Young people's experiences of participation in clinical trials: Reasons for taking part

Shortened version of title: Why young people participate in clinical trials

Abstract

Background: Given the lack of knowledge about safety and efficacy of many treatments for children, pediatric clinical trials are important, but recruitment for pediatric research is difficult. Little is known about children's perspective on participating in trials.

Purpose: To understand the experiences and motivations of young people who took part in clinical trials.

Methods: Qualitative interview study of 25 young people aged 10-23 invited to take part in clinical trials. Interviews were audio or video recorded and analyzed using framework analysis.

Results: Young peoples' motivations were both personal benefit and helping others. Both incentives appeared to be more complex than expected. We introduce the terms 'network of exchange' and 'intergenerational solidarity' to describe these motivations.

Conclusion: To improve recruitment, professionals should be more open about research opportunities, provide better information, and give young people feedback after the trial has ended.

Keywords

Young people, clinical trials, research ethics, helping others, personal benefit, autonomy

Introduction

Clinical trials are essential for producing evidence regarding effectiveness and improvement of healthcare interventions. Just as adults, children and young people have the right to receive the highest attainable standard of healthcare, but there is a lack of knowledge about safety and efficacy of many treatments given to children. Currently, more than half of the medicines used in children are only

tested in adults or not tested at all (Conroy et al. 2000; Saint Raymond and Brasseur 2005). Children differ from adults in their physiological, developmental, psychological and pharmacological characteristics. Besides, some conditions are unique to children and cannot be studied in adults (Ginsberg et al. 2002; Rocchi and Tomasi 2011; Sauer and Ethics Working Group, Confederation of European Specialists in Paediatrics (CESP) 2002). Therefore, clinical trials with children are of the utmost importance.

Recruitment of children for clinical trials is difficult because they are vulnerable (World Medical Association 1964, US Federal Regulations). Possible harm may have a greater impact on children in comparison to adults (i.e. taking blood samples). There is debate about whether children may be exposed to such risks, and if so, what level of risk would be acceptable. In addition, there is uncertainty about the age at which children are capable of fully understanding information. Therefore, they cannot give informed consent, though assent may be gained in some cases. This raises the question if their autonomy can be respected by letting them participate in clinical trials (Joseph, Craig, and Caldwell 2013). Because children are unable to give fully informed consent, they rely on the decisions made by their parents or guardians. Children should be informed about all important aspects of the trial in a way they understand. If possible, children must be asked if they agree with taking part, also called giving assent (Declaration of Helsinki 1964; Stanford university HRPP policy guidance). Children's ability to provide assent depends on their development, both emotionally and cognitively. This varies across and between age groups. There is an on-going debate about at what age and to what extent children should be involved in the decision-making process (Tait, Voepel-Lewis, and Malviya 2003; Weithorn and Campbell 1982). It is not clear at what age transition to adulthood occurs (Hagell, Coleman, and Brooks 2013). The UK's Goverment's Children and Young People's Health Outcomes Forum recommends that data on adolescence are presented in the following age bands: 10-14, 15-19, and 20-24 years, while the WHO uses ages of 10-19 for adolescence (Lewis and Lenehan 2012, World Health Organisation 2015). Giedd found that cognitive development can continue until the age of 25, suggesting the transition age to maturity greatly exceeds the age of 19

(Giedd 2004). This unclarity translates in different regulations for participation in research of young people. Whereas e.g. in the UK 16 year is the limit for giving individual consent, in the Netherlands it is 18.

Professionals are concerned about therapeutic misconception. When there is lack of proper informed consent, this misconception may occur. It refers to participants' misunderstanding that the purpose of the study is to benefit them, while the primary purpose is to obtain scientific knowledge. Then, participants focus on the benefits and may forget the potential harms involved in a study (Vries de and Leeuwen van 2008, Henderson et al. 2007).

Research benefits are often related to health outcome, for example by receiving better treatment or prevention of illness. This includes both personal benefit and benefit for future patients. Research benefits may also contribute to patients' quality of life by factors such as providing a different route of drug administration, or reduced treatment duration (Recommendations of the ad hoc group for the development of implementing guidelines for Directive 2001/20/EC 2008). Many studies have investigated why parents enroll their child in medical research (Fisher, McKevitt, and Boaz 2011). Hope for improvement of their child's health condition is one of the main motivators (Masiye et al. 2008; Pletsch and Stevens 2001; Stevens and Pletsch 2002; Vanhelst et al. 2013; Varma, Jenkins, and Wendler 2008).

