

# Women's health and gender perspectives in the history of modern Norwegian epidemiology

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## ABSTRACT

In this chapter, we will discuss selected aspects of the impact of women's movement on the development of modern epidemiology in Norway based on the experiences of leading a research program in Women's Health (RPWH, 1991-96) aimed at mapping and assessing gender based public health research in Norway, and the establishment in 1997 of a research group in Women's Health at the Department of Public Health and General Practice, NTNU. During the 1990s, several steps were taken both internationally as well as nationally to ensure that diseases which were affecting men and women unequally were given adequate attention. Examples of such diseases include osteoporosis and hip fractures. Studies of diseases seen as a typically men's, such as coronary heart disease, were often conducted exclusively on men. The inclusion and separate analysis based on gender, and the establishment of special cohorts of women, yielded a more complex understanding. Further the gender perspective revealed gendered patterns of risks. Traditionally risks such as cigarette smoking were shown to have a differential effect dependent on gender. Perinatal epidemiology, traditionally used to assess outcomes related to the new-born, were expanded to also assess impact of pregnancy on women themselves during and after childbirth. Disorders such as pelvic pain, urinary and anal incontinence as well as fear of pregnancy and depression during and after childbirth came to the attention of researchers. New risks were uncovered as women started to disclose the experience of violence and abuse both as adult and when growing up.

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## INTRODUCTION

Epidemiology textbooks have until recently been written by men. As an example, 14 out of 17 contributing authors in the much used textbook by Rothman are men (1). Historically, women's contribution to epidemiology has traditionally been less appraised than that of men. For example, nearly every student of epidemiology have heard about John Snow, but less is known about Florence Nightingale's substantial contributions to health statistics and hospital epidemiology than about her role as a pioneer in nursing (2,3).

Before the Norwegian Society of Epidemiology (NOFE) was founded (1990), the field in Norway was dominated by a few men. At the Department of Public Health and General Medicine (ISM) in Trondheim, the RPWH initiated a network of women health researchers to encourage more female researchers to enter the field of epidemiology. One of the needs of women was to acquire methodological competence. This need led to the establishment in 1986 of an informal study group at ISM inviting both women and men, and researchers from this group were among the initiators to the establishment of NOFE.

Epidemiology as we saw it and still see it, does not have an inherent gender bias. Rather, we consider epidemiology as a base from which men's and women's health can be understood specifically. Actually, epidemiology understood as a systematic application of logic, and a method to assess biases in general, can be

used to *overcome* biases based on gender stereotypes. So, the women's health perspective in epidemiology came to build on existing structures and contributed to expanding the scope to obtain solid based knowledge to combat important public health issues.

## THE ROLE OF THE NORWEGIAN RESEARCH COUNCIL

In 1989, a committee was established in the Norwegian Research Council to assess whether a research program was needed to address women's health. The initiative had been taken within other fields as well, such as psychology and the humanities. The program raised several health issues which were under-researched and needed special attention. A broad range of health issues were listed which were considered particularly relevant for women's health. A coordinator was appointed by the Council in 1991, to deal with the task to initiate and build research within epidemiology and public health which was particularly relevant to women. The budget allowed for 1-2 PhD students and running costs for some seminars. The most important task was to initiate networks among researchers and increase awareness among other researchers to include a gender perspective.

In the USA, a separate Office on Women's Health within the National Institutes of Health was established in 1993. This officially acknowledged the need to institutionalize women's health perspective in order to

make a difference. As we shall discuss later, this move initiated large scale projects with high impact on the handling of women's health issues and triggered huge funding opportunities for epidemiological research counteracting the historic bias overlooking women's needs.

The acknowledgement of the low priority of women's health issues in epidemiology resulted in several initiatives such as establishment of special programs and medical journals, and extended research on women. Special conferences on women's health were launched, such as the yearly Women's Health Conferences in the USA. Special journals were established including *Gender and Medicine*, *Women's Health*, and *Journal Watch for Women's Health*, and the number of publications is increasing. After the women's health perspective put the inclusion of violence on the agenda, several specialized journals on violence and health followed.

In the Nordic countries, for several years from 1984, special conferences have been held; in Norwegian called "medisinsk kvinneforskning", not a term used in Anglo-Saxon literature, but may be translated as Women's Health Research in Medicine. From 1990 in Norway, policy makers, health authorities, research bodies as well as voluntary organizations, put on their agenda the need for particular women's health initiatives and special installments. A comprehensive governmental report was written and completed in 1999. However, the perspective were only included as a chapter when the White Paper (Stortingsmelding) on Public Health followed.

