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From accident to diagnosis.
Cultural response to the risk of osteoporosis

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Introduction

New biomedical knowledge is produced and new disease categories are created. Biomedicine and especially epidemiology focus at the determination of health risks and risk factors and how to diminish these health risks. This fact changes the medical discourse and influences lay people's perception of health and health risks. The aim of this article is to discuss the changing ideas of bone fractures as a natural accident to the invisible risk of osteoporosis (brittle bones). My concern is to examine how women's body experience changes due to new biomedical knowledge and in particular how they articulate this change in the context of a new disease, osteoporosis. How women comprehend and have experiences with bone fractures, osteoporosis and the risk of bone fractures, provides knowledge of society and cultural values. A cultural analysis of perception of risk and osteoporosis contributes to a more profound anthropological understanding of the human condition in a changing world. The present study explores the narratives of elderly women and their perceptions of bone fractures and osteoporosis.

Osteoporosis is defined by biomedicine as the loss of bone mass or the phenomenon of bones becoming brittle. It is known mainly as a female condition (see Wingerden 1996, Lock 1993). The World Health Organisation WHO defined osteoporosis as a disease in 1991 and the biomedical discourse related to the condition has changed a lot over the last 10 years. Osteoporosis leads to increased bone fragility and a consequent increase in risk of fracture. Mostly it occurs among elderly people. In practice, it means that people will be diagnosed as osteoporotic using a bone scan, when their bone masses are lower than the young adult mean. Nearly a quarter of white women aged 60-69 is in this group with an increased risk of fracture (WHO 1994). Osteoporosis will remain invisible in the body

until a fracture occurs. Because of hospitalisation expenses, the most important osteoporosis-related fractures are those of the hip. Secondary to this is the fractures of the backbone, which also have great significance (Scheper-Hughes & Lock 1987).

Two or three factors have contributed to the attention on the idea of preventing bone fractures (especially of the hip). The first is the growing attention that is being given to health risks and prevention, based here on the predicted probability of bone fractures. The second is the development of medical technology and the growth of pharmaceutical companies with the possibility of scanning for osteoporosis and treating the condition. In this connection, Lock argues about a triangulation of interest, which also includes the medical profession (Lock 1993). Another important issue is that the growing elderly population, especially the disabled elderly, increases the workload involved in state care for the elderly in the Western countries.

Previously, a hip fracture was mostly seen as a natural accident. Today, along with many other health risks, it has changed from an unpredictable misfortune into a preventable misfortune as argued by Judith Green in her book *Risk and misfortune* (1997). She points out that an accident should be an unmotivated event that is unpredictable and unique. The occurrence of a particular accident cannot be foreseen. In this context, she argues that accidents today have almost disappeared (Green 1997). This applies to hip fractures, when it is now possible to find people with osteoporosis and to predict the event, which might happen 10-30 years in the future.

Information about osteoporosis is now freely available. The Health System defines osteoporosis as a disease that can be found and treated with medicine. Guidelines about how to handle osteoporosis in the Health System are now available in Denmark and many other countries. These describe the importance of prevention by changing lifestyle and finding women with high risk of osteoporosis and offering them treatment. In the medical literature, articles about osteoporosis have increased from 1258 (between 1966 and 1970) to 5116 (between 1996 and 1999) and articles about risk and osteoporosis have increased from zero to 1604 in the last 4 years (Skolbekken, 2000). The Press and Osteoporosis patients' associations tell that we face a new and widespread disease. The Osteoporosis patients' association tells that we have a new serious national scourge, which primarily hits women and almost one third of women will get the disease. The aim of the association is to fight against this anonymous disease, which is

characterised by the crumbling of the skeleton, pain and the fact that it causes disability. Lay people also know the term osteoporosis.

This changing discourse in medicine and the creation of the new disease category of osteoporosis both as a visible as well as an invisible disease will have impact on women's comprehension and experience of their body.

Study of women's' experiences with osteoporosis

The present study was conducted in relation to a population study in the County of Copenhagen, Denmark. The aim of the study is to explore women's experiences and perceptions of osteoporosis and bone fractures, their perception of health, health risks and prevention. The women in the study were born in 1936 and participated in the population study based on a questionnaire and a health examination at a Danish hospital, but without a bone scan (for osteoporosis). In the questionnaire, the women were asked whether they were prepared to participate in small focus groups or in-depth interviews to be held at a later date to provide qualitative information about their experiences and perception of osteoporosis. Four focus group discussions were conducted with 22 women (group size raged from 4-6 participants); aged 60 to 61 selected from the questionnaire. Assignment to groups was organised according to criteria based on the women's responses in the survey to questions about osteoporosis. The selection criteria for the focus groups were that the women had a knowledge of osteoporosis, had experiences with osteoporosis, had had a bone scan, thought that they themselves were at risk of osteoporosis or had experience of bone fractures.