It is of great importance that children are heard. Varma et al. found that 93.3% of the children in their study thought the research treatment might make them better. 86.6% reported they wanted to help others and the majority said that they were convinced because their parents or doctors wanted them to enroll (Varma, Jenkins, and Wendler 2008). Chappuy et al. reported that all children in their study who were involved in the decision to take part mentioned receiving the best available treatments, or, to a lesser extent, learning more about their disease as reason to take part (Chappuy et al. 2008). These studies had a predominantly quantitative approach and analyzed experiences of participants mainly in terms of frequencies. The overall aim of our qualitative study, part of the Youth Health Talk studies,

was to explore children and young people's experiences of taking part in clinical trials and other medical research, including how they felt about the information they were given, why they agreed (or not) with taking part, what it was like actually being in a study, and their level of understanding about the research methods and aims (Youth Health Talk 2015). This study focuses on the narratives told by the children and young people themselves. To cover as wide a range of experiences as possible, we recruited young people between the ages of 10 and 25.

Methods

Recruitment and sampling

Primary data collection was performed by the Health Experiences Research Group (HERG) at the University of Oxford. The study was approved by Berkshire Research Ethics Committee (09/H0505/66). Participants were approached through national research networks including Medicines for Children Research Network (MCRN), support organizations, media advertising, and word-of-mouth. Potential participants were given an information pack which included a reply slip to state that they were happy to be approached by the researcher. An advisory panel was set up including young people and parents, researchers, clinicians from a range of disciplines, and representatives from the funding body. This panel advised on methods, including selection and recruitment of participants. Recruitment aimed for a maximum variation sample (Coyne 1997). This method is designed to represent as broad as possible a range of experiences rather than aiming for numerical representativeness. The data obtained was used to contribute to the Youth Health Talk website (http://www.healthtalk.org/young-peoples-experiences). This is a website about young people's real life experiences of health and illness. It is part of the wider Health Talk website (http://www.healthtalk.org/). Health Talk is a site based on qualitative interview research into people's experiences of health and illness. Summarized findings are presented in accessible language and illustrated by video, audio and written extracts from the interviews. The aim is to offer practical information and emotional support for people and their families, and insights for clinical professionals.

The website comes from a unique partnership between a charity (DIPEx) and HERG at The University of Oxford's Nuffield Department of Primary Care Health Sciences.

Participants in the primary study for the Youth Health Talk website were 32 children and young adults in the UK aged between 10 and 23 who had been invited to take part in clinical trials and other forms of medical research. All Youth Health Talk studies recruit young people between the ages of 10 and 25 thus including transition to adult care and young adulthood.

It is worth noting that young people themselves were not always sure whether the study they took part in was a clinical trial or some other form of medical research. For this paper, the analysis focuses only on the subset of 25 young people who we could determine with certainty from their transcript had been invited to take part in a clinical trial. The sample included healthy volunteers as well as young people with particular health conditions, including both serious and relatively minor illnesses and conditions. Some participants had taken part in more than one trial, one had decided not to take part, and one decided to withdraw from the trial she was involved in. We decided to include all these participants because they all thought about whether to take part in a clinical trial. This was our main focus point. Participants belonged to different ethnic communities in the United Kingdom. Most of them were still at school, but a few of the older participants were working or attending a university. Table 1 is an outline of the patient characteristics and the trial they took part in.

Informed consent

Young people aged 16 and over were asked to sign an informed consent form. Young people under the age of 16 years of age needed a legal guardian who could give consent but were asked to sign an assent form. Participants were informed about the website and the research. Separate leaflets for different age groups were developed. The age groups were 10-15 and 16-25 years of age. Before the interview started the Youth Health Talk website was demonstrated to participants to explain how clips from their interviews might be used. The interviews were either video or audio recorded and fully transcribed. The transcripts were returned to the participants in order to check and remove any sections

they wished not to be used. For participants aged 10-15 transcripts were reviewed by parents as well. In this way, informed consent was sought in two stages, before and after the interview took place.

