

John-Arne Skolbekken

FOR BETTER, FOR WORSE

CRITICAL REFLECTIONS ON RISK, MEDICALIZATION
AND OSTEOPOROSIS

Thesis for the degree of Doctor Philosophiae

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Norwegian University of Science and Technology
Faculty of Social Sciences and Technology Management
Department of Social Work and Health Science



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Norwegian University of
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ABSTRACT

Preventive medicine comes with the potential for making our lives both better and worse. In this thesis reflections around this situation are offered, supported by empirical research. The reflections are offered from a social constructionist position. Three themes are covered – the concept of risk in medicine, medicalization and osteoporosis.

The study is based on six sub-studies applying a mix of qualitative methods. It covers data sets from medical literature databases, newspaper articles and focus groups.

Among the findings of the study is the risk epidemic in medical literature, which has hitherto been found to peak in the first decade of the 21st century. Furthermore, the development of the medical understanding of osteoporosis has been traced, showing how the introduction of medical technology transformed it into a risk factor available for risk reducing interventions. The introduction of such reductions through chemoprevention was subject to controversy, and this controversy has been analysed through the newspaper coverage of what became known as the Fosamax-case. Knowledge of osteoporosis among women in Nord-Trøndelag has furthermore been shown to be based on everyday experiences wherein falling has become the ultimate test of osteoporosis. The experience of screening for osteoporosis among the same women illustrates that the medical definition of osteoporosis made little sense to them. Variation in risk categorization and measurement technology contributed to confusion over the test outcomes, as did the communication of test results as standard deviations. In the last paper reflections are offered on whether the pathologization of normality presents a possibility for unlimited medicalization.

These findings show how modern information technology paired with the idea of risk in medicine has prepared the ground for the medicalization of everyday life. The medicalization of osteoporosis is described as happening three times over, through the medicalization of everyday life, the medicalization of menopause and the specific medicalization of osteoporosis. Bone density measurements are described as a crucial ingredient in the medicalization of osteoporosis, alongside chemoprevention. Recent developments show that bone density measurements may come to play a minor role in the future, however. Among the limits of medicalization are what in medical terms is described as lack of risk awareness and knowledge of osteoporosis, alongside a reluctance to take chemoprevention as a measure for reducing the risk of fractures. These limits to medicalization are unintended, however, unlike earlier feminist resistance against the medicalization of menopause. The consequences of screening for osteoporosis show that it has a reassuring effect on the women told that their bone density is OK, whereas for others it is a source of confusion. For some it also has the effect of demonstrating the frailty of their bodies.

ACKNOWLEDGEMENT

Although I take the full responsibility for what is stated on the pages that follow, I also acknowledge the contribution of luck in preparing the ground for this thesis. It has thus been my luck to be born into one of the most peaceful corners of the world at a time of great prosperity. Furthermore being raised by two loving parents who taught me the value of doing my homework, letting me fulfil what they themselves only can have dreamt of, has also been among the privileges of my life.

Luck has furthermore let me start my academic career at a time of great expansion in the number of positions available in psychology. As a consequence the Departments of Psychology at the University of Oslo, the University of Tromsø and the Norwegian University of Science and Technology (NTNU) have all paid my wages and offered me office space to do the work which has now been completed. It did take a move to the Department of Social Work and Health Science for the finishing touch, reflecting that although a psychologist by training, I am a health scientist at heart. HUNT Research Centre has furthermore generously assisted in the recruitment of participants for this and other focus group studies over the years. I am grateful to all these institutions for providing the basics which have made my work possible.

Coming from a working class background, academic work has not always been second nature to me. Literal pats on my shoulder from the late Ivar Lie, Olav Helge Førde, Bjørn Backe and Steinar Westin early on have had a decisive impact on my belief that I could make this my career. The interest shown in my early work by the Norwegian Society of General Practitioners, and in particular Elisabeth Swensen, has also been most encouraging. To be invited by such scholars as Dag Steinar Thelle, Alan Petersen and Iain Wilkinson to contribute to their edited anthologies has been most helpful in the production of two of the texts in this thesis.

Three of the other texts would not have been completed without the efforts of my co-authors, Lidia Santora, Wenche Østerlie and Siri Forsmo. I am grateful to you all, but clearly Siri stands head and shoulders above any other academic mentioned on this page, for being my twin soul in research. We have both been part of the Bioethics Research Group at NTNU, which over the years has provided a forum for developing and challenging ideas like the ones presented in this thesis. You know who you are and I thank you all, but I reserve a

special mention for the brave Ann Rudinow Sætnan who has quietly provided inputs to my reflections from the time of the early discovery of the risk epidemic to the present.

For a young man that has moved well into middle age before completing his PhD it has been a privilege to feel the love and acceptance of my family. Unimpressed by any publication list, slightly disinterested in my work, Doris, Oda and Jan have made sure that I rarely return to an empty home. Thank you.

*THESE ARE STRANGE TIMES, WHEN WE ARE HEALTHIER
THAN EVER BUT MORE ANXIOUS ABOUT OUR HEALTH. ACCORDING
TO ALL STANDARD BENCHMARKS, WE'VE NEVER HAD IT SO HEALTHY.*

- Roy Porter -

INTRODUCTION

Among many other things life confronts us with problems. What the problems are and how they are dealt with is influenced by the time we live in, the fabric of our society, what generation we belong to, and what features define us as individuals. Some of these problems are perceived as health problems, diseases even, for which medical help can be found. When we seek this help we have accepted that they are medical problems, falling within the realm of biomedicine. When we take the time to reflect about this common situation, which many of us have come to take for granted, a possible outcome of the reflection might be the sneaking recognition that it could have been different.

Acknowledging that things could have been different, we may realise that there is little room for determinism and simple cause-effect relationships. When simplicity is replaced by complexity, we may come to realise that uncertainty prevails. In the face of uncertainty people will live their lives hoping for the best and fearing the worst. This has been, and will continue to be, a significant part of the human experience. In modern society, however, this experience is also different in important ways from that of our ancestors. The difference is related to the impact of science and technology. One such impact has come through the notion of risk, which has contributed to making us more aware of the potential dangers in our everyday life.

Another facet of the notion of risk is also that we are no longer at the total mercy of fate, but that science and technology can also be seen as having gifted us an increased ability to control our fate. Such control seems to require that we accept that medical interventions can be implemented on individuals who perceive no symptoms of disease themselves. For some this is an unhealthy sign of medical imperialism, whereas others see this as a major improvement of the human condition. Whatever the interpretation, besides solving some of our problems, the present situation is also creating some new ones. Being provided the option

of choosing, gifts us the problem of making the right choice, which calls for further reflections.

This thesis is the product of such reflections, supported by empirical research.

Overall aim of the study

The overall aim of this thesis is to offer critical reflections on preventive medicine. For a long time I believed that this could be done by answering the question ‘for better or for worse?’ My reflections have taught me, however, that this is an impossible question to answer. Instead I have come to realise that preventive medicine does not come with the option of choosing between good and evil, but rather with the option of balancing good and evil. Like a partner in marriage, you accept that you will come to live with his/her good sides and bad sides. Hence, the title - ‘for better, for worse’.

A characteristic of modern medicine is that it is easily portrayed in extreme terms, as an activity offering both miracles and disasters. This is also illustrated by the contrasting titles of scholars like Porter (1997) and Illich (1976), who have indicated that medicine can be ‘the greatest benefit to mankind’ and a ‘nemesis’ in modern society, respectively. It is within this love/hate relationship with modern medicine that this thesis is placed.

Looking beyond the outliers of miracles and disasters in modern medicine there is a lot of medical knowledge and practice that is more challenging to analyse and categorize. One of these areas is the recent developments in preventive medicine, in particular the part that is preoccupied with the concept of risk. Preventive medicine can on the one hand be seen as making things better, summed up in Geoffrey Rose’s (1992:4) humanitarian argument “It is better to be healthy than ill or dead.” As with other well intended pursuits, preventive medicine has its downsides, however, which has led some to raise the question whether there is a pathology of prevention when people feeling perfectly healthy are being told that they are at risk of a potentially serious and fatal disease (Sachs, 1995). Acknowledging the disaster potential of interventions at the population level, Skrabanek (1990) questioned the ethical status of preventive medicine. Similar sentiments have been expressed by Rosenberg (1997:45):

“With our increasing diagnostic capacities, we have provided altered narratives for millions of individuals who might otherwise have lived out their lives in ignorance of a nemesis lurking in their bodies.”

The status of preventive medicine has in recent times also been characterised as morally problematic as it is contributing to medicalization (Verweij, 1999). Among Verweij’s concerns is the possibility that it erodes people’s confidence in their own health, as the cumulative offering of various screening tests may serve as a constant reminder of the frailty of their bodies. In addition he questioned the attributions of responsibility that can be made in relation to preventive medicine and health promotion.

Furthermore, this dissertation is inspired by the question posed by Roy Porter (1997:3-4):

“Have we become health freaks or hypochondriacs luxuriating in health anxieties precisely because we are so healthy and long-lived that we have the luxury of worrying?”

As it is hard to believe that Porter saw health freaks and hypochondriacs as honorary titles, it seems a fair interpretation to think that he posed this question from a critical angle. It is as much an observation as a question, reflecting the relativity of our present situation.

A similar observation was made by LeFanu (1999) who described the worried well as one the paradoxes of modern medicine. He also observed that this situation was brought upon the population as they are consistently told about threats to their lives. In his words this has happened because people ‘have been led to believe’ (p. XIX) certain things. His choice of words is interesting, as there are numerous implications attached.

One such implication relates to reality and our perception of it. When somebody is led to believe something, this something may be different from that which is true, indicating that people are led to believe in a distorted reality. Such deceiving powers have been attributed to the pharmaceutical industry (Angell, 2005). Another implication is that somebody has the power to lead others, who are willing to be led. In health matters this power has been attributed to the medical profession, through what is known as medicalization – ‘a process by which human problems come to be defined as medical problems.’ (Sadler, et al. 2009).

LeFanu’s assumption and its implications call for a critical reflection, which will be offered on such phenomena as risk, medicalization and osteoporosis in the presentation of the

theoretical perspectives behind this thesis. By offering my critical reflections I lean on Martin Hammersley's (2005) description of the role of the critical social scientist. In this thesis I will critically examine medical research and knowledge, in an effort to challenge its validity. As the goal of medicine is to benefit humanity, I will problematize whether that is what is actually happening. In accordance with Hammersley's prescription I will try to do so prudently, as the field of study is a complex one. As a consequence of this prudence critical reflections will also be offered on the theoretical perspectives applied in this thesis.

The presentation of these reflections will in part be done through what has been called methodology-as-autobiography (Hammersley, 2011), acknowledging the central position of the researcher in the research that is to be presented.

Aims of the sub-studies

This study is by no means the outcome of the successful pursuit of following a master plan. Rather, it is the result of a journey where new questions have been discovered along the road, questions that have led to new reflections. In academic terms it may be described as the outcome of an explorative design, where most of the research questions have entered the researcher's mind after gaining new insights leading to the discovery of new questions.

My starting point came when I realised that my understanding of risk was somewhat lacking, if not outright naive. In the second half of the 1980s I was employed at the Norwegian Institute of Hospital Research (NIS), working with a reporting system for incidents involving medical devices in Norwegian hospitals. Such incidents had a few years earlier been identified as a major threat to hospitalised patients. My experiences from working with the incident reporting soon taught me that medical devices were not the largest iatrogenic risk to patients, after all (Skolbekken, Jystad & Elvemo, 1995). I also gained the important insight that the presentation of risk was not the mere presentation of facts, but also a result of actors' selective presentation of the facts that suited their interests. This made me interested in the social construction of risk in health and health care, which has a central focus in this thesis.

Eager to learn more about risk in modern medicine, the first aim of this work was

- *To study how risk is constructed in the medical literature.*

This led to the discovery of the risk epidemic in medical literature, which is described in Paper I.

The risk epidemic paper generated quite a few questions, some of which I have tried to answer in the other works included here. One of the conclusions about the risk epidemic was that it could be placed in a particular historical and cultural context. To better understand the history of this development thus became an aim, but the overall history was far beyond my ambitions and capabilities. For various reasons osteoporosis had come to my attention, and when asked to write a follow-up chapter to the risk epidemic in a Norwegian anthology (Swensen, 2000a), I included a literature search on the association between risk and osteoporosis. The outcome demonstrated how rarely articles about osteoporosis published in the 1960s and 1970s were articles about risk. By the end of the twentieth century, however, every third article about osteoporosis was also an article about risk (Skolbekken, 2000). Curious about what had happened in those few decades, the second aim of this thesis became

- *To trace the historical transformation of the medical understanding of osteoporosis in the latter half of the twentieth century*

My interest in the medical literature on risk also led me to regular visits to the library. Looking at the new issues of such journals as the BMJ and the New England Journal of Medicine in the late 1990s it was striking to notice what a prominent place risk reductions were given in advertisements for cholesterol reducing drugs. This eventually led me to write a paper about the risk communication in these advertisements (Skolbekken, 1998). About the same time there appeared a debate in Norway over the reimbursement of new drugs for osteoporosis, in what was called the 'Fosamax-case'. This case caught my attention as it had obvious parallels to the issues I had covered in my risk communication paper. Furthermore, as Kristiansen (1998) commented that it was a fitting task for social scientists and historians to tell the "truth" about the case, it seemed a challenge worth pursuing when I shortly thereafter received an invitation to contribute to a Norwegian anthology. Without actually aiming for THE truth about the Fosamax-case it became my aim

- *To make a critical analysis of the Fosamax-case*

An issue regularly debated in the academic circles I frequent is the moral side of the present medical focus on risk. These debates tend to focus on the concern for possible negative effects

about the medical attention on risk. Anecdotal evidence, in particular from general practice, was frequently brought up in the discussions, but research based knowledge on the issue seemed to be lacking. To do research on what happens in healthy people lives when they are made aware of their own health risks thus became pertinent, and medical screening was found to be a most suitable area wherein this is done to whole populations. When the HUNT Research Centre were going to measure the bone mineral density of women in Nord-Trøndelag, and tell them about their risk of osteoporosis, we were given an opportunity of studying how this affected these women's lives.

The HUNT survey was comprised of bone mineral measurements and questionnaires about the women's personal health status and history in relation to osteoporosis. This also meant that the survey provided an opportunity

- *To gain insight into women's knowledge and beliefs about osteoporosis*

To make decisions about whether a person wants to know her risk status when she feels healthy can be challenging in many ways. Whether it is best to know or not to know a potential health problem is both an ethically and personally challenging question. For those feeling healthy, finding out that they are not can be mind-blowing. To examine how the measurement of bone mineral density influenced the women of Nord-Trøndelag, we decided

- *To scrutinize some of the challenges faced by lay people in their interaction with disease categorization based on risk estimates*

All along my journey working with this project I had been grappling with reflections about whether there actually are any limits to the enterprise of modern medicine. Reading Williams and Calnan's (1996) analysis of the 'limits of medicalization' made me realise that medicalization was not as straightforward as the first impression had lead me to believe. Still, as there seem to be few things that cannot qualify as a risk factor, I decided

- *To present a critical analysis of the close connection between risk calculation and medicalization*

As the reader will notice when getting to the papers that present the outcome of this research, the chronological order of their publication is not in a perfect match with the order of the aims stated above. There are several reasons for this discrepancy, the main one being a lack of

linearity in my reflections on these issues. Other contributions have come as a result of the timing of the different opportunities to do the research, and a third influential factor has been the variation in time between the writing of the different papers and their actual publication. The order of the papers is therefore admittedly constructed, with the purpose of presenting the reader with a comprehensive story of the subject under study.

What observations a researcher makes and how he/she interpretes them depends on the position of the researcher. Before moving on to the theoretical perspectives that have guided my research, the reader will be informed about my position as a researcher, to better understand the choices that have framed this project.

Position of the researcher

As indicated above my research has been a journey spanning decades. My position as a researcher has thus developed along with the progress of my research. Pushed for an answer by one of our reviewers we claimed a critical realist position in one of the papers. With hindsight, and some regret, this is not entirely true. What is true, however, is that the statement reflects my blurred perception of an objective world and a socially constructed one, grappling with what Hacking (1999:14) has called the “difficult distinction between object and idea.” Rather than going into a discussion about essentialism here, I opt for the more pragmatic and simplistic reflections that have inspired my research. For a long time the words history and culture have made me reflect that things can be different. This has made me curious about the things we take for granted, and in particular things that are labelled as ‘natural’. Realising that most things are not inevitably natural has spurred me to ask critical questions about the status quo, which can be seen as putting my work within the frame of social constructionism (Hacking, 1999).

In the process of doing this research I have made the following statement about my position:

behind this text lies both scepticism and doubt in solid proportions. My scepticism is related to an apparently unlimited medicalization of the population, wherein resources are reallocated from the sick to the healthy. My doubts are related to how central dilemmas in health policy are to be solved, and thereby doubts about what constitute the ‘right’ decisions.

This scepticism was not always there, as my training as a psychologist left me with a conviction that prevention is better than cure. As I came to realize that this first impression might have been deceiving, I started on the journey towards more critical positions that is still going on.

My scepticism has influenced the issues that have become my subject of research. In this sense my research is ethically motivated, as an effort to contribute to the improvement of the human condition under investigation (Kvale, 1996). When performing the research, however, I have done my best to keep an open mind about the outcome, in a conscious strive to avoid drawing conclusions that go beyond my data.

This is a position that I have held throughout this project, and it still remains my position. What has changed, however, is my understanding of my subject of study. This understanding has changed as the research has given me further insight into these interrelated topics. These factual clarifications have not changed my initial doubts about what the right decisions are. Rather than finding simple answers that enable me to draw clear conclusions, I have learned that matters are much more complex than what they seemed to me at first.

Despite being critical about biomedicine I align with Roy Porter (1997) in his belief that it is the one current medical system that will remain dominant a hundred years from now. As indicated by my research question it is my position that our marriage to biomedicine will bring us good days and bad days. Rather than filing for a divorce, it is my belief that the most viable option is to work to improve the relationship. Summing up the above, it is my conclusion that my position is within reformist constructionism (Hacking, 1999).

In line with the description of the aims of my project I identify myself as a researcher close to what Kvale (1996) describes through the traveller metaphor. According to this metaphor the researcher is a person who goes on a journey before returning home to tell the tale of the conversations he has had with the people he has met on his journey. This concurs well with my personal experience of doing focus group research, which over the years has taken me to places and people I otherwise would not have met. Besides being a traveller, much of my research has also been performed in an armchair, reading and reflecting on the tales told by researchers that pursue the search for objective knowledge.

My position as a researcher has also influenced my choice of research tools. Without claiming that questionnaire-based research is without its virtues, I have a clear preference for

qualitative research. One of the reasons behind this inclination is my exposure to numerous questionnaires that asked me questions I sometimes found irrelevant and forced me to provide answers that were not really mine. To be able to learn from people that view things differently from myself, through various forms of qualitative research, has had far greater appeal to me than to be able to measure how thousands of other people respond to my limited edition of possible answers. A pivotal reason for doing research is discovering new things and hearing histories I have not heard before to gain genuinely new insights. Such insights will primarily be gained by asking open ended question and keeping an open mind to the answers, which I see as the main asset of qualitative research.

My curiosity for learning about other people's views has also led me to seek knowledge beyond my original academic discipline, psychology. Porter (1997) stated that the questions he posed regarding our present state (p. 7) may be questions fit for a psychologist to answer. I can thus claim to fulfil Porter's requirement to perform this study, but the scope of psychology strikes me as too narrow for the pursuit of this work. As research is becoming increasingly complex, no single discipline will manage to provide all the answers. To be able to work within the frame of various cross-disciplinary research groups has thus enlightened me about what can be offered from such disciplines as sociology, philosophy and medicine. Add to that my personal conviction that we can always learn a lot from history, and we have the mix that has inspired this project.

From the description of the aims of the study and my position as a researcher it is fair to conclude that this is not a project driven by theory. Although not driven by theory there are clearly theoretical perspectives that have guided the interpretation of my research stronger than others. It is to these perspectives we now move.

Theoretical perspectives

It has been observed that "risk looms large in present-day society" (Zinn, 2008a). As this thesis will show this is certainly true in medicine, whilst others have claimed that risk has come to define our present society (Beck, 1986). Judging from the rich variety of books and articles published on risk from various social science perspectives published in recent decades, there are ample theoretical perspectives to choose from. A complete review of the theoretical

literature on the social theories of risk is clearly outside the scope of this thesis. The interested reader will find a useful overview in Zinn (2008b).

When choosing my theoretical perspectives I have opted for those that I find having a scope that best embraces the scope of my empirical work. To be able to refer to such scholars as Beck, Douglas, Foucault, Giddens, Habermas, Luhmann, and Marx has been tempting. I have refrained from this as I see their work as having a much wider and less concrete scope than what is aimed for in this thesis. As my overall framework is within social constructionism I have opted for perspectives that have enlightened the social construction of health and illness, by applying various perspectives on medicalization, including that of scholars inspired by the work of Michel Foucault.

The social construction of health and illness

Ideas about health and illness vary across cultures and historical times. For the people living in a particular culture at a particular time these ideas are often taken for granted and as naturally given, whereas for a person from another culture or another time they may come across as strange, giving rise to a lot of questions. This situation is the basis on which the claim of health and illness as social constructions is built (Barber, 2010).

As social constructionism come in many shapes, its introduction here calls for a clarification of my own perspective. Among the challenges posed by social constructionism is the degree of reality in the phenomena under study. My perspective on this matter generally agrees with that presented by Brown (1995), acknowledging the existence of objective problems that we as humans make social constructions about. In the context of this thesis this means that I consider what in medical and lay terms are constructed as heart attacks, strokes and osteoporotic fractures are indeed real problems to the people experiencing them. I also acknowledge that what we know as biomedicine provides the most effective treatment of these problems today, giving it a dominant position among medical systems. In choosing a social constructionist approach, it follows that this thesis is about 'how illness is shaped by social interactions, shared cultural traditions, shifting frameworks of knowledge, and relations of power' (Conrad & Barker, 2010:569).

The core construction of this thesis is the medical concept of risk. As Ewald (1991) observed, anything can be a risk although nothing is a risk in itself. This point is also made by Heyman & Titterton (2010:11) who state that “In contrast to disease, pain, and death, risks never ‘exist’ independently of observers’ knowledge, beliefs and values.” A risk is furthermore a possibility of an unwanted event, but in many cases a risk also represents an event that will never happen. These statements illustrate very well some of the intellectual challenges that are posed by the concept of risk.

Before moving to a closer presentation of the medical concept of risk, it is useful to remind ourselves of the difference between the medical study of risk and the social science study of risk. Heyman & Titterton (2010) describes this as the distinction between the study of risk and the study of risks. Whereas risk in medicine is mainly studied with the purpose of reducing negative outcomes, the social science study of risk is focused on understanding risk thinking in society. Rather than managing risk, the social science study of risk focuses on the social processes that are involved in risk management (Alaszewski, 2006). In the presentation that follows I not only introduce theoretical concepts and perspectives, but also make an effort to place them in a historical context. This is done because I find this valuable for the understanding of the present situation.

Risk in medicine

Whether medicine has a ‘theory of risk’ is doubtful, but it most certainly has several concepts of risk. As such concepts are at the core of this study, I find it necessary to introduce it in this section.

Risk in medicine is tied historically to the development of statistics and probability (Hacking, 1990). Its place in modern medicine is well established, albeit controversial. Life insurance companies were the first to make risk calculations based on medical information, with the purpose of preventing their own bankruptcy by not selling life insurance policies to high risk customers (Rothstein, 2003).

Risk is a concept that reflects the complex causal relationships when epidemiologists seek to explain why various diseases occur. If the causation of a disease is monocausal and deterministic, it would be meaningless to talk about risk as the disease would then occur with

certainty. In medicine the belief in such monocausal models was held under what has been called the doctrine of specific aetiology (Rothstein, 2003). This doctrine was influenced by the 19th century identification of bacteria as a cause for infectious diseases, holding the presence of bacteria as a sufficient cause for such diseases. Although incorrect, it held for preventive purposes, as measures against the spreading of bacteria addressed a necessary cause of infections. A consequence of this is that preventive measures can be implemented despite imperfect knowledge about the causal mechanisms behind a disease. This imperfection has given a lot of room for negotiations around various public health policies, which has been eloquently described as the difference between sick individuals and sick populations (Rose, 1985). This insight gives rise to what has become known as the prevention paradox, implying that to achieve sickness prevention at the population level addressing people judged to have a low risk can be more effective than addressing those categorized as having a high risk.

The statistical discovery of correlation at the turn of the twentieth century laid the ground for modern epidemiology, and the doctrine of multifactorial aetiology. It provided a way of pairing disease with any other measurable factor that came to be known as risk factors. It did not necessarily lead to the discovery of causality, but it provided a relation that served well for preventive purposes. Although both the technology for risk calculation and a technology for risk factor measurement (blood pressure measurement) was available from the early parts of the 20th century, it was not until the Framingham Heart Study half a century later that the concept of the risk factor was introduced to epidemiological research and public health medicine (Rothstein, 2003). Another factor introduced around the middle of the twentieth century was medicines that could lower blood pressure, thus reducing the risk factor. This medical treatment of risk factors made a whole new disease categorization possible (Greene, 2007).

Throughout history there have been strong beliefs about associations between various behaviours and health outcomes, providing a strong link between morality and health. According to Brandt (1997) this linkage was broken with the introduction of germ theory and the belief in specific aetiology, which placed disease outside individual control. It was reintroduced, however, with the Framingham study which prepared the ground for the belief in the relation between individual behaviour and health. Basically this connection was established through the perceived control attributed to the knowledge about risk factors,

making it possible for individuals to choose their own fate. Such a belief can be contested in the light of social epidemiology, but for the purpose here it is important to note that this relationship made what has been called the medicalization of everyday life a distinct possibility. We will return to issue under the presentation of medicalization below.

In modern epidemiology risk is defined as the probability that a person will develop a given disease (Rothman, 2002). Despite the eagerness to measure risk at the individual level, most medical risk calculations are based on studies of groups. The transformation of group-based data into data meaningful at the individual level represents one of the major challenges when risk is communicated within various medical settings (Edwards & Prior, 1997). It also provides major challenges when public health policies are to be decided, research results are presented, or a single individual is making choices about his/her own risk behaviour.

Another complicating factor is the existence of several epidemiological risk concepts (Thelle, 2001). When the proportion of diseased in a population is calculated, the outcome can be described in terms of absolute risk. To know the absolute risk of one population has limited value if the ambition is either to understand the causality behind the disease or what measures that might help to prevent it. Epidemiologists have therefore developed several study designs for comparing the absolute risk in various populations. Doing so, they are able to calculate a relative risk, and thereby identify risk factors in the environment, life styles or bodies.

These concepts have further been developed in the discipline of clinical epidemiology, where risk reductions have become have important measurements of the efficacy of therapeutic and preventive measures in medicine. Such outcomes can be stated both in terms of absolute and relative risk reductions, and the concept of number needed to treat has also been introduced as a concept in the measurement of the efficacy of medical interventions. Clinical epidemiology can thus be seen as providing the tools that, paired with the ideological reflections of Archie Cochrane (1972), prepared the ground for the introduction of evidence based medicine (EBM) (Sackett, Richardson, Rosenberg & Haynes, 1997).

One of the consequences of the medical understanding of risk is that everybody can be seen as potentially sick, as we are all at risk of something (Armstrong, 1995). This knowledge has opened for new social identities as 'being at risk' (Novas & Rose, 2000), which implies that the person feels well, experience no symptoms, but has an awareness that the potential for becoming sick is always there (Scott, et al. 2005). Diagnostic uncertainty as the outcome of

medical surveillance can also be seen as leading to a status as ‘patient-in-waiting’, leading to extended medical attention over time as uncertainty prevails as to whether the person’s test results are to be perceived as normal or pathological (Timmermanns & Buchbinder, 2010). As medical treatment of ‘at risk’ conditions have become more frequent, a convergence between the experience of risk and disease has also been described. This has led to profound transformations in the lives of both the chronically diseased as well as those identified as being at risk. Among these are the constant and lifelong medication, continued screening and lifestyle modification. For the individual this development can represent a disturbance to peace of mind, whereas for society it carries substantial economic costs and carries the potential of making distractions from other health goals (Aronowitz, 2009).

It can thus be argued that the medical notion of risk has played an important role in making things that have historically been outside the realm of medicine become legitimate targets for medical interventions. Such transformations can be seen as examples of medicalization, which literally means “to make medical” (Conrad, 1992). To better understand what this implies we now turn to the literature on medicalization, keeping in mind that medicalization is another social construction.

Medicalization

Just like risk, medicalization has become one of those terms that has been integrated into our everyday language. In Norway the term is commonly expressed as ‘sykeliggjøring’, indicating the ability to define something or someone as sick. This coincides well with what can be seen as the classic way of defining medicalization in the professional literature. Medicalization has also for a long time been associated with something negative. As we shall see this is an association that is now being challenged.

The study of medicalization has been one of the central subjects in the sociology of health and illness since the late 1960s. It is worth noting, however, that the idea of medicalization has existed long before it caught the attention of social scientists. This point is vividly illustrated by this quotation from an interview with Søren Rognstad on his 90th birthday in 1916:

“Have you never been sick?”

No, says the old timer. We didn't know anything about sickness in the old days, as we didn't have any doctors or medicines or such things. And then, you know, people stayed healthy." (Inlandsposten, 1916). (My translation).

To date medicalization itself depends on how we define it. If medical doctors are seen as the only prerequisite for medicalization, it can be argued that it has been around as long as medicine, which in the Western world is traced back to antiquity and Greece (Porter, 1997). Another historical tracing of the concept indicates that medicalization has been around for the past couple of centuries, arising with the development of public health in the new national states (Nye, 2003). This correlates well with the observation that the idea of periodical medical examinations of healthy people has been dated back to 1861 (Han, 1997).

Others have traced medicalization to more modern times, related to the formation of the profession of medicine as we know it in the 20th century (Freidson, 1970; Collyer, 2010). Similar claims have been made by Conrad & Schneider (1992) who describes medicalization as a process reflecting the rising power of the medical profession, through the transformation of various forms of social deviance into medical diagnoses. In her recent description of the development of medicine Clarke (2010) describes the period from 1890 to 1945 as the rise of medicine, and medicalization as starting as late as after World War II, only to be replaced by biomedicalization around 1985.

In his most recent book on medicalization Conrad (2007) has defined it as a process wherein a nonmedical problem is transformed into a medical one. This definition is intended to be descriptive and aim to depict medicalization as a neutral term. Neutral as the definition may be, medicalization is very much a contested process, illustrated by what has been called the medicalization critique. A central tenet of this critique is that medicalization puts an individual in an undesired state of being, which should be resisted (Lupton, 1997). Another important part of the medicalization critique was the distinction between legitimate and illegitimate domains of medicine, seeing medicalization as illegitimate extensions of medical realm (Davis, 2006). Such extensions also at times appear under the name of overmedicalization (Conrad, 1992).

This conceptualization points to some kind of medical essence, indicating that something medical exists beyond the social construction of it. Conrad (2007) can be seen as doing the same when stating that it is beyond his expertise to assess what is *really* a medical

problem, as he indicates that somebody else may have that capacity. In one of his latest contributions to the medicalization literature Conrad (and co-workers) can be interpreted as having this capacity after all, as they make a distinction between medicalized and non-medicalized conditions in an effort to estimate the costs of medicalization (Conrad, Mackie & Mehrotra, 2010). Their own observation that their exercise may lead to discussion about the inappropriateness of medicalization underlines this. These examples illustrate two points; the challenge of holding a consistent social constructionist position, and the difficulty of being neutral about medicalization. In an effort to get around the question of medical essentialism Sadler, et al. (2009) have replaced 'nonmedical problems' with 'human problems' in Conrad's definition, thus defining medicalization as 'a process by which human problems come to be defined as medical problems.' (p. 412). In an even more pragmatic approach Clarke (2010) has offered the term 'things medical', indicating that it is what people construct as being medical that belongs there. Such notions of medicalization opens the possibility that medicalization can happen without the presence of doctors. As such this notion of medicalization challenges what for a long time has been the accepted conceptualization of it. Despite this, I find it appealing as it reflects the complexity of recent developments, refuting the depiction of medicalization as a tool reserved for doctors.

The medicalization critique

Among the classical contributors to the medicalization critique were such scholars as Freidson (1970), Zola (1972) and Illich (1976). Through terms such as medical imperialism and professional dominance they placed the medical profession in a cardinal position. Zola (1972) described medicine as replacing law and religion to become the major institution of social control in society. Illich (1976) defined the outcome of the professional dominance of medicine as a form of iatrogenesis, sickness inflicted by doctors leading to the medicalization of life. By doing so, doctors were depriving people of their ability to take care of their own health, rendering them dependent on the medical profession.

Among the negative outcomes of medicalization were its detrimental effects on women, through the reinterpretation of what had previously been seen as natural bodily processes into medical conditions. Although fostering a strong feminist criticism, it has also been concluded that the early sociological criticism of medicine overstated the medical

imperialism argument, whilst at the same time downplaying the benefits of medical interventions (Ballard & Elston, 2005). The medicalization process was also depicted as much more complex than what the original theories portrayed it as (Fox, 1977). Historically, the medicalization of women could also be seen as the outcome of interactions between doctors and women within particular historical contexts (Riessman, 1993). This illustrated how women were not merely passive victims of medicalization, but active co-constructors of it, and that this was particularly true for middle-class women.

In recent decades the medicalization critique has also been supplemented by texts taking a more positive angle on medicalization. Whereas it for a long time has been subject to feminist criticism, demands for more medicalization under a feminist ethos have now been aired. Rather than condemning medicalization altogether, the critique is aimed at what is seen as undesirable medicalization (Purdy, 2001).

We have thus far noted two notions complicating the construction of medicalization - that it can happen with and without doctors, and that it can be both positive and negative. As we shall see, the simultaneous appearance of limitations and expansions makes it even more complicated. Before we go there we also need to look at the medicalization of everyday life, which has been viewed somewhat differently within the medicalization literature.

The medicalization of everyday life

The connection between risk and medicalization is to a large extent related to the medicalization of everyday life. This connection was observed already by Zola (1972) in his seminal paper. To see health as the outcome of human behaviour was not a new idea, as this connection had been established through the religious construction of sin (Rosenberg, 1997). What was new was the secularized notion about behaviours, wherein scientific observations of risk became a part of the moral reasoning about health and behaviour. This placed the medical profession in a central position for social control.

Noticing that concerns about health had become a national preoccupation for the middle classes in the USA, Crawford (1980) introduced the concept healthism as the ideology making personal health a primary focus for well-being. Such well-being was achieved through certain life styles associated with good health, based on the assumption of individual

responsibility for health. This can be seen as one of the first observations where not only sickness, but also health were seen as being subject to medicalization.

One interpretation of healthism is that it can be seen as an effort by ordinary people to regain control of their health, as a countermeasure to what Illich (1976) called social iatrogenesis. Such an interpretation could furthermore lead to seeing healthism as a form of demedicalization, a description that also was offered by other scholars in the 1970s (Fox, 1977). A different interpretation was offered by Conrad (1992), however, when he argued that risks for what he called well-established medical conditions did not belong under his definition of medicalization. Instead he suggested that this should be called healthicization. This is a position he has since renounced, and he currently places risk and surveillance among the themes of medicalization (Conrad, 2007).

Whether a healthy lifestyle can be traced to medical dominance or is seen as the healthy choice of the well informed consumer, both represent a form of medicalization (Lupton, 1997). The defining factor is whether a person performs an act with the purpose of promoting health or preventing disease, not whether the idea came from a doctor or some other source of information on health matters. This concurs with my position on the medicalization of everyday life.

Limitations, extensions and expansions

Medicalization is rarely seen as complete and only a few conditions are seen as fully medicalized. No formal categorization or analysis has been performed on this subject, but Conrad (1992) has implied at least three degrees of medicalization (minimally, partly and fully). Competing definitions of a problem, availability of treatments, support of the medical profession and acceptance among the people affected by medicalization are among the factors influencing to what extent medicalization can be seen as complete or not.

Another conceptual issue is related to its limitations. Whereas the early notions of medicalization took the professional domination of patients for granted, later theorists have claimed that there are several developments in modern society that represent limits to medicalization. (Williams & Calnan, 1996). As a consequence medicalization is portrayed as

a process that will be subject to the lay population's reflections, challenging the authority of the medical profession.

Reflexivity among doctors can contribute to the limitations to medicalization. This is illustrated by what happens when patients experience symptoms, but doctors are reluctant to make a diagnosis, like in the case of chronic fatigue syndrome (CFS) which has been described as a situation leading to incomplete medicalization (Broom & Woodward, 1996). It has further been argued that this was a situation where medicalization should be mobilized in collaboration between doctors and patients, but with the avoidance of the involvement of medical dominance.

The ultimate form of limits to medicalization can be seen as happening through the process of demedicalization. This occurs when a problem is no longer defined in medical terms and is no longer subject to medical treatment. Demedicalization is extremely rare, however, and Conrad (2007) mentions masturbation and homosexuality as the most prominent examples. Medicalization is thus a difficult process to turn around once it has been established. Despite resistance from various groups in society, the general picture is one of an ever expanding medicalization.

Conrad (2007) thus also describes medicalization as going through extensions and expansions. The medicalization of male aging, through the construction of the andropause, baldness and erectile dysfunction are presented as examples of the former. Typically these are conditions that are established through interactions between aging men, their doctors and the pharmaceutical industry. Expansions may come in the form of diagnoses expanded to new categories of people, as when hyperactivity among children became an adult diagnosis. This is also shown when an effective treatment is expanded to wider groups of people through the design of diagnostic tests that lead to an expansion of the diagnostic category, as has been the case with serotonin reuptake inhibitors (SSRI) and depression.

Pharmaceuticalization

Parts of these expansions are clearly related to what has been called the shifting engines of medicalization. Through this shift the medical profession has lost its central place in medicalization to the pharmaceutical and biotechnology industry (Conrad, 2005), and the

perceived transformation of patients into consumers have provided a marketplace where doctors play a mediating role between other actors (Conrad & Leiter, 2004). This is seen as particularly true in the USA where direct-to-consumer advertising is allowed for prescription drugs.

Busfield (2006) stresses the importance of studying the production of scientific facts about drugs, and also talks about the importance of the drug companies' ways of proving the effectiveness of their products. Based on the global expansion in the use of medicines in recent decades, it has been concluded that prescribing medicines have become the dominant form of health care, in particular in high- and middle-income countries (Busfield, 2010). Cholesterol reducing drugs are furthermore among the best selling drugs world-wide, illustrating the impact of drugs with risk reducing qualities.

