Life World: research participants co-constructing our knowledge of their deliberations

Angus Clarke and Shane Doheny, Medical Genetics
Orhan Uzun, Paediatric Cardiology
Sonya Lloyd, Yr 3 Med student
with colleagues in Southampton, Exeter and Bristol
and funded by the ESRC
“Framing the trajectories of decision-making ….”

- Predictive genetic testing: especially for adult-onset neurodegenerative disorders (Huntington’s disease)

- Prenatal genetics: approach to managing the pregnancy (including diagnostic testing or decisions about terminating the pregnancy)
“Framing the trajectories of decision-making .....

• Categories of Data

• Audio recording of genetic counselling consultations (=> transcripts)

• Diary kept by the research participant - paper, audio recordings of monologue or of conversations, blog, .....

• Final closing interview
“Framing the trajectories of decision-making ....”

- Categories of Data
  - Audio recording of genetic counselling consultations (=> transcripts) before results
  - Diary kept by the research participant - paper, audio recordings of monologue or of conversations, blog, ....
  - Final closing interview (after results)


“HD audio log pre-result

“I’ve been trying to cut down on my drinking and uh, trying to give it up, not drinking in the house or anything. And then suddenly thought to myself, “Well when they take the blood on Monday, they um … it's probably gonna become more real to me and where I'm finally gonna start thinking about it more often and thinking about it properly. And then getting all wound up about it and all despair-ee ... and stuff like that”. Who knows? Who knows? Who knows how I'm gonna feel?

I think my main concern is that I'm going to end up becoming less caring of my ... uh, of ... of the consequences of my actions. And end up doing something stupid. Like tell somebody in work, how I really feel [higher tone] about them for example .....”
"I believe I am relying on the results of this test whether they're positive or negative to give myself the kick up the arse that I need to maybe make myself a better person in some way or another. Whether it's ... whether it's for [stutter] ... for X amount of years or to plan for the rest for my life or whatever.

And I [stutter] hope it does. I hope it works either way. And I can then become a better me. But, um, at the moment, I'm sort of kind of just plodding along, just carry on with my stuff in the job that I don't enjoy in an industry that I don't enjoy."
HD mutation positive: interview

“I went through a real up and down rollercoaster until I had the diagnosis and when I had the diagnosis that first week I don’t remember it, I literally just was here in the house, I didn’t wanna go out, didn’t wanna do, I hit rock bottom if that makes sense, you know what I mean, erm, and I’ve only had to kind of build up from there then really, you know.”

“But I did find the diary helpful and I thought well, you know what I mean, if it is helping me then it’s gonna benefit me and hopefully somebody else in the future, I was happy to carry on doing it, …”

“After I told my Manager on the Monday, she tried to allocate me a case on the Tuesday and it seemed very, very straightforward and whatever and then I was reading through it then and the mother had Huntington’s disease ….. “I’m so sorry, I can’t take this case, you know read this bit by here” and she come back, she said, “oh, right, okay, I didn’t see that far into the paperwork and whatever, so, er, yeah”. ”
“Even years would go past without me thinking and worrying about it and in fact it only really came to a head when the test result was in and the actual point where I started to really worry was when [Dr.] took the blood out of my arm and that was when I, when it became properly real for me ... “

“Yeah (laughs) and so I’m a bit concerned that I’m almost, almost disappointed ... that now, because I now don’t have an excuse to be, er, carefree and stuff. I was like, oh, what’s the point, I’ll only be getting fifteen years, that’s fine, I’ll just go and do my own thing and free my mind and not worry about consequences of things cos I tend to have a lot of you know self-guilt and all that kind of stuff ....

So almost I, almost like it hasn’t mentally freed me in that way, but that’s just stupid really (laughs) when you analyse it cos now I am properly mentally free and I can plan for the rest of my life, I can.”

“I don’t have any excuses anymore now, I’ve just gotta get on with it.”