Definitions of women's health and gender perspective vary, but include the following: A critical gender perspective involves the inclusion of both women and men in epidemiological research. It acknowledges the need to develop gender specific models (not only adjust for gender!) to understand causes for and targets of the prevention of diseases both among women and men, and add a gendered view to the interpretation of findings. The investigations include the goal to identify areas in which women and men need to be treated differently in order to achieve equal results. In the following we give some examples of how this perspective influenced development of modern epidemiology in Norway.

## EXPANDING THE SCOPE OF HEALTH SURVEYS

The Cardiovascular Disease and Risk Factor Survey conducted by the National Health Screening Service of Norway (NHSS) has a long history starting at the beginning of the 1970s. Both men and women were invited and health screenings were conducted in subgroups of the population in three counties (Oppland, Sogn og Fjordane and Finnmark) three times during the period 1974-88. These surveys were succeeded by the so-called 40-years surveys of the total population aged 40-42 years. The participants were examined for risk

factors of coronary heart disease, such as blood pressure, cholesterol and triglycerides. The results were used to monitor the level of risks over time and also compare the findings with trends in CVD mortality. The selected age groups were based on the assumption that CHD could be prevented if risks were identified and counteracted by healthy lifestyle and preventive medication, e.g. by cessation of cigarette smoking and treatment of high blood pressure.

The main rationale for these surveys was the observed and threatening rise in death rates among men from CHD. Women die of CHD at a later age compared to men, thus the chosen age group may have been less adequate for women by classifying women incorrectly into patients, as cut offs for cholesterol and hypertension had been less explored in women (4). The Tromsø study had already in 1986-87 included questionnaires specifically addressing women's health. Researchers focused in particular on the role of gender in coronary heart disease but also on osteoporosis and fractures (5).

When the National Health Screening Service planned a survey in the county of Sør-Trøndelag, around 1993, the RPWH, based on discussions among female researchers at the Faculty of Medicine, took the opportunity to address whether a special questionnaire could be given to women. Both the Office of County Medical Officer (Fylkeslegen i Sør-Trøndelag) as well as the National Health Screening Service were very supportive of such a study. The subsequent study was conducted in a total population in the given age group. An example of the information obtained was the inclusion of this question: "have you ever suffered from endometriosis?" This simple question resulted in one of the first population based studies on endometrioses (6). Fertility was assessed by asking "Have you ever tried for more than a year to become pregnant?" Responses were linked with questions on pregnancies and child-births, resulting in one of the first population based studies in Norway on involuntary childlessness (7). Also, questions of pelvic joints symptoms, fibromyalgia, whiplash and arthritis were included which made it possible to estimate prevalence and associated risk factors (8).

As part of the task of the RPWH, meetings were organized with those in charge of setting up health studies. The Tromsø study had already included women's health and a gender perspective. The preparation for HUNT2 had started when the RPWH program was established, so the HUNT leadership was approached. Assessing the questionnaires applied in HUNT1, the group in RPWH found that HUNT lacked some basic information on women. For instance, crucial questions like age of menopause, menstruation pattern, and questions related to birth and breastfeeding as well as relevant life circumstances and reproductive events were missing.

So, in HUNT2 it was decided to give women a special questionnaire in which a broad range of women's

health issues were addressed. To be able to conceive and to avoid unwanted pregnancy are crucial questions for women world wide. Fertility estimates in the population are based on the proportion of women actually giving birth among women in reproductive age. Other types of studies are needed in order to assess whether childlessness is intended or a result of infertility. These issues were included in HUNT2 and 3. That made it possible to assess both factors related to fertility status and changes over time in reproductive pattern. Findings that fertility decreased, subfertility and childlessness increased, but involuntary childlessness decreased over time, added new knowledge to the field of reproduction (9). The latter study showed adverse effect of infertility on health and life satisfaction, but no significant differences between infertile and non-infertile women in distress-related measures (10).

