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Exploring Bioethical Reasoning in Children and

Adolescents Using Focus Groups Methodology

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**Abstract**

The present case study focuses on the exploration of bioethical reasoning in children and adolescents using focus groups methodology. The case study is based on a research project that aimed to explore the ethical considerations that children and adolescents might have, concerning recent developments in medicine and biotechnology. These developments (e.g., xenotransplantation, nanotechnology, treatments based on stem cell usage) and innovative techniques may provide a better quality of life or treatment to life-threatening diseases, but raise ethical considerations regarding the limitations of human intervention in life and death, animal rights, human embryos rights, and so on. The exploration of children and adolescents’ thoughts and reasoning on bioethics could provide us with fruitful information, such as intuitive r e a s o n i n g a n d o r i g i n a l t h o u g h t s o n t h e s e i s s u e s . A l t h o u g h w e u s e d a m i x e d - d e s i g n methodology, including interviews, questionnaires, and focus groups, in the present case, we will focus only on the use of focus groups methodology in children and adolescents. We would like to address the reasons why focus groups methodology was chosen over other research methods, the benefits of this approach for our research project, and also the challenges that we faced while conducting the focus groups with children and adolescents. These challenges raise from participants’ age and age-related characteristics as well as from the research topic itself and range from the preparation and duration of the focus groups to the mediator’s role during focus groups discussion with children and adolescents.

**Learning Outcomes**

By the end of this case, students should be able to

Reflect on how focus groups discussions can be used with children and adolescents Consider how bioethical reasoning in children and adolescents can be explored, as a relatively new area of research



Examine implications of the use of bioethical dilemmas devised by the researchers



**Project Overview and Context**

Current scientific developments in the fields of biotechnology, genetics, and medicine provide knowledge and implementations that could potentially improve or even prolong human lives. On the contrary, these developments lead to discussions regarding the limitations of human intervention in life and death, the value of life as well as society’s role in socio-scientific decision-making. Citizens are invited to contribute to public debates regarding the ethical limitations of science This research project focused on exploring children’s and adolescents’ bioethical reasoning. More specifically, we aimed to explore the ethical considerations that children and adolescents might have, concerning recent developments in medicine and biotechnology. We focused on issues such as the priority for transplantation, xenotransplantation, brain death, as well as stem cell and nanotechnology’s usage for treating life-threatening diseases. These developments and innovative techniques may provide a better quality of life or treatment to life-threatening diseases, but raise ethical considerations regarding the limits of human intervention in life and death, animal rights, human embryos rights, and so on.

As moral values shape these judgments, we assumed that the stage of moral development, factors that relate to moral development (i . e . , self - esteem, parenting style), and moral emotions, such as empathy and altruism, could relate to children’s and adolescents’ responses. In the present case method, we would like to focus only on the exploration of bioethical reasoning, using the focus groups methodology.

As we were interested in bioethical reasoning from a developmental perspective, we decided to address our research questions to children and adolescents. However, the research topic itself —because of the complexity of the bioethical issues—did not allow us to include participants younger than 11 years. Moreover, to address these issues to different age groups, two studies were designed. The first study was designed for primary school children (aged 11-12 years), whereas the second study was designed for adolescents (aged between 12 and 19 years). The two studies followed the same research design seeking to explore the same research questions. However, due to participants’ age and after considering age-related characteristics, we decided that we could not administer the same questionnaires and dilemmas to children and adolescents . Thus, we adapted the research tools (questionnaires and dilemmas) accordingly to each age group, at the pilot phase of the research study.

**Research Practicalities**

In the field of Bioethics, there is a fascinating ongoing discussion concerning society’s involvement in the socio-scientific decision-making. It is argued that society itself should decide and set the limits of human intervention in life and death. As it is mentioned above, although the scientific development provides opportunities to save human lives, these opportunities are usually accompanied by violations of ethical principles, such as the violation of animal rights. For example, xenotransplantation is a life-saving solution for patients who wait in priority lists. However, it presupposes the use of animal organs. Thus, xenotransplantation raises instantly ethical considerations about animal rights. Moreover, these innovative techniques raise discussions about the definition of human life, for example, in the case of brain death and stem cell usage. Philosophers argue that the society should provide the answers about which innovative methods are acceptable and which are not.

