

Aesthetics and the impact of technical aids



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What are the effects of the appearance of an aid on the lives of users?



Standard idea:

- Stigma-effect: the aid refers to and magnifies impairment (*impairment* becomes *disability*)
- Aid is a symbol for being handicapped
- Can be a reason to not use the aid or to hide it
- Aid-users passively endure stigma



Our research



27 biographic interviews with users of hearing aids, incontinence products or arm prosthesis

Focus was on the role of medical aids in mechanisms of in- and exclusion

So how do people actually deal with stigma?

They tinker with the appearance of their medical aids!

Questions



- How do users tinker with the appearance of an aid?
- And how does such tinkering change the experience of the impairment and of disability?
 - Needed: Concepts to understand the effects of aesthetics in everyday situations
 - Theoretical perspective: anthropology of art

Alfred Gell: anthropology of art



- On the power of art objects
- *Distributed agency/ personhood:*
 - Your personhood and your influence are not limited by your body.
 - In all objects that you cause (by making, buying, owning or carrying it) your agency is enclosed.
 - In this capacity, objects, as secondary agents, can exert influence on others

The neighbours' Ferrari



Alfred Gell: anthropology of art



- But, an object is not the result of the acts of one person, but of multiple heterogeneous actors
- Though its impact (on an onlooker) often derives from just one of those actors

Portrait of King Willem Alexander



Picture by Erwin Olaf



Impact portrait caused by:



- **Causes :**
 - Qualities of the painter
 - Power of the portrayed
 - Art genre
 - Commissioner
 - Owners
 - Life course of the portrait
- **Impact can be any of those**

What about medical aids?



- Distributed agency can also take place unwantedly, like with a medical aid

Agency/ AID



- **Causes**

- Impairment (missing limb, incontinence, limited hearing...)

- **Unintentionally an aid often refers to just one cause: the impairment.**

- The impact of the aid is determined by the impairment.

- The person who uses the aid can 'become' the impairment in the eyes of an onlooker (and sometimes themselves)

Agency/ medical aid



- However, the aesthetics of an object can be tinkered with by the user, emphasising other causal relations

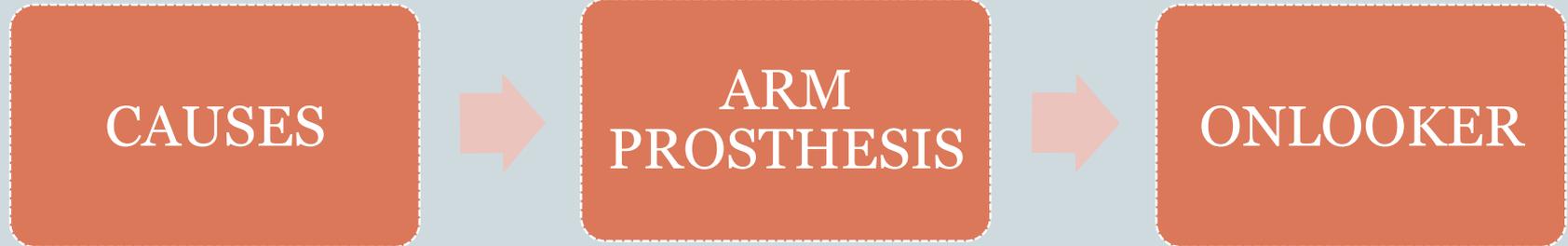
An example: Wim's robotic arm



- Wim: 'I like emphasizing the mechanical side of the artificial arm. I have asked for a decoration on the arm of the mechanics inside. As if it is a real robot arm.'



Impact appearance arm prosthesis Wim

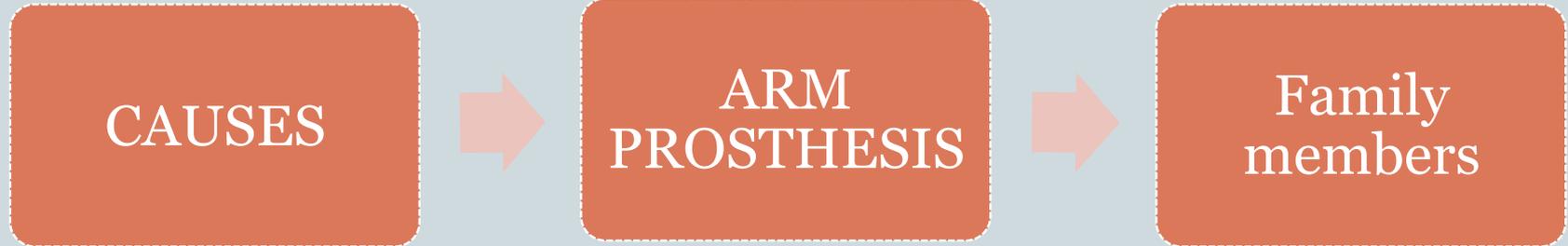


-Causes

- Wim's technological expertise
- His history with the manufacturer
- Impairment/ accident

-But this does not always work

Impact appearance arm prosthesis Wim



- Causes
 - impairment

The impact of an aid is situational

Technical aids that are not public: incontinence material



- Incontinence is associated with being incompetent, not being able to take care of yourself, not having self discipline, not being an adult, being impure.
- The taboo is big and in the public domain hiding is the only option
- Thus: incontinence material should first and foremost be invisible.

