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"Opportunitites and Obstacles

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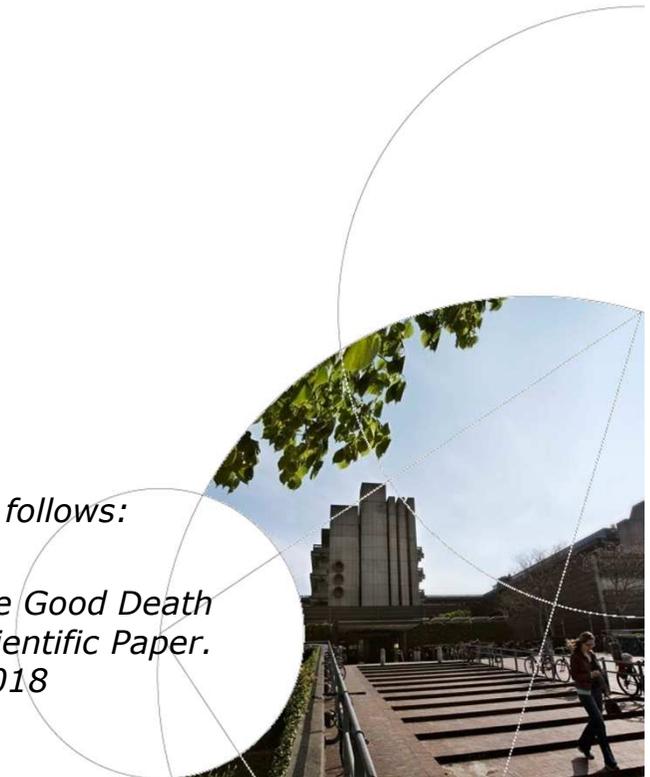
Opportunities and Obstacles: DCD and “the Good Death” among Donor Families and ICU personnel.

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My agenda for the talk:

Donation after Cardiac Death can challenge:

- How we understand the death of an organ donor
- How families can say goodbye
- How staffs perform end of life care for patients and families



This talk: Presents the **opportunities and obstacles** for DCD based on the results of 10 years of anthropological research:

- Among Danish donor families,
- Among Danish non-donor families
- Among Danish Neuro-ICU staffs.

“Good death” = Peaceful, Respectful,
Decision that makes sense for family,
Time to say goodbye, well-informed
Trust, good relation to staffs.



Research Projects and methods

2008-2011: Families who say YES to organ donation

Field studies in neuro-intensive care units (on call 14 months)
 Interviews: 80 family members
 58 doctors and nurses

PHD Funded by Danish Independent Research Councils



2012: ICU Staff and Cardiac Resuscitation of Organ Donors

Interviews: 12 doctors and nurses
 Focus Groups: 4 with 47 doctors and nurses

Funded by Danish Centre for Organ Donation



2014-2017 Families who say NO to organ donation

Interviews: 22 family members
 22 doctors and nurses

Senior Stipend Funded by Danish Heart Foundation



Results: Families who say YES

Brain Death – a **Sensory Paradox**

– The Breathing Corpse

Doubt: is organ donation a decision to let the patient die? (NB: DCD)



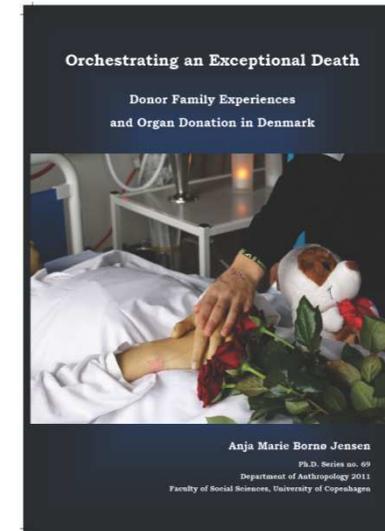
Lack information about the organ procurement

Many families are familiar with brain death and **initiate organ donation themselves**

Are very **happy about the care** they receive (YES AND NO-families)

Families should **NOT be regarded as an obstacle** for organ donation (NB: DCD)

Yes to donation is a way to create “a good death”
– **ORCHESTRATING DEATH**



The Reasons for Saying Yes

Body **not go to waste**: comfort and logic

"The only sense-making in the tragedy"

Organ donation is **about helping others**
AND for the sake of the **donor and**
the family – usable organs provide HOPE

In accordance with personality (helpful)

"Make sure somebody will survive" – **Pride !**

Decision to donate is about creating a **meaningful**
aftermath or legacy for the deceased
(Jensen 2011, 2016)

Jensen, A.M.B. (2016). "'Make Sure Somebody Will Survive From This' Transformative Practices of Hope among Danish Organ Donor Families." *Medical Anthropology Quarterly* 30(3) 378-394

Jensen, A. M.B. (2011). "Orchestrating an Exceptional Death: Donor Family Experiences and Organ Donation in Denmark." PhD Thesis no. 69, Department of Anthropology, Faculty of Social Sciences, University of Copenhagen.



