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Ethical reflections when research includes refugee children – a study of ethics review applications

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ABSTRACT

Background: The global number of refugee children was 43 million in 2025, highlighting the urgent need for research that supports their well-being. Such research must carefully balance children's rights to be protected from harm and to be heard.

Objective: This study explores how researchers in Sweden address ethical considerations when planning studies involving refugee children, particularly in the context of abuse and neglect, as presented in applications to the Swedish Ethical Review Authority (ERA).

Data: The data consists of fifteen ethics review applications submitted to ERA between 2019 and 2021 and concerning research about abuse and neglect involving refugee children.

Methods: The data was analyzed with reflexive thematic analysis using manual coding with the Computer-Assisted Qualitative Data Analysis Software NVivo to identify how researchers present ethical challenges and justify their studies.

Findings: Three main themes were identified: *A particularly vulnerable group*, *Being both a child and a refugee*, and *Psychological aspects of refugee children participating in research*. Researchers emphasize both the risks and potential benefits of participation and give an extensive view of their ethical reasoning when planning research with refugee children.

Conclusions: The emphasis on protection over participation in the applications highlights the importance of dialogue between researchers, ethical committees, and children's rights advocates to ensure that research both protects and empowers the children it seeks to understand.

1. Introduction

In most countries, depending on study design, research involving human subjects requires an ethics review before research can begin. The laws and regulations in relation to child participation in research vary between countries (FRA, 2014). There have been reports among researchers that performing research with children regarding sensitive subjects, like having experienced child abuse and neglect, might be difficult to get approved by the ethics review agencies (Fisher et al., 2013; Sikes & Piper, 2010). Childress and Thomas (2018) argue that targeting research participants that have multiple vulnerabilities, such as being a child *and* having a mental disorder, sometimes leads to rejections of research although it is ethically sound. There is some legitimacy to this claim from a survey study performed with ethics review committees in Australia (Powell et al., 2018; Taplin et al., 2022) that shows that research on

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sensitive subjects that involve children are less likely to be approved. This study will examine how researchers in Sweden, performing research with refugee children, present ethical aspects of this research for ethics review.

1.1. Rights of refugee children

A refugee child is a person under 18 years of age, as well as one who is outside of their country of origin or habitual residence, and who cannot return due to fear of prosecution (Convention Relating to the Status of Refugees, 1954). During 2025, UNHCR estimated that there were more than 117.3 million forcibly displaced people (refugees, internally displaced, asylum seekers, and others in need of international protection) out of which 36.7%, or 43 million, were children (United Nations High Commissioner for Refugees, 2025). The UN Convention on the Rights of the Child (UNCRC, 1989) states that “the best interest of the child shall be a primary consideration” (Article 3.1), that to “ensure to the maximum extent possible” (Article 6) the child's right to life, survival, and development, and that “all appropriate [...] measures to protect the child from all forms of physical or mental violence” (Article 19.1) must be taken into consideration. There are still millions of children who are being denied these rights by being forcibly displaced (Kukrety & Knoppik, 2023). Without research conducted on the situation of these children, they remain hidden (Eliffe et al., 2020) and the knowledge base, needed for interventions and policies, becomes watered down. This in turn means a weakening of the children's rights as well. In addition to the protective rights outlined above, there is also Article 12.1, concerning a child's right to be heard in “in all matters affecting the child”. These rights, among others depending on type of study, need to be balanced by researchers and should be a part of the ethical considerations when having refugee children as participants. In addition, the research must be in line with national or regional ethical laws and regulations.

1.2. Research with refugee children

Since World War II, studies have shown that refugee children suffer in various ways, including alienation in the host country, language barriers, delinquency, and acute depression (Baumel, 1983). Being a refugee child is related to a host of different stressors and mental health problems, including cultural bereavement (Eisenbruch, 1988), and the children are also affected by their parents' trauma and stress (Ajdukovic & Dean, 1998). Violence and harmful experiences often occur both before and during the flight (Isakov et al., 2022), and problems can continue after arrival in the new host country. Discrimination, poverty, inappropriate or inaccessible services, symptoms related to grief and loss, separation anxiety, and depressive disorder are common occurrences (Davies & Webb, 2000; Joshi & Fayyad, 2015). Post-traumatic stress disorder (PTSD) is commonly observed among refugee children (Almqvist & Brandell-Forsberg, 1995; Davies & Webb, 2000; Derluyn & Broekaert, 2007; Gunes & Guvenmez, 2020; Karaman & Bulut, 2024). The stressors of war affect all children but displaced and refugee children are affected the most (Ajdukovic & Dean, 1998). Given this background it can be stated that although not all refugee children have been exposed to all risks associated with flight, basically all refugee children have been exposed to some kind of adversity (e.g., abuse and/or neglect), which may contribute to traumatization.

It should be noted in this context that experiencing potentially traumatic events does not equal the development of mental health problems. Although research has shown the troubles affecting refugee children, research has also shown that many refugee children are remarkably resilient and have a diverse set of more or less effective coping strategies (Ajdukovic & Dean, 1998; Almqvist & Hwang, 1999; Chikoko et al., 2024; Höhne et al., 2022; Kaprielian-Churchill, 1996; Mattelin et al., 2024, 2025; McCarthy & Marks, 2010). To further understand refugee children's perspective on the harm caused to them, their resilience, and areas of their lives that may be affected, such as school performance, friendships and sexuality, more and more research has focused on studies *with* children instead of *about* children (Candappa, 2000).