As these possibilities result from recent developments that have not reached the public yet, the conversation concerning these issues is limited only to groups of experts. Soon enough though, citizens will be called to make judgments on bioethical issues. However, is society ready to engage in this discussion? Research shows that the public understanding of the scientific knowledge involved is limited (e.g., Lanie et al., 2004). Consequently, attitudes toward bioethical dilemmas are based mainly on intuition and/or prejudice, rather than knowledge and ethical principles . Education could contribute to citizens’ informed decision - making by developing educational programs that aim to enhance students’ scientific understanding, argumentation skills, and moral values. This was the first reason that led us to engage with the present research project. Our initial goal was to explore children’s and adolescents’ bioethical reasoning about factors that could promote or weaken the understanding of bioethical issues and the relevant reasoning processes. Our ultimate goal was to design an educational program that could enhance children’s and adolescents’ bioethical reasoning.

The moral dilemmas about the limitations of human intervention in life and death are directly affected by a values system, which is strong enough to guide judgments in favor or against those bioethical dilemmas. Thus, we decided to explore bioethical reasoning about moral development and moral emotions. We assumed that the stage of moral development and the level of moral emotions would directly affect bioethical reasoning. We chose to include in our research design Kohlberg’s (1976) stage of moral development, empathy, altruism, self-esteem and parenting style. Apart from the other variables, by exploring students’ bioethical reasoning per se, we collected fruitful information, such as intuitive reasoning and original thoughts on the issues addressed. This information has also broadened our understanding of the development of moral reasoning.

**Research Design**

As it was mentioned above, Studies 1 and 2 were designed to explore bioethical reasoning (and the other variables that were included in the research project) in primary school children and adolescents, respectively. Due to the nature of our research questions, it was evident from the beginning that we would employ a mixed-methods research methodology. More specifically, besides the exploration of bioethical reasoning, we were also interested in the relation of bioethical reasoning to moral development and moral emotions. To collect reliable data concerning participants’ bioethical reasoning, moral development, and moral emotions promptly, we decided to employ different methodologies. Thus, we combined widely used (e.g., Kohlberg’s dilemmas for the assessment of moral development) and reliable assessment tools (questionnaires about the factors that relate to moral development were considered appropriate for children and adolescents, and previous studies have reported good psychometric properties) with focus groups (for the exploration of bioethical reasoning).

In the case of the assessment of bioethical reasoning, in our knowledge, there were not any available and suitable research tools that could fit our research topic and research design. Thus, we concluded that we would need to develop our research materials. The dilemmas that we used were also suitable for each age group and were previously tested in a smaller scale, pilot study. The use of dilemmas and participants’ age led us to focus group methodology. We also had considered individual interviews. However, we assumed that focus groups would allow us to ensure participant’s understanding of the issues addressed to them and, at the same time, would give them the opportunity to reflect on these issues.

In the following subsections, we would like to describe briefly our research design for Studies 1 and 2.

**Study 1**

**Participants**

A total of 55 primary school children (27 girls and 28 boys) participated in Study 1. The participants were allocated into two age groups (29 eleven-year-olds and 26 twelve-year-olds).

**Method**

We used a mixed-design methodology, including interviews, questionnaires, and focus groups.

**Procedure**

Participants were examined in the framework of focus groups in their classrooms. Each focus group consisted of six to nine students coming from the same classroom. Nine focus groups were designed and delivered. During the focus group discussions, students were presented with seven bioethical dilemmas . Participants were encouraged to ask questions to the researcher, as well as to exchange views, ideas, and conceptualizations and interact with the group. Afterward, they have been invited to make judgments individually and argue in favor and/or against the presented dilemmas. They were also individually interviewed based on Kohlberg’s dilemmas. Finally, they were asked to complete a series of questionnaires. The scales, dilemmas, and the accompanying questions were given in written format, and the data we collected were also in written format

**Measures**

**Bioethical Dilemmas**

Children were presented with seven stories that were accompanied by seven bioethical dilemmas. The dilemmas concerned transplantations (two dilemmas), xenotransplantation (two dilemmas), brain death (one dilemma), and stem cell usage (two dilemmas). For example,

Human transplants are rare in our country. Only 1 out of 10 has volunteered as an organ donor. Every year in Europe 3.6 million people will be diagnosed with heart failure. Researchers report that they have reached the final stage of a very hopeful, but at the same time, risky experiment on the development of vital human organs in animals’ bodies and, in particular, in sheep. What do you think? Can we replace for health reasons vital organs of our body (e . g . , heart) with ones that have been developed inside the body of other living organisms?

