Struggling to Catch Up: Families, Identities and Narrative Care

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Personal Identities: A Web of Stories

- Acts
- Experiences
- Characteristics
- Roles
- Relationships
- Commitments
The Practice of Personhood

- Perform who we are
- Recognize others’ performances of who they are
- Respond appropriately to these performances
Holding and Letting Go

- Hold on to the stories that depict the person accurately.
- Let go of stories that used to portray the person properly but no longer do.
Three Cases

- Where the identity has changed radically
- Where the identity lies at the limits of responsibility
- Where the patient has lost her second nature
The Argument

- If health care professionals recognize and respect the familial labor of holding patients in their identities, they improve patient care.
Radical Change
Second-Order Volition

- Endorsing or repudiating a desire
- Wanting (or not wanting) to want something
Wantons

- Act on their desires without reflecting whether they want to act on them
- Lack second-order volition
Changing Your Mind

- Repudiating what you used to endorse
The Wife

- Helps her husband stay true to his lifelong commitments
- Holds him in his identity
- Possibly wants to keep him from complicity in evildoing
Identities at the Limits of Responsibility

- First, some theory: where do our responsibilities come from?
Philosophical Accounts

- “Easy rescue” (the beneficiary has everything to gain, the helper, nothing to lose)
- “Compensatory justice” (I have wronged someone and now owe her something to make it up to her, or have received benefits beyond my due and my acts ought to reflect that)
- Voluntary and informed consent (I promised to help or willingly assumed a certain social role)
But in Families?

- Responsibilities to my children: easy rescue?
- Responsibilities to my husband: compensation?
- Responsibilities to my sister: consent?
Ned and Sam
Sam’s Brotherly Responsibilities

- To consider getting tested
- To recognize Ned as his brother
Justification

- Genetic ties are valued: isn’t that what IVF is about?
- Responsibilities arise from genetic ties and shared history
Second Nature
Second Nature

- Ability to use concepts
- Sense of what is ridiculous, ordinary, similar, different
- Sense of self and of who others are
- Ability to participate in the practice of personhood
Holding in Personhood

- Preservative love: being kept safe from moral harm
The Tragedy of Alzheimer’s

- To become a nonperson
A True Tragedy
No Tragedy?

- For people in advanced dementia, not being held in personhood is no tragedy
  - The goods of personhood are closed to them no matter what
  - They won’t know the difference
Reply to Objection 2: They won’t know the difference

- You can be wronged even if you never find out
  - Rich aunt
  - Jealous friend
Reply to Objection 1: The goods of personhood are closed

- It matters to us now how we’ll be treated later
- We all deserve respect
Health Care Professionals

- Pay attention!
Thank you

This talk is a contribution to the work of the Consortium on the Ethics of Families in Health and Social Care.