The location of the focus group discussion was in a meeting room at the Centre of the Population Study, a building close to the hospital in Glostrup. Tea, coffee and bread were served at the meeting, which lasted between 2 to 2½ hours. The researcher had the role as moderator for all 4 focus groups. The researcher was presented as a researcher related to the population study, an anthropologist, a social scientist and GP. The idea with the focus group, to get knowledge about women's comprehension of and experiences with osteoporosis and bone fractures, was explained several times. The moderator kept a low profile, trying to let the women discuss the subject without disruption, but still tried to get everyone to participate in the discussion. In the first two focus groups, a co-referent that is also an anthropologist participated. Field notes (including observations about the participants and their setting) were recorded after the interviews.

Each discussion was audiotaped and transcribed in full (verbatim). The tapes were listened to and the transcripts read repeatedly. Data from the focus group discussions were coded to explore potential themes related to content and concepts.

After the focus group discussions 18 women diagnosed as osteoporotic or at risk of having osteoporosis (defined by them) were followed over 3 years and ethnographic interviews were conducted, mostly in their homes. In the interviews the women often told about their experiences in narratives (Polkinhorne 1993: 6), a story, where events and actions are drawn together into an organised whole by means of a plot (Ibid. 7, Good 1994:144). A plot is a type of conceptual scheme by which a contextual meaning of individual events can be displayed (Polkinhorne 1993: 7). My analyses of the narratives focus on the phenomenon of osteoporosis and to see this in context, not only in relation to what will happen now and here, but also in relation to what has happened before, and what will happen in the future. As well as the focus group discussions and the ethnographic interview, I participated in meetings with the patients' association and collected material concerning osteoporosis from newspapers and magazines to supply my data. The study is still ongoing and the analyses of the interviews have not been finished. In this paper, I have used 2 women's stories of osteoporosis to illustrate how the diagnosis of osteoporosis has affected their lives. In particular, I focus on how they comprehend bone fractures and the risk of having osteoporosis. To comprehend these stories in the context of my study I will include material both from the focus groups and the interviews.

Bone fractures as a natural accident

Most of the women in the study who had not been diagnosed as osteoporotic talked about fractures as understandable. Fractures were reported as natural accidents related to a fall. For some women this perception will change when they get a diagnosis of osteoporosis.

When the focus groups discussed bone fractures in general, the talk concentrated on the accident or misfortune of falling and getting a fracture.

One woman explains:

> *«To fall at the age of 70 to 90, you accept that something will happen. You don't break the fall the same way that a younger person does. You just fall. When I broke my wrist, that was also from falling, but I managed to break the fall and then I broke my wrist.»*

Another woman explained the accident as a result of being clumsy and mistaken. When she tried to break the fall, she was really unlucky. Bone fractures were not seen as a disease, but as a question of an accident and the way, you fall.

The fall and the fracture are seen as an unmotivated and unpredictable event. It just happened. Only you must accept that you have a greater probability of falling and getting a fracture when you grow older.

One woman commented that she did not think that it was natural to break bones. To understand her we must look at her perception in the context of her own experience. She commented first that she has a friend whose back collapsed one day when she was getting off her bike, and to day she is in a lot of pain. But the woman herself has osteoporosis and lives with the feeling that one day her bones will suddenly collapse. Her perception of bone fractures is based on her experience with her friend and her image of osteoporosis, which I will return to later in the paper. First, I will introduce the stories of Linda and Rose.

Linda's story and how she embodied the experience of a bone scanning

Linda is 61, married and works in her husband's silverware shop. She lives in a big house in the countryside. She has always been enthusiastic about sailing and she presents herself as a nature lover.

She said that, three years previously, she had learned the fact – by chance – that she had calcium loss. She got the idea of having a bone scanning from another women, who had a normal bone scanning, so she expected the same result.

She goes on to say:

> *«I was scanned. Afterwards, the doctor showed me on a small screen, what was wrong and said that normally I should be up there, but if we went backwards and saw all the way down here I was there and in really great danger. I must walk carefully on the way home or something might happen». «And you must go to your own doctor tomorrow to start treatment».*

Telling her story Linda reflected on how she comprehended her situation and the information given. First, she had never experienced her body being in danger. Linda had not expected to have osteoporosis, even though she had had bone fractures – of the ribs and also of the shoulder when she had to push the car and she fell right onto her shoulder. Before the bone scanning, she could understand the bone fractures being the

result of a fall – a natural accident, an unpredictable misfortune, but now it is different.

