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Is there a duty to participate in a health research? A viewpoint of children 6–8 years of age and their parents

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It has been discussed in recent years whether participants should have a duty to participate in health research. Despite these theoretical discussions, there is little empirical evidence about study participants' perceptions of duties. We studied children's and their parents' sense of duty regarding participation in The Physical Activity and Nutrition in Children (PANIC) Study. In addition, we evaluated whether the sense of duty was related to the long-term participation in the study. The original study group of PANIC Study consisted of 512 children aged 6–8 years. Complete data of this sub-study were available for 312 children and their parents. Data on long-term participation were evaluated after 24 months. Analysis protocol was exploratory. The data show that 30% of parents felt a duty to participate in the study. However, only a minority of children (11%) felt the same. Parents' sense of duty in the early stages of the study improved long-term commitment to ongoing research. Thus, we can state that study participants have a sense of duty to participate although we cannot impose a duty to take part in any research.

Key words: Duty, Children, Parents, Participation, Health, Research

Background

Voluntariness is the most important ethical aspect to protect potential study participants in health research. Voluntariness in research has been stated in international declarations, such as Declaration of Helsinki by World Medical Association (1964, last amendment 2013), as well as in national regulations (Finnish Medical Research Act 488/1999, last amendment 2010). It is also important to inform potential study participants about the possibility to withdraw from the study at any phase of it.[1,2]

It has been discussed whether individuals should have a duty to participate in research.[3–7] Especially in biomedical research, it has been considered that, there is a positive moral obligation to pursue and to participate.[3,5] In addition, it has been argued that we must change the standard view of research participation. The change from a principle where participation is supererogatory to thinking that individuals need to give a good reason not to participate.[5] The obligation to participate rises because biomedical research produces the public good that everyone has access to. In addition, it retains its value no matter how many individuals have access to it, e.g. vaccines, drugs or medical devices.[5] However, all this discussion has not led to changes in official documents or statements.[1,3] Autonomy of the participants is the main ethical principle in research. Current legislation and practices emphasize the possibility to withdraw from research at any time and individual decision to consent or not. This has been unchangeable in the latest revisions of Declaration of Helsinki and national legislation in Finland.[1,2] In addition, concerning duties, the responsibilities of participants have also become a subject of consideration. These responsibilities could be based on duties of being beneficial, reciprocation of service, keeping promises and avoiding harm to oneself or others.[8] It has been stated that participation in research is a critical way to support an important public good.[5]

Biomedical research on paediatrics is strictly regulated by law. Research can be performed on children only if it is not possible to obtain the same scientific results using other research subjects and where the risk of harming or distressing the research subject is only very slight. In addition, the research should likely to be of direct benefit to the research subject's health or of special benefit to the health of people in the same group or with the same state of health.[1,2] It is well known that obtaining consent for paediatric research can be challenging, both the child and the parents must be informed, competence of the child must be evaluated and often the recruitment situation is very discreet.[9,10] A numbers of studies have shown that children do not understand the basic aspects of given information especially the risk associated with participation, the right to withdraw and the difference between care and research.[10–13] Based on our knowledge, there is quite little empirical evidence about the sense of duty of study participants especially with children.

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Participation in research is an active and important way to contribute to public good.[5] However, the increasing prevalence of overweight and related cardiometabolic risk factors in childhood [14] and the consequent increase in the prevalence of overweight, Type 2 diabetes (T2D) and cardiovascular diseases (CVD) in adulthood[15] are major public health and clinical problems worldwide. To obtain reliable results, it is important for the participants commit to long-lasting studies. A situation where many participants refuse or withdraw is untenable to an ongoing research. The combination of voluntariness, the possibility to withdraw at any phase and the importance of getting trustworthy knowledge, creates a challenging situation to researchers and potential participants.[10,16]

The objective of this study was to explore children's and their parents' sense of duty regarding participation in The Physical Activity and Nutrition in Children (PANIC) Study. In addition, we investigated whether children's or parents' sense of duty regarding participation at early stage was related to the long-term participation, as evaluated after 24 months of intervention.

Methods

Study design and subjects

The present study is part of PANIC Study, which is an ongoing exercise and diet intervention study. The PANIC Study is a multidisciplinary health promotion and scientific effort to collect comprehensive information on children's health, quality of life as well as to study the physical, cognitive and psychological effects of physical activity and diet. This enables the promotion of children's health and wellbeing more effectively and pays special attention to high-risk children.

