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Risk communication in consultations about hormone therapy in the menopause – concordance in risk assessment and framing due to the context


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2,643 words, 2 tables, 0 figure
Abstract

Background

It is important for the physician and the patient to have a mutual understanding of the possible consequences of different treatment alternatives in order to achieve a partnership in decision making.

Objective

The aim of this study was to explore to which degree first-time consultations for discussion of climacteric discomfort achieved shared understanding of the risks and benefits associated with hormone therapy in the menopausal transition (HT).

Methods

Analysis of structure and content of transcribed consultations (n=20), and follow-up interviews of the women (n=19 pairs of consultations and interviews), from first-time visits for discussion of climacteric discomfort and/or HT with five physicians at three different outpatient clinics of gynaecology in Sweden.

Results

Four distinctively different interpretations of risk, depending on whether or not benefits were discussed in the same context, emerged from the analysis. On average 5 advantages (range 0-11) and 2 (0-3) disadvantages were mentioned during the consultations. In the interviews the women expressed on average 4 advantages (0-7) and 1 disadvantage (0-3). There were major variations between advantages and disadvantages expressed in the consultation and the following interview.
Conclusion

Even though the consultations scored high in patient involvement, the information in most consultations was not structured in a way that made it possible to achieve a shared or an informed decision making.

Keywords

Risk
Risk assessment
Communication
Physician-Patient Relations
Professional-Patient Relations
Introduction

Today the relationship between patients and health care professionals is changing into a more active partnership, often with the goal of achieving either **shared** or **informed decision making**\(^1\). Central for partnership in decision making is a concordance in knowledge of outcomes to expect from different treatment alternatives\(^2\).

The understanding of risks and benefits associated with different alternatives is pivotal in this discussion. The concept of risk differs, from individual to individual, from situation to situation, and from the societal to the individual perspective\(^3\). In a consultation in health care the concept of risk is even more compounded by choices between different treatments, including the choice not to treat, with different pros and cons and different uncertainties. Qualitative studies have shown that most consultations do not fulfil even basic criteria for involving the patients\(^4\text{-}^9\). In addition, there is a lack of consensus on how to measure patient involvement\(^10,11\).

Few consultations seem to address the pros and cons of different alternatives and/or the uncertainties associated with them. This is true even when otherwise healthy patients have to understand and balance long-term risks and benefits, such as in treatment of hypertension, or hormone therapy in the menopausal transition\(^5,12\text{-}14\). The observed major differences between patients' and physicians' estimation of risks associated with the disease and the benefits of treatment might be explained by this\(^4,15\).

A lot of attention has been paid to different ways of discussing risk with patients. Several aids for conveying risk level have been suggested such as standardized language; strictly numerical expressions; choice of numerical expressions (absolute and relative differences or number-needed-to-treat/number-needed-to-harm); frequency with which an outcome occurs in
a certain cohort size; the so called safety-degree scale (with the logarithm of the cohort size in which one adverse event would be expected to occur); the average loss of life expectancy from a given exposure; or risk-age (the age at which the patient would have the same total risk given that he/she did not have the risk factor discussed)\textsuperscript{16}.

Several different strategies for overcoming the difficulties of risk communication in a medical consultation have been described\textsuperscript{2,17-19}. A systematic review of articles indexed in MEDLINE concluded that there is a paucity of evidence of the most effective way for physicians to share clinical evidence with patients facing decisions, and that studies of decision aids rarely addressed patient-physician communication directly\textsuperscript{19}.

Framing due to different presentation format has been discussed extensively. Less attention has been given to context framing, i.e. whether the risk is presented in isolation, in association with other risks associated with the same or other treatment alternatives, or in association with possible benefits. The aim of this study was to explore to which degree first-time consultations for discussion of climacteric discomfort achieved shared understanding of the risks and benefits associated with hormone therapy in the menopausal transition (HT).

**Methods**

Twenty-one women, aged 45-59 years, were recruited from three clinics of gynecology in 1999-2000. One clinic was an out-patient clinic of gynecology at a large teaching hospital; the other two clinics were community-based. All three clinics provided health care to the general public without requiring a physician referral. The study protocol was reviewed and approved by the local ethics committee of the University of Linköping.