Linda explained her further reflections:

> *«You feel that it is OK that you break the bones when you fall, when you don't know the real background»*. (She now knows that she has osteoporosis).

She continues:

> *«Besides the fractures I have mentioned, I have never broken anything - and therefore I was very much astounded that I was in such great danger as the doctor told me»*.

Telling her experiences Linda turned back several times to her perception of the actual danger and her earlier fractures. Through her reflections of her experiences, she came to a new recognition about her situation, before she had the experience of her physical body being hit by misfortunes. In her story, she explained her primary astonishment over the danger, but she accepted it. At a bone scanning two years later, she asked the doctor if she could stop treatment when she felt it was better. She was told that the medication was absolutely necessary also in the future. She had no possibility of checking up on the doctor's statement.

In the beginning, Linda did not embody the risk of osteoporosis but now, she continues:

> *«Well then, I really must say that since I got osteoporosis, I'm very very cautious. I'm much more cautious than I've ever been. When I am walking now, for example in such bad weather, I walk very carefully, I must admit. I've never done that before... I've never been thinking... I guess I've hurried too much, you see... but luckily I've been spared... so I dare not do that any longer»*.

Linda's comprehension of her body has changed over the last three years. The risk Linda experiences is not a statistical risk in numbers, but the meaning of risk as an unacceptable danger (Douglas 1992). Even if Linda doesn't feel sick she now has a lived body experience of an "at-risk" health status, where the risk of bone fractures in some way is predictable and an always present danger in the body. Linda explained her fear of being disabled, but she is also afraid that osteoporosis will change her appearance. She has to be careful to prevent the risk of future sickness by taking her medicine and walking carefully.

I will now turn to the story of Rose. Her story is similar in the way the diagnosis of osteoporosis changes her comprehension of bone fractures, but she is even more affected by the risk that having osteoporosis involves.

Rose's story of uncertainty

Rose is 62, a married housewife living in a flat. This story is from my first meeting with Rose in 1998 in an office at the Centre of the Population Study. She didn't want me to visit her in her home the first time we met.

She starts:

> *«It was in 1991 when I broke my arm. It was examined and I was told that my calcium was varying. So to stop that I was given hormones. Then in 1996 I broke this shoulder. I didn't think of anything before, I was only told what to do about it, but after breaking this, I started being scared of falling again. I have never been scared of anything. I have always walked with my head held high. You see, when I was on my way over here today I couldn't decide if I should walk, should I bike, or should I drive? Then I said to my self, I don't want to become crippled. I don't know what is wrong, now I walk. There are some places where I have to walk my bike, which I have never done before. Now I walk my bike. My husband is also nervous about what might happen next time I fall, what would I break then. That is what has entered our lives that wasn't there before.»*

I will focus on how Rose's story shows how her present activity is related not only to earlier experiences, but also to her present life situation and how she experiences herself in this. The content of the story contains descriptions of earlier events together with experiences from the same day. At the same time elements in her story should tell me what kind of person Rose is.

It seemed not to affect Rose that much when she broke her arm and had the examination for osteoporosis. She refers to the result of the examination and how she comprehended osteoporosis to be the result of the calcium leaving the bones quickly and varying. She expected that the hormones could prevent the problem. But after the second fracture, an experience of uncertainty has entered her life and she cannot trust hormones to protect her.

What has entered Rose's life is a lived experience of the possibility of falling, breaking her bones and being crippled. She tells us that before the bone scan she had fractured her ankle, but that she didn't think of osteoporosis at that time. After the fracture she is retrained, it was painful, but only for a time. The broken shoulder was much worse. Rose talks about her fear to become an invalid. She doesn't like to feel like an invalid because she has osteoporosis, but she is really afraid of being an invalid and depending on others. The family wouldn't be able to get by. Rose keeps trying to make me understand her and what sort of person she is. She tells me how she has taken care of her disabled son for many years and how she saw her father as an invalid; it was discreditable to him. Rose explained that

she has always been the central person in the family. She is the person who takes care of both the practical works in the house as well as any emotional problems in the family. Telling her story she creates connection and meaning and puts her perception of osteoporosis into this context. Rose sees herself as an individual caught by the disease of osteoporosis. She experiences it as a chronic sickness; because of the way she lives her life in fear of a new fracture.