We invited 736 children 6–8 years of age who, started the first grade in 16 primary schools of Kuopio in 2007–2009, were able to communicate in Finnish, and were thus eligible for the study (Figure 1). We received the contact information of the children's principal custodians from the city of Kuopio and sent them the invitation letters by mail. Altogether, 512 children (248 girls, 264 boys), who accounted for 70% of those invited, participated in the baseline examinations in 2007–2009. The participants did not differ in age, sex distribution or body mass index standard deviation score (BMI-SDS) from all children who started the first grade in the city of Kuopio in 2007–2009 based on data from the standard school health examinations performed for all Finnish children before the first grade.[17–19] From this sample, 440 (86%) participated in the 2-year follow-up. Altogether, 321 (63%) children and their parents filled in the questionnaire at baseline. Complete data on sense of duty to participate in the study were available for 312 (61%) children

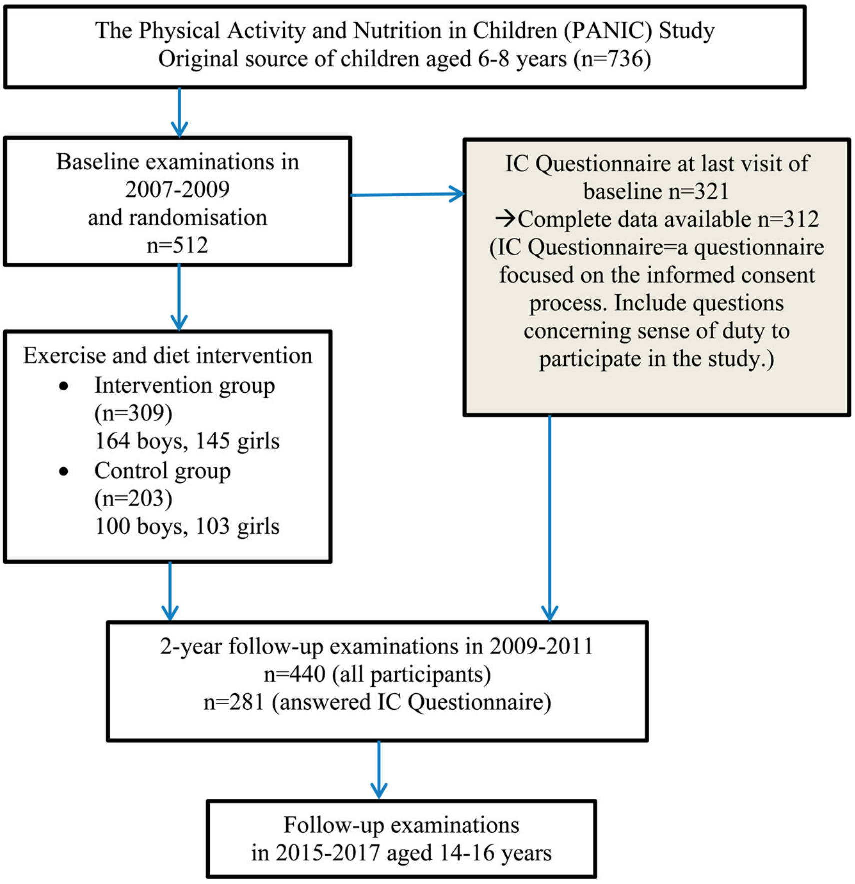

Figure 1 Study design.

and their parents at baseline and of those 312 for 281 (90%) at 2-year follow-up. The design of the study is presented in Figure 1.

The study was approved by the Research Ethics Committee of the Hospital District of Northern Savo (Kuopio, Finland). All children and their parents gave their informed written consent. According to Declaration of Helsinki and Finnish Legislation, children can be research participants only if it is not possible to obtain the same scientific results using other research subjects and where the risk of harming or distressing to participants is only very slight. Additionally, the research should be likely to be of direct benefit to the research subject's health or the research should be likely to be of special benefit to the health of people in the same age group or with the same state of health. It is also addressed that the potential participant must be informed of the right to refuse to participate in the study or to withdraw at any time without reprisal. Special attention should be given to the specific information needs of individual potential subjects as well as to the methods used to deliver the information. The child's own opinion and supposed will must be obeyed taking into account his/her age and level of understanding.[1,2]