Some sociologists have also taken this analysis one step further by introducing the concept 'pharmaceuticalization', which Abraham (2010:604) has defined as 'the process by which social, behavioural or bodily conditions are treated or deemed to be in need of treatment with medical drugs by doctors or patients.' What makes pharmaceuticalization different from medicalization is that the former is the process that takes place when other ways of treating an already defined medical condition are replaced by drug treatment. In the case of risk factors this is what happens when life style interventions are replaced by chemoprevention. Where medicalization and pharmaceuticalization are seen as mutually reinforcing, as with health risks, Abraham (2010) talk about the 'medicalization-pharmaceuticalization complex'. The development of hypertension as a disease can be explained in this way, as illustrated by the half a century that passed from the availability of blood pressure measurements to the definition of it as a disease in its own right that appeared after the introduction of thiazides (Greene, 2007).

In an effort to describe a sociological program for the study of pharmaceuticalization, Williams, Martin & Gabe (2011) have identified several key dimensions for its sociological analysis. Although not being able to claim that their suggestions have inspired the work on the papers included in this study, several of the studies included in this thesis can be claimed to be in accordance with their suggestions.

Governmentality

Whereas the medicalization critique focused on medical power as a tool for repression of the population, an alternative interpretation of medical power has been inspired by Michel Foucault's writings. In these interpretations medical power is seen as being used for the benefit of the population, by persuading them to believe that their health will benefit from certain ways of thinking and behaving. Although never labelled as medicalization by Foucault, it has been interpreted as offering an alternative perspective on medical power (Lupton, 1997).

The theoretical framework on risk which has been applied in this work is the Foucault-inspired work on governmentality (Dean, 1999a). This concept is based on the combination of 'government' and 'mentality'. Government is further described as the 'conduct of conduct', which in modern society is achieved through the governments' ability to influence the mentality of its citizens. Among the goals of government is the health and well-being of its citizens, which is believed to be achieved by a certain conduct from the citizens. By convincing the citizens that abiding to such conduct is both moral and rational, the government is exercising its power. Risk thus becomes a tool in this exercise of power, through what is described as a calculative rationality (Dean, 1999b). In the context of health and illness this power is exerted with the aim of keeping the population as healthy as possible.

In this theorizing, risk is described as a social construction, as it is seen as not existing in reality. In its calculable form it is a number which gives significance to whatever it gets attached to (Dean, 1999b). Such attachments can be made through epidemiological calculations, identifying risk factors. What has been called the discourse of risk has been described as being central to public health practices in contemporary societies. The dominant theme of this discourse is the individual's responsibility to avoid health risks, which can also include such practises as undergoing risk assessments like various forms of screening (Lupton, 1995). In what has been called "the new public health" risk knowledge based on epidemiological studies provides the basis for guiding individual behaviour (Petersen & Lupton, 1996).

The perhaps most ardent critique of the medicalization concept has come from within the ranks of scholars standing on Foucault's shoulders. Nikolas Rose has claimed that medicalization has become a cliché. Rather than using the concept as a starting point for critical social analysis, he claims that medicalization has made us what we are (Rose, 2007a).

This is a position he has deepened in his analysis of the politics of life itself, wherein he claims that medicine plays an important role in this politics, which has largely been to the benefit of humans (Rose, 2007b).

The latest theoretical contribution to the literature on medicalization is somewhat harder to place. As it in part is based on the ideas of governmentality, and in particular the work of Rose, I choose to put in under this heading. Acknowledging the rising complexity in medicalization Clarke, et al. (2003/2010) argue that it has now reached an entirely new stage which they have named biomedicalization. The process of risk and surveillance can be seen as particularly salient in these developments. Where medicalization has focused on control over medical phenomena, biomedicalization is said to study the transformation of the same phenomena. It is thus claimed to cover nothing less than the technoscientific transformations of health, illness and US biomedicine. Its scope and ambition goes far beyond the work presented in this thesis, but it is still included here as a reminder of the complex theorizing that is currently framing the area of medicalization.

Osteoporosis

Major parts of this thesis are related to osteoporosis. For readers unfamiliar with this condition I find it appropriate to give a short description of the medical construction of it. In brief, the medical discourse on osteoporosis is summed up quite aptly in this message from a publisher promoting a book doctors are urged to read:

‘Osteoporosis is a devastating disorder with significant physical and psychosocial consequences. One in three women and one in 12 men over the age of 50 in the UK already suffer from osteoporosis, and every three minutes it is estimated that someone has a fracture due to this disease. However, due to the remarkable progress in the scientific understanding of its causes, diagnosis, and treatment, this disease is now largely preventable.’

(Researchandmarkets)

Whether this optimism is substantiated or not is open for debate, but the core message of ‘there is plenty of reason to worry, but help is at hand’ catches the modern medical ethos quite well. We will proceed with a more sober description, however.

In medical terms osteoporosis has a natural history related to a lifelong process of continued renewal of the mineral structure of the bone (Ballard & Purdie, 1996). It is when this process is disturbed that osteoporosis and eventual fractures will occur. To achieve the highest possible peak bone mass is believed to be the most important way of preventing osteoporosis. This is achieved early in life through dietary measures and exercise, in addition to avoiding such risk factors as smoking and alcohol abuse. The attainment of peak bone mass is followed by an age-related loss in bone mass. When women are more frequently affected by osteoporosis than men this is related to the higher peak bone mass achieved in men, and oestrogen's effect on the bone resorption/formation balance. Lack of oestrogen is thus depicted as having a major impact on the bone rebuilding process in women, although how this 'deficiency' affects men is poorly described in the medical literature.

In a frequently cited article, Cooper, Campion & Melton III (1992) have made a projection for osteoporosis portraying it as a world-wide health problem in the years to come. Their projection is based on population data and hip fracture incidence rates from various regions of the world. Whereas osteoporosis in the late 20th century was a disease affecting people in high income countries of the western world, this is believed to change drastically towards the middle of the 21st century. This is mainly related to demographic changes that indicate that by 2050 three quarters of all elderly people will be residents of Asia, Latin America and Africa. About 70 % of the fractures were believed to affect women, as 4.47 million women were projected to experience hip fractures in 2050. Although the authors see limitations to their projection, due to varying quality of available epidemiological data, they still believe their numbers to represent an underestimate of the incidence rates for low income countries. I do not make any assessment of the validity of the presented numbers, but take its frequent citation as an indication that it is against the background of these projections that the present preoccupation with osteoporosis and its prevention should be understood.

At the individual level osteoporotic fractures are characterised as painful, having disabling effects, and have also been described as contributing to excess mortality (Haentjes, et al. 2010). The present interest in the prevention of fractures can thus be seen against the background of a globally escalating health problem causing great suffering in the affected individuals. Much of this interest is related to the construction of osteoporosis as a risk factor for low impact fractures, and it is this notion of osteoporosis that we will be attended to in major parts of this thesis. Central to this understanding of osteoporosis is the WHO-definition,

which contains the classifications normal bone density, osteopenia and osteoporosis in addition to osteoporotic fractures (Kanis, et al. 1994). These categorizations are based on the normal distribution of bone mineral density in the population and risk assessments made by the medical expertise.

A prime example of the current medical interest in osteoporosis is the development of the Fracture Risk Assessment Tool (FRAX®) (Kanis, et al. 2010). As indicated by the name this is a tool which has been developed to identify individuals in need of treatment for osteoporosis, based on the presumption that effective treatment is now available. Whereas bone mineral density (BMD) has been the centre of attention in calculations of the risk of osteoporosis for some time, the 10 year fracture probability that is calculated in FRAX also takes into consideration a series of other risk factors. A somewhat unique feature of this risk calculation tool is also that it has been constructed to embrace the global variation in fracture risk.

A primary aim of the application of FRAX® is to identify people that are believed to benefit from drug treatment. This drug treatment is at present primarily provided in the form of bisphosphonates, which in randomized controlled trials have been shown to reduce the fracture risk among people with previous vertebral fractures, although the evidence about what can be achieved in people with osteopenia but without prior fractures is characterized as inconclusive (Eastell, et al. 2011).

This concludes the introductory part of the thesis. We will now proceed with the presentation of the methodology applied to reach the aims of this study.

METHODS AND MATERIAL

The diversity of the aims in this project has demanded the application of several research methods. Each method has been selected because it was believed to fit the purpose of its respective sub-study. My data are thus based on various sources such as literature data bases, academic texts, newspaper articles and interview transcriptions. Overall the study is qualitative in design, although it can be argued that the first sub-study clearly has a quantitative element. It would be possible to claim that this study contains elements of both methodological and data triangulation (Flick, 2007).

Literature study

The literature study that led to the identification of the risk epidemic in medical journals started off in an explorative fashion, as the findings simultaneously clarified the answers to some questions as well as generating new ones. Observing what looked like a trend led to a more systematic study of the publication rates in five year intervals. The chosen intervals may seem arbitrary in our accustomed thinking about decades, but the starting point was simply taken from the first year MEDLINE was available at the library (of the Norwegian Institute of Hospital Research).

The first sampling decision was to look for articles with the word risk(s) in title and/or abstract of the articles. This choice was based on the belief that if risk appeared there it could be considered as a significant theme in the article. These articles were then characterized as ‘risk articles’.

As the trend appeared the question arose as to whether this was merely a reflection of a general increase in the total number of articles published. To check this out the total number of articles published for the same periods as the risk articles were found. Then the percentage of risk articles was calculated, demonstrating that the percentage of such articles in MEDLINE increased in every five year period. Having done this, this search was repeated for several subsamples of journals. These subsamples covered some of the most prestigious and well read generalist medical journals in the world, as well as similar Scandinavian journals.

Another question that arose from the dialogue with other researchers around my findings was the question on whether the risk epidemic could be seen as the outcome of a

change in the academic vocabulary. To check this out the search procedure was repeated with the terms ‘hazard(s), ‘danger(s)’ and ‘uncertainty(ies)’ replacing ‘risk(s)’.

In addition other journals from the same countries were selected, mainly medical specialities that were considered to be ‘risk prone’, as anaesthesiology, and obstetrics and gynaecology. A couple of epidemiology journals were also added, as risk was seen as a particularly important concept in that field.

History study

Paper II is based on a selected reading of the medical literature through a strategic sampling of articles and other medical publications. As with other qualitative studies we tried to identify key informers in the form of medical publications that contained the most important information about the various medical definitions of osteoporosis. Starting with literature searches containing the terms ‘osteoporosis’ and ‘definition’ in the ISI Web of science database, we identified a first set of articles. From these articles we checked both the citations made in those articles, as well as articles citing them. Through this process we also came across other documents, of which reports from consensus conferences proved particularly useful.

Before starting the study we had identified the publication of the 1994 WHO definition as the endpoint for our study. We also sent a letter to the WHO asking for access to their archives, to be able to trace whatever documents they might have from the work of their expert group. Unfortunately, we never received any reply. In the early phases of our sampling we identified Albright’s work as the foundation for what can be called the modern medical understanding of osteoporosis. This helped us narrow the study to the time period from 1940 to 1994. From there on the work became more analytical in an effort to understand the historical development of the medical conception of osteoporosis. This was done by identifying the different forms of osteoporosis that were described in the literature and analysing the basis for these different conceptions of osteoporosis.

Media study

This can be described as a case study based on the articles that the newspaper Aftenposten printed in 1996 and 1997 covering what was then known as the Fosamax-case. By using the search engine provided on the newspaper's website using the Norwegian words for osteoporosis (benskjørhet), drugs (legemidler), and Fosamax. This material was sampled through purposeful sampling, as this newspaper's coverage of the case was found to be the most comprehensive coverage of it. After identifying the articles on the internet, they were also found on microfisch, so that the analysis could be based on the original print versions of the articles. Attempts to access more tabloid descriptions of the case were also made from Dagbladet and Verdens Gang, with a meagre outcome. The Aftenposten articles were then subject to a content analysis resulting in a narrative about the Fosamax-case.

Focus group study

The focus groups study that is the base for papers IV and V was designed as a prospective study, acknowledging the value of doing a study that would cover the women's reflections before, just after and some time after having the bone scan. This design was also based on descriptions of designs used when women's reactions to undergoing mammography had been studied (Swanson, McIntosh, Power & Dobson, 1996).

Focus groups were chosen as a method for both practical and principal reasons. The practicality was related to the fact that the interviews had to be performed in a different county than we as researchers live in. Locations for the focus groups were therefore chosen within a range of places being no more than two hours travel from Trondheim. Another very decisive factor on our choice of locations was the sites that HUNT Research Centre had picked for their screening. Among those locations we chose the towns, simply to avoid recruiting too many women that had made acquaintance before meeting with their group.

With the travelling distance that had to be covered semi-structured interviews with separate individuals was no real option, as that clearly would be outside both our time- and financial budget. The design was further influenced by our preconception that osteoporosis is an issue that may have a different significance to women at different times in their lives. Subsequently we decided to perform the study among different age groups. Our knowledge of the sampling for the HUNT screening also made us go for a further stratification in our

sample, selecting groups of women that had or had not experienced a bone scan before. Following Krueger's (1994) prescription that a focus group study should consist of at least three groups, our stratifications led us to three categories of women. With three groups for each category the total amount of groups became nine, and each group met three times.

In some places we were allowed to use the same locations as HUNT Research Centre used for their survey, whereas in others we used public buildings well known to our participants. We made sure that the sites of our focus groups could be reached by public transportation, as we anticipated that our eldest participants belonged to a generation of women who had not acquired a driving licence. In line with local tradition of hospitality we served refreshments during the group sessions.

The focus group discussions were done in the mode of a semi-structured interview, based on a structure of five core questions, which were followed up by the moderator depending on the topics the women brought into the conversation. We had allocated two hours for the group sessions, leaving around 25 minutes for each topic. All the questions had been printed out and copied, and were handed out to the participants. This made it possible for the women to see the questions, not only hear them. This gave us the possibility of posing somewhat longer questions than what is normally viable when the questions are asked verbally, which we saw as an advantage. Another advantage was that the moderator could lead the women's attention back to the paper in front of them whenever he felt that the conversation was getting too far off topic. To avoid women turning to the next question before being finished with the present topic of discussion, we passed the question one at the time rather than handing out the complete set at the beginning of the discussion. Before the start of each discussion we gave the women a briefing about what was expected from them, stressing that there were no right or wrong answers to our questions, but that their honest answers were the best data we could hope for. In addition we also asked them to make an effort to talk one at the time, not only because it would be considered polite, but because it would make the transcribing of the discussions much easier.

All group sessions were audiotaped on two cassette players. The double recording was done in an effort to have a back-up in case of equipment failure and the possibility of getting clear recordings from various positions around the table. We were always three people in the research team – a moderator, a co-moderator, and a person taking notes for identification

purposes. As we recorded the sound only, this last job was introduced to record who was talking. This was done by writing down the three first words uttered by the woman presently talking. Albeit not an easy task when the participants got warmed up, this procedure gave a good start to our subsequent transcriptions.

In the group sessions it was quite evident that we as researchers were seen as experts, leading the women to talk to the moderator and not to each other in the beginning of the first group meeting. Another common feature of the first meetings was that the women had quite a few questions about osteoporosis which they hoped to get an answer to. This became most evident at the very first group meeting, where the co-moderator (SF) had introduced herself as a medical doctor and epidemiologist specialising on osteoporosis research. As a consequence any question the women had that night was passed with a look in her direction, hoping for the expert's answer. As our purpose was to get access to the lay opinions and experiences this became a situation we had to deal with. In the rest of the study we did this by SF presenting herself as a researcher, without giving further information about her field of expertise. Furthermore, the moderator consequently returned any question directed at him to the group for further discussion. To calm the women's interest in getting expert answers we also made the deal with them that we would provide an expert to give a talk about osteoporosis for them at the end of the final group meeting. By doing this we believe that we created a win-win situation by meeting the participants' craving for information, whilst at the same time motivating them to turn up for a third meeting almost six months after the first two meetings.

Data analysis was performed in accordance with procedures described by Kvale (1996). For Paper IV we divided the material between us after reassuring that we had developed a common and reliable coding practice. For Paper V the data analysis was initially performed by one member of the team (JAS), and the data analysis was thereafter checked and discussed with the co-authors as a form of reliability-check.

Ethical approval for the project was given by the Regional Committee for Medical Research Ethics (REK) (Appendix). The participants were recruited by means of a personal letter (Appendix), sent by the HUNT Research Centre. This procedure ensured that we did not know the identity of our participants until they themselves replied to our query. Upon arriving at the location for the focus groups the women gave their written consent. In addition to giving their written consent they were also asked to sign a declaration of confidentiality

(Appendix). This was done in an effort to ensure that the women's confidentiality was ensured not only by the researchers, but also among the group members.

Critical reflection chapter

This paper does not contain any empirical data of its own. Rather it is based on a critical reading of the literature that concerns the development of medical guidelines based on risk factor epidemiology. As mentioned in the presentation of the aims it was originally spurred by my reading of Williams & Calnan's (1996) article on possible limits of medicalization, and also influenced by matters discussed within the Bioethics Research Group at NTNU.

A first version was presented and discussed at an international conference, and was among the presentations from the conference chosen to be published in an anthology.

FINDINGS

Paper I

Skolbekken J-A. (1995). The Risk Epidemic in Medical Journals. *Social Science & Medicine*, 40, 291-305.

Reflections on the prominent place of risk in thoughts about health and health care in the late 20th century triggered an interest in studying the risk concept in medical literature. The aim of this paper was to get a better understanding of the mechanisms leading to this observation, seen as an outcome of the social construction of risk in health and health care. This improved understanding came in the form of a description of trends in the occurrence of the term risk in the medical literature and the suggestion of hypotheses on the causes behind these trends. Covering the period from 1967 to 1991 the overall finding was that the frequency of risk articles (articles containing the word risk(s) in the title and/or abstract) had risen from 0.1 per cent in the late 1960s to around five per cent of the articles published in Medline in the early 1990s. A significant finding was that more than half of the then published risk articles had been published from 1987 to 1991.

Further analyses were performed on several subsets of journals from the UK, USA and Scandinavia. The overall trend was replicated in most of the subsets, to the extent that the trend was shown to be even stronger in the majority of the subsets. The general medical journals and journals in obstetrics and gynaecology peaked at 12 and 19 per cent, respectively. Although the American journals peaked higher than the rest, the overall trend was the same in all three geographical areas that were studied.

The overall trend was not replicated in journals covering anaesthesiology, though. This finding could be due to a lack of epidemiologically based articles in these journals. Such articles can be seen as taking a more prominent place in the other subsets of journals that were studied. The prominence of risk in epidemiology was further underscored by data from two epidemiology journals where risk articles constituted around half the published articles in the last five year period covered by the study. A manual analysis on the subset of articles from the Journal of the Norwegian Medical Association showed that the number of risk articles covering iatrogenic risk was by far outnumbered by articles on risks without iatrogenic origin.

One possible explanation behind what was now described as a risk epidemic could be a change in terminology. To look closer at this possibility further analysis were performed including the terms hazard(s), danger(s) and uncertainty(ies). The trend found in association with risk was not replicated for these other terms, underscoring the trend as unique for risk.

As the original article was published 16 years ago, it is fair to ask if its findings are still valid. The answer to this question is a very strong yes. Two minor updates have been published since, both showing that the risk epidemic is still rising (Skolbekken, 2000; 2010). The trend proved to be strongest in the last period studied, as noted in the original publication. This is still true today, making the developments in the last decade most interesting. As can be seen from Table 1, the number of risk articles published so far in the 21st century outnumbers the total number published before that decade; at any prior time in history.

Table 1. The risk epidemic in the 21st century.¹

YEAR	RISK ARTICLES	PUBLICATIONS	% RISK ARTICLES
2001	36 397	543 250	6.7
2002	39 357	560 434	7.0
2003	43 962	590 783	7.4
2004	48 491	635 180	7.6
2005	56 183	695 760	8.1
2006	62 160	741 376	8.4
2007	67 808	779 022	8.7
2008	75 326	827 541	9.1
2009	81 015	865 219	9.4
2010	89 835	923 711	9.7
TOTAL	600 534	7 162 276	8.4

¹ Based on a search performed in Pubmed on 2011-11-14.

Paper II

Santora, L. & Skolbekken, J-A. (2011). From brittle bones to standard deviations – the historical development of osteoporosis in the late 20th century. *Science Technology & Human Values*, 36, 497-521.

Osteoporosis is at present described as a major global public health problem, which has been predicted to become a catastrophic epidemic by the year 2050. In modern medicine it is understood as a skeletal disorder leading to increased risk of bone fractures at various skeletal sites in the body. The present definition of osteoporosis is clearly related to medical risk assessments, which represents a rather new approach to the medical understanding and definition of osteoporosis. Our aim for this article was to trace the historical transformation of the medical understanding of osteoporosis in the latter half of the twentieth century.

Although osteoporotic fractures have a long history in medicine, we took Fuller Albright's work around 1940 as our starting point. His studies can be seen as the first scientific study of osteoporosis, through the identification of its relation to oestrogen. This discovery led to the concept of postmenopausal osteoporosis, where a lack of oestrogen production is believed to affect the calcium metabolism. This again affects bone remodelling processes, eventually leading to osteoporosis.

Although Albright's model was widely accepted, it had limited impact in terms of diagnosis and treatment of osteoporosis. This limitation was due to a lack of measurement tools that could produce the necessary diagnosis of osteoporosis. It thus remained an enigma for several decades, as its only confident detection could be made by the occurrence of an osteoporotic fracture. Further research within this biological framework identified oestrogen imbalance, calcium deficiency, aging and heredity as the major causal factors behind osteoporosis.

As a consequence of these unfruitful developments, researchers eventually turned their attention towards early diagnosis of osteoporosis, in an effort to identify the best methods of prevention. Among the challenges faced in the transformation of the medical focus from causality to prevention, was the resolution of the definition of asymptomatic osteoporosis. This definition was based on the notion of osteoporosis as a statistical deviation disorder, and the bone status of the young population was given a central position.

The identification of asymptomatic osteoporosis was achieved through bone density measurements. Although technology for such measurements had been available earlier, the technological breakthrough in this field is related to the introduction of the DXA-machine in the late 1980s. Despite critical voices, this technology has since been at the centre of attention in the medical understanding of osteoporosis.

Central to this transformation was the shift from an individual focus on osteoporosis to one of populationbased epidemiological research. Recognized as a public health problem, osteoporosis became a topic for consensus conferences, identifying menopause as a time for identification of women at risk of developing osteoporosis. This new approach to osteoporosis originated in the USA, but has since spread worldwide.

Further efforts in seeking consensus about the definition of osteoporosis and the identification of the population that would benefit from early diagnosis eventually lead to the official definition of osteoporosis by the WHO in 1994. According to this definition osteoporosis is a bone mineral density value 2.5 standard deviations below the mean of the young adult reference range. This cut-off point was chosen as it was believed to be the point most accurately identifying those at risk of having osteoporotic fractures. Despite being widely discussed in the current medical literature, the WHO definition of osteoporosis has retained its hegemonic position in modern medicine.

The history of the transformation of the medical understanding of osteoporosis in the latter half of the twentieth century thus serves as a prime example of how the notion of risk has made a defining impact on the diagnosis of osteoporosis.

Paper III

Skolbekken, J-A. Risk reduction on the drug reimbursement scheme (Unpublished manuscript²).

² An earlier Norwegian of this manuscript was published in Norwegian in an anthology about risk (Skolbekken, 2001). (My translation).

The aim of this paper was to critically examine what in Norway became known as the Fosamax-case, which concerned the inclusion of a drug against osteoporosis in the drug reimbursement scheme. It is described against the background of public health as a common ground for many interests, but also as a battleground for conflicting interests. In this particular case the conflict was between the health authorities and a drug manufacturer, but it also involved doctors, patients, politicians and the media.

Knowledge about risk and its reduction is at present important in the discourse around preventive medicine. It is used by both health authorities and the pharmaceutical industry in their efforts to legitimize their interventions on people who otherwise perceive themselves as healthy. In the Fosamax-case the Norwegian health authorities and a multinational pharmaceutical company clashed on the interpretation of the efficacy of a drug that had been proven to reduce the risk of vertebral fractures in a randomized controlled trial. This disagreement was about the interpretation of the outcome of this research, but also a conflict between different economical interests.

The publicly available story of the Fosamax-case unfolded in the columns of the newspaper *Aftenposten*. In the initial phase of the story the health authorities were presented as the villains, denying suffering old ladies available treatment against osteoporosis. This treatment was provided by a drug manufacturer, who was denied their rightful economical compensation for their efforts in producing the most effective measure against osteoporosis.

A case of social injustice and discrimination of women was apparently resolved when the Norwegian parliament decided to bypass the health authorities and include Fosamax in the drug reimbursement scheme. This outcome was the achievement of a broad political coalition of female MPs.

Not long after this decision a new story was presented, indicating that the decision had been somewhat premature. Now experts appeared to tell about hitherto hidden facts that had not been taken into consideration before the parliamentary decision had been made. As a consequence the roles changed, as the pharmaceutical company now became the villain of the story. The climax of the case came when the company tried to stop the health authorities from publishing their health economical analysis about Fosamax by a court order.

Paper IV

Skolbekken, J-A., Østerlie, W. & Forsmo, S. (2008). Brittle bones, pain and fractures - Lay constructions of osteoporosis among Norwegian women attending the Nord-Trøndelag Health Study (HUNT). *Social Science & Medicine*, 66, 2562-2572.

According to the medical literature there are serious deficits in lay people's knowledge of osteoporosis. This conclusion is based on studies that measure women's ability to reproduce medical knowledge of osteoporosis. It does not, however, reflect people's understanding of osteoporosis in a wider social and cultural context.

To gain further insight into women's knowledge and beliefs about osteoporosis was the aim of this study, done amongst women undergoing bone density measurements as part of a follow-up of the Nord-Trøndelag Health Study (HUNT).

Pain was recognized as the most defining characteristic of osteoporosis, which was pictured through an old, bowed woman. More modern tales about the condition included a sneaking and invisible condition. Despite being acknowledged as a condition that had been around for a while, it was seen as one that only recently had been given its rightful recognition. This recognition was seen as a feminist breakthrough, as it had hitherto been outside medical and public attention due to its low status as a disease mostly affecting women.

A rising incidence of osteoporosis was attributed to the aging of the Norwegian population. Although chiefly a women's disease, anecdotal evidence also confirmed the belief that men could get osteoporosis. Falling played an important role in the women's assessment of their personal candidacy for osteoporosis, underscoring the significance of their lived experiences for these assessments.

Previous bone density measurements had led some of the elderly women to perceive themselves as fragile and porous, although they had no bodily experiences confirming this perception. Feedback from the bone density measurements provided confusion among the women, leaving them in dependence on professionals for information and reassurance.

A healthy diet and exercise were frequently described as factors that could prevent osteoporosis. Exercise was seen as a double edged sword, as it was hard to fit into the schedule of the modern double working woman. It thus became a source of bad conscience. Oestrogen therapy was also among the factors mentioned to have a preventive function. Whereas this measure was perceived as positive among the younger women, the older women's perception of it was clearly negative.

The origins of osteoporosis were described differently across generations, and with varying moral attributions. In the generations before them, the women saw osteoporosis as the outcome of the hardships of manual labour outside the control of those affected by it. In their own generation osteoporosis was seen as the outcome of a stressful, modern life. Although perceived as potentially controllable, their busy modern lives provided ample excuse for not making the most of this opportunity of prevention. No excuses were made for the present young generation, however, who were portrayed as being outright lazy with questionable eating habits, thus failing to exercise the expected self-governance.

Paper V

Skolbekken, J-A., Østerlie, W. & Forsmo, S. Risk categorization through standard deviations – the challenge of bone density measurements. A focus-group study among women attending the Nord-Trøndelag Health Study (HUNT). *Health, Risk & Society* (Accepted for publication).

Bone density measurements are central in the medical pursuit of early identification of osteoporosis. A prerequisite for this task is professional agreement about the categorization of osteoporosis. In this study aimed at scrutinizing the challenges facing lay people in their interaction with disease categorization based on risk estimates, lack of unified categorization proved to be a substantial challenge.

For the majority of women the bone density measurements were perceived as much more important just before and after the actual measurements, than they were six months later. In this sense undergoing a bone scan did not make very lasting impressions on them, as they were mostly told that their bone status was OK.

Prior to the measurements we noticed considerable variation in the women's expectations. A relaxed attitude was common, whereas among women who perceived their personal risk to be high expectations were tenser. For them the time before the scan represented a flux between hope of reassurance and fear of diagnosis. In general the opportunity of having a scan was seen as favourable.

Despite this the scans proved a fearful experience for some, as did the participation in the focus groups. This latter experience was related to the discovery of knowledge about preventable measures known by their peers, but not by themselves. To discover that one's bone mass had diminished despite following professional advice about a healthy lifestyle, was another negative experienced among our participants.

To comprehend the measurement outcome which was communicated in terms of standard deviations proved an insurmountable challenge in all of the focus groups. Not be able to make sense of the scores themselves, they were left at the mercy of the interpretation communicated to them by the professional staff at the scanning stations. The bone scan results also tended to undermine the value of their own lived experience, generating an insecurity leading several of the women to make private appointments for new scans.

Another reason for having a new scan was lack of trust in the measurements provided by HUNT. Their scans covered the wrist, whereas other bone scan providers offered scans of greater parts of the body. These scans were perceived as more trustworthy, a belief also supported by other health professionals the women had contacted. Further distrust in the bone scans were generated by the fact that HUNT and other institutions offering bone scans made different categorisations of osteoporosis. As a consequence some of our participants were told that they were osteoporotic by some professionals, whereas others told them that they were not.

Paper VI

Skolbekken, J-A. (2008). Unlimited medicalization? Risk and the pathologization of normality. In A. Petersen & Wilkinson, I. (Eds.) *Health, Risk and Vulnerability*. (pp. 16-29). London: Routledge.

The aim of this text is to present a critical analysis of developments in the past decade, which can be seen as an escalation of the medicalization of life. This escalation has come through the pathologization of normality and the removal of the divide between preventive and clinical medicine. Risk calculations combined with chemical modes of prevention are central in the way reality is ordered in modern medicine.

Whereas risk is outside the realm of our bodily experiences, it can be mediated through risk measurements and calculations. As part of a surveillance medicine designed to protect us against our unavoidable vulnerability, it is a constant reminder of just that vulnerability. Factors that tend to be easily measured, calculated and then manipulated have been given central positions in our efforts to control life itself. In the pursuit of this control the criteria for medical interventions have been substantially expanded, through the construction of pre-diseases. This has been achieved through the pathologization of normality.

In recent times we have witnessed what may be seen as the success of preventive medicine. This success is based on the development of various pharmaceutical products which have been proven effective through their risk reducing effects. To identify individuals in need of this chemical prevention computer programs have been developed. Promoted as news articles about research findings, appeals are made not only to healthy citizens, but also clearly to modern health consumers. In this communication a message of control is given priority over messages of uncertainty.

Whilst several observers have attributed a more central role to the pharmaceutical industry recently, it is clear that the observed escalation in medicalization is that it appeals to several actors in society. Backed by a scientific rationality and representing a sound business, appealing to the consumerist ethos, framed within the rights of the citizen and the duties of civil society, the potential of medicalization seems unlimited.

DISCUSSION

The findings and reflections from my six papers focus on various facets of modern medicine. The subjects under study can be seen as interrelated in many ways, as can the papers. A common feature of all the papers is that they are concerned with risk and medicalization. Three of the papers (I, II, and VI) cover these themes on an international basis, related to biomedicine as a global enterprise, whilst the rest (III-V) are focused on related themes within a Norwegian context. Osteoporosis is covered in all the articles from the Norwegian context, as well as paper II on the historical development of the medical understanding of osteoporosis. A historical perspective is also presented in paper I on the risk epidemic, whereas the rest of the papers have their focus in a more detached time-frame. Three of the articles (I, II and VI) are studies of professionally based representations whereas the focus groups study (IV and V) is based on lay people's views. Last, the paper on the Fosamax-case (III) involves the media representation of many voices, lay and professional.

Paper I gives furthermore a background picture for the study, whereas paper II-V present different sides of osteoporosis as an example of how the risk discourse has become central on various stages in society, before returning to the more general picture in paper VI.

In this section of the thesis I will discuss some of the issues that are raised in the papers, in an effort to demonstrate how they can be seen as contributing to the themes of risk, medicalization and osteoporosis. It takes the risk epidemic as a starting point, as a potential for making virtually everything statistically associated with a negative outcome a 'thing medical'. Then the focus turns to osteoporosis in an attempt to offer explanations for the medicalization of osteoporosis, including limits to this medicalization. Furthermore, the consequences of screening for osteoporosis are discussed. Methodological reflections are then offered, before some final reflections are made. These reflections cover such topics as lay acceptance and professional resistance against medicalization in Norway, alternatives to the risk discourse, and finally reflections on the dilemma of modern medicine.

The risk epidemic and the potential for medicalization

In the introduction to Paper I it was noted that the present preoccupation with risk seemed paradoxical given the present state of health affairs in the Western world. Taking the

governmentality perspective into consideration, the situation may not be paradoxical at all. Risk provides an opportunity of control through calculative rationality (Dean 1999ab), thus the medical literature on risk has become a vital part of the governance of ourselves and others.

As noted in the paper a substantial increase in the number of published risk articles appeared from the mid-1980s. It is perhaps accidental, but this provides an almost perfect correlation with Clarke's (2010) dating of the start of biomedicalization. Without further investigations this remains an issue for clarification, but it is outside the scope of my present work. There are stronger reasons to claim that the risk epidemic provides ample opportunity for the expansion of medicalization as described by Conrad (2007). How this expansion may happen through the expansion of what are defined as treatment groups was also discussed in Paper VI. The potential for medicalization comes from the way risk blurs the dichotomy between healthy and sick, normal and pathological. This leaves plenty of room for negotiating cut-off points for intervention, reflecting that these are modern ways of constructing health and illness.

A most striking feature of the risk epidemic is the actual number of risk articles that has been published. Also taking into consideration that the vast majority of articles that have been published are not risk articles, it seems safe to conclude that we are witnessing what has been called 'Big Science' (Price 1986). This illustrates that research has taken industrial proportions, providing considerable challenges for people that try to stay updated on the research in their own limited field. Then again, this also illustrates that research serves other purposes than the accumulative gathering of knowledge, career building being one of the obvious candidates.

As mentioned in Paper I, information technology is a pivotal instrument for the development of the risk epidemic. The rise in calculation power and the distribution of computers in society over the last couple of decades should not be underestimated when we seek to explain why there have been published more risk articles in the first decade of this century than the accumulative publication in all the preceding centuries. Calculating disciplines such as epidemiology and clinical epidemiology have contributed with their fair share of papers, as have recent developments in genomics.

In addition to the disciplines providing the numbers, the risk epidemic is also fed through a considerable number of papers offering interpretations of the numbers, whereas others are produced in an effort to disseminate numbers. As there is no general agreement on the interpretation of the numbers, this has stimulated further publications involving disputes over their interpretation. Add to that a considerable amount of papers that are being published about risk communication, which has become ‘the main work of doctors.’ (Smith, 2003). Ironically, the research presented in this thesis comes within this category of research that lives off and contributes to the risk epidemic.

Returning to the issue of the potential for medicalization, we can observe that just as surveillance medicine can lead to the definition of every human as ‘potentially sick’, so everything identified as a ‘risk factor’ carries the potential for medicalization. This is the basis for the medicalization of everyday life. Some risk factors carry a greater potential for medicalization than others. As has been argued in several of my papers this can be seen as particularly true for those risk factors that can be measured by a specific medical technology and also be reduced by a pharmaceutical intervention. In the next part of the discussion I will try to illuminate this further by using the example of osteoporosis, with support from historical observations about similar risk factors.

How can the medicalization of osteoporosis be explained?

As can be seen from the above question I take the medicalization of osteoporosis as a fact (sic). It can be argued, however, that this has happened three times over and in somewhat different manners, as part of the medicalization of everyday life, as part of the medicalization of menopause, and finally as the specific medicalization of osteoporosis. (As a matter of convenience I will refer to this medicalization as the medicalization of osteoporosis in the remainder of the text). These three forms of medicalization can be seen as co-existing. Before explaining this I will furthermore claim that osteoporotic fractures have never been medicalized, but have been a ‘thing medical’ for as long as we know. By this I mean that I do not know of other ways of handling fractures than within the frame of health and illness.

Three forms of medicalization

The first form of medicalization including osteoporosis can be seen as coming through the medicalization of everyday life, wherein osteoporosis is on the list of diseases to be prevented by a 'healthy' lifestyle. In accordance with the identified risk factors for osteoporosis, such a lifestyle should include a diet rich on calcium and vitamin D, bone strengthening exercises, abstinence from smoking and a moderate alcohol consumption (Ballard & Purdie, 1996).

Secondly, osteoporosis became a part of the medicalization of menopause through its aetiological connection with the discontinuation of oestrogen production in women. This medicalization originated from the 'discovery' of sex endocrinology in the first half of the 20th century (Bell, 1987). The introduction of the first synthetic oestrogen paved the ground for hormone replacement therapy (HRT), on the basis of the understanding of menopause as a situation that represents a hormonal deficiency. Although originally prescribed on symptomatic indications, the list of indications for HRT changed and expanded over time (Palmlund, 1997a). The link to osteoporosis is based on the understanding of oestrogen deficiency as representing a risk factor for osteoporotic fractures, which can be reduced by oestrogen treatment (Palmlund, 1997b).

The medicalization of menopause, defining all women as suffering from a bodily deficiency in the latter half of their lives, has been heavily criticized. Its adverse consequences on women's health and well-being have been characterized as 'enormous' (Meyer, 2001). Without going into the substantial literature on this issue, the point worth noting here is that HRT in retrospect has survived despite heavy criticism over many decades (Krieger, et al. 2005). Despite recent setbacks through the publication of the results from the Women's Health Initiative study, demonstrating that HRT can lead to an elevated risk of both coronary heart disease and breast cancer (WHI, 2002), current claims are still made that "estrogen replacement is an obvious treatment approach to counter the problems associated with the loss of ovarian function and subsequent estrogen deficiency." (Stevenson, 2011:197). The medicalization of menopause, and thereby osteoporosis, can thus be seen as a form of medicalization that has become limited compared to the time prior to the WHI-study. Thus it would be premature to state that we have witnessed a demedicalization of menopause.

The third, and specific, form of medicalization has come from the research identifying the loss of bone mineral density as a risk factor for osteoporosis.

The specific medicalization of osteoporosis

From a medical perspective great progress has been made in the efforts to treat and prevent osteoporosis over recent decades. This progress has been attributed to such achievements as the ability to diagnose osteoporosis before fractures occur, the efficacy of bisphosphonate treatment and the establishment of the WHO-definition of osteoporosis (Blake & Fogelman, 2010). Three such concurrent achievements may be seen as the result of a master plan. One way of explaining the current situation would therefore be to see it as the outcome of ‘disease mongering’ – “trying to convince essentially well people that they are sick...” (Payer, 1992:5). Recent developments have further been described as the outcome of the efforts the marketing departments of the pharmaceutical industry (Moynihan & Cassels, 2005).