Data collection and analysis

Semi-structured interviews were conducted by researchers from HERG in Oxford. Participants were interviewed at home. Experienced qualitative researchers, specialized in interviewing young people, collected the interviews, using a narrative approach (Mishler 1986). With these methods, an oral history of each young person's experience of taking part in a clinical trial was collected. Supplementary questions included how and why the decision to take part was made, what participants knew about the elements of informed consent (such as study purpose, methods, risk, the right to withdraw), what it was like taking part, and if they had any advice for professionals running trials or children considering taking part.

HERG researchers LP and LL undertook a first coding and analysis of the complete set of interviews. Summaries of themes from the interviews were produced for the Youth Health Talk website, and reviewed by the advisory panel. A secondary framework analysis (Smith and Firth 2011) was performed at the University of Groningen by ML, supervised by EM and with advisory input from LL. This framework approach involved initial identifying of themes, synthesizing data by refining these themes, and development of theoretical concepts and associations between the themes. Our initial themes were: 'informed consent', 'facing risks and burden', 'reasons for participating', 'advice', and 'other remarks'. These topics were chosen inductively after reading and discussing three interviews in order to find recurring and interesting themes. The themes produced for the website did not influence the choice of themes for the secondary analysis. In order to ensure our participants' experiences were accurately interpreted, we reflected on the original data after development of the theoretical concepts. All authors have contributed to reflection on the emerging findings and the preparation of the final paper.

Results

The most notable finding from the analysis was the degree of variety of motivations that the young people expressed. They often mentioned a combination of personal benefit and helping others as their reasons for taking part in a clinical trial, but in a few cases they occurred separately from each other. We found differences between personal benefit considered as an incentive for taking part, and personal benefit, like restoring self-esteem, which the participants noted after participation. Table 2 summarizes young people's reasons for taking part in clinical trials. Apart from personal benefit and helping others, the young people had several messages to professionals about recruitment and trial participation.

Personal benefit

Nearly all participants who reported self-benefit as a motivation for taking part hoped for improvement of their health situation. They mentioned a broad range of ways for improving their health. Three main themes that were expressed are access to other or better treatment options, improvement of understanding of their disease, and getting closer attention and monitoring from professional caregivers. In addition, participants talked about whether getting a (financial) reward was one of their reasons for taking part.

Health benefit – Access to other or better treatment options

Young people mentioned that taking part in clinical trials was a possible way to have access to other treatment options. For example, one boy with polyarthritis took part in a clinical trial to get another way of administering a drug instead of the weekly injections. He described his motivation:

> *"…Because the needle just made me sick and sometimes I just didn't want it."* [YPCT 12, p. 5]

> *…I didn't want to have the needles anymore because [um] it was making me angry at my mum a lot and it was making me a bit sad as well."* [YPCT12, p. 7]

Another way the young people hoped to obtain health benefit from participating in a clinical trial was to receive medicines that would otherwise not be available to them. Some participants took part because they wanted to get a certain medicine approved or wanted to get access to new or expensive drugs that were not yet routinely available through the UK National Health Service (NHS). Some people also mentioned they had the opportunity to stay on the new drug after finishing the trial.

Health benefit – Improved understanding of their disease

Another predominant theme that the participants reported was getting a better understanding of their disease. Regardless what type of trial, they learnt from the experience. For most of them it was not an incentive to take part, but more a positive side effect they gained from participating in a clinical trial.

One girl explained she hoped that taking part would also help her come to terms with her disease. The interviewer asked her whether she thought that, at the time she was making the decision to participate, the trial might help her. She responded:

> *"Yes, yes, I thought that would help me. And I also thought that if I did the trial I might feel better about myself and better about having this illness, kind of disease kind of thing. I didn't like it."* [YPCT25, p. 5-6]

This suggestion of 'feel[ing] better about myself' implies that trial participation was partly about restoring her self-esteem and re-establishing a sense of control.

