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Ethical issues for staff providing care to people at the end of life

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SOCIAL JUSTICE ETHICAL FRAMEWORK

Interests:

• equity
• individual and collective rights and obligations
• a “fair go”

Aim:

• pursuit of equal and just society

(Charmaz, 2005; Detering et al, 2010; Foster, 2006; Lawrence, 2002; Moore, 2007)
THE STUDY

Questions

- Current Status?
- A Good Dying is? Skills needed?

Method

- Focus Group
- Written response 1:1 Interview

Participants

Residential Care Staff
Found...a lot of ethical issues and a lot of stakeholders....
...his [Donald’s] father is dying but he’s refusing to tell Donald. It’s not our job obviously to tell, or to convince the father either, but we just think it’s sort of morally wrong. Just because he [Donald] has an intellectual disability doesn’t mean he’s not entitled to know…

**ETHICAL DILEMMA**

- Right to awareness?
- Who is obligated to tell?
- When will he be told?

**CONSEQUENCES**

- Client participation in post-death rituals?
- Client’s knowledge of awareness of dying?
[at the hospital]. The doctor said, “Look [the client] he’s NFR. What do you want us to do about it. What did you bring him in for?”

Well! They said that to the wrong person didn’t they, because I got really feral. To me everybody has a right to die with dignity. You wouldn’t have a dog screaming in pain… and I think the medical fraternity have got very little training in disabilities to know that they’ve got as much right as anybody to die peacefully.

Well, I phoned his specialist upstairs and said “I’m down here with Paul, he’s climbing the walls in agony, what do you suggest I do?” and she said “put the Registrar on the phone” …. She ordered morphine …

And I just think that if it was anybody else that didn’t have the guts I’ve got, that guy would have died in horrendous pain.
OTHER CLIENTS

ETHICAL DILEMMA

• Individual versus collective obligations?

• Whose wishes take precedence?

CONSEQUENCES

• Someone is disenfranchised

• Other clients either develop awareness or, remain unaware of dying

As much as our goal is to allow a client who wants to die at home to do so, in the real world it can’t be at any cost...this client is dying and as much as possible you need to meet their needs.

But... these [other] clients are still living and they have lives to go on with. We can’t completely turn their lives upside down around one other person.
They took his brain out... So the person is buried without his brain... and [the Coroner] rings up later and sort of says, “Oh what do you want us to do with the brain?”

And you’ve got to tell that to the family?

POST-DEATH LEGAL SYSTEM

ETHICAL DILEMMA

• Procedural necessity?
• How to relay to family?
• Different but equally important ethical positions?

CONSEQUENCES

• Disrespect of the ritual
• Remembrance of the dead
• Disrespect between professions
[on the topic of respecting wishes] How do I approach him [John, the client]? ...I said, “You know when Alex [John’s friend] died? Remember we went to the funeral, how Alex was in a coffin? ...Coffins go in the ground, or sometimes they make ashes”.

I didn’t want to say “burn” because I didn’t want to frighten him...

It’s trying to find out if he wants to be buried or if he wants to be cremated and how can you explain - “you go under the ground or you fry in an oven”. You know...how to put it?

So that’s the torment…

ETHICAL DILEMMA

• Client capacity?

• Explicit language?

• Protectionism?

CONSEQUENCES

• How do we know he knows?

• Care staff’s social justice “torment”
DESPITE ETHICAL ISSUES...

Every participant affirmed their desire to provide end-of-life care at the client’s home, including the death.
ADDRESSING THE COMPLEXITY....

• This is common in broader aged care community

• End-of-life care = lot of people

• Social justice common ground

• Skills in navigating ethical dilemmas
FOR FURTHER INFORMATION

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REFERENCES