in the decision-making process reduces distress.

PRIX DE CONFÉRENCE SCHERING 1993 PROCESSUS DÉCISIONNELS FAMILIAUX SE RAPPORTANT AU TRAITEMENT DU CANCER DU SEIN DE STADE PRÉCOCE ABRÉGÉ

On a déjà porté beaucoup d'attention au rôle que les patients et leur famille devraient jouer au niveau des décisions prises au sujet des soins que ces patients vont recevoir. Par contre, on s'est peu intéressé au rôle que ces deux groupes assument et veulent assumer et à la façon dont ils prennent leurs décisions. Cet article présente des données sur les prises de décisions familiales se rapportant au traitement du cancer du sein, données tirées d'une vaste enquête longitudinale s'intéressant à l'adaptation familiale au cancer du sein de stade précoce. On a réalisé les entrevues avec les familles au moment du diagnostic et puis 3 semaines, 3 mois, 8 mois et 12 mois plus tard. Les données qualitatives ont été analysées par le biais de méthodes théoriques. 52 femmes et leurs partenaires et enfants, le cas échéant, ont participé à l'enquête. On a identifié quatre types de prise de décisions familiales: soumission à l'avis du médecin, exploration minime, participation conjointe et, examen approfondi et délibéré. Ces types reflétaient divers degrés et divers genres de participation de la patiente, de la famille et du médecin. Des facteurs particuliers y influençaient la prise de décision familiale, la nature du processus et les résultats. L'article décrit des stratégies qui visent à faciliter la prise de décision familiale, stratégies que les infirmières voudront peut-être employer dans la pratique.

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Table One: Family decision-making patterns and their characteristics

Property	"Defer to Physician"	"Minimal Exploration"	"Joint Engagement"	"Extensive Examination"
NATURE OF THE DECISION PROCESS				
Degree & type of involvement	Negligible-passive Prefer to be told	Minimal Quite passive	Moderate Active	Extensive Active
Complexity	Straightforward	Generally straightforward	Varied	Complex
Go with physician's recommendation	Automatically	Usually	Often after consideration	Not necessarily. Question physician's approach
Information search	Avoidance preferable - feel no need for other opinions	Avoidance preferable - feel no need for other opinions	Moderate search	Extensive search Likely sought other opinions
Nature of family involvement	Not involved or also defer	Talk, listen, some reading	Generally active	Generally quite active
Conflict	Not usually	Not usually	Possibly esp. if reluctant participation OR options not palatable	Generally yes
NATURE AND PERCEPTION OF CURRENT SITUATION				
Threat	Variable	Variable	Moderate	Moderate-large
Where is control	Physician/higher power	Physician/higher power	Physician/themselves	Themselves/physician/higher power
Feeling of choice	Not usually	Not much	Yes	Want/demand choice
Importance of understanding & knowledge	Low - info threatening	Some - info minimally helpful	Important - info helpful & gives control	Critical - info helpful & gives control
Preference for technical info	No	Little	Some	Yes
Number of options & decisions	One	Generally one	Often more than one	Often more than one decision - may see more viable options than presented
Options	Not usually chemotherapy	Not usually chemotherapy	May mean chemo	Chemo often required
PATIENT/COUPLE/FAMILY FACTORS				
Usual patterns of family decision making	Generally passive. Did not involve other members OR women more independent	Generally somewhat passive	Mixed but often involved partner & family members	Generally rational & active problem solvers. Generally involved family
Communication patterns	Often not talkers or incongruent re need to talk about fears/emotions	Often not talkers or incongruent re need to talk about fears/emotions	Varied patterns	Usually both feel important to talk about fears
Private decision areas	Sometimes	Not as likely	No	Not as likely
Age	Generally older	Generally older	Younger	Younger
Education	Less	Less	More	More
PHYSICIAN FACTORS				
Confidence in physician	Yes	Yes	Generally	Less so - negative experiences
Nature of physician's style	More directive- presents material so no other choice seems reasonable	Less directive	Indicates it's their decision. Usually presents options with/without detail	Initially often directive indicating little choice
Whether physician involved family	Not usually	Perhaps	Perhaps	Perhaps
SATISFACTION WITH PROCESS AND OUTCOMES				
Whether satisfied with health care team & system	Yes	Usually	Varied	Often not - often changed physicians
Satisfaction with process	Generally good	Generally good	Mixed - negative if pushed to make decision but not prepared	Varied
Satisfaction with outcome	Generally good - some reservations	Generally good	Generally good	Mixed

The literature about treatment decisions and decision-making in the context of the family, however, is almost negligible. The purpose of this paper is, therefore, to highlight the process of family decision-making about treatment identified from a large study of family adjustment to early stage breast cancer.