Health benefit – More and better care

A third theme emerging from the analysis was young people's belief that they would get more attentive care. The participants mentioned feeling reassured that they would be intensively monitored and that any new problems would be detected early as an important indirect form of health benefit. Closer contact with physicians and care from an expert medical team were also reasons for them to take part in a clinical trial. All participants said there was always someone to contact if there were any problems or in case they had questions.

In many cases, they had both a phone number to call or text, and an email address to reach one of the researchers. A few participants reported that getting more attentive care and monitoring was more an incentive for their parents than for themselves.

Receiving a (financial) reward

Some participants mentioned getting a reward at the end of the trial. This reward was mostly a voucher or other form of payment, but was occasionally a small gift such as a magazine. Only two participants mentioned financial reward as being something of an incentive for taking part. This included one person involved in a randomized placebo controlled drug trial for cystic fibrosis, and one person involved in a clinical trial for type 1 diabetes where the participant had to complete a questionnaire at each routine clinic visit. Getting a reward did not appear to be a very strong motivation, given the fact that the two participants said they also would have taken part if it did not include a reward.

Although receiving a reward was not an important reason to take part, participants mentioned a reward at the end to be a good thing to know that their help is being appreciated. They also noted that a reward can help recruit participants, because other young people might be motivated by money. However, some mentioned that payment might encourage people to take part for the wrong reasons or was not necessary. One of the participants (aged 15), who participated in a clinical trial for type 1 diabetes said:

> *"I think people should do it just out of the good of their own heart really because, I mean a payment, it's just, because it's helping yourself really and helping other people.*
>
> *...It's not about money, yes. It's about helping people get better and get over things that it's hard to get over like long-term illnesses. So, no, I don't think payment is really necessary for research."* [YPCT11, p. 22]

Another participant, aged 12, who declined to take part in a drug trial for acute lymphoblastic leukemia, also said payment was not important. However, she said that it might depend on the type of trial:

"Because this drug could change your life isn't that payment enough? This drug could change everything for the better and surely that is enough, I know like with things like acne trials and stuff that's different then yes payment is a good idea because children will be more reluctant to take part but when it comes to serious trials like this I don't think there should be payment in that." [YPCT 19, p. 48]

...With serious trials like chemotherapy and protocols or any other serious illness I don't think payment is needed. Because it is basically saying that this drug could change your life and make you so much better so surely that is payment enough." [YPCT19, p. 49]

<u>Positive experiences during or after taking part in a clinical trial</u>

Participants mentioned that during or after the trial they noticed other forms of personal benefit. These benefits were not originally what motivated them, but they do contribute to a positive attitude towards participation in clinical trials. Almost all young people said they would be willing to take part in a similar trial again.

Some were very excited after making the decision, thought the tests were fun to do, or were interested in science. By participating in a clinical trial, young people experienced a better understanding of their disease and they experienced a sense of personal enrichment.

They learned a lot about themselves and gained more confidence. Being part of a trial made them feel good knowing that they were helping other people. It enabled them to integrate their own experiences in a wider context:

"I think it's made me like a bit more considerate because I could have a lot more serious illness and I could be on like 20 tablets a day but I'm not and I should be like grateful for that really." [YPCT15, p. 70]

"You kind of feel like, the reason, because you've got this like horrible thing, you're actually doing something good for, you're doing something good for it. And it's kind

of, you kind of think better about it than what you did. Because I used to, I used to, "I hate it." But because of doing the trials I've, I've learnt to accept it so much better than I think I would have done if I didn't do the trials." [YPCT25, p. 29-30]

"Well I've tried describing it to my friends and just like it's quite nice going up and being part of something quite big and only a few people involved, it's quite nice and you can just, it's nice just going up somewhere." [YPCT17, p. 37]

Helping others

While helping others was mostly reported in combination with personal benefit, a few participants talked about helping others as their only or key motivation to take part. By 'others', many participants meant future patients. One boy mentioned specifically that he wanted to help a friend who had just been diagnosed, and one mentioned wanting to help parents of future patients. Several young people also reported wanting to help their doctors. In addition, they experienced a feeling of moral duty, and acknowledgement of the contribution made by past generations. These themes could be summarized with the concept of a 'network of exchange'.