1.2.1. Child participation in research

Until the 1980s most data in studies about the situation of children were collected from adults in the child's context, like parents and teachers, or retrospective data. The differences in first and secondhand data, in relation to children, have been shown to be palpable (Derluyn & Broekaert, 2007; Goldin et al., 2008; Skar et al., 2021; Smith, 2021) but studies that record refugee children's experiences firsthand, while they are still children, are scarce (Ali & Gibran, 2020).

In order to adapt direct data retrieval from young refugee children, different play models have been used, allowing for indirect information by observing the children (Almqvist & Brandell-Forsberg, 1995), or creating an environment that encourages the children to speak freely (Almqvist & Hwang, 1999; Masser, 1992; McCarthy & Marks, 2010). Methods and study design need to be adapted to match the child's age and capabilities (Graham et al., 2013). A plethora of alternatives (Ali & Gibran, 2020; Kirova & Emme, 2007; Mann, 2010; McCarthy & Marks, 2010) have been developed to create a more child-centered methodology and to mitigate issues like language or writing difficulties, due to possible education disruption or effects of trauma and/or neglect. To further develop the methodology in child research, there is an increase of involvement of children in the research process, for instance in the form of participatory research, giving children voices and opportunities to research their own lives, a different avenue to talk about and share their own experiences (Kirova & Emme, 2007; Kosher & Ben-Arieh, 2020; Smith, 2021).

1.2.2. Ethical challenges in research with refugee children

In addition to the above-mentioned stressors and possible trauma that refugee children may have experienced, there are further ethical aspects to consider. Firstly, the vulnerability connected to age, of being a child under development, and secondly being outside of or unknowing about society and culture are aspects that need to be taken into account. Thirdly, there is the risk of causing distress as highlighted both in *Ethical Research Involving Children* (Graham et al., 2013) and in ISPCAN's *Ethical Considerations for the Collection*,

Analysis & Publication of Child Maltreatment Data (Smith et al., 2016). When children participate in research on sensitive topics, researchers are cautioned to address this beforehand and make sure that the children can receive the professional help and support they might need. However, an increasing number of studies have shown that only a very small share of children participating in research regarding abuse and neglect experience distress from participating (Fagerlund & Ellonen, 2016; Finkelhor et al., 2014; Neelakantan et al., 2023, 2025; Stewart-Tufescu et al., 2025), and those that do, do so because of the trauma they have experienced, not because of the research (Franchino-Olsen et al., 2025). This does not mean, of course, that these children are to be ignored. Their negative experiences should be taken into account and they should be cared for if need be.

A further ethical challenge when performing research with refugee children is the issue of informed consent to participate in the research. The age when the child can consent to participation in research on their own differs, depending on what country the research is conducted in, how the study is designed, and what the study is about (FRA, 2014). And no matter who gives the consent, be it a parent/guardian or the children themselves, there are concerns in relation to language. Does the participant really understand the information given? In relation to a group that might have problems with trusting authorities, or being used to forced compliance (Habib, 2019), issues of power relations in research are important to consider. Since consent in research is an *ongoing* issue throughout the study, and participants have the right to withdraw consent at any time, it is important to consider the relationship between the refugee children and the researchers. There is not only the power difference between researcher and participant, but also an unequal power balance between child and adult, immigrant and citizen, and differences in social status (Kirova & Emme, 2007).

Research ethics does not only concern how researchers design and prepare the study, but also what happens during and after the research. Children might disclose information that implies that they need legal or professional help or might directly ask for help. Different ways of handling these situations are offered in *Ethical Considerations for the Collection, Analysis & Publication of Child Maltreatment Data* (Smith et al., 2016). The children's own agency in difficult circumstances is something that needs to be considered, and they "need to be given the opportunity to reflect and act upon their own lives" (Hart, 1992, p. 24). The agency of the child might even complicate the practice of anonymization as the participant might wish to take credit for their work, as was the case for Kor-kiamäki and Kaukko (2023).

Internationally, research about sensitive subjects in combination with young children participating appears to be of concern for ethics approval. The method of data retrieval has been shown to matter in the decision of approval as ethics review committees were more likely to approve of studies on sensitive subjects if the researcher performed face-to-face interviews with the children, compared with if the children were asked to answer a survey in school (Taplin et al., 2022).

1.3. The Swedish ethics review process

In Sweden, research that involves human participants is regulated by the *Act on Ethical Review of Research Involving Humans* (SFS 2003:460). Research concerning children's exposure to abuse and neglect may be subject to ethics review on mainly two grounds. Firstly, if the research processes sensitive personal data or personal data on crimes, criminal convictions, coercive measures in criminal proceedings or administrative detention, or secondly, if the research affects the subject physically or psychologically, the research needs to go through the Swedish Ethical Review Authority (ERA) for approval. The ERA is multidisciplinary and reviews research from all disciplines with human participants.

The application process for having research reviewed by the ERA is performed with a preset application form that includes sections such as *method, time plan, data collection*, as well as a separate section specifically for *ethical considerations*. In the ethical considerations section, the researchers must specify the risks and benefits of participation as well as how the researchers will minimize the risks involved for the participants. The forms are predefined and must be entered in full, in Swedish, by all applicants and there is no verbal communication between researchers and the ERA in the process. Application and decision are communicated solely in written form through a web-based system called *Ethix*. Research may only be approved if the risks it may entail for the health, safety and personal integrity of research subjects are outweighed by its scientific value. The ERA can *approve* or *approve with conditions*. The latter means that the applicant is permitted to proceed with the research given that certain conditions, often minor and about formal aspects, set by the ERA are met. During the proceedings, the ERA can issue a *supplementary decision*, which often means a request for more information or motivations from the applicant that needs to be supplied in written form before a new decision can be considered. If an application does not meet the legal requirements, it is *denied*.