Results: Families who say NO:

They are **very eager** to have a voice in the debate on organ donation !

They are **not against** organ donation

They have many suggestions on how to get more organs



NO IS MEANINGFUL because they feel that is how they can create a **"good death"** for their family.

Yes-families hope to help - The same for no-families

The usable body: *"He was perfectly healthy and in good shape"* – but more important to care for daughter

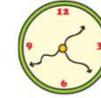


Respect family members *"Actually I am completely Pro-Donation"* - But more important to care for Dad



The Reasons for Saying No

TIME: The time span... longing for closure

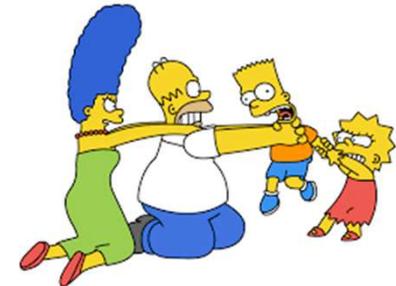


DEATH Need to be present when heart stops

Not *"dying alone among strangers"* in the OP

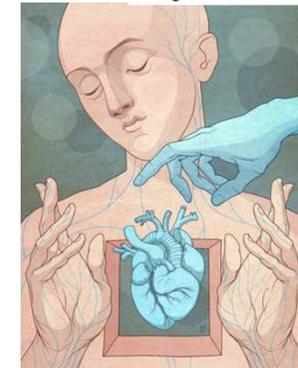


FAMILY RELATIONS: Unknown wishes of the deceased
Family dynamics – agreement, care



INFO The (missing) information - organ donation
as *"a closed door"*

RITUALS Lack of ceremonial alternative
to *"normal death"* – *"how do we say goodbye"* ?



BODY Not to be cut open – being whole (Sque 2013)

Sque, M., & Galasinski, D. (2013). "Keeping Her Whole": Bereaved Families' Accounts of Declining a Request for Organ Donation. *Cambridge Quarterly of Healthcare Ethics*, 22(1), 55-63.



Results: ICU personnel (neuro-surgeons and anesthesiologists)

Different attitudes to organ donation:

- **"A donor is a patient we lost in our department"*
- **"The family said no? – did you ask them again" ?*



Hard to be negative towards donation
AND hard to be TOO positive..... (nicknames)

The shift from patient to donor is challenging
"Dead but not a corpse" (Meyer et al 2008); Jensen 2011)



Aggressive donor management constitute ethical challenges - and creates a need for guidelines
(Hoeyer & Jensen 2013)

Hoeyer K. and A. M.B. Jensen. (2013). "Transgressive Ethics: Professional Work Ethics as a Perspective on 'Aggressive Organ Harvesting'." *Social Studies of Science* 43 (4): 598618.

Jensen, A. M.B.(2011). "Orchestrating an Exceptional Death: Donor Family Experiences and Organ Donation in Denmark." PhD Thesis no. 69, Department of Anthropology, Faculty of Social Sciences, University of Copenhagen.

Meyer, K. and I. T. Bjørk. (2008). "Change of Focus: From Intensive Care towards Organ Donation." *Transplant International* 21: 133139.



Results: ICU personnel (neuro-surgeons and anesthesiologists)

"It's hard asking about donation, its 50 times harder telling the family that donation did not happen"

ICU staff work enthusiastically to make donation happen – know its comforting for families and gives them hope (Jensen 2016)



Very engaged in **family well-being, and care** and will not manipulate to get a YES.

Many work in their spare time to improve or promote donation (ildsjæle)



Some find it challenging to communicate with families on donor management and time span (routine specialized teams)

Jensen, A. M.B. (2016) "Make Sure Somebody Will Survive From This' Transformative Practices of Hope among Danish Organ Donor Families." *Medical Anthropology Quarterly* 30(3) 378-394



If Donation after Cardiac Death ???

