

SAMW Tagung „Autonomie und Verantwortung“, 2. Juli 2015

# Solidarität als regulatorisches Konzept in biomedizinischer Praxis und Forschung

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# Kritik am Fokus auf individuelle Autonomie

## Choosing Life, Choosing Death

The Tyranny of Autonomy  
in Medical Ethics and Law

Charles Foster

## Autonomy: A Moral Good, Not a Moral Obsession

by DANIEL CALLAHAN

A major attraction of the concept of autonomy is that it helps to establish moral independence. Not only does it entail that, as an individual, I am to be treated by others as a moral end rather than a moral means, it also requires that they allow me to pursue my own moral goods. Autonomy can thus be understood as the basis for

But if autonomy may serve me in some fundamental ways, what would it be like to live in a community for which autonomy was the central value? What kind of a medical practice might emerge with patient autonomy as the sole goal? Let me try to answer that question by first reviewing some of the benefits of giving moral priority to autonomy. Among them are a recognition of the rights of individuals and

system of values might be best for our individual welfare and desires, then autonomy is a prime candidate. But if we ask what system of values might be best for our life in community, for sustaining a viable society and culture, then autonomy may fare less well.

We need to give some thought to that latter question. Yet, in doing so, we may well grant that the notion of autonomy, especially patient autonomy, has hardly become triumphant in the daily life of medicine; in fact, it is probably still more curtailed or denied than honored. We may also grant the powerful tendency of technological medicine to dehumanize and depersonalize, to efface or erase individuality, to attend to our organs and parts rather than our persons. Nor need we deny that, faced with budget pressures and cuts, individual welfare and freedom of choice

## The Inaugural Address

### AUTONOMY: THE EMPEROR'S NEW CLOTHES

by Onora O'Neill

**ABSTRACT** Conceptions of *individual autonomy* and of *rational autonomy* played large parts in twentieth century moral philosophy, yet it is hard to see how either could be basic to morality. Kant's conception of autonomy is especially different. He predicated autonomy neither of individual selves nor of processes of choosing, but of principles of action. Principles of action are *Kantian* if they are law-like in form and could be universal in scope. If so, then the claims linking morality, reason and autonomy are grossly overstated, and the distinctiveness of Kantian autonomy.

## I

In the last half-century appeals to autonomy have played a major part in ethical and political philosophy. A larger part in ethical and political philosophy is played by advocates of autonomy still disagree about what is most important. At times it seems that they agree that autonomy has a noble, Kantian pedigree that links it to the

It is probably right that Kant links autonomy to morality. He claims both that '*Morality* is thus the relation of the will to the autonomy of the will'<sup>1</sup> and that '*Autonomy* is the principle of all moral laws and of duties in general.'<sup>2</sup> However, I believe that there is little evidence linking between morality and twentieth century

