What can policy makers learn from the messages and advice young adults' give to their peers in interviews about growing up with a chronic illness?

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ILCP conference - 7 September 2012,

The Law Society, London

…I see CF as a challenge.
It's something that does affect me on a daily basis but it's not something that rules my life.
And it's not something that stops me doing the things I want to do all the time.
It does sometimes stop me doing a few things and makes me sometimes reconsider going on a night out when I've already been on two other nights out and I'm quite tired and run down.
But it's not something that will stop me going on holiday or stop me visiting friends at a different uni because I have to do my physio in the morning for example.
It's not something that will stop me doing things I want to do in my life.
And I feel that if I want to achieve something and I set my heart on it then I will do that.
And I won't let CF rule it.
Female, 19, cystic fibrosis (C15)

Background

- ‘Personal mastery’ = ‘the extent to which one regards one’s life chances as being under one’s control in contrast to being fatalistically ruled’ Pearlin and Schooler (1978: 5)
- David Kelleher (1988) Diabetes

Aims

1. To examine young adults' sense of mastery of a range of long-term conditions and how this relates to their lived experience of chronic illness and its medical management while growing up.
2. To examine the nature of the advice young adults give to other young people and young adults with a long-term condition about managing it while growing up, and how this relates to their sense of mastery of their condition.
3. To examine if there are any variations in 1 and 2 above, for example, according to the type of condition, age at interview, age at onset, gender.
4. To consider the implications of the findings for health service policy and services concerning young people and young adults who have long-term conditions.

Datasets/conditions

- Epilepsy
- Diabetes type 1
- Long-term conditions (14 conditions)
  - CF, Scoliosis, Sickle cell anaemia, Arthritis, Asthma, CFS/ME , Hyperplastic left heart syndrome, Senior Loken Syndrome, Eczema, Masangio Capillary Glumenonafitas T2, HIV, chronic (pelvic) pain, Morphea, DMD

Final sample

	N transcripts	N subjects	Average age onset	Average age at diagnosis	Average age at interview	Average time with condition
Epilepsy	40	40	12	14	21	9
Diabetes t1	38	39	9	9	19	10
LTCs (n=14)	24	24	6	7	21	14
Overall ave	102	103	10	10	20	11
Range (yrs)			0 to 19	0 to 22	15 to 29	1 to 25
Male		42				
Female		61				

The interviews

- Personal experiences of living with and managing their condition
- Loosely structured
- Included questions on if participants had any messages or advice for others with the same condition, and professionals

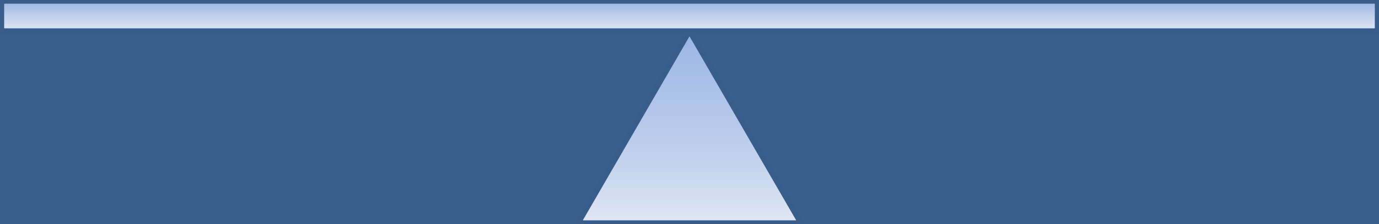
Methods of analysis

- Combination of narrative and thematic analysis (cf Flick 2006)
- Case by case summaries of all interviews
- Coding framework developed and coding done using Atlas.ti software
- Analysis carried out using Atlas.ti and by hand, using tables summarising participant's views on particular topics or themes

Findings: Messages & Advice for peers

1. Shift in feelings
2. Stay positive
3. Don’t let it control you
4. Work with doctors
5. Personalisation
6. Be pro-active
7. Be careful
8. Get support
9. Top tips

