Re-thinking network theory

The influence of informal networks on social care in the internet age

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Research topic

- My PhD research programme concerns: ‘completeness and accessibility of care for people concerned with genderdysphoria’. (more popular: transgender and transsexual care.)

- Transsexuals manage multiple networks. Many of those networks they do not have any previous experience with.

- An important role in gender transition is played by peer networks like internet communities for knowledge sharing and mental support.

- No research is available on if and how these peer networks influence the real life networks these people live in.

- Case stories show influence of peer networks on major transition questions like:
  - changing and managing social networks
  - selecting medical treatment and doctors
  - strengthening of social position and self esteem
Networks involved: overview

The following networks are involved from a ‘patient’ perspective:

- **social networks of the patient**
  - family
  - friends
  - sports and other social networks

- **professional network of the patient**

- **medical networks**
  - medical care: doctors (endocrinologists, surgeons, general physicians, voice trainers)
  - psycho-social care (psychologists, psychiatrists)
  - social care: social workers including voluntary aid workers

- **peer group networks**
  - self aid groups
  - online communities

- **legal network**
  - court of law
  - local community

- **spiritual and religious networks**
  - church and other spiritual or religious communities

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The average network of a transsexual during his / her transition influencing daily life probably doubles. Still most of them feel left alone for most of the process.
Networks involved: a simple visual representation

- **Medical network**
  - Surgeons
  - Psychologists
  - Endocrinologists
  - Speech trainers

  **Surgery**
  - Treatment

- **Legal network**
  - Lawyers

  **Legal gender change**

- **Professional network**
  - Customers
  - Managers
  - Co-workers

  **Work**
  - Learning

- **Peer Group network**
  - Companions

  **Group meetings**

- **Social network**
  - Friends
  - Family

  **Friendships**
  - Sports
  - Social act's

- **Spiritual network**
  - Pastor

  **Companions**

  **Internet fora**

  **Individual meetings**

  **Pastor**
Network linking

Many of the fore mentioned networks are interlinked. Either by formal process links or informal content links.

For example:

- the family network is usually interlinked with medical networks thru process links (protocol) and is interlinked with peer group networks thru content (peer support)

- the medical network is interlinked with the legal network thru process links (law) and is interlinked with peer group networks thru content (influencing patients treatment choices)

Some links between networks are hidden for some of the actors.

For example:

- the medical network is not aware of the influence of (and has no access to) peer group networks on the patient’s choices and opinion on the medical network and individual doctors. (people frequently ‘flee’ from treatment in the Netherlands based on information shared within internet communities on track records of specific surgeons.)
Networks involved: some hidden links

Professional network
- Customers
- Co-workers
- Managers
  - Work
  - Learning

Social network
- Friends
- Family
  - Friendships
  - Sports
  - Social act's

Peer Group network
- Companions
  - Group meetings
  - Individual meetings
  - Internet fora

Medical network
- Surgeons
  - Surgery
- Psychologists
  - Consults
- Speech trainers
  - Training

Endocrinologists
- Treatment

Legal network
- Lawyers
- Legal gender change
Networks involved: some hidden links

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Networks involved: some hidden links

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**Peer Group network**
- Friends
- Group meetings
- Individual meetings

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- Lawyers
- Legal gender change

**Social network**
- Friends
- Sports
- Social acts

**Spiritual network**
- Pastor

**Internet fora**
Network research domain

Medical network
- Surgeons
- Psychologists
- Speech trainers

Peer Group network
- Companions
- Internet fora
- Individual meetings
- Group meetings

Social network
- Family
Possible ‘missing link’ effects

So what are expected effects of the hidden or missing link between for instance the medical and the peer group networks?

- Increase of alternative treatments outside the Netherlands
- Possible reputational damage to medical workers
- Decreasing knowledge within the medical network on extend and demography of the group involved
- Decreasing knowledge within the medical network on developments within the group involved (e.g. shift in gender thinking from gender dichotomy to gender continuity)
- Possible mismatch between treatment offered en desired
- Possible decrease of treatment in the Netherlands
- Possible decrease of medical budgets
Challenge: networks found when life is incomplete...
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No work
Challenge: networks found when life is incomplete...

No work

Legal network
- Lawyers
- Legal gender change

Medical network
- Surgeons
- Psychologists
- Endocrinologists
- Speech trainers
- Treatment
- Training
- Surgery
- Consults

Peer Group network
- Companions
- Group meetings
- Internet fora

Social network
- Friends
- Friendships
- Sports
- Social activities

Professional network
- Customers
- Co-workers
- Managers
- Work
- Learning

Legal network
- Lawyers
- Legal gender change

Spiritual network
- Pastor

No spirituality

Medical network
- Surgeons
- Psychologists
- Endocrinologists
- Speech trainers
- Treatment
- Training
- Surgery
- Consults

Peer Group network
- Companions
- Group meetings
- Internet fora

Social network
- Friends
- Friendships
- Sports
- Social activities

Legal network
- Lawyers
- Legal gender change

No work
Challenge: networks found when life is incomplete...

- **Medical network**: Surgeons, Psychologists, Endocrinologists, Speech trainers, Treatment, Training, Surgery, Consults
- **Peer Group network**: Companions, Group meetings, Internet fora
- **Social network**: Friends, Family, Friendships, Sports, Social activities
- **Legal network**: Lawyers, Legal gender change
- **Spiritual network**: Pastor

No work

No peers

No spirituality
Challenge: networks found when life is incomplete...

No work

Medical network
Surgeons
Psychologists
Endocrinologists
Speech trainers
Treatment
Training
Surgery Consults

Peer Group network
Companions
Group meetings
Internet fora
Individual meetings

Social network
Friends
Friendships
Sports
Social activities

Professional network
Customers
Co-workers
Managers
Work
Learning

Legal network
Lawyers
Legal gender change

Spiritual network
Pastor

No spirituality

No peers

Legal network
Lawyers
Legal gender change

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often seen...
Other challenges

- How to separate valid and non-valid information transferred through online communities?
  - Simple statistical analysis on postings seems not to be enough due to alias-behaviour and differences between online behaviour and opinions compared to those in real life.
  - Does this require specific psychological analysis of content?
- How to analyse and proof influences of online information transfer that effect care processes?
- How to construct a trustworthy overview of hidden links and their effects?
- How to analyse network hub behaviour?
Any questions?

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