In the American context the pharmaceutical industry has made dedicated efforts in putting the treatment and diagnosis of osteoporosis together. According to Grob (2011) the pharmaceutical industry funded much of the osteoporosis research. In an effort to aid people unaware of their need of treatment for osteoporosis in its direction, the manufacturer of Fosamax invested in a bone scanning equipment manufacturer prior to putting the drug on the American market. Having thus prepared the ground for the scans, the company furthermore financed a toll-free phone number that the public were informed about through direct-to-consumer advertising on television (Fausto-Sterling, 2005). Similar tactics, including fear arousing, have also been described to motivate American women for bone scanning and treatment against osteoporosis (Kazanjian, Green, Bassett & Brunger, 1999).

As has been pointed out, however, it is too simple to reduce this form of medicalization to “a clever marketing effort or a centrally planned form of medicalization...” (Greene, 2007:5). Without denying that the above achievements may have been planned, or that pharmaceutical marketing is effective, it can also be argued that the fulfilment of the mentioned achievements are less predetermined than they may seem at first sight. We will therefore look closer at the developments leading to the specific medicalization of osteoporosis. These developments can also be seen as example of what Abrahams (2010) calls the ‘medicalization-pharmaceuticalization complex’.

As shown in Paper II densitometry played a pivotal role in transforming osteoporosis from a clinical entity to a risk factor that could be subject to control. It is worth noting, however, that it did not take just any form of densitometry to accomplish this, but densitometry in the shape of the DXA scanner (Fogelman & Blake, 2005; Griffith & Genant, 2008). The craving for such a technology had been there for some time, but it had not been fulfilled. This illustrates that although technology can be claimed to be central to the invention of a disease (Hofmann, 2001), it takes the right technology to be introduced at the right time. This point is illustrated by other technologies that are presently used to identify people at risk. Although serving that purpose today, this was not always the case. One example is the ‘Pap Smear’ which at present is an established tool for cervical cancer screening. This technology was available for half a century before being accepted as ‘the right tool for the job’ (Casper & Clarke, 1998).

The sphygmomanometer is another instrument that was around for more than half a century before it became the tool we know it as today. Introduced early in the 20th century and widely distributed and used by medical doctors in the USA for life insurance purposes, it was not until the discovery of drugs with the ability of lowering blood pressure that it became a tool for the identification of people in need of antihypertensive treatment (Greene, 2007).

Greene’s (2007) account of the history of hypertension also shows that even when possible to lower a patient’s blood pressure, it was not necessarily seen as an acceptable option as it for a long time was seen as unethical among doctors to lower a person’s blood pressure. A reason for this was the belief that a high blood pressure was the heart’s adaptive process when faced with the challenge of squeezing blood through hardened tissues. To interfere in such a natural process was thus perceived as wrong.

The simplistic notion of medicalization by means of a master plan is further refuted by the knowledge that the antihypertensive effect of thiazides was discovered by accident. As Greene (2007) points out, the same happened to be the case with the drugs that later became central in the medical construction of what has become diabetes II. Summing up, the historical examples of the social construction of hypertension, diabetes II and hypercholesterolemia illustrates very well how what we today may perceive as taken for granted examples of disease mongering, as the outcome of complex processes that have developed over time. Drugs and diagnostic technology are central ingredients in these

histories, and the pharmaceutical industry a central actor, but these developments are far from linear. In this manner the analysis of expanding categories of treatment groups through the pathologization of normality (Paper VI) is limited to the present, whereas it could have benefited from a more historical approach.

Returning to osteoporosis, the second factor contributing to the perceived medical success is the efficacy of bisphosphonate treatment, which has become the most established drug against osteoporosis. As with other drugs that at present serve to treat risk factors that have become diseases in their own right, bisphosphonates come with a history. Although discovered late in the 19th century (Petroianu, 2011), it was not until well into the second half of the 20th century that they were used for medical purposes (Graham & Russell, 2011), and their introduction as a treatment for ‘postmenopausal’ osteoporosis came as late as 1976 (Eastell, et al. 2011).

The perceived efficacy of bisphosphonates has been established through randomized controlled trials. It was one of the first trials, the Fracture Intervention Trial (FIT) (Black, et al. 1996), which was involved in the controversy between the drug manufacturer and the Norwegian health authorities in the Fosamax-case (Paper III). As described there, and also in another paper about the communication of the risk reducing effect of other drugs (Skolbekken, 1998), there are reasons to challenge perceptions of drug efficacy based on the communication of relative risk reductions alone. Despite this, it is now the established view in medicine that the efficacy of bisphosphonates is well proven (Eastell, et al. 2011).

The last achievement seen as contributing to the successful treatment and prevention of osteoporosis is the WHO definition (Kanis, et al. 1994). This categorization provides a standardization of the risk of osteoporosis, preparing the ground for the identification of individuals seen as being in need of a medical intervention (Wylie, 2010). Although vital in the establishment of the WHO classification, the ability of bone density measurements to predict the occurrence of osteoporotic fractures has since been shown to be far from perfect. As a consequence, its suitability as a screening instrument has been questioned (Marshall, Johnell & Wedel, 1996).

A possible next step in the medicalization of osteoporosis

In the period from the establishment of the WHO definition research has been performed to identify other risk factors that can be applied in the prediction of osteoporotic fractures. This research has contributed to the development of the Fracture Risk Assessment Tool (FRAX®) (Kanis, et al. 2010). The application of this instrument serves the goal of identifying the individuals that should be offered treatment, and has been developed at the WHO Collaborating Centre for Metabolic Bone Diseases at Sheffield University. In addition to BMD, FRAX® includes such clinical risk factors as age, previous fractures, low body mass index, parental history of hip fracture, smoking habits, alcohol intake, use of drugs known to increase the fracture risk, among others. The instrument calculates the 10-year probability of hip fracture or a major osteoporotic fracture. It is freely available for use by anybody with internet access, and is located on the webpages of Sheffield University. In addition it is also available as an app for Iphone and Ipad. This enables a lot of people to calculate their own risk of an osteoporotic fracture, with the exception of one element - they still need to measure their BMD at a testing site. Until now, that is.

In a most recently published review, Kanis, et al. (2012) have concluded that it is now feasible to predict fractures by using the clinical risk factors in FRAX alone, so that BMD measurements are no longer necessary when making these predictions. This has wide implications and the FRAX-group highlights the possibility of making predictions widely available in countries with sparse facilities for BMD-testing. Considering the scenario that has depicted osteoporosis as an epidemic on the rise in some of the densest populated areas of the world, this can be seen as another important breakthrough.

An alternative interpretation is that we are witnessing an important step in the development of the medicalization of osteoporosis. As was described in Paper II, BMD has played a crucial job in the development of getting osteoporosis established as a risk factor. It became the chosen technology because of its perceived speed, accuracy and economy. With the new directions in the research related to the development of FRAX, an even cheaper, speedier and more economical approach has arrived. Described as a tool intended for primary health care, BMD-scans can now be replaced by a visit to the GP who will be able to offer the relatively simple screening test that FRAX is becoming. Knowing that FRAX is now also available through information technology, osteoporosis screening can now be offered to health consumers without involving doctors at the diagnostic stage. Doctors may thus in the

future become merely the intermediary, providing the necessary prescriptions. A logical next step may also be that drugs believed to prevent osteoporosis can become over the counter drugs, eliminating the doctor from the process all together. This fits well with the observation that “the growth of medicalization coexists with the diminishing of professional authority and power.” (Furedi, 2006:15). For the record; Kanis, et al. (2010) declared no conflicts of interest, several of the authors of Kanis, et al. (2012) declared the reception of ‘unrestricted research funds’ from a host of pharmaceutical companies.

Before moving on to the limitations of medicalization, there is time to place Paper III within the above context. One interpretation of the Fosamax-case is that it can be seen as an example of the pharmaceutical industry’s disease mongering tactics. At one level there was a dispute over calculative rationality, in the form of different interpretations of the efficacy of the drug expressed in messages about risk reduction. This dispute was mainly between the professional parties in the conflict.

Not being able to win this dispute, the company demonstrated that its repertoire was wider than the appeals for calculative rationality. By framing the case as a political issue involving social injustice and discrimination against women, alliances were formed which enabled the company to fulfil its ambitions by bypassing the health authorities.

It is tempting to see the case as an example of how American tactics of medicalization were applied in Norway. Such tactics may also be seen as playing an important role in the final outcome, as the frequently used American tactic of taking ones opponents to court backfired on the company.

Limits to the medicalization of osteoporosis

From the above it can be concluded that the pharmaceutical industry is an important actor in medicalization, which has also been observed by others (Conrad, 2005). Even so, there is also ample evidence that there are limitations to the medicalization promoted by this industry. If osteoporosis were to be fully medicalized we would expect to see a pattern wherein people would be knowledgeable about the risk of osteoporosis, the measures to be taken to prevent it, and the drugs that are available to treat it. Furthermore, such knowledge would be matched by a healthy lifestyle, adherence to screening, and compliance to therapy when needed. It could

also be argued that such knowledge and behaviour would be in accordance with governmentality. As we shall see, this is not the case.

Knowledge about osteoporosis is seen as a prerequisite for its successful prevention, although other factors are seen as equally important for preventive behaviour to occur. Studies from around the world has been summed up as painting a rather glum picture, as knowledge about prevention, therapy and the consequences of osteoporosis are characterised as generally poor (von Hurst & Wham, 2007).

In addition it has been shown that women underestimate their risk of osteoporosis (Gerend, et al. 2006), which is seen as impeding their screening behaviour (Nayak et al. 2010). Such findings are not unique for the risk of osteoporosis, however, and several psychological mechanisms have been suggested as explaining why people do not feel personally at risk (Chambers & Windschitl, 2004; Taylor & Brown, 1988; Weinstein, 1980). What has been labelled as poor risk awareness has also been observed among women who have been diagnosed as having osteoporosis, including those taking medication against osteoporosis (Siris et al. 2011).

When lay people's knowledge of osteoporosis is characterised as deficit (Giangregorio, et al. 2010), limited (Costa-Paiva, et al. 2011), inaccurate and insufficient (Jalili, Nakhae, Askari & Sharifi, 2007) in the professional literature, it is interesting to notice what is defined as knowledge in this literature. A striking feature is that what goes as knowledge in the medical literature is mainly seen as right or wrong notions of osteoporosis. Among answers perceived as wrong is a disease of the bones without further specification, describing it as a crippling disease, or as a disease resulting in a crooked spine without telling that it is a disease of the bones. Believing that 'walking has a great effect on bone health' is wrong according to NIH guidelines, although this is characterised as confusing by the researchers (Giangregorio, et al. 2010). Another conclusion from this Canadian study is that the participants' knowledge was even poorer on risk factors for osteoporosis than for osteoporosis as a manifest disease.

Somewhat opposite conclusions to the global picture have been drawn about the knowledge about osteoporosis among Norwegians. A national survey indicated that the knowledge of osteoporosis and its consequences were generally high among both men and women (Magnus, Joakimsen, Berntsen, Tollan & Sogaard, 1996). Furthermore knowledge was found to be higher among women than men, and higher among the young and the well-

educated. Looking at the questions posed in this survey, however, there is reason to believe that the Norwegians passed an easier test than their counterparts in other countries.

Reviewing the medical literature studying knowledge about osteoporosis, Werner (2005) concluded that it was characterized by a lack of theoretical framework and methodological flaws. These flaws were mainly defined from a positivist position, addressing such issues as lack of randomization, cross-sectional design, and so on and so forth. Reading the review from another perspective, it can also be argued that a problem with this literature is that it is decontextualized and reductionistic, which leads to a limited comprehension of lay people's understanding of osteoporosis.

In biomedical terms the knowledge of osteoporosis is a universal knowledge, valid all around the world. Qualitative studies provide illustrations of how this knowledge is interpreted within a cultural frame, however, as when the late Danish Queen Mother became an icon for osteoporosis in Denmark (Reventlow & Bang, 2006), and when falling over on icy pavements has become a real life test for osteoporosis in Norway (Paper IV). One limitation to the medicalization of osteoporosis may thus also be seen as coming from medicine's failure to look outside the box of calculated rationality.

Looking outside this box it has been observed that middle-aged women show little or no interest for osteoporosis (Beckett-Milburn, Parry & Mauthner, 2000). In this group knowledge about osteoporosis was greater among those having personal experience with osteoporosis in their local community and social network than among those without such personal points of reference. Furthermore, this study showed that what the researchers interpreted as resistance against medicalization was based on the everyday experience of lives filled with more pressing issues than their future risk of osteoporosis. This illustrates that one of the major limitations for medicalization in modern society is the lack of time available for it. Time available for the medicalization of everyday life, that is. As medicalization in the form of chemoprevention is less time consuming, this could become a more appealing form of medicalization, as has been observed in the US (Greene, 2007). Such appeals have also been observed as part of the disease mongering repertoire of the pharmaceutical industry, by means of advertising campaigns telling that efforts to achieve lifestyle changes are basically in vain, making chemoprevention a more viable option (Malterud, 2002).

The cultural context also plays an important part in the medicalization of osteoporosis, which is illustrated in Paper IV. As indicated in the paper both the Norwegian Women's Public Health Association and the HUNT Research Centre have contributed to this in Nord-Trøndelag. Among our participants, accepting the screening offered by these two actors was perceived as a benign form of medicalization, i.e. medicalization was not a word mentioned in the focus groups. We noted only one limitation among our participants, the experience based resistance against HRT among the elderly women.

As the Scottish women our participants expressed a limitation to the medicalization of everyday life as there was limited time for it. Their report of bad consciences for not living up to the perceived expectations of the health promoters indicated that they had accepted the idea of medicalization through self-governance. Furthermore, they reported to a much larger extent than the Scottish women knowledge about the lifestyle expected to prevent osteoporosis. These differences can be seen as reflecting the different position of osteoporosis in the respective cultures, but it may also reflect differences in the research designs. Whereas the Scottish study had a low profile about osteoporosis as the theme of interest, osteoporosis was the prime concern in our study. Ironically, the awareness created by participation in HUNT, and in follow-up studies like our own, can clearly be seen as contributions to the medicalization of osteoporosis.

A final limitation to medicalization to be mentioned under this section is the possibility of the existence of a 'screening saturation'. This has been illustrated by a Belgian survey among female employees at a university hospital. Despite showing a high uptake on various medical screening procedures, including pap-smears and mammography, the relative uptake on bone density measurements was small (Rozenberg, et al. 1999). This may indicate a prioritizing among screening procedures when they are offered in abundance. Again, this may be seen as reflecting that there is limited time available for medicalization, even among those favouring it.

The limited appeal of drugs against osteoporosis

Another limitation to the medicalization of osteoporosis is the failure of patients that have been prescribed drugs against osteoporosis to actually take their tablets. This situation is not unique for this kind of medication, but can be seen as a universal phenomenon. In real life this

threatens the efficacy of drugs that have been proven to be so in RCTs. Compliance, persistence and adherence are the medical terms used to describe the patient's behaviour in relation to medical instructions. Adherence is the combination of compliance (the taking of the pill) and persistence (the length of time the pill is taken) (Lee, Glendenning & Inderjeeth, 2011).

In a recent review, poor compliance is summed up as a major problem related to bisphosphonates. Many patients stop taking their medication, in particular during the three first months. Although this behaviour can be seen as the outcome of forgetfulness, it was further concluded that in most cases it is the deliberate choice of the patients to stop the medication. The reasons for these choices can be such factors as direct experience of adverse effects, believing that the risk of osteoporosis is small, scepticism about the effectiveness of the drugs, worry about long term side effects and not being able to afford continued medication (Silverman, Schousboe & Gold, 2011). In the professional literature bisphosphonates are described as generally safe, with few serious side effects. The most common side effect, however, is gastrointestinal pain which is perceived immediately. This is the most common reason given by patients who stop taking their medication (Pazianas & Abrahamsen, 2011). Non-compliance has also been found to be a problem related to the consumption of calcium and/or Vitamin D (Sanfelix-Genovés, et al. 2009).

Our study did not cover this topic, but there are indications that non-compliance is less of a problem in Norway than what has been reported elsewhere. A study based on data from the Norwegian Prescription Database has shown that $\frac{3}{4}$ of the users of drugs against osteoporosis refilled their prescriptions annually over a three year period. Another noticeable finding from the same study is that the Norwegian counties with the lowest incidence of hip fractures are the counties with the highest prescription rates. As the incidence rates are historically based, they are not the outcome of the drug use (Devold, et al. 2010). This may thus be seen as a local Norwegian pattern of medicalization. According to the study some of the lowest prescription rates were observed in the two Norwegian counties without DXA-machines.

Identification of the people in need of osteoporosis treatment is at present seen as a crucial step in the prevention of osteoporotic fractures (Kanis, et al. 2010), and securing the patients' understanding of their bone scan outcome is furthermore seen as a prerequisite to

ensure persistence with osteoporosis therapy (Brask-Lindemann, et al. 2011). In the medical literature BMD measurements are mainly understood within this frame of reference. Below we will present data from a different frame of reference; that of bone scans as experienced by the women being scanned.

Before doing so it is worth noting that limitations mentioned above are not the outcome of an ideologically based resistance against medicalization, as was the case with the medicalization of menopause and other natural processes of the female body. As was shown in Paper III the parliamentary decision to put Fosamax on the drug reimbursement scheme was at first hailed as a feminist victory. Similarly, the participants in our focus groups also saw their bone density measurements as being a feminist victory (Paper IV). From this it can also be possible to make a distinction between two sorts of limitations to medicalization, the intended and the unintended.

What are the consequences of screening for osteoporosis?

As observed in the introduction, questions have been raised about whether there exists a pathology of prevention (Sachs, 1995). This question was based on the observation of what happened when people feeling perfectly healthy were given feedback about their cholesterol levels which labelled them as being at high risk. Faced with 'scientific proof' that their own bodily experiences were wrong, led to confusion and strong reactions (Adelswärd & Sachs, 1996).

This concern was also the main reason for performing our focus group study, and as shown in Paper V having a bone scan proved to be a mixed blessing for our participants. The majority felt reassured by a negative scan, whereas some experienced confusion and worry albeit having a negative scan. This was caused by contradictory messages about their status and the trustworthiness of the applied technology. Such concern led to active pursuit of what was believed to be more reliable screening results from alternative screening providers. Rather than fostering a resistance against medicalization, the craving was for better medicalization among those not trusting the technology offered. When comparing our study with other studies of women undergoing bone scans, there is good reason to believe that this outcome cannot be seen as a generalizable consequence of having a bone scan, but was related to the particular context of our study.

Another noticeable effect among our participants was the confusion caused by the format of the feedback, by means of standard deviation scores. Confusion has also been reported from a group of British women interviewed after bone scans. Their confusion was related to an unclear understanding of the outcome of the scans, but also because the scans could be interpreted as showing that healthy behaviour had been in vain (Salter, et al. 2011). This is similar to effects experienced by our participants and this has also been reported by others (Griffiths, 1999; Richardson, et al. 2002). This confusion is not triggered by having the scan alone, but by the conflicting messages communicated through health education and the actual risk status indicated by the scan. Having a scan may thus undermine the belief in the value of a healthy lifestyle.

In contrast to these findings, no confusion was reported in a Danish study asking women who had had a bone scan of its outcome (Brask-Lindemann, et al. 2011). One explanation for this may be that the outcome was primarily given as a diagnostic category (osteoporosis/osteopenia) and not as a number that the women had to interpret themselves.

Reassurance was another outcome from our study, which has also been noted among British women. These women expressed confidence in their screening service, despite demonstrating what was described as ‘incomplete understanding’ of the screening outcome. This led the researchers to conclude that the women rely heavily on health professionals when it comes to defining their individual risk of osteoporosis (Green, Griffiths & Thompson, 2006). This is similar to our observation that the perceived reassurance among our participants relied heavily on the explicit feedback from health professionals that the scan was ‘OK’. A common feature in all three studies is thus the dependency created by the screening, which revives old notions of negative medicalization through professional dominance.

An even greater dependency on health professionals in relation to BMD measurements has been noted among a group of elderly British women (Weston, Norris & Clark, 2011). For these women a positive screening result was reluctantly accepted as an inevitable consequence of getting older, although the lack of symptoms led them to downplay the seriousness of the condition. Despite the described difficulty of understanding the diagnosis, they all reported great trust in their GPs, leading them to accept medication for osteoporosis. These women were furthermore not aware of other measures to improve their condition than taking the prescribed medication.

Apart from checking people's risk status, a leading idea behind scans is that they should lead to greater risk awareness and improved health behaviour. The opposite has also been shown to be true, as women who have received scanning feedback indicating that they are osteoporotic or have lowered bone mass have responded with impaired physical activity (Reventlow, 2007). This response is fear aroused, but passivity may not be the only possible response. In a group of Swedish women fear has been reported as the basis for what has been labelled 'healthy risk awareness' which has been described as guiding motivation for risk reducing behaviour such as physical exercise (Hjalmarsson, et al. 2007).

Scanning feedback to the Danish women was given by means of graphic presentations on a screen, and not as numbers (Reventlow, Hvas & Malterud, 2006). These images left lasting impressions that were vividly reconstructed years after having the scans. Among the most vivid images was the metaphorical image of a collapsing building (Reventlow, et al. 2008). When the interest in, and recall of, the bone scans faded rather quickly among our respondents, this can be explained by the 'screening negative' outcome experienced by most women in our study, but also by the less imaginable nature of the standard deviation number (Paper V). Another quality of the 'screening positive' outcome among the Danish women was the integration of risk information from the scans into their interpretation of their own bodily experiences (Reventlow, Hvas & Malterud, 2006). Once having received the message about having osteoporosis, back pain could be interpreted as a symptom of osteoporosis. This can be seen as an example of the fusion between risk and disease. Similar experiences were reported among our participants that had been told they had osteoporosis on previous scans (Paper IV).

A noticeable feature of all the studies discussed above is that they are all European and they have all used health surveys as their base for recruiting participants. This influences the generalizability of the data, in the sense that there may be a selection bias among the participants in these studies. None of them have shown similar impact on participants as those that were found among the Swedish men screened for hypercholesterolemia. A possible explanation for this is that the risk of osteoporosis rarely has the drama of immediate lethality that can be connected with a risk factor for CHD. Despite this, it seems fair to conclude that screening for osteoporosis can have a significant impact on the lives of those that are told that they have osteoporosis.

METHODOLOGICAL REFLECTIONS

In this section of the thesis I will present some reflections on the methodology applied in my research. Rather than applying a check list approach I will offer critical reflections about what I see as strengths and weaknesses of my research. Where I find appropriate I will also reflect on such issues as validity, reliability and generalizability of this work. When doing so it will be from a social constructionist perspective, acknowledging that these concepts are also social constructions and not representing laws of nature (Kvale & Brinkmann, 2009).

The main strength of this thesis is that it illuminates the subject of study from many angles. In doing so I have taken on the role of what has become known as a bricoleur (Denzin & Lincoln, 2011). Portrayed as a handyman, this researcher metaphor can also be described as a ‘Jack of all trades’, instead of a master of one. In this metaphor lies also the major strength and weakness of this thesis.

As mentioned in the description of the methods this research can be seen as containing both methodological and data triangulation. Following my explorative travel through the aims of the sub-studies it is my conclusion that this triangulation is accidental, or the outcome of opportunities taken rather than the outcome of some intelligent scheme I can claim to be my own.

Through its elements of triangulation the study has made it possible to illustrate some of the complexity involved in the matters studied. On the other hand, such illumination from many sides may also have left spots that have remained in the shadows. The papers of this thesis can thus be seen as sub-studies that could have been developed into projects worthy of their own, separate PhD-work.

Paper I

Methodologically the risk epidemic paper can be seen as simple, but solid. It is based on a step by step search strategy, whereby its validation was done by checking out questions that could invalidate the finding. It is also based on an openly available data source which makes it well suited for replication. A replication of sorts has been performed by Heyman & Titterton (2010), who have demonstrated the increased frequency of articles combining risk and coronary heart disease.

Another potential strength of the paper is that it has been well received among other researchers. This is illustrated by the number of citations registered in Google Scholar and the ISI Web of science, which is 200 and 88, respectively. Without having performed a review of the citations, it is my impression from the citing articles that I have read that the citations are generally used to establish a fact about the position of risk in modern medical discourse. It may have escaped me, but I have not come across texts that question or challenge the content of the article. Herein lies a potential problem with using citations as an example of validation of the study, as the people citing it may have failed to ask critical questions about it beyond the face value of the rising numbers. As Medline covers more than medical journals, there is a slight possibility that articles from other sub-disciplines may have contributed to the epidemic as well. Checking out the increase in risk articles in specific journals can be seen as a validation of the risk epidemic happening in the medical journals, though.

Paper II

In retrospect the title part "... the historical development of osteoporosis ..." can be seen as too ambitious. Replacing "the historical" with "a history of" would have acknowledged that there is more than one history about the development of the medical understanding of osteoporosis. From a social constructionist position this is perhaps the only truly viable option. This point becomes rather obvious when reading the histories published by Wylie (2010) and Grob (2011).

Our own presentation has a further limitation in that it is based purely on the academically published literature, whereas Wylie (2010) has had access to some of the central actors in the development of the WHO definition of osteoporosis, and Grob (2011) has benefited from the use of non-academic publications as well. This has contributed to an illumination of the role of the pharmaceutical industry, which is missing in our analysis. A possible strength of our paper, however, is that it covers more in depth the various medical positions that were held prior to the introduction of the WHO definition. There is, however, no indication that what has been presented in the two other studies invalidates our observations.

The three histories cover the topic with variation in focus, and can be seen as providing a thick description of the medical understanding of osteoporosis. This description

would become even thicker if it were to include the perspectives of other stakeholders as well. As with other topics of historical research, there are still numerous other accounts that could be given.

Paper III

As with the previous sub-study this study could have become richer if additional sources had been applied. To interview the actors involved in the case would have given access to a deeper understanding of their positions. The major limitation to this study is that it depends too much on one source – the coverage of *Aftenposten*. It can thus be seen as giving a valid presentation of this coverage, but it cannot be generalized as to telling the complete story of the Fosamax-case. Applying both methodological and data triangulation in this study would have made it into a proper case study.

Papers IV & V

In this study we chose focus groups mainly for practical reasons, and we acknowledge that the study could have improved if we had been able to combine focus groups with individual interviews, as was the case in the Danish studies performed by Hvas and Reventlow. Our prospective design made it possible for us to follow the screening experience as a process when it happened. We have come across only one other study with a pre-post screening design (Richardson, et al. 2002), which makes our study quite unique compared to other studies that have all used retrospective designs, interviewing women that they have identified as having received the message that they are osteoporotic.

There are two major limitations to the generalizability of our study: that it was based on a population of women participating in a health survey, and that another form of scanning than DXA-scanning was used in the HUNT survey. The women recruited for our study were probably better educated than most women in Nord-Trøndelag, and in particular in relation to osteoporosis. Despite this we noticed that many of them came to the focus groups with questions they were eager to get an answer to. If this reflected a genuine lack of knowledge about osteoporosis, it seems fair to conclude that it is probably lower in other segments of the population. Despite these limitations, our data still contains similarities with findings from

other studies, which make it possible to claim that these elements tell something about the general experience of screening for osteoporosis.

‘How many participants do we need?’ is the classic question for any research study, and in particular for qualitative research (Kvale, 1996). In retrospect we can conclude that we included too many in our study, as much of the information we gathered was repeated several times over in the various groups. Under other circumstances we would probably have done well to stop before we reached nine groups. As our logistics pretty much depended on the order of the bone scanning, however, these decisions were not entirely ours to make. From a methodological perspective we would have benefited from doing analysis between the group sessions, to be able to use these analyses actively in the forthcoming groups. Doing so would have made it difficult to follow the logistics of the bone scanning, which is the main reason for not starting analysing the data in between group sessions.

Furthermore the setting of our study, in particular the questionnaire that the women responded to as part of the HUNT study, may have influenced the information that the women were sharing in the group discussions. Another factor that may have influenced the discussions was the presence of women who were familiar to one another. Although choosing towns to avoid this, we noticed that several of the groups contained women who knew each other. We did not notice that these prior relationships affected the discussions in particular ways, but there is a possibility that some of the participants may have withheld information in the presence of other participants whom they knew they would face later outside the group settings.

Another presence that could influence the participants’ willingness to share information was the male moderator. Although remarks about this were made by the participants, in particular when ‘feminist issues’ were discussed in the group, it was also clear that they considered the moderator as outnumbered. As commented in Paper IV, and in the methods and material section of this text, the presence of a doctor claiming to be an expert on osteoporosis had a very specific effect. This is an issue that has also been observed by others (Griffiths, 1999; Reventlow & Tulinius, 2005; Hvas, et al. 2005). We believe, however, that we handled this situation in a way that benefited both the participants and the study, by acknowledging their need for information by providing it at the end of the last group session.

In performing the analysis of our data we strived to achieve a sort of interrater reliability. This does not mean that our analysis represent objective facts, rather we see them as representing the outcome of our efforts of reaching intersubjective agreement.

Paper VI

Although qualitative research is rarely open to exact replication in the manner a chemistry experiment would be, to make the methodology as transparent as possible is still an ideal for qualitative research. Among the challenges I have faced when writing up this thesis is reflecting on what is meant by a critical analysis in this paper. In doing so I have come to realise I have done this analysis based on a form of tacit knowledge. In retrospect it seems as a type of knowledge I have picked up during my travels in academia, without actually being able to point to any specific references.

This paper and its analysis can partly be seen as having been subject to a communicative validation through its presentation at an international conference, and then through the peer review process prior to its publication. In retrospect it is my reflection that it would clearly have benefited if the insights offered by Conrad (2007) and Greene (2007) had been available at the time when it was written. Then again, that would be asking for the impossible. Rather, it should be taken as the best I could do under the circumstances. Hopefully the analyses offered in this thesis can be seen as a development and an improvement of my previous work.

Ethical reflections

Most of the texts included in this thesis are texts about other texts, placing them in a different ethical category than the two papers that include research on humans.

The focus group study was performed according to ethical guidelines, following standard procedures for securing autonomy through informed consent and voluntary participation, confidentiality through anonymous transcripts, and integrity through respectful listening, data analysis and presentation of the research findings. Despite following these guidelines, we experienced a couple of issues that caused ethical concern.

The first concern was raised when we experienced that some of the women had experienced fear as a consequence of participating in the groups. This fear was triggered by

the experience of not being as knowledgeable about disease prevention as other group members, making them think that they had failed in taking preventative measures against osteoporosis. This fear had not prevented them from having their bone scan, however, and as their scans were experienced as reassuring the possible harm was soon forgotten. It is my judgement that this experience was within the range of acceptable risks in this kind of research, but it is none the less an experience that illustrates the vulnerability that can be triggered within the frame of the health discourse that makes people individually responsible for their own health. This in a sense reflects the finding from another study, showing that thoughts about osteoporosis can be fear-arousing in themselves (Hvas, et al. 2005).

The other ethical challenge we experienced concerns the confidentiality among the group participants. As described in the methods section the women were asked to sign a declaration of confidentiality, in an effort to instill confidence in the exclusive use of the material for research purpose only. For this project that procedure was accepted by REK. When we designed a similar study a few years later, the declaration of confidentiality among research participants was not accepted on the grounds that it did not have any legal consequences. Whereas we as researchers could be subject to prosecution if we were to break the confidentiality rules, no such sanction could be executed if the participants were to do the same. REK therefore argued that the signing of the declaration would create a sense of false reassurance about confidentiality among the participants. We accept this as a legally valid argument, but it does not solve the ethical challenge in the matter. How can we act to ensure the confidentiality issue among the group members? The only answer we have found to this issue is that we cannot give the participants any guarantees of mutual confidentiality. In subsequent projects we have made this point explicit to the group members, much in line with Tolich's (2009) argument for practising the principle of *caveat emptor* in focus group research.

FOR BETTER, FOR WORSE - FINAL REFLECTIONS

Having discussed the findings from my sub-studies earlier, I now return to some more general issues which also belong among the reflections on risk, medicalization and osteoporosis. Both Clarke, et al. (2010) and Conrad (2007) stress that their contributions are limited to the USA. A brief reflection on the situation in Norway is therefore offered. Furthermore, the medical discourse on risk is so dominant it can be easy to forget its alternatives. Some alternatives are therefore presented, as a reminder. Lastly we turn to some of the dilemmas risk medicine is facing us with, facing us with the act of balancing good and bad.

Lay acceptance and professional resistance

An observation about medicalization in Norway is that we are witnessing wide acceptance among the lay populace and pockets of resistance among the medical profession.

Valuable insight about the medicalization of everyday life in Norway has come from a longitudinal study over three decades in a small coastal community in Northern Norway (Anderssen, 2010). Starting in the 1980s these observations describe a community that was fairly isolated from medical influence. Modernization, including improved transportation, opened this society for medicalization through surveillance medicine in the 1990s. This was met with both gratitude and resistance. In the 21st century, however, medicalization had become the norm and was an integrated part of everyday life in this community. The study illuminates how medicalization over time becomes the status quo that everyone takes for granted.

As noticed in Papers III, IV and V, the medicalization of osteoporosis has been welcomed among the lay people involved in those sub-studies as an effort to improve women's health. A possible explanation for this is that it is perceived as a form of desirable medicalization, serving a feminist purpose (Purdy, 2001). Unfortunately, their notion of a feminist triumph also signalled a common misconception, reflecting the underestimation of their own risk of CHD, which is not uncommon among women (Ruston & Clayton, 2002; Frich, Malterud & Fugelli, 2007).

In Paper IV we also mentioned the activities of the Norwegian Women's Public Health Association (NWPFA). Their contribution can be seen as that of a consumer group

organizing what they see as a valuable health service for women. By doing so, they have contributed to mammography before a national screening programme was established, and also contributed to bone density screening. This illustrates how medicalization has come as an outcome of an alliance between feminist stakeholders and private entrepreneurs within the medical profession. This alliance can therefore be seen as having similarities to those established during the Fosamax-case (Paper III), in an effort to bypass the health authorities' attempt to limit some forms of medicalization.

Within the ranks of professional medicine, there are not only entrepreneurs thriving on medicalization, but also pockets of resistance. The publication of Paper I coincided with what the Norwegian Society of General Practitioners (NSAM) called their "risk project". This project was started in 1994 with the aim of contributing to more and better reflections about the risk concept in medicine (Swensen, 2000a). It was based on critical reflections about the challenges general practitioners faced in clinical practice when meeting people 'at risk' of various diseases. Among these critical reflections was also a concern about the medicalization of people who perceived themselves as healthy. Their project was thus an effort to curb what they saw as a potentially negative development in medicine. The critical reflections in the project were summarized in an anthology (Swensen, 2000b).

Another accomplishment of the Norwegian general practitioners behind this project was a petition against the 1999 WHO guidelines on hypertension. The petition was published internationally on the internet and national in Norwegian newspapers. More than 400 doctors from 42 countries signed the internet petition which was sent to WHO Director-General, Gro Harlem Brundtland (Woodman, 1999).

Academically this Norwegian resistance against medicalization peaked with the publication of a series of articles that were to become the doctoral thesis of Linn Getz (2006). Briefly summarized, these articles problematized the outcomes when clinical guidelines were paired with epidemiological data about what could be seen as one of the healthiest populations that has ever been around. Ethical concerns were thus raised relating to what was seen as a wrong turn in modern medicine. Closely related to the Norwegian efforts has been the establishment of the Nordic Risk Group, which has also accomplished the publication of an anthology with texts critical of medicalization (Brodersen, et al. 2009). Despite the

dedication of these professionals it can also be seen as based on limited resources compared to its perceived adversaries.

Much of the mentioned resistance has been focused on clinical guidelines as tools of medicalization of the healthy part of the population. It may thus be seen as a paradox that some of the critics have recently contributed to the development of Norwegian guidelines on the prevention of cardiovascular diseases, with the option of using statin treatment as a measure of primary prevention (Norheim, et al. 2011). Through the story about the process behind the guidelines, its authors have strived for a transparent process, indicating that the end result is a compromise between general practitioners and hospital experts. Although the group also has patient representatives and a representative from the health authorities among its members, their role is less clearly described. It can be seen as a form of medicalization through democratization, rather than the form of medicalization by experts when such guidelines normally are negotiated. A possible conclusion from the above is that efforts have been put into limiting what the critics may see as more devastating forms of medicalization. The resistance against medicalization may thus be seen as losing ground.

These examples, and many more that could be given, illustrate that medicalization through the application of knowledge about risk has become an established part of the Norwegian society. Its demedicalization thus seems highly unlikely. It is still interesting to note, however, that there are alternatives within the frame of medicalization that are worth looking into.

It could have been different

The medical risk discourse has become a dominant way of constructing matters of health and illness. Its dominance may lead us to think that it represents the only way of constructing these issues. As indicated earlier, history and culture can provide us with valuable food for reflections about how things could have been different. Hopefully I have also been able to show in the previous discussion that our ‘reality’ is not developing in a deterministic fashion. If the medical risk discourse represents the ‘status quo’ of our present situation, it may help our critical reflections about it if we also take into consideration some alternative discourses.

One noticeable part of the medical risk focus is that it has a heavy individualistic bias. As a consequence the responsibility in matters of health and illness is attributed to the individual. This relates to the concept of calculative rationality, where a healthy citizen behaves in accordance with available risk information. In this sense the risk discourse can be seen as being based on what in social psychology is known as ‘the fundamental attribution error’, reflecting preference for individualized explanations over contextualized ones.

The latter set of explanations would lead us to focus more on the rich literature on the influence of socioeconomic status on health. Such a focus would take us away from the medical gaze towards the nonmedical determinants of health (Mechanic, 2007). It is perhaps telling when we find the medical literature on osteoporosis and socioeconomic factors to be literally non-existent. Despite that there have been observed large disparities in the fracture risk around the world, this has triggered little interest in the structural factors behind these numbers. Instead the dominant view in the osteoporosis literature seems to be that differences in race and ethnicity are the major explanation for the disparities. As a consequence a major feature of FRAX is that it is based on a growing number of reference groups in countries around the world, supposed to reflect the effect of race and ethnicity on fracture risk (Kanis, et al. 2010). This is not only a development that can be seen as ignoring the impact of socioeconomic factors on osteoporosis, but also one that has been criticized for lacking a theoretical foundation in biology (Fausto-Sterling, 2008). These critiques resonate well with the early medicalization critique, which claimed that medicine took the focus away from social problems by offering individual solutions at the patient level. If the key to the prevention of osteoporosis is building peak bone mass, then the solution is hardly BMD screening and bisphosphonates. Building peak bone mass may have much wider implications though, as it clearly challenges certain lifestyles. Its achievement would surely involve the medicalization of everyday life, but not pharmaceuticalization.

Another alternative to the medical risk discourse has been offered through the concept of local biologies, acknowledging that what in biomedicine is understood as universally biological is constructed differently across cultures. This is indicated by the differences in perceived symptomatology among middle aged Japanese and North American women (Lock & Kaufert, 2001). Offering an explanation related to the work ethic of Japanese women as one not allowing time “for succumbing to an illness associated with luxury and indolence” (Ibid, p. 502), resonates with the situation described earlier among Scottish women (Backett-Milburn,

Parry & Mauthner, 2000) and to a certain extent the participants of our focus groups (Paper IV). It furthermore also resonates with Porter's (1997) rhetorical question about our status as hypochondriacs. If life does not leave time for handling symptoms, then bothering about the asymptomatic things in life makes little sense.

