

the
children's
hospital at Westmead



The Sydney children's
Hospitals Network

PERSUASION OR COERCION?

CASENOTES 1

Date	Details
23.2.14	Healthy infant diagnosed at 5weeks with a moderate bilateral SN loss.Pacific islander family
28.2.14	DNA appointment with Australian Hearing
9.3.14	Unresponsive to AH home visit
April x4	Unresponsive to 4 SW calls. Hangs up on some. Takes up offer of 2 nd ABR, but then cancels. Community praying and fasting each Friday
7 May	Inform SW they 'Want to wait. We think he can hear'
21.5.14	Considered to be a case of medical neglect reported to FACS
2.6.14	FACS discusses with SW, and contacts family
4.6.14	FACS then seeks audiological advice

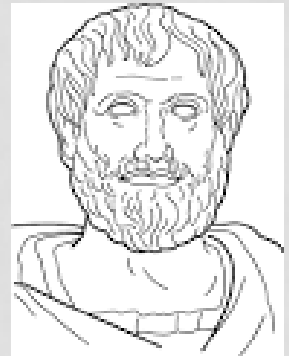
HEALTHCARE ETHICS : 'THE FOUR P'S'

- Autonomy : respect the decision of the person
- Non-maleficence : do no harm
- Beneficence : benefits to outweigh the risks and costs
- Justice : the benefits, risks and costs are distributed fairly

(Gillon,R,1994)

Only a framework, not moral theory

Recent return to Virtue Ethics – 'the golden mean' - Aristotle



HOW TO APPROACH A CLINICAL ETHICAL DILEMMA

- Consider whether principles conflict ,or whether there is uncertainty about what a particular principle (e.g. beneficence, respect for autonomy) directs you to do.
- Construct a question that reflects the conflict.
- Decide which principle should have priority in this case and support that choice with relevant facts , or find an alternative that avoids the dilemma.
- If still uncertain, look for missing information that would help you to resolve the dilemma.

(Rhodes 2007)

ON THE ONE HAND...



PARENTAL AUTONOMY

- ‘Law has strong presumption in favour of parental authority, free from coercive state intrusion’
- ‘Law is a blunt instrument and lacks the capacity to supervise the delicately complex interpersonal bonds between parents and children’
- ‘Clinicians should not make value judgements in the place of parents *when the child’s life is not at stake* ‘

(Diekema 2004)

- “Little in the way of mandatory intervention available” (for non-life threatening conditions) (Menahem 2000)

ON THE OTHER HAND

Family responsibility to

- Maximise the child's autonomy
- Prevent the child from suffering irreversible harm
- Not limit the child's future autonomy 'held in trust'
- Not let their values interfere with what the child might want in the future



(Newson 2006)

SANCTIONS

- Against the law not to send a child to school
- Recent social distancing in US schools for antivac families “state can use its police power in ways that supersede religious and parental preferences” (Yang 2015)
- Australia considers reduced access to Family tax benefit for antivacs
- Would the state ever reduce a family's access to HI Centrelink/Better Start benefits? What about distributive justice ?

INDIRECT FACTORS

- Paradox revealed in a study of behaviourally disturbed kids: parental non-compliance to learning new techniques increased if therapist used directive style .Decreased only slightly if techniques of reframe/support /facilitate were used(Patterson,1985)
- 'Non-presenting symptom': extreme anxiety created by diagnosis causes acute mental pain and in turn leads to withdrawal. Can be furious, argumentative. Compliance=more pain
- Tease out background (previous trauma or recent event?), develop trust and treat non-presenting symptom along with, or before returning to, diagnosis (Menahem 2000)
- 'parental stress can be sustained for at least 2 years after diagnosis' (Hansen 1990)

STIGMA AND SUPERSTITION

- A majority of *teachers* surveyed in Africa and Asia felt that HI children were not capable of developing speech
- Tanzania : punishment from God for sins of this, or previous, generation
- Nigeria: mother is blamed , child often hidden
- China: attitude tends to be deeply negative, parents go on intense search for cure. As well, this 'one child' has to be perfect. If HI, need to prove it's ototoxicity, not congenital , in order to have second baby.

(Stevens 2000)

CASENOTES 2

date	
4.6.14	FACS ring us for advice. I offer to try persuasion
21.7.14	Mo not ruling out amplification: maybe at 12m
5.9.14	Agrees to a 'check-up' VROA, and chat with another P.I. mother
14.10.14	VROA, then conversation between mothers
15.10.14	Mother calls and agrees to fitting
5&19.11.14	Visit and fitting AH
27.11.14	ENT and SW visit CHW. Amiable, compliant
6.1.15	Cancelled MRI, DC, ENT.
Up to now	DNA all AH and CHW appointments.No longer answers my mobile calls or texts.

DISGUISED COMPLIANCE

- Lack of engagement – ‘attendance not the same as participation’ (Roach,2008)
- Paying lip service to the social power of the health professional ; apparent obedience without authentic agreement (Cassell 2005)
- Parents will balance benefits of attending appointments against the costs eg travel/childcare/time off work (Andrews1990)



MY CONTACT WITH TEACHER

- Her contact with mother was pleasant, affable, but not engaged : 'not yet, I will talk to my husband and get back to you...'
- Their experience is that FACS often doesn't apply pressure during the earlier years -they might wait until child is 6y before taking it up with parents
- Knowing this, ITD does not want family pushed away any further , hoping she will 'park' nearby and engage more fully when child starts school



POSSIBLE PI CULTURAL FACTORS

In her experience of many PI families ,

- the extended family provides long term social support
- there is a lower consumption of health care resources
- there can be an acceptance of 'God's will'
- might be praying for a miracle, but can also see a spiritual aspect to carrying the burden
- 'more laid back than we are'

SHADES OF GREY

We are told notification is mandatory as non-compliance constitutes medical neglect, but what about...



- Mild losses
- Deaf Culture
- Oncology
- IWL

'It is sometimes difficult for audiologists to accept anything less than maximum utilisation of auditory potential' (Clark & English 2004)

'CONSTRUCT A QUESTION THAT REFLECTS THE CONFLICT'

- Autonomy : should respect for the parent's decision outweigh child's right to flourish?
- Non-maleficence : does social/emotional harm of taking child from the family outweigh harm resulting from poor speech and language development ?

What do you think?

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