Methods

This qualitative grounded theory study involved family interviews at five points over the first year - at diagnosis, and then three weeks, three months, eight months and 12 months post surgery/initial treatment. The families were encouraged to participate. For the purposes of this study, family was defined as at least two people who are emotionally involved with each other and live in close geographic proximity. Several families wanted adult children to participate and one even invited their close neighbours. Although the first part of the interview involved all of those present, the last part was for the couple. These interviews were tape recorded, later transcribed verbatim and analyzed using grounded theory methods as explicated by Strauss and Corbin (1990) (see Hilton, 1993 for further detail).

The sample consisted of 55 families, 41 where the women were partnered and 14 where they were single, separated, divorced or widowed. About half of these families had adult children, while a third had children living at home and a quarter had no children. In terms of age, about half were between 45 to 64 years with one quarter each being younger than 45 or older than 64. All women had been diagnosed with either stage I or II breast cancer, meaning that their cancer was localized or found in the lymph nodes but not beyond those nodes thereby giving them a good chance of no further recurrence. Almost 60% had lumpectomy or partial mastectomy while the remainder had mastectomy. Of the 49 women who had node dissection, 19 were node positive. A third each had radiation following their surgery, or chemotherapy with or without radiation, or no further treatment with or without tamoxifen. Two women had their chemotherapy and radiation prior to surgery. During the course of the first year, two women had recurrence, two had prophylactic mastectomy performed and five had reconstructive surgery.

Results

One of the major themes of family coping that emerged in the analysis was that of family decision-making. Different patterns were noted in the decision-making process about treatment. As well, particular factors influenced how families made the decisions, the nature of the decision process and the outcome. In terms of the factors that influenced the process, the nature and perception of the situation, patient, couple, family factors, physician factors and satisfaction with the health care team and system seemed influential. In terms of the nature of the process, the degree and type of patient and family involvement, the complexity of the process, the nature of the information search, the degree of weighing of pros and cons and the presence and source of conflict were major characteristics. Outcomes from the process, in turn, also influenced future decision-making processes (See Table One).

Four major patterns were evident in the process. These reflected, on one end of the spectrum "Defer to Physician" where the woman only or the couple or the family mutually deferred to the doctor, through to the other end of the spectrum where the woman and her partner with or without other family members took ownership of the decision and the process "Extensive Deliberative Examination". The other two patterns "Minimal Exploration" and "Joint Engagement" reflected increasing patient/family involvement done either voluntarily and eagerly or reluctantly. These patterns will be described as to their characteristics, together with some illustrative quotes from the transcripts.

"Deference to Physician"

Deferrers distinguished themselves in their passivity, showing negligible involvement in the decision-making process and clearly preferring that the doctor assume responsibility for the decisions. The process was primarily between the woman and her doctor. If the partner was involved, however, that involvement also reflected a deference style. These families did not complicate the process by asking questions, seeking information or second opinions. It was almost as if no decision was made - they went along with whatever the doctor directed, recommended or suggested without question

and there was no evidence of conflict.

The perception of recurrence or death threat varied in these families and body image issues were completely secondary. Deferrers acknowledged doctors as being in control or named a higher power, usually God. As their submissive attitude and their perceived lack of control would suggest, they did not see themselves as having much choice in their treatment decisions. Their need for understanding the health issues associated with their diagnosis was low, with technical information considered particularly undesirable. One got the impression that a number of them considered information threatening. This being the case, it is probably not surprising that deferrers generally only considered one surgical procedure and chemotherapy was generally not involved.

Consistently, these women and their partners who deferred to the doctors proved passive in their usual, pre-diagnosis communications as well, not involving members of the family in discussions. These families were not talkers in their daily interactions or they reflected differing needs from their partner about discussing fears and emotions (also see Hilton, 1993 about communication patterns). Sometimes these couples had private decision areas and these were mutually respected, so decisions about breast surgery, prosthesis, etc. were considered to be the woman's domain as explicated by one husband who said of his wife's decision: "It's her decision (about reconstruction) because it's her body."

These couples were generally older than the couples in the other groups and had generally enjoyed less education. Several of the widows used this pattern. These families expressed thorough confidence in and satisfaction with their doctors. Their doctors seemed to frame the option in a way that no other choice than his recommendation appeared reasonable. It did not seem that their doctors made any effort to involve the patient but particularly the family members in the decision process.

Deferrers sometimes had questions about the treatment or health care process, but expressed general satisfaction with it as well as with the outcomes. However it is noteworthy that a few had reservations, with a couple of women saying that in future they would be more involved in the decision process because they now questioned whether the right choice was made.

Generally, any additional treatment decisions were made by physicians with seemingly no input sought from or by the patient. One woman, however, told her physician she didn't want cobalt but she was quite comfortable going into surgery not knowing whether she would come out of it with a breast.

Typical quotes:

"There's no decision....I had to do it and that's it. I didn't ask if I had any options. I just did exactly what they told me....It never occurred to me that I had an option." Later "My doctor told me 'You'll never have trouble with the cancer again' and I don't think he would have said that unless it was true."