The women were consecutively identified through a manual search of the appointment lists for 5 gynecologists (2 male, 3 female) who agreed to participate in a study about risk
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communication. The physicians were selected through convenience sampling and were informed about the objective of studying risk discussions but were asked to use their usual strategy. Women, who had a scheduled consultation for a first-time visit for discussion of climacteric discomfort and/or hormone therapy in the menopausal transition (HT), were identified consecutively and invited by letter to participate in a study about risk communication. Before the consultation, each woman met one of the investigators (LLÅ) who explained the study and asked for the woman’s consent.

Both the consultations and the subsequent structured interviews were audio-taped, except during the gynecological examination. They were then transcribed in a broad transcription format capturing pauses and verbal support. The interview was conducted immediately after the consultation by one of the authors (LLÅ). Several differently formulated open-ended questions exploring the women’s perception of risks and benefits associated with the menopause and HT were used.

The transcriptions were compared and validated against the tape-recordings by three of the authors (LLÅ, MiH and KK) independently. The analysis of the material was performed on the actual tape recordings. The transcriptions were used as a support for identifying and arranging structures with the help of QSR NVIVO® (version 1.3.146, Qualitative Solutions & Research Pty. Ltd.), a computer software specifically designed for this purpose. Quotations in this article were translated from Swedish by a professional translator with English as his native language and with the verbal support from the other participant of the consultation put in brackets.

Interview data were analyzed by two of the investigators (MH and KK), working together. Classification of different benefits and risks associated with HT in the consultations and in the
interviews was done by MH. The result was independently validated by KK. The inter-
observer agreement was good (Cohen’s kappa 0.78).

Results

Twenty-six women were contacted. Out of these four were willing to participate but a suitable
time for the consultation, including audio-taping and interview, could not be arranged. One
woman refused to participate. One consultation and one interview could not be analyzed due
to technical reasons. In total, twenty consultations, and nineteen pairs of consultations and
interviews, were analyzed. The audio-taped parts of the consultations lasted between 15 and
25 minutes, with two exceptions lasting 32 and 43 minutes, respectively.

One of the women included had tried HT for a short period during a blinded clinical trial three
years before the consultation. The structure and content of the consultations, as well as the
fact that the consultations scored high on criteria for informed consent, have been presented
elsewhere\textsuperscript{14, 20}.

The discussion of risk comprised on average 21 \% of the consultations (median 652 words,
range 0-2688) with a ratio between physician and woman of 4:1. In total, the word risk (plus
its compounds such as “risk factor”) was used 102 times in the consultations with a
physician/woman ratio of 12:1. Decision aids such as printed material or multimedia
presentations were not used, neither before, nor during or in direct connection with any of the
risk discussions and prescriptions. In nine cases, a leaflet was handed over together with, or
immediately after, the prescription. The actual content of the leaflet was not referred to by
verbal cues in any of the consultations. HT was prescribed in all consultations. In three of the
consultations the physician prescribed HT even though the woman was indecisive or reluctant
to use HT, and with the expressed intent that the woman should make her mind up after the consultation.

Four distinctively different interpretations of risk, depending on whether or not benefits were discussed in the same context as risks, emerged through the analysis of the transcribed material. These interpretations were named assigned risk (risk\textsubscript{A}), balanced risk (risk\textsubscript{B}), compared risk (risk\textsubscript{C}), and risk difference (risk\textsubscript{D}). Table 1 shows the relationships between the different interpretations of risk discussion, and in how many consultations the different ways of discussion risk were used. Several different interpretations of risk could be used in one consultation. Risk\textsubscript{A} describes the simplest way of communicating a risk. This is where the risks associated with a specific alternative are presented without reference to other alternatives, including inaction. It is termed assigned risk to emphasize that it is a personal choice, conscious or unconscious, which values are attached to, and what type of function of probability and consequence, an individual uses in a specific situation.

Pat 7 Ye-es. I have this picture in my head of estrogen and the cancer risk ...

Risk\textsubscript{B}, or balanced risk, is when the assigned risk, risk\textsubscript{A}, is discussed in the same context as the possible benefits of one alternative in isolation.

Dr A And the thing is that it has both advantages and disadvantages (hm hm) The biggest disadvantage is that there is a bit larger risk of getting breast cancer compared with other non-treated women ...

... (6 rows omitted)

And if you put the disadvantages on one side
of a pair of scales and the advantages on the other, the advantages clearly outweigh the disadvantages.

Table 1: Risk discussion in consultations

Relationship between different interpretations of risk, depending on whether or not benefits were discussed in the same context and the number of consultations with at least one instance classified according to this. Total number of consultations = 20.