As the issue of women's health increasingly became part of mainstream research, the scope of women's health was expanded further when HUNT3 was planned. Among the burning issues put on the agenda was the potential role of vaginal delivery to harm women's future health. The mechanic pressure on the pelvic floor when the baby is born, and potential harm to the fine regulation of both urinary as well as bowel function, had been overlooked in epidemiology. The descending of vagina and uterus as a long term complication of vaginal birth was also assessed through the inclusion of question on prolapsus uteri in HUNT3. The researchers were able to assess both prevalence of this disorder and contributing factors which may be prevented even when women are giving birth by the vaginal route (11). Another example of overlooked disorders was the potential harm of childbirth on bowel functions. After childbirth women had previously been too embarrassed to ask health care providers for help for this sometimes disabling condition. When planning HUNT3, women were asked about leakage of flatus or faeces (12). By including these questions researchers were able to assess both population based estimated on prevalence and potential risks, hence contributing to the knowledge which may in the future prevent such disorders.

### **HIP FRACTURES – AN IMPORTANT WOMEN'S HEALTH ISSUE**

Norway has one of the highest incidences of hip fractures worldwide. Hip fractures are far more common among women than men. Mortality following a hip fracture is high. One of the first non-CHD disorders to be addressed by applying data from the NHSS, was hip fractures (13). Even though the data collected by the NHSS had been chosen to assess factors potentially related to CHD, the same factors were then assessed as to their link to hip fractures. Applying data from HUNT1, studies assessing various risk factors for hip fractures were conducted linking HUNT1 information to hospital information on hip fractures, prompting

acceptance to include hip fractures as a topic for HUNT2 (14). In order to be able to include also measurements on bone mineral density (BMD), extra funding was needed. The Norwegian Women's Public Health Organization (NKS) in Nord-Trøndelag responded immediately to an application, and the first BMD machines in the HUNT studies were purchased. This demonstrated NKS's role as a key player for the advancement of women's health research in Norway. The population based measurements of BMD enabled researchers to estimate prevalence and risk factors of osteoporosis (15). Osteoporosis and fractures in health surveys had started in Tromsø, and planning was ongoing in Bergen. So, when the Norwegian Osteoporosis Society received applications from three sites, the review board concluded that given a collaboration between the universities, funds were granted and the Norwegian Epidemiological Osteoporosis Studies was founded ([www.norepos](http://www.norepos)).

### **CORONARY HEART DISEASE – CAUSAL MODELS HAD BEEN BASED ON STUDIES MAINLY OF MEN**

The increased risk of dying from lifestyle related diseases during the 1950s led to a levelling of the prior increase in life expectancy particularly among men. A large number of epidemiological studies explored potential preventive factors for men. Even though cardiovascular disease once was called "the director disease", epidemiological studies demonstrated a clear social gradient among men. Men in low income employment and men with low education were more likely to die of coronary heart disease. Causal models included social differentials in health related behaviour, psychosocial factors and use of health care facilities. High diastolic blood pressure, high total cholesterol and cigarette smoking were established as important risk factors. But the knowledge was mainly based on studies of men. Both in Norway, the Oslo study (16) and the first Tromsø study (17), as well as in the United States important pioneering CHD epidemiological studies on potential preventive factors were established. But the earlier studies of this kind included only one gender, men, including the MRFIT study (Multiple Risk Factor Interventional Trial) (18).

### **WOMEN ONLY IMPORTANT AS A MEAN TO PREVENT CHD AMONG MEN?**

Traditionally the woman's role had been her unpaid work as a housewife shaping the lifestyle and health behaviour of the whole family. So much so, that already in 1978, a call to educate women to take care of their husbands after myocardial infarction was launched, as it was shown that she had significant impact on men's recovery (19). A curious and from a gender perspective interesting discussion took place in the medical literature: might the potential benefit of

having a highly educated wife assumed to have high knowledge of how to prevent CHD in their spouse, be outweighed by the assumed stress for the man not to be the social superior and the breadwinner? In the Framingham study, men married to women with more than 13 years of education were 2.6 times more likely to develop CHD! The potential hazardous effect of being married to a highly educated wife is likely to be related to general gender norms; and thus it was not surprising that in Norway, no such hazardous effect was found. Information from the Cardiovascular Disease and Risk Factor Survey conducted in 1977-83 by the National Health Screening Service of Norway was linked to information of mortality. Men married to highly educated women were *less* likely to die from CHD. This was so for men with high or median education, but not for men with low educational attainment, who seem to be stressed by not being social superior to their wives (20).

