

# **WE WHO FEEL DIFFERENTLY**

## **INTERVIEWS**

***My wish would be that any lesbian woman with a health problem would be taken very well care of when she went to seek healthcare, that her resources would be appreciated, that her sexual orientation would be taken into consideration as part of her problems, as well as solutions, and that the doctor would know how not to meddle with what he/she thinks of as a different lifestyle. The doctor should easily and quickly create a context for her to be the person she is and get the help she needs.***

### **An Interview with Kirsti Malterud**

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**Kirsti Malterud:** My name is Kirsti Malterud; I am a Norwegian medical doctor living in Bergen. I am 60 years old, a general practitioner and a professor of general practice. In the last few years I have been doing and supervising research on lesbian health and on health services for lesbian women. I am a lesbian myself.

I was also one of the founders of a public health service for gays and lesbians in Oslo in the mid 1970s. We were lucky to have strong support from the health care authorities. From doing that kind of work, I found that health problems and health care for gays and lesbians, especially lesbian health, which has been my focus, is actually not very different from the healthcare and health problems of other people. My research has mainly been on women's health problems, medically unexplained disorders and on the understanding of what health is, what disease is and on the way the medical system encounters what it doesn't understand.

On the lesbian health research issue, I did some small register studies in the early 1980s counting up numbers from our healthcare service, telling what kind of problems we saw and how many. It was a kind of awareness rising on which were the specific problems and how could these problems be better solved by the ordinary healthcare system.

**CM:** What were those problems?

**KM:** They were issues of discrimination, questions about how to get out of the closet, psychological problems and how to discuss the situation with the parents. Also questions such as: Am I really a lesbian or not? Is this just something that will pass? Or: Will I need some therapy to change and is there some therapy available for that? We always answered that it would better for them to continue being themselves.

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**CM:** What was the general understanding from the medical and psychology establishments about homosexuality at the time when you were doing this work?

**KM:** At that time, which is now 30 years ago, homosexuality was much more pathologized than it is now. In medicine there were strong opinions about development programs, identity programs and about seeing gay and lesbian people as having some inherent big problem. I was also connected to a team working on transsexuality on a national level in Norway, which was at that time considered as something very special, very fascinating, and we felt it was important to work on that, but it was actually very medicalizing: Come to us and we'll help you fix it. Since then, there isn't such a strong focus on medicine pathology anymore. The problem now is more the rejection that there are problems at all because we have come so far: We have the partnership law and Norway is the country of equality. Why should we discuss problems at all? This, I would say, neglects some of the specific problems. The attitude is: Oh fascinating, since you are depressed and you are lesbian that is certainly the explanation!

In the last years I have been more involved in questions such as what could be the best healthcare for lesbian women, what are the problems when lesbians need healthcare, or what are the problems in how medicine consider being a lesbian.

**CM:** What changed from the 1970s to now? What was the platform that facilitated that change? Did it come from the political work; did it come from work within the medical institution, or from work from LGBT activists rejecting medicalization?

**KM:** I would say mostly from the LGBT activists. The associations have been the most important in pushing a general political change of attitudes in Norway very strongly. And I would also say that the work related to the health service we established in Oslo played a part. It was not only about seeing people in trouble, but also about informing the institutions of education and institutions of treatment. We went to hospitals, we went to prisons... I think for a couple of years, I did 40 presentations in important institutions in Oslo, mainly presenting a few facts, and something more about attitude, because at that time discrimination was really an issue.

**CM:** What was the background before the 1970s? What was the medical establishment's idea of these issues since the 1940s?

**KM:** This is a disease, you need treatment, and we might help you. It is a pity you have this problem but we can help you change.

**CM:** When is homosexuality removed from the list of pathologies?

**KM:** There was not a specific Norwegian list, but the important year for that in Norway was, I think, 1977 when the *Norwegian Psychiatric Association* concluded after a very strong discussion that they should not pathologize this. However, many years later, Norwegian psychiatrists and psychologists still regarded this as a developmental problem, but the conclusion at that meeting made a strong impact on professional attitudes.

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**CM:** Are you suggesting that there has been, since early on, a kind of tragic understanding of homosexuality? First as a kind of disease and then as a kind of lack of fortune...