# OBSERVING BIOETHICS

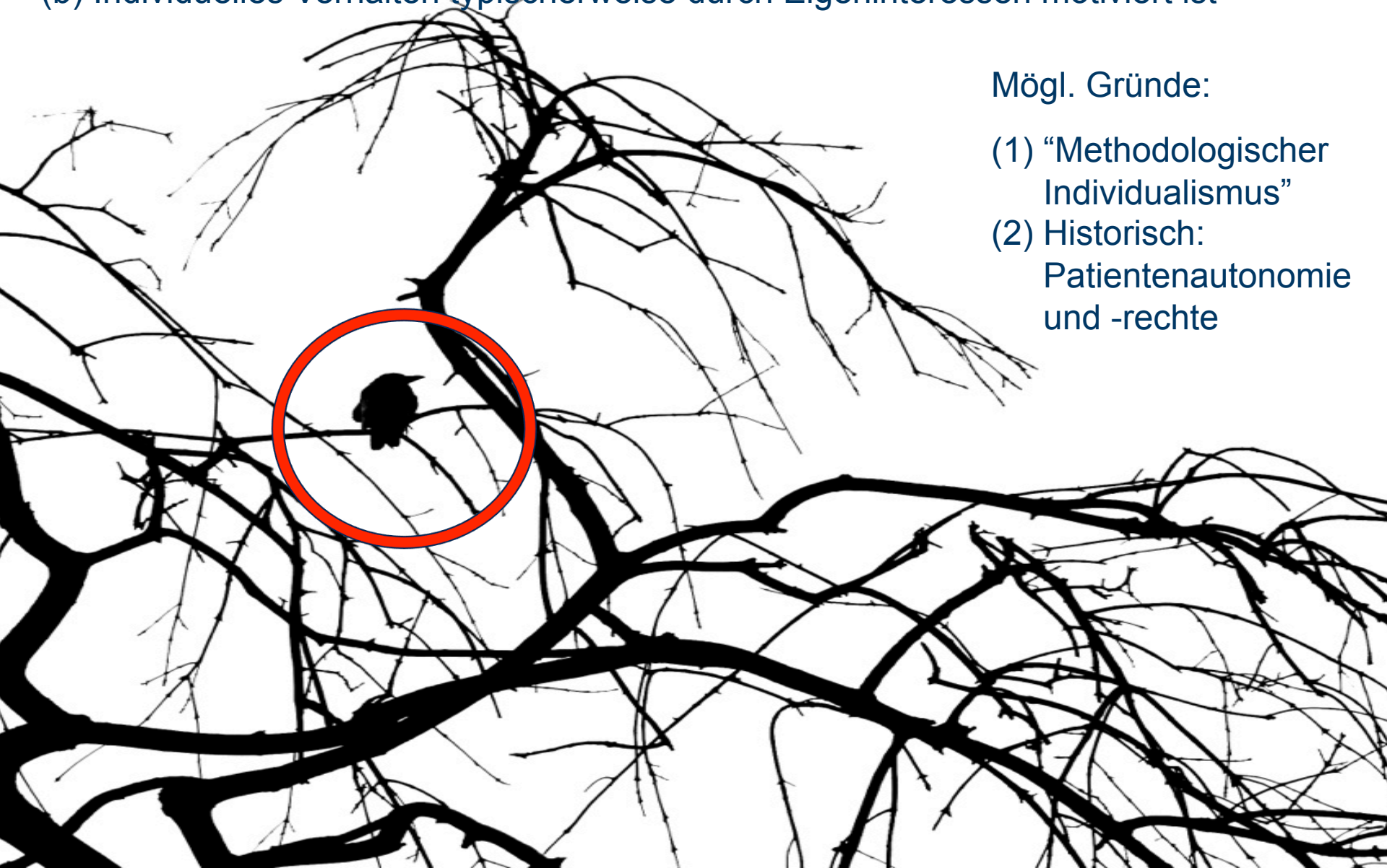


RENÉE C. FOX  
JUDITH P. SWAZEY

Regulation und Policy im Bereich der Biomedizin gehen regelmäßig davon aus, dass  
(a) Entscheidungen von einer einzelnen Person getroffen werden, und  
(b) Individuelles Verhalten typischerweise durch Eigeninteressen motiviert ist

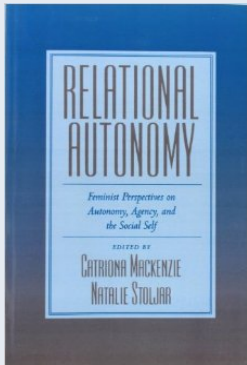
Mögl. Gründe:

- (1) “Methodologischer Individualismus”
- (2) Historisch:  
Patientenautonomie  
und -rechte



## „Korrekturbewegungen“

Theoretisch: neuere  
Debatten um  
relationale  
Autonomieansätze



In der Praxis: Solidarität  
als regulatorisches  
Konzept



Bild: Jan  
Henne

## Was ist Solidarität?

- „Handlungen, um andere zu unterstützen“ (Bayertz 1996)
- „non-calculating cooperation“ (Häyry 2005)
- „ a way of organising social institutions“ (Gunson 2009)
- “the sort of intersubjective relations required to keep the fabric of modern society intact” (Houtepen/ter Meulen 2000)
- „affective disposition to respect and support justice and human rights“ (Gould 2007)
- „moralische Relation von Personen gegenüber Angehörigen bestimmter Gruppen“ (Derpmann 2013)