Among the strong appeals of the risk discourse is our perceived ability to control matters of life and death. Another observation that crosses the medical risk discourse is the role that luck still can be seen as playing in our lives (Fredriksen, 2005). This leaves room for such factors as place of birth, genes, environments, epidemics and accidents as playing vital roles in our lives. Such factors go along with the social epidemiology mentioned above, in undermining the validity of the discourse that portrays us as the masters of our own fate. Ironically this has been shown to be part of 'lay epidemiology' (Davison, Smith & Frankel, 1991), which has been shown to offer more sophisticated observations about life than the arbitrary dichotomies of the risk/no risk – high risk/low risk format. It has furthermore been argued that a better way to address matters of health and illness comes through the salutogenetic approach focusing on people's health resources rather than their health risks (Malterud & Hollnagel, 2000).

All the alternative discourses mentioned above can be seen as being within the frame of the medicalization of everyday life. Still, their intuitive appeal lies in the argument that there are problems that would be better dealt with by other means than pills, implying that some kinds of medicalization are better than others (Busfield, 2006).

For better, for worse

In this closing part of the thesis I take the opportunity to make some ethical reflections, as ethical concerns are among the major motivations for performing the research in this thesis. By doing so I take it for granted that we seek to make the human condition better and avoid making it worse when there is a clear choice between the two. As risk carries the potential for spending resources (including personal worry) on something that may never happen, the choice between better and worse is somewhat muddled when risk is involved.

Knowledge about risk is supposed to be a good thing, because it offers the opportunity of controlling fate. Therein lies its potential for making our lives better. It can, however, also

be a constant reminder of our frailty. The proponents of a risk factor based preventive medicine have tended to take the first possibility for granted, ignoring the second. This has contributed to a situation wherein knowing your risk has become an imperative. As a consequence of this imperative the sharing of such knowledge has become both a professional duty and a consumer right. We may do well to sit back and reflect on both sides of the table whether this is really what we want.

Another good thing would be to acknowledge that we do not know what our response to knowledge about our personal risk will be. As it has both the potential for making our lives better and worse, we should be prepared for both options. It should therefore be part of the information given before people make the decision about undergoing various forms of medical testing aimed at calculating their risk. In the Norwegian Biotechnology act this is acknowledged when it comes to genetic risk information. This law is based on the idea of ‘genetic exceptionalism’, based on the belief that genetic risk information is qualitatively different from other risk information (Green & Botkin, 2003). If recent developments in genetics teach us that this is not necessarily the case, we may also do well to reflect on whether the practice hitherto reserved for genetic tests should also be applied in other areas of risk testing.

Screening comes with a built-in dilemma that puts us in the position of being damned if we do and damned if we don’t. There will always be room for regret. Being informed about your health risk carries the possibility that you may regret it if it changes your life for the worse. On the other hand, if you choose to abstain from screening and you later discover that you have the disease screened for, there will be another reason for regret.

Even if the test result is negative, there is always the possibility that it can change. Herein lays perhaps the strongest potential for medicalization that is provided by risk factors. There is no way that the patient with confidence can know their own health status, as there are no signs to observe. Once the idea of the symptom free body as a source of risk has been accepted, there is only one thing to be sure of – you can never be sure.

Another potential problem of risk-based medicine is that the different risks tend to be seen in isolation. As illustrated in Paper VI the idea of the Polypill has been introduced with the prospect of reducing the risk of cardiovascular disease by more than 80 % (Wald & Law, 2003). It has also been suggested that bisphosphonates also could be added as another

ingredient, to make it work against osteoporosis as well (Greene, 2007). As immortality is still outside our reach, we should perhaps ask what other risks we opt for by taking the Polypill. A possible consequence could be that the Polypill-boxes should be labelled with warnings about the increased risk of cancer that will follow from taking it.

Much of the current discussion about the ethical challenges of risk medicine has revolved around treating healthy, asymptomatic individuals as if they were already sick through the construction of 'at risk' individuals. Lately, concerns have also been aired as to what is happening when the notion of risk is entering in the other end of life. This is illustrated by how implantable cardiac cardioverter defibrillators (ICDs) have come to be used in patients who have not yet had a cardiac event (Shim, Russ & Kaufman, 2006). In the ethical reflections about risk-reducing medicine, it is thus important to remember that there are limits to what should be done even if they are doable. This is perhaps the most important limit to risk-based medicalization.

Future research

As noted in my methodological reflections one of the weaknesses of this thesis is that all its sub-studies can be seen as areas in need of more in-depth studies. The risk epidemic for one thing begs for a closer examination as to looking behind the face value of the increasing number of articles.

As for osteoporosis there are a number of issues that need looking into. The development of FRAX is among the obvious candidates, both when it comes to scrutinizing the understanding of the relation between osteoporosis and race/ethnicity, and the current devaluation of BMD as a risk factor for osteoporosis. Making risk assessment freely available by means of modern internet technology is another issue that offer new options.

Our present knowledge about the consequences of being screened for osteoporosis is restricted to studies in populations that participate in health surveys. To gain further insight into the experiences of people who have bone scans outside this context will be another source of new insights. Such studies would also benefit from more longitudinal designs, covering both the short term and long term impact of bone scans.

Concluding remarks

The ultimate goal of research is to change the human condition for the better. How this is achieved in social science is not always obvious. By sharing my reflections on the themes covered in this thesis I hope to have offered new insights into these matters. Hopefully I have been able to demonstrate that things are more complex than they seem at first. Medicalization, for one thing, has become much more complex since the original medicalization critique was introduced.

During this research I have also discovered that osteoporosis provides a most fascinating case for studying both the impact of the risk concept in medicine and the development of medicalization. Much attention has been given to the risk factors associated with coronary heart disease, but osteoporosis is a social construction deserving of just as much attention. On this matter I agree totally with our study participants.

It is further worth noting that medicalization happens because it makes sense to a lot of people. This is to a large degree so because the scientific study of risk provides it with a strong foundation. As I have also hopefully been able to illuminate, medicalization is an on-going process, just like life itself. Thereby it provides us with ample opportunity for further studies and lived experiences, becoming an integrated part of our lives and hence ourselves.

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Paper I

THE RISK EPIDEMIC IN MEDICAL JOURNALS

JOHN-ARNE SKOLBEKKEN

Institute of Psychology, University of Oslo, PB 1094, Blindern, 0317 Oslo, Norway

Abstract—Searches in *MEDLINE* databases show a rapid increase in the number of articles with the term 'risk(s)' in the title and/or abstract in the period from 1967 to 1991. This trend is found in medical journals giving a general coverage of medicine and journals covering obstetrics and gynaecology in U.S.A., Britain and Scandinavia. The most rapid increase is, however, found in epidemiological journals. Comparisons of the developments in the occurrence of such terms as risk, hazard, danger and uncertainty show that the increasing frequency of the term risk in the medical literature can not be explained as a change in terminology alone. It is hypothesized that the ongoing trend, which resembles an epidemic, is a result of developments in science and technology, that has changed our beliefs about the locus of control from factors outside human control to factors inside our control. The origins of the epidemic may be traced to the development of such disciplines as probability statistics, increased focus on risk management and health promotion, with recent developments in computer technology as the factor responsible for the escalation seen in the past decade. With the cultural selection of risks in mind, the social construction of risk is discussed. Potentially harmful effects of such an epidemic are discussed, exemplified through controversies over current epidemiological risk construction and strategies for coronary risk reduction. It is finally argued that the risk epidemic reflects the social constructions of a particular culture at a particular time in history.

Key words—risk, epistemology, epidemiology, health promotion, risk management

INTRODUCTION

In present thinking the concept of risk has, as Hayes [1] has noted, become prominent in our thoughts about health and health care. This point is further underlined by The British Medical Association's statement [2] that "risk . . . touches upon every single aspect of health and human welfare".

The medical profession has an important position in giving meaning to their own and the public's concept of risk and risk factors. This makes the study of the risk concept in medical literature interesting. One of the most striking features about present day conceptions of risk and the behaviour related to these conceptions, is a paradox or rather a set of paradoxes. The lack of coherence between the estimated magnitude of different risks and the subjective perception and acceptance of these risks, is one example of this paradox. This paradox has been illustrated through numerous papers on risk communication and risk perception [3].

A related phenomena is found in both prophylactic and curative health care. In prophylactic health care this is shown by the fact that the life expectancy at birth at present is higher in Europe and North America than ever before and among the highest in the world [4]. Despite this there has never been so many people occupied with identifying and fighting risks to our health as at present. One consequence of this is that we today are regularly informed about "The Menace of Daily Life" [5] through numerous epidemiological studies.

In curative medicine we have never before had a safer and better medical technology. On the other hand, there has never been a larger emphasis on the hazards of malpractice than today [6]. The vast resources applied to further reductions of the risks of iatrogenic diseases, may be seen as a symptom of this risk paradox. In curative medicine increased use of monitoring devices, introduction of risk management, systematic surveillance of perioperative complications and development of medical device simulators are among the risk reducing remedies presently applied in western countries.

The cost-effectiveness of measures aimed at reducing already minute risks is not altogether verified through scientific investigations. In anaesthesia, for instance, there has been controversy over the amount and type of patient monitoring needed to provide acceptable patient safety [7, 8]. One strategy adopted to resolve such controversies has been the development of standards for patient monitoring [9, 10]. The outcome of this strategy has been questioned [11], as anaesthesia related deaths were few prior to the introduction of practice standards. As a consequence it is difficult to get sufficient statistical evidence of an improved patient safety related to monitoring. A further methodological difficulty has been the lack of control with other factors that may influence the outcome.

Another medical technology wherein we have seen the same symptoms is obstetrics, where substantial practice variations are found between such countries as U.S.A., The Netherlands and Norway [12]. With

regard to what is seen as a safe practice in perinatal care. U.S.A. has adopted a 'worst case-strategy' (all patients treated as high risk patients) whilst The Netherlands are at the opposite end of the risk pendulum, with midwife assisted home-births as the rule. Norway has adopted a strategy somewhere in between these two extremes.

There seems therefore to be other, more subjective factors behind resource allocation in both prophylactic and curative medicine. As such these examples correspond well with Douglas and Wildavsky's [13] statements regarding cultural selection as to which risks are attended to and how they are handled.

To study and understand the mechanisms behind these developments should be a challenge for social scientists. This paper presents the first results of a series of studies aimed at taking up this challenge regarding the social construction of risk in health and health care.

The purpose of this article is to describe some recent trends in the occurrence of the term risk in the medical literature, which resembles an epidemic, and to suggest some hypotheses regarding the causes of these trends. Furthermore, some possible implications of 'the risk epidemic' are discussed.

METHODS AND MATERIALS

The data presented in this paper are based on searches in the MEDLINE databases, covering the 25 year period between 1967–1991.

The first set of searches was performed to identify articles containing 'risk(s)' in the title and/or abstract. [To avoid a constant repetition of "articles containing 'risk(s)' in the title and/or abstract", these articles will be referred to as 'risk-articles'.] To be able to find the percentage of 'risk-articles', searches were also performed for the total number of articles published in the selected journals. For this part of the study all MEDLINE databases and seven journals with a general coverage of medicine were chosen. The former was chosen to find the overall trend in MEDLINE. The 'generalist' journals were selected from the U.S.A. (*The New England Journal of Medicine*, *The Journal of The American Medical Association*), Britain [*The British Medical Journal (BMJ)*, *The Lancet*] and Scandinavia (*The Journal of The Norwegian Medical Association*, *The Journal of The Swedish Medical Association*, *The Journal of The Danish Medical Association*).

The American and British journals were selected because they are read throughout the world and are considered among the most reliable and prestigious journals, thus being among the most influential medical journals [14]. The Scandinavian journals were selected to see if the trends found in the internationally most renowned journals also were found in Scandinavia.

According to Mary Douglas [15] the meaning of the word risk has changed throughout history. This made

it relevant to ask whether such changes also may have taken place during the 25 year period studied. Risk is a word with several meanings, as gamble, hazard, danger, probability, uncertainty, and odds ratio may all be used as synonyms for risk. The results of the first set of MEDLINE searches could therefore, to some extent, be due to a change in terminology, as the same topics may have been covered under one of the synonyms in the sixties, seventies and early eighties. To find an answer to this question a second set of MEDLINE searches was performed for the terms 'hazard(s)', 'danger(s)' and 'uncertainty(ies)'. Unlike the on-line search for the word risk(s), searches for these words were restricted to all MEDLINE databases and *The British Medical Journal*, *The Lancet* and *The New England Journal of Medicine*.

Thirdly, another set of searches for 'risk-articles' and the total number of articles was performed for a set of more specialized medical journals. This search was done to see if the results found in the 'generalist journals' could be reproduced in journals covering medical specialities anticipated to be 'risk prone' specialities. Would the identified development be even more profound in these journals?

The selected specialities were anaesthesiology (*Anesthesiology*, *Anaesthesia*, *Acta Anaesthesiologica Scandinavica*), obstetrics and gynaecology (*Obstetrics and Gynecology*, *American Journal of Obstetrics and Gynecology*, *British Journal of Obstetrics and Gynaecology*, *Acta Obstetrica et Gynecologica Scandinavica*) as well as epidemiology (*American Journal of Epidemiology*, *International Journal of Epidemiology*).

Following the thesis that we choose the risks we concentrate on [13], a separate analysis was performed on the basis of the titles and abstracts of the 325 'risk-articles' published in *The Journal of the Norwegian Medical Association*. This analysis was done to see if there was any difference in the frequency of articles concerning risks that are introduced in health care and risks which have their origin outside health care.

The Norwegian articles were sorted into two categories:

- (1) *Iatrogenic illnesses/diseases*, i.e. illnesses/diseases which originate from the health care system. This category was divided into four sub-categories: side-effects of drugs; perioperative complications; postoperative complications; and other iatrogenic illnesses/diseases. The sub-categories were chosen according to the category of medical procedure seen as causing the iatrogenic illness/disease. As such the sub-categories could have been subject to even further categorization, but this was not seen as necessary to fulfill the purpose of this study.
- (2) *Illnesses/diseases without any known iatrogenic origin*. This category was also divided

into four sub-categories: cancer; coronary heart disease (CHD); HIV/AIDS; and other illnesses/diseases. The sub-categories here were well accepted categories of medical diagnoses. Again further sub-categorization might have been possible, but the chosen categorization proved sufficient for the purpose of this study.

The categorization was done in accordance with the perspective of the authors of the involved articles. This was done for practical purposes and does not take into consideration any possible controversies over classification, as may be the case for some preventive interventions like screening etc.

As this analysis was performed manually it was restricted to *The Journal of The Norwegian Medical Association*, which had the lowest actual frequency of 'risk-articles'. Another reason for choosing these articles was that they will be included in a follow-up study, where the use of the term 'risk' will be subject to a more thorough analysis.

RESULTS

The word risk has rapidly gained frequency in medical journals over the past three decades. As shown in Fig. 1 the same increasing trend has appeared in all the generalist journals, perhaps with the exception of *The Lancet*, which seemed to have reached a plateau. The results are given in per cent of the total number of articles published in each journal. There is therefore more to this increase than a mere reflection of the overall increase in the total number of articles published.

Representing 0.1% of the articles registered in *MEDLINE* in 1967, there has been a steady increase of 'risk-articles', reaching up to 5% of the articles

published in 1991. The increase has been even more rapid in the 'generalist journals' studied here, where the 10–12% level was reached in 1991, again with the exception of *The Lancet* (6.5%). Another striking feature was the escalation of this trend. More than 50% of the 'risk-articles' were published in the last five years. The number of articles registered in *MEDLINE* in the same period sums up to 27% of all articles registered between 1967 and 1991. 'Risk-articles' seem therefore to have been rising in numbers much faster than the general increase in the total number of published articles. Although minor variations were found between the journals, the same general pattern was shown in the British, American and Scandinavian journals.

More of the same trend was shown in the specialist journals studied, although a different pattern was shown in the anaesthesia journals. The results from these journals are shown in Fig. 2.

In these journals there had also been an increase in the number of 'risk-articles' from almost 0 to close to six % in the first half of the eighties. The most remarkable feature in the figures from the anaesthesia journals however, were that the increase in risk-articles had been brought to a halt and there were signs of an actual decrease.

In obstetrics and gynaecology journals there were again indications of an ongoing rapid increase in the number of 'risk-articles'. The results are shown in Fig. 3.

The trend was even stronger for these journals than for the 'generalist journals', reaching close to 20% in one journal for the latest five year period and not dropping below 11% in the three others.

The most remarkable increase was to be found in the epidemiological journals, whose results are shown in Fig. 4.

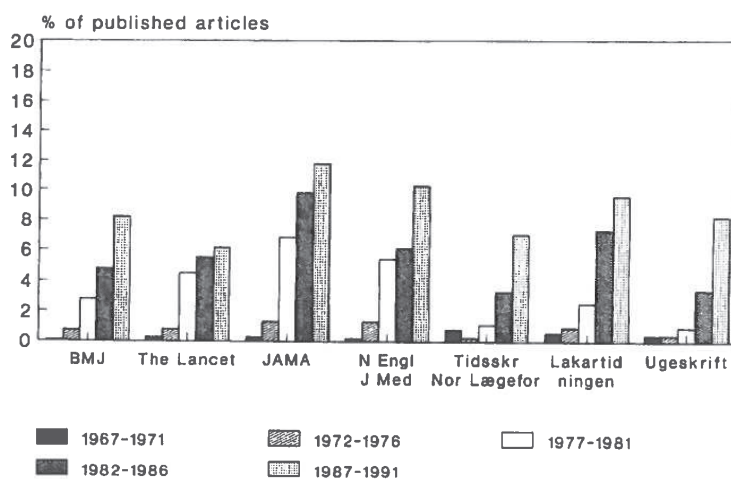


Fig. 1. Percentage of articles with risk(s) in title and/or abstract. Various general medical journals 1967–1991.

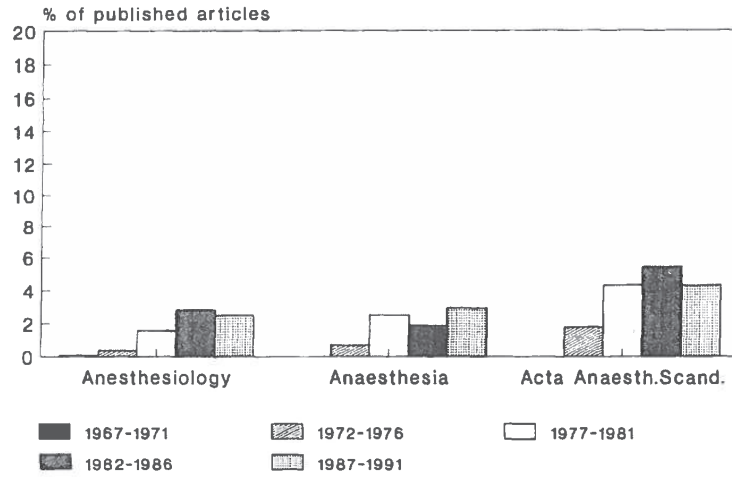


Fig. 2. Percentage of articles with risk(s) in title and/or abstract. Various anaesthesiological journals 1967-1991.

For these journals the figures had grown to around 50% 'risk-articles' in the last five year period. This may not have come as a surprise, considering that risk identification and estimation is at the nucleus of this discipline. It was, however, striking to see the amount of increase in 'risk-articles' over the past ten years. For the two journals studied, more than half the 'risk-articles' have been published within the last five-year period. In actual numbers this means that 1054 'risk-articles' were published in the first 20-year period, whilst the number for the last five-year-period was 1193 'risk-articles'.

One possible explanation for all the results mentioned above, could be that they were due to a change in terminology. If this were true we should expect the number of articles with 'risk' and its synonyms to be fairly constant over the years, and that 'risk-articles' should be taking over an increasingly larger part of this fairly constant number of articles. The results of the second set of searches, with risk and its synonyms are shown in Table 1.

As we can see there has been no similar development in the occurrence of terms that might be used as synonyms for risk. Hazard(s) occurred slightly more

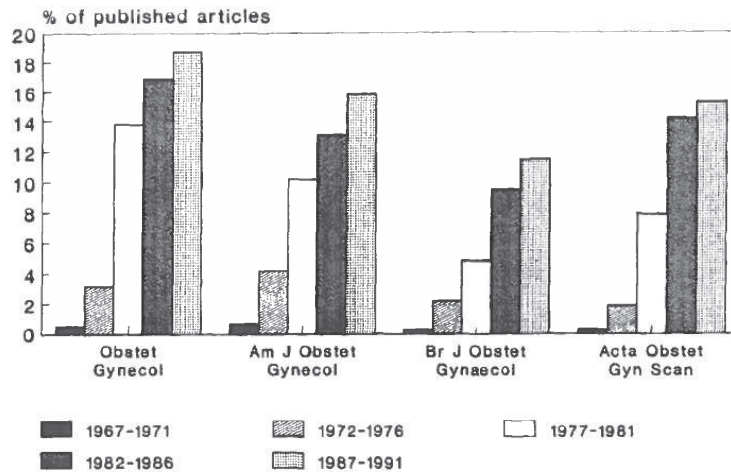


Fig. 3. Percentage of articles with risk(s) in title and/or abstract. Various journals of obstetrics and gynaecology 1967-1991.

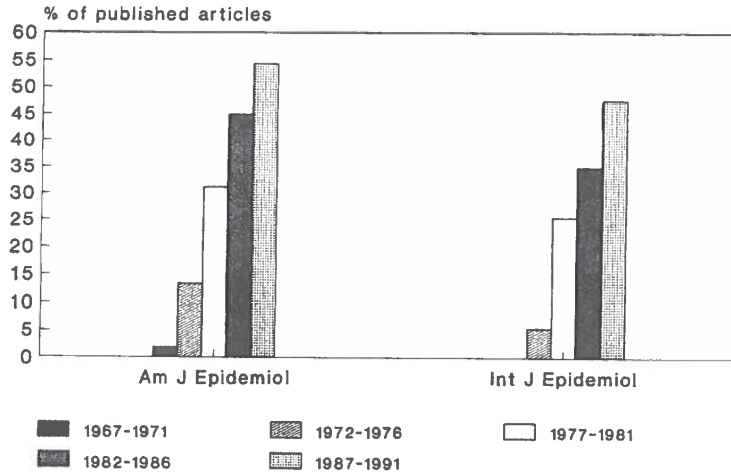


Fig. 4. Percentage of articles with risk(s) in title and/or abstract. Various epidemiological journals 1967-1991.

frequently than risk in the late sixties and early seventies, but has only had a minor increase since. As for danger(s) and uncertainty(ies), none of them seem to have been contesting risk as the most frequently used term in this terminology. The same trends as in MEDLINE overall were found in the *BMJ*, *The Lancet* and *The New England Journal of Medicine*, although

hazard was more frequent in these journals than in all of MEDLINE.

Even though a shift in terminology may have occurred, so that phenomena that previously were referred to as hazards, dangers or uncertainties today are labelled as risks, there has been an actual and dramatic increase in the use of the term risk in the medical literature.

As shown in Fig. 5 there has been an increase in 'risk-articles' for both iatrogenic and non-iatrogenic illnesses/diseases in *The Journal of the Norwegian Medical Association* in the period studied. The increase in the number of articles on illnesses/diseases without iatrogenic origin was shown to be substantial in comparison to the increase in the number of articles on iatrogenic diseases.

The most frequent risk related illnesses/diseases among the former were, not surprisingly, cancer, CHD and HIV/AIDS. The observed increase in the number of articles on risk related to these three medical conditions did, however, only account for <50% of the overall increase. The largest part of the increase was due to a large number of illnesses/diseases represented in the material with one or two articles each. This indicates that risk is no longer exclusively associated with the large 'lifestyle illnesses/diseases', but has become a term commonly applied in various approaches to other medical conditions as well. Although this last result may be seen as restricted to Norway, the spreading of the use of the term risk to a wide set of illness/diseases might prove another trend well worth looking into. This possibility will be focused on in the follow-up study on the Norwegian articles.

Although the increase in the number of articles published on the risks associated with iatrogenic

Table 1. Percentages of articles with risk(s), hazards(s), dangers(s) or uncertainty(ies) in title and/or abstract. MEDLINE, BMJ, The Lancet and New England Journal of Medicine 1967-1991

	Risk(s)	Hazard(s)	Danger(s)	Uncertainty(ies)
<i>MEDLINE</i> 1967-1991				
1967-1971	0.1	0.1	0.04	0.01
1972-1976	0.6	0.2	0.08	0.02
1977-1981	1.8	0.2	0.1	0.05
1982-1986	3.0	0.2	0.09	0.07
1987-1991	4.5	0.3	0.1	0.1
<i>BMJ</i> 1967-1991				
1967-1971	0.1	0.6	0.2	0.00
1972-1976	0.7	0.7	0.4	0.04
1977-1981	2.8	0.8	0.2	0.06
1982-1986	4.8	0.6	0.3	0.08
1987-1991	8.2	0.4	0.2	0.08
<i>The Lancet</i> 1967-1991				
1967-1971	0.3	0.2	0.01	0.01
1972-1976	0.8	0.3	0.1	0.00
1977-1981	4.5	0.5	0.1	0.02
1982-1986	5.5	0.4	0.2	0.04
1987-1991	6.1	0.4	0.1	0.02
<i>New England Journal of Medicine</i> 1967-1991				
1967-1971	0.2	0.6	0.2	0.02
1972-1976	1.3	0.4	0.1	0.03
1977-1981	5.4	0.6	0.1	0.06
1982-1986	6.1	0.4	0.1	0.2
1987-1991	10.3	0.7	0.1	0.2

Percentages of articles with risk(s), hazard(s), danger(s) or uncertainty(ies) in title and/or abstract.

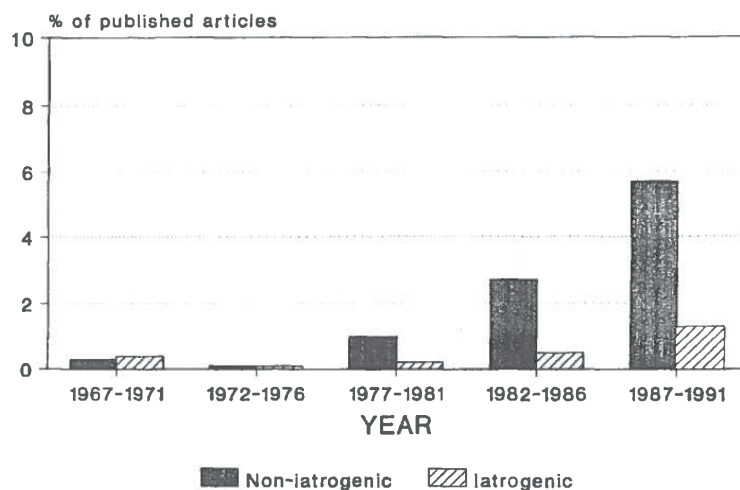


Fig. 5. Percentage of articles with risk(s) in title and/or abstract. Iatrogenic and non-iatrogenic illnesses/diseases. *Journal of the Norwegian Medical Association* 1967-1991.

illnesses/diseases was less impressive than that from non-iatrogenic conditions, their number have quadrupled in the past five years, of which the last two have shown a particularly large growth. Most of these articles covered perioperative complications and side effects of drugs.

The differences in frequency of articles addressing risk related to iatrogenic and non-iatrogenic illnesses/diseases respectively, probably reflect a time difference in the emphasis on these risks. Health promotion has been a major interest in the Norwegian medical community for some time, with the Oslo heart study [16] as one of the most well known examples. Risk management and quality assurance, on the other hand, have only recently come to its attention in a manner which makes it acceptable for publication in medical journals.

DISCUSSION

There are several questions to be considered regarding the quality of these data. One issue is whether the results may be due to changes in the registration practice at *MEDLINE*, thus introducing systematic bias in the results. To avoid such a bias the search was performed by searching for the word risk in title and/or abstract, and not using risk as a medical subject heading. One systematic registration bias in the data was found, as *MEDLINE* changed their registration practice between 1974 and 1975. Before 1975 abstracts were not registered systematically, but this was put into practice from that year. This resulted in more than a doubling in the number of articles with risk, hazard, danger or uncertainty in title and/or abstract in 1975 compared to the year before.

Although the increase in the total number of articles registered in *MEDLINE* was larger between these years than the years before, it was nowhere as evident as the increase in the number of articles with the above mentioned terms. As a result of this bias the percentages for the two first five year periods are most likely too small, making the increase between 1972-1976 and 1977-1981 too large. This does not, however, take away the effect that has been noted in the last three periods. The effect in these periods seems to have been substantial in all but one of the 'generalist journals', and in the epidemiological journals. In the obstetrics and gynaecology journals the increase has been a more steady one.

Do we see a risk epidemic?

The rapid increase in the occurrence of the term risk in medical journals, gives rise to the question of whether we see the symptoms of an epidemic. This certainly seems to be true with regard to both prevalence and contagiousness in its use in the medical community. As for actual frequency, the number of 'risk-articles' published has risen from about 1000 articles in the first five year period covered, to > 80,000 in the last, which also means that more than half of these articles have been published in the years 1987-1991. The contagiousness is indicated by the increase in the number of illnesses/diseases that are subject to some kind of risk approach.

A crucial issue, however, is whether the present occupation with risk may be seen as leading to illness/disease. This is an issue of considerable controversy, which can not be answered on basis of the data presented in this paper. As can be seen from other studies, which will be discussed below, there has been

an indication that the consequences of the present occupation with risk are not exclusively healthy ones.

Based on the fulfilment of the criteria of contagiousness, high prevalence and, at least partly, of possible side effects that may lead to illness/disease, it seems a fair conclusion that what we are facing clearly resembles what, at least metaphorically, might be labeled a 'risk epidemic'.

Some possible origins of the 'risk epidemic'

A point of crucial importance for the analysis of the origins of the 'risk epidemic', is that the risk epidemic is not a homogeneous phenomena. Just like the term cancer covers a widespread set of cell dysfunctions, various notions of risk make up the 'risk epidemic'. The diversity of these notions of risk has been demonstrated earlier by Hayes, who has also pointed out the lack of interest in the epistemology of risk [1]. This lack of interest may reflect the strength of the impact of the 'risk epidemic'. It seems that the various notions of risk may already have reached a 'taken for granted' status in our present conceptions of health and health care, as part of our social construction of reality [17]. What we see are the results of a constructional process wherein risk has been reified, i.e. established as natural phenomena which can only be identified by means of scientific tools, and not as products of human conduct. To trace this process is far beyond the scope of this article, which will be limited to indicate some of the paths along which the tracing should proceed.

A characteristic of the present situation, then, is a lack of conceptual coherence, due to the diversity of the origins of the risk epidemic. This may pose a problem to those interested in the development of a more uniform conceptual framework. Lack of conceptual coherence does not, however, seem to be a problem for most of the scholars contributing to the 'risk epidemic', which is illustrated by the fact that >80,000 'risk-articles' were published in the period from 1987 to 1991. Which risk concept they applied has probably not been a problem to the majority of the authors of these articles or the editors accepting them for publication. This conceptual incoherence should be kept in mind when reading the rest of the article, as the various paths of the risk epidemic may apply several notions of risk, which is one of the characteristic symptoms of the 'risk epidemic'. This symptom seriously imply that risk is not a neutral concept, but a set of concepts to which various ideological meanings have been attached [1, 18–20].

Various explanations of the observed phenomena may be given from different positions within the social sciences. It is not the aim of this paper to launch a grand theory on the occurrence and use of 'risk' in health and health care, but merely to point out some likely hypotheses that might be fruitful for future studies. The hypotheses suggested here are based on

the development of several disciplines and run along the same lines that Fielding [21] has described as influencing the development of the health risk appraisal approach. The considered factors include disciplines that have been developed for various risk calculations expressed as statistical probabilities, recent developments in computer technology, risk management, quality assurance and health promotion. Contributions have also come from various social sciences, through studies of such subjects as risk perception, health behaviour modifications, health education, and risk communication.

The general background against which the development of the 'risk epidemic' may be seen, is one in which beliefs about the locus of control have changed from factors outside human control to factors well inside our control [22]. Throughout the human history the major threats to our health have come from risk factors outside our control, from nature itself or what we have seen as supernatural powers.

Correspondingly, our attitudes towards these risks were mainly fatalistic, our perceptions dominated by religious beliefs, superstition and destiny, and the means of handling risks were mainly restricted to prayers, sacrifices and other ritualistic behaviours [23].

Substantial changes in the beliefs regarding risks and the handling of them have come about in the past three centuries, due to scientific and technological developments within medicine and other disciplines. Nature may no longer be the main reason for risks to our health. Most present risks can be seen as created by humans, being side effects of developments that are mainly viewed as benefits to humans.

These recent advances have contributed to a change in the basic attitudes where matters of life and death are concerned. The risk acceptance that is internalized in a fatalistic attitude to these matters is being replaced by an ideology whose primary goal is to gain control over life and death, where identification of and the struggle to reduce/eliminate risk factors have become activities of considerable importance and prestige within the health professions.

These changes have first and foremost taken place within the professional communities, wherein the basis for the risk epidemic has been laid. Davison, Frankel and Davey Smith [24] have shown that fatalistic attitudes towards risks to our health are still common in a lay population in South Wales and probably also within the lay community at large. This observation is of importance when we look at the possible consequences of a 'risk epidemic', which is done at the end of this article.

Increased human control over nature has led to a much more scientific and optimistic approach to the handling of risks. Risks are no longer haunting ghosts, but something that may be subject to concrete estimations. This optimism over what can be achieved by the scientific handling of risk, was thus illustrated in a recent issue of *Scientific American*; "Inadequate approaches to handling risk may result in bad policy.

Fortunately, rational techniques for assessment now exist" [25].

The most vital contribution to the 'risk epidemic', then, has come from the development of scientific thinking itself. Within this thinking there has been a movement from a paradigm of monocausal determinism towards a paradigm of multiple causes and effects, accepting uncertainty as a vital factor. When physicians, epidemiologists in particular, talk of factors causing illness or disease, this is seldom expressed as a certain, ever reproducible cause effect relationship. There is most often uncertainty involved, which along with probability constitute a central element of many of the various notions of risk. This combination does also contribute to a certain perpetuality of this research field, as conclusions of '*further research is needed*' may frequently be called for.

A further path for tracing the origins of the 'risk epidemic' would be to look at the development of risk calculations. The scientific basis of risk calculations are probability estimates, which are essential in all types of risk calculations. Risk, as a measurable construction, may therefore be traced back to the middle of the seventeenth century [26]. Several disciplines have been developed for the purpose of risk calculations. The first was actuarial science, developed to meet the insurance companies' need of risk estimates for the pricing of life insurance policies [27].

In preventive health care risk estimation is an essential part of epidemiology, a discipline developed for the purpose of tracing the origins of diseases, whose prevention is hoped to be achieved through the elimination of these origins. This discipline is often seen as established in the middle of the nineteenth century, but which has risen to prominence in the past two or three decades [28].

Along with what has been called the critical clinical school [29] and the introduction of double blind randomized therapeutic trials, there has also been the development of biostatistics. Related to this comes the development of clinical epidemiology. Altogether this methodology has been developed over the past few decades as an answer to critical questions being raised over the effectiveness and efficiency of medicine. The first concerns the evaluation of whether various medical interventions actually alters the course of a disease for the better, the second concerns whether medical interventions are used optimally [30]. This methodology should then help the physician to choose the most effective therapy on the 'right' group of patients with the most optimal use of available resources.

Although traceable to the old Babylonians, we have also in this century had the development of risk analysis [31]. It was developed within the engineering disciplines, mainly since World War II, as a result of the need for estimating (and legitimizing) the risks involved in the handling of various types of energy like nuclear power and potentially dangerous chemicals.

Applied to medicine this type of analysis may be used in the pursuit of identifying and estimating risks connected to various medical procedures and technologies, as well as a management technique for risk handling—risk management—which will be treated later in this article.

One origin of the 'risk epidemic' may therefore be found within the frame of the present statistical paradigm of scientific medicine and the tools mentioned above. This may also in part explain why risk has become such a frequently used term, or more correctly, why various notions of risk has become so frequently used. Compared to danger, hazard and uncertainty, risk is more frequently associated with probability estimates than the others, as is shown in epidemiology where various risks as attributable risks, relative risks and risk ratios may be calculated. Given the present emphasis on statistically supported data in medical journals, this may very well be a factor contributing to the 'risk epidemic'.

The mentioned methods for risk calculation have existed for a much longer period than the 'risk epidemic' itself. They may therefore be seen as necessary conditions for the epidemic, but not as sufficient ones. Other factors must also be considered. This leads us to another path along which the origins of the 'risk epidemic' may be found.

Why then, did the risk epidemic not emerge until the 1980s? A fair hypothesis seems to be found in the developments of computer technology during the past two decades. The spreading of this technology has enabled an enlarged number of medical researchers to perform far more statistical analyses on large amounts of data than were possible only a few decades ago. Computer technology and probability statistics thus look to be vital factors contributing to the 'risk epidemic'. These factors do, however, remain mere tools or techniques, which needs to be placed within the frame of a medical technology, providing the ideological background wherein the application of these techniques becomes legitimate.

A path providing such an ideological background is health promotion. Our belief in past successes has left us with a substantial optimism as we take on new challenges in the pursuit of eliminating risks and promoting health. The elimination of various infectious diseases as the major cause of death in the western world in the first half of this century, has undoubtedly generated such optimism, and may be seen as one of the reasons for the raise of health promotion as an important ideology of health. Whether this success can be rightfully attributed to medical interventions has been challenged, from different angles, by both McKeown [32] and Illich [33].

This criticism has not, however, severely harmed the beliefs of what may be achieved within the frames of health care. For various health promotion strategies the identification and estimation of risk factors have been regarded as basic knowledge and a major path on the road to improved health. Health promotion, here

considered as a medical technology covering various techniques as health education, immunization programmes etc., may therefore contribute with the ideological frame needed to explain the present emphasis on factors regarded as risks to our health.

Through the ideological frame of health promotion we can get a glimpse of some of the functions served by the 'risk epidemic'. These functions may be seen as mechanisms contributing to the shaping of the 'risk epidemic', thus being a part of its origins. They are not necessarily the results of goal-directed efforts of the involved parties, but it can be argued that there are beneficiaries of these functions. The most obviously accepted function is the prediction of unwanted events as loss, disease and death. Through this function it sets the scene of risk identification and estimation as a modern, rational way of gradually gaining control over illness and disease, as compared to our not too distant history. It thus confirms our optimism and the belief of what can be achieved through science. This is probably reflected through both raised funding of projects taking on this pursuit and the willingness to print articles giving the results of these projects. Strongly related to this function is also the assumption that part of the rationality here involves cost savings. Health promotion not only serves to keep the healthy free from illness, but it is also expected to save us from expensive health services.