**KM:** Yes.

**CM:** How is that is that situation today and how do you position yourself in regards to this narrative?

**KM:** I came out in the 70s and was happy to do it when the movement was strong. I was very lucky because I came out to a strong and proud community. This also helped me as a professional to mediate what I thought about homosexuality and health. Since then the discussions on “Is this something you are was born with or did you create it?” has developed, although among the ordinary population in Norway you still find a lot of people who are reluctant towards homosexuality unless they can declare that it is an in-born error and “I can't blame you.” You still find among the ordinary population and among young homosexuals and their parents, a lot of people that think it is inevitable, that you can't do anything about it... I think that things can change in a life; it is very good that we are not in the dichotomous or trichotomous divisions, which had been ruling for such a long time.

**CM:** Can you explain these dichotomous and trichotomous divisions?

**KM:** When I came out in the 70s, I had a very clear feeling that you had to choose. If you go for a lesbian life there is no return. We also thought that people who called themselves bisexuals were not brave enough to come out or that they would have to make some guarantees both ways. At that time you were either one or the other. When I say dichotomous, I mean people that are born like that, and you put them here or there. Sometime in their life they will, sooner or later, find out what they *really* are. Since then, my own views have broadened very much, also because I have been married for many years to a woman who was previously married to a man, and that was no mistake of hers. These life experiences of my own came to me at the same period when we understood much more about how identity and sexuality is developed. When I said “trichotomous,” it is almost the same but putting in the “bi” concept in the middle: Either you are *homo*, *bi* or *hetero*, which I don't think is a useful conceptualization.

**CM:** You have gained an understanding of a sexuality that is more diverse...

**KM:** Much more fluid and more dependent on what happens and what creates windows of opportunity, or what closes windows of opportunity.

**CM:** Is this an understanding that goes against the medical establishment's understanding of sexuality?

**KM:** Not necessarily. I think that is moving ahead in Scandinavia, at least. Although you find old-fashioned doctors, psychologists or psychiatrists that are sitting there clinging to the old

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concepts, I think a lot of people know that things are changing. Professional conceptualization is also changing, we are not at the end of that road, but we are on the road for sure.

**CM:** How is LGBT health different from heterosexual health?

**KM:** Whose opinions would you like me to express?

**CM:** The opinion of the mainstream and the one you have applied in your research about lesbian women.

**KM:** I will start with the second one because it is easier and you could think about it comparatively. In my research on lesbian women, my point of departure has always been that *this is not a tragedy*, and then why consider it as a health problem by itself? Just to mention an example, I am now supporting a master student's thesis on a study where lesbian women present their experiences of the health promoting aspects of a lesbian life. I think it may not shock, but perhaps it will help change the minds of Norwegian doctors. It has now been accepted for publication in the journal of the *Norwegian Medical Association*.

**CM:** Can you further expand on that example?

**KM:** Our preconception was that although some lesbian women have clear health problems related to sexual orientation and identity, perhaps most lesbian women have good health and are happy about being lesbians. We formed a focus group where we asked happy lesbians to explain the potentially health-promoting experiences they had had: Could there be aspects of a specific lesbian life, which perhaps protected you against some health problems that you would have encountered if you were not a lesbian? We asked them about the possible effects of being free from narrow structures and some of them told us: "Me and my partner can decide our rules" or "Okay, I don't have to use these terrible shoes, I use my boots instead because it is more comfortable and I don't have to use high heels because I am not on that market where that would not be a nice thing to wear." We also found out about lesbians that gained something through the trouble of coming out: "I feel stronger, I know learned about finding myself, I have found some important aspects of identity, which I will never let go that can also be applied to other aspects of my life."

**CM:** When you are speaking about health you are speaking about mental and physical health?

**KM:** Certainly. Yes, I can't think of these apart. That research project came up in opposition to all the "tragedy" reports. In the years before we had some reports about how terrible things were, reports about suicide narratives, about a destiny that you can never escape, and especially a big statistical report on bad health and suicide behavior among gays and lesbians. My point was there is a need for some other voices because this "tragedy voices" can reproduce themselves just by being told and told again and again.