1.4. Current study

There is need for an ongoing dialogue about research ethics in relation to refugee children as participants, to make sure that research both safeguards and empowers the children. Given the need for ethics review of research including refugee children, being participants with multiple vulnerabilities, the aim of this study is to explore applications for ethics review in relation to research with refugee children and improve the possibility to perform research in this area. This is an area of the ethics review process that has not been previously researched, giving insight into the discourse researchers use to justify these studies as well as the persisting tension between protection and participation. In this study we specifically explore the following: (I) how research with refugee children is justified in the applications, (II) what ethical concerns and considerations are highlighted in the applications, and (III) in what manner the rights of the refugee children are described in relation to the research.

2. Method

2.1. Context of the study

This study is linked to a larger project called “Researchers' arguments and ethical boards' decisions concerning children's participation in research about child abuse and neglect - right to participate, benefits and risks”. The project studies how researchers and board members of the ERA argue and make their decisions from a legal and psychological perspective. Part of the data for this project consists of applications for ethics review when research includes children exposed to abuse and neglect. The present paper focuses on these applications for ethics review where the research is with refugee children.

During the period the data was collected (2019–2021) 27,926 children applied for asylum in Sweden. The years prior to this, 2015–2018, 159,907 children applied for asylum in Sweden. (Statistics Sweden, 2025).

In contrast to other sources of data about research ethics, such as interviews with researchers or ERA members regarding their experiences, these applications contain arguments that are de facto used to justify ethical approval of the studies and the tensions between participation and protection that are publicly communicated.

2.2. Data collection

The data consists of applications submitted to the ERA as well as the ERA's decision regarding the application. All applications submitted between January 1, 2019, and June 30, 2021, excluding clinical drug trials, were requested. A screening of headings ($n = 9248$) was performed to exclude studies with adults, registry studies and studies concerning somatic diseases, which resulted in 664

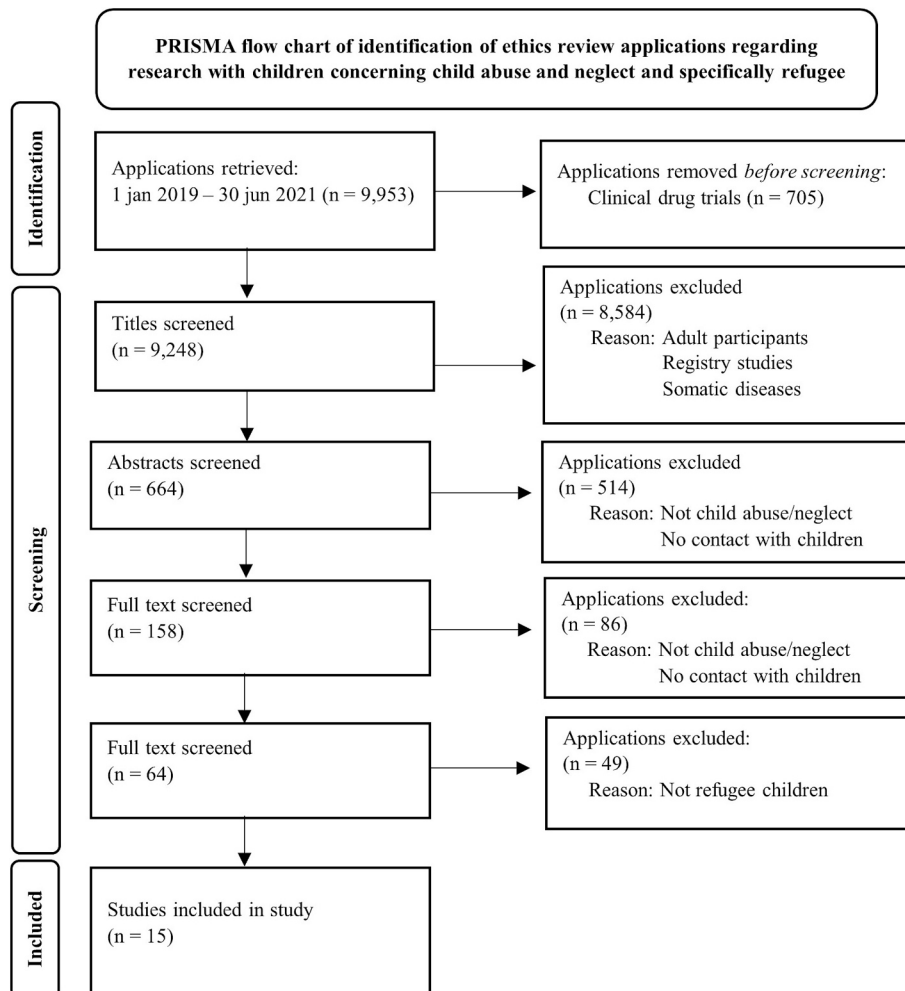


Fig. 1. Screening process of applications for ethical review

Note. This diagram is adapted from “PRISMA_2020_flow_diagram_new_SRs_v1”, (Page et al., 2021 BMJ 2021;372:n71. doi:<https://doi.org/10.1136/bmj.n71>) used under CC BY 4.0. This version “PRISMA_2020_flow_diagram_screening”, is licensed under CC BY 4.0 by Mikael Hagström.

applications. Screenings of abstracts and full-text followed (see Fig. 1) to further ensure that the applications concerned research about abuse and neglect with children as participants, resulting in 64 applications. Of these 64 applications, 15 studies concerned refugee children and were included in this study.