### THE ESTROGEN “MYTH” IN CORONARY HEART DISEASE

When gender differences in CHD were addressed, simple stereotypical causal models were developed: As women die of CHD later in life, premenopausal women were considered to be protected by their “female hormones”. The raise in CHD after menopause had been taken as proof of a causal relationship between the decrease of endogenous estrogens and CHD. This simplified causal model contributed to the notion that replacing the body’s own estrogen production with drugs, so called hormonal replacement therapy (HRT), could prevent new cases of CHD. Knowledge was mainly based on cohort studies such as the Nurses’ Health Study in the USA. Throughout the 1990s, an increasing number of women, also in Norway, were subjected to HRT medication. With the establishment of the Office on Women’s health at the National Institutes of Health in the USA a huge randomized control trial was set up – the women’s health initiative (WHI) – to address whether HRT was beneficial to women’s hearts. The study did not demonstrate protective effect of HRT on CHD in women, and is thus a good example of the pitfalls in generalizing potential preventive measures based on cohort studies alone, particularly when strong commercial interests are involved (21). However, the debate is still ongoing as to the external validity of this study.

As the attention to women’s hearts increased in epidemiology, another debate became an issue: Are women with CHD less likely to be correctly diagnosed and hence exposed to suboptimal treatment? A large number of studies found a higher mortality in women than in men after myocardial infarction (MI). One of the assumptions was that women were more prone to delays in being admitted to hospital. However, in studies in Norway comparing men and women admitted because of MI, the delays from symptoms to admission

to hospital were similar for men and women in the same age group, but women were more likely to need several contacts with the health care system before eventually being admitted (22). A recent epidemiological study from Norway shows that there is a shifting burden of CHD, from middle aged men toward middle aged women and elderly persons making the issue of gender based analysis a very important task for further studies (23). With the establishment of a national wide patient registry, the gender issues can be further studied in the future (24).

### GENDER BASED VIOLENCE – A HIDDEN CAUSE OF DISEASE

As epidemiological studies started to address other diseases than CHD, other causal models were developed. For example, when mental health entered into the realm of epidemiology, life events such as loss of employment, death in the family and experience of accidents became explored. This probably also contributed to efforts to look more closely into gender specific differentials in these factors, one of these being the exposure to gender based violence (GBV). The UN developed a definition in what has been and still is a very important document: “Any gender-based violence that results in, or is likely to result in physical, sexual or psychological harm or suffering to women including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or private life” (25).

When the first epidemiological study in Norway addressing gender based violence was planned in Trondheim in 1986, it was met with considerable resistance. Psychologists warned that women would not disclose such intimate information to a researcher and traditional (male) epidemiologists did not recognize such experience as a “real” exposure. Comments such as “All couples quarrel”, and “women do like to be treated a bit tough” were heard. The study demonstrated that women did disclose experience of gender based violence and even rape and sexual abuse both in marriage and in childhood (26). As the awareness of gender based violence became part of the public debate, a need for national studies emerged. The first nationwide epidemiological study on gender based violence was conducted in 2003 (27). The study was modelled on the first large scale study on gender based violence in the world, the Canadian study on Violence Against Women. In this study, both women and men were asked about various types of violence, both physical, sexual and emotional. They were also asked specific questions on the perpetrator.

A limitation of these types of special studies was the inability for the researchers to conduct follow up through merging information to registries, in order to assess potential health outcomes, since the studies did not ask for consent for follow up. Neither HUNT2 nor HUNT3 included questions on violence and abuse, but

HUNT3 included a limited set of questions on violence to adolescents (28). The first Health Survey that included questions on GBV was the Oslo Health Study (HUBRO). This enabled researchers to assess long term impact of GBV on health by linking information from the survey to the Norwegian Prescription Registry (29). This was a huge step forward in acknowledging the impact of GBV in public health. So, when the special health survey in areas with both Sámi and Norwegian Populations (SAMINOR 1), was preparing the follow up, SAMINOR 2, researchers with background in violence were invited to develop questions on violence (30). In the ongoing preparation of HUNT4, several sub-projects are interested in including questions on violence and abuse.

### **“WHERE IS THE M IN MOTHER AND CHILD HEALTH?”**

was the title of the international call for critically assessing pregnancy and delivery in relation to women's health (31). This kind of critical comments contributed to moving the agenda for global initiatives within the perinatal field. Maternal health and women's health became part of the scope to combat dangers for both the woman and the unborn child. Currently the international societies are assessing the post 2015 millennium goals. This debate has further moved the issues of women's health to include factors related to the gender inequality; sectors which shape and influence health as education and employment (32).