Helping future patients or parents

Depending on the type of trial, several ways of helping future patients were mentioned. These include improvement of treatment options in drug trials or preventing illness in vaccine trials. Participants said they wanted to help other patients dealing with their disease. Some wanted to help others have more understanding of their illness. They were enrolled in trials about different ways of giving young people information about their condition, or different approaches to supporting self-management.

"I thought about it for a couple of days and then I decided that I wanted to do it. And I wanted to do this trial because it was the first trial that I'd ever done including, for diabetes. And to me, I felt like because I didn't have a good time to begin with doing it, I wanted to help other people. And if this was one way that I could help them in the future, I wanted to do that." [YPCT25, p. 5]

One participant mentioned the benefit for parents. This boy, aged 13, took part in a randomized trial on the management of type 1 diabetes in young people. He explained the importance of parents recognizing symptoms when their child has a low blood sugar level:

> *"If there were younger people, then you get the parents to help them with it. And like there, they could say, "Do you feel shaky when, when you're low?" And they'll say, "Yes." And then if they're like, the kid's like sweating a lot, because sometimes you do when you're low, they would know. Because if you were young, like you couldn't really explain because you wouldn't know that many like feelings and words and everything and you wouldn't know the symptoms properly, but your parents would. So it would help your parents as well."* [YPCT07, p. 11]

Helping doctors and owing society

Participants wanted to be able to do something in return for what they received from others. Some participants saw their participation as a way of helping their doctors in exchange for their good care.

This reciprocity also emerged in the feeling of moral duty that was reported. They felt they owed something to both past and future patients. Participants acknowledged the need for clinical trials for the development of health care. The fact that it can only be carried out with help of patients with the particular illness encouraged them to take part for their future community of patients. Even one girl who decided not to take part said:

> *"I think you have to take the next step for the next generation. And you have to be able to understand and that you could change millions of children's lives in the future and whether that is worth taking your risk on your own."* [YPCT19, p. 50]

One participant, aged 22, had taken part in several clinical trials since he was young. He explained how he realized he benefited from past research and felt a desire to give something back. This is an example of intermingled motivation of helping others and helping oneself:

> *"But as I grew older I began to realize the importance of medical research and clinical trials to directly benefit me. And when developing that point of view I saw how important it was that I had taken part in these trials and also it gave me the motivation to want to carry on in taking part in them. Particularly when I think that the difference in the quality of life for people with Cystic Fibrosis now as opposed to when I was born is vastly different and so much better and solely due to medical research. And so I feel that because I'd benefitted from it then in a way I owe something back, you know, to future generations to help in whatever way I can."* [YPCT05, p. 1-2]

Young people's recommendations

A very clear message young people gave was that professionals should do more clinical trials with children and make children aware of research opportunities. Some participants mentioned that they had wanted to take part in clinical trials before, but were never offered the chance. Therefore, they said, it would be nice to have a protected website where young people can show their interest in participating in clinical trials and professionals can give details about research that is going on. To give young people examples, they should provide information about research that has been performed in the past. Such a website could also give young people the opportunity to come in contact with other young people who took part in the same or a similar trial to share their experiences. Other suggestions for improving recruitment were to get young people interested in the aim of the study, and to use patient support groups for recruitment.

The third important message the young people had for professionals was to let participants know that they have helped. Many of them did not know the results of the trial they took part in, but would like to. One participant said it was important to give people feedback about the trial as soon as possible, and perhaps not to wait until after formal publication has been completed because that can be a long time. Another participant noted the fact that as a patient you might not have access to results published in medical journals anyway.

Discussion

This study gives a better understanding of young people's experiences with participation in clinical trials. Where quantitative studies are often biased by preliminary conceptualizations, this qualitative study provides a much wider picture because the participants themselves came up with relevant themes regarding their experience.