"Now whether or not there are other options, I am not aware of that. I have done a bit of reading, but there is a tendency, and it's true of my whole family -- just do it to me. Don't tell me what you're gonna do, just do it. I'm in your hands, God."

"I've resigned myself to whatever the surgeon says."

"Minimal Exploration"

Patients who fell into the "minimal exploration" pattern were also quite passive about their treatment, only involving themselves minimally and being generally doctor-directed. This decision process was usually straightforward, as these patients generally went along with the doctor's recommendation without searching for extra information, or being satisfied with very little extra information. Minimal explorers felt no need to seek second opinions and spent little time weighing the pros and cons of the decisions made, essentially, for them. The families of these patients talked about the treatment, listened to one another and did some reading to inform themselves. As this description suggests, minimal explorers, much like the deferrers, evinced little conflict throughout the decision-making process.

The degree of threat of recurrence or death perceived varied in this group and body image issues were generally, but not always, secondary. As in the previously described group, the doctor and a higher power were exclusively

named as being in control, leaving these patients to feel little choice in the treatment process. They did, however, find some information minimally helpful, though usually not of the technical kind.

Minimal explorers made only one decision and were usually only presented with one choice, or the options were presented in a way that the decision was obvious to them.

The usual family communication patterns of minimal explorers were somewhat passive, though not quite as passive as in the deferrer families. But still, they were not particularly active talkers or there were differing needs between the partners when it came to discussing fears and emotions. These families too tended to be older and to have enjoyed less education than the subsequent groups.

Decisions about other treatments such as chemotherapy and radiation were really non-decisions and were generally presented as such and not questioned. One woman, however, decided that she would prefer chemotherapy that would extend over a longer period of time and be less toxic to her than the short-term protocol. None of these women underwent reconstruction or prophylactic mastectomy and none seemed to have explored these as options.

As one would expect, perhaps, given their passivity, these patients had confidence in their doctors. Doctors in this category were seen to be less directive and somewhat more likely to try to involve the family in the treatment process. Usually this satisfied the patients, however satisfaction with the decision was not unanimous and it was noted that at least one patient who went for lumpectomy had second thoughts that perhaps she should have had a mastectomy and in future would want more clarification.

Typical quotes:

"We really haven't made those decisions. We just knew they had to be done. We never even considered changing anything that the doctor wanted to do. We just went along." Her husband said: "If you second guess what your professional tells you that's that, when you start having second thoughts or difficulties, and we went with their recommended treatment. It didn't require any decision on our part." She further adds: "We never even considered discussing any other treatment or waiting or having a second opinion or anything like that. I never even thought of it. I was just glad to get it over with. I knew it had to be done, so I just wanted to get it over with."

"The doctor said he would leave it up to the cancer clinic to decide about further treatment and they never said 'Do you want chemo and radiation or simply radiation?' That was not a question. They just put it to me that all I would need possibly is radiation."

"Dr. [X] told me about the choices and told me whatever choice I made was going to be the right choice because they have both been proven to be just as successful. Not one over another. It's an emotional thing. Some women feel that once they get rid of the whole breast that the whole problem is gone. Others....don't see it that way. I don't think of it as being my breast that's the villain or the bad part of my anatomy that's done this to me....having this breast doesn't make me any more who I am rather than not having it. That's never concerned me." Her husband said: "Having a body part removed when it really isn't necessary seems a little extreme when there's another option which is equally effective."

Another woman who didn't like drugs was told that she should have chemo. Her husband found it frustrating that medicine was not an exact science. One doctor presented chemotherapy as a type of insurance for women with negative nodes so she felt she had no choice but to have it. However, another doctor said it didn't make sense for her to have the "mild version (of chemotherapy) because that was like going out and washing only half the car. He told me....I needed to go the whole nine yards and lose my hair."

"Joint Engagement"

Patients who engaged in moderate, joint decision-making often went along with their doctor's recommendation, but usually only after consideration. This consideration took the form of a moderate search for information, may have involved a second medical opinion or the opinion of others and generally involved the family and a careful weighing of the pros and cons. The complexity of this process varied and was occasionally fraught with conflict with either the doctor or the family, particularly if the patient didn't want to make their own decisions, but preferred that the doctor do so.

This category of families perceived a moderate degree of threat of recurrence or death, still saw the doctor as in control of the treatment process, but listed themselves before a higher power. They felt they had more choice than patients in the previous two categories did and still considered body image issues secondary. As their greater involvement in the decision-making process indicates, they found information important and quite helpful because it gave them a sense of control. Thus, they saw knowledge as power and even desired some technical information.

