

# Managing medication for chronic illness: the perspectives of young people and parents

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## Government policy: listening, hearing, responding (2002)

‘Involving users and carers in decision-making at all levels is a key aim of all health and social care agencies... Children with illness, particularly those with long-term conditions must be cared for not only in terms of their medical, social and educational needs, but also in the light of their own views and decision-making.’

# Research with young people and parents

- Study with young people with asthma or diabetes:
  - primary care population
  - independent interviews in respondents' own homes
- Study with young people with cystic fibrosis:
  - observation and audio-recording in clinic setting followed by
  - independent interviews with young people and parents in respondents' own homes, and with health professionals

# Research with young people and parents

- Study with young people with a range of chronic conditions: respiratory, GI, rheumatology and endocrine
  - interviews with young people and parents in outpatient clinics regarding using medicines in school
- Study with young people receiving infliximab therapy regarding treatment options:
  - interviews with young people and parents during hospital visits

# Young people (aged 8-15 years) with diabetes and their medicines (n=26)

(Newbould, Francis and Smith)

Task	Performed by parent	Task shared	Performed by young person
Ordering supplies	23	1	2
Collecting prescriptions	25	1	0
Monitoring blood glucose levels	2	4	20
Remembering / reminding	13	4	9
Administration of insulin	4	9	12

# Young people and medicines

Interview with young person with diabetes

I just do my prick (monitor blood glucose level) and if I am high or low I just dial up what I need. I don't bother Mum with it. [Girl, 11 years].

Young person with CF in consultation with dietitian

D: have you had any tummy ache with that (*new bowel symptom*), any bloating, anything you've eaten differently in the past two days, anything a bit more fatty

YP: erm no, I think I might have not had enough Creon at school lunch

D: yeah

[Boy, 14 years]

# Young people and medicines

He [consultant] and my mum, they both want me to go on to three jabs a day. But I won't do it. I've told them I won't. I refuse to have one when I'm at school, whatever they say.

[Boy, 10 years].

# Supporting changes in patterns of responsibility between young people and parents

I tried to mention it to her [diabetes nurse] but she sort of said 'Oh, you can work it out at home'. They are very nice and all that, but they are more concerned with the results, you know the blood levels, rather than who does what. [Mother of girl, aged 12].

She [asthma nurse] didn't really give us any advice or help. I didn't come away feeling reassured. I mean I want [*name*] to be independent, but I don't want to give her more responsibility than she can handle. [Mother of girl, aged 10].

# Medicines and School

- Guidance often unclear
- Variation between schools
- Limited research on experiences of young people and the impact on condition management

# Medicines and school

- Access to medicines
- Using medicines at school
- Special activities: school trips
- Roles of school staff
- Home-school interface

# Medicines and school:

## Access to medicines

- school policies
- regular dosing v. *prn*

# Using medicines at school

- *If you have it in the school office you have to have it at a scheduled time... I just take it when I need it. It's actually against the school rules to have it in your bag but I found no other way.*
- *“When I wasn't feeling well and I needed my medication, they said I needed a note.”*

# Using medicines at school: administration

- *Lack of suitable location and privacy was most common concern*
- *But many and varied needs:*
  - *“... the teachers were informed about her taking medicines.... but they did not remind her to take them and so she often forgot.” [Parent of young person]*

# Using medicines at school: side effects

- *He doesn't take his medication because of the side-effects... it makes him go to the toilet. [Boy, 17 years]*
- *...they make me nauseous and sleepy That's why I don't like taking it. If I'm at school and I need to take it then there is no point being there because it makes me go to sleep. [Girl, 15 years]*

# Using medicines at school: school trips

- *Varied experiences of young people*
- *Important role of individual teachers*
- *They didn't allow her to go on the trip. They saw what medicines she was on and the problems she's got and wouldn't take her. I said 'she's got to have a normal life.' ...she was discriminated against. [parent of girl, aged 10]*

# Medicines at school: peers

- *My old friends from primary school know. But my new friends sort of know I have diabetes. But I don't mind answering if they ask because it's good for them to know in case anything happens. [Boy, 13 years]*

# Medicines at school: peers

- *Parent: I came to notice that she wasn't taking her Metformin at school because of the other children.*

*Young person: I used to take it and people used to ask me why.*

*Parent: she doesn't like being questioned a lot... especially about her diabetes... I had a word with the nurse and the dose has been changed. She's stopped taking it at school now.*

# Home-school interface: parental concerns

It's just complete madness that they (the school) don't want her to be doing her blood sugars whilst at school, it's all to do with AIDS and that, and them not wanting bodily fluids around... I said to the head teacher, 'would you rather have her safely testing her blood, or her being rushed to hospital in a coma because she can't tell what her blood sugar is?'

[Mother of girl, aged 11].

I do talk to them, but in secondary school she goes all over the place - you can't, it's different teachers. Whereas in primary school it's one teacher really, so there has been less involvement now she's older. [Mother of girl, aged 12].

# Using medicines at school: role for health professionals

- When I first started (insulin pump) the hospital were in contact with my school, which was very helpful.

# Implications for health professionals

- Young people are actively involved in managing and using their medicines
- They understand a lot and make decisions
- They have difficulties in fitting medicine use into their daily lives: especially at school where there is often less support.

# Infliximab at home?

- An infliximab infusion is currently given in hospital
- Adulimumab at home is another option.
- A high quality and safe service is of greatest importance

# Information and health care professionals: young people's perspectives

- information in leaflets was often considered 'uninteresting'
- consultations with nurses were identified as providing an opportunity to ask questions and discuss
- nurses viewed as having time, being interested and unintimidating
- long-term relationships with professionals were valued

# Young people and their medicines: concluding points

- high level of engagement with condition management
- context of partnerships between young people, parents and health professionals
- difficulties arise in application of knowledge in their daily lives
- timing of information and setting is important

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