

ARTICULATING TRANSITIONS BETWEEN DIAGNOSIS AND INTERVENTION

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New diagnoses, new modes of life



- Changing diagnoses → new enactments of conditions → new interventions → new modes of living with a condition (for drs and patients) ?

Story 1: early onset puberty



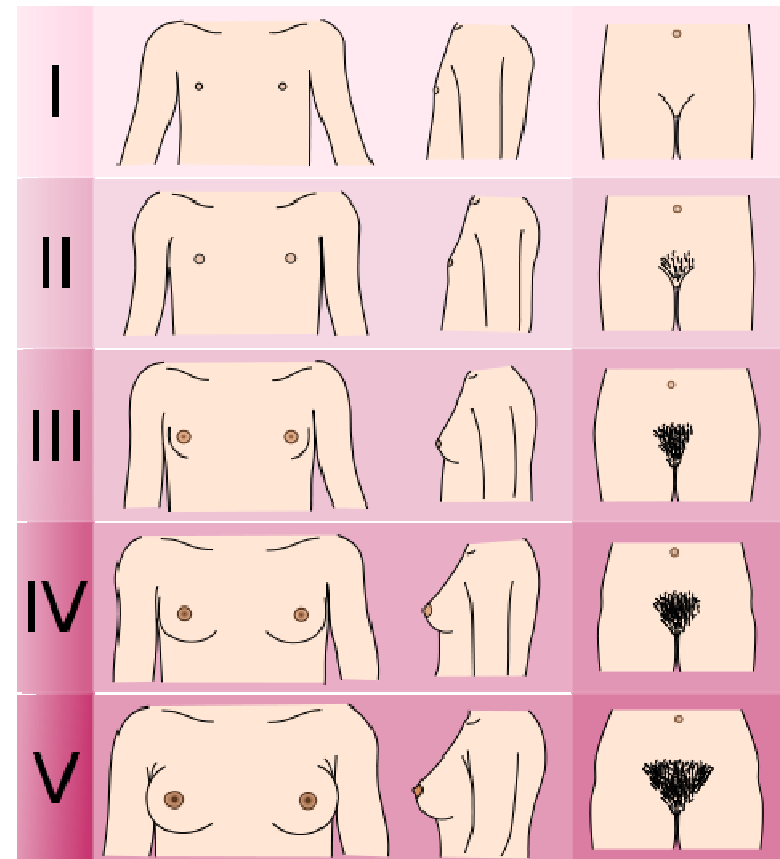
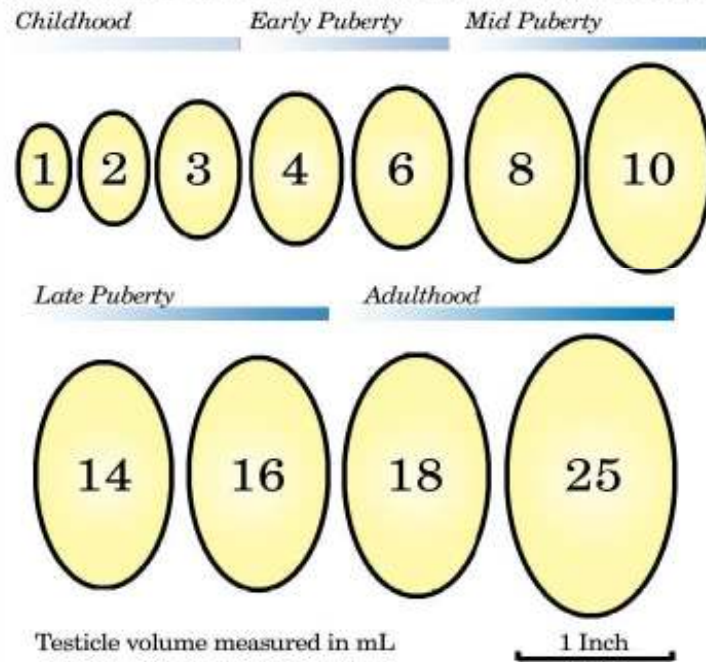
- Widespread concern about increasing rates of early onset puberty globally
- Diagnosis = a highly contested field: how to diagnose, what to count as 'early' and/or 'pathological'

Technologies of diagnosis



Orchidometer

Used to measure testicle size and track sexual development in boys.



- Old techniques but new (ethical) concerns → self assessment
- New definitions → too much/too little intervention? (negotiations between clinicians and parents about how to live with this condition)

What parents should know about CPP

LUPRON DEPOT-PED[®]
(leuprolide acetate for depot suspension)



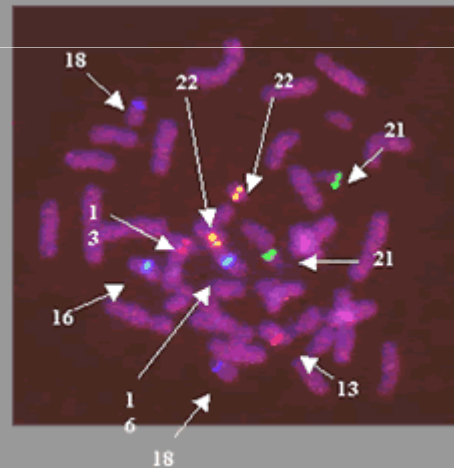
New diagnoses, new responsibilities



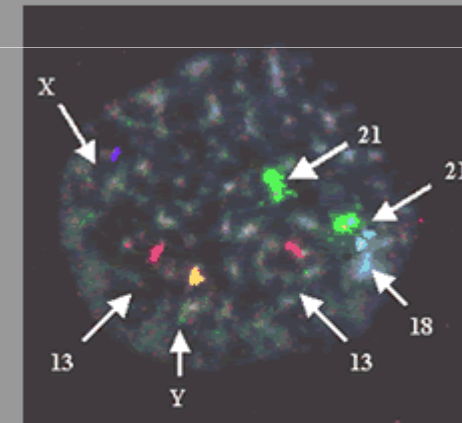
- Do new diagnostic technologies → new organisational practices, i.e. new responsibilities and roles?