These families generally had more than one option to choose from and many of them required chemotherapy. Generally, when they were told that lumpectomy was not an option, this was taken as fact. One woman in this group who was told this, however, did seek opinions of family, friends and another doctor before agreeing to the mastectomy. In fact, once they made up their minds, "I wanted it off as soon as I knew - right now. If [the surgeon] said I'll meet you in your kitchen in an hour and I'll do it on your kitchen table, I would have." In addition, as in the other groups, although there was little questioning of radiation or chemotherapy or whether nodes should be taken, there were some who did question these procedures. One woman declined radiation therapy because it would only decrease her chance of recurrence from 30% to 15% and she wanted radiation to be an option if she had a recurrence.

When it came to additional procedures such as reconstruction or prophylactic mastectomy, this was more where choice and weighing of pros and cons came in for the woman and her family and it involved a rational decision-making process.

Previous to their diagnosis, these patients had generally been problem solvers, with only a minority being passive in their commonplace family interactions. Although their communication patterns may be varied, these families tended to turn to one another more frequently for help and mutual aid and were unlikely to have private decision areas or taboo subjects.

Demographically, these families were younger and better educated than the previous two. They generally expressed confidence in their doctor, but not as consistently or to the same extent as deferrers or minimal explorers. The doctors in this category generally indicated that the final treatment choice was the patient's to make and so, usually presented options, either with or without detail. Their doctors were also fairly likely to attempt to involve the family or the family were insistent on their involvement in the process, but satisfaction with this process was inconsistent. The more a patient was pushed to make a decision, the more negatively they were likely to feel toward the decision-making process, so this category was characterized by distinctly mixed reviews of the process; however, the outcome was generally deemed good.

Typical quotes:

"I called my family doctor and we chatted and the surgeon asked if I'd like to go to the cancer agency and I said, 'Yes, that would be another opinion.' I have confidence in the surgeon, but I still wanted another expert's opinion. I went to the cancer agency and they agreed that this was the best way to deal with the situation, so that's how I dealt with it. The surgeon showed me pictures and we discussed a bit about reconstruction....so I felt I had enough information that I felt confident that this was the way to go. I haven't asked questions about the statistics for this kind of breast cancer. I talked to some friends. I phoned my friend who is a doctor, talked to my mother and my sister. {My husband} and I talked about the fact that I would have only one breast after this and he said he wouldn't mind."

"If I had a tremendous work problem, I might not have taken it as personally as I have this problem, but we (husband and

her) would still thrash it around. We would go out for a walk on the beach and really thrash it around and do positives and negatives and the implications of doing one thing versus another.... We would come to some kind of best decision or best process that we might use to solve that problem." In this situation, however, it initially began differently. In the operating room, she was told the results and recommended course of action to which she responded, "sounds reasonable to me, let's do it." On further deliberation, however, she realized that "I needed to be part of that decision....and appreciate that that was the best course of action for me." She phoned the surgeon and said: "I want to own that decision as well. I know that that's possibly the right decision that we've got to do, but tell me about it so I can own it because right now I'm not sure I own it." She asked if her husband could come in with her to see one of the doctors, but was told he probably wouldn't want to hear about it. Her husband was interested and they were particularly appreciative of their talk with the oncologist who involved them both. "He found it very useful because then he becomes part of the process. He's just not sitting out there having to cope with it and not being part of it." They were both active in reading and listening to large amounts of information and sharing it with each other.

A couple of families who were basically minimal explorers or perhaps even deferrers, were pushed by their doctors to become more involved in the decision process. They reluctantly became more involved with varying results. One family was particularly dissatisfied because they didn't feel that sufficient information had been supplied while another was perturbed because they had gone through a difficult process which could have been eliminated.

"The doctor said to Mom, 'Here are your alternatives. Go away and make a decision.' And what an extremely hard decision to make when you don't have a basis for comparison, like talk to this group, talk to that group, then make a decision....I think that's extremely unfair." Her mother (the patient) later said: "It's my fault that I didn't go any further because at that time I just didn't even want to dwell on going and doing any research. I wanted to have some time to think about it and I still am not sure that I made the right decision by going for a partial rather than a full, but I've signed the papers and I'm the one that has to live with that decision and, as your Dad said, it would be nice if there was someone right there to....pick up whether a patient wanted that information or not."

One divorced mother wanted to refuse chemotherapy but her teenage daughter was very adamant that she had to have it. "Whatever the doctor tells you to do - you do - I'd rather have you bald and here than hair and not here."

