

The appropriation of disease

**Educational analysis of so far hardly noticed
learning processes**

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Introduction

In our globalized world, medical knowledge has grown continuously. On the Internet, this knowledge is – filtered and with a time lag – also available to patients.

Nevertheless, interested patients have to cope with their disease completely on their own.

The first learning process of diseased individuals is to appropriate the disease: Only after the affected individuals learned that they have a certain disease, or are ill, further learning processes can take place in the context of the disease.

Introduction

How this appropriation process takes place was developed in my doctoral project.

⇒ “***Disease as a teacher?***“ (*Seltrecht 2006*)

On this basis, the same material supplemented by newly collected data was (re-)analyzed in a follow-up project supported by the German Research Foundation (DFG) .

⇒ “***Lifelong learning in the context of life-threatening diseases***“ (cf. *Nittel/Seltrecht 2013*)

With this study the “chronology of disease appropriation“ could be confirmed. In addition, a comparative comparison of breast cancer and heart attack allowed for more differentiation.

“Disease as a teacher?”

Project “Disease as a teacher” (Seltrecht 2006)

| | | |
|----|--------------------------|---|
| 1. | Questions | <p>Where in life is a breast cancer disease located in one's life-history?</p> <p>What learning phenomena emerge in the context of the diseases?</p> <p>What consequences do the learning phenomena have for the identity of the image of oneself and the world?</p> |
| 2. | Object | <p>Biographies of diseased individuals:</p> <p>20 women suffering from breast cancer</p> |
| 3. | Survey method | <p>Autobiographical narrative interview</p> <p>(Schütze 1983)</p> |
| 4. | Evaluation method | <p>Narrative structural procedure</p> <p>(Schütze 1983)</p> <p>Grounded Theory</p> <p>(vgl. Strauss 1991)</p> |

Results I

Chronology of disease appropriation (cf. Seltrecht 2006)

| | | |
|----|--------------------------------|---|
| 1. | "having cancer" | subjective pain without medical categorization |
| 2. | "having cancer" | external (medical) characterization |
| 3. | "having cancer" | cognitive appropriation of the disease |
| 4. | "being ill with cancer" | physical and emotional appropriation of the disease |
| 5. | "being ill with cancer" | differentiation pattern: "world of the affected" vs. "world of the non-affected" |
| 6. | "had cancer" | self-positioning |
| 7. | "had cancer" | external (medical) characterization |

Comparative comparison of breast cancer and heart attack

As this chronology of disease appropriation was developed on the basis of just one life-threatening diseases it had to be verified by adding another life-threatening disease.

⇒ “*Lifelong learning in the context of life-threatening diseases*“
(cf. Nittel/Seltrecht 2013)

“Lifelong learning in the context of life-threatening diseases“

| Project “Lifelong learning in the context of ...“ (cf. Nittel/Seltrecht 2013) | | |
|---|--------------------------|---|
| 1. | Background | - based on the study „Disease as a teacher?“ - funded by German Research Foundation (DFG) - 2009-2012 (realization: Nittel/Seltrecht) |
| 2. | Questions | The project aimed at clarifying further research questions on learning in the context of life-threatening diseases. |
| 3. | Object | The research design of the project was similar to that of the doctoral project, but enclosed an additional comparative perspective: Both women and men suffering from breast cancer Both women and men experienced a heart attack (13 re-analyzed+57 newly collected= 70 interviews) |
| 4. | Survey method | Autobiographical narrative interview |
| 5. | Evaluation method | Narrative structural procedure, Grounded Theory |

Results II

- ⇒ *Breast cancer and heart attack are among the most diseases and the most frequent causes of death.*
- ⇒ *Biological differences become apparent in the physical impact (invasive cross-organ cell growth vs. body cells die // loss of something vs. addition of something)*
- ⇒ *Differences between breast cancer and heart attack are also characterized by the period of time passed until a doctor is seen.*
- ⇒ *The treatment procedure following the medical diagnosis of heart attack or breast cancer is characterized by processes of both healing and suffering (for instance: amputation of a breast or hair loss due to chemotherapy)*
- ⇒ *And also after the acute treatment phase has ended the disease still affects the life situation.*
- ⇒ *From a medical perspective, both diseases are of significance in the long run.*
- ⇒ *The second project provided confirmation of the main underlying principles of the “chronology of the disease”.*

Outlook

The detailed examination of the disease of the appropriation process has so far not been part of an educational research project. However, the results bring two phenomena to attention

1. *On the one hand, it becomes apparent that the public discussion about diseases or their early detection has an impact on how people act when noticing something unusual about their bodies. Learning processes induced by enlightening information contribute to self-care and the consultation of a doctor.*
2. *On the other hand, it becomes apparent that the appropriation of a disease is a subjective process that – irrespective of all kinds of technical support for learning (online-research, internet platforms etc.) – follows its own speed.*

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