Results: A sense of mastery



control

counterpoise

resistance

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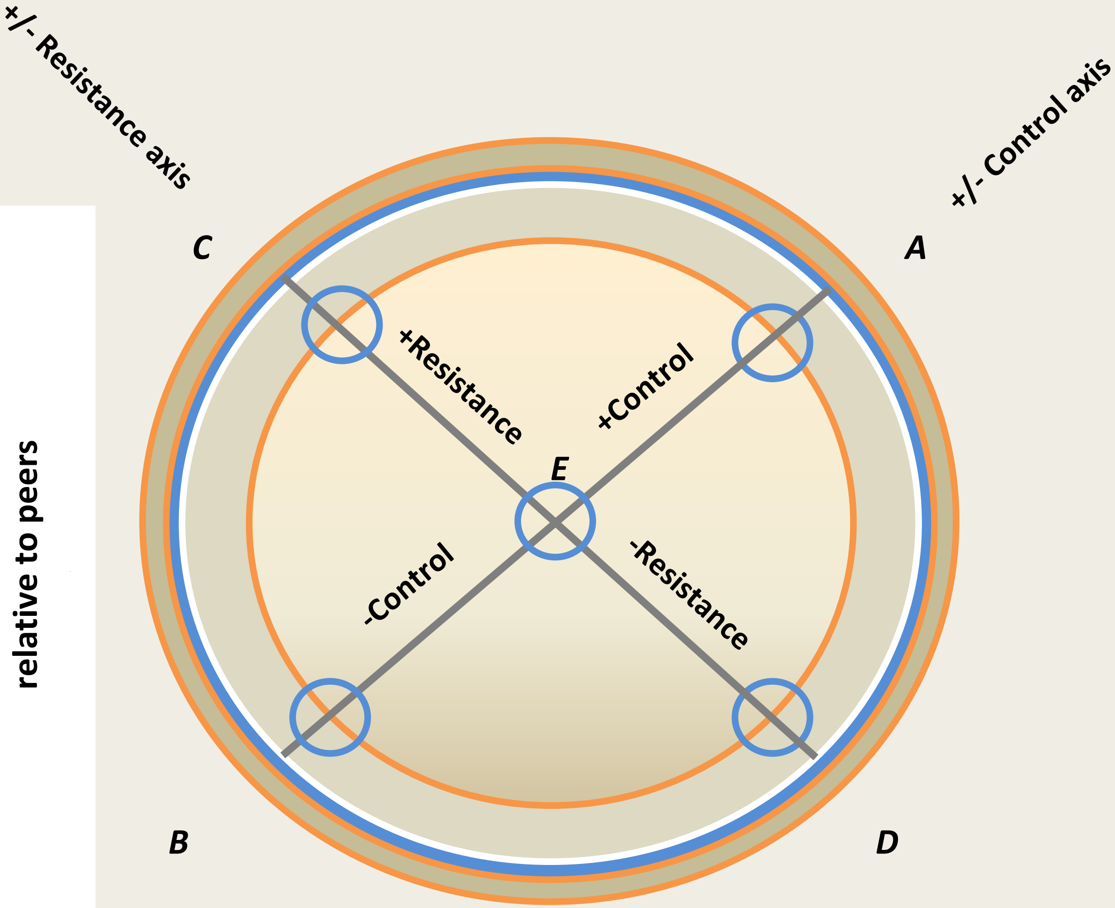

< Low Autonomy relative to peers High >

< Low Engagement with condition/regime High >

I: Now what advice would you give young people who are just being diagnosed with diabetes? Or they're starting to get treatment?

Well, be open about it.
Take it seriously.
But don't, don't let it govern your life completely, don't let it change your way of way of life too much because then you'll end up being a diabetic and not [laughs] you know, you're still, you've still got your lifetime as you always would.
But, make it a priority and make sure you've got a good doctor.
If you don't like the doctors you've got, maybe try and find another one because it is really important.
Make sure you trust them.
I, the ones I've got now I just find brilliant and it's helped a lot.
Female, 21, diabetes (D1)

Implications for policy

- Important to understand the nature of gap in patients’ and professionals perspectives, to develop policies and practices which help to close this gap.
- From a traditional medical perspective, being in control is achieved through following a regime strictly, avoiding risky behaviour, to maximise adherence and stablise symptoms.
- For YAs, their SoM is dependent on finding a more flexible and acceptable balance between the work they do to engage with their condition (control) and their desire and efforts to be autonomous agents (resistance).
- Ultimately managing a chronic illness is not just about controlling the condition but enabling people to live as normal a life as possible.
- Interventions and services need to be effective not only in terms of enabling YAs to control their condition, but also in terms of promoting autonomy and minimising the disruption and burden of care regimes.

Websites

GUCI:

http://sites.pcmd.ac.uk/guci/

YouthHealthTalk:

http://www.youthhealthtalk.org/

I: What do you mean 'in control'

Well the ideal blood sugar is between 4 and 10 but I mean it's really hard to keep in between that all of the time.
So I mean you're never going to be a perfect diabetic person. [laugh]
You're always going to have a hypo or you're going to go high or something like that.
Female, 17, diabetes (D18)

When I started there was, I mean obviously my blood sugars when I was first diagnosed were very high, and then I kind of got them down.
And that kind of honeymoon period got me used to kind of expecting to have kind of 5s and 6s all the time and that kind of thing.
And as that kind of started to wear out I was kind of trying to aim for the same kind of numbers without really being able to manage it.
So I was getting a lot more hypos as a result.
And my doctors sort of said, you know, "You're doing perfectly well. You don't need to kind of maintain such a, such low numbers all the time. You can kind of let things go a little bit higher and have fewer hypos. And it's your life, you can kind of..."
Once I'd just allowed them to go up to kind of 6s and 7s without kind of stressing about them in any way the number of hypos dropped off lots.
So there was a kind of a period where I was kind of controlling it too tightly just because I'd been used to my body being able to do that anyway.
And when that stopped working I was kind of trying to do the same thing, which wasn't really a good idea.
Male, 26, diabetes (D19)

I: What was your attitude before? I want to understand that bit when you were not taking good care of yourself?