The full dataset consisted of the complete applications submitted to the ERA, including research plan, research participant information letter, possible interview guide, and so on, as well as revised documents of the same when it was required by the ERA. For this study we included those parts of the applications that specifically addressed refugee children, ethical aspects, and the research plan connected to each case. Excluded sections concerns funding, time plans, administrative details and more that are not relevant for this study.

Of the 15 applications that are included in this study, 3 applications were approved without conditions and 12 were approved with conditions. No applications were denied. Two applications used quantitative methods in their study, 11 used qualitative methods and 2 used mixed methods. The ages of the children included in the studies varied over the different applications and overlapped dependent on the study design. Only 3 of the 15 studies included children under 12 years of age.

2.3. Data analysis

The data consists of texts produced with a purpose: to convey the researcher's perspective on the planned study and to have the application approved by the ERA. To aim for an approved application is part of the process of thinking through the ethics of the study and planning accordingly. The intent of the text in the application is to show that the researcher has thought everything through very carefully and that the project is in compliance with the *Act on Ethical Review of Research Involving Humans* (SFS 2003:460), in other words, that any problematic issues in the design have already been worked around or addressed. Nothing can be said about the process before or beyond the submission except what is presented in the applications. Given this context, that the applications are performative and is part of a process that is otherwise outside of the scope of present data, the data will be analyzed with critical realism (Braun & Clarke, 2022). The application text is produced in a research environment, with logical argumentation based on research. The production of these texts, from project ideas to final applications, in combination with the ERA's assessment and possible conditions, creates and constructs something that is the ethics review process for the researchers.

Reflexive thematic analysis (Braun & Clarke, 2022) was performed on the applications to capture the researchers' argumentation in relation to refugee children. The Computer-Assisted Qualitative Data Analysis Software NVivo v. 14 was used for the coding of the data (<https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>). The analysis was guided by Braun and Clarke (Braun & Clarke, 2022) and consisted of six steps, being (i) familiarization with the data; (ii) coding noteworthy text based on expressions of different ethical aspects raised; (iii) generating initial themes by grouping related text extracts relationally dependent on the topic; (iv) developing and reviewing themes by exploring connections between themes that address the same issue; (v) refining and clustering themes into main themes (based on topic) and sub-themes (different angles within the same or similar topic), defining and naming themes; and (vi) finalizing and describing the salient aspects of the data gathered. This process is iterative and reflexive. Even if you have a preset of codes of relevance, when engaging with the material, you might find or become aware of issues of relevance that were not apparent at onset. Given the new information you might want to step back, recode, include, or alter codes and themes as you go along in the *reflexive* thematic analysis. Data extraction, thematic coding, and translation (performed after analysis) of quotes from Swedish to English were conducted by the first author in discussion with the other authors. Peer debriefing was used to increase credibility and dependability of the thematic coding. Analysis of the coded material is presented in the Result section together with quotes in regard to the same theme. The main structure of the analyzed data can be seen in Table 1. The results section presents the themes with supporting quotes, but the deeper explanation and analytical interpretations of what the themes mean is presented in the Discussion section, following the guidelines set out by Braun and Clarke (2022).

Table 1

List of themes and sub-themes with descriptions of characteristics.

Main theme	Sub-theme	Characteristics of the theme
A particularly vulnerable group		Addressing different aspects that constitute the specific vulnerabilities of refugee children.
	<i>Inherent vulnerability of being a refugee</i>	Issues specific to being a refugee
	<i>Prevalence of mental health problems among refugee children</i>	Argumentation in relation to mental health.
	<i>Need for social support</i>	Issues on a societal level as a consequence of previous grievous experiences.
Being both a child and a refugee	<i>School performance and integration</i>	Problems related to life-time success.
		Addressing intersectional aspects concerning multiple vulnerabilities.
Psychological aspects of refugee children participating in research		Addressing different aspects of how participation in research might affect refugee children.
	<i>Negative aspects of participation</i>	Issues regarding how participation might have a negative impact.
	<i>Positive aspects of participation</i>	Issues regarding how participation might have a positive impact.

2.4. Ethics

The local ethics committee at Karlstad University assessed that the data in this study does not fall under the Ethical Review Act (Dnr: C 2021/559). The material, that is, the applications, are part of the public record and were provided by the ERA after making a confidentiality assessment before the material was released. All applications have been pseudonymized with a number that is used when referring to a specific application.

3. Results

3.1. Thematic analysis

The data presented below is the result of reflexive thematic analysis of the composite argumentation presented in the applications based on topic contents. Each theme is a synthesis of the argumentation in all applications on the specific topic, highlighting similarities and differences. The contents of each theme and sub theme are based solely on the text provided in the applications, not on any external sources.

3.1.1. Refugee children - a particularly vulnerable group

The argumentation in the applications regarding the importance of research with refugee children focuses mainly on different aspects of the children's vulnerability. Being a refugee child comes with several issues connected to the situation of flight. The picture presented by the applications highlights the risk of trauma associated with the reasons for fleeing, how trauma affects the development of children who are uprooted from their home and school, and the challenges they are confronted with when settling in the host country. Although the argumentation differs depending on the angle of the study design, the arguments overlap, touching on the same aspects, and outline a complex picture of vulnerability relevant to refugee children as a group. The following sub-themes contribute to the collective argument in the applications for why research involving this vulnerable group is needed.