The danger and uncertainty of osteoporosis

The social anthropologist Douglas defined risk as the probability that a definite event, good or bad, will occur, combined with the size of loss and gain that it will bring. Risk is not only the probability of an event, but also the probable size of its result, and the value that is attached to the outcome (Douglas 1992: 31). Epidemiology works with risk as an objective probability. When risk is used in clinical medicine, it contains the value of normality in health as the optimal state of health and the acceptance of prevention in general as a good thing, also when it concerns prevention and treatment of such health risks as osteoporosis.

For the sociologist Ulric Beck, the public and the women in my study, the word risk is used as danger (Beck 1992, Douglas 1992: 39). The risk of osteoporosis is many times perceived as an unacceptable danger, which should be treated with hormones. Ulric Beck argues that the extent to which people are endangered by risk is to some extent dependent on knowledge, a knowledge which frequently the victims themselves do not have (Beck 1992:55). For Linda, the process of accepting danger – the threat to her health – was explained in relation to her acceptance of the biomedical knowledge.

The danger of osteoporosis includes the concept of uncertainty; when and where will the next unexpected danger of falling happen and what will it do to them? Linda and Rose explained that they are afraid of walking in bad weather and riding a bike. Risk as described by Douglas can be measurable while uncertainty is immeasurable. To control uncertainty some of the women act as if the risk is high.

As in the stories of Linda and Rose, the study illustrates how many women feel a kind of uncertainty about osteoporosis. Linda's interpretation of the risk communication is that she has a disease in addition to her previously experienced, but not frightening, fractures. The threat concerns a phe-

nomenon whose consequences she is familiar with, but when the risk is part of an unknown system such as osteoporosis, then the risk seems greater (Slovic 1987). Some of the women in my study relate other bodily symptoms to osteoporosis too, as one woman says:

> *«I am a little scared of one day looking like that, I have it everywhere else but my back, also my arms and knees hurt. I am afraid of my hips, because they hurt. Then I think that they are even more porous, but I don't know that and I would like to know».*

Osteoporosis is invisible until you get a fracture. This uncertainty causes other (many different) bodily symptoms to be associated with osteoporosis. Uncertainty, then, concerns both the interpretation of risk as immeasurable and osteoporosis as part of an unknown system.

The diagnosis of risk or belonging to a risk group of osteoporosis

Many women in the study perceive themselves as belonging to a group of risk.

One woman explains:

> *«I belong to the group of risk, I have had the menopause since I was 36. I was a smoker and I was thin, so he would very strongly recommend that I took hormones».*

In her perception of her risk of osteoporosis, she includes her menopause and hormone production, her lifestyle and her body weight. Many of the women in the study have the idea that they lack hormones and hormones are perceived as one of the treatments for osteoporosis. Another woman says:

> *«I realised that I lacked these hormones and when that happens you cannot absorb calcium».*

The women's perception of the risk of osteoporosis concentrates on osteoporosis as a disease related to women and hormones and a disease related to lifestyle, which has a profound moral impact on their lives. They accept that they live with an invisible disease or risk only because they have some of the defined risk factors [(1)] as mentioned here by the women. A woman says:

> *«I haven't drunk milk is synonymous with I will not get away with it».*

The quotation illustrates how the women's comprehension of belonging to a risk group of a new disease category such as osteoporosis affects them not in the meaning of risk as probability, but rather that they expect to have the disease in the future.

Images of osteoporosis

To comprehend Linda and Rose's stories in the context of my study I will now include some interview material about how the women express their understanding and image of osteoporosis. The image of the body should be understood as an individual's attitudes, feelings and fantasies about her body (Helman 1995). The image of osteoporosis should then be understood as an individual's attitudes, feelings and fantasies of her body having osteoporosis.

The women both speak about the image of osteoporosis as a frightening social sign of ageing but also how they perceive osteoporosis to look in the body.

In the words of two participants:

> *«The scary part about osteoporosis is those elderly people who actually fall forward». «My mother and my aunt fell totally apart and were completely pulverised, the new hips crumbled and their backs became totally hunched».*

Embodying a silent or invisible condition gives rise to many different performances of sickness and fear (Frankenberg 1993). This is based on the social and cultural meanings associated with being a woman in a Western (Danish) society and with how they perceive health and health risks (threats to health) in this context (Scheper-Hughes & Lock 1987, Monks & Frankenberg 1995, Douglas 1992, Kleinman 1988). Osteoporosis cannot be sensed and controlled by the individual, as long as it remains a symptomless invisible risk factor. The anthropologist Sachs argued that when the invisible in the body is made visible, many feelings and experiences arise in the body and a process is started in an attempt to make the experience meaningful (Sachs 1995). The uncertainty of osteoporosis is also a question of the fear of ageing and the cultural meanings associated to ageing in the Western Society (Bytheway & Johnson 1998).