Assessments

All assessments in The PANIC Study were supervised and performed by trained and qualified research personnel. Data on children's and their parents' sense of duty to participate in the study were collected by a self-administered questionnaire focused on the informed consent process (IC Questionnaire). The IC Questionnaire was modified from a questionnaire that was previously used in a randomized controlled trial on the effects of regular physical exercise and diet on inflammation, endothelial function, atherosclerosis and cognition in adults. The development of the questionnaire was based on international declarations and guidelines of research ethics, on national legislation, codes and guidelines of ethics, on relevant literature and on a pilot study.[20,21] During the last baseline visit, the children and their parents were given oral and written information how to fill in the questionnaire. They were asked to fill in the questionnaire at home and to return it within 2 weeks in an envelope. In the IC Questionnaire, the parents were asked whether they felt it was their duty to participate in the study and why they felt so. The children were asked whether they felt that they must participate in the study and why they felt so. The participants' long-term commitment in the intervention study was evaluated by attendance to the 2-year follow-up examinations.

Body weight was assessed twice after overnight fasting, empty-bladdered and standing in light underwear by a calibrated InBody® 720 bioelectrical impedance device (Biospace, Seoul, Korea) to accuracy of 0.1 kg. The mean of these two values of body weight was used for the analyses. Body height was assessed three times in the Frankfurt plane without shoes by a wall-mounted stadiometer with the accuracy of 0.1 cm. The mean of the nearest two values of body height was used in the analyses. BMI was calculated as body weight (kg) divided by body height (m) squared. BMI-SDS was computed by the national references.[22]

The level of education in the family based on the highest completed or ongoing degree (vocational school or less, vocational high school, university degree) and the annual family income (30 000 € or less, 30 001–60 000 €, over 60 000 €) were inquired by a questionnaire.

Statistical methods

Statistical analyses were performed using the SPSS for Windows software, Version 19.0 (IBM® Corp., Armonk, NY, USA). To describe the data means, standard deviations, frequencies and percentages were calculated when appropriate. Differences in background variables between those children whose parents filled in and those children whose parents did not fill in the IC Questionnaire were assessed with Mann–Whitney's U-test for continuous variables and Pearson's χ^2 test for categorical variables. Associations of children's and parent's sense of duty with background variables were assessed with Mann–Whitney's U test and Pearson's χ^2 test. The associations of the children's and parents' sense of duty with long-term commitment were tested using cross-tabulations and χ^2 tests. A p-value < 0.05 was considered to be statistically significant. The short supplementary open questions were included to provide a more in-depth understanding of the quantitative data. Content analysis was used to collate, synthesize and refine these qualitative data. The words in the open questions were classified into a few categories chosen according to their theoretical importance. This technique provides a systematic means of measuring the frequency, order or intensity of occurrence of words, phrases or sentences.[23,24]

Results

There were no statistically significant differences in sex distribution, age, BMI, BMI-SDS, parents' education or family income between 312 children whose parents filled in the IC Questionnaire and 200 children whose parents did not fill in the questionnaire (Table 1). However, children whose parents filled in the questionnaire were more likely to be present in the intervention group than the other children ($p = 0.011$).

Children's sense of duty

Altogether, 270 (87%) of the 312 children felt voluntariness to participate in the study and 251 (80%) of them considered the study important. However, 33 (11%) of the children felt that they must participate in the PANIC Study. The most common explanations of the children for this feeling were 'Mother or father forced me to participate' (46%), 'The aim of the study is important' (14%), 'I must but I also want to participate in the study' (14%), 'A promise to participate means

Table 1 Characteristics of the participants.