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The other example is a PhD study, which I am also supervising, which is about what the important things when lesbians seek healthcare are. That study was in opposition to claims that there is an increased prevalence of risk or several diseases in lesbian women such as breast cancer, drug abuse, depression, which of course might be so, but the support for that on an evidence base is very loose. There are myths about lesbian women, as a specific group, needing specific attention on their specific risks or specific disorders. Reading the literature on this subject we found that there was a need in the healthcare system when encountering lesbian patients, to be aware of the specific personal needs of lesbian women instead of assuming their medical needs. Lesbian women complained of not being seen, not being heard or being taken as heterosexual by default. This study is about when it is important for lesbian women that their general practitioner or family physician knows about her sexual identity and when it is not. What is the impact of knowing? What difference does it make?

**CM:** Could you name a few cases in which it is important and in which it isn't according to your research?

**KM:** A woman lost her partner, she became a widow. Her doctor did not know that she had been married to a woman. In that case, it is very important that her doctor knows that this death is not that of a friend but that of her darling, of her closest partner ever.

Also, for certain gynecological things, doctors may assume that the woman's partner is a man. Women have told us that if the doctor knew that their partner is a woman, the conversation would be much easier for the both of them. This study is about when it is important for doctors to know a woman's sexual orientation and when it is not. How can doctors ask and what kind of responses should they expect?

Another part of this study is about healthcare experiences and how lesbian women are met when they see their doctors. In that study I started by describing perfectly fine relationships and events where the doctor had an awareness of the woman's sexual orientation and treated her respectfully. On the other hand, I describe bluntly provocative discrimination, such as doctors talking about who the woman was bed with the night before, while doing pelvic examinations. We found a broad range of specific knowledge needed by the doctor, awareness on heteronormativity, and the need for breaking that, and also a need for the woman to be herself when she came to a consultation.

**CM:** Is there a specific law in place to prevent this type of discrimination from occurring in medical practice?

**KM:** Not especially. We have a law on discrimination, but it is on a much higher level. I was actually in the group preparing that law 20 years ago. That law has almost never been used. It is there more as a preventive measure than a measure for action, and it was meant more for discrimination in the work place and things like that. Of course there are ethical rules, there are rules of behavior in medical encounters, but not specifically based on sexual orientation. There is one regulation I could mention, which is about quality in healthcare. Quality in healthcare

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should be professionally sufficient, which means being evidence-based and it should be considerate. In the worst the cases that we found in the study, these regulations could have been applied because these were not considerate attitudes towards the patient.

**CM:** How are transsexuals and intersexuals protected from issues of medical discrimination and mistreatment?

**KM:** No special regulation.

**CM:** Are there accounts on the way that these two types of subjects are treated within medical practice?

**KM:** I have been following with special interest the intersex case because it has been completely silent. It is as if in Norway every child is born a boy or a girl. In the last few years we have heard about what happens at the clinics when intersex babies are born, and this is not out in the open. It is interesting that all of the discussions on that subject are going on in a closed medical room as if there were no political or ethical aspects to it. Like in other countries, where in doubt, doctors just change the sex of the child, thinking that this would be the best for him/her, and we never hear about it.

**CM:** There is no consent from the family in Norway?

**KM:** Yes, there must be consent from the family, but the doctor giving them advice would certainly convince the parents. Regarding transsexuality there have been discussions on service opportunities. I think these service opportunities have become better the last years, but I haven't been following that as closely.

**CM:** What do you mean by service opportunities?

**KM:** Who could help? Is there help to be given? Is there a system for assessment? And, if people are assessed for change, is there a service to do that and to follow up? There have been complaints about the lack of availability on that.

**CM:** Returning to the issue of intersex, I recently encountered a fascinating film about an intersexual child whose parents reject the medical decision to operate, and move to a different place, but they give the child hormones so that she starts to develop as a female.

**KM:** I watched that film, *XXY*.

**CM:** There is a moment in the film in which the father tells the girl that eventually she will have the possibility to decide. And she says, why do I have to decide? From a medical perspective, do you have to make a decision and take hormones or testosterone, or could you just live a normal life without any medical treatment?

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**KM:** I also think that is the most important question because why couldn't she just be herself? Why push her in this or that direction? I don't think Norwegian parents would wait and see and Norwegian doctors would most likely not support that decision.