Many of the women use the image of sponges, where osteoporosis is explained as the bones becoming porous and looking like sponges. Similar to this is the metaphor of bone flour and the image that the bones start to pulverise.

One women says:

> *«But really it is when one starts having osteoporosis it is like a ghost. I'm not so afraid of a fracture in a rib because it grows so easily together, but of the structure of a bone itself and then the flow of liquid».*

The skeleton is described as the foundation of a house and if it doesn't function, then nothing is okay. As one women describes earlier in this pa-

per she expects that one day her bones will collapse. The women's images of osteoporosis contain some very strong metaphors, which illuminate not only their understanding of the phenomenon of osteoporosis, but also what osteoporosis means to them in their everyday lives.

Netteton & Watson argue that the image we hold of our bodies will, to a greater or lesser extent, impact upon how we experience our bodies in everyday life (see Nettleton & Watson 1998). The body image is shaped not just by what we perceive our body to be like, but what we see and how we interpret our vision of our body, mediated by our social and cultural context. The act of perception is a socially constructed process (ibid.). This involves both the experience of bodily changes and their social perception. Many of the women in the study argue that they have never thought of osteoporosis like this before. Earlier, when they had talked about how elderly people looked, they said that they had worn themselves out (a bent old lady is now one with osteoporosis). Now when the women talk about osteoporosis, they reinterpret the past from their present knowledge, saying that they now think that their mothers might have had osteoporosis and from this construct a new promise of sickness and ageing.

Conclusion

Biomedicine produces definitions of health risk based on risk as a statistical concept that is knowledge of epidemiology on a group level (Reventlow et al. 2001). The medical profession can predict the probability of fractures, but for the women the important thing is that they live with the uncertainty of a danger in the body, meaning that they suddenly might become crippled and old. They don't know when or if it might happen. As one of them says:

> *«You can have something without knowing it, something that doesn't hit you until you get older».*

This article demonstrates how the new disease of osteoporosis, which can be treated with hormones, creates fantasy both as a disease with symptoms but also as an invisible disease that gives a feeling of insecurity and fright. The uncertainty of osteoporosis is also a question of the fear of ageing and the cultural meanings associated to ageing in Western society (Bytheway & Johnson 1998). It shows how women imagine the phenomenon of oste-

oporosis in its most distinct and advanced cases as the image of a bent old lady and crumbling bones. Women's images of osteoporosis shed light not only on their understanding of the phenomenon of osteoporosis, but also what osteoporosis means to them in their everyday lives.

Decades ago, a bone fracture would have been regarded as a natural part of old age. Bone fractures as natural accidents still exist among women not affected by a personal experience of osteoporosis, but experience of osteoporosis has changed all this. Today, women describe osteoporosis as a ghost or a phantom in the body and the bone structure of the skeleton as a house, with the scary metaphor of crumbling bones and a bent old lady. Still, to women, the risk of osteoporosis remains invisible. Osteoporosis cannot be sensed or controlled by the individual, as long as it remains an invisible risk factor. The stories of the women show how new medical knowledge about osteoporosis influences women's' bodily experiences. When women have a bone scan the danger of osteoporosis becomes part of their present life, and at the same time they reconstruct their past in their narratives and construct an anticipation of the future. With the focus on prevention, the health system has created a being in the present based on the prevention of future sickness as a full-time present danger.

Osteoporosis as a biomedical diagnosis has stimulated a cultural response in society. The women in the present study tell of their experience in the context of their cultural understanding about health, illness and self, resulting in different behaviour and sickness performances. Women's accounts of bodily experiences should then be understood as the ground of culture and self (Csordas 1990). The experience of osteoporosis must be viewed not just as a physical body experience in a biological sense but as a lived embodied experience, that is, which acknowledges the complexity of human embodiment and accounts for the way we experience a particular phenomenon.

Notes

(1) In epidemiology, risk is defined as a statistical probability that an undesirable event – disease or death – may strike people. Now it is possible to determine the probability of disease associated with many factors – risk factors. The term 'risk factor' refers to a characteristic of the individual, or in relation to the individual, that is statistically associated with an increased probability that a certain undesirable state of health will appear (Reventlow *et al*. 2001).

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