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Genetic Risk and Individual Responsibilization. 'Breast Cancer Susceptability Genes' as a Matter of Self-management.

Abstract:

It is commonplace that contemporary subjectivity implies the sense of responsibility for one's own health. Health has become a matter of competence and an outcome of one's own decisions rather than fate. New genetics and the search for genetic predispositions for illnesses such as breast and ovarian cancer form a part in the promise of an individual risk management to prevent the actual onset of disease. (Carriers of certain mutations in the BRCA 1 and BRCA 2- gene are said to be exposed to a breast cancer risk of 50 to 80% compared to 10% in the average female population.) Based on my fieldwork carried out in German genetic counselling centres I want to question this promise. I will focus on the gap between the rhetorics of informative literature and counselling sessions, the medical practices and the self-perception of women who have undergone genetic testing for breast and ovarian cancer in combination with genetic counselling.

On the one hand, an ideology of “free decision” and risk management is propagated, that constructs women as economic “decision-makers”. The analysis of the counselling sessions and the hermeneutic interpretation of my interviews with the women can show how this concept fails for the women due to various reasons. It is not only that the possibilities of individual prevention are questionable in general; many of the women don't perceive themselves as active agents in the process of testing and treatment following the test. Nevertheless this neoliberal concept has an ideological effect: even women who question their possibility to control the outbreak of the disease accept their personal responsibility to “do something about it”.

Text

It is commonplace that contemporary subjectivity implies a sense of responsibility for one's own health. Health is to be seen as a matter of competence and an outcome of one's own decisions rather than fate. New genetics and the search for genetic predispositions for illnesses such as breast and

ovarian cancer take part in the promise of an individual risk management to prevent the actual onset of diseases. This scenario has been called the “political economy of hope” by Niklas Rose/Carlos Novas (2005).

Drawing here on my fieldwork carried out in German genetic counselling centres, my aim is a change of perspective: instead of just giving you another example for the medical discourse of responsible, enterprising selfhood, which often has been called “neoliberal”, this paper takes a closer look at the narratives of women who have undergone the process of genetic counselling and testing. These narrative often are not congruent with the concept mentioned above. They will also show how illusionary the promises are that drive the economy of hope.

Relying on population studies, medicine already proposed earlier, that 5-10% of breast cancer has a genetic component. In the mid-90s, the BRCA 1 and BRCA 2- gene were decoded and carriers of certain mutations in those genes are said to be exposed to a breast cancer risk of 45 to 80% compared to 10% in the average female population, and 10-60% for ovarian cancer compared to 2%.

Women considered to be 'at risk' because of their family history are encouraged to undergo genetic testing in combination with a genetic consultation. During the time of my fieldwork, the tests were made in the course of a multi-centered clinical trial financed by the German Cancer Aid. In the meanwhile, it has become part of the regular health care for so-called “high-risk families” covered by insurance.

In my research I analysed medical publications and guidelines, hand outs of the clinical study and the genetic counselling sessions. In addition, I carried out in-depth interviews with genetic counsellors and other staff as well as with women who have undergone genetic testing. The time point of these interviews was at least one year after they received the test result. None of the women had cancer herself.

Before I focus on the stories of the women I want to give you a brief impression of the clinical trial's self-portrayal.

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In a hand-out for patients called

„Inherited breast and ovarian cancer.“

with detailed information about inherited cancer and the procedure of the study, genetic counselling is described as follows:

„The decision for or against the molecular genetic analysis of the BRCA1- and BRCA2 gene is not

easy to take. To give a basic help for the decision, a detailed consultation is conducted prior to the molecular genetic analysis. Only the woman herself can decide, whether a molecular genetic analysis is useful for her.⁴¹

The leaflet ends with the call: if you have the suspicion to be part of the high-risk-population, please get in touch with one of the centres of the study.

I cannot go into details with this, but what we encounter in the case of genetic testing for breast-cancer in Germany is similar to other medical fields and other countries as it has been described e. g. by Sahra Gibbon, Nina Hallowell or Thomas Lemke: Women (just as men in other cases) are encouraged to become active patient-subjects, to inform themselves, to find out about their so-called risk-status and to get involved in practices of risk management of which genetic testing is to be one. And they are encouraged to make up their own mind about it: the emphasis on the “woman's own decision” in the handout is typical for the whole clinical trial and stressed many times during the counselling sessions.