“When you get to that fork and this point here has been the only thing on your mind and it’s gone ... and I was like, ah, okay, now I have to think about something else."
Discussing the keeping of diaries in the interviews

- Keeping a diary was spoken of as positively helpful by several participants

- Helped to maintain relationship with partner
  - Off-loading in diary spared the partner
  - Organised thoughts so that discussion with partner was more focused and helpful
Prenatal case: Down’s syndrome with cardiac anomaly, including an Audio Log.

Characters: M (mother of the fetus), F (father of the fetus) and MM (mother of M)

Clear understanding of the complexity of the fetal cardiac anomaly (septal defects, underdeveloped ventricle, need for multiple surgical procedures, perhaps a transplant)

Paediatric cardiologist warned them that the cardiac surgeons in another hospital might refer to the cardiac problem as life-threatening.

Multiple offers were made by different members of staff to say that a termination of the pregnancy would be available
Mum’s diary - 1

• Concern that other people would think them cruel to put the baby through multiple surgeries

• Wish to keep secret the fact that they had been offered ToP ... as people may feel they should have done this

• Close family members have been (implicitly) critical and given details of other babies who died after multiple operations for heart defects

• Mixed feelings about several friends who have announced they are pregnant: she anticipates comparisons between the babies
Mum’s diary - 2

• Repeated expression of a strong fear of bonding with the baby and the baby then dying - “would not cope”:

• “I feel like I will look at our child and just cry every day either through fear of losing him/her or feeling sorry for everything that child has been through because I chose to bring him/her into the world”

• Has been reluctant to talk about her feelings with professionals (but might talk with her older child’s health visitor)

• Cried when she saw happy scene of child with Down’s syndrome greeting her dad at nursery; she still sometimes wishes the baby didn’t have Down’s
Mum’s diary - 3

• Wants even more than before to work at home (in financial role), so her training course really matters to her

• Anxious in case she doesn’t pay enough attention to her 3 year-old daughter

• “Not knowing or dwelling on things is better for me. Researching every angle of something and then storing that in my mind for when it does/doesn’t happen is not good for me …. Throughout the whole pregnancy I have been very well looked after. There isn’t anything that I would change in the support that I had. What I would change is my own thoughts and actions, but I’m working on that now”
Diary continued after delivery

• Having to control her thinking to avoid negativity: “I was terrified and started to fear that I would never take <Name> home. I don’t even like writing that. I won’t write or think that again”

• “I was worried sick but to look at she was great. The doctor made no qualms in telling me that it was the medication keeping her here at this stage. That is how the first chat went. A positive followed by a kick in the teeth”

• Gradual adjustment: a journey
Audio Log of family conversation

• Raw hurt .... alongside mundane aspects of everyday life

• Discussion on how a couple can discuss the question of terminating a pregnancy. Undue influence by the man?

• Wife’s mother giving support, being non-directive

• Discussion about staff and whether they were trying to “influence” the couple’s decisions

• There was also a discussion about being recorded and participation in this ethics research (data not included here)
MM: Christ, that baby’s got a lot to go through.
M: I was like fucking hell, could there be anything else?
F: Well like I said to you [NAME], earlier, at this late stage, this to me is like a late stage
M: This is what?
F: A late stage, you’re halfway through aren’t you? So we know there’s a baby in there. We’ve had three scans, we’ve seen the baby three times moving about. I don’t think that I could live with myself if we decided to terminate now.
MM: I know it’s so hard. ..... But then you’ve also got to think is it fair on the baby, what that baby’s got to go through?
M: ..... I don’t want any of this to be happening. But I’m so scared of giving birth and getting an attachment with that baby, and then it’s your physical child has died. That’s what frightens me, I don’t want to lose a child.
M: I know, but that poor child having to go through all of that. We’ve got [daughter] to think of as well, she’s going to be going through all this as well. Having her brother or sister that’s in hospital all the time, and we’ve got to think of her .... It’s just shit isn’t it really, shit fucking situation. Now I do feel like I want to give up everything. Work, college, everything. How the hell am I supposed to concentrate now on college and pass exams and shit, and go and listen to their problems all day?