3.1.1.1. Inherent vulnerability of being a refugee. Being a refugee child brings heightened risk for traumatizing events. These risks span the whole situation, from the reason for flight, dangers during the flight, as well as problems during the settlement in the new host country. Given these heightened risks there is an ambivalence. The applications caution about having refugee children as a population for any kind of study at the same time as they argue that this vulnerability underlines the ethical importance of the research.

... *exposure to traumatic events (sexual abuse, violence, accidents or witnessing violence in armed conflicts) is not only a direct danger to a child, but also has long-term consequences for the mental and somatic health* —No. 18.

... *unaccompanied minors are a particularly vulnerable group. Experiences before, during, and after the flight to Sweden entail risks for mental disorders.* —No. 14.

3.1.1.2. Prevalence of mental health problems among refugee children. The prevalence of mental health problems as a result of having experienced potentially traumatic events, suffered by the children themselves or experienced by witnessing abuse of others, and other detrimental aspects of the refugee children's lives, highlights the need for support of different kinds. Therefore, the applications argue the need for research with this population to render the best aid possible. At the same time, this connection between a refugee background and mental health problems underscores the need for society to have valid research to base policy on, to meet these consequences properly, and thereby the applications justify the involvement of refugee children as participants.

... *these are children and youths below the age of 18. Mental health problems are common occurrences among these individuals who are also faced with the challenge of trying to integrate into society. Earlier experiences in their home country and during the flight, as well as post-migration factors, are contributing causes of mental health problems.* —No. 9.

30.6% of the unaccompanied minors had PTSD upon arrival with no significant change upon follow-up. —No. 18.

3.1.1.3. Need for societal support. The applications argue that the refugee children, upon arrival in the host country, with possible traumatization experiences behind them, still risk harm or hardship. The extra need for support from different societal services that arises as the refugees establish themselves in the new country is regarded as equally important as addressing harm caused in the past. The applications emphasize the increased demand for resources and competence needed from society given the circumstances of the refugees. Discovering and treating possible mental health issues of the refugees is considered crucial both in terms of support and as a way to handle social costs.

Teachers, principals, parents among others, give witness to the fact that many refugee children show symptoms of mental health problems, but there are not enough resources and/or competence to address the need. —No. 9.

Based on the high prevalence of mental disorders, it is also a group in great need of support and interventions. —No. 24.

3.1.1.4. School performance and integration. In relation to social costs, issues of poor school performance and lack of social integration are brought forth as reasons for why further research is required. Poor school performance and issues with integration into the new society are part of the expressed vulnerability of these children. The applications highlight low school performance, risks of radicalization due to social isolation along with cultural difference, and lack of knowledge regarding laws and rights in the host country as problems that affect the outcome of the establishment in a new country.

The proportion of immigrant youth who succeed in school is low. In addition, there is growing concern about radicalization and social isolation among immigrant youth, especially in segregated areas. —No. 58.

Cultural differences, stigma, fear and poor knowledge about sexuality increase the vulnerability of young migrants to sexual and mental health problems. [...] language barriers, lack of family support, isolation, previous experiences of sexual violence, lack of basic knowledge about the functions of the body, sexual rights and poverty increase the vulnerability of these young men to sexual and mental health problems. —No. 1.

3.1.2. Being both a child and a refugee

The intersectionality of the different aspects of being both a child and a refugee is highlighted in most applications. The main vulnerabilities brought up in the applications involved various aspects of being a child in a dangerous and exposed situation. For example, some applications focus on the risks before and during flight, specifically the increased risk of experiencing or witnessing abuse of different kinds, resulting in possible trauma. Others focus on the period following the flight and issues such as risk for discrimination and racism and insecurities regarding the future, for instance in relation to the asylum process, housing, and lack of social support. These different foci show parts of the complex picture and the multiple facets of being a child refugee.

... the subjects of the study are both children and migrants/refugees simultaneously and there is a risk of increased vulnerability. —No. 39.

... people who are in the asylum process have different types of or no residence permit. This means great uncertainty about their own situation, insecurity and uncertainty about the future. [...] uncertainty about and difficulties in understanding the Swedish healthcare system, what help is available and what a person is entitled to. Conducting research among people who live in this uncertainty can be questioned. —No.24.

Another intersectional aspect of the theme being both a child and a refugee is the risk of mis-communication or lack of cultural understanding. An insufficient awareness or knowledge about their own rights, as can be hard for any child, is compounded by an unknown language and society. When asked to participate in a study, the refugee children might as well think that participation is a requirement for, or might have a positive or negative effect on, the asylum process as a result of language difficulties.

There is a reported lack of awareness of sexual and reproductive rights, while the group might have limited access to health measures and psychosocial support. —No. 62.

This vulnerability stems from factors that put migrants at greater risk of participating in research without understanding the risks or the overall purpose of the research, or even participating in research under duress. —No. 27.

Children are under development in terms of language, maturity, and intellect, making them vulnerable participants. Taken together, the applications generate a picture of the need to consider the power balance of a research project in relation to the participating refugee children. This power balance does not only include the difference between being a child and an adult, but also between a refugee and a citizen, and being a participant and a researcher.