<table>
<thead>
<tr>
<th></th>
<th>Discussion of risks only</th>
<th>Discussion of risks in the same context as benefits</th>
</tr>
</thead>
<tbody>
<tr>
<td>One alternative in isolation</td>
<td>risk_A</td>
<td>risk_B</td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>18</td>
</tr>
<tr>
<td>Comparison between alternatives</td>
<td>risk_C</td>
<td>risk_D</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>4</td>
</tr>
</tbody>
</table>

When the assigned risk is discussed for more than one alternative at once, the risks are compared to each other, compared risk, risk_C.

Dr A Yes. Oh, yes! Oh, yes! It´s the same effect

(Hm) The difference between the two treatments is that the estrogen from the
plaster, it doesn’t go through the liver before having effect.

... (3 rows omitted)

So if you’ve got a problem – something about the liver to consider then it can be dangerous (Yes yes) But for most of the patients it doesn’t matter.

A discussion of balanced risks, the risks and benefits associated with more than one alternative, we have defined as risk difference, risk_D.

Dr C ...

And to sum up when it comes to estrogen, the... the advantages clearly outweigh, medically speaking, the disadvantages (Hm) but what is most important is that you feel comfortable with it. (hm hm)

And what else can one do? If you don’t take estrogen for what you are describing. (Hm) So we know that exercise alleviate flushing - but I suspect that you do.

... (12 rows of discussion of the beneficial effects of exercise omitted)

And having a little subcutaneous fat is good, and that you don’t have. But women who have a bit more subcutaneous fat, estrogen is formed there. They often have less menopausal problems. (Hm hm) Hm hm!
For classification of comparison between alternatives (riskC and riskD), at least one alternative treatment/strategy had to be mentioned in the risk discussion.

The benefits and risks mentioned in consultations and interviews of the women are listed in table 2. In both the consultations and the interviews an effect on the general well-being, reduced incidence of hot flushes, and a beneficial effect on both osteoporosis and on cardiovascular diseases, were the most commonly described benefits. The most common disadvantage discussed was breast cancer. On average 5 advantages (range 0-11, median 4) and 2 (range 0-3) disadvantages were mentioned during the consultations. In the interviews the women expressed on average 4 advantages (range 0-7) and 1 disadvantage (0-3).

**Discussion**

In Sweden hormone therapy in the menopausal transition is most often initiated and followed-up by specialists in gynaecology at out-patient clinics. The consultations in this study might be considered best-case scenarios. The participating women were healthy, had initiated the consultation, had a clearly defined problem known beforehand, and both women and physicians volunteered to participate and were informed about the nature and objective of the investigation. There was also ample time to address the issue of HT. Still, there were major variations in the information given, and how it was structured\textsuperscript{14, 20}.

In more general discussion of the pros and cons of a given treatment alternative, for instance a pharmaceutical, the term benefit-risk ratio is often used\textsuperscript{21}. Risk can be seen either as the probability of an adverse event (absolute or relative risk as for instance used in epidemiology), or as a function of the probability of an adverse advent and the consequence\textsuperscript{22}. The lay person's anticipation of future events differs however often from the opinion of experts\textsuperscript{23, 24}. This is not surprising since most of our daily decisions are based on insufficient
Table 2: Benefits and risks expressed in consultations and interviews

Classification of different benefits and risks associated with HT mentioned and agreed upon in the consultations, and expressed by the women in the interviews (C = consultation, P = patient interview). Number of pairs of consultations and interviews = 19.

| Physician | A | A | A | A | B | B | B | C | C | C | C | C | C | D | E | E | E | E | E | Mentioned in consultations | Mentioned by woman in the interview |
| Woman     | 1 | 2 | 6 | 13| 3 | 7 | 10| 4 | 5 | 9 | 11| 15| 16| 8 | 17| 18| 19| 21|-----------------------------|----------------------------------|
| Advantages|   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |------------------------------|----------------------------------|
| Insomnia                             | W | W | W | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | 3| 4 |
| Vertigo                              | W | W | W | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | 7| 0 |
| Dementia, memory, ability to concentrate | W | W | W | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | 8| 2 |
| Uterine & ovarian cancer             | W | W | W | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | 2| 0 |
| Palpitations                         | W | W | W | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | 3| 3 |
| Skin                                 | W | W | W | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | 7| 2 |
| Arthralgias, stiffness               | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | 7| 3 |
| Dry eyes                             | W | W | W | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | 7| 2 |
| Gastrointestinal discomfort          | W | W | W | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | 7| 2 |
| Osteoporosis                         | W | W | W | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | 7| 2 |
| Teeth                                | W | W | W | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | 7| 2 |
| Looseening of the teeth              | W | W | W | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | 7| 2 |
| Other & unspecified advantages       | W | W | W | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | 7| 2 |
| Disadvantages                        |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |------------------------------|----------------------------------|
| Breast cancer                        | W | W | W | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | 15| 13 |
| Uterine cancer                       | W | W | W | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | 7| 3 |
| Thrombosis                           | W | W | W | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | 8| 5 |
| Other & unspecified disadvantages    | W | W | W | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | C | 8| 5 |

