

ORIGINAL ARTICLE

Awareness of risk of osteoporosis may cause uncertainty and worry in menopausal women

LOTTE HVAS¹, SUSANNE REVENTLOW¹, HANS L. JENSEN¹ & KIRSTI MALTERUD^{1,2}

¹Central Research Unit and Department of General Practice, University of Copenhagen, Panum Institute, Denmark, and

²Section for General Practice, Department of Public Health and Primary Health Care, University of Bergen, Norway

Abstract

Aims: A study was undertaken to explore how menopausal women are affected by awareness of potential risk of osteoporosis. *Methods:* A qualitative interview study, including analysis of in-depth interviews with 17 women who independently gave views on risk, out of 24 women interviewed about their menopausal symptoms. The women were selected on the basis of a survey including 1261 women chosen at random, to cover a broad spectrum of Danish women, their menopausal experiences, and contact with the healthcare system. The study was part of a larger project targeting menopause. *Results:* Awareness of osteoporosis risk caused a feeling of uncertainty and worry in some women. Only women reacting in this way seemed to act in order to prevent future fractures. The affected women were puzzled to realize that risk-reducing medication could introduce new hazards. Most of the women had heard about osteoporosis related to menopause as culturally embedded knowledge. *Conclusions:* Making individual women uncertain and worried must be considered a potentially serious side effect of health promotion. The findings raise the question of whether introducing healthy people to the threat of future diseases is ethically justifiable. As hormonal treatment is no longer recommended for long-term use, it is suggested that the strong link between osteoporosis and menopause should be toned down when counselling menopausal women.

Key Words: *Awareness, communication, counselling, family practice, menopause, osteoporosis, qualitative research, risk, uncertainty*

Background

The most recent decades have seen a growing interest in osteoporosis in relation to menopause, and information on the risk of osteoporosis is communicated to menopausal women by doctors, the media, and advertisements. For years it has been advocated that it is necessary to find and inform those who may be at risk in order to motivate them to accept lifestyle changes or fracture-preventive medication. However, results from the Women's Health Initiative [1] and the Million Women Study [2] have changed the recommendations, and hormone therapy (HT), formerly seen as the drug of choice for all menopausal women, is no longer considered favourable as first line treatment for

osteoporosis [3]. But the focus on increased risk of osteoporosis in menopausal women still remains, especially through the media and advertisements, bringing other forms of medications, such as bisphosphonates, to attention. Our knowledge of how women perceive such risk information is, however, limited, and as GPs we share recently voiced concerns over such information [4–6]. In our clinical work, we have realized that risk information may have unintended negative consequences [7–9].

Aims

As part of a larger study concerning women's views on menopause, this part of the study aims to explore

how menopausal women are affected by knowledge of the potential risk of osteoporosis.

Methods

A purposeful sample [10] of 24 menopausal women, 52–53 years old, from all over Denmark, was in-depth interviewed by the first author (LH) in 1999–2000. The sample was selected in order to cover a varied and broad spectrum of Danish women, their menopausal experiences, and contact with the healthcare system. The women were selected primarily on the basis of their answers to a preceding survey about menopause, sent to 1,261 Danish women, 51 years of age in 1998, who were chosen at random (response rate 77%). Findings from the questionnaire have previously been presented elsewhere [11]. The menopausal experiences differed across the sample. Some had almost no symptoms, others were much bothered. Half of the women had taken hormone therapy at some time. None of the women had diagnosed osteoporosis. Three had had a bone mineral scan, in all cases with a normal result. Only Danish-born women, being Danish citizens, were selected.

The women were only selected for interview if they had menopausal experiences. The definition of being menopausal was based on self-reported menopause status [11]. The Danish word for menopause equates to the English “transitional state” or “perimenopausal”. All 24 women, except one, described themselves as being menopausal. Only one stated herself to be postmenopausal. Thirteen of the women had had at least one menstrual bleed within the last year, some because they took HT. Those who were not taking HT had experienced irregular or sparse bleeding, and they had all experienced some degree of hot flushes. Among the 11 women not having experienced menstrual bleeding in the last year, the average age for their last period was 48.5 years.

In order not to force risk concerns, risk of osteoporosis was explored only if the woman mentioned it herself during the interview, which happened in 17 cases. The interviews with these 17 informants constituted the material for the analysis reported in this paper. The interviews with the seven women not mentioning risk did not differ from the others, for instance by providing poorer information or being of shorter duration.