Although one woman who was initially classified as Stage II was reclassified later as somewhat more extensive, the comments made by her and her husband about the process are very poignant and are likely relevant for those with Stage I or II. She refused to participate in a clinical trial where a computer would decide the treatment because "it was too important to leave up to a heads or tails situation". They stressed that "too much is put on the patient to actually research the illness and possible ways of recovery. At first I was too fatigued to actually go out and do the research and I'm a little disappointed in the medical community. They have support groups, but I didn't feel I needed support groups. I wasn't feeling insecure in any way, however when you have a disease that I have and you are in the later stages, it's very different if you're in stage I, I mean they get the darn tumour and life is good after that - the statistics are great. I really wish they would give more than intellectual support groups to look at the various medical and non-medical ways to approach the illness rather than you as the patient having to go around to dig, to go to the naturopathic, to go to a library to read book after book after book and having to take the initiative to approach your oncologist and your surgeons and ask them for their opinions." Her husband said: "You should get courses on being sick - Breast Cancer 101 at the

community colleges." "They give you four pages on where to buy a wig and yet not one page on books to read about the illness." "Not just little pamphlets that really just slightly skim the surface....the consensus was that you had to go through the radiation and the chemo, no doubt about it, no matter what other options you decided for your treatment, those were necessary. But they don't go into anything beyond that, the vitamins, other drugs....a lot of physicians are taking a very, very conservative approach to the treatment and being a patient, once you've classified beyond stage II, I think you have to take a more aggressive approach because you're talking about the possibility of life and death and a shorter number of years whereas when you're looking at stage I or II you're actually talking about a cure of the disease....I've listened to the doctors, I've done the treatment, but there's no security in it. If I was to have a reoccurrence I would start looking at a lot of things that the physicians haven't made available to me."

In terms of making decisions about reconstruction and prophylactic mastectomy, her male surgeon asked what sports she did and said she should definitely go for reconstruction. He said, "You bend over to play tennis and people will know." She wasn't thinking of (reconstruction) at the time, but started more to think about it for appearance sake. She thought if she had the other one removed it would give her incredible advantage swimming. Her husband was supportive, whichever way she decided. "When I run, I really notice the other side bobbing up and down. It doesn't feel comfortable....I'm going to get both boobs done....so that they're a matching set."

"Extensive, Deliberative Examination"

Those families in this category chose extensive, active involvement in that they made a joint and generally quite complex decision-making process. They did not necessarily go along with the doctor's recommendation, but instead tended to question his whole approach. They engaged in extensive information searches, which were very likely to involve second opinions and the opinions of the family and other non-medical people. Conflict with doctors or family was the general rule.

These people seemed to perceive the greatest threat of recurrence or death. Body image concerns were generally secondary to their treatment decisions. Extensive examiners saw themselves in control of the treatment process, citing their doctors as the next strongest influence and higher powers, if they mentioned them at all, as last. These patients didn't just feel that they had some choice, they wanted choice, demanded it. They found an understanding of the process and diagnosis, particularly of technical information, critical to their decision-making and sought it out because it gave them a sense of control over the situation.

Invariably, these patients made more than one treatment decision and were presented with more than one option. Even if the doctor presented them with only one option, these patients and their families were likely to see more. In fact, they often felt the doctor was closing options off to them prematurely or in error. More often than in any other group, extensive examiners tended to require chemotherapy. The two women who had prophylactic mastectomy reflected deliberative, extensive examination styles of decision-making - probably not surprising. They weighed the pros and cons carefully so as to reduce the risk of future cancer. Although appearance was considered, one wanted reconstruction while the other clearly did not. The women were strong-willed and independent thinkers. In one case, a separated woman, where many in her family had died of breast cancer, had to fight for the surgery because the surgeon didn't want to do it. She got several opinions, talked with friends, talked with family. She found it difficult to make the decision by herself. The other woman, a wife and mother of two small children, was well supported by her husband in the decision to have a prophylactic mastectomy, but didn't consider reconstruction an option because "it wouldn't be her".

They were generally problem solvers and open in their communication and they involved the family in decisions. Both partners

in these families felt that it was important to talk about fears and concerns, free of taboos or areas which required strict privacy. These families tended to be younger and better educated.

Extensive examiners often had negative experiences related to the diagnostic process. A more deferring style initially was not satisfying because the problem persisted or results varied. They often had to fight to get diagnosed. It is perhaps not surprising that extensive examiners felt less confidence in their doctors as the decision-making process progressed. These patients often changed doctors, because the first had been too directive and offered too few choices and most likely had not sought the active involvement of the family. These patients, needless to say, were frequently dissatisfied with the medical team and system and with the process. Satisfaction with the outcome of their decisions was, however, also mixed. Generally, once they got on the right course they were more satisfied.

Typical quotes:

"In typical fashion, we wanted to read everything we could possibly find on the subject....I'm kind of ambivalent about that, because some of the material was quite frightening....At the same time, it was important for me to do that exercise. I must have had over a hundred books and I read and read and read....Once I knew what was wrong and I got the info and we figured out what they were going to do then I really felt in control and he was very helpful in helping interpret for me, listening for me, hearing stuff I didn't hear and once that happened I think we just saw it as a glitch that had to be taken care of."

One woman did not approve of the manner or plan of the surgeon to whom she had been referred. "We didn't feel that was the right decision for us, so I phoned the cancer clinic myself and I phoned another surgeon recommended to us. Since they didn't have any reports, I had the hospital fax the report and I picked up the mammogram files. I left a message on the [other doctor's] answering service, telling him to give me a referral for Dr. [X]. We felt very comfortable with her and we both sat down and talked to her."