If a woman gets in touch with one of the clinical centers and meets the study-criteria, she is invited to three consultations: a gynaecological, a psychological and a genetic one. The genetic counselling sessions are to inform about the genetics of cancer in general and the BRCA-genes in particular. Also they tell about which options there are if the result is positive: The options range from intensified screening (basically mammography and ultrasound) to taking part in other clinical trials with anti-hormons to prophylactic surgery of breast and ovaries. Additionally, general life-style-advice thought to be protective of cancer are given, as there are: “eat five portions of fruit and vegetable every day”, “do modest sports and avoid smoking”, and after all: “try to maintain the joy of life”. Again, it is stressed that because all the options have (sometimes massive) side-effects and none of the options will completely abolish the risk, the woman herself has to make the choice which is right for *her*.

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So far, the picture seems to comply the diagnosis of Rose and Novas, that “Medicine, including medical genetics, notwithstanding its resolutely somatic understanding of the mechanisms of disease, has been one of the key sites for the fabrication of the contemporary self – free yet responsible, enterprising, prudent, encouraging the conduct of life in a calculative manner by acts of choice with an eye to the future and to increasing self well-being and that of the family.” (Rose, Nikolas/ Novas, Carlos (2000), 490)

But looking at the interviews, other aspects get into focus.

There is some accordance with other findings: the women I talked to as well *do* feel responsible to

inform themselves from different sources, they *do* make the test, be it for the benefit of cancer research, for their children or for themselves. Also they could be described as forming “biosociality”, engaging in a community of others having the same condition: some of them *do* engage in internet chats or self-help groups (as it has been described e.g. by Rose/Novas for carriers of other genetic mutations.)

But the concept of “free, enterprising personhood”, calculating the choices, being lay experts and active partners of the doctors, must be differentiated:

(Slide with Types)

Interpreting my interviews I basically found two different types of dealing with the test. The first type I called “informed risk-manager”. The second, I named “care-seeking client”.

In the following, I will show the failure of the characterized concept of risk management on different levels:

The women of the second type actually don't perceive themselves as active agents in the process of testing and treatment following the test. Whereas the first type-women *do*, their narratives can still serve to indicate, how illusionary the notion of control through risk management is.

1. Type “informed risk-manager”:

The first type of women that I called “informed risk-manager” matches the model of neoliberal personhood.

Concerning *decisions*, they describe themselves as informed decision-makers, informing themselves and calculating the costs and benefits of the knowledge as well as the different options. The risk figures make sense to them and serve as a rule to make decisions, as you see in the following quote:

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„I would recommend everybody, who belongs to the risk-population, to take the test, (...) simply because I appreciate being in the *know* about the things that are inside of me, and if there is a risk inside of me, then I am really the first person who should know about that, so that I can deal with it, no matter *how* I deal with it. Well, basically it is *my* problem how I deal with such a thing, (...) And I think the risk *not* to know and to be unnecessarily anxious is so high.“ⁱⁱ

The genetic risk – a statistical relationship that doesn't say anything about the individual - is reified to something inside oneself; and it is obviously perceived by this woman as something you can deal and calculate with; she can even weigh the costs and benefits of the test against the emotional risk *not* to know. That shows that she presupposes a situation in which women are aware of their risk-status and therefore anxious anyway, which is illuminating:

she already is constrained in her choices by the discourse on cancer heredity and the fact that she knows about the possibility of genetic testing, and in this situation of general awareness the choice to make the test seems the only rational one.

Another woman explains that before she made the test she decided, having *calculated all the possible options*, to have prophylactic breast-surgery (mastectomy) when having a positive result (which she hadn't): **Slide**

„because if I know I have a risk of maximum eighty percent, that is really much; then it doesn't make sense to go to the check-up every three months. It makes much more sense if I do something really serious then.“ⁱⁱⁱ

Concerning the *relationship to doctors*, I found that these women appear very self-confident, they actively ask for information and often decide against recommendations.

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In the *self perception* of these women, risk management really seems to make sense. The

embodiment of risk, the notion, that a statistical relation between cancer and a set of bases in the DNA has something to do with their own body, and that this is a call for action, is working. Anyhow, in the subtext of some interviews, it becomes obvious that the promise of more control is not fulfilled:

Interestingly especially some of the 'risk-managers' are very occupied with cancer thoughts, very anxious before the test and not totally relieved after a negative test result: the fear of cancer is still a central topic. One woman even asks herself, how certain the test is. So the hope to have an instrument of control turned out to be illusionary. The "reduction of risk" doesn't seem to be as satisfying as expected.