... difficulty that can arise in conversations with children, partly due to the vulnerability that a child finds himself in, in relation to an adult, but also because it can be difficult for a child to talk about their world and their experiences. [...] For all interviewees, there needs to be an awareness of power relations, not only as researchers and informants (Kvale, 2009, p. 77 ff.), but also in the adult-child and citizen-migrant/refugee relationship. —No. 39.

3.1.3. Psychological aspects of refugee children participating in research

Given the structure of the ethics review process, the benefits of the research are to be weighed against the possible risks to the participants. Since these studies mainly focus on psychological or social science aspects, this balance is described in psychological terms such as psychological discomfort, distress and re-emergence of memories of traumatic experiences. Personal benefits for the participants are also included in the applications and are also used as arguments for the ability of the research design to mitigate the possible harm of participation. These types of arguments include values such as an opportunity to have one's own voice heard or achieve self-reflection and growth as a person. Apart from a few applications that argued that there would be no risk for negative consequences of participating, most applications mentioned both positive and negative aspects of participation in their research.

3.1.3.1. Negative aspects of participation. In describing the risks of participation, the applications highlight what might affect the participants in a negative manner during the study, or in the future as a consequence of participating in the study. A large portion of the possible risks that were brought forth in the applications involved discomfort or distress in one way or another, caused by answering what might be uncomfortable questions about personal subjects or potentially traumatic events.

... conversations with children, partly due to the vulnerability that a child finds themselves in, in relation to an adult, but also because it can be difficult for a child to talk about their world and their experiences. —No. 39.

Participants may experience some discomfort in connection with the interviews and feel uncomfortable discussing their sexuality or their experiences with sexual and reproductive health care. —No. 27.

In the sections on negative aspects, the issue of research induced distress or distress by memories stands out by being addressed in all applications. Although worded differently, applications refer to the possibility of reigniting or awakening thoughts, memories and emotions connected to earlier trauma as a result of being asked/interviewed about earlier experiences during research studies. This is discussed in the applications either as a possibility (for example if the study directly addresses potentially traumatic events), which means a need for preparation of professional aid, or as something very unlikely (for example if the study addresses other issues not directly related to trauma), depending on the planned study.

... exposure to, for example, thoughts and feelings that children have otherwise avoided coming into contact with, precisely because they are perceived as difficult to handle. When the child is exposed to these thoughts and feelings, it can cause discomfort. —No. 9.

However, it does not mean an increased risk for the individual. It is an expression of the strain that the individual lives under and not something that suddenly ‘emerges’ out of nowhere or is triggered by the situation. —No. 24.

Any discomfort that participants may experience during the study is however unlikely and probably no greater than what may be encountered in everyday life or during the performance of other psychological examinations and tests. —No. 29.

3.1.3.2. *Positive aspects of participation.* Through the applications, an optimistic view is constructed. Participation in research is seen as something that is personally beneficial for the refugee children. It is argued that participants gain a feeling of worth, in the sense that they are contributing to something bigger, such as generating better knowledge about, and support for, others in the same situation, and so on.

Talking about one's experiences in research interviews can have a positive impact on health. Experience also shows that informants often find it valuable to participate in studies and be able to contribute to change for others in the long term [...] a positive development for young people, with an increased sense of opportunity to influence their own lives and also in social issues. —No. 18.

Initially, we assumed that these questions would be experienced as traumatic, given the vulnerable situation of the participants, but our pilot studies show that the participants appreciate being able to share their experiences and that it is good that someone takes their situation seriously. —No 8.

Aspects that, earlier in the application, have been addressed as risks are in some cases discussed as beneficial for the children. Some reason that exposure is an important part of rehabilitation of trauma, thereby reasoning that even though participation is not a treatment per se, it can be considered helpful.

It is researchers' experience [...] that talking about experiences in research interviews can have a positive impact on health. —No. 18.

However, exposure is an effective and productive method for reducing discomfort and PTSD symptoms in the long term. —No. 9.

Furthermore, participation in studies gives the children an opportunity to be seen and heard, to have a possibility to speak their minds about subjects that are usually hard to talk about or rarely discussed with the adult world, and an opportunity for self-reflection and personal growth.

... telling about their experiences of mental health care can have positive consequences for participants as it can be experienced as valuable that someone is interested in their experiences —No. 14.

... the interviewees, who are young people, feel through the interviews that they are seen and are allowed to speak —No. 5.

4. Discussion

In this study, we have examined and analyzed applications sent to the ERA for ethics review during the time period of January 1, 2019 to June 30, 2021. The applications included were those for research projects that concerned child abuse and neglect and have refugee children as participants. Three main themes were identified: *A particularly vulnerable group*, *Being both a child and a refugee* and *Psychological aspects of refugee children participating in research*. The themes give an extensive view of the reasoning that researchers include in applications for ethics review concerning refugee children's participation in research. The three main themes all highlight different ethical aspects of involving refugee children in research.

In relation to the first aim (I) of this study, to investigate how research with refugee children is justified in the applications, the importance of such research is presented as an imbalance between the plight of the child and the societal support system. The theme *A particularly vulnerable group* underlined the plethora of problems that affect the refugee children, in accordance with the current literature in the field, and the general need for research to be able to help and support them on their journey to a safer and healthier life, underlining the children's right to safety and protection from harm (UNCRC, 1989). Throughout the subthemes the applications highlight the refugee children as a vulnerable group in much need of support and advocacy given the experienced hardship. They also implicitly show a society not being able to properly meet the needs of these children without further support from research. Out of context this might seem like a harsh view, both pitying a group of participants that might fare well under better circumstances with proper support systems and relations, and exposing a societal system that is failing these responsibilities. Given the context, an application for ethics review, this is likely a strategy to ensure that the importance of the research is apparent and as a means to strengthen the likelihood of the application being approved.