MM: When are you back, next week?

M: Monday. What would you do mum? How would you get yourself through this?

MM: I don’t know.

M: Give it some time and I’ll be back, got to be strong, got to think positive and I’ll be OK but right now I just feel I’ve just heard the worst of the worst. It’s shit isn’t it?
Difficult discussions

F: It’s basically have the heartache of terminating now, or have, and a lifetime of thinking what if, what if that baby was okay? What if he was going to be fine? We know he’s going to be Down’s syndrome, but that doesn’t make any difference to us.

M: It’s like just when you get over that bit there’s another fucking kick in the bum. I don’t want to terminate, I really don’t, but then I don’t want to bring a child into the world just to suffer and have a shit life, and surgeries. Mum, why can’t I do what my friend’s doing, and all that? I mean that’s not a reason to get rid of a baby. I’m scared of having a baby, having a child, and then losing it, because that is so much harder.
M: I’m just scared that I’m not going to have this baby, or if I do have this baby it’s not going to be for long. That’s what I’m scared of.

MM: I know, but don’t think like that. Don’t think like that.

M: I know, but when you’ve got someone sat telling you it’s a life threatening condition, it’s like fucking hell, that baby is clearly not going to live a long happy life then is it?

MM: But it might love, he or she might. Another sandwich anyone?
Undue Influence?

F: Yeah, I don’t want to feel like I’m pushing my thoughts on you though. I mean I think you probably have more of a say than I have because it’s your body ...

M: It’s just as much your child as mine. I’d never go over your head on anything. Because not only have I got to live, like I say, for the rest of my life thinking what if? it’s also then I’ve got rid of a baby that you wanted. So I’d never go, “He was just saying he doesn’t want to talk me into anything”, because it’s my body and I’m going through it. ... Yeah I’ve got to live with that I got rid of a baby, and what if? what if? all my life. What if it came out okay? Also then I got a rid of a baby that he wanted. I’d never go over your head.

F: You can easily turn that around though and say I told talked you into keeping the baby, and then we’ve just had to go through a lot of.

MM: Yeah, it works both ways doesn’t it? Either way it’s so hard. ... Yeah, you’ve got to make the decision together.
M: I just felt like I was getting okay with the Down’s syndrome, and oh right there’s a heart problem and it’ll need surgery. That’s okay.

F: Yeah, we got our head round that bit didn’t we? But I think maybe two or three times today I think they’ve told us that if we did want to terminate they’d support. But they were mentioning it more this time than on the last scan.

M: Yeah, well all three people we saw said it today.

F: Yeah.

M: All three of them, termination is still an option.

F: And the one doctor said it’s your right, it’s your right, and I don’t know, it just didn’t sound right to me.

M: I think it came out wrong. He said it would be advisable.
MM: Was it sounding like they were saying they think you should or?

M: The one doctor said “**oh it’s your right to terminate**”, I think he said advisable. And what he meant was it’s advisable that we’re given the option.

F: Yes, he wasn’t advising us to have no, he was saying he needs to.

M: He said “**I’ve got to give you the option to terminate**”. That’s what he was saying.

F: Yeah.

M: Because when he said that, oh you know de, de, de, it’s advisable. **I thought, “so you’re basically saying you think that we should then”**. That’s what I was thinking.
Genetics and the Life World

• To understand how genetics impacts patients and their families, we need to access how a person experiences and values their life-world.

• Patients and families have sophisticated discussions about the problems they face.

• We need to develop better ways to co-construct this research with our research participants.

• Decisions about reproduction:
  • depend upon judgements of how worthwhile our lives are.
  • these judgements have consequences within the family // society.

• In some contexts, stigma is a key factor that shapes quality of life.