We first will address the professionals concerns about the therapeutic misconception. It is thought to compromise parents' and young people's capacity for decision-making and their ability to analyze the risk-benefit ratio. The notion of therapeutic misconception, however, does not capture the narratives of our participants entirely. The concept of therapeutic optimism might provide a more accurate understanding of their experiences. Woods et al. identified two forms of hope, or the so-called 'blind optimism', that may play a significant role regarding therapeutic misconception. One is the blind optimism that exists when parents' hope for a treatment for their ill child is irrational and becomes a kind of self-deception. This form has the potential to feed a serious misconception and should be distinguished from a form of hope that does not result in despair (Woods, Hagger, and McCormack 2014). Horng and Grady used the term 'therapeutic optimism' for this and described it as a positive attitude towards coping with illness. It refers to hope for the best outcome rather than conflating research with clinical care (therapeutic misconception) or a misunderstanding of the possible benefits relative to the possible risks or burden (therapeutic misestimating). This therapeutic optimism is tolerable because it does not compromise a person's autonomy to decide whether to take part in a clinical trial (Horng and Grady 2003). Although research elements may not always be fully understood by our participants, they showed in several ways that they were aware of the fact the research may not benefit themselves. Some of them explained the trial would not help them improve their health condition. They realized the possibility of being in a control group and receiving the standard treatment. Using the terminology of therapeutic misconception might underestimate the autonomy of participants. Therapeutic optimism might do more justice to the decision-making process of people considering participating in research. Researchers have the responsibility to properly inform young people and their parents about the uncertainties associated with being in a trial and its possible risks,

but information about possible benefits should also be given. These benefits include much more than direct health benefit and may be experienced both during and after taking part, for example learning more about their disease, restoring their self-esteem, and having a sense of control after being diagnosed with an illness. Trial participation may also mean closer monitoring and care by a highly specialized team. Young people held the view that taking part in a clinical trial made them feel special, and that it could enrich their personal life in various ways. We are aware of the fact that we are reliant on self-report in this interview study, and we bear in mind that all narrative accounts are constructed to create personal meaning, rather than being a 'true' account.

While some studies concluded children mainly take part in clinical trials because of hope for personal (therapeutic) benefit, our participants often showed a combination of personal benefit and helping others as their motivation for taking part. For example, Susman et al. concluded that '*being cured is the primary issue that obscures all other scientific issues*'. They also found that not many children understood about the benefit that trials gain for others (Susman, Dorn, and Fletcher 1992). In contrast, we found that nearly all young people were aware of the fact the trial aimed to help medical science and thereby future patients. A few participants said they didn't mind that the trial was not benefiting them at the moment, but they wanted to do it for other patients. There seems to be an altruistic motivation. Altruism is often opposed to 'egoism'. Some people believe there is a common tendency of humans to see themselves as the center of the world (Richard 1976). If this is the case, doing something simply for the benefit of others is not possible. However, people are dependent on each other and do act for the benefit of the other (Schramme).

In this research we see that participants express altruism as motive and intention for their action. We refer to the form of altruism as 'psychological altruism'. According to Batson this is *"a motivational state with the ultimate goal of increasing another's welfare"* (Batson 2011). Whilst many defend that this aim should be pursued 'for its own sake' (Frankena 1963), Schramme argues that altruism based on an ultimate goal asks for a purity that does not exist in the real world, because there is always some personal gain involved. Altruism is about the welfare of others, but does not necessarily exclude self-interested desires. Schramme distinguishes between egoism and self-interest and describes altruism as

"people act altruistically if they identify with their behavior" (Schramme). In this sense a young person can participate in a clinical trial because he wants to identify himself as a person who reciprocates the efforts of previous generations of patients in making a contribution for future patients. Given the complexity of the notion of altruism, we suggest that 'network of exchange' and 'intergenerational solidarity' better describe the diversity in motivations the respondents reported. Young people wanted to do something back for their doctors for the good care they received. They reported a feeling of moral duty; to acknowledge the contribution made by past generations, and a sense of owing it to future patients. They wanted to help future patients and their parents to improve treatments options, manage their disease, and to have more understanding of their condition. Young people realized that future patients need them just as they have benefited from patients in past research. This latter can be referred to as 'intergenerational solidarity'.

Implications for practitioners

We have some recommendations to possibly improve recruitment of young people for clinical trials. First, practitioners should be aware of young people's willingness to take part in clinical trials. The most notable message our participants had for professionals was to do more clinical trials. They would like to be offered more opportunities to learn from the research and to help improving health care for themselves and future patients. Shilling et al. found that parents, even if they declined to let their child take part in a clinical trial, mentioned the value of research. While practitioners showed concerns that parents might be overburdened, some parents saw participation as an exciting opportunity (Shilling et al. 2011). Both children and parents seem to be more positive about being approached for participation in clinical trials than researchers anticipate.