	All children	Children whose parents filled in the IC Questionnaire[1]	Children whose parents did not fill in the IC Questionnaire[1]	*p*-Value[2]
Amount, *n*	512	312	200	
Sex, *n* (%)				0.197
Boy	264 (51.6%)	168 (53.8%)	96 (48.0%)	
Girl	248 (48.4%)	144 (46.2%)	104 (52.0%)	
Age, years, mean (SD)	7.6 (0.4)	7.6 (0.4)	7.6 (0.4)	0.770
BMI, mean (SD)	16.1 (2.2)	16.2 (2.2)	16.1 (2.1)	0.605
BMI-SDS,[3] mean (SD)	−0.2 (1.1)	−0.2 (1.1)	−0.2 (1.1)	0.609
Parents' education (as treated by higher -educated parent), *n* (%)				0.235
University degree	178 (34.8%)	118 (37.8%)	60 (30.0%)	
Vocational high school	224 (43.8%)	130 (41.7%)	94 (47.0%)	
Vocational school or less	99 (19.3%)	62 (19.9%)	37 (18.5%)	
Missing	11 (2.1%)	2 (0.6%)	9 (4.5%)	
Annual family income (euro), *n* (%)				0.111
Over 60 000	181 (35.4%)	123 (39.4%)	58 (29.0%)	
30 001–60 000	208 (40.6%)	121 (38.8%)	87 (43.5%)	
30 000 or less	105 (20.5%)	62 (19.9%)	43 (21.5%)	
Missing	18 (3.5%)	6 (1.9%)	12 (6.0%)	
Research group, *n* (%)				0.011
Intervention group	309 (60.4%)	202 (64.7%)	107 (53.5%)	
Control group	203 (39.6%)	110 (35.3%)	93 (46.5%)	
Filled in the IC Questionnaire, *n* (%)				
Mother and child	–	207 (66.3%)	–	
Father and child	–	20 (6.4%)	–	
Mother, father and child	–	83 (26.6%)	–	
Missing	–	2 (0.6%)	–	

Values are expressed as frequencies (%) and for age, BMI and BMI-SDS as means (standard deviations).

[1] IC Questionnaire = a questionnaire focused on the informed consent process.

[2] Differences between children whose parents filled in and children whose parents did not fill in the IC Questionnaire were assessed with Mann–Whitney's *U*-test for continuous variables and Pearson's χ^2 test for categorical variables.

[3] BMI-SDS was computed by the national references.[14]

commitment to the study' (7%), 'I want to participate for the sake of my health' (7%), 'I want to participate because others have also participated' (4%), 'I don't feel like leaving at home every time' (4%) and 'The small gifts persuaded me to participate in the study' (4%). Children's sense of duty was not associated with sex, age, BMI, BMI-SDS, parents' education, family income or parents' sense of duty (data not shown).

Parents' sense of duty

Two hundred and seventeen (70%) parents of the 312 children felt that they do not have a sense of duty to participate in the study. Of the 91 (29%) parents who did feel a sense of duty to participate, the most common explanations of the parents for this feeling were: 'I will obtain information on my child's health' (21%); 'I will be able to help other people now and in the future' (17%); 'The aim of the study is important' (17%); 'I am responsible for my own health' (17%); 'A promise to participate means commitment to the study' (8%); 'I want to support medical research' (8%); 'I belong to the group selected for the study' (4%); 'I have a pressure to participate in the study because others have also participated' (3%) and 'I have other individual feelings of responsibility' (11%). Parents' sense of duty was not associated with children's sex, children's age, children's BMI or BMI-SDS, parents' education or family income (data not shown).

Long-term participation

Children whose parents filled in the questionnaire were more likely to participate in the 2-year follow-up examinations than the other children (90.0 vs. 79.5%, $p = 0.001$). Children whose parents felt a sense of duty to participate in the study were more likely to attend in the 2-year follow-up examinations than children whose parents did not have this sense of duty (97.8 vs. 86.6%, $p = 0.005$). Children's sense of duty was not associated with the participation in the 2-year follow-up examinations (data not shown).

Discussion

This study provides new knowledge about study participants' sense of duty to participate in health research and its associations with the commitment to the study. Our results indicate that almost a third of the parents had a sense of duty to participate in the exercise and diet intervention study (PANIC Study) for their children. Common explanations for the parents' sense of duty were to obtain information of their children's health and willingness to help other people. These findings are similar to our earlier observation that half of the adult participants of the exercise and diet intervention study stated it was their responsibility to participate in the study.[21] The explanations were also consistent. Although parents could perceive participation as a duty, the explanations also showed that participation appeared to be voluntary, and not coercive. The main finding of our study is that the sense of duty is closely associated with the long-term commitment to the study. In addition, children whose parents conscientiously filled in the questionnaire were more likely to participate in the study after 2 years compared with those children whose parents did not fill in the questionnaire.