### **INCREASING INFLUENCE OF WOMEN INTO THE FIELD OF CHILDBIRTH**

In Norway women have for the last 2-3 decennia entered into higher education and into fulltime employment even when having children, and gained positions which traditionally have been held by men. Women are members of the government and parliament, and hold high influential positions in the Norwegian Society. Also, professions traditionally subordinate to the medical doctors, such as as midwives, came to speak up on behalf of the childbearing women. When women's voices entered into the debate about where and how to give birth, two opposite positions emerged; one which emphasized the birth process as natural, and hence kept open the option for home delivery, and one which emphasized safety and hence favored institutional deliveries. Still, epidemiological studies are inconclusive and might be influenced by the researchers' position in the debate. One recent study reported a lower rate of intervention and complications if birth were planned at home (33), while another study reported that unplanned out of institution birth was associated with adverse outcomes such as higher mortality among the newborn, in particular within the lowest weight group (34).

### **WOMEN'S HEALTH PERSPECTIVES IN THE NORWEGIAN MOTHER AND CHILD COHORT STUDY (MOBA)**

When the Medical Birth Registry (MBR) was established in Norway in 1967, the main focus was the unborn child and not the health of the pregnant women. The MBR yields information on many aspects of pregnancy and childbirth, however information is limited. This sparked the establishment of the large mother and child cohort study (MoBa). This initiative coincided with increased attention to women's health. Women when being pregnant in a country like Norway are rarely faced with serious danger, but pregnancy can be seen as a risk factor for many disorders in women's lives. In the development of the MoBa study, researchers were invited to suggest topics which then were assessed by the steering groups and potentially included. Several researchers, as our group in Trondheim, voiced the need to include women's health topics as subprojects and hence proposed specific questions to be included in the questionnaires.

There were many stakeholders when MoBa was planned, and tough competitions took place as to where and how questions could be included. Researchers based in physiotherapy had for years been studying various pregnancy related pelvis disorders. The condition had also been put on the public agenda by strong advocates among women suffering from pelvic girdle pain. Questions on pelvic pain and lower back pain were included in the MoBa questionnaires (35) and created the opportunity for researchers to both look into the prevalence and potential risks (36). Another condition related to pregnancy which had grossly been overlooked, was urinary incontinence, a potentially disabling condition which during the 1990 had been put on the agenda in particular by general practitioners with particular interest in women's health (37). Postpartum depression had received limited attention in Norway when the planning for MoBa took place. So, in the process of developing questionnaires, validated instruments for both depression in pregnancy and postpartum was reviewed and ultimately included (38). Another pregnancy related phenomenon which received increased attention from a women's health perspective, was fear of childbirth and maternal preference of mode of delivery. Should women have the right to demand a caesarian section? Ardent discussions have risen in the professional communities following this trend. When MoBa was planned, this debate was at its infancy, and only a very limited number of questions were included in the formulas to assess women's own thoughts and wishes, and validated instruments were not used (39). Since the reporting of previous experience can be significantly influenced by the current situation, such as fear in current pregnancy, the MoBa dataset allowed for follow up of women reporting a poor experience of their childbirth. When being recruited to MoBa in her

next pregnancy, fear of pregnancy could be assessed as a potential outcome of her birth experience reported in the MoBa after the previous childbirth (40).

Suggestions on including violence and abuse caused huge debate when planning MoBa. Questions on GBV were not included when the first pilot study was conducted in 1997. However, one of the pilot women contacted one of the recruiters and asked where in the questionnaire she could indicate that she had been raped! This paved the way to the steering committee to accept questions on GBV. However, on the list given to participants of type of perpetrator, intimate partner was omitted, the rationale given was that it could offend the father. This led to limitations when assessing impact on violence committed by a known person

(41). When eventually questions on violence were included in MoBa, this has proved very important in a large number of studies.

## CONCLUDING REMARKS

During the last 25 years significant improvements have taken place to include women's health perspective into Norwegian epidemiology. Now, equality between men and women is in some respects taken for granted, and hence, it may be tempting to not let it matter. However, the task for an epidemiologist with a crucial gender perspective is always to critically overcome the inherent gender bias still threatening our mission to generate solid knowledge for public health.

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