In relation to the second (II) aim of the study, to show what ethical concerns and considerations are highlighted in the applications, the applications highlighted the duplicity, or even multiplicity, of the refugee children's situation as seen in the theme *Being both a child and a refugee*. The argumentation corresponds with ethical issues highlighted in *Ethical Research Involving Children* (Graham et al., 2013) and *Ethical Considerations for the Collection, Analysis & Publication of Child Maltreatment Data* (Smith et al., 2016) in regard to being a child exposed to abuse and neglect as well as being a refugee. It is obvious from the aspects within the theme that the multiple vulnerabilities and intersectionality of being a child (under development, being a refugee, not a citizen, without or limited knowledge of language and society, being of a different ethnicity and nationality, as well as having experiences not shared except with other refugees) should be considered when planning to involve refugee children in research, as previously highlighted by others (Childress & Thomas, 2018; Joshi & Fayyad, 2015; Vervliet et al., 2015). The focus in this theme is mainly on the negative aspects of the past and future, connecting with issues present in the *a particular vulnerable group* theme, in a way that paints a bleak picture, but given the context, this type of argumentation can be intended to demonstrate the researchers' awareness of the situation and vulnerability of the population and thereby underline the children's right to protection from harm.

Further aspects in relation to the second (II) aim include that participating in research can have both negative and positive effects on the children, detailed in the *Psychological aspects for refugee children participating in research* theme. The applications present a

generally positive outlook regarding the effect of participation, mainly based on the fact that it gives participants the opportunity to be heard and to be part of something bigger. The most important negative aspect of participation that all applications touched upon was the possibility of some kind of *research-induced distress* as an effect of talking about sensitive subjects or trauma, which is also covered in *Ethical Research Involving Children* (Graham et al., 2013) and *Ethical Considerations for the Collection, Analysis & Publication of Child Maltreatment Data* (Smith et al., 2016). The degree of concern varied from no concern at all to a possible risk needing the preparation of professional aid in case of need. There might be a preconception of the researchers that mentioning a more substantial risk might make the application less likely to be approved. There are always risks in research, however, and the question is how you prepare to be able to handle them (Görman, 2023). In contrast to concerns of research-induced distress, research has shown that the probability of this kind of distress affecting the children is very low (Fagerlund & Ellonen, 2016; Finkelhor et al., 2014; Neelakantan et al., 2023, 2025; Stewart-Tufescu et al., 2025), and the distress that was caused was due to the *violence* the children had experienced, not participation in the research (Franchino-Olsen et al., 2025). Although there is a low probability, this does not mean that these children are to be ignored. They should always be considered and be cared for if need be.

In relation to the third (III) aim of the study, to explore in what manner the rights of the refugee children are described in relation to the research, the right of the child to express their own thoughts in matters that affect their own life (article 12.1 in UNCRC), is not *directly* addressed in the argumentation in the applications. The positive aspects that are brought up about participation as a way of giving the children an opportunity to feel heard, can be seen as granting them agency, but is mostly part of the argumentation to validate the choice of data collection methods, such as interviews, focus groups or a combination of interviews with creative segments. The balance in regard to the children's rights leans towards protection. This might be due to protection from harm being an explicit part of the Swedish *Act on Ethical Review of Research Involving Humans* (SFS 2003:460) that constitutes the basis for the decisions of the ERA, as well as a deduction of the argumentation present in the applications, i.e. the *a particularly vulnerable group* and *being both a child and a refugee*. This could also be seen as a sign of the times. The applications were sent in 2019–2021 and during that period, in 2020, the UNCRC became Swedish law. Research into risks and benefits of children's participation in research about sensitive subjects has been published before 2020 but even more has been published lately (Kosher & Ben-Arieh, 2025). Given this development, it is possible that the basis and angle of argumentation have shifted during this time.

A further aspect in relation to the third (III) aim is that children's rights are mentioned briefly in some applications. There might be room for further methodological considerations in regard to children's rights and participation within research with refugee children. Participatory research with children was mentioned in a few methodology sections. One could argue the need for more width and depth in participation, as in more involvement in different parts of the research and perhaps deeper involvement in the analysis and interpretation. It would be of interest as well to see the effects of child participation, both out of participatory research perspective, how the participation affects the research, as well as what effects participation has on the children in the long run. Children's rights do not only concern protection from harm or the right to be heard. UNCRC concerns all the *human rights* of the child, encompassing all aspects of life.

