What children think about having a thyroid disorder: a small scale study

By Shannon Davidson
Age 10
Introduction (1)

- I have a thyroid disorder called Graves Disease
- Medications stop my thyroid making too many hormones
- Some children were born with no thyroid
- Some children either have under-active or over-active thyroids

This is where your thyroid gland is
I wanted to find out what other children think about having a thyroid disorder because I’ve no one to talk to

Graves disease is most common in adults, so I feel quite lonely being the only person I know who has it
Finding out about my topic

- At the moment I can’t find any research on what children think about having a thyroid disorder
- The British Thyroid Foundation support groups are only for adults and they’re local
- If you want to find out more about thyroid disorders go to [http://www.btf-thyroid.org/](http://www.btf-thyroid.org/)
- There are not many children with thyroid disorders and they live all over the country so a local support group wouldn't do any good for children around the country
My research questions

- How does having a thyroid disorder affect children’s day to day lives?
- Do people treat them differently because they have a thyroid disorder?
- Do children think there should be a support group for children with thyroid disorders?
Method

- I chose to have a questionnaire because the children live all over the country
- I couldn’t interview the children because they live all in different places and I might not be able to get there
My sample and method

- I wanted to give out questionnaires to other children with thyroid disorders but I didn’t know anyone with one.
- Someone who works for the British Thyroid Foundation gives information to families and she had a list of addresses.
- She sent out my questionnaires with a letter explaining what it was about with stamped envelopes for the questionnaires to be sent back to school.
- 70 questionnaires were sent out and 28 have come back and they have all given me good data.
- The children were year 4 to college age and girls and boys.
Data analysis

- My questionnaires had open and closed questions
- When I got my questionnaires back I tallied the answers to the closed questions into boys and girls and different age groups
- I coded the answers to the open questions
- This means that you sort them into different categories
- Then at this point I had an adult to help me when I had to put my data on a spreadsheet
Ethics (1)

- I had to think of my questions very carefully because I was told that a lot of children didn't like talking about it.
- I wanted to find out what they thought about their thyroid disorder so I was asking questions that were personal and medical.
- I had to promise them that it would be anonymous and confidential.
- My adult helper looked after my questionnaires so no one else can look at them.
Ethics(2)

- I gave everyone a choice to fill in my questionnaire
- The lady from the British Thyroid Foundation also told the children in her letter that they had a choice and also about it being anonymous and confidential
- I promised to destroy all the questionnaires at the end
This is what I wrote on my questionnaire:

Please do not write your name on this form. Anything you tell me will remain anonymous.

My name is Shannon. My research is about people who have Thyroid Disorders. The reason why I’m doing this research is because I’ve got a thyroid disorder and I want to know what other people feel about it because I don’t have anyone my age to talk to about it. Would you like to complete this questionnaire for me please. The information you give me is between me and you and no one else. If you don’t want to do this questionnaire you don’t have to fill it in. When I finish my project I will destroy any sheets at the end.
Findings
How does your thyroid disorder affect your day to day life?

- Having to remember to take my tablets (14/28)
- No effect (10/28)
- It makes me tired (5/28)
- Makes it hard to concentrate (3/28)
- Mood swings (3/28)
- Having to have blood tests (2/28)

- Others: feeling anxious and worried
  feeling cold
  having bags under my eyes
Do people treat you differently at school because of your disorder?
Do people treat you differently at school because of your disorder?

- Most of the girls and all the boys felt that no-one treated them differently.
How do people treat you differently at school?

These are the different categories of answers from the children that did think that they were treated differently:

- You can’t tell – nobody knows
- They understand why I’m not too good at concentrating
- They’re caring and supportive
- They want to know about my disorder
Do people treat you differently at home because of your disorder?
Do people treat you differently at home because of your disorder?

- Most children say they don’t get treated differently at home but there are some children who say they do get treated differently at home.
- But more children say they get treated differently at home than school.
How do people treat you differently at home?

