

Phenomenology of Bodily Integrity in Disfiguring Breast Cancer

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Outline

1. The meaning of bodily integrity (etymology, feminist theory, medical ethics)
2. Phenomenology of bodily integrity
3. Bodily integrity in breast cancer care

What is bodily integrity?

- According to its etymology it has a double meaning:
 - 1. *Integrum* = wholeness, unity, intactness
 - 2. *In-tangere* = not touching, not hurting
- Bodily integrity = respect for a certain wholeness (normative counterpart of actual vulnerability).

Bodily integrity in feminist theory

- Often emphasis on specific issues/interventions related to female body: rape, reproductive autonomy, abortion, opportunities sexual satisfaction.



- Often politically motivated (human rights, fair distribution of health care).

Bodily integrity in current medical ethics

PRIMUM
NON
NOCERE



- Since 1970s shift from "*primum non nocere*" approach to "principlist" approach (Beauchamp and Childress 1979).
- Emphasis on autonomy (liberal stance)
- Respect for bodily integrity = respect for personal autonomy.
- Bodily integrity secured by (informed) consent.

A normative principle in its own right

- Liberal stance is limited
- Bodily integrity is not just about giving permission to intervene.
- Normative principle: does not only refer to one's actual body but to the inviolability that *should* be secured; "ethical fiction" (Zwart 2000).
- Ethical – religious ideas about integrity



Phenomenology of Integrity

- *Experience* of wholeness.
- Following De Beauvoir (1948) and Merleau-Ponty (1945): bodily integrity is affected if one's engaging in the world ("I can") is disturbed.
- However, a disfigurement not necessarily affects one's "I can", but still may affect one's experience of wholeness.

Phenomenology of embodied self-experience

- Phenomenology of self-experience (Husserl, Merleau-Ponty):
 1. Experience of one's body as an object or thing (perspective, adumbrations): *Körper, corps objectif*
 2. Experience of one's body as lived and "hereness" (localized sensations, no adumbrations): *Leib, corps vécu*

Having and being one's body

- Körper experience: distance toward oneself, no coincidence, (strangeness), body one *has*.
- Leib experience: experience of me-ness and hereness (ownness), body one *is*.
- Experience of bodily integrity: being the body one has (identification with the body such as it appears according to its Körper perspective).

Not being able to be the body one has

- Psychiatric:
 - BIID



- Psychological/phenomenological:
 - Experience of strangeness in one's own body which is hard to bear (negative emotions/feelings, e.g. shame).

Evaluation of body experiences in breast cancer care

- “Body image” evaluation in clinical trials, mainly based upon quantitative tools, such as BIS (Body Image Scale):



Pictures Sjaak van Beek

BIS: In this questionnaire you will be asked how you feel about your appearance, and about changes that may have resulted from your disease or treatment. Please read each item carefully, and place a firm tick on the line alongside the reply which comes closest to the way you have been feeling about yourself, during the past week.

1. Have you been feeling self-conscious about your appearance?
2. Have you felt less attractive as result of your disease or treatment?
3. Have you been dissatisfied with your appearance when dressed?
4. Have you been feeling less feminine/masculine as a result of your disease or treatment?
5. Did you find it difficult to look at yourself naked?

6. Have you been feeling less sexually attractive as a result of your disease or treatment?

7. Did you avoid people because of the way you felt about your body?

8. Have you been feeling the treatment has left your body less whole?

9. Have you felt dissatisfied with your body?

10. Have you been dissatisfied with the appearance of your scar?.

Reply ratings:

Not at all (score 0)

A little (score 1)

Quite a bit (score 2)

Very much (score 3)

(Hopwood, Fletcher, Lee and Al Ghazal, 2001)



Shortcomings of current “body image” evaluation

- “closed” questions; negative phrasing forecloses positive expressions.
- “body image” reduced to actual appraisal of one’s body; lacks temporal dimension.
- Practice: evaluation only after interventions.

Normative dimension of body experience evaluation

- Evaluation of experience of bodily integrity by means of “body-biography”; making explicit temporal horizon against which people construe their identity/integrity.
- Practice: prior to interventions to support decision-making (which intervention fits best a patient’s experience of bodily wholeness?)



Future research

- Development of a vocabulary of body experiences that can be used as a basis for prospective “joint narrative work”
- Empirical-phenomenological research: how do breast cancer patients and survivors express experiences of bodily wholeness or loss of bodily wholeness?



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Thank you for your attention !