The interviews were semi-structured and included various aspects of menopause (e.g. course, symptoms, and treatment), a short social status (education, family relations, work), and finally questions on

attitudes to ageing and femininity. When risk issues were mentioned, this topic was handled in detail.

The study was granted approval by the Scientific Ethical Committee and the Danish Data Control.

Analysis

The interviews were audiotaped and transcribed verbatim. Analysis aimed to elicit descriptive knowledge derived from everyday experience [12–14]. All interviews were browsed for text concerning considerations regarding risk of osteoporosis. The interviews were re-read by LH and SR. The text strings were analysed for emerging new themes and categories according to editing analysis style [15]. Perspectives on risk as an individual concern focused the reading and contributed to the choice of categories presented below. Analysis across the material was validated by a summary for each woman, specifying the details of her account in relation to the general themes.

Results

Most of the women had heard about osteoporosis, and were aware of this as a potential risk related to menopause.

It was not possible to find out who first had told them of the risk. It was mostly something they just “had heard about” – a kind of culturally embedded knowledge. But the women’s ways of perceiving the risk of osteoporosis divided our material into two groups of about equal size. One group was aware of the risk as a general risk connected to menopause but remained unaffected, while the other group felt personally affected and responded to the risk with uncertainty and worry. They were also puzzled to realize that risk-reducing medication might introduce new hazards. Below, we explore the underlying understanding as explained by the women. Annotations attributing quotations to the different informants are marked by (I-#).

Women who remained unaffected

When these women heard about osteoporosis in the media or from their GP, they understood that menopausal women in general were at increased risk of osteoporosis, and the topic had caused them to reflect on their situation. But the risk was not perceived as being really important to them; it was just something they had heard about, and perhaps reflected on, but they had not had an experience of being at risk themselves:

I have thought about this osteoporosis, you see. Well, I have never been checked if I have got it ... but I think, since I do not feel any discomfort in my body, I do not think I have got it ... and I don't think I will suffer from that, my body is so strong. (I-5)

Some women stated that nobody in their family was suffering from osteoporosis; others saw themselves as being really fit or too heavy to be "really exposed".

Women quickly rejecting the possibility of being at risk often presented attitudes showing that they were not ready to set their minds on sickness, medicine, and future diseases:

I think I am the type who says: As long as the accident has not happened, it will not happen. I can read about diseases without getting ill ... and I do not get nervous if I read about what I can expect in the future, so I think it must happen before it will make any impression on me. (I-1)

Only a few of the unaffected women took any action in relation to osteoporosis. Some already had a healthy lifestyle – they had not changed their diet or exercise habits because of the risk. Only one woman mentioned having started taking vitamins, because "all the hot flushes tired her body". Another said she ought to take calcium, "but always forgot it".

Half of the women in this group had discussed menopause with their GP. When they did, it was because of menopausal symptoms, not because they wanted to discuss risk. The unaffected women seemed convinced and secure in their acceptance or rejection of hormonal therapy. Only one of the women wanted treatment, primarily because of symptoms. She also thought that the possible ability of hormonal therapy to prevent bone loss was a "plus in the total sum".

Women who were beset by uncertainty

The women in the other group perceived the risk as important to them personally, and feared that they might suffer a fracture:

I would really be sorry, if I ... walked down the street, being so brittle in my bones that I sustain some fracture, don't you see? (I-12).

They had assessed their situation, as had the unaffected women, but had concluded that

osteoporosis did, indeed, matter to them, often because of a combination of risk factors such as heredity, other diseases, and early menopause.

My mother got osteoporosis when she got ill, and therefore I thought a lot about that. (I-20)

Informants who felt that the osteoporosis risk affected them personally said that they felt uncertain. When they also realized that risk-reducing hormones introduced new hazards, such as the risk of thrombosis or breast cancer, they described the ensuing dilemma as one where they were caught "between the devil and the deep blue sea". This last quotation came from a bank assistant, who was totally confused after listening to different doctors and reading different materials on the pro and cons of hormone replacement therapy:

You cannot always read what it is all about, what is dangerous and so on. I have been very afraid of taking hormones ... maybe it would be good for something, but you could also get breast cancer.... It is not easily seen through. (I-23)

The feeling of dilemma was accompanied by worry. A number of emotionally charged expressions were presented, such as "to be in extreme doubt", "nervous", "worried", "insecure", "afraid", "frustrated". The women had apparently thought a lot about their risk. The risk of osteoporosis was seen as "frightening", and the medication was described in words like "dangerous" or "poisonous".