"I'm having a little bit of difficulty with people out there making a whole lot of decisions about my life. Like they call and say 'We need blood work or we need you in, or we need this or we need that' and it's hard to feel that you're really a participant in the things that are happening to your body....The system is set up so that I should be the recipient of the decision, not a participant in the decision, and I have some trouble with that."

Discussion

Other studies that emphasized patient, not family, decision-making indicate that the majority of patients prefer to defer to their doctor's authority, that only a minority want a collaborative role and a smaller minority yet want an active role (Degner & Sloan, 1992; Pierce, 1993). This study found similar patterns but higher numbers of participants. Although about half of the families generally deferred decisions to their doctor, the other half participated reasonably to extensively in the process.

Pierce categorized women making decisions about their breast cancer surgery treatment into three distinct types: Deferrers, delayers and deliberators. Considerable similarity is evident in the decision-making patterns identified within families. In this study, although patients were usually more involved than their partners, often couples were quite congruent in their participation so that both either participated passively or actively. The family members, particularly partners, participated in a number of ways and found their involvement important to them. Some couples involved their teenage or adult children while others merely informed them of what was to happen or what had happened. Non-partnered women with teenagers were more likely to involve their children than partnered women. Widows were more likely to defer to their doctor.

Because little study has been done on family involvement, little comparison is possible; however, Ward and colleagues (Ward, Heidrich & Wolberg, 1989) did find that half wanted to share it with their physician,

spouse or other family members. In addition, although Ward found women who chose mastectomy wanted the decision to be fully their own and women who selected conservative treatment wanted to share the decision, this was not generally the case in this study. This study did find more active family participation when chemotherapy was indicated.

Generally, families had little difficulty making treatment decisions and expressed satisfaction with both process and decision. However, when conflict did arise, it was usually a conflict between the family and the health care system or health care professionals - most frequently the doctor - or between the expectations - particularly role expectations with the family. In both cases, the greater the similarity or compatibility in approach, style or expectation, the less conflict arose.

How the family perceived health care professionals and particularly the doctor's role in this decision was important. Many saw the doctor as the authority figure and accepted the doctor's choice/recommendation with little or no questioning as has been stated in other studies (Siminoff & Fetting, 1989). Although these families may have gathered some information and minimally weighed options, they generally engaged in little debate. Where decisions were made with little family input, it was generally believed that it was a woman's decision. Other families, although they saw the doctor as an authority figure, saw themselves as also having an active role in joint information gathering and in the weighing of options. A minority of families wanted even more control, usually when trust in their doctor or the health care system had been shaken. Problems arose, however, when the doctor wanted more patient and family participation than they wanted to give, when the family wanted more involvement than the doctor preferred, and when the doctor wanted greater patient/family ownership of the decision while the family didn't feel they had adequate information to make a decision.

Within the family, similarity of views and the presence of private decision areas often determined the amount of information shared by the partner. Little or no information might be shared between a couple which sees the decision as the woman's responsibility. On the other hand, partners and/or family members involved in seeking, collating and synthesizing information, actively listening and perhaps contributing views, may still have seen the decision as hers. Occasionally, conflict arose when family members, including teenagers and adult children, wanted considerable influence while the woman felt it was solely her decision. This was illustrated well the night before surgery in a Moslem family when the woman felt she might still be swayed out of surgery by a son who was adamant that she fight her cancer by prayer.

The findings were examined in terms of selected decision-making models. A family decision model by Scanzoni and Szinovacz (1980) describes decision-making as a process of joint rather than individual effort, determined by the disparities in the partners' gender role expectations, in their tangible and intangible resources as well as by the presence of third parties, by prior patterns of decision-making and by their place in the life cycle. They postulate that when both partners share traditional role expectations, they experience little decision conflict since each partner's purview is clearly defined. However, couples who share modern gender role expectations may require more time to reach consensus because their roles are not as clearly defined. In addition, they predict little conflict when the woman has traditional gender expectations while the husband has more modern expectations because it is assumed that the woman will comply with her spouse's wishes. However, their model predicts there will be stronger resistance and conflict when the husband has traditional role expectations and the woman has modern ones because he may expect deference where she demands consultation. Both these couples and traditional couples are less likely to use avoidance to cope. By extrapolation, Scanzoni's family model also predicts conflict when the role of child and parent is less well differentiated and the mother expects the teenager or adult child to participate fully or the child expects to be treated as an equal in the decision process. Such conflict was noted in this study particularly when divorced women had teenagers living at home.

To a great extent, pre-diagnosis communication and decision-making patterns were carried into the cancer situation, but with a notable bias toward increased passivity. Those who had been passive in the past usually continued that style, but a substantial number who had been more active deferred the treatment decision to their doctor, often because they felt they had no choice. A similar finding was noted in Beisecker's (1988) study

where younger patients, although they claimed more consumerist attitudes toward the doctor-patient relationship, did not act more consumerist in the doctor's presence. In this sample, however, younger couples were less likely to be passive participants than one might expect from studies on individual decision-making (Pierce, 1993; Blanchard et al, 1988; Cassileth et al, 1980; Beisecker, 1988; Ward et al, 1989).