Another function stems from the linkage between risk factors and causal factors. Risk factors do in many cases serve as causal hypotheses, a status which is frequently stretched beyond the rules of good science, when these hypotheses are treated as if they were already verified. This is most clearly shown within the area of coronary risk factors, where presently > 300 risk factors have been identified [34]. Having gained this causal status, rightly or not, makes the risk factors subject to treatment. They become diseases to be cured. The expansion in the number of risk factors identified, therefore also means an expansion in the number of diseases to be treated, and of course an expansion in the 'turf' available for medical intervention. A 'risk epidemic' may therefore also be seen as serving such an expansion, on part of the medical profession and others parties with interests in this field [35].

As *medicalization* is a term that comes to mind in such circumstances, it does also seem likely that there is a need for legitimation of these interventions. This legitimation has been established through the scientific means by which risks are identified and measured. 'Proper' risks may to a lesser and lesser extent be identified and validated through everyday experiences. The proper identification and handling of risks is more and more becoming a question of having a scientific approach to the matter. This also serves to draw a line between those competent to do this and those that are not.

The 'risk epidemic' may thereby also be seen as part of a concerted effort to make medicine a more scientific

discipline. Within the art/science debate the increase in the scientifically constructed risks is a movement from the art dimension towards a more scientific medicine. The 'risk epidemic' may thus be seen as a tool moving medicine as a discipline based on 'beliefs' towards a discipline based on 'knowledge'.

The paths of the 'risk epidemic' does also include paths for clinical medicine

Recent technological innovations in medicine may also be seen as having enlarged our sense of control. Symptoms of this are seen through an enlarged number of malpractice claims and raising expectations as to what may be achieved in health care. Whether this sense of control is called for or not may be subject to controversy. The matter of interest here is what happens when control is attributed to doctors; by themselves, lawyers, media or the public.

This perceived control has raised the expectations concerning the identification, reduction and elimination of risks involved in medical procedures, thus giving raise to such disciplines as risk management and quality assurance. Risk management is, as mentioned, based on the development of risk analysis. Its introduction to health care has been heavily motivated by the raising insurance premiums and other raising costs of health care [36]. The development of these disciplines may be seen as yet another path along which to seek for the origins of the 'risk epidemic'.

Related to the development of risk analysis and risk management has been the rise of other disciplines as risk perception and risk communication. These disciplines arose as the results of risk analysis did not have the impression on lay people as the experts behind the methodology had expected. In its 'neutral' version the purpose of studying risk perception may be stated as the 'study of how people form their opinions about risk'. Risk perception studies soon lost their neutrality, however, when the real purpose behind the studies was uncovered as to "... aid policy makers by improving communication between them and the lay public, anticipating public responses to experiences and events ... , and directing educational efforts" [37]. These disciplines constitute the last path of the origins of the 'risk epidemic' to be mentioned here.

Judging from the data from *The Journal of The Norwegian Medical Association* and the two epidemiological journals, the paths including health promotion as an ideological frame and epidemiology as a main tool for identification and estimation of risks seems to be the most travelled of the paths at present. The increase in 'risk-articles' in the 'generalist journals', may be due to an increased number of epidemiological articles submitted to these journals. Angell [38] has indicated such a tendency to be true for *The New England Journal of Medicine*. For this reason, most of the discussion in the remainder of this article will build on epidemiological examples.

Risk construction—a study subject

A fundamental question is whether the 'risk epidemic' is reflecting enlarged dangers to our health or whether it is mainly an epidemic that has entered the minds of a substantial number of persons involved in health care. Judging from the fact that the risk epidemic has been paralleled by increased life expectancy in the Western world, the latter suggestion may certainly have something to it. By saying this, I do not mean to indicate that present conceptions of risk are mere fantasies, but that social construction plays an important part in shaping these conceptions.

As the 'risk epidemic' is a reflection of present scientific activities, the scientific construction of risk is central to this process, whereby risks and risk factors may become 'realities of our everyday life'. If 'rationality' applied, the construction process should be simple: risks are identified by scientists doing proper science, the results of proper science are communicated to the public, who changes their behaviour accordingly, thus prolonging their life expectancy. There is, however, no determinism related to whether scientifically constructed risks will gain the status of 'reality' or not [18]. This is, as mentioned, one of the puzzles that has triggered the interest for research on risk perception and communication.

One of the problems of this puzzle, is that risks may also be constructed through 'improper' use of scientific methods and still gain the status of 'fact'.

Ideally, scientific constructions of risk are made according to descriptions given in methodological textbooks. These descriptions often represents ideals that are hard to follow, so that more practical appliances of these ideals are frequently chosen.

Thus, in epidemiology 'fake' risks may be constructed due to methodological errors, when confounding variables are not controlled for [5, 39, 40]. Many factors have been identified as risk factors because they appear together with a factor actually contributing to the illness/disease, which is one of the reasons that so many coronary risk factors have been identified [41].

Once published, these factors may gain acceptance as 'facts' in the medical and lay community. As Lipton and Hershaft [42] have shown, serious methodological flaws are not sufficient hindrances when it comes to accepting dubious research findings. In response to this problem there have been tutorial efforts by the journals, regarding the interpretation of epidemiological research [38, 43]. The implicit assumption behind such efforts is that there are two sets of risk, 'fake' risks constructed through methodological flaws and 'true' risks constructed through the proper use of epidemiological methodology. Both still have the potential to become 'real' risks though, through the social construction process. Tutorial efforts may influence this construction process, but whether they will be successful or not remains to be seen.

To fully understand the development of the 'risk epidemic' would, as mentioned, require in depth studies of this process. Studies of the social construction of risk in health and health care should prove useful and interesting in this respect. A methodology for studying these constructions in the development of science and technology has been suggested by Latour [44]. Basic to this methodology is the assumption that science is made up of two parts, one consisting of established 'knowledge' and another where there at present is no such knowledge, where this is still sought and controversy over the constitution of this knowledge still prevails. The characteristic of established 'knowledge' is that it is perceived as if no such controversy exists and never has, having reached the position of what is labeled 'closed black boxes'.

The purpose of this methodology is to open these black boxes, studying the scientific controversies of the past and how they were closed, thereby studying the scientific construction of facts and artifacts. This can be done through studies of the scientific literature, where, among other things, the selective use of references plays an important role in the establishment of knowledge. An interesting example of this has been done on the success of cholesterol lowering trials. According to this study, these claims for success have been constructed through the selective citation of supportive trials [45].

Concerning the risk epidemic this methodology could be used for tracing how some risk factors have gained status as facts, whilst others no longer exist in the risk literature. By applying such a methodology we would hopefully get a clearer picture of the processes in which risk factors are chosen, studied and become facts or artifacts in the pursuit of scientific inquiry.

The scope of such studies should, however, not be restricted to simply gaining knowledge of these developments. This knowledge should also be used for the benefit of health and health care. As such, studies of the social construction of risk could be helpful in the assessment of health promotion and other medical technologies. The need for such assessment is indicated by some of the possible consequences of the 'risk epidemic'.

Potential harms of the risk epidemic

In accordance with the constructionist view the question of possible harmful effects of the 'risk epidemic' remains open to construction, as few black boxes have been closed and many of the subjects covered by the 'risk epidemic' are still subject to controversy. There is no simple answer to whether the present occupation with risk may be seen as leading to diseases or not. We see both symptoms of a disease and indications of a state of health. Whilst cherishing the healthy symptoms, the disease symptoms should be treated seriously, because they may lead to what Illich [33] called social iatrogenesis or, rephrasing McKee-own's [32] warning: "misinterpretations of the major influences on health improvement, leading to misuse

of resources and distortion of the role of medicine'. To avoid this is one of the major challenges that lies ahead. The examples given below will therefore focus on some of the potentially questionable sides of the 'risk epidemic'. It should be kept in mind, of course, that these are examples and not the results of an extensive, all-inclusive evaluation of the possible effects of the 'risk epidemic'.

Misinterpretations and misuse of resources in prophylactic medicine may come from focusing on the 'wrong' risk factors or even from focusing on risk factors at all, if promoting health may prove to be something different than avoiding risks, and there should prove to be serious limitations to the presently applied methodology for risk identification. Problems are also showing in curative medicine, where risk aversion may lead to defensive medicine, preoccupied with avoidance of malpractice suits, thus hampering the progress of medicine and health care.

One set of criticism that has been raised, concerns the present scientific methodology. It has been claimed that problems related to scientific risk construction is not limited to erratic appliance of epidemiological methodology, but that it stems from shortcomings of the methodology itself. The apparent ease with which associations between fatal diseases and everyday activities are established by current epidemiological methods, is at the core of this criticism [5, 46, 47].

In accordance with the criticism, it becomes tempting to raise questions about the relationship between the present number of identified risk factors and the tools available for risk identification and estimation. One comparison that was made more than a decade ago, is that between the witch-processes of medieval Europe and the increase in attention to risk factors [48]. During the witch-processes there was a development of more and more sophisticated methods for witch identification. This development may be compared to the present situation, where increasingly sophisticated statistical tools give us the option of finer and finer risk estimations. Are we then in a situation of introducing self-fulfilling prophecies? At present the answer to this is not known, but it is definitely an option we should be aware of.

Another methodological criticism of what can be achieved by further focus on risk and risk factors, has come from authors seeing the limits of present linear models on which risk estimations are based. They claim that human bodies are complex non-linear systems, which can not be grasped wholly by the presently applied methodology, and that application of chaos theory will be called for in the future [49, 50]. Such arguments would, if given credit, raise serious questions about an important part of the foundation on which the 'risk epidemic' is based, thus undermining the value of present activities.

In the pursuit for identification, quantification and elimination of risks there is invariably the possibility of introducing new ones. The magnitude and acceptability of the risks involved in various health

promotion programs have therefore been subject to substantial controversy. This seems particularly true for screening programs for various types of cancers [51–53] and coronary risk factors such as cholesterol [45, 54, 55], and has led to claims for the application of the same ethical principles for prophylactic medicine as are presently practised for curative medicine [56]. The already mentioned controversy regarding sufficient patient monitoring serves as an illustration of similar controversies regarding risk management in medicine [7, 8]. These controversies cover a wide range of questions regarding various ethical, medical, economical and psychological issues.

To further illustrate such controversies and possible ill effects of the risk epidemic, an elaboration of the controversy over cholesterol lowering trials serves the purpose. Cholesterol has for a long time been identified as a coronary risk factor, and little controversy remains over its status as a risk factor. Ample controversy remains over the strategy for reducing this risk factor and the effects of such efforts, however.

Some of the central issues of this controversy are who should be tested, at what intervals, who belong to the treatment groups, how should they be treated and what are the effects of the treatment? The alternative answers to the first question has been a choice between a population strategy and a high risk strategy. In a population strategy the whole population is tested, whilst in a high risk strategy only those considered to be at high risk will be subject to testing. The definition of high risk groups remains one of the problems of the latter strategy, as various factors as age groups, gender, genetical dispositions, single/multiple risk factors have been suggested as possible inclusion criteria [57]. Whatever strategy chosen, a large percentage of the healthy population will be subject to cholesterol testing procedures.

Regarding the interval between tests, suggestions have been ranging from every time a person consults a physician to once in a life-time. Controversy has also prevailed over which cholesterol scores that qualify for treatment. In the U.S.A. recommendations that would put 60% of the population in the treatment group have been given [58], whilst the entry criteria for a particular British study would include a third of the British population [59].

Although the above mentioned strategies represent the more extreme recommendations given, they are not untypical of the atmosphere that has prevailed around cholesterol monitoring. As such strategies sound rather expensive and involve a large potential for medicalization, one would expect that such efforts should be supported by the effectiveness of the applied treatment.

The available treatment is dietary modifications and/or drug treatment, of which dietary changes is the most widely recommended. Whether cholesterol reducing trials have been successful or not, is at the

nucleus of the present controversy, which can be illustrated by some of the papers published on the subject in the *BMJ* over the past two years. In 1992 doubts about the success of efforts to prevent CHD were expressed in an editorial, due to dispute over the effectiveness of the cholesterol reduction trials and indications of a raised total mortality in intervention groups, in particular the mortality related to suicide and violent deaths [54]. Claims for a much more restrictive use of cholesterol lowering drugs were also made [59].

Two years later another editorial claimed that "Lowering population cholesterol concentrations probably isn't harmful" [55], lending support from studies claiming that the association between serum cholesterol concentration and ischaemic heart disease has been underestimated [60], that significant reduction of the risk for such disease is achieved through reduced serum cholesterol concentration [61], and that the risks of such reductions are outweighed by the benefits [62].

New chapters in this controversy will obviously be written and it should not come as a big surprise if the pendulum swings back and forth for some time still. The present status of the cholesterol controversy does, however, serve to illustrate that effectiveness and efficiency in preventive medicine is as important as it is in clinical medicine, perhaps even more important.

Considering the large number of people affected by the potential side effects of such massive interventions, this certainly calls for a more cautious approach than what has been demonstrated through many of the recommendations given on cholesterol monitoring and treatment during the 1980s. If what we have seen are medical experiments on large populations of healthy people, despite insufficient knowledge about their effect and side effects, this is truly unethical and supports the call for the implementation of ethical standards in preventive medicine [56].

Coping with a 'risk epidemic'

If we are to believe the epidemiological risk constructions, there seem to be few, if any, things in life that are purely healthy or unhealthy. This is clearly shown when many of the identified risk factors turn out to be factors related to our daily living [2, 5]. Research in recent years has made us aware of more risk factors than ever before in history. This does not automatically make us healthier and happier human beings. In fact, this knowledge may in some instances lead to a duller way of life, restraining people from a quality of life that is open to them.

The present emphasis on risk may also influence our self-evaluation of health. As Fylkesnes and Førde [63] have pointed out, several studies have shown that our health evaluations are found to predict mortality. Some people may therefore be seen as having entered a vicious circle in which knowledge of risk factors reduces their subjective health which again may lead

to diseases, whose presence confirms their concern for risk factors in the first place.

If the 'risk epidemic' may be seen as imposing unnecessary strain and fear on what are basically healthy individuals, there may be some comfort in lay people's own coping strategies. Davison, Frankel and Davey Smith's studies from South Wales [24, 64] indicate that people have their own strategies for coping with the professional community's increased emphasis on risks. These strategies have more fatalistic elements than what may be appreciated by the most ardent supporters of health promotion. At best these coping strategies may lead people to avoid unhealthy stress and reduced quality of life related to worrying about the uncontrollable, in line with Skrabanek and McCormick's advice [34]:

Since life itself is a universally fatal sexually transmitted disease, living it to the full demands a balance between reasonable and unreasonable risk. Because this balance is a matter of judgement, dogmatism has little place. Present-day preoccupations with health are largely unhealthy as the media constantly draw to our attention hazards to health. Many of these hazards are rare and our individual risk of being harmed extremely small; in this circumstance they should be ignored.

At worst such advice may lead to ignorance of health hazards that might have been avoided. Then again, knowing which is which, remains an unsolved enigma.

From 'beliefs' to 'knowledge'—the rich world's hope and illusion?

A final reflection on the effectiveness and efficiency of the 'risk epidemic' may be Marshall H. Becker's conclusion that we at present have reached a stage where former 'beliefs' about what promotes health have become 'knowledge' through extensive and costly investigations, and the old proverb '*moderation in all things—and moderation in that*' is the best conclusion that can be drawn from these efforts [65]. If so, several of the activities reflected by the 'risk epidemic' may prove to be costly and ill-devised efforts of mind seduction. The apparent success of such efforts should not surprise us, though, if we accept our strive for a sense of control as central to our well being.

This finally shows another vital characteristic of the risk epidemic. It is reflecting the socially constructed reality of a particular culture at a particular time in history. In a global and historical context it may be seen as a luxury problem of the richest part of the world. After all, '*moderation in all things—and moderation in that*' requires a freedom of choice that so far has been denied the majority of humans.

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	Risk articles	Published articles	% Risk articles
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	1977-1981	6527	6.8
	1982-1986	6026	9.8
	1987-1991	6475	11.8
	<i>Tidsskrift for Den norske lægeforening</i>		
	1967-1971	2102	0.8
	1972-1976	2570	0.2
	1977-1981	2020	1.1
	1982-1986	2016	3.3
	1987-1991	3103	7.0
	<i>Läkartidningen</i>		
	1967-1971	2592	0.6
	1972-1976	2819	0.9
	1977-1981	2486	2.5
	1982-1986	1427	7.3
	1987-1991	3028	9.6
	<i>Ugeskrift for læger</i>		
	1967-1971	2024	0.4
	1972-1976	3007	0.4
	1977-1981	3466	0.9
	1982-1986	4028	3.4
	1987-1991	4322	8.2
	<i>Anesthesiology</i>		
	1967-1971	988	0.1
	1972-1976	1224	0.4
	1977-1981	1471	1.6
	1982-1986	2019	2.8
	1987-1991	2438	2.5

APPENDIX

The Risk Epidemic in Medical Journals: Numerical Data Tables

	Risk articles	Published articles	% Risk articles
<i>MEDLINE</i>			
1967-1971	990	1029289	0.1
1972-1976	6485	1160317	0.6
1977-1981	23190	1298885	1.8
1982-1986	44077	1487893	3.0
1987-1991	81586	1802671	4.5
<i>The British Medical Journal</i>			
1967-1971	11	8062	0.1
1972-1976	79	10709	0.7
1977-1981	330	11789	2.8
1982-1986	423	8821	4.8
1987-1991	724	8814	8.2
<i>The Lancet</i>			
1967-1971	27	10231	0.3
1972-1976	106	14204	0.8
1977-1981	564	12656	4.5
1982-1986	666	12180	5.6
1987-1991	798	13101	6.1
<i>New England Journal of Medicine</i>			
1967-1971	8	5490	0.2
1972-1976	84	6461	1.3
1977-1981	351	6558	5.3
1982-1986	352	5765	6.1
1987-1991	510	4962	10.2
<i>Journal of the American Medical Association</i>			
1967-1971	17	5938	0.3
1972-1976	88	6679	1.3
	1967-1971	432	0.0
	1972-1976	685	0.7
	1977-1981	1090	2.5
	1982-1986	32	1694
	1987-1991	67	2329
	<i>Anaesthesia</i>		
	1967-1971	124	0.0
	1972-1976	228	1.8
	1977-1981	444	4.3
	1982-1986	682	5.4
	1987-1991	736	4.3
	<i>Acta Anaesthesiologica Scandinavica</i>		
	1967-1971	911	0.3
	1972-1976	960	2.2
	1977-1981	1015	4.9
	1982-1986	1233	9.5
	1987-1991	1404	11.5
	<i>British Journal of Obstetrics & Gynaecology</i>		
	1967-1971	2666	0.7
	1972-1976	2888	4.2
	1977-1981	3031	10.2
	1982-1986	3372	13.1
	1987-1991	3848	15.8
	<i>American Journal of Obstetrics & Gynecology</i>		
	1967-1971	1526	0.5
	1972-1976	1738	3.2
	1977-1981	1888	13.8
	1982-1986	2020	16.9
	1987-1991	2535	18.7

—continued

	Risk articles	Published articles	% Risk articles		Risk articles	Published articles	% Risk articles
<i>Acta Obstetricia & Gynecologica Scandinavica</i>				1977-1981	248	795	31.2
1967-1971	1	373	0.3	1982-1986	479	1065	45.0
1972-1976	7	369	1.9	1987-1991	788	1451	54.3
1977-1981	45	572	7.9	<i>International Journal of Epidemiology</i>			
1982-1986	104	732	14.2	1967-1971			
1987-1991	114	745	15.3	1972-1976	14	247	5.5
<i>American Journal of Epidemiology</i>				1977-1981	67	263	25.5
1967-1971	12	618	1.9	1982-1986	154	441	34.9
1972-1976	80	596	13.4	1987-1991	405	850	47.6

Tidsskrift for Den norske lægeforening

Period	Non iatrogenic illnesses/diseases			Iatrogenic illnesses/diseases		
	Risk articles	Total number of articles	% Risk articles	Risk articles	Total number of articles	% Risk articles
1967-1971	7	2102	0.3	9	2102	0.4
1972-1976	2	2570	0.1	2	2570	0.1
1977-1981	20	2020	1.0	3	2020	0.2
1982-1986	56	2016	2.7	10	2016	0.5
1987-1991	177	3103	5.7	39	3103	1.3

Paper II

Is not included due to copyright

Paper III

Treatment for osteoporosis is an example of disease treatment where the future benefit is uncertain – whilst there are money to be made in the meantime.
(Leader of the Norwegian Society of General Practice, Bjarne Haukeland)ⁱⁱ

RISK REDUCTION ON THE DRUG REIMBURSEMENT SCHEMEⁱⁱ

John-Arne Skolbekken

On Thursday December 19th, 1996 *Aftenposten* told its readers about a breakthrough for patients suffering from osteoporosis. Thanks to the efforts of a broad coalition of female members of the Norwegian Parliament (Stortinget)ⁱⁱⁱ, the majority of MPs had voted so that medicines against this condition were placed on the drug reimbursement list. A long battle against the Government and the Norwegian Medicines Agency (NMA) was victorious, as the provision of these pharmaceuticals was no longer reserved for the more solvent part of the female population. The State would now cover the majority of the costs, and the patients' own expenses would be limited to a co-payment. The parliamentary decision was thus a victory for social justice.

It was also a victory for women. Osteoporosis is a painful and disabling condition that primarily affects women. The fact that a “women’s disease” was entered into the drug reimbursement list, was further seen as a just way of balancing all the pharmaceutical products against “male diseases” (i.e. coronary heart disease) that were already on the list. There was seemingly no reason to doubt that the long wait for the decision was due to the fact the sufferers were mainly women and old women in particular.

Judging from the presentation in *Aftenposten* this day there was little doubt that an important step had been taken on the road to an improvement of the conditions of suffering women, and that Stortinget had reached the right conclusion. During the year that followed, however, *Aftenposten* did provide its readers with new information; information that undermined the picture of the positive health effects and economical expectations that had been presented for these tablets. The involved pharmaceutical company that prior to the decision was portrayed as suffering women’s benefactor in the columns of *Aftenposten*, was now transformed into a profit hungry, manipulating “pill firm”. A firm that was making serious attacks on the freedom of speech, by asking the court to stop the distribution of independent information about its products. This caused a major upset among physicians and the Norwegian Medical Association concluded that the firm sustained a much deserved defeat when the court decided in favour of the distribution of the health economy analysis that had previously been held back.

Preventive medicine – a conflict area

The dispute that is described in the above introduction has since been named the “Fosamax case”, after the name of the involved pharmaceutical product. Scientifically this was a dispute over the risk reducing effect of these pills, as demonstrated in a randomized controlled trial^{iv}. Such studies are often described as the best scientific tool for proving whether a form of medical treatment is effective and not simply the outcome of the body’s ability for self-repair. Although it is considered to be the gold standard in medical research, it is by no means obvious what the correct interpretation of such a study is. One of the reasons for disputes over the interpretation of the outcomes is related to the many ways in which the results can be presented, leaving widely different impressions of the size of the risk reductions that have been achieved. This will be illustrated later on, when we return to some examples from various RCTs.

Decisions about risk are often made within a wider social context. Not only does this context influence which decisions that are made, it also contributes with a series of other factors that contribute to the decisions that are made. In this and in many other situations it is important to remember that risk is not something given by nature, but a measure that is applied for specific purposes, as when individuals or groups are putting risk on their social, cultural or political agenda. The starting point of this paper is thus the same as what Nelkin & Lindee (1995:21) proclaimed about how genes represent various cultural and social agendas:

We suggest that the powers attributed to heredity in both the historical and contemporary contexts reflect cultural and social agendas more than they do the state of scientific knowledge.

It is not difficult to replace heredity with risk in this sentence. One of the major aims of this paper is to remind the reader about such agendas when risk is addressed. In this presentation we will also touch upon the relation between scientific knowledge about risk and the political application of it. What risks we get information about, and how, is by no means the result of random processes. When faced with this information it useful to ask these two simple questions:

- Who has an interest in this?
- Who can earn money from this?

To promote one’s interests and to make money are of course legitimate activities, and it is hard to imagine any progress if there are no interests or money involved. Disease, health and safety are areas where we all have many common interests. This contributes to cover the fact that there are lot of particular interests also within these areas, although they are not always portrayed as such. When we take a closer look at the actors within the health care area and the interests that they represent, we soon discover that their interests are irreconcilable. This is the other main reason for the disputes over the interpretation of RCTs.

A vital part of the context in the story which is about to unfold here are the so-called drug reimbursements, an arrangement whereby the Norwegian state subsidises medicines for the

chronically ill, so that the citizens are provided necessary health care independent of their socioeconomic status. This is a political goal with univocal support in Norway. Through this arrangement the state contributes to the health of its citizens, and as citizens and potential patients we have an interest in this form of health insurance against diseases that strike at random. It also gives the doctors an opportunity of offering their patients the same treatment independent of their income. The arrangement also represents a source of increased sales for the pharmaceutical industry, as drugs that are covered by the National Insurance Scheme (NIS) are prescribed in larger numbers than drugs that patients have to pay out of their own purse. The drug reimbursement scheme can therefore be seen as one of the true assets of the welfare state, one that all the actors on the health arena have their interests in.

Behind this idyll there is a substantial conflict potential. As we have seen in the introduction, it is possible to claim that the scheme has been used to give men's health needs priority over women's needs. In this way the scheme may be seen as a source of conflict between various patient groups, related to the question about whether a form of prioritization is hidden within the reimbursement scheme. There is nothing that indicates that the patients backed by large patient organizations are the losers in this battle, particularly if they work in alliance with the medical expertise and the pharmaceutical industry.

Although the state and the pharmaceutical industry have the helping of the diseased as a common goal, they can also be seen as having conflicting economic interests. When the health authorities and the industry interpret the outcome of a clinical study differently, it may be related to the fact that one of them wants to save money, whereas the other wants to earn money. We shall see how such a conflict of interest may be presented in the media later in this text, as the media also has an important role to play on this scene. Its role appear to be ambiguous on the arena of health policy, as critical journalism often is walking hand in hand with journalism that appear to have no other function than to be a loudspeaker for other powerful actors. This appears to be particularly true for the relationship between the media and the pharmaceutical industry.

A central question to address is linked to the interpretation of the risk reducing effect of drugs, is the question of who is competent to make such interpretations. Traditionally it is the medical expertise in the shape of hospital consultants that has performed these interpretations, within a paternalistic context where these doctors have been attributed the authority of knowing what the patient's best interests are. This expertise has gradually been challenged by general practitioners, which have broken the medically unison interpretation of what constitutes a good and legitimate medical risk intervention.

Many of the decisions that are made in medical contexts are made by ordinary people, in their roles as patients or politicians. The development of our modern society is moving in a direction where people are given the opportunity to decide what is best for them. Ideologically, patient autonomy has become a central principle in modern medicine, although the real impact of this autonomy is open to debate. There is still reason to believe that this remains an area where the expertise is still in power, although their mode of influence takes on more subtle forms than the ones normally associated with medical paternalism.

When the question of interests is portrayed as important in this context, it is also opportune to demand to know the interests behind this text. The answer is that behind this text lays both scepticism and doubt in solid proportions. My scepticism is related to an apparently unlimited medicalization of the population, wherein resources are reallocated from the sick to the healthy. My doubts are related to how central dilemmas in health policy are to be solved, and thereby doubts about what constitute the 'right' decisions. To clarify the dilemmas and to transfer some of the scepticism and doubts to the reader is my claim to be the main interest behind the current text.

Risk reduction and the legitimation of interventions on healthy people

An important function of risk knowledge is that it makes it legitimate for actors like health authorities and health care personnel to tell the healthy part of the population how they should live their lives. When good citizens are encouraged to eat 'five [vegetables] a day', it is because it reduces their cancer risk. This message is based on scientific studies that have documented the mentioned risk reduction. In this manner risk becomes a central element in the state's influence on people's choices when it comes to what kind of food they eat, as well as other facets of their lifestyles. This influence is perceived as legitimate because the state knows what is in the people's best interest, which it can document through its access to expert knowledge. Researchers, health care personnel and educators are important actors in the legitimatising of interventions on healthy people. The base for this influence is thus a modern form of paternalism, where the power of the state is legitimised through its access to risk knowledge.

Both the pharmaceutical industry and the health authorities will emphasise the philanthropic motives behind their efforts for health promotion and disease prevention. At the same time it is quite evident that both these stakeholders have fiscal reasons behind their policies. The state is well served by a health policy that contributes to its strength through the availability of a strong and healthy work force (Elvbakken, Fjær & Jensen, 1994). This is achieved through various injunctions and prohibitions, but also through its contributions to a discourse where the citizens' duty to control their own health is central. When people are encouraged to eat 'five a day' or be physically active for a number of half hour periods every week, the implementation of this policy is not under the surveillance of the health police. In the modern state the surveillance and control is performed through the messages that are communicated in more subtle manners about what is expected from responsible citizens. This practice is an example what has been called governmentality (Petersen & Bunton, 1997).

To eat apples is something people can do because they like apples, much in the same way that they may go on bicycle trips because they love the fun of it. Such hedonistic motives are replaced, however, by more rational ones, when both the consumption of apples and bike trips are based on the knowledge that they are both healthy. What it is that is healthy is quite well documented through research that demonstrates what behaviour that leads to reduced risk

of disease and death. A dominant trait in the modern health discourse is that it is extremely future-oriented. Our present lives are thereby losing some of their value, as they are reduced to an instrument of our future lives. Risk knowledge is central in this discourse because it has the potential of telling about our future. These future prospects are to a large extent based on calculations around an arithmetic mean, which means that we are faced with an epistemological challenge. The challenge is related to what conclusion we may draw about individuals based on research findings on the group and population level. Research may for example tell us that we can reduce the incidence of coronary heart disease in the population if we succeed in lowering the cholesterol level in the whole population. The same research will not be very helpful when it comes to identifying the individuals that will have a personal gain from this, however. As a consequence risk interventions will have to cover individuals who will not have any demonstrable benefit from such measures^v. Based on this challenge it is thus possible to see this as a conflict between the interest of the individual citizen and those of the state. It is in the interest of the state to promote public health, which may mean something different than promoting the health of the individual citizen. The role of the state on the health arena thereby becomes dubious, as it can be seen as acting in the best interest of its citizens, whilst it at the same time presents itself as a guardian that dictates people on how they should live their lives.

The pharmaceutical industry and disease prevention

The pharmaceutical companies do more than provide measures for curing diseases. They do also provide dividends for their shareholders. To achieve both these goals they require the largest possible markets for their products. As such, the healthy part of the population constitutes a far larger market than the sick part of the population. To gain access to this market the industry has developed products that prevent serious diseases, to be used by healthy people. It has thereby gained an important position in disease prevention, by offering chemical prevention with a proven risk reducing effect. These products have several advantages compared to its alternatives. Risk reduction in the form of tablets is well suited for RCTs. In an era where this type of study is reaching religious proportions in medicine, the industry is able to provide preventive measures with proven effects. It has thereby created an economically healthy business, based on the knowledge that it provides the goods for the never ending market of the potentially sick.

The logic of medicalization

A significant feature of the developments over the past decades is an increased medicalization, involving a continuously growing number of people. This medicalization is, among other things, related to an epidemical growth in our knowledge about risks (Skolbekken, 1995; Skolbekken, 2010). It can be tempting to see this development as the outcome of a conspiracy between the state, the pharmaceutical industry, and the medical profession. To look for this conspiracy will most likely lead us down a blind alley. A more fruitful path would be to look

for what the Scottish epidemiologist Archie Cochrane (1972:9) called ‘a marriage between two ideas – between the wish to help and the wish to be helped.’ The three mentioned institutions’ wish to offer help, by means of disease prevention, can be seen as one prerequisite for medicalization. The will to help is not a sufficient condition for medicalization, however, unless it is the will of the population to receive this type of help. These two minds meet in the common belief that the preventive measures actually achieve what they are set out to do. This belief will, among other things, depend on the perceived efficacy of the measures, which in the modern medical discourse is expressed as the risk reduction achieved through its implementation. We will soon have a look at some examples that illustrate how the risk reduction can be communicated to make the impression of great effectiveness. Before we do so, we will have a closer look at how risk knowledge is also used to expand the limits of those that are to be treated, from the manifestly sick to the potentially sick.

Risk conditions – between healthy and sick

Coronary heart disease (CHD) is believed to cause nearly half the number of fatalities in Norway. In addition to a lethal outcome, heart attacks and strokes are serious diseases with potentially disabling consequences. Another serious disease with disabling consequences as fractures of the femur, spine or wrist is called osteoporosis. To reduce the incidence of these diseases are important aims in Norwegian disease prevention. Common to these diseases, is that they develop over long periods of time, before their rather abrupt manifestations, based on a complex combination of causal factors.

Knowledge of their causation is necessary to perform disease prevention, and this is where risk enters the picture. In lack of a complete picture of the causality, risk factors are identified through epidemiological studies. These factors are statistically associated with the disease, and have in many cases been given status as diseases in their own right. Despite the complex causal background it is quite common that certain risk factors are seen as significant markers of serious diseases as coronary heart disease and fractures. For heart infarctions, stroke and fractures it is hypercholesterolemia, hypertension and osteoporosis that have been identified as the most serious risk factors.

There are several reasons for the specific attention given to these risk factors. One basic premise for their identification as risk factors is that they are measurable, as our blood cholesterol level, blood pressure and bone density are normally outside our repertoire of bodily experiences^{vi}. The availability of measuring instruments is therefore a crucial prerequisite for the attention given to certain risk factors. Once identified the work to find effective measures to reduce the risk factor can begin. The three factors mentioned here do all have in common that they are believed to be related to people’s lifestyle. Lifestyle advice is therefore an available preventive measure, but it can be seen as a sign of the times that one of the main reasons behind the current interest in these risk factors, is the fact that we are now led to believe that there are effective means of chemoprevention available.

Inverse help seeking

When the presumption of therapeutic effectiveness has been met, what we may call the inverse help seeking can start. A common way to perceive the order of contact between a doctor and a patient is that the patient first becomes ill, contacts the doctor, who subsequently sets the diagnosis and effectuates the therapeutic measures. Things are different when it comes to the risk conditions, however. As the risk factors mainly are asymptomatic, an initiative from the health services is required to map the patient's risk profile^{vii}. This can be achieved when the patient contacts the doctor for other purposes, as what in medical terms is known as case finding. If case finding is seen as an inefficient procedure for the purpose of identifying individuals at risk, stronger initiatives need to be taken by the health services. Such initiatives may come in the form of health education campaigns, advertisements from private radiology units or personal letters to individuals who fulfil the criteria for being included in medical screening. Media coverage of risk conditions is seen by doctors as another vital source for help seeking by individuals who contact them in order to check whether they are as healthy as they feel^{viii}. In this way the wish to receive help is developed in considerable parts of the population.

Parallel to this the doctor's wish to provide help is also developed, through professional information about the various risk conditions and the treatment of them. This information is frequently provided by those who have developed the therapy and/or the measurement of the condition^{ix}. We do thereby view the contours of an inverse chain of events that starts with the availability of treatment. This availability leads to an increased attention on a possible diagnosis for an asymptomatic condition. To not make use of these possibilities when they exist may appear as both unwise and irresponsible by doctors and patients alike. Through these processes a reciprocal set of wishes are created, which in due time can become a set of rights and duties.

At risk – a chronic condition?

A central theme in this process is the diagnosis, the actual definition of whether a person is sick or not. Traditionally the categories sick and healthy are seen as mutually excluding, but the concept of risk is contributing to an understanding of the categories as being the extremities on a continuum. The line between the healthy and the sick thereby evaporates, and as a consequence most of us can no longer see ourselves as really healthy or really sick^x. This leaves a large space for negotiations about the status of those that do not have a manifest disease in the traditional sense, but who have an asymptomatic risk condition. Such negotiations are taking place on a lot of arenas, from doctor-patient consultations to the development of clinical guidelines by the WHO. The outcome of these negotiations has a considerable impact on how large a part of the population that is defined as and/or perceive themselves as in need of treatment, the workload on the health services, the size of public health budgets and the income of the people and organisations providing tests and treatment. There are thus many and strong interests that are involved in these processes.

It is not unusual that risk conditions are seen as lasting for the rest of the lives of the people affected by them, meaning that they may even be seen as chronic diseases. Diagnoses are frequently a source of rights. In Norway one of these rights for the chronically diseased who are dependant upon medication, is the reimbursement of the majority of their costs through the drug reimbursement scheme. The scheme thus becomes a way for the Government to handle risks. Contrary to privately financed health insurance NIS is designed as if all the citizens run the same risk of becoming sick. It is thus based on solidarity, as everybody who pays tax in Norway are also contributing to a health insurance common to all.

CHD is perceived as a lifestyle disease, but in the NIS there are no attempts to differentiate the costs to be covered for the sick according to their lifestyle. From time to time there are surfacing arguments about how smokers should cover their own treatment costs, but this has so far not led to any changes in the NIS as a health insurance that does not take people's lifestyle into consideration. The costs of the NIS are clearly related to the definition of risk conditions as chronic diseases, for which there exist pharmaceutical treatment. Drug sales in Norway had a substantial increase in the 1980s and 1990s, and the NIS is covering just over 50 % of the sales of pharmaceutical products in Norway. This increase has been explained as coming from a general rise in prices, increased consumption and a change towards new and more expensive products (NOU 1997:6; NOU 1997:7). Among the drugs which have had the largest increase are medicines against CHD, where drugs lowering blood pressure and blood cholesterol level are the major groups.

Gaussonomies – normally distributed risk conditions

Hypercholesterolemia, hypertension and osteoporosis are three examples of asymptomatic risk conditions that at present have been given the status as diseases in need of treatment. Common for all three conditions are that they are presumed to be normally distributed in the population, which makes it possible to call them gaussonomies. The bell curve is in this manner used to separate the normal and the pathological. There is no way naturally given where on the bell curve the line between those in need of treatment and those not in need should be drawn. The answer to what constitutes a high blood pressure and an elevated cholesterol level, and who should be treated for these conditions, varies according to whom you may ask. As a consequence of these discrepancies strong efforts are made to reach professional consensus on these categories. At the moment these efforts seem to be furthest developed for osteoporosis, where the WHO has given a definition that seems to be more widely accepted than the corresponding definition of hypertension.

To be characterised as osteoporotic it is assumed that a person have a bone mass density (BMD) that is considerably lower than what is normal in the general population. To establish what is defined as a normal BMD, measurements are made in a reference population. WHO has established four categories of BMD – normal (a BMD score within one standard deviation^{xi} lower than the mean in the reference population), low bone mass (BMD between 1 and 2.5 standard deviations lower than the mean in the reference population), osteoporosis

(BMD more than 2.5 standard deviations below the mean of the reference population) and established osteoporosis (as category three, but with manifest fractures)^{xii}.

How large groups of the population that are affected is illustrated in Figure 1.