All the women in this group had seen their GP, not only because of symptoms but also to discuss their doubts and worries about risk and risk prevention. They had typically seen their GP several times and, except for one woman, they had all seen a gynaecologist. Several women had also discussed their doubts with other specialist doctors or doctors among their friends.

The encounter often triggered further examinations and tests, such as bone mineral scans, smears, referral for mammography, and blood samples. These medical consultations and supplementary examinations were described as "very reassuring" and "safe". However, when seeking medical advice, the women realized that there were no exact answers to be found, and this further contributed to their feeling of frustration.

I do not know who to turn to in order to get help, since there are so many opinions about this stuff. (I-19)

For further clarification, the women had also read books or pamphlets, attended lectures, and discussed the problem with friends or family. All these women strongly considered taking hormones, not only because of their symptoms but also to prevent fractures, and many, but not all, mentioned the importance of preventive lifestyle habits.

The uncertainty could be a strong motivator for action, as described by an academic and reflective woman, who felt herself at high risk because of heredity, and who had started intensive exercise training and changed her diet.

I think the doctor should tell about the importance of taking vitamin D and calcium, and tell about the possibility of hormones and exercise, what you could do yourself. Because, since I am like I am, I have to turn this anxiety about osteoporosis into something I can act on. (I-24)

Discussion

Awareness of osteoporosis risk caused a feeling of uncertainty and worry in some women. Only women reacting in this way seemed to act in order to prevent future fractures. Yet, they were puzzled to realize that risk-reducing medication could introduce new hazards.

Strengths and weaknesses of the study

This study departed from a position focusing on unintended, negative consequences of medicalization and risk. We therefore examined the material cautiously for conflicting statements. Challenging our preconceptions, we found that several women were unaffected by the information about risk, whereas others made changes in lifestyle, with a possible positive influence on their health.

The interviewer's position (LH) as a researcher, GP, and woman in her mid-forties probably influenced the interviews. Risk was not mentioned, unless the woman herself raised the subject, which could lead to underestimation of unintended consequences. However, the women may have emphasized their knowledge of osteoporosis, believing that this was of importance to a doctor, even if it was not pertinent to them. But they could also have raised relevant matters of uncertainty in the hope of receiving further clarification.

The study included healthy women from all parts of Denmark, representing a wide variety of menopausal experiences. In this study we have only spoken to Danish-born women, and the experiences

in different countries and in subcultures in Denmark may vary, depending on the cultural focus on the menopause-related risk of osteoporosis. This study was carried out before the new evidence and recommendations regarding hormone replacement therapy (HT) were published. But even if this latest evidence is new, most of the women in our study were aware of the possibility of side effects, therefore illustrating dilemmas in medical prevention.

Even if this study mostly focused on HT as medical prevention against a future disease, we find it probable that the findings could be transferred to other areas involving medical treatment of risk factors.

Relation to other studies and theories

Most women in our study paid great attention to risk, which confirms sociological and anthropological theories [16–18]. Risk simply popped up during the interviews as a sign of the “risk society”. Yet there are different ways of perceiving and handling risk. Such differences in risk perception were demonstrated in two recent studies on osteoporosis [4,19]. In the former, Ballard reported risk perception at a “collective” and at an “individual” level, corresponding to our findings of the risk being perceived as general or personal, whereas, in the latter, Backett-Milburn et al. reported that osteoporosis was only found to be a particularly salient issue among women who had “experiential knowledge”. The British women in these two studies only rarely mentioned the risk of osteoporosis spontaneously, and few considered themselves at risk. These differences could be due to different samples in the two studies, but they could also stem from differences between the cultural settings in Denmark and Great Britain.

Information on risk: A two-edged sword

The feeling of uncertainty and worry demonstrated by our informants may act as a strong motivator in healthcare promotion. People are more eager to change behaviour if they realize there is a threat to their health [20,21]. If the purpose of the encounter is to motivate the patient to accept lifestyle changes, or to increase compliance with medication for preventive purposes, it seems necessary to make a person believe that she is facing a personal rather than a general, abstract threat.