**Other Assessments**

To choose which factors that relate to moral development we should include in our project, as well as the appropriate tools for the assessments, we contacted a literature review before research design. After the review of the existing literature, we concluded that Kohlberg’s Dilemma II (see Colby et al., 1983) was going to be used to assess students’ stage of moral development. For the assessment of empathy, we used the “Feeling and Thinking” scale (2005), a child-friendly modification of Davis’ (1980) Interpersonal Reactivity Index (IRI). For the assessment of altruism, we used a questionnaire that was based on Ma and Leung’s (1991) Child Altruism Inventory, as well as Nakamura and Watanabe-Muraoka’s (2006) Global Altruism Subscale of Global Social Responsibility Questionnaire . Finally, for the assessment of parenting style, we used Darling and Toyokawa’s (1997) Parenting Style Inventory II (PSI-II), whereas for the self-esteem assessment, we used the Greek adaptation of Self-Perception Profiles (Harter, 2012).

**Study 2**

**Participants**

A total of 151 adolescents (90 females and 61 males) participated in Study 2, aged between 12 and 19 years. Participants were allocated to two groups based on their level of education. The first group consisted of junior high school students (68 students) and the second group of senior high school students (83 students).

**Method**

Similar to Study 1, we used a mixed-design methodology, including interviews, questionnaires, and focus groups.

**Procedure**

Research data were collected in schools, following the same procedure, as in Study 1. A total of 18 focus groups were scheduled. Each focus group consisted of six to nine students coming from the same classroom. During focus group discussion, students were presented with 14 bioethical dilemmas.

**Measures**

**Bioethical Dilemmas**

Participants were presented with 14 stories that were accompanied by 14 bioethical dilemmas. The dilemmas concerned transplantations (two dilemmas), xenotransplantation (three dilemmas), brain death (two dilemmas), and stem cell usage (seven dilemmas). For example,

1. 38-year-old mother who has been brain dead for four months has given birth to a baby boy in Al Khobar in the Eastern Province of Saudi Arabia. The mother was transferred to the hospital four months ago in a terrible state. She was 11 weeks pregnant and was artificially fed and given antibiotics. The baby boy was delivered 28 weeks and two days after conception and was in good condition. All post-natal tests did not reveal any abnormalities. What is your opinion? Is it good to keep alive a brain-dead pregnant mother until the moment the baby is ready to be delivered?

**Other Assessments**

To assess the stage of moral reasoning, we used Dilemma I (Heinz dilemma, see Colby et al., 1983). The Davis’ (1980) IRI was used for the assessment of empathy. For the assessment of altruism, parenting style, and self-esteem, we used the same scales as in Study 1.

**Method in Action**

The interviews and questionnaires that we employed in the present research project are well-known established measures and have been used in numerous different studies. Thus, in the present section, we would like to focus on focus groups methodology and its use in children and adolescents, to explore their bioethical reasoning. First, we are going to describe the benefits of this methodological approach for our study and the reasons why we preferred this methodology over other methodological approaches . Next, we will be addressing the challenges that we faced during the focus groups discussions. These challenges derived from

the research topic, as well as from participants’ age and age-related characteristics.

**Benefits From Focus Groups Methodology**

Bioethical dilemmas are complex socio-scientific issues that involve the understanding of scientific knowledge and its applications. In this research project, we assumed that primary school children and adolescents are not well informed about the issues that we explored. Thus, it was important to utilize a methodology that would allow us to explore the issues under investigation in depth. That way, we were able to answer our participants’ queries, further explain the procedures under discussion, and provide stimuli for thought and debate. As we have seen in action, if we were not able to further analyze the hypothetical situations and the dilemmas, a significant number of participants would not be able to provide arguments, either because of lack of scientific knowledge—and therefore misunderstanding of the stories—or because they could not reflect on the benefits and subsequently the consequences.

In addition, bioethical dilemmas also involve moral reasoning and a strong values system that shapes moral judgments in favor or against those dilemmas. As Kohlberg and Gilligan (1971) defined it, moral reasoning includes judgments about wrong and right and they suggested that its development is closely associated with age. During adolescence, the way we think about moral dilemmas is supposed to develop from an egocentric orientation to a more complex communitarian perspective. However, in our experience, at the beginning of the procedure, adolescents were not able to adopt a wider social perspective. Their first arguments were limited to the benefits for the patients that were mentioned in the story. It was only after the discussion that they were able to reflect on bioethical issues from a social perspective and consider the benefits and consequences for the society per se. Then their arguments focused on the greater good.

