CLINICAL ETHICS

Women's preferences for information and complication seriousness ratings related to elective medical procedures

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Objective: To study the preferences of patients for information related to elective procedures.

Methods: A survey was carried out using a sample of 187 women. The majority of whom were on a low-income, who obtained obstetric or gynaecological services at St Joseph Regional Medical Center in Milwaukee, Wisconsin, while they were in a waiting room.

Results: Many of the complications, including those that are uncommon and less serious, were considered to be relevant to the medical decisions of most patients. Average seriousness ratings associated with complications of various elective procedures were in the range of moderate to high. A frequency of complications of 1:100 or higher would factor into most women's elective treatment decisions. Women indicated a preference for receiving as much or more information pertaining to complications associated with particular elective obstetric or gynaecological procedures as other elective procedures.

Conclusion: Most women wish to be informed of risks and treatment alternatives, rate many complications as serious, and are likely to use information provided to make elective treatment decisions.

Informed decision-making is widely acknowledged as occurring when patients adequately understand their disease or condition, comprehend the treatment (including benefits, risks, limitations and alternatives), have identified their personal decision preferences and make decisions consistent with their preferences.¹ A well-documented variability exists in patients' understanding of how participation in decision-making may benefit them, preferences for information, decision-making styles, capacity to use data and ability to articulate preferences.²⁻⁸ For example, older adults, men and people with a lower income tend to express less desire for active participation in decision-making than younger people, women and people who are more financially stable.⁹⁻¹⁰ Despite this variability, the available literature generally suggests that most patients wish to be fully informed, with a considerable number of patients feeling dissatisfied with the amount of information provided.¹¹ Evidence also indicates that patients who are more severely ill are less inclined to choose informed decision-making than those patients who are less severely ill,^{4,12} suggesting indirectly that patients considering an elective medical procedure may have the greatest desire for information and participation in decision-making.

Given that very little previous research has explored patients' preferences for information pertaining to elective medical procedures, this study focused primarily on them. Although most data collection dealt with patients' preferences for information regarding elective procedures in general, they were also specifically asked to rate their desire for information relative to four specific obstetric or gynaecological elective procedures in relation to their general preferences. Patient perceptions of the seriousness of a wide range of physical and mental health risk factors relative to elective procedures were also examined.

METHODS

Participants

Women who were seeking obstetric or gynaecological services at St Joseph Regional Medical Center in Milwaukee, Wisconsin, were approached while they were in the waiting room and asked to complete a short survey during a period of

a few weeks in 2004. Consent to participate was high (97.3%). More specifically, the participants included a sample of 187 patients between the ages of 15 and 62 years (mean 31.62 (SD 10.9)); 32.6% were ≤ 24 years of age, 34.8% were between 25 and 34 years of age and 32.6% were ≥ 35 years of age. Most patients reported that they were on low incomes (61%), with the remainder reporting average incomes (36.6%) or high incomes (2.5%). With regard to education, 52% had ≤ 12 years of formal education and 48% had between 13 and 19 years of formal education. Most of the patients had been to visit a healthcare provider fewer than four times in the past year (66.5%), 28.6% had visited a provider between 4 and 20 times in the past year and 4.9% reported more than 20 visits.

Procedure

The Institutional Review Board of the Medical Center, where the data were collected, approved the study. After the patients consented to participate, they were given a survey while in a waiting room. The survey contained the following sets of items:

1. Demographic questions (5 items)
2. General questions related to preferences for information regarding alternative treatments and risk of complications (2 items)
3. Ratings of the importance of specific forms of information (risk of complications, likelihood of success, cost if not covered by insurance, cost if covered by insurance) in deciding whether or not to seek an elective treatment designed to improve quality of life (4 items)
4. Ratings of the seriousness of a wide range of physical and mental health complications relative to elective treatments (25 items), some of which were qualified by the duration of symptoms or by the percentage of increased risk to assess the impact of such qualifying information on seriousness ratings (10 items)
5. Assessments of the frequency rate of complications necessary to impact patients' decisions regarding a particular elective treatment (4 items)
6. Assessments of the importance of complication or risk information regarding obstetric or gynaecological procedures

Table 1 Desired information regarding treatment alternatives and complications

Item	Response percentages
Level of information desired when a doctor recommends a drug, surgery or other treatment	Informed of all alternatives, 69% Informed of only alternative treatments, 25%; endorsed by the doctor as offering a reasonable balance among effectiveness, cost and risk Follow doctor's recommendation without discussion of alternatives, 6%
Level of information desired regarding complications of a drug, surgery or other treatment recommended by a doctor	Only most serious complications, 1.7% Only most common complications, 2.2% All possible complications, 95.0% Follow doctor's recommendation without discussion of risks, 1.1%

(sterilisation or tubal ligation, treatments for infertility, abortion, spinal block for pain during delivery) compared with other elective procedures (4 items)

Tables 1–5 show the details of specific survey items.