Genetic knowledge, just as other forms of modern knowledge, reveals its paranoic structure here: the more you know, the more you are haunted by the unknown, and a point of certainty, which was the original aim, is never reached. This is even more the case with a knowledge which can only be expressed in probabilities, because there are many factors interacting and there is no direct causation. What makes it especially unpleasant in this case, is, that the unassertive knowledge concerns the future condition of one's own body. The background of this genetic risk-management is a development in cancer research: to concentrate on genetic and life-style factors, which can be individualized, instead of environmental or working-place factors.

In addition, the women's stories reflect how questionable the possibilities of individual risk-management are in the BRCA case: there is no effective prevention except removing these parts of the body that are in danger, like breast or ovaries, which is, with regard to the uncertainty of the test, not a very satisfying answer. That raises the question what value the genetic testing has for the women at all.

Now I come to **Type 2: "care-seeking client"**

1. Decision

In the narratives of the second type of women, they don't appear as active subjects informing themselves and then *deciding* what to do. When being asked how it came that they made the test, they would say for example:

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"that was completely by chance"^{iv}

or: "I didn't think much about it."^v

or describe only what the doctors suggested without talking about their own actions.

2. Relationship to the Physicians

With regard to the *relationship to the physicians*, they don't see themselves as well-informed patients or lay experts having an equal relationship to the medical expert, but seek for the “good doctor” that they can trust. A central topic is “being in good hands” (“gut aufgehoben sein”). They prefer to know a doctor personally and reject the anonymous atmosphere in some of the breast cancer centers, as in the following quote:

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„I don't go to the university hospital in a town any more for all the examinations, because there is always a different assistant doctor. (...) I just need somebody I can trust, who knows me, who knows my case; my gynaecologist, she decides when I go have a mammogram, she decides *if* I do it or if I *don't* do it, and now I go to the check-up every half a year.”^{vi}

Following her gynaecologist's advice, she also decided not to take part in the anti-hormone study which was offered to her at the university hospital after her positive test result. The only preventive practice she concentrates on is “positive thinking” and “healthy living”.

One woman explicitly rejects to be an informed decision-maker, narrating an anecdote where she was told about some changes found in her breast radiographs:

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“then, you see, I ask a *doctor*, I *am* no doctor myself: 'so, what do you recommend' or 'what shall I do now', and then he tells me: in my eight-month-experience, women mostly react like that and that. And then I looked at him, and I said, ok, I said, (...) I go to my gynaecologist.”^{vii}

Obviously, his statement referring to percentage and leaving the decision to her, doesn't make sense to her.

3. Risk-Management

Characteristic for the second type of women is also that they don't see a direct connection between knowledge and actions. The information the test gives can not be translated into a demand for certain choices to take. As one woman says:

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„that's why I, actually I really would like to know how it works, but probably nobody can tell you definitely. Well, I have that *gene*, indeed, but what is it that happens so that the gene becomes *cancer*? (...) Is it because I have emotional problems, because it just happens, or is it because I don't

eat healthy? You know, that's what I would like to know, but I think that is what they actually don't know, otherwise everybody could do something against it, isn't it?"¹

So obviously, the gene-mutation is not perceived as a calculable risk, but as an unpredictable danger. Therefore, it is completely uncertain, what effect the own actions will have. A risk-management to gain control over the future is not possible.

Illustrating is a story one woman tells: she says that when she would get cancer, she probably would think: "why didn't I stop smoking?" But then she recounts how her son got a rare coughing disease, although she and her husband never smoked in the house. Had they smoked in the house, they probably would have blamed themselves for the cough. Her bottom line concerning cancer is:

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„That's how it is. That's why I think by myself, maybe you stop smoking and get it anyway.“²

What she talks about here is the paradox, that you *feel responsible* for the supposed consequences of your behaviour, *although* you cannot trace them back to it.

4. Knowledge

Nevertheless, knowledge and enlightenment are important topics for the second type of women, but being informed about breast cancer, seeking second opinions, for them seems to be more a necessity because they don't trust their doctors and are anxious, than an act of sovereignty.

And on the other hand, they also talk about knowledge as *danger*: if people are (unlike themselves) not able to deal with the test-information, they could become mad about it, being so anxious watching oneself.