Incontinence material: invisible



Causes:

- Incontinence

Hardly any options to diversify causal relationships towards onlooker

And for the users themselves?



-Causes

-Incontinence

Tinkering possible ?



-Causes

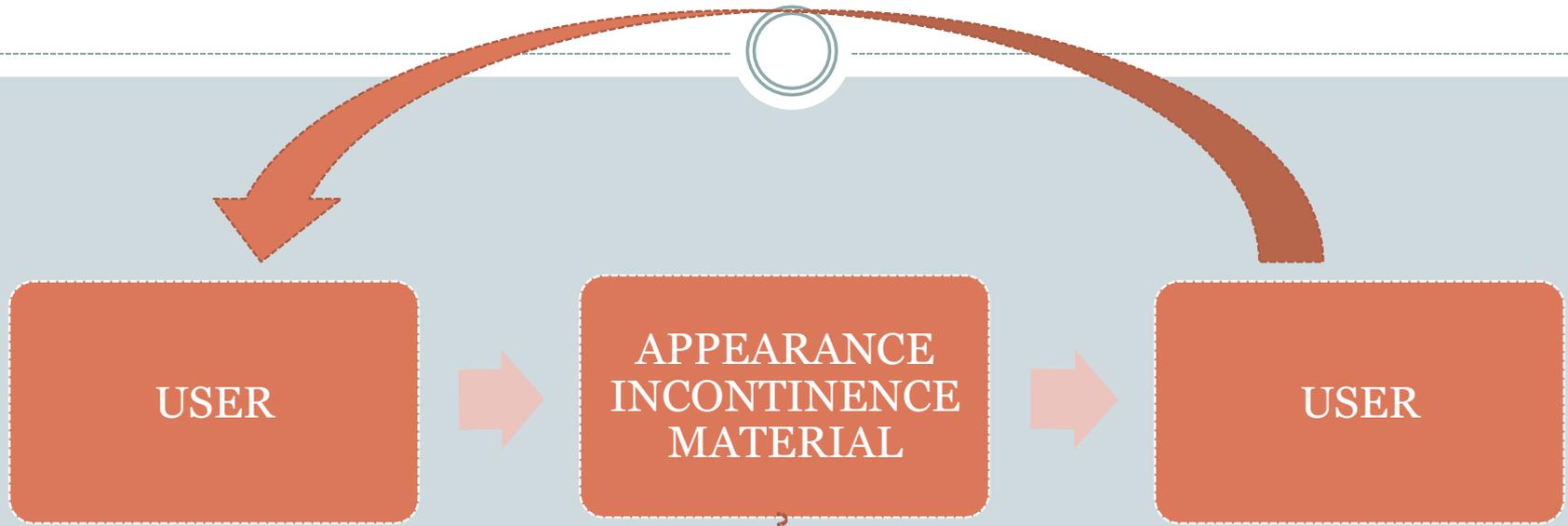
- Incontinence
- Agency/personhood of the user?

Tinkering with incontinence material



- ‘I was a young woman of 19 years, just discovering my own femininity.’ This was incompatible with incontinence. By cutting the material the two could be reconciled.
- ‘They do not know what’s in the bag’: material in nice Samsonite bag.
- Suggestion: More appealing colours and design of products
 - I am worth something as a user

Effects on impairment and disability



Tinkering with appearance is not always directed at onlookers. It might affect users themselves as well as their relation to the impairment.

Contribution to Disability Studies



- Moving beyond the notion that the appearance of medical aids simply magnify the impairment
- and that their users passively endure the resulting stigmatisation



Summary (1)



- In our interviews we saw several people tinkering with the appearance of their aids.
- With Gell's models and the concept distributed personhood you can clarify
 - The effects of such tinkering
 - Whom they affect
 - Whose personhood/ agency is distributed in the aid

Summary (2)



- By tinkering with the appearance, the user often introduces new causes of impact other than the impairment.
 - The aid looks this way because he/she wanted it to.
- Sometimes this tinkering is directed at an onlooker, sometimes at the self
- At the same time, through the tinkering with the aid, the relationship with the impairment and the experience of ‘disability’ changes as well