My attitude was. It's like me, I was walking and my diabetes was coming behind me. It was like I wasn't pushing it away. I didn't think, 'Oh I don't want it, go away'. I didn't mind if it was there but I'm not taking care of it. You want to come with, come but I'm not taking care of it. You know. Because like I didn't mind it was there. I didn't ever have like, 'Oh why me? or 'I hate this,' you know. It was never like that. If, if I have it fine but you. I'm not going to look after it. I'm not going to take care of it, you know. If it wants to be there I'll do my insulin and I'll do basics to survive, you know but no extra care, not extra, you know.

But now it's kind of like I want to make my diabetes, you know, like here like you know, like come together so that I know what I'm doing and it becomes like part of me, you know. I want it to be that I'm more in charge and I. It's not something that I just do my insulin. I forget I have diabetes for the whole day [laugh].

I think so, I don't know. I can't really think about what the reasons why I didn't, you know. I just, I felt. I didn't feel it was important enough. It wasn't important enough to me. It doesn't, then a couple of years ago it didn't matter if I did my insulin or I did no insulin. I didn't care if I felt bad or I felt good. I didn't, you know it wasn't important. I didn't feel like it's important to have good control and to eat well and to be healthy. Wasn't important to me.

Female, 20, diabetes (D6)

And, I go, “Ah, well it means I'm must take my medication”, and that's when I realise that I just think, “God, what could my life be like, how would I feel, what would my personality be like, if I wasn't so heavily reliant on Tegretol.” I'd like to come off it slowly but it's, I know that it's a part of medication and I'd just like to understand how it affects me and even the doctors have said we don't really know why you have epilepsy, we can only give you the drugs that stop the symptoms of it really. I have to go with the doctor's best opinion but again I was so scared of the kind of the results of what happens with epilepsy and everything and I just followed doctor’s orders. I didn't complain when I was feeling doped all day, I would never complain I would just be like, “Nope, that's part of what having epilepsy is about, you feel doped.” And now, I feel a little bit more like well, I'm doing things now that are against the doctor's advice and so it makes me question more what can I really get away with? And if I wanna have a good time and I feel like I've had a good week on medication prior to it, and I'm like right I'll go out all night tonight and have a great time, I'll take maybe half the medication that I'm meant to take, or I'll skip a night's medication and that is very very much frowned upon, and I know it is. I know it's bad for me, but I go out and I just feel like I'm free I feel like the chains come off my back and I can run around and just be my old self before epilepsy, and it's fantastic and I love it. Next morning I always make sure I take my medication early and I know that if I told the doctors, they'd say you have to stop, and that's fair enough but, I've tried a few times now, and I feel that I can control it. If I had a seizure then I'd stop because I really have had so many seizures over the years that I really have no fear anymore. **Male, 21, epilepsy (E10)**

I maybe, towards my teenage years once I realised that it was a life-threatening condition that was something that I hadn't previously been aware of.
It's not maybe something you necessarily want to sit a five-year-old down and discuss. And there was not actually any official discussion.
It was just a matter of at one day I don't know how I just found out that I might not live very long. And that was obviously really upsetting.
And I think that's when I started to go off the rails a little bit.
Not to the extent that most people do.
But I started rebelling.
I didn't want to take my medication. I found that if I didn't take my medication for a few days it didn't seem to have much effect on my health, my immediate health.
What I didn't realised is that long-term it, it had a massive effect because it would lead, if I didn't take my vitamins it would lead to deficiency.
If I didn't take my enzymes it would lead to bowel problems.
And so obviously I was doing myself more harm than good.
I mean I gradually got over that. I just started to mature and started to see that really I was being silly. I was being immature.
There was nothing to be gained by not taking my treatments.
Female, 23, cystic fibrosis (C14)

I think the point with me is that I should have been more limited in the stuff than I have done than I actually have been because I decided to do stuff and pay the consequence by being ill and having longer time to recover than not doing them and not being as ill and not having to recover for as long.
Do you see what I mean?
Just because I want to do stuff.
I have sort of always been determined sort of not to let it rule my life.
Which is not exactly fool proof.
Male, 23, chronic fatigue syndrome (C11)

…see the epilepsy has always been like my main, it’s been the main thing in my life.
It’s ruled everything.
You know, I never had a social life as I was growing up really, you know I never had sort of, from sort of 15 to 19 where my friends was all going out drinking and clubbing, I never did any of that, ‘cos for one, it wasn’t really a good idea to drink when you’re on medication, it don’t really go, and for two, I didn’t want to be going out and having a fit when all my friends were out enjoying, enjoying themselves, I didn’t want to be a burden on them.

Female, 28, epilepsy (E15)