This study provides new aspects about children's involvement in health research. It is self-evident that research with children is needed to provide more knowledge of children's health. Commitment to improve children's health is a wise investment for the future in the global community. To address health disparities at early age is important.[25] For instance, childhood obesity has become a clear example of this new type of challenge. For greatest benefit, family-based approaches to prevent obesity should be coupled with interventions in the school and in the community.[26] Even though children can be regarded as a vulnerable group, it is essential to perform research also with them. However, it is important to recognize children as individual participants and not only objects to carry out parents' decisions. Today, consent provided by parents on behalf of their children is widely seen valid and accepted for the participation in studies.[1,27] We also agree with Harris that parents making decisions for their children are fully justified in assuming that their child will wish to do that which is right.[3] By participating in studies, children get used to ethical thinking and promoting public good. Nevertheless, our results indicated that some of the children felt that their parents forced them to participate. Should this result worry us? From an ethical point of view, if any group abstains from participation, its members will be less able to share in on the rewards.[28] Therefore, children should be better acknowledged in the recruitment. Children, as stated in, for example, Declaration of Helsinki, must be adequately informed about voluntariness to take part to the present study and also possibility to pose own opinion about participation. Limitation of our study is the fact that children 6–8 years may have limited understanding what participation to study means as its wholeness. Therefore, the reliability of their answers must be considered. However, it is important to find out children's opinion and make efforts that they are taken into account. A major limitation in promoting this is that our data on the sense of duty are quite restricted. There is little empirical evidence about sense of duty of study participants, especially in studies with children.

Although empirical data are scarce, there is a great deal of theoretical discussion about the duty to participate in research. Evans claims that it is a duty to take part as a subject in research that can lead to improvement of future treatments.[29] Further, Harris argues that biomedical research is so important that there is a positive moral obligation to pursue it and to participate in it.[3] This argument should be compelling for anyone who believes there is a moral obligation to help others, and/or a moral obligation to be just and do one's share. The core idea is that since each of us stands to benefit one way or another from the ongoing research, we have a moral duty to contribute to it.[30] It is one way for individuals to serve a community from which they derive many benefits.[31] Again, it is also important to get wide data about the whole social context.[32] Also Rhodes agrees that there is a duty to participate in research, but it is noteworthy that research participation also promotes participants' own interests.[28] Participation in research is still not an established duty.[33]

Because our results strongly indicate that one reason for participating in the studies is the sense of duty, it raises out questions about the role of participants in research group. Are our participants considered as only a sample? Should we transform the role of participants towards equal partnership? Undoubtedly, as Sharp and Yarborough [34] introduced, research practices which reflect meaningful research partnerships and informed trust between researcher and volunteers will embody the good far better than compulsory research participation.

Conclusion

Our opinion is that participants' voluntariness is absolutely essential and therefore the duty to take part in research projects remains unresolved. As researchers, we crave that all our participants continue to the end of our project so that we gain as trustworthy results as possible. However, from an ethical point of view, we cannot appeal to participants to act against their own free will. It is worth asking at the beginning of a research project/recruitment whether the participants feel a responsibility to participate. This question gives us a prognosis on how the participant will commit to the research. Of course, we cannot ignore those participants who do not feel this sense of duty, but we can make sure that our project is proceeding according to good clinical practice. As for researchers, continuous evaluation and discussion on high ethical standards remain among their important responsibilities.

In PANIC Study, we have already shown that cardiometabolic risk factors cluster almost identically in children and adults[35] and that this cluster of risk factors predicts the development of T2D and CVD in adults.[35,36] Pathophysiological processes underlying overweight, T2D and CVD are known to begin in childhood [14] that emphasizes the early prevention of these diseases. To develop strategies for the early prevention of overweight, T2D and CVD, it is important to carry out long-term lifestyle intervention studies in large population-based samples of children and adolescents and to investigate the effects of physical activity and diet on the pathophysiological processes underlying these diseases.

In conclusion, the parents' sense of duty to participate in the study was associated with a better long-term commitment to the study. The most common reasons for the parents' sense of duty to participate were the importance of their children's or their own health, their willingness to help others or the feel of importance of the study, whereas the most common reason for the children's sense of duty was the feeling that parents forced them to participate. The results of the study emphasize that it is important to provide the children and their parents' positive, but realistic, information about the benefits of the study. If the participants have a positive feeling of duty, they are more likely to commit to the study. These findings highlight the need for future research of duty to participate. At the title, we posed a question: Is there a duty to participate in a health research? According to our results, many study participants have a sense of duty to participate; however, this does not mean that researchers should impose a duty on participants to take part in any research.

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