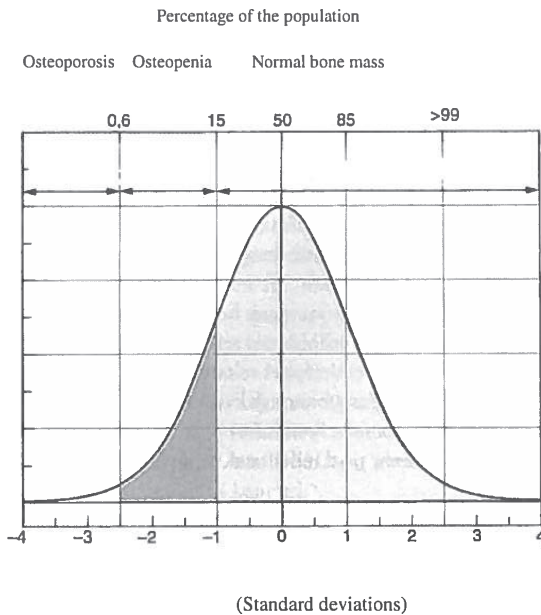


Figure 1 Bone mass distribution in the population

What is defined as normal varies with factors as age, sex, and ethnicity. The bone mass decreases with aging, and the interpretation of this carries significance as to how many elderly people that are defined as belonging to the treatment group. In a reference group of young females, as shown in Figure 1, 0.6 % of the population are categorised as osteoporotic. If the proportion of women with a low bone mass is to be included among those in need of preventive treatment, the treatment group grows to 15 % of the population. The impact of aging is illustrated by calculations based on data from the Nord-Trøndelag Health Survey (HUNT). If the women aged 70+ in Nord-Trøndelag are compared to a young female population nearly 70 % of them will be categorized as having osteoporosis according to the WHO definition of osteoporosis. Similar calculations can be made for hypertension and hypercholesterolemia as well, as blood pressure and blood cholesterol level increases with aging.

The impact of people's sex has been seen as playing different roles in these three risk conditions. In osteoporosis the difference in BMD between men and women has been fully acknowledged. Osteoporosis among women is thus defined on the basis of the normal distribution in a young female population, just as osteoporosis in men is defined on the basis

of a male reference population. This differentiation between the sexes has not been made to the same extent where hypertension and hypercholesterolemia are concerned. A problem related to this lack of differentiation has meant that definitions of these conditions have been exclusively based on male reference populations. A possible outcome of this is that women may have been subject to wrongful treatment, which has led to criticism of the current medical understanding of the relation between a person's sex and CHD.

The definition of osteoporosis is also taking race and ethnicity into consideration, as comparisons are made with reference groups from the same ethnical groups. Osteoporosis may in this sense be seen as a relativistic enterprise, meaning that a Lebanese and a Norwegian woman with the same BMD may still be categorised differently with respect to osteoporosis. Yet again we are confronted with a type of differentiation that is not applied to the other risk conditions.

It is perfectly normal to be sick

One of the observed trends related to these three conditions is that larger and larger proportions of the population are defined as sick as the cut-off points for the treatment groups are moved. As a consequence of this development increasing parts of what is statistically normal is defined as sick. A possible interpretation of this situation is that we are living in a sick society. Whether this is so because the society is defining the majority of its citizens as sick, or whether this is so because the normal life in modern society makes substantial parts of the population sick, is an important theme for reflection and debate.

According to the Parliament's decision there are only persons diagnosed with established osteoporosis that have the right to drug reimbursement for osteoporosis medication. Already when the decision was made, proposals were made to increase these rights to also include people at high risk, but without manifest fractures^{xiii}. Such a widening of the criteria, which can be seen as a move from secondary to primary prevention^{xiv}, will have significant consequences, as the size of the treatment group thereby grows rapidly.

One of the related problems is that the prescription of these drugs is not always in accordance to established clinical guidelines (Hetlevik, 1999). An example of this is the policy that lifestyle interventions should have been implemented before the doctor start to prescribe preventive medication. In reality the doctor's prescription pad is a much more convenient tool to apply than lifestyle changes. To make the doctors the scapegoats responsible for this development is a simplistic approach to these matters, however. Patients who know what they want, and a pharmaceutical industry who are familiar with the market potential of primary prevention, are other actors contributing to the present situation^{xv}.

One of the consequences is that the established practice has important fiscal consequences, as costs for the NIS and an income for the pharmaceutical industry. In a prosperous country like Norway this is an accepted practice, as long as the drugs are effective. Whether this is the case is a matter of interpretation. The interpretation is, among other things,

depending on how the risk reducing effect is communicated. We will now have a closer look at this type of risk communication, through examples of advertisements for a group of cholesterol reducing drugs called *statins*. Statins are at the moment the drug in Norway with the largest turnover, and there has been a significant increase in the turnover over the past years. This communication is to a large extent related to the use and understanding of numbers presented as absolute risk reductions (incidence rates) or as relative risk reductions (relation between rates).

Communicating the risk reducing effects of statins

Drugs that have a cholesterol reducing effect have existed for over fifty years. In the 1970s large trials demonstrated their effectiveness when it comes to reducing coronary mortality, but the effect was too small to have an impact on total mortality. There was furthermore known that there were several side effects attached to the use of these drugs. A literature review had even shown a statistical association between cholesterol reducing drugs and suicide and other forms of sudden death. This made the leader of the British Heart and Lung Institute, professor Michael Oliver, make a public warning against the use of these drugs (Oliver, 1992).

Towards the mid-1990s studies were published that showed that new cholesterol reducing drugs could lower both coronary mortality and total mortality. An important study in this domain was the Scandinavian Simvastatin Survival Study (4S study) (The Scandinavian Simvastatin Survival Study Group, 1994). To the delight of the pharmaceutical industry this made Oliver change his mind (Oliver, 1995), a fact that was made into a major point of an advertisement campaign for Simvastatin (sold under the name Zocor) in the prestigious medical journal *The Lancet*. According to the text of the advertisement the 4S study had proven that Zocor reduces total mortality by 30% and coronary mortality by 42%. These numbers were accompanied by other numbers presenting extremely high significance levels^{xvi}, indicating that the research findings could not be attributed to chance. The advertisement did also mention that the results were valid for patients who had already had a heart attack or had been diagnosed with angina pectoris, i.e. it told that this was a study about secondary prevention.

At first sight the effectiveness of this drug is very impressive, which is just the impression the advertisers want to leave. An equally impressive study was presented in an article published in *The New England Journal of Medicine* in 1992 (Manson, et al., 1992). The results presented in their literature review is summarised in Table 1, showing the risk reducing effect on heart attack risk achieved through various preventive measures.

Table 1. Risk reduction for heart attacks achieved through preventive measures (in per cent). Based on Manson, et al., (1992).

Measure	Risk reduction
Quit smoking	50-70 %
Reduced cholesterol levels	
Dietary measures	20-30 %
Chemoprevention	40-60 %
Treatment of hypertension	40-60 %
Physical activity	35-55 %
Normal body weight	35-55 %
Postmenopausal oestrogen treatment	44 % ^{xvii}
Moderate alcohol consumption	25-45 %
Intake of Aspirin tablets	33 %

As with the effects of statin treatment the initial perception of these numbers can very well be one of great effectiveness. It could even be tempting to conclude that the cumulative effect of these measures may reduce the risk of a heart attack by 300-400 %. On second thoughts, however, we may wonder why anybody gets a heart attack at all if the effect of apparently simple measures is that good.

The answer is related to the fact that these numbers can not summarised. All the measures may be applied in the same individual, thereby giving away the simple fact that the reduction can never be more than 100 %. The above numbers are all showing the *relative risk reduction* achieved by these measures. They are giving us a good indication of their effectiveness compared to not doing anything to prevent a heart attack. Whether they should be implemented or not is to a great extent depending on the prevalence of the disease in question. If we want to know something about the effect in a public health context we will also need to take the *absolute risk reduction* into consideration. A main reason for doing so is that different studies may give different risk reductions in absolute terms, whilst at the same time showing to have the same relative risk reducing effect. Some such examples are given in Table 2. In all four examples we are comparing the outcome in the treatment group with the outcome in the control group that is not given any treatment. (In RCTs this can be done by giving the treatment group the drug whose effectiveness is tested, whilst the control group is given placebo).

Table 2. Some examples of combinations of relative and absolute risk reductions (Source: Skolbekken, 1998).

Treatment group		Placebo group		Relative risk reduction (%)	Absolute risk reduction (%)
Survivals	Mortalities	Survivals	Mortalities		
9000	1000	8000	2000	50	10
9900	100	9800	200	50	1
9990	10	9980	20	50	0.1
9999	1	9998	2	50	0.01

As can be seen from Table 2 the four interventions all achieve a relative risk reduction of 50 %, indicating that they can all cut the risk in half. The number of people that are affected in the different examples differs significantly, however, as the absolute risk reductions are so variable. In a public health perspective the first intervention will have the greatest impact, as 1000 lives are saved, whereas the last example gives the least impact, saving only one life. We will do well to keep these numbers in mind when the newspapers are reporting about another super pill that is cutting the risk of a disease in half.

The numbers not mentioned by the advertisements

If we go to the original publications from the 4S-study, we find that the absolute risk reduction achieved is 3.5 % for coronary mortality and 3.3 % for total mortality, respectively^{xviii}. These numbers are not as impressive as the relative numbers, a fact which has been established in numerous studies testing how doctors and other decision makers relate to such information. By exclusively presenting the risk reductions as *relative risk reductions* in the advertisements, it is an understatement that the pharmaceutical industry is being economic about the truth of the matter in this context^{xix}, without ever crossing the line of telling something that is not true.

In clinical epidemiology the matter has been taken one step further by calculating the number needed to treat (NNT) to save one life^{xx}. For the 4S-study the NNT is 29 people to prevent one coronary death and 30 people to prevent all forms of death, respectively. When these numbers are presented the doctors' willingness to prescribe is even lower than when the effect is presented as absolute risk reductions. Taking the matter even further it is also possible to calculate the number of tablets that need to be taken to save one life^{xxi}. With the 4S-study as point of departure it can be calculated that people with angina pectoris or people with a previous heart attack will have to swallow 57 159 tablets to avoid one coronary fatality. These numbers increase considerably if we move from the prevention of one fatality among those that have already experienced a heart attack to apparently healthy men. This is aptly illustrated by the following quotation:

Medicine is not an exact science. Therefore, 200 men without any prior heart disease have to swallow 357 700 tablets over five years to save one of them from dying from coronary heart disease. This is due to the fact that no exact knowledge exists as to whom of these 200 men will benefit from the treatment. (Skolbekken, 1998: 1957).

The understanding of and implications from these numbers are not intuitively given, and there is an ongoing debate about these issues among the experts^{xxii}. It is still worth to reflect on why,

to a large extent, it is only the relative risk numbers that are used when the effect of some preventive measure is presented in advertisements or the mass media.

If these numbers are difficult to grasp or there arises doubts about their significance, there are other ways of getting the message across. It was thus interesting to observe how the risk numbers eventually vanished from the Zocor advertisements, and were replaced by messages illustrating the drug's effect on quality of life. Another example of how other ways of communicating is applied when controversy arise over the interpretation of risk numbers stems from what in Norway is known as the Fosamax-case. We will have a closer look at this case, mainly through its long presentation in *Aftenposten*.

The Fosamax-case

As mentioned in the introduction of this text the decision to include Fosamax in the drug reimbursement scheme had both a background story and an aftermath. In 1996 and 1997 *Aftenposten* published a number of articles about what the newspaper called the war over Fosamax^{xxiii}. The scientific dispute over Fosamax was about the interpretation of the findings from the so-called FIT-study (Fracture Intervention Trial) (Black et al., 1996). It was discussed in the *Journal of the Norwegian Medical Association* in the spring of 1997. This discussion came as a response to a letter the manufacturer had distributed to doctors around the country, in an attempt to meet what they saw as misleading information from the minister of health. The letter contained scientific documentation on the effectiveness of Fosamax in the format of relative risk reductions, which in the FIT-study meant a 50 % reduction of the risk of hip fractures. Furthermore, information about the study's status as secondary prevention was missing. The letter fostered a rapid response from two female general practitioners (GPs), who claimed the information stated in the letter could be misleading although it did not contain any factual errors (Hetlevik & Grimstad, 1997). By studying the original publication they calculated the absolute risk reduction for hip fractures to be 1.1 %, so that 91 women had to be treated over 2.9 years to prevent one such a fracture.

Once more we see that the impression given of the risk reducing effect of the drug is different when presented as relative and absolute reductions, respectively. This was also illustrated when another drug against osteoporosis was introduced on the Norwegian market. According to the manufacturer's advertisement (Figure 2), the fracture risk was reduced by 68 % when Evista was used.

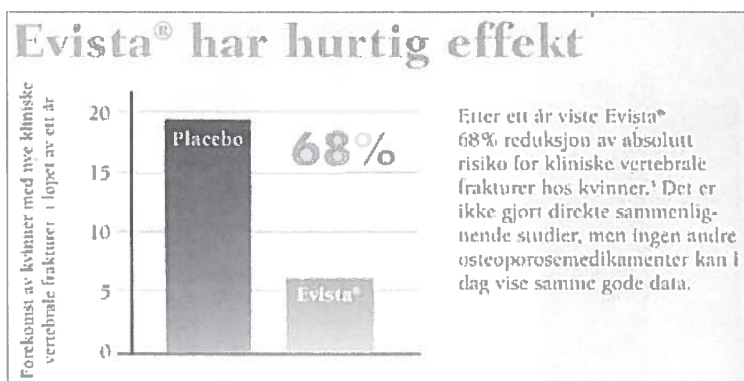


Figure 2. Advertisement showing the fracture risk reduction achieved by Evista. Reprinted from Skolbekken & Forsmo (2003)^{xxiv}.

When we checked the numbers from the original publication we found the absolute risk reduction to be far less impressive than the advertisement indicated. In the placebo group the absolute risk was found to be 0.8 %, whereas the same number for the treatment group was 0.3 % (Figure 3). The absolute risk reduction achieved was therefore 0.5 %. As Figure 3 illustrates, the vast majority of participants in this study did not suffer any fractures. Although the medicine can be said to have been proven to be effective, the decision makers are still left with a dilemma when choosing how this drug should be implemented in the population. We will return to this below.

Based on these figures it is tempting to state that the relative risk reductions tend to present the data in a deceiving manner and that they may be misleading. Despite this, such numbers were the most frequently used at the time of the Fosamax-case, and the only risk numbers given in the newest Norwegian textbook on osteoporosis at the time (Gordeladze, 1998).

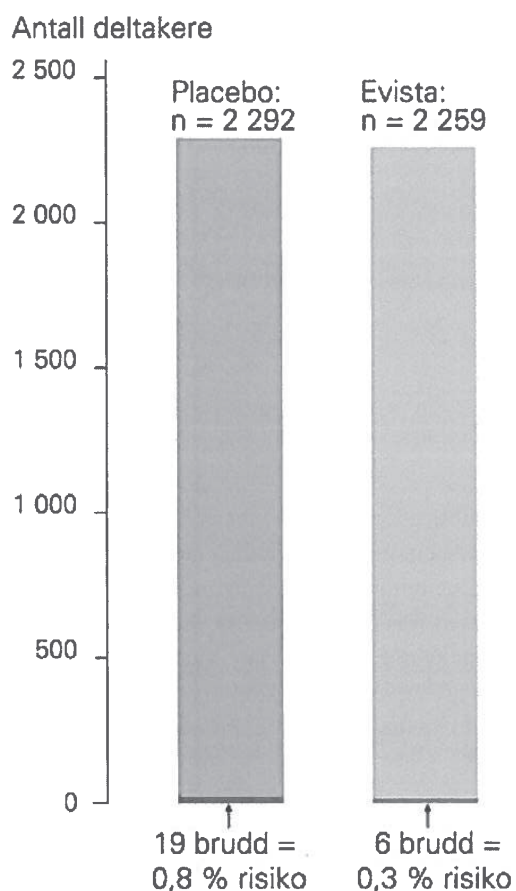


Figure 3. The effect of Evista presented as absolute risk reductions. Source: Skolbekken & Forsmo (2003).

From group to individual

The debate in the *Journal of the Norwegian Medical Association* was also about the challenge we are faced with when risk reductions achieved at the group level are to be translated to the individual level. An important limitation in this epidemiological knowledge is that it will only tell us about the benefits achieved at the population level if a preventive measure is implemented. Which individuals that will benefit from these measures, we know much less about. This problem is not always mentioned when research results are communicated, as when the consumer focused health journalism is addressing the individual reader with the truth about “your risk”. In reality this personal risk estimate is an expression of a group average. Paradoxically, what is required for this to qualify as your particular risk requires that you are pretty average.

In Denmark, professor Hanne Hollnagel has suggested a way of communicating risk information that stresses that what appears as a risk reduction at the population level involves uncertainty at the individual level. The thought behind this way of communicating is that the

doctor should avoid the use of words with a framing effect, like chance and risk, avoid relative risk numbers, and be open about the uncertainty related to these numbers. According to these principles Hetlevik & Grimstad (1997) demonstrated that doctors could communicate the outcome of the FIT-study in the following manner to patients who have already had a vertebral fracture:

If 100 people like you are given no treatment for 2.9 years, two people will get a hip fracture. Whether you are one of the 98 or one of the two, I do not know. Then, if 100 people like you are treated with Fosamax for 2.9 years, one person will get a hip fracture. Again, I do not know whether you are one of the 99 or the one getting the fracture.

This statement led to several comments and further debate over the correct interpretation of the study and the practical implications from it. The manufacturer argued that a correct presentation of the message from the study should also cover the risk for wrist fractures and vertebral fractures^{xxv}. These fractures had not been included in the original presentation, as the absolute risk numbers were not presented in the original data from the study. The numbers were presented by the company during the debate, however. If included, the above message to women with a prior vertebral fracture would be like this:

If 100 people like you are given no treatment for 2.9 years, 18 people will get a fracture of the spine, hip or wrist. Whether you are one of the 82 or one of the 18, I do not know. Then, if 100 people like you are treated with Fosamax for 2.9 years, 14 will get a fracture of the spine, hip or wrist. Again, I do not know whether you are one of the 86 or one of the 14.

One reaction to Hollnagel's mode of communicating is that nobody will take the drugs if the risk communication is done this way. Whether this observation is correct we do not know, as it has not been subject to research. Such reactions do, however, reflect a paternalistic attitude that is still frequent among doctors. For doctors that are convinced that it is important that people take these tablets, the message must be framed in a manner that ensures that people still believe that they are helped by them. If the message is communicated as demonstrated above, doubts are introduced as to what constitutes good medicine and the doctor's authority is undermined. In this manner a more sophisticated presentation of messages about risk can be seen as a way of destroying the base for medicalization. We will return to this point towards the end of the paper, but first we will have a closer look at the rest of the Fosamax-case. The battle over whether this drug should be included in the drug reimbursement scheme was not only fought among professionals. It was also fought in the newspapers, in Parliament, and eventually in court.

Brittle ladies and their noble knights

The readers of *Aftenposten* were introduced to the Fosamax-case through the description of a serious health problem (osteoporosis) that is costing the Norwegian society one billion kroner annually. The sufferers are old ladies that in many cases are unaware of their osteoporosis until they are lying on the floor with their broken hips. There is, however, hope for "brittle old bones", as a medical expert can tell the tale of a new drug that is coming soon. We are

therefore initially facing the obvious solution, as new medicines can provide good help for brittle old ladies whilst the society is saving its costs at the same time.

It is therefore shocking when the newspaper tells that what the experts call “the best drug against osteoporosis” is not coming to Norway. This is due to a conflict between the health authorities and the manufacturer over the price of this drug. The good helpers are in danger of not getting their development costs covered, which puts them in a difficult position. As medical experts can show that the drug achieves a 50 % reduction in the number of hip fractures, makes the health authorities’ choice even more of an enigma. *Aftenposten*’s initial coverage has a clear set of roles, with victims (brittle old ladies), a crook (the health authorities) and a hero (the manufacturer).

Among the heroes are also the guerrilla soldiers of osteoporosis, Norwegian doctors who are fighting the stupidity of the health authorities by importing Fosamax directly from an Icelandic pharmacy. This guerrilla warfare is fought with the patients’ money, however, which contributes to a division between those who can afford to pay and those who cannot. Female MPs from the opposition is therefore entering the arena, claiming the politics of the social democratic government to be discriminating women as well as promoting social injustice. A point is made of the fact that drugs helping patients with hypertension and hypercholesterolemia (meaning men) has already been included in the drug reimbursement scheme, whilst drugs against osteoporosis have not been included^{xxvi}.

To underline the obviously unjust situation, *Aftenposten* is also using an approach that is killing any statistically based argument – the suffering, personalised victim. The victim in this case is a woman who has shrunk from 167 cm to 139 cm, whilst at the same time suffering a series of painful fractures of the spine, hip and legs. To help this woman getting a better life costs 12 kroner a day. This is what the health authorities in one of the most prosperous countries in the world are denying her, despite the fact that the risk of a condition that affects every third woman can be cut in half^{xxvii}. It is thus a triumph for both social justice and justice for women when the Parliament includes Fosamax in the drug reimbursement scheme. The minister of health keeps fighting the decision, however, by making attempts to limit the right of making reimbursed prescription to hospital specialists, whilst the coalition of female politicians argue that also GPs should be able to do so. The question of the general practitioners’ right to make reimbursed drug prescriptions also ends the story of the brittle ladies and their noble knights. Another story begins, turning the hero of the first story into the villain.

Change of roles

The new story starts as an expressed worry about the consequences of the Parliament’s decision. General practitioners have already displayed a generosity when it comes to prescribing cholesterol reducing drugs, and there is reason to believe that they will be equally generous if they are allowed to make reimbursed drug prescriptions for Fosamax. Now another set of experts is entering the stage. In contrast to the experts that cited relative risk

numbers in the first part of the story, the new experts quote absolute risk numbers. They state that 90 women will have to be treated to prevent one fracture, whilst only two of 100 high risk patients suffer a hip fracture. What seemed obvious in the first part of the story is no longer so. This impression is further strengthened by hitherto unknown costs, showing that the cost of preventing the fractures is fairly equal to the earlier mentioned treatment costs.

A picture is now drawn of a well intended decision, made without sufficient knowledge about its consequences. Among them is the possibility that parts of the healthy population are exposed to expensive drugs with little effect. Now the thought of side effects enter peoples' minds, and it is further shown that drugs against osteoporosis can be reimbursed without any actual measurements of osteoporosis being required. The NIS' capacity to inform the doctors about the Parliament's decision is furthermore limited, leaving it to the pharmaceutical industry to provide the doctors with information. This information is seen as incorrect, and there are hints of this being an intended outcome. All this now makes what only a few months ago an obvious and just decision a rather dubious one. According to one expert this may have happened because the Parliament is an easy prey for pressure groups. Behind them the pharmaceutical industry is orchestrating the process, by means of lobbyist firms that are leading the politicians' and media's attention towards certain groups of drugs and patients^{xxviii}.

From being the brittle old ladies' benefactor being denied performing their philanthropic acts by the big bad state, the manufacturer is now portrayed as a money machine and the real crook. This is further illustrated by stories about the manufacturer's marketing strategy in the USA, where it is financing centres for bone density measurements, with the goal of recruiting 20 million female users of their drug. Among their goals is also the identification of 18 million women who are happily unaware of their osteoporosis. On top of all that is a potential market of a further 44 million women if Fosamax is accepted for the purpose of primary prevention. This portrait of a crook is fulfilled when the company is taking NMA to court in an effort to stop the publication of their information magazine. The company is now labelled as a "pill giant" and a "pill company", and is presented as a large multinational company that is threatening the freedom of speech. Doctors are threatening to boycott the company, as it is underestimating their ability to make their own critical assessments of the information provided by the NMA. The court decides that the magazine can be published, whilst at the same time criticising the NMA for their administrative practice. Thereby the Fosamax-case is closed by another just decision.

After the battle

The history of the Fosamax-case is not unique in Norway, or the rest of the world. It is presented here because the publicly available material about is larger than in comparable cases. A review of American news media's coverage of the effects of such drugs as pravastatin, alendronate (Fosamax) and aspirin show that 40 % of the coverage did not contain any numbers about their effect. When numbers were used, however, relative risk numbers only were used in 83 % and absolute risk numbers in two per cent of the published

articles. In the remaining 15 % both sets of numbers were used. Furthermore, side effects were included in about half of the articles, and the costs in 30 % of them (Moynihan et al., 2000). This indicates that the information that is provided to the public about the risk reducing effects of drugs in most cases is incomplete.

The Fosamax-case is not only a story about communication of risk numbers, but also about what measures are being used when the risk communication does not have the intended effect. The case is a story about a situation wherein the parts are fighting about construction the “true” story, putting themselves in the role of truth tellers. Looking back on *Aftenposten*'s coverage of the story prior to the Parliament's decision, it is easy to imagine that its sources had a certain impact on the journalistic angles chosen. In the aftermath the manufacturer admitted having been in contact with MPs, but underlined the patients' interests and the efforts made by doctors and other specialists as decisive in the matter. The claim that the Parliament was under pressure from interest groups has therefore, at least in part, been confirmed.

Aftenposten's coverage of the case after the parliamentary decision, illustrates that it had many facets, and one can only speculate what the Parliament's decision had been if they had been know prior to the actual decision. There is also reason to wonder why the journalists did not ask more critical questions in the initial process. As such the Fosamax-case can be seen as providing important lessons, so that such questions are asked when similar cases appears in the future. There are few reasons to doubt that such cases will appear again, as there are both significant interests and substantial amounts of money involved when decisions about what constitutes effective drugs and who are the parties worthy of being benefited by them, are to be decided

Useful idiots – deceived by relative risk?

As was mentioned in the introduction, an important question in these matters concerns who is perceived as qualified to make decisions in matters like these. This was a recurring theme in *Aftenposten*'s coverage of the Fosamax-case. To what extent did the minister of health understand the science, and to what degree did the coalition of female MPs do so?^{xxix} The same question can be raised about the competence of the doctors and the journalists. The doctors that claimed that the manufacturer underestimated their ability to read for themselves did obviously see themselves as qualified to assess the facts of the matter. In the *Journal of the Norwegian Medical Association* a researcher still found reason to clarify errors in the NMA's article as “the majority of Norwegian doctors hardly know this field of research well enough to discover the weaknesses in the article....” (Kristiansen, 1998). It is quite tempting to ask in this matter whether journalists^{xxx}, the coalition of female MPs^{xxxi}, and parts of the medical expertise in this and similar case behaved like useful idiots, deceived by relative risk numbers.

If they were, they are not alone in doing so. There has been published several studies that illustrates how doctors and other decision makers are influenced by the framing of these

messages (Skolbekken, 1998). According to these studies the perceived effectiveness of these drugs are diminishing as the data are presented as relative risk reductions, absolute risk reductions and number needed to treat, respectively. Similar findings have also been found when people have been asked about their willingness to participate in various forms of medical screening, and the effectiveness of the screening is presented in the three mentioned formats (Sarfat, et al., 1998).

When we know the effects of this use of risk numbers, there is little reason to believe that the frequent use of relative risk numbers is a matter of chance. There is rather good reason to believe that this is part of the communication strategy of those actors that have the biggest interest in presenting the preventive effects as large. To convince the highest number possible of healthy individuals that they really are in need of medical help, is a central part of the strategy of those that can provide help through testing treating (Payer, 1992). Selective use of numbers is not a privilege limited to the pharmaceutical industry. Criticism has also been aired in relation to public health authorities for exaggerating both women's risk of getting breast cancer and the effectiveness of mammography screening in its prevention (Bunker, 1998; Hann, 1999; Philips, et al., 1999). The aim of such communicative practices is to secure high participation rates for the screening. Such a practice may be criticised for accepting unethical measures as long as goal of the activity is sacred.

Another criticism of this practice is that it may draw the attention away from women's risk of CHD, which is the most common cause of death among women in the Western world. This makes the depiction of CHD as a 'men's disease' at best a misunderstanding, as the percentage of women dying from this disease is similar to that of men. The knowledge about CHD in women is not as good as the similar knowledge about men. The women's perspective in this is important, and it is different from the one presented in the Parliament during the Fosamax-case. According to this perspective what has happened is an example of an expanding medicalization of both the female body and old age (Kazanjian et al., 1999). From this point of view the debate over Fosamax is a prolongation of the debate that has been raging for some decades, over the meaning of providing oestrogen treatment for women after menopause. This debate is to a large extent a debate over medicalization, a debate that is by no means irrelevant when the focus on prevention is legitimising medical interventions on healthy individuals. Such interventions are undoubtedly well intended, but good intentions are not a sufficient reason if the outcome is making high numbers of healthy women dependent on the health care system.

Risk information, autonomy and informed choices

In this paper we have scrutinised the use of risk information in relation to some of the drugs included in the drug reimbursement scheme. The final choice about whether or not to swallow the tablets, however, remains with the patients. To round off we will have a closer look at a theme receiving more and more attention, the patient's informed choice. This activity has traditionally been related to participation in medical research, but is steadily become a more regular feature of medical treatment. It seems reasonable that the options of free choices

should be given when preventive measures are implemented. Traditionally the communication of risk has been connected to the risk of side effects in treatment and research. In the future information about the risk reducing effect of preventive measures may become central when lay people are about to make their choices. Such a choice should be based on sufficient information about risk and other relevant matters. It is thus important to know the framing effects attached when these choices are to be made, so that choices based on relative risk numbers alone are avoided.

A premise for being serious about the patient's free choice is that the patient is sufficiently informed about the available alternatives. Questions have been raised by several sources about whether this is the case when it comes to recruiting participants in medical screening, so that it is realistic to talk about an informed choice (Ward, 1999; Wolf et al., 1996). A possible consequence of giving the patients more information is that fewer will choose to participate in medical screening and chemoprevention. There are for instance studies that have shown that older men decline the offer of a screening for prostate cancer when they are provided with information about the uncertainty involved in the test results and the side effects of eventual therapeutic measures following the testing (Flood et al., 1996; Wolf & Schoring, 1998).

The introduction of informed choices may also contribute to questions being raised about the traditional doctor and patient roles. For a long time the doctor has had the privilege of making decisions on behalf of the patient, based on a perceived better knowledge. The increased emphasis on patient autonomy is in principle making doctors and patient more equal. At least theoretically it is possible to depict the doctor's role as a professional, communicating neutral information on which the patient may base his decisions. In reality things may be a bit different, as has been illustrated in genetic counselling.

The goal of such counselling is to give people with possible genetic risk of diseases information about their own or their eventual children's risk of getting a particular disease. The professional ethos for this kind of counselling has for a long time been that it consists of the passing of objective information that the patients interpret before making their decision. Empirical studies have shown that the perceived objectivity may be little else than wishful thinking, as the counsellor hardly can avoid passing on his/her own preferred choice in the matter as well (Bosk, 1992; Michie & Marteau, 1996). Another complicating factor is that some patients do not wish to make their own autonomous decisions, but prefer the doctor to make them for them. This illustrates that more freedom of choice also involves more responsibility, which can be quite challenging when the choice is between two evils.

A recently published study about Norwegian doctors' attitudes towards patient autonomy and paternalism show that a vast majority agree that patient autonomy and the patient's choice should be central elements of modern medical treatment (Falkum & Førde, 2001). A considerable majority of the same doctors do also think that doctors should try to convince patients about the advantages of a healthier lifestyle. This may indicate a certain amount of ambivalence among the doctors. Given that paternalism is perceived as not an

exclusively evil pursuit, and that autonomy is not always beneficial, this ambivalence is understandable.

In the late modern society many decisions about health risks are presented as individual choices. Questions can be raised, however, as to whether we as individuals have the necessary mental ballast to make these choices. One requirement for making the freedom of choice a reality is that society provides more basic knowledge about themes as risk communication and clinical epidemiology, perhaps at the high school level. Such a paternalistic suggestion may seem paradoxical, but the pedagogical challenge is formidable.

At the start of this paper we mentioned that the expanding medicalization can be seen as the outcome of a development where a series of decisions have an unfortunate end product without anyone in particular being responsible for it. According to leading sociologists the hallmark of the modern citizen is reflexivity. It is thus interesting to observe what questions the reader reflect on after reading this text, and if the consequence of these reflections will be a change of the reality that has been described on these pages.

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ⁱ Quoted in *Aftenposten* 12th November 1997.

ⁱⁱ An earlier version of this manuscript appeared in Norwegian as a chapter in an anthology about risk (Thelle, 2001). In addition to the coauthors and publishers of the anthology, Doris Brauten, Kari Brauten, Siri Forsmo

and Irene Hetlevik all gave valuable feedback on earlier versions of the Norwegian text. This translation has been made by the author, for the purpose of making the whole thesis readable in English. A few minor changes has been made to the original text, but no attempt has been made improve the text with the benefit of hindsight.

ⁱⁱⁱ The coalition had the following members: Magnhild Meltveit Kleppa (Sp), Annelise Høegh (Høyre), Kristin Halvorsen (SV) og Valgerd Svarstad Haugland (KrF).

^{iv} These studies have an experimental design. A group of people that have the same health problem are divided into two groups by means of randomization. One group is then treated with the active treatment, whereas the other group is treated with placebo. To make sure that the participants are unable to guess which treatment they are offered, it is important that the study is double blind. This means that neither the doctors administering the treatment nor the patients know who gets the active treatment and who gets the placebo.

^v See Rose (1992) for a closer discussion of this challenge.

^{vi} The existence of this knowledge does, however, enable people to perceive a bodily experience as elevated cholesterol. Lively descriptions of this have been given by Jorid Anderssen (1998 & 2000). As Alan Radley (2004) points out, a premise for the interpretation of bodily experiences as disease is the cultural provision of information about this experience leading to its identification as a symptom. When the symptoms are not there, it is still possible to perceive them on the basis of information that they should be present.

^{vii} This inverse help seeking can also be seen as creating such patient categories as the worried well and those that are deluded to believe that they are healthy.

^{viii} The sudden transformation from asymptomatic condition to manifest disease leads to frightening metaphors in the media, as when newspaper readers are made aware that they may carry an aorta aneurysm about to burst – leaving with the metaphorical knowledge that they may be carrying an undetonated bomb in their belly. The same metaphor has also been used about osteoporosis. A similar picture has been drawn by Eivind Myhre (1990) in his textbook on osteoporosis stated that “The disease is sneaking. One may say that it comes like a thief at night, because it is then that the calcium of the skeleton is stolen, due to immobility and fasting.” (My translation).

^{ix} According to Molaug & Spigset (2001) 90 % of the information GPs receive about pharmaceuticals are provided to them by the pharmaceutical industry.

^x In its uttermost consequence this way of thinking will have existential implications, as it is possible to think of life as consisting of two main phases; one of building up and one of breaking down. The earlier one views the break down to start, the longer the decline towards death will be.

^{xi} A standard deviation (SD) is the mean deviation from the mean in a normal distribution. In a normal distribution about 2/3 of the population will be in the area of one standard deviation below and one standard deviation above the mean.

^{xii} See Gordeladze (1998) and Sjøgaard (1999) for a closer description and discussion of these criteria.

^{xiii} This claim was, among others, made by Magnhild Meltveit Kleppa, who later became minister of social affairs in the Bondevik-cabinet. She was then criticized for not changing the criteria for drug reimbursement.

^{xiv} Secondary prevention is aimed at early detection/reducing consequences for those that are sickness, primary prevention is aimed at keeping healthy individuals free from disease.

^{xv} When it became public knowledge that Aspirin had a secondary preventive effect against heart attacks, the question about what was the appropriate way to advertise this effect arose. The relief among the industry representatives was substantial when FDA accepted that the drug could be advertised as having a preventive effect on heart attacks as long as the limitation in the proven effect was mentioned. Mann & Plummer (1991:11) give this description of the meeting at the FDA: "Surprised by the question, Young asked William MacLeod of the Federal Trade Commission whether advertising for second heart attacks were allowed. MacLeod replied that the subject was not on the agenda.

That was enough for Young. Deciding the matter quickly, he told the assembled aspirin makers that they could keep advertising second heart attacks, but that they should not touch first heart attacks.

'And then you could just see the lights clicking in their eyes,' Rheinstein recalled, laughing ruefully. Imitating the thought processes of a thunderstruck aspirin manufacturer, he said: 'Wait a minute – these guys are saying that the public can't tell the difference between ads for second heart attacks and ads for first heart attacks? And ads for second heart attacks are still okay? Great! Bye!' And they practically *ran* out the door. It was the shortest meeting I've attended in my life."

^{xvi} Significance testing is a statistical procedure used to calculate whether a research finding is a chance outcome or not. The more zeros that are put in a decimal position, the less likely the outcome is a result of chance.

^{xvii} This applies to women only, i.e. a decade after Manson et al's review, results from the Women's Health Initiative Study (Ref) indicated that there was no such effect of oestrogen treatment.

^{xviii} The 4S-study gave many other results than the two numbers that are treated here. We limit this presentation to these numbers, however, as these are the numbers used in the drug advertisements.

^{xix} Readers familiar with the classic "How to lie with statistics" may recognise the statistical creativity used in these type advertisement campaigns.

^{xx} The number needed to treat NNT is calculated as $1/ARR$.

^{xxi} Skolbekken (1998) suggested the name Tablets Needed to be Taken (TNT) on this calculation. The formula for TNT is Daily dosage x 365 days x NNT x number of treatment years.

^{xxii} See Kristiansen (2000) for a discussion of the understanding of NNT.

^{xxiii} Despite the fact that *Aftenposten* covered the case over two years, these articles can hardly be characterised as a series of articles. The number of journalists covering the case was relatively large, and the angles covered in the articles changed as the case developed. The presentation is in this sense different from how it would have been covered in a tabloid newspaper, where this type of material is covered in a consumerist ethos about "your health" or "on your side", in an effort to make it significant for the individual reader. Nor was it front page material, as it would have been in a tabloid newspaper. There is nothing in the way of headlines, pictures or general positioning within the newspaper that can be seen as making the reader aware of this as a particularly important or interesting story.

The articles on which I build my presentation were found through using the words *benskjørhet* (osteoporosis in Norwegian), *legemidler* (drugs) and *Fosamax* on *Aftenposten's* webpages. My presentation of the case is based on the following articles published in *Aftenposten* in 1996 and 1997:

- Håp for gamle, skjøre ben (Hope for old, brittle bones) 14.01.96

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- Benskjørhetsmiddel ikke til Norge (Drug against osteoporosis not to Norway). 25.08.96
 - Gi Fosamax på blå resept. (Include Fosamax on the drug reimbursement scheme). 28.08.96
 - Medisin mot benskjørhet: Fosamax-utspill møter motbør. (Drug against osteoporosis: Fosamax- utspill met with resistance). 29.08.96
 - Nå bør Regjeringen følge opp de benskjøre. (Now the Government should follow-up the osteoporotic). 02.09.96.
 - Oslo på verdenstoppen i benbrudd. (Oslo, a world leader in fractures). 09.09.96
 - Ingrid Dønhaug krympet til 1.39. Benskjørheten tærer. (I.D. shrunk to 139 cm. Osteoporosis is wearing [her] down.) 09.09.96.
 - Ny utsettelse for de benskjøre. (New postponement for the osteoporotic). 02.12.96.
 - Legemiddelfirma varsler Hernes. (Drug company notifies Hernes). 04.12.96.
 - Kvinne-koalisjon ga blå resept. (Coalition of women gave drug reimbursement). 19.12.96.
 - Enighet om pris på medisin mot benskjørhet. (Agreement on the price for drugs against osteoporosis). 14.02.97
 - Hernes får kritikk for nytt regelverk om benskjørhet. Få leger får skrive ut blå resept. (Hernes is criticised for new guidelines on osteoporosis treatment. Few doctors are allowed to prescribe on the drug reimbursement scheme. 22.03.97
 - Benskjørhet Hernes og medisiner. (Osteoporosis Hernes and drugs). 11.04.97.
 - Dobler utgifter med blå resept. (Drug reimbursements leads to double costs). 17.04.97.
 - Lårhalsbrudd til to millioner. (A femoral fracture costs two millions). 11.06.97
 - Osteoporose-medisiner: Forskere frykter unyttig bruk. (Drugs against osteoporosis: Researchers fear use without benefits). 11.06.97.
 - Pasientene er ikke redd den nye medisinen. (The patients are not afraid of the new drugs). 12.06.97.
 - Osteoporosemedisinene: Ingen kjenner bivirkningene. (The drugs against osteoporosis: Nobody knows the side-effects). 12.06.97.
 - BI-professor om blåresept-spørsmål: - Stortinget lett påvirkelig. (Economy professor on drug reimbursement questions: Parliament is easily influenced). 13.06.97.
 - MSD brukte interne skriv. (MSD used internal documents). 13.06.97.
 - Medisiner mot benskjørhet. Rikstrygdeverket om rundskriv til legene: - Kan ikke følge opp alle vedtak. (Drugs against osteoporosis. The National Insurance Scheme on information to doctors: - Cannot follow up on all decisions). 14.06.97.
 - Medisiner mot benskjørhet – Vi presses ikke. (Drugs against osteoporosis – We are not under pressure). 14.06.97.

