Moral distress, trauma and burnout in staff in relation to changes in PICU outcomes, challenging cases and media involvement in disagreements about end-of-life care

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Outline

• Background

• Questionnaire scores

• Main sources of distress

• Recommendations
How I first became aware – press coverage
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Donald J. Trump (@realDonaldTrump)

If we can help little #CharlieGard, as per our friends in the U.K. and the Pope, we would be delighted to do so.

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32,754 Retweets 102,993 Likes
Wider context

• Increasing numbers of children surviving with severe disabilities
• 24/7 social media
• Growing appreciation of stress in health professionals
• Limited financial resources in NHS
• Poor public understanding of science
Questionnaire data
• Moral distress

• Post-traumatic stress

• Burnout
Moral distress definition:

“when you know what the right thing to do is, but you are unable to do it”
Moral Distress Scale – Revised (Hamric et al 2012)
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Considering leaving because of moral distress

- Ever previously left a job for this reason: 9%
- Ever previously considered leaving: 45%
- Considering leaving now: 25%
- Association between feeling unsupported re moral distress and considering leaving: $p=0.01^*$
Post-traumatic Stress symptoms - in relation to case

*p=0.004 considering leaving

15%

Trauma Screening Questionnaire (Brewin et al. 2002)
Most highly endorsed post traumatic stress items on TSQ

Experienced **at least twice** in the past week:

• Q4 “Feeling upset by reminders of the event” **68%**

• Q9 “Heightened awareness of potential dangers to yourself and others” **53%**
Burnout – Emotional exhaustion

*p=0.001 considering leaving

44%

abbreviated Maslach Burnout Inventory
(McManus et al 2002)
Burnout – Depersonalisation

abbreviated Maslach Burnout Inventory
(McManus et al 2002)

17%
Main sources of distress

• Being accused of not caring
• Public condemnation without right to reply
• Fears for own safety
• Witnessing child’s suffering
• Protracted legal proceedings
• Impact on other families
• Constant changes to care plan
Moral distress
Strained relationship with family

Moral distress
Protracted legal process
Strained relationship with family
Moral distress
Intense coverage in media
Protracted legal process
Strained relationship with family
Moral distress
Public abuse and criticism

Intense coverage in media

Protracted legal process

Strained relationship with family

Moral distress
Recommendations

• **Further learning** – communications policy within hospital and public facing; implementation of behavioural contracts with families; staff support structures
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• New mechanisms – to consider moral/ethical aspects of care in regular forum; to trigger extra support in high profile cases and prompt debriefing afterwards
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• **Lobbying** - for improvements in legal process
Thank you for listening