Another strategy might be for practitioners to engage young people in the information process. Young people want to be encouraged to be involved in the process of informed consent. It is important that they speak to the child and not only to the parents. Practitioners can actively provide young people with and involve them in information about the trial, and encourage them to ask questions and give input. The information should not be restricted to the required information about the research elements. Being open about the risks is important, but young people should also get an idea of how

participation in research can affect their life in a positive way. It would be good to develop a website where young people may come in contact with each other. On such a website further information should be provided for parents and their children on research that is going on, and research that has been performed in the past. Young people in our study said they had not always been offered a chance to participate in a clinical trial. Practitioners could cooperate more with patient organizations in order to achieve better recruitment.

Third, practitioners should let young people know they have helped. Young people in our study were curious about the results, but mostly did not know if and when they would receive any. They said a small gift or financial reward may be good to make participants feel that they are appreciated. However, when payment becomes an incentive to take part rather than a fair compensation, it may cause some problems. It may unduly influence participation by reducing interest in understanding risks and burden, and it may encourage misrepresentation (Grady 2005). Therefore, perhaps a small gift at the end of the trial without focusing on it in advance may be best.

Study limitations and need for further research

Young people participating in this study were not always clear about the type of research they were involved in. Featherstone and Donovan concluded that adults had problems with understanding the trial they were involved in, and with respect to their treatment allocation (Featherstone and Donovan 2002). Young people in this study also found difficulties describing what trial they were involved in. This might be due to lack of explanation by the researchers, but it may also be that young people are just not that interested. Taking this into consideration, in some cases it was hard to decide whether we had to include or exclude a potential participant.

Considering the fact that participants knew in advance that the results would be published on a public website, this may have influenced their responses. However, they could be completely anonymous (text only) if they wished. In addition, we think that young people may be less troubled about visibility on social media than adults. The young people in our study were remarkably frank about their experiences.

Our participants seemed to be very mature and well able to express themselves. Young people that participate in interview studies probably are more motivated to speak, and more positive about their participation in clinical trials. It may be that they tend to be more mature anyway, or interested in science. This is an inevitable difficulty in recruiting for interview studies.

In our study we included only one participant who declined to take part, and one participant who withdrew. Hoberman et al. found several influencing factors between parents who consented for their child to participate in clinical research compared with parents who did not consent (Hoberman et al. 2013), but further studies are needed to explore these differences in children and young people themselves.

Qualitative research based on purposive maximum variation sampling cannot provide information about statistical significance of particular motivations mentioned by the participants. However, our study adds new evidence of young people's personal motivations and their experiences with participation in clinical trials. We provide an overview of experiences from young people with different illnesses, severity of their condition, and a wide range of ages. Further research is needed to obtain qualitative data on motivations and experiences of young people in different groups, based on illness severity. In addition, to get an even more detailed and nuanced picture a comparison between different age groups should be made. Such studies should also involve young people's parents in order to make a proper comparison between their motivations.

Conclusion

Our understanding of young people's experiences of participation in clinical trials has deepened. Young people's reasons for taking part included both personal benefit and helping others. These categories were more complex than expected. Regarding personal benefit, young people's experiences covered a wide range of interwoven motivations, which include much more than just health benefit. Participation also contributed to enrichment of their personal life and dealing with their disease. The young people felt special and acquired more confidence. Receiving a financial reward was not very important to them.

Our participants wanted to help future patients, parents, and their doctors. In addition, they experienced a feeling of moral duty and acknowledged the contribution made by past generations. For helping others in general, we introduced the term 'network of exchange'. When young people specifically aimed at helping future patients to acknowledge contribution made by patients in the past, we referred to 'intergenerational solidarity'.

Professionals should not be reluctant to ask young people to participate in clinical trials. They often welcome the opportunity to contribute to medical research, and to learn from it. Professionals should also be more open about research opportunities and provide better information. In addition, they should give young people feedback after the trial has ended. This may lead to better recruitment for clinical trials and thereby better healthcare for children.

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