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In summary, the second type cannot be described as the informed decision-makers the discourse proposes. They *do* engage and inform themselves, but

1 („deshalb es würd' mich ja, äh, eigentlich würd's mich ja schonmal interessieren wie's nachher funktioniert, aber so genau kann's einem ja sicher keiner sagen.

ich mein gut, ich hab zwar jetzt das gen, aber wiewie was passiert denn damit das gen zu krebs wird? (...)

is es weil ich mich (1) weil ich, was weiß ich psychische probleme hab

weil's einfach passiert, oder is es weil ich mich ungesund ernähre; # wissen se, des, interessieren würd' mich schon aber ich denk' das is ja das was se eigentlich nicht wissen /ja, ja/ sonst könnt ja jeder was dagegen tun, ne?“)

2 („so is das, ne. deshalb denk ich mir hörste vielleicht auf zu rauchen kriegst ((lachend) trotzdem.“)

1. they don't describe themselves as active decision-makers,
2. they don't see themselves as lay experts or equal partners of the doctors,
3. they are not able to calculate the risks and choices and don't feel they can control the future.

But although in the women's own narration it becomes obvious, how illusory the economy of hope is, they still take part in it, both when they still justify the test in retrospect and when they feel obliged to take certain preventive actions or feel guilty if they don't. The concept of genetic responsibility has an ideological effect: even these women who question their possibility to control the outbreak of the disease, accept their personal responsibility to do something. But they do this more out of anxiety than out of feeling as “prudent, enterprising selves”.

To sum up, I hope my examples could show how *illusory* the concept of being an active, risk-calculating subject of one's health is on different levels: on the level that in some people's self-perceptions this concept doesn't make sense, as type 2; and on the level that it can lead to a paranoiac circle of anxiety and control rather than a relief, even if you accept the semantics of risk-management, as type 1.

Regarding these 'side-effects' of genetic testing, it is the more to be criticized to *make* people responsible for their health and to attribute illness to decisions of conduct of life.

Thank you for your attention!

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i **(„Genetisches Beratungsgespräch**

Die Entscheidung für oder gegen eine molekulargenetische Untersuchung des BRCA1- und BRCA2-Gens ist nicht einfach zu treffen. Um den Frauen eine Entscheidungsgrundlage und eine Entscheidungshilfe zu geben, wird vor jeder molekulargenetischen Untersuchung ein ausführliches genetisches Beratungsgespräch durchgeführt. Nur die Frau selbst kann entscheiden, ob eine molekulargenetische Untersuchung für sie sinnvoll ist.“)

ii („also ich würd es jedem empfehlen den test zu machen, der in diese risikogruppe gehört, (...) einfach weil ich es gut finde über die dinge die in mir drin sind bescheid zu wissen, und wenn da in mir drin 'n risiko is, dann bin ich eigentlich die erste die's wissen sollte, und ähm damit ich auch damit umgehen kann, ganz egal wie ich dann damit umgehe, (...) und ich denke das risiko es nicht zu wissen und sich dadurch unnötich angst zu machen is so hoch.“)

iii („weil also wenn ich weiß ich hab n risiko von maximal achzich prozent das is verdammt viel; //mhm// dann=dann macht es keinen sinn regelmäßig alle drei monate zur kontrolle zu gehn. da macht es wesentlich mehr sinn wenn ich dann wirklich mal was gravierendes mach.“)

iv (“das war absoluter Zufall”)

v („Ich hab' da nicht groß drüber nachgedacht.“)

vi („ich geh' auch nicht mehr in die uniklinik nach b-stadt zu den ganzen äh untersuchungen, weil da is //mhm// jedesmal 'nen anderer assistenzarzt da, da is, da ich hab' überhaupt keinen Ansprechpartner, (...) ich brauch' einfach jemand, dem ich vertrauen kann

//mhm//, wo ich weiß, der kennt mich, der kennt meine akte, der weiß genau, meine gynäkologin die entscheidet, wann ich zur mammographie geh', die entscheidet OB ich das mach oder ob ich das NICHT mache und ich geh' halt jetzt alle halbe jahr, zur voruntersuchung“)

vii („dann ich mein' ich frag' dann 'nen *arzt*, ich *bin* ja kein *arzt*, //mhm//, ja was empfehlen 'se denn, oder was soll ich denn jetzt machen, und dann sacht der zu mir, in meiner achtmonatigen erfahrung, //(lacht)// reagieren die frauen meist so und so. und da hab' ich 'nen angeguckt //(lacht)//und hab'ich gesagt, alles in ordnung hab' ich gesagt, (...) ich geh' zu meiner gynäkologin.“)