

# How do doctors communicate and make decisions about assisted hydration (AH) at the end of life?

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# Background

- Importance to patients and families
- NICE: *'discuss the risks and benefits of AH with the dying person and those important to them'*
- The reality:
  - Discussions with < 1 in 10 patients
  - Discussions with < 1 in 3 families



# Impact of AH: previous work

## Systematic Review \*

- No studies of high quality and relevance
- Insufficient evidence to draw negative conclusions
- Practice varies with geography and between institutions

What are doctors basing their practice on?

\*Kingdon A *et al*, *BMJ Supportive & Palliative Care* 2020

# Aims

How do doctors **communicate** and **make decisions** about AH at the end of life?

How can we **improve practice**?

# Methods

- Semi-structured interviews with 16 doctors:

Specialties	Palliative Medicine, Geriatrics
Settings	Hospital, Hospice, Community
Grades	Consultant, Staff Grade, Specialty Registrar

- Face to face, or via Zoom, audio recorded
- First 5 transcripts dual-coded
- Thematic analysis as per Braun & Clarke (NVivo software)

# Results

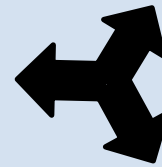
## Society & Culture

The  
“meta-conversation”

Building  
blocks of the  
conversation

Decision-  
making

Learning  
&  
Teaching



# The 'meta-conversation'

- **WHEN** – Timing of conversations
- **WHAT** – Content of conversations
- **WHO** is involved

# The 'meta-conversation': when?

- Multiple conversations frequently required
- Value of proactive discussion
- Early “normalising” of reducing oral intake

**P8:** *If it's never been thought of or discussed at any point and then you're going in the day someone's dying ... and having that conversation for the first time, that's always going to be difficult.*



# The 'meta-conversation': who?

- Most discuss AH with families, not with dying people
- Not routinely incorporated in advance care planning
- Mixed views on these practices

**PI4:** *There are so many situations, even with someone who is extremely palliative, where it would be good symptom control to give them IV fluids... I don't think it's very helpful to have someone say "I definitely don't want to ever have IV fluids," because I don't think you can really give them all the scenarios in which case that treatment might be appropriate.*

# The 'meta-conversation': content

- Discussing AH or discussing “hydration” more generally?
- Hospital / hospice split in practice
- Could discussion in all cases be inappropriate or burdensome?
- Starting vs stopping fluids – importance of trust

**P5:** *I think you might choose to talk about it pre-emptively with some people, but you could individualise it. Whereas if you bring it up with everybody, you might be bringing it up only to immediately shoot the idea down. Basically making it like resuscitation is.*

# Conclusions

- Challenging, ethically complex area of practice
- Importance of early recognition of dying
- Key questions
  - To what extent should dying patients be involved in AH decisions?
  - How to deliver truly individualised care?

# Discussion

- Your experiences relating to AH near the end of life
- Future research – what would be of most value?

**Thank you!**

***For any additional questions, comments or feedback –  
please contact me at [adnk2@medschl.cam.ac.uk](mailto:adnk2@medschl.cam.ac.uk)***

# Additional quotes - communication

***P3:** The first thing is to acknowledge why people might be asking you about assisted hydration and as I say to everybody, food and drink is the essence of life, why would you not question “why can’t I have something additional if I’m not eating and drinking so much?” ... it’s really important to listen to someone and ask why is it that you think that you need intravenous fluids? What is it that’s making you ask for this?*

***P12:** I say to them, you don’t need to make a decision, a lot of what is really helpful is just information gathering... it can just be a sit down, ‘how are things going?’ and just letting people speak and you find out so much information from that simple question... the more they can communicate in a natural way, in a humane way, in a way we’d talk to our family or friends, the easier it will be for them.*

# Additional quotes - communication

**P10:** *One of the most helpful things is to get the patient to voice how they're feeling... an awful lot of people will be able to say "I'm not very hungry" or "I'm not very thirsty"... it's not usually the patient themselves driving for stuff, it's usually their relatives, and once you enable someone to voice that "I don't really want it", then that is I think the most helpful thing, anything said in the patient's voice.*

**P14:** *It's like all difficult conversations. If you go into them task focused, I'm coming to have a conversation about resuscitation, about IV fluids... then you make it harder because you miss the clues from the patient and the family, whereas if you go in with a, "I'm going to have a conversation ... about how they think things are going and what needs to happen next," then you go in with a much more broad angled lens and that way you pick things up.*

# Additional quotes - communication

**P11:** *I don't think I would mention it [AH] to patients... the discussion becomes more relevant when they cannot drink, or when they're not awake enough to do so... in reality, I would suspect that the discussions are mainly with family and when the patients are drowsy or sedate.*

**AK:** *Do you see it [AH use at time of dying] as a failure?*

**P14:** *No, I see a lack of consideration of them as a failure. So if I see a patient who has been recognised to be dying and there has not been any consideration about whether any therapy has been reviewed, then that I see as a failure.*

**P4:** *I find that I'm a lot more proactive now, so even before families bring up I do bring it up myself, and last week for example I had a conversation with a patient who was just completely fatigued and just wanted to be left alone, and his very concerned loving family who were desperate for him to eat and drink, so it was a bit of translating how he was feeling to them.*

# Additional quotes - communication

***P4:** I've seen juniors sort of when people bring up these concerns, be quite certain in their assertion that it's not a good idea, so I think I try and encourage them to explore the thinking that's going on behind patients and families, what are they worried about, what do they hope it'll improve.*

***P10:** My feeling is the assumption should still be that we don't give people parenteral fluids at the end of life, that that is medicalising a normal process and that therefore our job is ... just to enable whoever needs to know to understand that... Explaining that to people in advance is probably overcomplicating things, without wishing to be paternalistic about it.*

***P3:** So it's that openness, that availability and transparency I think that people appreciate... Because I think sometimes people think that you're withholding certain treatments and that you're trying to harm someone but actually the fact that you're being proactive about it usually helps.*



# Additional quotes – decision-making

**P11:** *The dying process is hardest for the family... if I'm comfortable that it's not going to compromise the patient's comfort and I'm concerned that it's going to make the dying process very difficult for the family because they've got to live with all this and they've got to live with their feelings... they've got to be comforted that they've gone into bat for their relatives, I would definitely not draw a line in the sand.*

**P16:** *At that stage we all recognise we're treating the relatives and not the patient... It's not going to do a massive harm, but it's certainly not going to do anything particularly good. And so it's just that reticence to hook people up to bags of fluid that are probably pointless.*

# Additional quotes – decision-making

***P3:** Oh it's such a tricky one isn't it? And you really have to look at it on a case-by-case basis. I would never treat somebody if I, because the family wanted it. I just think there's a line. But it would have to be about the patient themselves, what the risks and the benefits to that patient's health... But it would be a difficult conversation I guess.*

***P10:** Here [hospice] one of the drivers is if that cannula goes in the middle of the night our out-of-hours doctor isn't going to come in and re-site it... whereas in hospitals there's always somebody that can do it, so that doesn't really form part of the decision-making process does it? Arguably that shouldn't form part of the decision-making process but it does.*

# Additional quotes – decision-making

**PI1:** *I know there's not strong evidence for this, but I tend to say that giving hydration, particularly intravenously, increases the risks of respiratory secretions which can make a patient uncomfortable.*

**PI3:** *I don't think I really believe that about the airway secretions and fluids making that worse, I think that's probably an old wives' tale.*