## Unser Solidaritätsansatz

Manifestationen der Bereitschaft, Kosten zu tragen um anderen zu helfen, mit denen wir Ähnlichkeit in relevanter Hinsicht (an)erkennen

*Solidarity signifies practices reflecting a willingness to carry “costs” (financial, social, emotional, or otherwise) to assist others with whom we recognise similarity in a relevant respect.*

[Prainsack, B., & Buyx, A. (2011). *Solidarity: Reflections on an emerging concept in bioethics*. Nuffield Council on Bioethics.]

# Drei Ebenen der Institutionalisierung

Tier 3 (contractual level):  
legal provisions and contractual norms

Tier 2 (group practices): manifestations  
of collective commitment to carry costs  
to assist others; communities of risk

Tier 1 (interpersonal level):  
manifestations of willingness to carry costs to  
assist others; similarity in relevant respect

Reciprocity



hellblau: Praktiken  
dunkelblau: Institutionalisierung

## Anwendung- und Umsetzungspotential

### Entwicklung neuer Versorgungs- und Forschungsformen

- Verstärktes Integrieren etablierter solidarischer Praktiken in die Versorgung (z.B. Patientenselbsthilfe)
- Entwicklung/Förderung neuer solidarischer Praktiken im biomedizinischen Bereich (Demenzdörfer; Organspende)
- Förderung neuerer Formen partizipativer Beteiligung an Forschung („citizen science“) und Politikentwicklung (Bürgerkonferenzen etc.)

### Umarbeiten existierender Regelungen





## Beispiel: Biobanken der Gesundheitsforschung

- ‚Neue‘ Forschungsbiobanken
- Ggw. Regelungen: Autonomieschutz-basiert
  - Schutz individueller Daten vor Missbrauch
  - Risikominimierung/-vermeidung
  - ‚fully‘ informed consent
- Regelungen reflektieren nicht die prosoziale Motivation vieler Teilnehmer
- Versch. Fehlregulierungen und Praxisprobleme
- Teils problematische Anwendung des Autonomieprinzips; regulatorische Korrektur sinnvoll





## Biobanken in der Gesundheitsforschung

Solidarität als zentrales Prinzip der Beziehung „Teilnehmer – Biobank“ **neben** Respekt vor Autonomie

- Mehr Fokus auf solidarische Bereitschaft der Teilnehmer, Kosten zu tragen → Broad consent
- Bei insgesamt geringen Risiken → von der Risikovermeidung zur Schadensminimierung (harm mitigation funds etc.)
- Privatheit als kollektive Angelegenheit und Aufgabe

[Prainsack B, Buyx A (2013) A solidarity-based approach to the governance of research biobanks. *Medical Law Review* 21/1: 71-91]

## Schlussfolgerungen

### Solidarität als regulatorisches Prinzip

- Hin zur Umsetzung „relationaler“ Autonomie
- Aufwertung der Bedeutung von Beziehungen
- Fokus auf Ähnlichkeiten vor Divergenzen
- Signifikantes korrektives und Umsetzungspotential

## Vielen Dank für Ihre Aufmerksamkeit!

Vielen Dank auch an:

Wolfgang Lieb, Peter West-Oram, Jasper  
Littmann, Graeme Laurie



# Solidarity:

[ Prainsack B, Buyx A (2011). *Solidarity: Reflections on an emerging concept in bioethics*. London: Nuffield Council on Bioethics]

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[ Prainsack B, Buyx A (2014) Nudging and solidarity: Do they go together? *Eurohealth* 20/2: 14-17.

[ Prainsack B, Buyx A (in press) Ethics of healthcare policy and the concept of solidarity. In: Ellen Kuhlmann, Robert H. Blank, Ivy Lynn Bourgeault, and Claus Wendt (eds). *The Palgrave International Handbook of Healthcare Policy and Governance*. New York: Palgrave.

[ Prainsack B, Buyx A. *Solidarity in bioethics and beyond*. Cambridge, UK: Cambridge University Press (2016).