The observations above and reflections on the advantages of focus groups discussions are also in line with the existing literature . It is known that discussion in focus groups could be cognitively, socially, and emotionally stimulating—especially among young people, as it gives the opportunity to participants to listen to other people’s arguments, to further reflect on complex issues—such as Bioethics and to develop a wider social perspective (for more information, you could see Bowie, Richardson, & Sykes, 1995; Peterson-Sweeney, 2005).

Finally, although scholars argue about the nature and the quality of the data collected during focus groups (e.g., see Fern, 1982), the discussion in focus groups allowed us to collect a great variety of data that otherwise would be missed. These data ranged from original thoughts, intuitions, synthetic models, as well as sophisticated arguments to core values. In addition, focus group discussion was inspiring for our participants who engaged with more enthusiasm in

the research project than in the individual interviews and self-reported questionnaires. The discussion was vivid, and almost all participants argued with each other in favor or against the scientific developments we discussed. The discussion in some groups was particularly interesting and included passionate opinions and arguments . Thus, these focus group discussions lasted longer than expected (and that could serve as a benefit and a challenge at the same time). The data collection was a particularly interesting experience both for the researchers and for the participants.

**The Challenges**

Reflecting on this research project, we identified some challenges concerning the exploration of bioethical reasoning in children and adolescents using focus groups methodology. These challenges are closely related to the topic and participants’ age-related characteristics. Below we offer a brief overview.

**Questions and Explanations**

During the focus groups, children were fascinated by the stories and the dilemmas. The majority of them had never heard about the topics discussed and found the information interesting. However, as it was natural, they addressed many questions to the researchers. Some of these questions were about further explanations, and clarifications about the scientific knowledge supported the innovative technique, or about the technique itself. Others were about thoughts that were afraid to express directly because they were feeling a bit unsure about them. The fact that children were so enthusiastic about the research topic was great. In practice, though, it was challenging to provide the children with the answers they needed and at the same time not to share too much information, namely, direct the children to a specific answer. Due to the nature of the topic under investigation, it was somewhat difficult to precisely set the limits of information that participants would be provided with. The literature suggests that moderator’s role during focus groups is very complex. One should facilitate the discussion and at the same time not to direct participants to a specific direction (e.g., see Kreuger, 1988). There are always limitations in regard to the knowledge that is adequate for children to understand the story and not enough to direct them to a specific answer. Within the framework of the focus groups, children addressed many questions, which did not refer specifically to scientific knowledge. They usually wanted to know more about possible harms and benefits. However, if the researcher responded to their questions, they tended to use her argumentation in their answers. For example, many children asked, “Isn’t it great to save human lives? Why not use sheep hearts for transplantation? Aren’t the doctors going to find other hearts for the sheep later on?” In a negative response, all the written arguments will be that we definitely should not kill the sheep. Thus, it was important to explain that in a dilemma, it is hard to decide what is wrong and what is right and always try to provide wider perspectives and alternatives to the children. Adolescents, on the contrary, made significantly fewer questions, because they were more familiar with study’s concepts.

**Discussion and Argumentation**

Discussions with children were fascinating. However, children tended to jump from one subject to another, or discuss with one another. Sometimes they wanted to share with the group personal knowledge or experiences that may not be relevant to the discussion in the focus group setting (such as what they did yesterday after school), or something that they have read about. For example, a participant in a focus group mentioned that he has read about some “tiny robots that are going to change the world.” Then, all the children wanted to discuss about robots and tried to relate their answers to these robots. For example, “It won’t be necessary to use animal organs. Soon enough, these tiny robots would work as hearts!” In addition, children spontaneously wanted to share with the group personal information (e.g., “My aunt is sick. Do you believe that this procedure would help her?”). Adolescents, on the contrary, were less enthusiastic than children. They provided less argumentation than children, and more effort was needed from the researcher to engage them in the discussion

**Researcher’s Facial Expressions and Body Gestures**

Children, as well as adolescents, were constantly trying to interpret investigator’s behavior, more than it was expected. Except for the discussion, they were also trying to interpret facial expressions and body language and give an “appropriate” answer. For example, many children responded that “This must be good. Otherwise, you wouldn’t smile!” (for moderator’s role, see also Morrison-Beedy, Côté-Arsenault, & Feinstein, 2001).