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- Halv medisinpris etter konkurranse. (Competition cuts drug costs in half). 30.06.97.
 - Pille-gigant knebler kritikk. (Big Pharma silences critics). 07.11.97.
 - Beklager stans av artikkel. (Regrets stopping publishing of article). 07.11.97.
 - Langt over streken. (Way over the line). 11.11.97.
 - Vi er ute å kjøre. (We're on thin ice). 12.11.97.
 - Full krangel om legemiddel. (Major brawl over drug). 12.11.97.
 - Lege maner til opprør mot pillefirma. (Doctor calls for rebellion against drug firm). 12.11.97.
 - Pille-firma vil nekte staten yttringsfrihet. (Drug firm wants to deny the state freedom of speech). 14.11.97.
 - Hernes: - Uholdbar munnkurv. (Hernes: - Unbearable munnkurv). 16.11.97.
 - Legemiddelkontrollen føler seg presset. (Norwegian Medicines Agency feels under pressure). 18.11.97.
 - Varsler omkamp om legemidler. (Calling for a rematch over drugs). 20.11.97.
 - En bitter pille å svelge. (A bitter pill to swallow). 23.11.97.
 - Legemiddelfirma tapte mot legemiddelkontrollen i retten. (Drug company lost in court to Norwegian Medicines Agency). 28.11.97.
 - Legeforeningen: En velfortjent lærepenge for bransjen. (Norwegian Medical Association: - A well deserved lesson for the industry). 29.11.97.
 - Kostbare lårhalsbrudd. (Costly femoral fractures). 28.11.97 (SJEKK DATO)

^{xxiv} The text in the advertisement says: "After one year Evista showed a 68 % reduction in absolute risk for clinically vertebral fractures in women. No directly comparing studies have been made, but no other medication against osteoporosis has to date demonstrated the similarly good data."

^{xxv} From the Correspondance section of the Journal of the Norwegian Medical Association, issue 10 and 12 1997. This was also one of the arguments the manufacturer presented in the court case against the Norwegian Medical Agency.

^{xxvi} In this argumentation lays the basis for an issue not covered by *Aftenposten*. The comparison between these three risk conditions is highly relevant. Critical questions could have been made as to why drugs against hypertension and hypercholesterolemia have been included on the drug reimbursement scheme. If the answer to such questions should be that this has happened for the wrong reasons, the next question could be whether compensating old mistakes by committing new ones is the right solution to the problem. In the continuation of these arguments lies also a possible approach to this practice as one that contributes to certain allocations of the health care resources.

^{xxvii} Later that year the newspaper prints statistics from the WHO, stating that almost every fifth woman in Norway is affected by osteoporosis. No attention is given to this discrepancy in numbers, however.

^{xxviii} This expert's claims were not left unattended. Annelise Høegh denied that there had been any contact between the politicians and the pharmaceutical industry in this case. They had to the contrary followed the professional advice of a Nordic medical conference. Høegh was also quoted as saying that "MPs are actually capable of reading the professional literature." She was supported by Valgerd Svarstad Haugland who, based on personal knowledge of women with osteoporosis claimed to have a basis on which to make independent decisions. Whether the readers were reassured about the politicians' competence by reading their comments, remains an open question. None of them have been quoted during this process for making factual claims outside quoting expert statements about relative risk numbers.

^{xxix} A politician that voiced the competence issue was MP Stephen Bråten, who stated the following in Parliamentary debate I 1996: "The finance committee's work on the balancing of accounts has been a strange experience. Those of us that have been bewildered to believe that the Parliament's finance committee first and foremost should pay attention to long perspectives and economical macro politics have had our illusions shattered.

I do in many ways feel that I have been off target when selecting my reference literature. Rather than professional publications and economy textbooks, I should have studied the Norwegian Pharmaceutical Product Compendium.

Here one is invited to include the drugs Epivir, Zerit, Invirase, Crixivan and finally Norvir into the drug reimbursement scheme. The majority of the committee is countering by demanding that Fosamax and Didronate against osteoporosis should also be included. After hard practice I am perhaps able to pronounce the names of drugs and diseases with acceptable precision. The reality behind this is of course serious enough, but I have no qualification as to having an opinion about the details of the matter.

^{xxx} In the aftermath of the case *Aftenposten* is describing Fosamax as a controversial drug. The experiences from the Fosmax-case did not, however, interfere with the paper's choice of the same initial angle to the material when the Hypertension Optimal Treatment (HOT)-trial was published in 1998. Also then the utility of the drug was shown by relative risk numbers voiced by a medical expert, and the patient perspective was taken care of by a visit to the same doctor's office. One may of course wonder what made it possible for the newspaper to bring the news of the outcome of the HOT-study the same day as it was presented at a conference in Amsterdam. Was this the outcome of critical journalism or was it simply the newspaper lending its columns to their sources? A contrast to *Aftenposten's* coverage was given in the magazine *Økonomisk Rapport* after the publication of the HOT-study (Hustadnes, 1999). Another example of critical journalism in this area is Gjesvik (1999), who describes the tactics applied by the pharmaceutical industry to get their products included in the drug reimbursement scheme. It was hard to believe that other journalists had read these articles when Pfizer invited the press for breakfast to tell about a study of Norwegian men's impotence problems so shortly after *Dagens Næringsliv's* publication on just these tactics, see Skolbekken (2000).

^{xxxi} *Dagbladet* took the liberty of printing the following quote in an editorial the day after the courts decision in the Fosamax-case: "On our part we are wondering about those of our MPs that previously supported the drug that is now being scrutinised by the NMA, and saw to that it was made available through the drug reimbursement scheme. Their motives may have been the best, but they had hardly much more than the MSD's boasting about their marketing of the drug to relate to when handling the case. This case illustrates that it is wise to wait for more neutral assessments before the millions of the National Insurance Scheme is put at the disposal of the pharmaceutical industry." Whether the windows of their offices were shattered following this statement I have no knowledge about. It is strange to observe, however, that this opinion should be voiced from the editorial offices of the newspaper that has made it a habit to commit the same sin as they are accusing the politicians of.

Paper IV



Brittle bones, pain and fractures – Lay constructions of osteoporosis among Norwegian women attending the Nord-Trøndelag Health Study (HUNT)[☆]

John-Arne Skolbekken^{a,*}, Wenche Østerlie^b, Siri Forsmo^b

^a Department of Psychology, Norwegian University of Science and Technology, Dragvoll, 7491 Trondheim, Norway

^b Department of Community Medicine and General Practice, Norwegian University of Science and Technology, Trondheim, Norway

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Abstract

Osteoporosis has been labelled the disease of the 21st century. Over the past couple of centuries there have been various notions of this disease in medicine. In the present medical discourse, the emphasis is on prevention rather than treatment, making osteoporosis into a major risk factor for bone fractures. In Norway, osteoporosis is a particularly prevalent condition, leading to bone mass measurements being included in several large health surveys. In a follow-up study of the second round of the Nord-Trøndelag Health Study (HUNT), women aged 55–75 years were invited to participate in focus groups to talk about their experiences in relation to their bone density measurements. Findings from these focus groups show that osteoporosis is perceived as a disease characterized by brittle bones, pain and fractures. The physical appearance of a hunchbacked old woman is a dominant way of portraying the disease. It is mainly perceived as prevalent among women, but evidence that men can get it is provided through the example of a famous male athlete who became osteoporotic. Causal explanations for the disease are dominated by culturally shaped anecdotal evidence wherein medical knowledge has been included. Limits to lay constructions of osteoporosis based on such evidence are discussed. Talking about osteoporosis across generations the women applied different explanations for the condition over time. In doing so, they also showed that they have adopted the morality of the new public health where the individual has control over her health through self-governance. Whereas this was no option for their grandmothers, their grandchildren's generation was seen as one failing to meet their obligations to become healthy citizens. The lay construction of osteoporosis can thus be seen as one that has developed from a situation where osteoporotic persons were perceived as victims of harsh circumstances to one of individual responsibility.

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Keywords: Norway; Osteoporosis; Disease; Lay perspective; Women; Individual responsibility

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* Corresponding author. Tel.: +47 73550643; fax: +47 73591920.

E-mail addresses: john-arne.skolbekken@svt.ntnu.no (J.-A. Skolbekken), wenche.osterlie@ntnu.no (W. Østerlie), siri.forsmo@ntnu.no (S. Forsmo).

Introduction

Osteoporotic fractures represent a rising health problem (Cummings & Melton, 2002), to such an extent that it has been questioned whether this is the disease of the 21st century (Clark, 2002). It may well be too early to answer this question, but osteoporosis already represents a fascinating epistemological challenge to both professionals and lay people.

Historically, the medical understanding of osteoporosis has changed substantially over the past two centuries. According to Schapira and Schapira (1992), the term originates from French medicine around 1820, as a description of a deteriorated, porous human bone. In 1882, Bruns noted that fractures were much more frequent among women than men, and he attributed this to women tripping over their long skirts (Gordan, 1978). The currently accepted definition incorporates that developed by Albright in the 1940s, on the basis of research on sex hormones (Oudshoorn, 1994), attributing the prevalence of fractures in women to post-menopausal lack of oestrogen. Somewhere between the 1940s and the present, a shift in attention from fractures to risk of fractures occurred. Until 1975 only four published articles registered in the ISI Web of Science database contained both the words 'osteoporosis' and 'risk'. By the late 1990s, however, every third article on osteoporosis was an article about risk (Skolbekken, 2000). The present focus on osteoporosis as a risk factor is thus in accordance with what has been observed as the risk epidemic in medical literature (Skolbekken, 1995). This has also led to a discussion on whether osteoporosis is a disease or a risk factor (Søgaard, 1999), reflecting a conceptual ambiguity which contributes to the epistemological challenge. Such discussions are not only related to osteoporosis, but is also part of a more general trend in modern medicine where risk factors as high blood pressure, high levels of blood cholesterol and high levels of blood sugar reflect similar ambiguities (Skolbekken, 2007). For practical purposes, we have chosen to refer to osteoporosis as a condition in this text, as a way of working around the conceptual ambiguity.

As a consequence of this changed definition of osteoporosis, attention has shifted from those who experience fractures to those at risk of doing so. The shift in attention from the sick to the potentially sick means that the number of women involved increases drastically. These women thereby achieve the status of being at risk, which implies that they feel well, are asymptomatic, but always will be aware of their potential

for becoming sick or even die (Scott, Prior, Wood, & Gray, 2005).

The present medical definition of osteoporosis

Central to the present medical discourse on osteoporosis is the World Health Organisation's guidelines on the condition, which defines it as a bone mass density (BMD) that is 2.5 standard deviations or more below the mean BMD in a reference population (WHO, 1994).

This definition is, however, also a source of controversy. Firstly, reference population standard deviations depend on the techniques and skeletal sites of measurement (Kanis & Glüer, 2000). Secondly, there is a growing attention that the individual fracture risk may be overestimated based solely on the presence of a *T*-score below 2.5 SD. It has, therefore, been claimed that other known risk factors should be considered before referral for densitometry or for clinical intervention, with the aim of assessing an individual's absolute fracture risk (Kanis, 2002; Melton, 2000). Additionally, there is not yet a general consensus concerning the definition of osteoporosis in men, although the same absolute threshold as in women has been proposed (Kanis & Glüer, 2000).

Present research on lay knowledge and beliefs about osteoporosis

Osteoporotic fractures are both painful and disabling once they occur. A major focus of the present medical preoccupation with osteoporosis is thus on the prevention of fractures. As with other types of medical prevention, its main focus has been on lifestyle factors like smoking, exercise and diet. A consequence of this has been attention to the public's knowledge about osteoporosis and their subsequent health behaviour. Seen as a health problem predominantly threatening females, studies have been performed on women's knowledge about osteoporosis and its prevention (Magnus, Joakimsen, Berntsen, Tollan, & Sogaard, 1996). The findings from this and similar studies (see Drozdowska, Pluskiewicz, & Skiba, 2004; Waller, Eriksson, Foldevi, Gran Kronhed, & Möller, 2002 as examples), reflect the dissemination of medical knowledge in the female population. In a recent review of the research on knowledge about osteoporosis, Werner (2005) concluded that serious deficits in knowledge of osteoporosis are reported among both lay people and professionals.

Within the medical literature, this knowledge has mainly been studied through the format of 'true or

false' questions. Such studies have been criticized from within the ranks of medical sociology, as they represent a rather narrow presentation of the meaning of health and illness in people's lives (Prior, 2003). In contrast to the above mentioned medical studies, the focus of recent sociological research has been set on women as reflexive individuals, who actively construct their own meaning of osteoporosis and other medical conditions, through their own lived experiences (Green, Thompson, & Griffiths, 2002). These experiences are gained within the frame of particular socio-cultural and historical contexts, wherein their knowledge is produced through social interaction (Reventlow & Bang, 2006).

Varying contexts may also provide quite different perceptions of osteoporosis. Interviewing Danish women, Hvas, Reventlow, Jensen, and Malterud (2005) found that awareness of the risk of osteoporosis caused uncertainty and worry in some of their informants. In contrast, disinterest in osteoporosis was found to be the most characteristic feature of middle-aged Scottish women's perception of osteoporosis. This was explained as a consequence of the peripheral place osteoporosis had in these women's daily life (Backett-Milburn, Parry, & Mauthner, 2000).

To gain more insight into women's knowledge and beliefs about osteoporosis is thus important for several reasons. On one hand, it represents a challenge for public health, including both the possibility of medicalization and of ignorance. On the other hand, it also represents an epistemological challenge. As we have shown, what constitutes medical knowledge on the issue has been, and still is, subject to changes and controversy. From a social science perspective it is of interest to study how a 'lay perspective' is developed under these circumstances. Furthermore, as Prior (2003) has suggested, there may be limits to lay knowledge on issues that are not directly experienced in people's daily lives. We have, therefore, undertaken a study with the purpose of contributing to the illumination of what has been stated to be 'a particularly pertinent issue' (Reventlow & Bang, 2006).

Being a cross-disciplinary research group we have done this through what can be seen both as compromises and quality improvements to this type of research, an issue which we have discussed elsewhere in relation to a similar project (Solbjør, Østerlie, Skolbekken, Sætnan, & Forsmo, 2007). Whilst acknowledging that fractures and bone scans are physical realities, it is also our common position that both professional and lay explanations of osteoporosis are socially constructed. If pressed to declare an

epistemological position we may see ourselves as critical realists, although neither of us would claim this to be a very strong part of our identity as researchers.

Fragile Norwegians

A crucial prerequisite for our study is the fact that osteoporotic fractures are a larger problem in Norway than in many other countries (Forsmo, Langhammer, Forsen, & Schei 2005; Meyer, Falch, O'Neill, Tverdal, & Varlow, 1995). This has contributed to the inclusion of bone mass measurements in several Norwegian health studies, like the Tromsø Health Study and the Nord-Trøndelag Health Study (HUNT) (Meyer et al., 2004). The aim of these studies has been to gain epidemiological knowledge on osteoporosis, in the hope that this would contribute to the prevention of fractures.

In this article, we will report on the construction of osteoporosis made by a group of Norwegian women, whose daily life has been influenced by their participation in a large health study, HUNT. Whereas, the overall aim of our study has a broader scope linked to the influence of medical technology on people's perceptions of their own health, the scope of this paper is limited to describe the participating women's construction of osteoporosis and its aetiology. Although we have gathered data at three different points in time, before and after bone scans, the main focus here will be on the women's constructions prior to undergoing a scan.

Methods and material

Our study was performed by means of focus group discussions among women who were invited for bone mineral densitometry as part of a follow-up of the HUNT 2 study in 2001. To study the women's screening experiences as they developed, a prospective study design was chosen, wherein the timing of our study was done in line with the performance of the bone scans. Three groups from each of three different categories of women were recruited for the study: women aged 70–75 years with previous screening experience from HUNT 2 (Groups 4, 5, 7), women aged 55–64 years (Groups 6, 8, 9) also with previous screening experience, and women 55–64 years without prior screening experience (Groups 1, 2, 3). All women in the oldest age-group and about 30% in the age-group 55–64 years had been included for bone mineral densitometry in HUNT 2. For the follow-up in 2001, the same cohorts were invited. The age-group 55–64 years was, however, expanded with an additional 20% of the female population at that age-level. Prior screening

experience was thus identified through the HUNT archives. The groups met on three different occasions: one week before the screening, two weeks after the screening and six months thereafter. The data material is thus based on a total of 27 focus group discussions.

Study recruitment

The participants were randomly sampled among the women receiving an invitation to participate in the BMD measurement. For logistical reasons, the recruitment was narrowed to the municipalities of Steinkjer, Verdal, Levanger and Stjørdal. These municipalities comprise four of the seven towns in the county of Nord-Trøndelag, and were chosen because they were easy to reach by public transportation by both the researchers and the participants. In order to achieve the right timing for the focus group discussions, the sampling was done in co-operation with the HUNT-research centre. Each woman sampled for this study received a personal letter a few days after receiving the bone scan invitation. Those who responded were then contacted by telephone to make an appointment for the focus group session. Another letter, confirming the place and the date of the focus group, followed a few days later.

A total of 72 women chose to participate and the vast majority attended all three sessions. The group size varied from 12 to 4 participants, with the lowest attendance noted in the third and final session. Most groups were in the 6–9 persons range. Although no formal background data were registered, it became apparent during the discussions that our sample represents a well educated part of their age-groups.

Procedure

All discussions were held in public buildings familiar to the participants. In most cases, the buildings were the same as the ones used for the screening. The sessions for the older women were held late in the afternoon, whereas the younger women met in the evening. To avoid interruptions or other disturbances, the discussions were located in conference rooms well suited for group meetings. In an effort to make the atmosphere relaxing and similar to other social settings wherein people meet to talk, light refreshments were served.

The same researchers functioned as moderator (J.A.S.) and co-moderator (S.F.) for all of the group discussions. A third person (most often W.Ø;) also participated, taking notes enabling identification of the participants during transcription. This was done by

noting the three first words stated every time a participant contributed to the discussion. All sessions were audio taped and then transcribed in verbatim prior to the data analysis.

For each group session we introduced five discussion topics in the manner of a semi-structured design. An example of the discussion topics used at the first meeting is shown in Box 1.

To reduce misunderstandings, all the participants were individually handed a written statement of each topic. The handouts were distributed one at the time by the moderator when the discussion of the current topic was judged to be coming to an end. By doing so, we aimed to avoid diversions from one topic to the next. In addition to the questions raised by the research team, the women brought their own questions to the groups. A time span of 2 h had been allocated for each group session. At the first meeting all the groups lasted the full 2 h, whereas meetings two and three showed a declining time pattern. No focus group meeting lasted less than 1 h.

Data analysis

The data analysis was done in co-operation by the research team to identify the participants' own construction of osteoporosis and its aetiology. This was done in accordance with what Kvale (1996) describes as meaning categorization. At first, one transcription was analysed by all three members to identify a common set of meaningful categories for the coding of the interviews. We then split the transcriptions between us, so that each researcher coded three groups (nine sessions) each. Whenever new categories appeared during the coding process we met to discuss and refine our coding scheme.

When all the transcriptions had been coded, the data material was reorganized into new files containing the

Box 1. Discussion topics at the first focus group meeting

1. What reflections have you made about the upcoming bone scan?
2. What reflections do you have about your own risk of osteoporosis?
3. How will the bone scan influence your own health?
4. What have you done so far to prevent osteoporosis?
5. How do you think the bone scan will influence your perception of the future?

quotations from each category. A short narrative was then produced for each category in every group. These narratives were then combined to make up the narrative presented in the findings section below. To illustrate these narratives we provide quotations from the discussions. In doing so, we have made an effort to find not only quotations from single participants, but also to show the discussion taking place to demonstrate how they help each other in creating meaningful information. Thereby, we hope to illuminate how focus groups can contribute to a richer material than individual interviews by the reciprocal triggering of memories and opinions among the women. It is, furthermore, outside the ambitions of this project to perform any in-depth analysis of the data, i.e. we present the meaning as stated by the women without intending to find the 'truth behind this meaning'. To make the quotations understandable to the majority of our readers we have translated them from Norwegian into English. We have tried to make the translation as close to the original statements as possible without editing them.

Ethics

The study design was approved by the Regional Committee for Medical Research Ethics. Each participant signed a written informed consent form prior to the first group meeting, acknowledging their voluntary participation, knowing that they could leave the discussions at any time without having to give any reason for doing so. They also signed a form acknowledging confidentiality amongst the participants with regard to any personal health information being revealed in the discussions.

Findings

Our participants approached the focus groups with multiple motivations. They saw the groups as an extension of HUNT and wanted to make a contribution to research, as an altruistic effort in helping coming generations. Alongside these communal motives they also saw this as a possibility of a more personal gain, by being given the opportunity of having what they hoped to be a reassuring experience. A common motivation was also the opportunity to learn more about osteoporosis. Many of the participants, therefore, came armed with questions that they wanted to ask the researchers, who they saw as experts on osteoporosis.

The curiosity became particularly clear at the first group session, where the co-moderator (S.F.) introduced herself as a doctor and researcher on the epidemiology of osteoporosis. As a result, she became the centre of

attention from the group, and the target of a substantial number of questions. To avoid this in the subsequent groups, she thereafter introduced herself as a researcher, without indicating any special competence on osteoporosis. Furthermore, we acknowledged the curiosity by encouraging the women to raise whatever questions they had in the group, to see what answers they could get. This proved a very fruitful way of stimulating the discussions in subsequent groups.

When talking about osteoporosis, the women used the concept as a disease, albeit one that has several forms. In its most manifest form, it is observable through fractures, but it can also be a less observable entity as brittle bones that can be experienced through pain. Although recognized as a major threat to women's health, it was not seen as a threat of the same magnitude as cancer.

Osteoporosis – the condition

Osteoporosis was in general recognized to be an extremely painful condition. It was pictured through an old, bowed woman who had got this condition through the toil and hardships of a physically demanding life, however, such observations were less frequent today.

I think they simply didn't know anything about it, our mothers and grandmothers. If they were hunchbacked it was because of the toil...they had very tough lives then our grannies, so they had reason to bend over, to put it that way. But was there any talk about losing bone mass? I don't think they ever thought along those lines. Besides, they rarely or never saw a doctor...so they didn't know any name for it.

(Group 6, first session)

In contrast to the picture of the old women suffering from osteoporosis, modern tales of the condition included a more sneaking and invisible disease characterized by pain and reduced quality of life. Fractures caused by falls or physical traumas occur more easily, but not necessarily.

Although recognized as a condition that has been around for a while, it was also seen as one that only recently has come to public attention. This was attributed to the fact that it is mainly women who suffer from osteoporosis, implicating that this has been a low status condition drawing little professional attention. Current interest, shown through research, the actual screening, and media attention, was seen as a feminist breakthrough.

It's not been seen as a high status disease, so it's never been given any priority for that reason. And

it's been a women's disease, you know. So, the men-folk who sit on the money bags...

(Group 6, third session)

Less politically coloured explanations were also given, as the rise in attention was seen as a consequence of a rising prevalence of the condition. This rise was seen as a necessary consequence of a steadily increasing number of elderly people in the Norwegian population. At the same time, it was a frequently repeated fact that men too could suffer from osteoporosis. This was partly a logical deduction of the fact that men had also been seen at the bone measurement stations. The main proof, however, was the anecdotal evidence about a famous Norwegian sportsman who had had osteoporosis.

Maggy: Think that the fellas can get it too.

Mary: So do I

Iris: I don't know if it's because it's been a female disease that it's been a trifle ignored over the years, but as soon as Oddvar Brå was diagnosed as having osteoporosis it was all over the front page, right? So, thinking about all the women who has suffered all this pain and endured it in silence, then I almost get a bit annoyed.

(Group 6, first session)

Whereas, bone density measurements provided one way of knowing whether they had osteoporosis or not, another important way of knowing was provided through the seemingly prevalent experience of falling. Such experiences were commonly quoted in support of a belief that osteoporosis was out of the question, as many had fallen without fracturing their bones. Also in cases where there had been fractures, osteoporosis was seen as an unlikely cause, as the strength of impact and other factors were judged as more probable causes.

Hillary: Has anybody here fractured anything?

[various voices mumbling — not me, no I haven't]

Anne: Never broken anything, so...

Elsie: I've broken my hand twice and I've also broken my ribs three times.

Clare: I've broken some ribs a couple of times too...fell off the chair sledge once...

Eleanor: I broke a rib...oh, sorry

Clare: You can get a fracture without having osteoporosis

[nodding around the table]

Eleanor: Broke a little bone in my back, but that was a car accident....

Hilary: My first time happened on the ice. I walked on the ice, fell and then it broke there [points]...and the other time I really don't know how it could happen...fell forwards, so I broke two ribs and my shoulder...

Anne: Oh dear, that sounds horrible

Ruby: That's terrible...

(Group 4, first session)

These latter two examples illustrate how the women applied logic reasoning when making sense of complex and seemingly divergent information. Logic was also applied by other older women, reflecting on whether the back-pain they experienced was osteoporosis or not. In most cases, osteoporosis was eliminated as the likely source, as other known sources of back-pain provided alternative explanations.

Among the older women, there were individuals who had previously been diagnosed as being osteoporotic through bone density measurement. They described themselves as fragile and porous, although they had no bodily experience indicating that this was the case. For these women, the forthcoming bone density measurement was both a source of hope and despair. Whereas, they made sense of their own bodily experiences, little sense was made of the feedback from the bone density measurements. The feedback rather seemed to foster confusion, but the women were often reassured by the staff at the screening station.

Personally I presume that the measurement was OK, it's 1.5. Minus 1.5. It means that I'm in the white area...and it's actually been clearly confirmed twice that I don't have brittle bones as I've been in a frontal accident with a car. So, this was no surprise — it turned out all right.

(Group 8, second session)

As a consequence the bone density measurement put them in a situation where they were totally dependant on professional information and reassurance.

Risk factors and protective factors

Another central issue in the focus group discussions was reflection on what causes osteoporosis and how it best can be avoided. We categorised these as risk factors and protective factors, but found them difficult to separate. This is due to the fact that lack of protection

in many instances can be seen as a risk factor. Milk serves as an example of this, as drinking it was seen as a protective factor, whereas not drinking it was seen as increasing one's risk of osteoporosis. A healthy diet was frequently mentioned as means of prevention. What this diet consisted of seemed to imply some sort of tacit knowledge, as its contents were rarely mentioned. When concrete examples were given, they contained such food and drink as milk, cheese, vegetables, brown bread and cod liver oil. This type of diet was not identified as a measure aimed at preventing osteoporosis in particular, but more as a diet serving a more general preventive purpose.

Along with the healthy diet, regular exercise was another protective factor frequently mentioned. This proved to be somewhat of a double edged sword. Knowing that it was a protective factor, not exercising was not only seen as a risk factor, but also as a source of bad conscience. Lack of exercise could be explained as a consequence of the chores of the modern working woman, as having a rest rather than going for a run after a tiresome day at work made good sense for the women. Exercise was also seen as a double edged sword in another sense, as both too little and too much was seen as potentially unhealthy. Evidence for the latter was found in the mentioned anecdotal evidence of the osteoporotic sportsman. This led to the conclusion that exercising had to be done with caution. For a woman in her 50s moving more carefully outdoors could serve the purpose,

Tina: I don't think like that, but it comes naturally when it's icy – you walk a bit more carefully.

Tanya:...and go slower downhill when skiing

Tina: yes...

Anita: yeah... and maybe find the ice spurs quicker

(Group 2, first session)

whereas for a 70-year old being careful when doing the housework would do the trick.

Eleanor: I do about the same as I always have, but I'm a little more careful...

Hilary: So do I, but it's just that I'm being more careful... think a little more about... the only thing I don't do is vacuum cleaning. And clean the ceiling... can't do that anymore...otherwise I do all the things that has to be done...but you have to think...it's good to be a bit careful.

(Group 4, second session)

Medication was another double edged sword in the discussions. In several of the groups there were women suffering from rheumatic diseases, who were taking medicines that have osteoporosis as a well known side effect.

Osteoporosis was often mentioned as related to menopause and a lack of oestrogen. Oestrogen treatment was identified as a medical measure for prevention of osteoporosis. At the time of these focus groups (2001), the general impression of oestrogen was positive, which was also reflected among our younger participants. A more negative position was taken by the older women, however, as they found menstruating both unnatural and unnecessary at their age. As a consequence, the older women who had been on oestrogen had stopped taking it.

Eleanor: Yes, there are calcium tablets...and then I'm on 'Activelle'.

Hilary: Yeah? What kind...?

Eleanor: Hormone tablets

Hilary: All right. I've tried them too, but I started to menstruate and then I don't want to use them. So I spoke with the doctor and he said that they didn't have anything else.

Eleanor: I'm a bit doubtful too. If I should keep using them.

Hilary: Have you...started to menstruate too?

Eleanor: Yes.

Hilary: Yes?

Eleanor: No, no.

Hilary: So you haven't?

Eleanor: was so old...

Hilary: It's no good to try another brand...the same thing happened...so I said no thanks. It wasn't right... against nature...that a woman in her seventies should menstruate. You're quite right, the doctor said.

Ruby: One must draw a line...

Elisa: There are certain limits...

Hilary: Yeah.

Ruby: Then I'd stop, for sure.

(Group 4, first session)

A related topic of discussion was whether osteoporosis could actually be healed once it was established.

This was an area reflected by vague opinions and substantial uncertainty. The possible inheritability of osteoporosis was also a frequently occurring discussion theme. Sense about heritability was made by referring to the occurrence (or more frequently – lack of) osteoporosis among close female relatives.

Osteoporosis across generations

Another observation from our study was the incorporation of the discourse of stress in the younger women's present lives. This stress was created through the life of the modern double-working woman. It, thus, contributes to putting their lifestyles into a frame that is not entirely under their own control. They know what is good for them, but at the same time they acknowledge that self-governance is an ambitious project. Their representation of their current lives thus presents them with a source of bad conscience, but their reflections also provides protection against self-blame.

Mary: ...very good at walking to my job...there's one thing that gives me bad conscience...It gets so busy in the afternoon, there's the shopping, meals to be made, and there's not enough time. Only...

Ellie: Yeah, how does stress influence bone fragility? It's surely a lot of this around in the housewives' lives today. They have several jobs, they're supposed to be mother, housewife and a working woman...so it's a busy life for some.

(Group 1, first session)

This framing also presents interesting contrasts and similarities with their representations of other generations. Former generations were also perceived as being at the mercy of their living conditions, represented through the hardships of manual labour as a source of osteoporosis.

Concern was raised over the diet and exercise habits of the younger generations. This was related to what was seen as excessive intake of soft drinks and fast food, along with lack of exercise due to preoccupation with computers and televisions. As a consequence, a rather dark picture was painted of the incidence of osteoporosis as the younger generations reach old age.

But our generation had a normal, healthy diet. There were no options to drinking milk and eating cheese. Nor were there any excesses like coke, crisps and that sort. It wasn't, so there's much more reason to worry about the next generation when you see the volumes of soft drinks they consume and the

amount of sweets that they eat. It's beyond words when you think about diabetes 2 and, yes osteoporosis in the future. They don't sell milk any more at our [school] canteen, as there's nobody buying it.

(Group 6, second session)

Whereas the hardships of the old times triggered empathy for the older generations, the unhealthy lifestyles attributed to the upcoming generation were a source of worry and, to some extent, blame as they represented a failure in self-governance. Where their own failures were found to be excusable, no such sympathies were voiced for the young.

Similar representations were presented through the reconstruction of their mode of transportation when going to school. Having used their own two feet as their major mode of transportation in their youth, this provided a contrast to the younger generation's liability to be bussed or driven to school by their parents. In the reconstructed version, the lack of cars and school buses in past times became solid examples of healthy living.

Discussion

This study among middle-aged and elderly women attending bone mineral density measurements shows that osteoporosis is regarded as a disease, mainly characterized by pain. Their lay constructions of the condition are based on the socio-cultural context wherein their bodily, lived experience is given meaning. A striking feature of our material is a relatively small variation among the groups. When variation occurred it was shown between the different age strata, reflecting that osteoporosis have different relevance to the younger and elder women.

Another characteristic feature of our study is the interest and curiosity about osteoporosis that was shown in our sample. The women in our study can be seen as representing a contrast to the Scottish women studied by Backett-Milburn et al. (2000), whose main response was disinterest in osteoporosis. Age differences may partly explain these differences, but there are other contextual factors behind the heightened interest in osteoporosis in our study group.

The major socio-cultural factor behind the attention on osteoporosis in Nord-Trøndelag is HUNT. There have been two extensive health surveys in Nord-Trøndelag (HUNT 1 and 2), performed in the mid 1980s and mid 1990s, respectively. Both have been well supported, with participation rates of 88.1 and 71.3% of the adult population (Holmen et al., 2003; Midthjell et al., 1999). HUNT has worked hard for more than

two decades to become a trademark of its county and its inhabitants, and at present HUNT 3 is in progress. These women may thus be seen as loyal supporters of what has been labelled as a big voluntary public health effort, through their participation in the health study. At the time of our study their bone scan was only a week away, so their attention on osteoporosis was already well fixed.

Another crucial cultural factor is the work of the The Norwegian Women's Public Health Association (NWPHA), which for years has provided information about osteoporosis and its prevention through their network of local groups. There has also been a co-operation between the association and private diagnostic units situated in the city of Trondheim. This has led to a tradition where women from Nord-Trøndelag have been bussed to Trondheim for a day of mammography and bone density measurement. Having been able to combine these health interventions with a social event has made these trips much more popular than more traditional public health efforts. These activities contributed to the recruitment for our study, as several of our participants also had experience with the work of the NWPHA. It also meant, however, that we were unable to make the planned comparisons between women with and without prior screening experience, as there were women with bone scan experience in the groups that were supposed to be without it.

Although these women may be perceived as relatively well informed, the major motivation behind their participation in the focus groups was curiosity and a need for information about osteoporosis. This need did not simply reflect a lack of available information or lack of knowledge among the participants. Rather, it may be seen as yet another example of well informed and knowledgeable people's efforts to know and understand even more. It did also to a large extent reflect that osteoporosis is a condition with a complex aetiology that makes it an epistemological challenge. In their descriptions, the women made what at first sight seemed to be paradoxical statements. Whilst their life experiences told them that they were not osteoporotic, they were at the same time eager to have their bone scans. According to their own logic there should be no reason for them to have the scans, but the technology seemed to represent an offer 'too good to refuse'. The technology offered confusion as the feedback from the scans made little sense, but was also seen as a source of reassurance. This raises some important and interesting questions related to the bigger scope of our research project. They are, however, outside the scope of the present paper and will be addressed in full elsewhere.

Beside the closeness of our study to the bone scans, there are also methodological reasons that can explain why our study provided richer constructions of osteoporosis than those reported elsewhere. By letting the women come forward with their own queries we managed to get richer material than that achieved by a method where the researcher is the only person providing the questions. This richness is further strengthened by the way the participants encouraged each other through the mutual exchange of experiences and opinions.

The limits of everyday experience

Our findings show that the women of Nord-Trøndelag in many ways have incorporated important elements of present medical knowledge on what contributes to and provides protection from osteoporosis. When it came to the construction of what constitutes osteoporosis itself, the experiences from their daily living played a much more important role. What they saw as the real test of whether they had osteoporosis or not was provided by what happened to their bodies when falling. Spending several months a year walking on icy pavements and roads provided them with plenty of real life experience of falling. This demonstrates the central position of the frame of their daily lives when giving meaning to osteoporosis.

To our informants osteoporosis was a disease defined through the bodily experience of pain or to be observed as hunchbacked bodies. In this sense, osteoporosis was found to be described much in the same manner as the descriptions given by Danish women who were paying much attention to the physical appearance of a person with osteoporosis (Reventlow & Bang, 2006). Whereas, the Norwegian women attributed osteoporosis to the hardships of former generations, their Danish counterparts also had available evidence that hardships were no necessary condition for osteoporosis through the example of their late Queen Mother.

This serves as a prime example of how the socio-cultural context shapes the participants' perceptions of osteoporosis. A similar role to the Danish Queen Mother was played by world champion skier Oddvar Brå in the Norwegian sample, as the indisputable evidence of the fact that men may also get osteoporosis. Both these examples can be seen as exceptions to the rule, in the same manner as the smoking and drinking Uncle Norman figure has been presented as proof that an unhealthy lifestyle does not necessarily mean a short life (Davison, Frankel, & Smith, 1992).

Although the women were knowledgeable, their knowledge on risks and prevention also illustrates the

limits of their lay knowledge. Their construction of the causes of osteoporosis in past generations may also be seen as a result of a logically based effort to make sense of their perceptions. Again this does not necessarily mean that these perceptions are knowledge based in the sense that they can be generalised to whole populations. As has been stated, lay people can be wrong, in the sense that 'experience on its own is rarely sufficient to understand the technical complexities of disease causation, its consequences or its management' (Prior, 2003, p. 53). This reflects that the experience of daily living is too limited for our participants (or anyone else) to become lay experts on osteoporosis.

The same epistemological problem is, of course, attached to the clinical experience of practising physicians. These problems have thus provided a major impetus for the research based movement of evidence based medicine wherein epidemiological studies play a major role. This knowledge also has its limits related to its epistemological uncertainty (Fox, 2002), based on the problem of drawing conclusions about individuals from epidemiological data. In the bigger picture, the limits of both experience based and research based knowledge illustrate the epistemological challenges that we as humans are faced with. Although these questions cannot be resolved by research, people's reflections about them remain a fascinating subject for research which may deserve more attention within medical sociology.