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data about the probabilities for alternative outcomes, thus leading to simpler algorithms for risk-benefit estimation in daily life. The different perspectives of a policy-maker and an individual directly concerned by the situation might also be one of several explanations for the observed discrepancy between medical decisions made by physicians for groups and individual patients\textsuperscript{25, 26}. The discrepancy has given rise to the often questioned distinction between “objective” (sometimes referred to as “scientific”) risk and “subjective” (or perceived) risk\textsuperscript{27}.

The perceived personal risk is also likely to be influenced by the acceptability of the risk, for instance if the risk is a consequence of a voluntary action\textsuperscript{28}. According to Slovic, the different risk factors can be grouped into at least two dimensions - dread risk and unknown risk\textsuperscript{29}. Risk assessment is further complicated by different heuristics and biases used by both patients and health care professionals\textsuperscript{3, 30, 31}.

An important distinction in risk communication is whether the communicated risk assessments are general probabilities applicable to a population group, or an estimation of the personal risk level. There is a tendency, also among women in the menopause, to view population risk as something that might happen to other people\textsuperscript{32, 33}. A personalised risk assessment might thus be more effective in influencing the complex decision-making process by involving the patient in translating population-based estimates of probability into a personal risk, including the patient’s own attitudes and beliefs\textsuperscript{34-36}.

Differences in addressing risk, depending on the context (i.e. benefits and/or other treatment alternatives) were identified in the analysis of the risk communication. A separate system of classifying risk communication depending on the context was developed in order to better understand the structures of the consultations, the different communication strategies of the physicians, and the understanding by the women of the benefits and risks with HT. The
classification was important in understanding and describing different communication strategies\textsuperscript{14}, but it’s usefulness has to be validated in another set of consultations.

The dominating way of discussing risk in the consultation was balanced risk, i.e. the risks were discussed in the same context of the possible benefits but for one alternative in isolation. This kind of risk discussion occurred in all 18 consultations where risk discussion was identified. One possible explanation for this dominance of risk might be that the decision of whether or not to treat with HT had already been made, either by the physician and/or the woman.

As expected, the variation in how the women described the benefits and risks with HT after the consultation was high. This is not surprising since the women had different symptoms, different preconceived conceptions of HT and of drugs in general, were in different social situations, and had different cultural backgrounds. When studying the information content of the consultations it is obvious that the consultations in most cases were not structured in a way that made it possible to achieve a shared or an informed decision making (14).

The consultations and interviews took place before the results from the Heart and Estrogen/Progestin Replacement Study follow-up study (HERS II)\textsuperscript{37}, the oestrogen and progestin trial of Women’s Health Initiative (WHI)\textsuperscript{38}, as well as the Million Women Study\textsuperscript{39} were published. This explains why two of the most commonly expressed advantages with HT in the consultations and the interviews were a preventive effect on cardiovascular diseases and on the development of osteoporosis.

Concordance in risk assessment rests not only on discussing and conveying levels or probabilities but also on exploring the different attitudes and beliefs of the patient and the health-care professional\textsuperscript{15}. The lack of concordance between the content of the consultations,
and the women’s expressed perception of benefits and risks with HT directly after the consultation, might be one of the explanations why so many women choose not to use their prescribed HT\(^4^0\). A common feature of the studied consultations was that decision aids were not used. Decision aids have been shown to be effective both in transferring knowledge and in enabling patients to participate in decision-making without increasing their anxiety\(^4^1\). In order to realize the potential of decision aids to help patients to understand the consequences of different treatment alternatives better, they have to be used in a structured way together with the patient before, during, and if possible in a follow-up of the consultation.

**Conflict of interest**

None.

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