RESULTS

The results of two general questions related to preferences for information regarding alternative treatments and risk of complications relative to medical interventions in general showed that most women wanted to be informed of all alternatives and preferred to be informed of all known complications (table 1).

The next section of the survey dealt with ratings of the importance of specific forms of information (risk of complications, likelihood of success, cost if covered by insurance and cost if not covered by insurance) in deciding on an elective treatment. The results are presented in table 2 and showed a high level of endorsement for information regarding each form of information. A multivariate analysis of variance was conducted, using age and education as independent variables and specific forms of information (risk of complications, likelihood of success, cost if covered by insurance and cost if not covered by insurance) as dependent variables was conducted. None of the multivariate effects was significant, precluding exploration of univariate effects. Finally, in a set of exploratory correlational analyses, no significant associations were detected between the number of times in the past year the respondents had received medical

attention and their ratings of the importance of the above four forms of information in elective treatment decisions.

Table 3 shows the summaries of ratings of the seriousness of a wide range of physical and mental health complications relative to elective treatments. The results indicated that physical complications like headaches and muscle aches received moderately serious ratings, mental health complications received moderate to high seriousness rating and potentially life-threatening complications received the highest seriousness ratings. Also as indicated in the table, when qualifying information in the form of the duration of the complication or when presenting the complications of the per cent of increased risk, discernable differences were detected between the more and less severe forms of each complication.

Table 4 shows the results pertaining to assessments of the frequency rate of complications, which is necessary to make a decision regarding a particular elective treatment on the basis of seriousness ratings. Ratings of the seriousness of complications did not seem to strongly influence the ratings of the frequency of complications, frequency necessary to impact decision-making. For most women who were sampled, a frequency rate of complications of 1:100 or higher would factor into their decisions regarding elective treatments with complications that were rated as not very serious, moderately serious and highly serious. One follow-up item to this assessment asked patients to rate the percentage increased risk that would be relevant to their decision whether to undergo an elective procedure if the complication was one that they had rated as moderately severe and it lasted for 6 months or more. The results indicated that for 36% of the sample an increased risk of 10% would be sufficient to influence their decision, for 18.5% of the sample an increase risk of 25% would be necessary to influence their decision, for 27% of the sample it would take an increased risk of 50% to influence their decision and for the remainder of the sample (18.5%) a 100% increase in the likelihood of the complication occurring would be necessary to influence their decision.

Participants were further asked to rate the importance of complication or information on risk regarding elective obstetric or gynaecological procedures in comparison to other types of elective procedures. The results indicated that the average respondent preferred to have as much or slightly more information relative to the obstetric or gynaecological procedures than elective procedures in general (table 5).

DISCUSSION

This study was undertaken to pursue the following objectives:

1. To measure female patients' preferences for information regarding elective medical procedures
2. To assess how seriously women viewed a wide range of possible complications associated with elective medical procedures
3. To compare women's preferences for information related to elective obstetric or gynaecological procedures with other elective procedures

Table 2 Ratings of the importance of specific forms of information in deciding on an elective treatment to improve quality of life

Item	Mean	SD	Observed range
Risk of complications	9.27	1.50	2–10
Likelihood treatment would be a complete success	9.20	1.50	3–10
Cost of treatment if covered by insurance	7.36	2.86	1–10
Cost of treatment if not covered by insurance	8.56	2.13	1–10

Potential range of scores was from 1 (not at all important) to 10 (very important).