4.1. Limitations

This study provides a unique insight into how researchers in Sweden articulate ethical considerations in applications for ethics review when planning studies with refugee children, particularly in the context of abuse and neglect. What we cannot say based on this material is if the result presented in this study differs from what would have been found in applications for ethics review including *non-refugee* children exposed to abuse and neglect. It would be an interesting avenue to explore possible *differences* in research argumentation and accompanying decisions from the ERA between research involving *refugee children* and research involving *non-refugee children* exposed to abuse and neglect. Even though the applications included in the study comprised *all* applications concerning refugee children in research about abuse and neglect over the chosen period of 2,5 years, they still only consisted of 15 applications in total during a limited period of time. The applications included in this study are transdisciplinary and the review process, although limited in this study to the Swedish process, and possible concerns included therein, should likely be transferable to an international setting. A key limitation concerns the nature of the applications, which constitute performative texts. These documents are shaped by institutional norms and researchers' expectations of ERA concerns. What is not included is what happens before the ethics review process, that is, what issues might have been discussed, altered, or given up before the application was sent. As such, the analysis does not capture ethical decision-making in practice. Neither does this study show how the ethics review process affects the research after possible conditions have been met. A further limitation is the absence of refugee children's own perspective on research ethics. The dataset contains a few mentions of child participation but apart from that the dataset consists of adult-authored applications, meaning ethical concerns are mediated through institutional and professional lenses. This reinforces the power dynamic of child/adult and participant/researcher. These limitations also point to directions for future research, including examination of ethics-in-practice via the researcher's experience of the process, the ERA members perspective on harm reduction and facilitation of child participation, dialogue with refugee children about the ethics and experience of participation, and comparative analysis of ethical considerations and decisions across contexts. Together, such work could extend understanding of and connect ethical dilemmas across the parties involved and work towards understanding the lived ethical relations.

4.2. Implications for research and practice

There is a need for an ongoing conversation in relation to research ethics when refugee children are involved as participants, to make sure that research both safeguards and empowers the children, to ensure that research involving refugee children is ethically

right, not just avoiding being ethically *wrong*. In the general discussion of research ethics, this is a unique material that highlights an unexplored but crucial part of research, present *within* the ethics review process. As mentioned earlier, there is literature (Graham et al., 2013; Smith et al., 2016) which aims to guide and prepare researchers in relation to what they have to consider in regard of research ethics when including children. There is also literature, though limited, on the decisions and motivations of ethics review committees (Taplin et al., 2022). What the researchers *actually* write in applications for ethics review has not been studied earlier. This gives a new perspective in the discussion of ethics that raises new questions, not only in regard to the ethics review process for research including refugee children that was the main focus of this study. And even though the purpose of an ethics review is to safeguard participants from *unethical* research, research in general could benefit from a discussion on what is *ethical*. We do not know what happened before these applications were sent in. The research process, often characterized by limited time and funding, might promote conservative wording and study design as well as an older age range of the participants (given the few applications that included children under the age of 12 years) in applications and design to increase the likelihood of passing the ethics review. Being denied or having to make adjustments to be approved takes time and resources that are needed for the research. It is possible that argumentation about *research-induced distress* is discussed as a possible risk for the participants to “be safe” in regard to what the researchers think that the ERA members want to hear, even though the risk is low.

An incidental finding from the data was the age of the participants. In 80% of the applications in this study, the children were 12 years or older. The reason for this is unknown in regard to these applications, but given that research about sensitive subjects involving young informants is associated with a lower rate of approval in ethics review (Powell et al., 2018; Taplin et al., 2022) and in the eyes of the general public as well (Helland, 2025), there might be a strategic connection here. Another possible reason might be a lack of measurements developed for lower ages, and that development and testing of new measurements is too costly and time-consuming to include in the project budget, as well as other reasons not apparent here. These matters need further exploration. What should be noted in relation to the issue of age is that, during the time period of 2020–2021, a total of 6320 children applied for asylum in Sweden. Of these children 78% were 0–12 years old (Migrationsverket (Swedish Migration Agency), 2020; Migrationsverket (Swedish Migration Agency), 2021) This negative skewness in the age of the participating children is most definitely a concern in relation to the rights of the child. The inclusion of young ages in study design and adaptation in methodology to accommodate this is recommended. Given the importance of the first years for children's development, increased knowledge about younger refugee children is of particular importance.

With the increase of research performed *with* refugee children, we increase the knowledge about their perspective and the effectiveness of different kinds of interventions (Kuru et al., 2024; Van Der Gucht et al., 2019), but not all refugee children are alike and their experiences can depend a great deal on social circumstances in their home country in regards to abuse and neglect (Emery, 2011). We need as clear a view as possible of what the refugee children have experienced, how they feel, and how the treatments and interventions we use affect them, to be able to give the best possible aid to those who need it the most.

5. Conclusion

The findings suggest that applications generally reflect an ethical awareness and preparedness, as evidenced by the fact that all applications were approved, although some with conditions. This appears to indicate that the ERA recognizes the importance of this research and is open to ethically sound studies involving vulnerable populations. However, the analysis also reveals a tendency to emphasize protective aspects over participatory rights, with limited explicit reference to children's agency in relation to research that concerns them. This may reflect a cautious approach shaped by legal frameworks but also highlights an area of growth – particularly in embracing participatory and child-centered methodologies as well as inclusion of younger ages.

Future research should explore how ethical considerations evolve from idea conception through ethics review and how, or if, the review process affects the intended research. Additionally, further investigation is needed into how young children can be ethically and meaningfully included in research on sensitive matters, and how the ethics review process can be a supportive structure to this end. Ultimately, this study contributes to a deeper understanding of the ethical landscape surrounding research with refugee children and underscores the importance of dialogue between researchers, ethical committees, and children's rights advocates to ensure that research both protects and empowers the children it seeks to understand.

CRedit authorship contribution statement

Mikael Hagström: Writing – original draft, Formal analysis, Data curation, Conceptualization. **Linnea Wegerstad:** Writing – review & editing, Investigation, Data curation. **Gisela Priebe:** Writing – review & editing, Investigation, Data curation.

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Declaration of competing interest

None.

Data availability

Data will be made available on request.

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