Story 2: Preimplantation genetic diagnosis

- New technologies and knowledge → new experience of possible control/ risk management



Control – peripheral blood lymphocytes



Monosomia 18

Liz: ...And it was interesting meeting the geneticists,

... who *explained* things ...in *more* detail and, and

actually, you know, sort of made us aware of the pitfalls... They had all these em-, pictures of embryos to *show* us and because, I mean it's taken me a long time to try and understand FISH, [laugh] because I just [more laughter] (yeah, us too....) [laughter] um, but, you know what was really good was to be *shown* examples of how something can be *just* hiding behind something else and those are things that you just, you know ... When I first sort of discovered it, I thought it would be so *easy*, so *clear cut*, 'cause it *seems* so clear cut, and it was very good to have it explained to us that it's *not*. And that um, some things are very difficult to detect.

Liz: But be-, I was on the one hand very lucky because I have just this *amazing* selection of embryos to choose from...

Celia: So they, and then they chose two.

Liz: They chose two. But it's funny because afterwards my - I got a bit sort of *paranoid* and um, when we had our follow-up appointment with Professor Braude, I was, I was, I had loads of *questions* as you do, and there's an anger there and, you know, but I, a) I had this problem with *why* the progesterone suppositories are not given earlier, and why do you wait till after the implantation, er, the transfer? And I, I couldn't get my head round that. One of the biggest problems for me was how the... *brain* tells the body to start preparing *if* you haven't been fertilised within the body and all that was explained to me.

Anne: We just couldn't go through with another baby with SMA Type 1, we just *couldn't* do it. We couldn't do it to *ourselves*, but we couldn't do it to another of our children, or our family. It would just be a definite no.

Anne: I mean if we was to find out that we was carriers of something else, and we were just going to produce a child that would inevitably be *disabled*, or whatever, we wouldn't *use* PGD. You know, we see it as something that can... prevent children dying, basically, that's why we're using PGD.

Daniel: And it's not even a case of um, I think with SMAs, it's not even a case of 'well they might die'. They *will*! There's no question about it, they will!

Anne: I can understand it is a very grey area. Because obviously...we've used PGD because we didn't want to have another child that was going to die within 12 months. But I mean, ... at what point do you draw the line? At a child that dies at 2 years, 5 years, 10 years, 20 years, 30 years? Where? ... What conditions are we going to allow PGD to be used for?... *I don't know where the line should be drawn.*

New responsibilities



- New responsibilities for parents, patient groups, clinicians, scientists
- New roles connected to the above
- New demands on NHS – balancing needs, benefits, costs (contribution to ‘science’ as well as clinical outcomes)

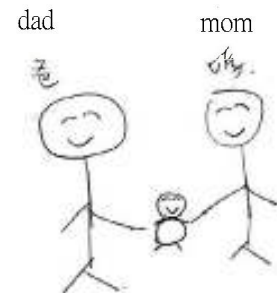
Story 3: Pre-natal ultrasound screening



- Li-Wen Shih: PST in Taiwan
- Desire for a healthy baby and a health system that facilitates 'shopping' → high investment in PST
- New experiences of motherhood: anxiety and pleasure
- Familial responsibilities – folding of old and new



Hong, 28 years old
32 weeks, teacher
Chang-Hsin County
20/03/2009



爸爸帶小孩一起去
的國家。

A image about dad and mom together bring *tiāo-hái* to a hospital



Tzi-Xing, 31 years old,
first pregnancy, 15ws+ 1d,
house wife, Taipei

Story 4: Pregnancy biosensors



- Intel Project (Roberts, Mackenzie, Mort) and Joann Wilkinson and Mette Kragh Furbo
- Technologies controlled by consumers; data shared online
- Possibility of continuous tracking → data overload (data of use to others?)
- Potential implications for dr/patient relations

Firefox | DuoFertility - Ovulation Calculator and ...

www.boots.com/en/DuoFertility/?cm_mmc=bmm-_-Google-_-Mother&Baby-_-Duo Fertility

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Questions/ areas for research



- Folding of old and new – topological rather than linear approach to historical developments
- Latrogenesis
- Significance of failure (vs hope)
- Changing relations between patients/consumers/clinicians/health bureaucracies/corporations
- Role of internet and related technologies of measurement, recording and statistical analysis

A reminder about ethical ('who lives and dies and how') questions



'These questions cannot have simple, single or final answers. However, a serious commitment to refusing both the culture of no culture and the nature of no nature means these questions have to be asked, as a *constitutive part of technoscientific practice*'

(Haraway, 1997: 113).