Table 3 Ratings of the seriousness of possible complications of elective treatments

Complication	Mean	SD
Unqualified indication of complication		
Death	9.76	0.81
Heart disease	8.98	2.07
Stroke	8.93	2.13
Suicidal thoughts	8.71	2.37
Pneumonia	8.64	2.09
Pelvic inflammatory disease	8.61	2.32
Psychiatric hospitalisation	8.56	2.29
Miscarriage	7.82	3.04
Sexual dysfunction	7.74	2.69
Anxiety	7.54	2.47
Infertility	7.14	3.20
Insomnia	7.04	2.53
Negative emotional reactions	6.71	2.69
Constipation or diarrhoea	6.50	2.59
Nightmares	6.20	2.34
Qualified indication of complication		
A 50% increased risk of cancer	9.23*	1.97
A 5% increased risk of cancer	8.49*	2.36
Depression for several months or years	9.01†	1.91
Depression for several weeks	8.08†	2.31
Muscle aches for 1 year	8.50‡	2.09
Muscle aches for 1 week	6.37‡	2.72
A 20% increased risk of infertility	7.14§	3.20
A 1% increased risk of infertility	6.01§	3.29
Headaches for 2 weeks	5.70¶	3.08
Headaches for 2 days	5.44¶	2.91

The potential range of scores was from 1 (not at all serious) to 10 (very serious) and the observed range on all variables was from 1 to 10 on all variables except death, which had an observed range from 5 to 10. Percentage increase in means on the basis of more severe qualifying information: *, 8.7%; †, 11.5%; ‡, 33%; §, 18.8%; ¶, 4.8%.

4. To explore the possible age and education differences in desired information related to complication risks, likelihood of treatment success and cost pertaining to elective treatments

The available literature suggests that most patients wish to be fully informed of risks associated with medical treatments.¹¹ The results of this study strongly support the conclusion that patients, particularly women considering an elective treatment, generally wish to be provided with a very

complete picture of risks associated with medical treatments, even if the risk is relatively uncommon or minor. Most of the women reported low incomes and the results contradict previous research suggesting that people with lower incomes tend to be more passive and lack interest in informed decision-making.¹⁰ No age or education differences in desired information related to complication risks, likelihood of treatment success and cost pertaining to elective treatments were detected.

Average seriousness ratings associated with all the possible complications were above 5 on a scale of 1 to 10, even for the least serious headache lasting for 2 days. Interestingly, perceptions of mental health complications were quite high, ranging from a low of 6.71 for negative emotional reactions to a high of 9.01 for depression. Moreover, the average woman sampled indicated that she would like to receive as much or more information related to complications associated with sterilisation or tubal ligation, infertility treatments, abortion and spinal block for pain during delivery than to other elective procedures.

The findings of the present study have obvious implications for doctors. Doctors should anticipate that most women desire information on every potential risk, even risks that doctors may judge to be less serious or inconsequentially rare, and they will generally consider this information to be relevant to their decisions regarding elective procedures. Supplying adequate information to patients and ensuring that proper informed consent is obtained may require improved and expanded means of disseminating risk information through written pamphlets and or internet-based mechanisms. Innovative means of informing patients should be explored more ardently in the future.

This study was limited in terms of the relatively small sample, the restricted geographical locality and oversampling of women with low incomes, all of which restrict the generalisability of the findings. More research employing large nationally representative samples is needed and comparisons should be made regarding patients' preferences for information related to elective procedures. Future research may also compare patients' preferences for information related to treatment against elective procedures. Finally, further work on patients' preferences for information and

Table 4 Frequency rate of complications necessary to make a decision regarding a particular elective treatment rated on the basis of seriousness ratings

Rating	Frequency rate of complications	Percentage	Cumulative percentage
If a particular complication was given a seriousness rating of 1–3	1:100000	12.1	12.1
	1:10000	4.5	16.6
	1:1000	15.3	31.9
	1:100	12.7	44.6
	1:50	14.0	58.6
	1:10	41.4	100
If a particular complication was given a seriousness rating of 4–7	1:100000	8.2	8.2
	1:10000	8.9	17.1
	1:1000	8.9	26.0
	1:100	15.2	42.2
	1:50	19.6	60.8
	1:10	39.2	100
If a particular complication was given a seriousness rating of 8–10	1:100000	15.2	15.2
	1:10000	3.8	19.0
	1:1000	9.5	28.5
	1:100	6.3	34.8
	1:50	12.7	47.5
	1:10	52.5	100

Table 5 Importance of complication or information on risk regarding elective obstetric or gynaecological procedures compared with other elective procedures

Elective procedure	Mean	SD
Sterilisation or tubal ligation	2.51	0.63
Infertility treatments	2.39	0.72
Abortion	2.05	0.85
Spinal block for pain during delivery	2.31	0.65

Potential range of scores was from 1 to 3: 1, less information; 2, same amount of information; 3, more information, and the observed range on each variable was from 1 to 3.

interpretations of the seriousness of various complications should explore possible differences based on other socio-demographical characteristics such as marital status, ethnicity or religiosity, as well as personality variables.

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