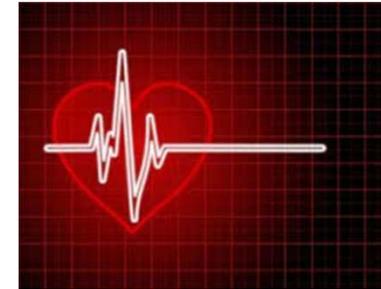
Opportunities:

More potential donors, more families **given the option**

Would provide families with the option of

being there when the heart stops

– more visible, well-known and recognizable death



Would (depending on status of donor patient) allow families **to limit waiting time** towards brain death (DBD – DCD)

Some DBD no-families would perhaps say yes ? – **more organs**

Obstacles:

How can a DCD death and DCD “goodbye” be peaceful ?

DCD protocol can create mistrust among staffs regarding

The boundary between caring for patient and caring for organs

How can staffs inform families about the many new DCD procedures?



Recommendations for moving forward: FAMILIES

Families:

Communication, predictability, TRUST
(Norway: Syversen et al 2017)



Families should be given the option to be with their family member until organ procurement starts (Denmark: DCO-report 2018)

Develop meaningful rituals for a DCD donor, so families feel it is a “good death”
= transfer practices from DBD & educate staff

Make new DCD procedures understandable and trustworthy to the public and to families experiencing sudden grief – new elements in family dialogue



USE DANISH DONOR FAMILIES AS ADVISORS – a Family advisory board

Syversen TB, Sorensen DW, Foss S og Andersen MH (2017): Donation after circulatory death - an expanded opportunity for donation appreciated by families. *J Crit Care* 43:306-311.

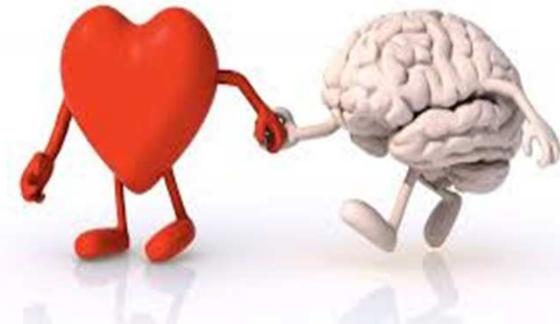
Danish Centre for Organ Donation: Working Group on DCD (2018): Donation after Cardiac Death an estimation of the basis for it in Denmark. Report www.organdonation.dk



Recommendations for moving forward: ICU-Personnel

UK: ETHICS IN DCD IS ORGANISATIONAL ISSUE - A PRACTICAL SET OF PROBLEMS (Cooper 2018)

Acknowledge the change in work practices that DCD constitutes for them – not only “ethics”.



Include ICU staff experiences with DBD when developing DCD guidelines

Introduce new guidelines face to face - Visit departments like the DCO staff

Invite Neuro-ICU staffs to transplant departments – BUILD RELATIONS - TRUST

Be better at communicating transplant outcomes to ICU staffs and have recipients engaged in telling their stories



MAKE SURE INTRO TO DCD HAPPEN IN DIALOGUE

Cooper, J. (2018). Organs and organisations: Situating ethics in organ donation after circulatory death in the UK. *Social Science and Medicine*, 209, pp. 104-110

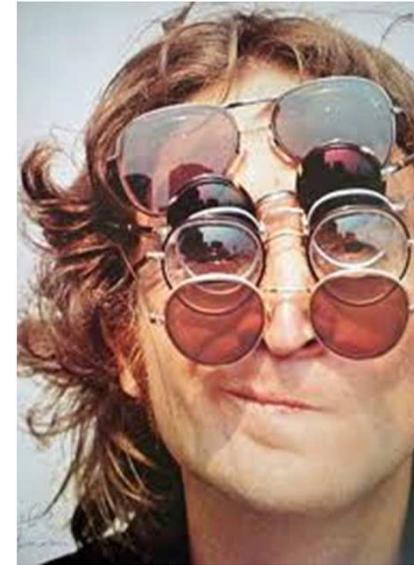


THANK YOU VERY MUCH



Questions and
comments
are welcome

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Thank you to the families who said yes and no, to the doctors and nurses who helped me,
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