However, creating an uncertainty in individual women must be considered a potentially serious side effect of health promotion, and our findings make us

ask whether introducing the threat of future diseases in healthy people is ethically justifiable [5,22]. For a long time, HT has been seen as one of the best ways to prevent bone loss, even if bone loss could just as well be seen as a result of ageing and lifestyle effects in modern societies, and is also seen in men. If a woman herself is asking for a risk assessment, it is important that doctors not only think of medical solutions to prevent fractures but also offer encouragement as regards non-medical solutions (dietary changes, exercise, and stop smoking). Since HT is no longer recommended for long-term use and in the light of our findings we suggest that the strong linkage between osteoporosis and menopause should be toned down when counselling menopausal women.

Acknowledgements

This research has been funded by the Health Insurance Foundation and the Research Foundation for General Practice, Denmark

References

- [1] Writing Group for the Womens' Health Initiative Investigators, Rossouw JE, Anderson GL, Prentice RL, Lacroix AZ, Kooperberg C, et al. Risks and benefits of estrogen plus progestin in healthy postmenopausal women: Principal results from the Women's Health Initiative randomized controlled trial. *JAMA* 2002;288:321–33.
- [2] Million Women Study Collaborators. Breast cancer and hormone-replacement therapy in the Million Women Study. *Lancet* 2003;362:419–27.
- [3] European Agency for the Evaluation of Medicinal Products (EMA). EMA public statement on recent publications regarding hormone replacement therapy, 2003. [available at: <http://www.emea.eu.int/pdfs/human/press/pus/3306503en.pdf>].
- [4] Ballard K. Understanding risk: Women's perceived risk of menopause-related disease and the value they place on preventive hormone replacement therapy. *Fam Pract* 2002;19:591–5.
- [5] Getz L, Sigurdsson JA, Hetlevik I. Is opportunistic disease prevention in the consultation ethically justifiable? *Br Med J* 2003;327:498–500.
- [6] Edwards A. Communication risks means that patients too have to live with uncertainty. *Br Med J* 2003;327: 691–2.
- [7] Illich I. Medicalization and primary care. *J R Coll Gen Pract* 1982;32:463–70.
- [8] Antonovsky A. Health, stress and coping. London: Jossey-Bass, 1979.
- [9] Hollnagel H, Malterud K. Shifting attention from objective risk factors to patients' self-assessed health resources: A clinical model for general practice. *Fam Pract* 1995;12: 423–9.
- [10] Patton MQ. Qualitative evaluation and research methods. 3rd ed. Newbury Park, CA: Sage, 2002.
- [11] Hvas L, Søndergaard K, Thorsen H. Discussing menopause in general practice. *Maturitas* 2003;46:139–46.
- [12] Giorgi A. Sketch of a psychological phenomenological method. In: Giorgi A, editor. Phenomenology and psychological research. Pittsburg, PA: Duquesne University Press, 1985:8–22.
- [13] Spradley JS. The ethnographic interview. Orlando: Harcourt Brace Jovanovich, 1998.
- [14] Malterud K. Shared understanding of the qualitative research process. Guidelines for the medical researcher. *Fam Pract* 1993;10:201–6.
- [15] Crabtree B, Miller W. Doing qualitative research. 2nd ed. London: Sage, 1999.
- [16] Beck U. Risk Society. 1st ed. London: Sage, 1992.
- [17] Lupton D. Risk. London: Routledge, 1999.
- [18] Douglas M. Risk Acceptability according to social sciences. New York: Russel Sage Publications, 1985.
- [19] Backett-Milburn K, Parry O, Mauthner N. 'I'll worry about that when it comes along': osteoporosis, a meaningful issue for women at mid-life? *Health Educ Res* 2000;15: 153–62.
- [20] Bandura A. Self-efficacy: The exercise of control. New York: Stanford University/W.H, Freeman, 1997.
- [21] Rosenstock IM, Stretcher VJ, Becker MH. Social learning theory and the health belief model. *Health Educ Q* 1988;15: 175–84.
- [22] Sackett DL. The arrogance of preventive medicine. *CMAJ* 2002;167:363–4.