Developing a health-related understanding of lifestyle direct-to-consumer genetic testing by users

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Wiebke Sick
Die Macht der GENE

Wiebke Sick


Focus, 22.12.2018, no. 52, pages 84-90 / WISSEN

Bunte, 01.06.2017, no. 23, page 58 / Lebensart_Beauty

Hamburger Abendblatt – Hamburg, 14.09.2019 page 1
Introduction

- Direct to consumer (DTC) genetic tests are usually sold online without consulting physicians
- Predictive genetic tests on disease risks or lifestyle genetic tests without medical purpose
- Pro: Enables changes in lifestyle (Guasch-Ferré et al. 2018)
- Con: may provoke anxieties (Su 2013)
- Clinical benefit questionable (Bates 2018; Covolo et al. 2015)
Situation in Germany

• Genetic testing for medical purpose is restricted to medical professionals
• Increased media coverage in the last few years
• Sold online or by consultants
  • Hybrid of an user and a commercial provider

https://www.cogap.de/de/
Procedure of use

Order at consultant
Cheek swab
Lab analysis
Receiving of report
consulting

Source: Deine DNA. Deine Diät. MetaCheck fitness. Musterauswertung zu Trainingszwecken.
## Sampling

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<th>Customers</th>
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<td>Personal Trainers</td>
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<td>Sales associate</td>
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Documentary Method (Bohnsack 2010; Nohl 2010)
Visualisation of genetic information of the body

- Genes as basic information of the body
  - Individuality
  - Unalterability
  - Determining and absolute
- Central role of genetic testing in gaining of knowledge about the self

- Visualising with technical device (genetic test)
  - Seemingly objective and scientific representation (Duttweiler 2018; Lupton 2016)
  - Allow informed decision
  - Control (Ruckenstein 2014)
Using the lifestyle genetic test

### Consultants
- Diagnosis
- Optimising

### Customers
- Efficiency
- Service
- Weight loss
- Healthy living
- Impression of control over diseases
- Display of genetic family traits
Using the lifestyle genetic test

Consultants

- Diagnosis
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Customers

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Wiebke Sick
Healthy living and optimising

but (. ) I think you do it only once in a lifetime, and then you really know (. ) if you eat something, if it's sugar or if it's fat or if you know it's high-carb; you know it's good or not; (. ) and I found that pretty exciting //mhm// and positive and then I actually started to tell my customers about it,

(Interview G, consultant; paragraph: 2; translation by the author)

and with that I noticed that people (. ) suddenly (. ) have changed the quality of life completely and really, they were- came back with feedbacks saying wow I am fully awake or I feel fully comfortable or I can sleep well again, um and they find it totally easy to do that

(Interview G, consultant; paragraph: 8; translation by the author)
Impression of control over diseases

I've already dealt with genetic analysis in another context and for example froze my father’s blood, //mhm// because my father is suffering from Alzheimer's disease, [...] and uhm I wanted to have the health insurance company pay me the test to see if I also have the predisposition to it; //yes// right one can have this checked on the basis of genetic tests on the basis of //mhm// of the blood of the father, that is of the sick person in the family in the previous generation and it would be great if we also had something of my grandmother from the previous generation; because she also had a very strong dementia of old age; [...] yes and that was also still the focus to see if you can perhaps find out by a DNA analysis in the field of nutrition how you can nourish perhaps already prophylactically //yes// to simply push it to the back;

(Interview O (customer); paragraph: 6; translation by the author)
References

- Covolo, Loredana; Rubinelli, Sara; Ceretti, Elisabetta; Gelatti, Umberto (2015): Internet-Based Direct-to-Consumer Genetic Testing: A Systematic Review. In *Journal of Medical Internet Research* 17 (12), e279. DOI: 10.2196/jmir.4378.
Building of “data doubles”

- Separating of the human body in data streams (Haggerty und Ericson, 2000)
- Generating actionable knowledge