**CM:** Is that a cultural or a medical decision, or both?

**KM:** Both, because the authority of the medical advice would be very strong, too strong perhaps. I don't think the medical experts in that field are very reflective on the cultural construction of gender, unfortunately. Having worked for many years in the service of transgender people, which was somehow a surgical view on gender, I would prefer a society where the voice of the girl in the film would be heard. Let her be herself and don't let her parents have a need to protect her from all the terrible things that would happen, if they make the decision for her.

**CM:** There is a performance artist in New York that has rejected to classify him or herself in terms of gender so he or she presents him or herself with a long beard and breasts. Sadly, she or he is often perceived as a kind of freak...

**KM:** That is what parents want to protect their children from. I have heard about similar performers. If they don't make it ridiculous to be in-between, they do a very important political work.

**CM:** In your work you are looking to define, in different ways, a positive thinking in relationship to health that rejects the negativist paradigm we have been living?

**KM:** Yes. That connects closely to the other part of my research, my general practice research, where I have been collaborating with a Danish colleague for many years on a project where we wanted to shift attention from risk to resources in medicine.

**CM:** Can you explain that?

**KM:** We became increasingly worried that all medicine was focusing on what was wrong with people. We read Israeli sociologist, Aaron Antonovsky who wrote about *salutogenesis*. His point is that it is more interesting to focus on what keeps people healthy than in what makes them ill. You become ill when the resources are not sufficiently strong. Why don't we focus on what keeps people healthy instead of just looking at what brings them down?

We have worked on resources, not as an alternative but as a compliment, to the path of a genetic view in medicine. That is not very original; there is a lot of medical research that focuses on salutogenesis. But we have done it, for many years, especially compared to the risk-focused attention in medicine, which believes that you can be protected even from death if you are sufficiently risk-focused and that any disease can be prevented. We think that that hides the possibilities of promoting health. And from that point, I thought that, of course gay and lesbian people have problems and some of them are specifically related to sexual identity and sexual

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orientation, I wouldn't neglect that and I would not dismiss that problem, but when thinking about health why don't we rather develop knowledge about how health can be created, developed and supported instead? I moved my views from the other research to the gay and lesbian research after so many reports were published on the *terrible* health conditions of gays and lesbians, which didn't match my work. I couldn't believe that was the *terrible* life of most of my gay and lesbian colleagues.

**CM:** I imagine that this is something that you practice literally in your medical practice, but how does the community receive your work?

**KM:** In the gay and lesbian community there has been a lot of opposition to my work. It is convenient for getting funding and receiving attention that gay and lesbians are regarded as people with problems. The Norwegian report, which was released ten years ago, received a lot of funding, but focusing on the problems. I met a lot of opposition from some activists and some organizations because they said I neglected the problems and that I didn't understand how difficult it was. I knew very well how difficult it was. I had been working on this for many years, but I also saw that we could re-enforce problems by just focusing on them. That is the social construction of tragedy. I knew from my own practice that knowledge about resources could help people cope with their situations. I met very strong reactions from the gay and lesbian community, and for many years I felt very much alone as a researcher and as an academic assessing the evidence that I am very capable of. I know how to read a paper and I know how to judge the statistical quality of a paper. Actually a lot of these previous studies about tragedy were academic rubbish.

**CM:** It was a political rejection...

**KM:** Yes clearly, but most of my research has also been driven by political motivations. Although I use the tools and I follow the rules, my motivation is clearly that I want to contribute to change.

**CM:** But that political rejection influenced the way that the heterosexual community viewed and read your work?

**KM:** We have not published much on the questions of lesbian health. But actually the reactions from the professional community are very good because my colleagues want to know what to do. They want to know how they could improve; they want to know if a special group of patients may need something special, so providing some insight and some tools has been very well received.

**CM:** In different interviews I have conducted here, it has come up that there is a kind of homonormative discourse in Norway. For example, Ellen Mortensen discussed the fact that she doesn't think that queer studies has really flourished in Norway because it has been politically rejected by the gay and lesbian activists. An understanding about a queer identity category, as opposed to a very specifically defined gay or lesbian identity category, is something that could

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hinder their political work. You seem to be facing, in a different field, a similar kind of opposition to a kind of *queering* of medicine.