Osteoporosis and the new public health

Extending the context beyond local culture, the constructions of osteoporosis are also formed within a larger system, that of the new public health which has been described as a new morality system (Petersen & Lupton, 1996). Within this frame it is the duty of the self-governing healthy citizen to take control over their own lives in pursuit of health (Nettleton, 1997). The women in our study indicate that they have accepted this role, albeit failing to fulfil its role expectations to perfection. This provides them with frustration and feelings of guilt. These emotions are curbed, however, by calling attention to the stressful life conditions of the modern double-working woman. The controllable, thereby, remains outside their control, but for a good reason.

With other generations things are perceived differently. The hunchbacked women of past times are perceived as being outside the realm of the morality of the new public health. They are thus portrayed as victims of a situation wherein they had no control, and hence no responsibility. Consequently, no blame is attributed to them. The younger generation, however, is

described as one completely failing the duty to become healthy citizens. As grandmothers they are worried but fail to find mitigating circumstances, like those found for their own and older generations. Instead of acknowledging that the lifestyle of the younger generation may also be seen as the product of a cultural context, they blame them for their perceived shortcomings. By doing so, they commit what is known in psychology as an attribution error, placing causal agency with the person rather than the circumstances. This indicates that accepting the discourse of the new public health also includes victim blaming, reflecting a strong moral enterprise.

Methodological reflections

An important factor influencing the design of this study was the ambition to monitor the women's experiences with the bone scans as they happened. In retrospect we see that we could have achieved the same findings with fewer focus groups, as there is considerable homogeneity among the findings from the different groups. To achieve our aims with a prospective design we had to follow the schedule set up for the bone scans, which did not allow for data analysis in between focus group sessions. This gave us the advantage of closeness to the experiences, but the design also represents a rigidity that did not allow us to make adjustments in the project as we moved forward.

Our groups were limited to well educated women living in urban areas, with a very positive attitude to both HUNT and bone scans. Although this raises questions about the transferability of our findings, we see that our findings share some common ground with the studies from Denmark. Furthermore, the altruistic motivation behind their participation has also been demonstrated among participants in HUNT's biobank research (Skolbekken, Ursin, Solberg, Christensen, & Ytterhus, 2005). The worry about the health of the upcoming generation has also been expressed in data from other yet unpublished projects.

Concluding remarks

In this study, we have demonstrated the dynamic and flexible nature of lay constructions of osteoporosis. Whilst being portrayed as a result of toil and hardships in earlier generations, it is attributed to stressful living in the generation studied, and seen as a result of an individualized moral failure in the upcoming generation. These constructions have also incorporated vital parts of present medical knowledge, without directly

reflecting it. This is most clearly demonstrated through the incompatibility between lived experience as a source of reflection about osteoporosis and that of confusion produced by the results communicated from the bone scans. As researchers we are, therefore, posed with two important challenges in our future work – to provide the skills to develop study designs that will reflect the involved dynamics, and the bravery to take on the epistemological challenges that so far have been avoided in the study of lay constructions of disease and illness.

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Paper V

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Paper VI

Chapter 2

Unlimited medicalization? Risk and the pathologization of normality

John-Arne Skolbekken

In June 2003 professors Nick Wald and Malcolm Law launched their strategy to reduce cardiovascular disease by more than 80 per cent in an article in the *BMJ* (Wald and Law 2003). As such disease affects nearly half the population in many Western countries, the strategy would be a triumph for preventive medicine, provided its implementation were to match its estimated success. This bold aim is to be achieved by the creation of the Polypill, a pill combining six different ingredients known to be effective against the most important risk factors for cardiovascular disease. Besides being offered to people who have already developed cardiovascular disease, Wald and Law (2003) proposed that the Polypill should be taken daily by everyone aged 55 and above for the rest of their lives, regardless of their risk factor level.

In his Editor's Choice column Richard Smith described the articles by Wald, Law and colleagues as possibly the most important articles to be published in the *BMJ* for over 50 years (Smith 2003a). He also predicted that this breakthrough could lead to the future redundancy of cardiologists and cardiac surgeons. Luckily, this redundancy could be turned into another health care triumph, depending on the successful transformation of heart specialists into psychiatrists. Provided that the Polypill would be made available in supermarkets and pubs, without any diagnostic interventions by doctors, the strategy would also find its way around medicalization as no doctor need be involved.

Whether such comments represent euphoria or sheer irony is a matter of interpretation. It remains to be seen whether the Polypill strategy will come true or remain science fiction. What is of interest here is that it represents no major breach from recent developments within preventive medicine. It may simply be seen as the next logical step in a trend of including ever-increasing groups of symptom-free individuals in the realm of medicine.

An illustration of this has been given through the combination of data from the Nord-Trøndelag Health Study (HUNT 2) (see Holmen *et al.* 2003 for a closer description) and the 2003 European guidelines on cardiovascular disease prevention (DeBacker *et al.* 2003). The outcome of this pairing of data from one of the longest living populations in the world and the medical experts' guidelines for clinical practice is that half the 25-year-olds and 90 per cent of the 49-year-olds have blood

cholesterol and blood pressure levels that place them above the guidelines' cut-off points for medical intervention. Implementation of the guidelines thus renders three out of four Norwegian adults in need of medical attention (Getz *et al.* 2004).

These interventions involve established diagnostic technologies such as blood pressure measurements and techniques for lifestyle change. As such there is little new in this compared to what has been described in earlier texts on the new public health and individuals' responsibility for their own health through self-regulatory behaviour (see Ogden 1995 and Petersen and Lupton 1996 for examples). What we witness is the medicalization of life, which has been going on for some time already. There have been developments over the past decade, however, that are worth noting. An escalation of the medicalization of life has taken place, through the pathologization of normality and the removal of the divide between preventive and clinical medicine. This latter change is demonstrated by the replacement of lifestyle changes by chemical prevention as the major mode of achieving the goals of preventive medicine.

About this chapter

The aim of this text is to present a critical analysis of recent developments. In doing so the emphasis will be on investigating how risk calculations within modern medicine are playing a central role in the ordering of reality. These calculations form the basis for a 'rationality for governing the conduct of individuals, collectivities and populations' (Dean 1999: 177). Within this frame of analysis risk is not seen as a realist entity, but as something that 'is a way of representing events in a certain form so they might be governable in particular ways, with particular techniques and for particular goals' (*ibid.*). The goal in question is nothing less than human well-being, which actors in society are trying to achieve through the management of life itself within the frame of what has been called risk politics (Rose 2001).

A central theme of this analysis is to investigate the close connection between risk calculation and medicalization. According to Conrad (1992: 209) 'medicalization describes a process by which nonmedical problems become defined and treated as medical problems, usually in terms of illnesses or disorders'. Within the calculated rationality of risk this process happens through the discursive transformation wherein normal body functions become risk factors that subsequently become diseases that demand medical attention. So, rather than observing a pattern wherein people experience symptoms that lead them to see their doctor, we are witnessing a process wherein research findings indicate that people without symptoms are in need of help. This leads doctors to actively target people who feel healthy through various screening programmes or case finding in general practice. Another characteristic of this medicalization process is the constant widening of the categories of symptom-free individuals in need of medical attention. Such expansions more often than not come subsequent to what is perceived as a successful medical intervention on the risk factor in question.

The analysis will be focused on the present risk discourse. As this discourse is clearly normative, the analysis will consequently also have normative elements. This normative aspect is based on scepticism about the uncritical presentation of possible positive outcomes of preventive medicine. As such it is partly situated within what has been called the medicalization critique (Lupton 1997). Central to this critique is that medicalization involves processes in which people are dominated through the practices of medical interventions that are at best useless or at worst directly harmful to people's health. Within this literature much attention has been given to the role of the medical profession; however, lately the pharmaceutical industry has also come to be seen as a central actor in the medicalization processes (Conrad 2005). In its most simplistic form the medicalization critique may be seen as an attempt at identifying a grand conspiracy within modern medicine. The ambition behind this text is to provide an analysis that also takes into consideration the critique of the medicalization hypothesis.

It is rather an attempt at showing how humans, armed with the power of scientific knowledge and a belief in their increased control over life and death, have created a situation whereby life in the modern world can be perceived as somewhat of a failure in need of constant medical attention.

Risk and surveillance

The medicalization of life is rooted in the development of surveillance medicine as the dominant form of medicine in the twentieth century (Armstrong 1983, 1995). Its cardinal feature is the targeting of everyone, as nobody is perfectly healthy through its gaze. We are all potentially sick or at risk of developing a disease and eventually dying.

These ideas have been central to preventive medicine since early in the twentieth century (Armstrong 1983). It has, however, taken on a new meaning in the second half of the century, through the identification of risk factors, a conceptual invention attributed to the Framingham study (Rockhill 2001). This has also become manifest through the risk epidemic, seen in the medical journals as a reflection of the rise in scientific knowledge about risk factors in the latter half of the twentieth century (Skolbekken 1995). In its original version this epidemic was shown as an increase from around 1000 articles about risk in the latter half of the 1960s to more than 80,000 two decades later. A follow-up showed that the epidemic has resulted in another quarter of a million articles in the last decade of the twentieth century (Skolbekken 2000).

Present preoccupation with risk within surveillance medicine is not only reflected in the rising number of 'risk-articles', but also in the paramount importance, if not omnipotence, attributed to risk in the present medical discourse. The quotations below serve as illustrations of this:

- 'risk...touches upon every single aspect of health and human welfare' (British Medical Association 1987).

- 'Life is a mixture of risks, what would a risk-free life be like? – life is a process of selecting a cause of death' (Lowell Levin). Aphorism of the month in *Journal of Epidemiology and Community Health* November 2005.
- '...life in developed countries at present almost inescapably entails long term exposure to major risk factors...' (Rodgers 2003).
- 'Communicating risk: The main work of doctors' (Smith 2003b).

Risk's importance is also reflected by the general acceptance in the social science literature of the risk discourse as one of the dominant discourses in this time and age. It is at the same time blurring the traditional dichotomy of health and illness, as well as reflecting complex and unclear notions of causality. This is illustrated in the challenges posed in the process of communicating what may look like causality at the epidemiological group level to uncertainty at the individual level (Skolbekken 1998; Hollnagel 1999; Olin Lauritzen and Sachs 2001; Rockhill 2001).

Another significant characteristic of risk is that it cannot be perceived directly through experiences of the lived body, it can only be mediated through risk measurements and calculations. A person's blood sugar, blood pressure or blood cholesterol level can only be revealed through the application of surveillance technology. The same is true for a person's bone mass, which if reduced beyond certain limits is considered to be a major risk factor for osteoporotic fractures. As a consequence, individuals cannot trust their own bodies and become dependent upon the medical profession for confirmations of their health status.

This implies that the risk discourse leaves us with a constant awareness of our vulnerability (Skolbekken 2000; Robertson 2001). This is the at-risk status, which leaves the individual in a state of being healthy and ill at the same time (Gifford 1986). It 'is to feel well, to be asymptomatic, yet always to be aware of the potential for becoming otherwise' (Scott *et al.* 2005: 1870). A consequence of this status achieved through the practice of surveillance medicine is a state of worry. This worry is not necessarily the result of the identification of risk, but comes as a result of the health surveillance itself. It may thus affect people not seen to be at risk as well as those at risk (Olin Lauritzen and Sachs 2001).

This presents us with a paradoxical situation. Whereas the rationale behind surveillance medicine is the protection against our unavoidable vulnerability as humans, it also creates a constant reminder of this vulnerability. It is against this background that criticism has been raised, claiming that preventive medicine based on epidemiological risk factor epidemiology has severe side effects (Førde 1998).

The pathologization of normality

The continuous construction and reconstruction of deviance and normality has played an important role in surveillance medicine. It has contributed to medicalization through the calculation of risk as deviance from the statistically normal. An illustration of this is to be found in the World Health Organization's guidelines on

osteoporosis which defines it as a bone mass density that is 2.5 standard deviations or more below the mean bone mass density in a reference population (WHO Study Group 1994). Osteoporosis is similarly a condition that has been identified as a risk factor quite recently. This is illustrated by the number of articles found by the combination of the words 'osteoporosis' and 'risk' in searches in Medline. Until 1970 no matches were found and only 59 such articles had been published a decade later. Changes happened during the next two decades, however, and at present every third article about osteoporosis is also an article about risk (Skolbekken 2000).

Manifest osteoporosis is not lethal in itself, but has severely disabling and painful consequences with its fractures of the hip, vertebra and/or wrists as its most common consequences. Equally disabling consequences are caused by cardiovascular disease. Besides causing heart attacks and strokes, it is a major cause of death in the Western world. These manifest diseases have several common features. They are all characterized by a long period of latent development, a rather abrupt manifestation, and a complex causal background.

To reduce the incidence of these diseases is an important goal in preventive medicine. Through epidemiological studies researchers have identified risk factors associated with the diseases. Despite the complexity of the causality behind cardiovascular disease and manifest osteoporosis, risk factors such as hypercholesterolaemia, hypertension, type 2 diabetes and osteoporosis have been given central positions in the aetiology of these diseases. As a consequence, interventions aimed at reducing these risk factors have become central targets in current preventive medicine. This central position can be seen as a result of the fulfilment of three vital criteria – these factors are easily measured, their risk status can be calculated and they can be made subject to manipulation. They are thus prime targets for human control and therefore play an important role in risk politics.

It is in the transformation of physiological factors into risk factors that the pathologization of normality occurs. An essential feature of blood pressure, cholesterol, blood sugar and bone mass is that they all serve important functions in the human body. It is only when they reach certain levels that they are defined as risk factors and become potentially pathological and receive a status that makes them legitimate for medical intervention.

This status is a result of negotiations within scientific and clinical medicine, resulting in clinical guidelines. Just as in the case of osteoporosis, medical experts make decisions about arbitrary cut-off points, drawing the line between those who are in need of medical attention and those who are not. Development of such guidelines is a prime example of risk politics at the macro level. For risk politics to be successful it also needs to be transformed into micro politics, which is happening at the personal level of doctor–patient communication. As those in need of medical attention have no experiences that they perceive as symptoms, it then becomes the work of doctors to make sure that they are made aware of their needs.

As medical knowledge expands, the arbitrary cut-off points are renegotiated, with revised guidelines as the outcome. A characteristic feature of these guidelines is that they include an increasing number of the population among those in need of

medical intervention. In the latest revision of the American guidelines on hypertension such negotiations resulted in the reconstruction of what had previously been defined as a normal blood pressure into prehypertension (Chobanian *et al.* 2003). As a consequence it has been estimated that 60 per cent of the US population are affected by prehypertension or hypertension (Wang and Wang 2004). A similar estimation from India found that 47 per cent and 35 per cent of the urban population fulfil the criteria of prehypertension and hypertension, respectively, leaving a mere 18 per cent of one of the largest populations in the world without need of medical intervention (Chockalingam *et al.* 2005).

Hypertension is not the only condition judged to have a pre-condition. The same is also true for type 2 diabetes, where another set of guidelines is covering prediabetes. In the 2003 revision of the guidelines of the American Diabetes Organization, the criteria for impaired fasting glycaemia was lowered, with an estimated growth in the number of people who fulfil the criteria in the middle-aged populations of urban India, urban China and the USA by 78, 135 and 193 per cent, respectively (Borch-Johnsen *et al.* 2004).

Turning back to Norway and the part of the HUNT study that included bone scans to identify possible risk of osteoporosis, it has also been demonstrated that more than two-thirds of the women over 70 years fulfil the WHO criteria for osteoporosis (Forsmo *et al.* 2005). This is because the criteria of what constitutes normal bone mass density are based upon a young reference population. Despite the vast number of individuals at risk only 1 per cent of these women will experience an osteoporotic fracture. This illustrates the problem of predictability related to current risk estimates. It remains a paradox that, whilst 90 per cent of the 50-year-olds are at risk of cardiovascular disease, the death rate for the same disease is around 45 per cent in the Norwegian population. Hence the prediction will be correct in about 50 per cent of the cases. In other words, the same prediction could be achieved by the flipping of a coin. This does not, however, have the same aura of controllability attached to it as risk calculations.

The age criteria suggested for the introduction of the Polypill may be seen as a consequence of such imperfect predictions. Acknowledging that the best predictors of risk are those factors that cannot be changed, such as age, sex and previous disease, Law and Wald (2002: 1574) conclude that 'age is the most important determinant of risk'.

In sum these examples illustrate that the pathologization of normality works in various ways. Starting off with the construction of the statistically deviant as pathological it has developed into defining the statistically normal as pathological. In doing so we are also faced with the pathologization of normal life in the modern world as well as the pathologization of the ageing process. So far as longevity can be seen as an achievement of the progress of humans, it is an intriguing paradox that ageing has become the major risk factor in the pursuit of further longevity.

Faced with these masses of people in need of medical intervention, the picture of our future looks pretty glum. There is hope, however, if we are to believe the recent triumphs achieved by preventive medicine.

The success of preventive medicine

Whereas risk for some time has played an important part in documenting the vulnerability of humans, it has recently also come to play an important part in proving the success of preventive medicine. The most important proof has come through the demonstration of risk reductions achieved by preventive efforts. These demonstrations have mainly been produced by randomized controlled trials (RCTs), recognized as the 'gold standard' of scientific medicine.

When the West of Scotland Coronary Prevention study was to be published a press release told the public that 'People with high cholesterol can rapidly reduce their risk of having a first-time heart-attack by 31 per cent and their risk of death by 22 per cent, by taking a widely prescribed drug called pravastatin sodium' (cited from Skolbekken 1998: 1956).

Similar success stories appear regularly in the media, making people aware of new triumphs or 'landmark studies', as they are appealingly labelled. In its tabloid format, these messages are personalized and aimed at the reflexive consumer as 'good news for *your heart*', illustrating the complementary privatization of risk reduction. The good news is often based on a drug's risk-reducing effect, as proven through a RCT. Taken literally these messages can be read as if the ultimate controllability is to be achieved as death soon will be made extinct.

Framed as science news stories, such news can also be interpreted as the pharmaceutical industry's way around the ban on direct-to-consumer advertisements for their prescription drugs; that is, in all countries except the USA and New Zealand where this kind of advertisement is allowed. This development does also imply a change in the role of what Petersen and Lupton (1996) called the healthy citizen, characterized by the individual's responsibility for his or her own health through their lifestyle choices. Whereas the risk discourse for a long time has appealed to the moral virtue of this responsible citizen, there is a twist aimed at the smart consumer. The appeal is no longer only aimed at a healthy lifestyle, but at a consumer aware of available products that can benefit his or her health.

A related feature is the offering of risk factor tests in newspapers and on various web sites, like that of the American Heart Association. Again the emphasis is on the smart consumer rather than the moral abiding citizen. In one such newspaper story readers were told that a computer program was now offered for free by the producers of the test to every physician in the country. The consumers were thereby urged to bring their doctors out of their state of ignorance if they were unable to offer the test to their patients. Such programs are now quite commonly used by doctors, serving as a reminder of their duty to offer risk measurements and a calculation of the patient's personal risk of dying in the coming decade.

Computer programs are not the only reminder doctors get. They are also regularly reminded of the success of chemical prevention, through the marketing efforts of the pharmaceutical industry. Such prevention is offered as well-documented examples of evidence-based medicine. This also illustrates the fiscal nature of the present success of preventive medicine. As the risk discourse has

provided us all with the status of being potentially sick, in need of intervention, a new and vast market has been opened for the pharmaceutical industry. The nature of their products provides the industry with two major advantages compared to its competitors: they are well suited for testing in RCTs and it demands no major lifestyle change from the consumer/patient.

Not only is the entry of the pharmaceutical industry into the domain of preventive medicine based on the success of its risk-reducing products, it also contains a discourse undermining the existence of the healthy citizen. Risk-reducing drugs are offered as the effective solution where the efforts of the healthy citizen fail. If hypertension and hypercholesterolaemia are seen as risk factors created by a sedentary lifestyle, as well as wrongful diet and smoking, the pharmaceutical industry offers the perfect solution by means of effective prevention without changing behaviour. Health problems acquired by means of consumption through the mouth may thus be cured by the same mode of consumption. This is a point that has also been made clear for doctors through the pictures used for an antihypertensive drug (Malterud 2002), as well as in academic texts presenting the lifestyle efforts of lay people as failures (Wald and Law 2003). Chemical prevention is thus presented as a winner because it appears to offer better control.

Another conspicuous feature of the apparent success of preventive medicine is to be found in a selective use of risk information. In the vocabulary of epidemiology, risk reductions may be communicated both as relative risk reductions and as absolute risk reductions. The relative estimate is normally a much bigger figure than the absolute one, leaving an impression of a higher risk-reducing effect. This is illustrated by the press release presented above, where the numbers given are relative risk reductions. In terms of absolute risk reductions, the achieved effects could be stated as a 1.9 per cent reduction for first-time heart attacks and a 0.9 per cent reduction of deaths. Stated otherwise, people improved their chances of survival from 98.3 per cent to 98.8 per cent by taking the drug (Skolbekken 1998). The selective communication of relative risk reductions has proved profitable, as doctors and other decision makers are more inclined to prescribe drugs when faced with messages in this format compared to other formats. Not only has the strategy been used when addressing the medical profession, it has also been extensively used when risk reductions have been communicated through the mass media (Moynihan *et al.* 2000).

Judging by the sales numbers for drugs with a risk-reducing effect, this has been a successful communication strategy. The size of the success of chemical prevention remains somewhat of an enigma, however. This is in part related to the amount of uncertainty involved. Taking uncertainty into consideration, I was able to make the following statement based on the outcome of the West of Scotland Coronary Prevention study:

Medicine is not an exact science. Therefore, 200 men without any prior heart disease have to swallow 357,700 tablets over five years to save one of them

from dying from coronary heart disease. This is due to the fact that no exact knowledge exists as to whom of these 200 will benefit from the treatment.
(Skolbekken 1998: 1957)

Rephrasing the message in this manner can be seen as a way of undermining the power of risk calculations and thus making them a less useful tool in the governing of human conduct. This illustrates that for risk to be a tool of governance it must be communicated in ways that emphasize control rather than uncertainty. In the current risk discourse governance is achieved through the presentation of group risk as individual risk, thereby disguising the uncertainty involved. As there are indications that patients' compliance is reduced the more informed they get, the success of preventive medicine can be seen as relying on the withholding of information about uncertainty. To tell the truth, the whole truth and nothing but the truth may therefore be a poor way of governance.

Medicalization and its limits

From what has been presented so far it is reasonable to conclude that there has been a continuous escalation of medicalization, involving the expansion of categories of the potentially ill over the last decades. When analysing the medicalization process it may be overly tempting to launch a conspiracy theory with two obvious culprits – the medical profession and the pharmaceutical industry. The medical profession has traditionally been seen as the powerful party towards whom the medicalization critique has been focused (Lupton 1997).

Without explicitly mentioning medicalization, Rose (2001) gives the pharmaceutical industry a prominent position in modern risk politics through its funding capacity within the life sciences. This view seems to be seconded by Conrad (2005) who notes that the pharmaceutical industry has played a more active part in the development of medicalization and portrays the industry as the new engine of medicalization. Further support for this claim is also given by Moynihan and Cassels (2005) who portray recent developments as a result of the pharmaceutical industry's efforts to sell sickness to the healthy population. The move away from lifestyle interventions towards chemical prevention described above is thus one of several observations of the connection between medicalization and the efforts of the pharmaceutical industry. In line with Rose's (2001) claim that risk politics makes life open to shaping and reshaping at the molecular level, preventive medicine is moving away from changing behaviour to changing cellular processes by means of chemical prevention.

To state that the escalation of medicalization is taking part because patients are being made victims of medicalization by doctors and their allies in the pharmaceutical industry would, however, be a mechanistic simplification. Taking as a starting point that recent developments are not just random events, it may prove fruitful to ask who it is that has an interest in an escalation of medicalization. In seeking the answer to this question we should look for the actors who support the

goal of human well-being through the application of risk politics. This widens the number of possible suspects, as the prevention of premature deaths may be in the interest of public health authorities, health insurance companies, the mass media, politicians, lay people and patient organizations, as well as the mentioned profession and industry.

A way of expanding our understanding of medicalization would be to study the practices of these actors within the frame of risk politics through an interconnected set of analyses. At present many such studies can be found involving risk communication between doctors and patients. These studies can, however, only be properly understood against the background of other similar interactions, such as those between doctors and the pharmaceutical industry, in the format of drug advertisements or personal communication between doctors and sales representatives, and between the industry and the media, politicians or patient organizations, respectively. Rather than using Conrad's (2005) engine metaphor, a perhaps more useful metaphor is that of the pharmaceutical industry as the spider weaving a web of interactions upon which medicalization is based.

When studying such interactions, a likely discovery is that there are both common interests and conflicts of interest between these actors. These conflicts of interest also reflect a power struggle between the involved parties. An example of such a process was demonstrated by what in Norway came to be known as the Fosamax-case, after the name of a drug aiming at the reduction of osteoporotic fractures (Skolbekken 2001). At the knowledge level this was a conflict between a pharmaceutical company and the Norwegian health authorities over the interpretation of the results of a randomized controlled trial. On an economical level it was a conflict about who should pay the bill for chemical prevention of osteoporosis. Politically the conflict was about whether the provision of chemical prevention was to be seen as a feminist triumph or medicalization of women. Finally, on a moral level it was a question about defining the heroes and the villains in this conflict.

The development of the conflict was presented over a two-year period through nearly 40 articles in one of the largest national newspapers in Norway. A characteristic of the newspaper stories was that the pharmaceutical company started the process as heroes and ended up as villains. Despite losing the moral battle, they won the financial battle as their drug ended up on the blue prescription list, meaning that the national health insurance scheme is paying the majority of the prescription costs. Whether the outcome was a victory for feminism or another defeat at the hands of medicalization remains a matter of opinion. This also illustrates that what is going on is also a power struggle over the framing of the issue.

The Fosamax-case also illustrates that there are several modes of governance at work simultaneously. The blue prescription system is an example of social insurance whereby treatment is based on the solidarity principle; the economic risk is equally shared among the members of society. In the case of lifestyle diseases this solidarity also provides for those that fail to fulfil their personal responsibilities as healthy citizens. In the case of chemical prevention/treatment

help is portrayed as contributed through a risk-reducing technology that has been developed within a liberal market economy.

An intriguing question that arises is how medicalization can happen if we know that it is bad for us and we know who is to blame for it. Indeed, if we know that the pharmaceutical industry is selling sickness, who is buying and why? Moynihan and Cassels' (2005) answer seems to be that people buy out of fear brought upon them by the pharmaceutical industry. If this is true, then medicalization may be seen as the outcome of irrational thoughts and behaviour.

Although fear and worry play a part, my claim would be that medicalization primarily is the outcome of the rational actions of major actors in modern society. In line with Dean's (1999) analysis the answer is to be found in the ordering of life constructed through risk calculation, which is rendering medical interventions into normal people's lives as most rational, backed by the best scientific evidence modern medicine can provide.

Part of the explanation behind the escalating medicalization is therefore to be found in the present discourse that makes it a duty for doctors to identify people at risk of cardiovascular disease and to offer them risk-reducing chemical prevention. Central to this discourse is that it is supported by science, thus making a refusal to fulfil the role obligations not only immoral, but also an act of irrational proportions in denial of scientific evidence.

Despite this there is considerable resistance against medicalization, which makes it possible to argue that there are limits to medicalization (Williams and Calnan 1996). One reason for such resistance is to be found in the existence of a lay epidemiology, reflecting the imprecise nature of epidemiological knowledge (Davison *et al.* 1991). Resistance among patients may come from many sources, and come to be explained in various ways. Whether what has traditionally been labelled non-compliance is an act of ignorance or the rational act of an empowered autonomous agent is open to debate.

Resistance to the present medicalization has also been offered from within the ranks of general practice. Based on the observation that current guidelines not only contribute to making the healthy into patients, but that they are also taking the medical profession's attention away from the really sick in favour of the healthy, current preventive practices have been claimed to be unethical (Hetlevik 2000). Such resistance is offered in opposition to the dominant position within the medical profession, mainly fronted by cardiologists. Central to this power struggle within the profession is the epistemological struggle over what represents the truth in scientific medicine, as well as the struggle over what identifies the good doctor.

The fact that the BMJ published a special issue (13 April 2002) on medicalization can also be seen as a form of resistance, reflecting a state of critical self-reflection within the medical profession. Whether such reflection will lead to changes in the practice of medicine remains to be seen. Current sales of drugs for hypertension, hypercholesterolaemia and osteoporosis indicate that medicalization is not suffering severe setbacks as a result of such reflections.

Existing guidelines and chemical prevention, including the Polypill, illustrate that there is a considerable potential for unlimited medicalization within the present discourse. Whether this potential will be realized or not depends on the outcome of several ongoing battles over what constitutes valid medical knowledge and how good medical practice is to be defined. These battles are literally about people's hearts and people's minds. The expansion of medicalization is due to the fact that it has a lot of appeal. It appeals to both the helper and the helped, and it can be backed by a scientific rationality as well as being a sound business. It is in line with the consumerist ethos as well as being framed within the rights of the citizen and the duties of civil society.

Concluding remarks

The present risk discourse represents a particular ordering of reality, providing a way of protection from and control over the vulnerability that we as humans are faced with. If what really is at stake here is people's lives, there should also be room for critical reflections about whose lives and whose vulnerability are excluded from the dominant discourse. As has been mentioned above, the morals of present risk politics may be questioned if it results in a reallocation of resources from the sick to the healthy.

On a larger scale this reallocation can already be seen to be taking place as the majority of medicines that are produced today are for the benefit of the lifestyles of the rich world, whereas lifesaving medicines for the poor are not available (Trouiller *et al.* 2001). A possible explanation for this is that the vulnerability of the poor fails to come into the realm of risk politics. Whereas the risk of poverty and its related miseries can be calculated, remedies are not to be found on the individual and molecular level. A major feature of current risk politics is thus that it provides for those that can pay rather than for the most vulnerable among us.

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APPENDIX 1



Post doc.
Siri Forsmo
Institutt for samfunnsmedisinske fag
Medisinsk teknisk senter
7489 Trondheim

Saksbehandler
Arild Hals
Telefon 73 86 71 52
E-post arild.hals@medisin.ntnu.no

Vår dato:
08.12.2000

Vår ref.:
Sak 173-2000

Deres dato:

Deres ref.:

**Sak 173-00 Vurdering av prosjekt:
Lav beintetthet – og så? En kvalitativ studie av kvinner som møter til undersøkelse
for osteoporose.**

Prosjektleder: Post doc Siri Forsmo

Regional komite for medisinsk forskningsetikk, helseregion Midt-Norge vurderte prosjektet i sitt møte fredag 17. november 2000 med følgende merknader og vedtak:

Hensikten med studien er å fremskaffe kunnskap om hvordan deltakelse i en helseundersøkelse påvirker deltakernes opplevelse av egen helsetilstand. En vil se på deltakernes motivasjon for å delta i undersøkelsen, positive og negative opplevelser i forbindelse med undersøkelsen, forståelse av lidelsen og tanker om fremtiden i forhold til påvist risiko eller ikke.

Metoden som skal brukes er fokusgruppeintervju, med til sammen 12 grupper med 7-10 kvinner i hver gruppe. Det skal gjøres tre intervju som blir tatt opp på bånd og skrevet ut for analyse. Båndene slettes etter at det er gjort utskrift.

Komiteen har ingen særlige merknader til opplegg og plan for gjennomføring; prosjektet synes godt strukturert og med en nyttig og relevant problemstilling.

Komiteen viser til informasjonsskrivet og til tredje avsnitt. Komiteen vil forslå at det sies noe mere om hvilke tema som er aktuelle å ta opp i intervjuet. Det må sies klart at deltakelse er frivillig, og at en kan trekke seg på ethvert tidspunkt i undersøkelsen. Det bør også stå at prosjektet er vurdert og tilrådd av Regional komite for medisinsk forskningsetikk, og at det er meldt til NSD.

Vedtak:

”Komiteen tilrår at prosjektet settes i gang med de merknader som er gitt”

Vi viser til dette. Ved henvendelse tilbake til komiteen ber vi om at vårt saksnummer brukes som referanse.

Med vennlig hilsen



Ola Dale
leder
professor



Arild Hals
sekretær
rådgiver

APPENDIX 2



Kari Nordtrønder
Kommune
Nordfylket

Førsteamanuensis
John-Arne Skolbekken
Telefon + 47 7359 1960
E-post JohnAS@svt.ntnu.no

Vår dato:

Vår ref.:

Deres dato:

Deres ref.:

Forespørsel om å delta i forskningsprosjekt

Gjennom Helseundersøkelsen i Nord-Trøndelag (HUNT) er store deler av fylkets befolkning tilbudt deltakelse i masseundersøkelser for oppdagelse av sykdomsdisposisjoner og sykdom. Et av spørsmålene forskere har begynt å interesse seg for i forbindelse med slike undersøkelser, er hvordan deltakelse i slike undersøkelser er med på å prege folks opplevelse av sin egen helse og deres helseatferd. For å få nærmere kunnskap om dette henvender forskere ved Institutt for samfunnsmedisinske fag og Psykologisk institutt ved NTNU seg nå til personer som deltar i HUNT med en forespørsel om å delta i et forskningsprosjekt om dette temaet.

Innsamling av data til undersøkelsen skjer ved at kvinner som har gjennomgått eller kommer til å gjennomgå benetthetsmålinger med tanke på osteoporose, kommer sammen i en diskusjonsgruppe og utveksler erfaringer/synspunkter omkring nærmere oppgitte tema. Diskusjonsgruppene vil bli samlet tre ganger – før undersøkelsen, kort tid etter undersøkelsen og noen måneder etter undersøkelsen.

Diskusjonene tas opp på lydbånd for å sikre en mest mulig korrekt gjengivelse av det som blir sagt. Det vil bli foretatt utskrift av diskusjonen som er tatt opp på lydbåndet. Etter at utskrift er foretatt blir lydbåndopptaket slettet. Intervju-utskriftene skal kun oppbevares i anonymiserte versjoner, dvs de vil ikke inneholde navn på personene som deltar. Utskriftene vil kun bli gjort tilgjengelig for forskerne, som alle er underlagt taushetsplikt. Publisering av undersøkelsen skal skje i vitenskapelige tidsskrifter. Alle deltagerne vil i etterkant av undersøkelsen få tilsendt et sammendrag av resultatene fra undersøkelsen.

Deltakelse i prosjektet krever således at du har anledning til å sette av tre kvelder i løpet av det neste halvåret til å delta i en slik diskusjonsgruppe. Gruppene vil samles på nærmere angitte steder i Nord-Trøndelag. Det vil bli en enkel bevertning under diskusjonen.

Vedlagt finner du en svarslipp som vi ber deg returnere innen en uke dersom du ønsker å delta i undersøkelsen. Vi ber deg også legge ved et av de to tilsendte eksemplarer av både samtykke- og taushetserklæring i utfylt stand. Dersom du velger å bli med og sender inn svarslippen, vil du bli kontakt over telefon for nærmere avtale om tidspunkt for undersøkelsen.

Med vennlig hilsen

Siri Forsmo
Lege/Dr. med

John-Arne Skolbekken
Psykolog/Førsteamanuensis

SVARSLIPP

Jeg ønsker å delta i undersøkelsen

Jeg ønsker mer informasjon om undersøkelsen pr. telefon

Navn:	
Adresse:	
Postnummer:	Postadresse
Telefon:	

APPENDIX 3

SAMTYKKEERKLÆRING

Ved å undertegne denne erklæringen samtykker jeg til å delta i undersøkelsen på de betingelser som er skissert i orienteringsbrevet.

Min deltakelse i prosjektet er frivillig. Jeg er ikke forpliktet til å svare på spørsmål eller fortelle om egne opplevelser og erfaringer dersom jeg ikke ønsker det. Jeg kan når som helst trekke meg fra undersøkelsen uten begrunnelse eller at dette skal ha noen form for negative konsekvenser for meg. De opplysningene jeg allerede har gitt kan imidlertid brukes til prosjektets formål.

.....den .../.... 2001

.....
Gruppetaker

TAUSHETSERKLÆRING

Ved deltakelse i denne undersøkelsen vil jeg kunne få innsikt i de andre deltakernes helseforhold. Gjennom å undertegne denne erklæringen erkjennes taushetsplikt om de opplysninger som måtte bli utvekslet mellom gruppedeltakerne.

..... den.../....2001

.....
Gruppedeltager

APPENDIX 4

Lav bentetthet – og så?

Introduksjon

Velkommen
Presentasjon av staben
Inntil to timer
To båndspillere hvorfor?
Fornavn
Temaene lever ut etterhvert
Ingen riktige og ingen gale svar
Snakke fritt, men ikke i munnen på hverandre
Pappkrus m.m.
Toalett-besøk/pause
Ny avtale før dere går.

Spørsmål på første samling

1. Hvilke tanker har dere gjort dere i forkant av bentetthetsmålingen?

Tenkt mye/lite?
Forventninger?
Spenning?
Usikkerhet?
Snakket med noen?
Utført bentetthetsmåling før?

2. Hvilke tanker har dere gjort dere om egen risiko for benskjørhet?

Høy/lav?
Disponerende faktorer
Atferd/arv

3. Hvilken betydning har masseundersøkelser som denne bentetthetsmålingen for deres helse?

Ingen/stor betydning
Betryggende/skremmende
Viktigere enn mammografi?
Viktigere enn blodtryksmåling?

4. Hva har dere gjort så langt for å forebygge benskjørhet?

Mat/mosjon/røyking
Kalktabletter
Medisiner
Bentetthetsmåling

5 Hvordan tror dere at bentetthetsmålingen vil påvirke dere i fremtiden?

Positivt/negativt resultat
Hjelpsløshet
Legesøking

Spørsmål på annen samling

1. Hvordan gikk benmassemålingen?

Resultatet – tallene, normalitet, risiko

Prosessen – undersøkelsen, kommunikasjonen

2. Hvilket utbytte har dere hatt av benmassemålingen?

Hva slags utbytte?

Stort/lite

Begrunnelse

3. Når vil dere foreta benmassemåling neste gang?

Intervall

Begrunnelse

Behov

4. Vil dere anbefale andre kvinner å foreta benmassemåling?

Hvilken anbefaling?

Til hvem?

Hvordan?

5. Bør helsemyndighetene gi alle kvinner tilbud om benmassemåling?

Alle eller noen?

Tanker om prioriteringer

Spørsmål på tredje samling

1. Hvilke tanker har dere gjort dere i etterkant av benmassemålingen?

Bekymring/trygghet
Out of sight, out of mind?
Snakket om/lest om?

2. Hvordan gikk benmassemålingen?

Resultatet – tallene, normalitet, risiko
Proessen – undersøkelsen, kommunikasjonen
I glemmeboka?

3. Når vil dere foreta benmassemåling neste gang?

Intervall
Begrunnelse
Behov

4. Bør helsemyndighetene gi alle kvinner tilbud om benmassemåling?

Alle eller noen?
Tanker om prioriteringer
Klinisk epidemiologi

5. Bør medisiner mot osteoporose gis på blå resept?

Begrunnelse
Effektivitet
Prioriteringer
Klinisk epidemiologi