Scanlon's model emphasizes how couples reach decisions out of disagreement rather than out of uncertainty which plays a far greater role in treatment decisions. What was seen instead was often a joint process which involved varying degrees of rational decision-making where the individual, couple or the whole family collected information and consciously deliberated and evaluated options and outcomes. Of course, as it was unlikely that all possible outcomes were considered objectively, if a decision was made it was more likely the first satisfactory alternative - generally the first and only option considered.

This process is explicated in the "satisficing" form of the rational decision-making models and illustrates the importance of option framing, i.e. whether information is presented in terms of survival or mortality. For instance, O'Connor (1989) found that cancer patients preferred more effective toxic treatments until the chance of survival fell below 50%, at which point quality of life became more salient than quantity of life. Other studies on framing were generally conducted with people imagining themselves to have cancer and therefore cannot be considered seriously (McNeil et al, 1982). In this study, framing was important. When asked to decide between lumpectomy with radiation and mastectomy, most people chose lumpectomy because they saw it as unnecessary to have more extensive surgery when equal success was cited for both procedures. Unlike Ward's and colleagues' study (1989), which indicated that women chose mastectomy to avoid radiotherapy, this study did not identify radiotherapy as a concern. However, similar to Ward, when given equal survival rates, women selected more conservative surgery over mastectomy, because of body image considerations.

Rational decision-making processes were more evident in decisions related to reconstruction and prophylactic mastectomy than to other treatment decisions. Decisions about chemotherapy and radiation therapy were based almost without exception, not on whether to have treatment, but where or perhaps what type of schedule to select.

Many families seemed to passively accept the information they got as though they would be told everything they needed to know. Lenz (1984) proposed that an active information search might not be considered necessary, if people felt that the needed information can be acquired passively.

Although some families did not want technical information, others found it helpful in their decision-making. Other studies have also cited that few patients found statistical information helpful in making decisions (Pierce, 1993). This pattern of information-seeking may be due to the threatening nature of the topic, unfamiliarity with the system and not knowing the appropriate information to get. Also, patients often feel thwarted when seeking information or clarification from physicians or nurses because of time pressures, lack of privacy or obstructive professional attitudes and norms regarding information giving. Because of this, informal and at times less than reliable and up-to-date information are used. The impact of information obtained from friends, colleagues, other cancer patients and informal sources may be insufficiently recognized by health care professionals. For example, Hughes (1993) found that choice of treatment was unrelated to the amount or manner of how information was provided to women making decisions about breast cancer surgery, but was related instead to the amount of information that the women had received from friends, relatives, the media and brochures prior to their first clinic visit.

The conflict rational model addresses the influence of stress and predicts that one option may be adhered to despite negative feedback (Janis & Mann, 1977). Redelmeier, Rozin and Kahneman (1993) concluded from their review of patient decision-making literature, which did not focus on cancer, that rational discussion with a patient about treatment options and associated statistics often does not lead to good decisions, nor does it guarantee satisfaction even with good decisions later. They suggested that health professionals should develop an understanding of the "pitfalls in [patient] reasoning and....the role of emotions"(p.75).

Implications

The findings provide important implications for nurses and other health professionals in facilitating decision-making for patients and their families and increasing their satisfaction with the process and their decisions. Although the emphasis in this analysis was the family decision-making about treatment in early stage breast cancer, it is likely that the findings are relevant to other cancer and illness situations and to other types of decisions. Therefore, many of the following interventions may also be relevant for these other situations.

The findings illustrate, for instance, that treatment decisions are usually not solely patient matters, but often involve the family, so nurses must recognize the importance of family involvement. Because families use different decision-making patterns, nurses can be more effective by identifying these patterns and gearing their interventions accordingly. Although families may use different patterns for different kinds of decisions, the patterns still provide some initial direction. Rather than aim a broad battery of interventions at everyone alike, particular sets of interventions are more effective for particular patterns.

Even though a substantial number of families prefer to defer to the doctor's authority, some defer because they feel that they have no choice. Therefore, health professionals need to make clear that there are options and need to provide simple and clear information on those options. Although most were satisfied, some women indicated they were not particularly satisfied with the process or the outcome and in future would want to be more involved in the process. Generally, those who were extensively involved in the decision had been very dissatisfied with health care professionals and the system.

Health care professionals need to be more aware of whether they are really making decisions for the client or whether the client is the real decision-maker. The strong influence of the health professional may not even be recognized by the professional (England & Evans, 1992). Sometimes we may think we are involving the patient and family but on closer scrutiny, the amount, type and way the information is presented denies choice. If we want the consumer to be involved, our strategies must change.