**Control of the Focus Group Duration**

In many focus groups with children, as well as with adolescents, participants showed a keen interest in the stories we discussed. That was important and fulfilling for the researchers. Often the discussions were very enlightening. Participants wanted to share their thoughts and feelings and argue with each other. However, the discussion could go too far, and in some cases, we needed extra time, to continue with the procedure.

**Practical Lessons Learned**

The above challenges were obvious early on when we conducted the pilot study. Thus, when we launched the main study, we tried to make some adjustments and keep in mind the following facts:

Researchers should be very well prepared regarding students’ questions. It is obvious that the researchers should have an excellent understanding and knowledge of the issues to be discussed. Furthermore, researchers should be well prepared and decide before the focus groups what kind of additional information and clarifications should be given to the participants.



Researchers should also be very thoughtful when designing the research materials. Materials provided for discussion within the focus group should match the children’s cognitive abilities—for conducting effective focus groups with children, a moderator, apart from having knowledge of interviewing skills and group dynamics, also needs experience of working with children, together with knowledge of their developmental stages, processes, and abilities.



Researchers should try to monitor their nonverbal behavior . Every change in facial expressions and body language during the discussion could be interpreted as an attitude toward the issue.



Researchers should have a timeline and try to keep that. It is critical to share time equally across the subjects that are planned to be discussed. Otherwise, the conversation could be too long for some issues and not long enough for others.



Besides the adjustment of the material, researchers should also adjust their behavior according to participants’ age and age-related characteristics. For example, while working with children, one should keep in mind that children engage more easily and are more enthusiastic, but might lose their interest quickly. On the contrary, more efforts are required for adolescents to be engaged in the discussion and to feel comfortable to share their thoughts with the group. Sometimes the researchers may have to ask open questions, construct debates, and be provocative (see also Gibbs, 1997) to open up adolescent participants.



In a view to facilitate evaluation and in-depth analysis, it is highly recommended to record the focus groups on video. This is something that we did not do in this study but opens up the visual level for analysis and interpretation. The nonverbal behavior can be a valuable source of information, especially important in certain kinds of qualitative research.



Finally, researchers ought to create a safe and comfortable environment for the discussion. It is important to clarify from the beginning that all thoughts and opinions are very welcomed within the group and that there are no wrong and right answers. Moreover, especially when dealing with children, it may be necessary to clarify that participants may not share any personal information with the group and in case they want to, it is better to discuss them individually with the researcher.

**Conclusion**

During this project, we conducted 30 focus groups (27 in the main study and three in the pilot study). Conducting them, besides the challenges, was a very positive experience. Discussion in focus groups allowed us to gain a better insight in children’s and adolescents’ thoughts and feelings about the discussed issues. Focus groups provided rich data that it would be tough to collect otherwise.

In addition, focus groups participation was a great experience for both parts, researchers, and participants. The focus groups were interesting for all the discussants. By the end of the research study, participants admitted that they had expected a boring “examination,” but instead they had a perfect time. Researchers, on the contrary, gain great experience while working with children and adolescents. Their attitude toward the research project was very rewarding.

In conclusion, focus group methodology could be proved very rewarding in many different ways. Researchers should keep in mind, though, some considerations, such as their ability to lead discussions, handle group dynamics, and adjust to participants’ characteristics.

**Exercises and Discussion Questions**

1.What do you think the role of the moderator should be in a focus group setting?

2.What are the main steps to be followed when designing and delivering research with focus groups?

3.What are the main ethical considerations when conducting a focus group discussion?

4.In your context, what is the policy guidelines to be discussed with children and adolescents about bioethical issues (transplantation, stem-cell research, and brain death)?

5.Can you de sign within the framework of a working group a bioethical dilemma?

6.What type of questions/prompts will you be using? Can you draft an interview schedule on this specific topic under investigation?

7.Can you pilot it within your group?

**Further Reading**

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**Web Resources**

Nuffield Foundation: <http://www.nuffieldfoundation.org/>

The Association for Qualitative Research: <https://www.aqr.org.uk/>

The Hastings Center: <http://www.thehastingscenter.org/>

ETHIKA EU project: <http://www.ethics-education.eu/home/index.htm>

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