These are the different categories of answers from the children that did think that they were treated differently:

- They make sure I’ve taken my tablets
- No differently
- They’re kind and sympathetic
- Others: family members have it too
  - they worry if I get tired
  - they watch me more
  - they restrict what I can do
If people treat you differently at school do you tell a teacher so they can help you?
If people treat you differently at school do you tell a teacher so they can help you?

- Most children who feel they are treated differently don’t tell a teacher but some do.
How does the illness make you feel?

n=29

- very happy
- happy
- neither happy nor unhappy
- unhappy
- very unhappy
How does the illness make you feel?

- Quite a lot of the children are neither unhappy or happy about having a thyroid disorder
- Some of the children seem happy about having a thyroid disorder
- Only a few are unhappy or very unhappy
- Generally most of the children don’t seem to be bothered about having a thyroid disorder
Do friends know about your illness?

- Yes: 25 children
- No: 1 child

Total: 26 children
Do you talk about your illness with your friends?
Do you talk about your illness with your friends?

- Some of the children never talk to their friends about their illness
- Most of them do a little bit
- But 1 person says she speaks to her friends all the time!
it's ok
as long as I'm ok, they're ok
not bothered
doesn't make any difference to our friendship
they don't know because I lie about it
they ask questions and are interested
helpful and sympathetic
someone to talk to
don't know what they think
pick on me sometimes

What do your friends think about it?
How do your friends support you?

- They don't really support me
- Treat me the same
- Helping when needed
- Yes, but
- Don't need to support me
- Asking questions
- They don't really understand it

Categories

- Number of answers in this category: n=23
Do you think that children (with thyroid disorders) should have support groups?

**GIRLS**

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<td>College</td>
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**BOYS**

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Do you think that children (with thyroid disorders) should have support groups?

- 16 out of 20 girls said yes
- 1 girl said no
- 2 were not sure

- 3 out of 8 boys said yes
- 3 said no
- 2 were not sure
Reasons why young people think that there should be support groups for them

- More difficult for kids to understand
- Not knowing what's going on
- Meeting other people with disorder who understand/talk about it
- It's a pain
- Having disorder is difficult
- It isn't fair
- Need information
- Some children might need it
- Might be hard to go/feel embarrassed
Reasons why young people think that there should be support groups for them

- These are the 3 main categories of answers
  - Meeting other people with a disorder who want to talk about it and understand it
  - It isn't fair that adults get support groups and we don’t
  - Some children might need it
Reasons why young people think that there shouldn’t be support groups for them

(Three boys and one girl)
Reasons why young people are not sure about having support groups for children

(Two girls and two boys)
How old were you when you got your thyroid disorder?
How old were you when you got your thyroid disorder?

- 21 out of 28 children were diagnosed when they were babies or very young
- But some were diagnosed when they were older
Discussion and Conclusion
I am very happy that my research has worked.

I found answers to all of my research questions.

Some of the children put in letters saying what a good idea my research was.

I think this means that they wanted to talk about their thyroid problems.

It has helped me talk about my thyroid more and I even made a pen pal with one of the girls who put a letter in with her questionnaire.
Getting everybody together would have been a better idea than sending out questionnaires but I could not do that because all the children live too far away.

I was very pleased when I got loads of questionnaires back.

Researchers don’t usually get loads of questionnaires back when they do it by post but I got 28/70 back.

That was more than I expected but if I got more back my research would be more accurate.
I didn't get as much back from the boys than I did girls
I don’t know why this is
These are the possible reasons:
- boys might not like filling in questionnaires
- they might not like talking about their thyroids (the boys did not like the idea of having a support group as much as the girls)
- maybe girls just get it more so there is more girls then boys who have a thyroid disorder
If I could do some more research I would find out is if girls like talking more about it than boys
The effects that I have with my thyroid disorder some of the other children have too.

If I hadn’t done this research I would not have known that the other children have the same side effects as me because there is no support groups children but there is for adults.

My research has shown that loads of children want support groups as well.
At the end of this research I hope that there will be support group for us and that it won’t be a problem getting there because there aren’t many children with thyroid disorders and they live all over the country.

Maybe instead someone can help us set up:
- a web site
- a chat room
- a blog
- a pen friend group

And if we have them other children can join in if they want to.