**KM:** I don't see clearly your parallel, but I could speak about the question of queer theory. I was also a professor of feminist studies in medicine for 7 years just at the time when queer studies and queer theory were introduced here. There is a tension that I can understand because queer theory is very challenging theoretically. It is interesting, it broadens my mind and it gets very close to *XXY*, the movie we talked about earlier. If categories would destroy her life, why do we cling on to them? At the same time as a medical practitioner and living a lesbian life, I can't escape from categories. Although I am 60 years old and I am very confident in my lesbian identity, I feel challenges almost everyday as a lesbian. There is a tension between the theoretical aspects and the applicability of queer theory. I think Ellen Mortensen is right that especially the gay and lesbians organizations have clinged on to the dichotomous divisions for political purposes and for funding reasons. I agree with the objection that queer theory somehow makes discrimination a more subtle thing and that diving into queer theory is some kind of luxury.

**CM:** A kind of silly question: what would be the ideal application to your work if you lived in an ideal place?

**KM:** That is not a silly question. The best gift you could give me, as a response to my research would be that there would be no need for special healthcare for gay and lesbian people in Norway, especially lesbians since that is my primary interest. My wish would be that any lesbian woman with a health problem would be taken very well care of when she went to seek healthcare, that her resources would be appreciated, that her sexual orientation would be taken into consideration as part of her problems, as well as solutions, and that the doctor would know how not to meddle with what he/she thinks of as a different lifestyle. The doctor should easily and quickly create a context for her to be the person she is and get the help she needs. In other words, take away the wish for specialist care, which a lot of my American lesbian friends voice very strongly. I interviewed a group of lesbian academics, I asked them about their needs in healthcare and the only thing they wanted was a lesbian healthcare provider, which in Norway is not possible, it is not feasible and is not what we want. I rather wish that my medical colleagues would be sufficiently enlightened to provide excellent care and appreciate the choices of the patient.

**CM:** Why do you say it is not possible, because of how small the population is?

**KM:** Not only that. I think I know less than 20 lesbian Norwegian general practitioners. I don't not know all of them, but I know some of them. We are a few and we are not spread all over Norway, but secondly and more importantly, the Norwegian healthcare system is based on a broad service to everyone. The system is so that the general practitioner should serve everyone and then you go to specialist care if needed. The Norwegian GP should be capable of serving any kind of patient, and that is political, that is a choice that has been given both for good use of health services and also for access to services all around Norway. It is not that I would like to

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clone hundreds of lesbian doctors and spread them all over Norway, but actually I appreciate our system and our problem is not the lack of lesbian doctors, it is the lack of knowledge on what lesbians need from their doctors.

**CM:** It seems like you are going in the right path in Norway.

**KM:** Yes, certainly. I am very happy to see these moves but I still see we have something left to do.

**CM:** What is the biggest challenge, what does it take to get there?

**KM:** For the medical community and the gay and lesbian community to be able to balance what is specific and what is general and how do these two things match. How can we put these things together, what is specific and what isn't? In which ways is specialized knowledge needed? I think that is some how a queer medical point of view.

**CM:** Is there something that you would like to add?

**KM:** A research article, which was recently published by me and my coworkers in an international journal on methodology and epidemiology, which is about how often a disease occurs and how it is distributed in the population. In this article we have reviewed most of the studies on lesbian health, not on which diseases are to be prevented, but where are the challenges in research within this area. Such as, what is actually a lesbian? Is a lesbian a woman that says she is a lesbian? Is it a woman with a positive lesbian test, whatever that test would be? Is it a woman that practices sex with other women? Is it a woman who falls in love with other women? Studies range broadly within this field, which means that a lesbian in one study is not the same as a lesbian in another study. It would be more important for a study on sexually transmitted diseases to know about the sexual practices, than about the identity of the women. But perhaps for a study on depression it would be probably more important to know about attraction and identity. Studies are not comparable because you can't define the lesbian population. In this article we reviewed all these research problems, especially the fact that most studies say things like "55% of lesbians suffer from this disease as compared with 23% of heterosexual women." Most of these studies are not drawn from representative population samples, which means that you can't compare at all. So what does this 55% represent? We don't know.

**CM:** So, what are they drawn from exactly?

**KM:** They are drawn from opportunity samples, from a group of people recruited for this study, maybe because they were especially interested in these problem, etc. Most of the studies within this field are convenience samples from which you can't draw any kind of conclusions at all. This doesn't mean that you can't do any research, but it means that you have to very careful about the conclusion you draw. Most of the research within this field creates an artificial reality of medical facts.