Understanding the importance of patient involvement, but being aware that many patients feel inhibited from asking questions or involving themselves, Neufeld, Degner and Dick (1992) devised the "Nursing Intervention Strategy", which sees the clinical oncology nurse as the facilitator between the physician and patient, encouraging the latter's involvement and at the same time ensuring that they are and feel responsible for this involvement. In this manner, the nurse helps to activate the patient's sense of control over the process and their commitment to making it work. The whole approach aims to create meaning in the confusion of the decision-making process - the truest sense of the word, an empowerment of the patient. This process could easily be extended to include family involvement.

Although the nurse should respect patients' and families' wishes regarding involvement, s/he should also keep in mind that many consumers believe medical science to be exact. Despite this, blind faith and the desire to defer, it is important that people be knowledgeable consumers, that they give informed consent, that they know how to get more information if they want it and that they feel comfortable contacting health professionals either for clarification or for discussion and assistance. Involvement does not have to mean complete immersion, but it does mean being sufficiently informed to feel the decision is theirs or is shared with the health professionals. Even though the doctor may see one option as clearly superior, reasons why other options should not be considered need to be given. Health care professionals, and particularly physicians, need to make their thinking processes more transparent to the lay person. Doctors who spelled out their train of thought and information about the options were particularly appreciated and this led to fuller understanding. Some families want to be very much involved so that they can be true "captains of their ship" or at least equal teammates. However, despite their best efforts, clients may perceive a failure to obtain the information they need, particularly from health professionals who hold erroneous views of what and how much patients and families want to know.

All consumers need accurate, readily available and clear information, information geared to them and presented in lay language. This information must be available in a variety of forms because some people find it difficult

to read about cancer, but might be open to talking about it. Often patients don't even know what questions to ask, so information needs to be meaningful to them. Many families indicated that this was not so and that this made the process even more difficult. Sometimes they were given large amounts of information which they were unable to sort, sift and weigh. Because many indicated that it was helpful to talk to someone who had already gone through a similar process, a listening ear may be all that is required. That is, more opportunity needs to be available for them to share concerns, etc. with "Reach to Recovery" volunteers who are similar to them, not only post-operatively but also pre-operatively.

Because recall of information is often problematic, nurses should consider taping sessions. This would allow patients and families to listen to it again and also to play it for others unable to be present at the session. Involvement of family members, particularly the partner, needs to be encouraged by inviting them into the discussions. A number of families indicated how helpful it had been for them to be part of the study, particularly because it gave them a forum to talk about the cancer situation together, but while it is important for family to have time together, it is equally important to provide opportunity for them to talk in the presence of a competent person to help them share their concerns and to clarify and correct misperceptions. Even when families feel that the ultimate decision is up to the woman, this does not necessarily mean that family members are not involved in the process in varying but important ways. Furthermore, although family wishes must be recognized and generally respected, eg. the presence of private decision areas, some families need assistance and permission to talk about these issues and to discuss and explore options.

Unfortunately, patients may have had little or no contact with nurses until they come into the hospital for surgery, when many decisions have already been made. Nurses could have a major role to play in this early, stressful period, but to date have generally not capitalized on this critical time period. Because of this, there is a need to tune in to how families are doing throughout, but particularly in the early phase. While family is obviously more visible in a home setting and perhaps appears easier to involve in the home, nurses must make a conscious effort to involve them more in the care in the hospital setting.

Often the public feels that it is imperative to move quickly when cancer is diagnosed and this perceived time pressure might lead them to blind

acceptance of what they are told. Although undue delay is not recommended, nurses can assure families that taking reasonable time to deliberate is not only appropriate, but highly recommended.

Although a minority of families sought second opinions as a way of getting fuller understanding, others did not, partly because this would imply a lack of trust in their doctor and could lead to repercussions. Time pressure was also a likely factor. Nurses can assist families to be more confident that obtaining other opinions is acceptable. In fact, in the United States, some states require that patients be given a choice and some insurance companies require that there be a second opinion (Ward et al, 1989). Although this increases the expense and may be too extravagant as a general procedure, it does normalize the process of obtaining information from several sources.

In addition to the implications for practice, these findings indicate many recommendations for further research, including exploration of decision-making when the cancer is more extensive, obtaining the perceptions of the process by the health care professional involved and comparing them with those of the patient and their families and identifying preferred family decision patterns and testing the effectiveness of identified strategies for that pattern.

In conclusion, the diagnosis of cancer is a stressor not only to the patient, but to the whole family. Making decisions under conditions of uncertainty can be harrowing, with long-term implications for both individual and family well-being. Nurses have a role in assisting families through this process, a role similar to that of a tug boat. The patient, together with their family, are captains of their ship, but nurses and other health professionals can help them navigate their ship to keep it on the selected course and off the rocks and hidden shoals. Let us navigate the seas together by being good tug boats and keeping the patient and family as captains of their ship!

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