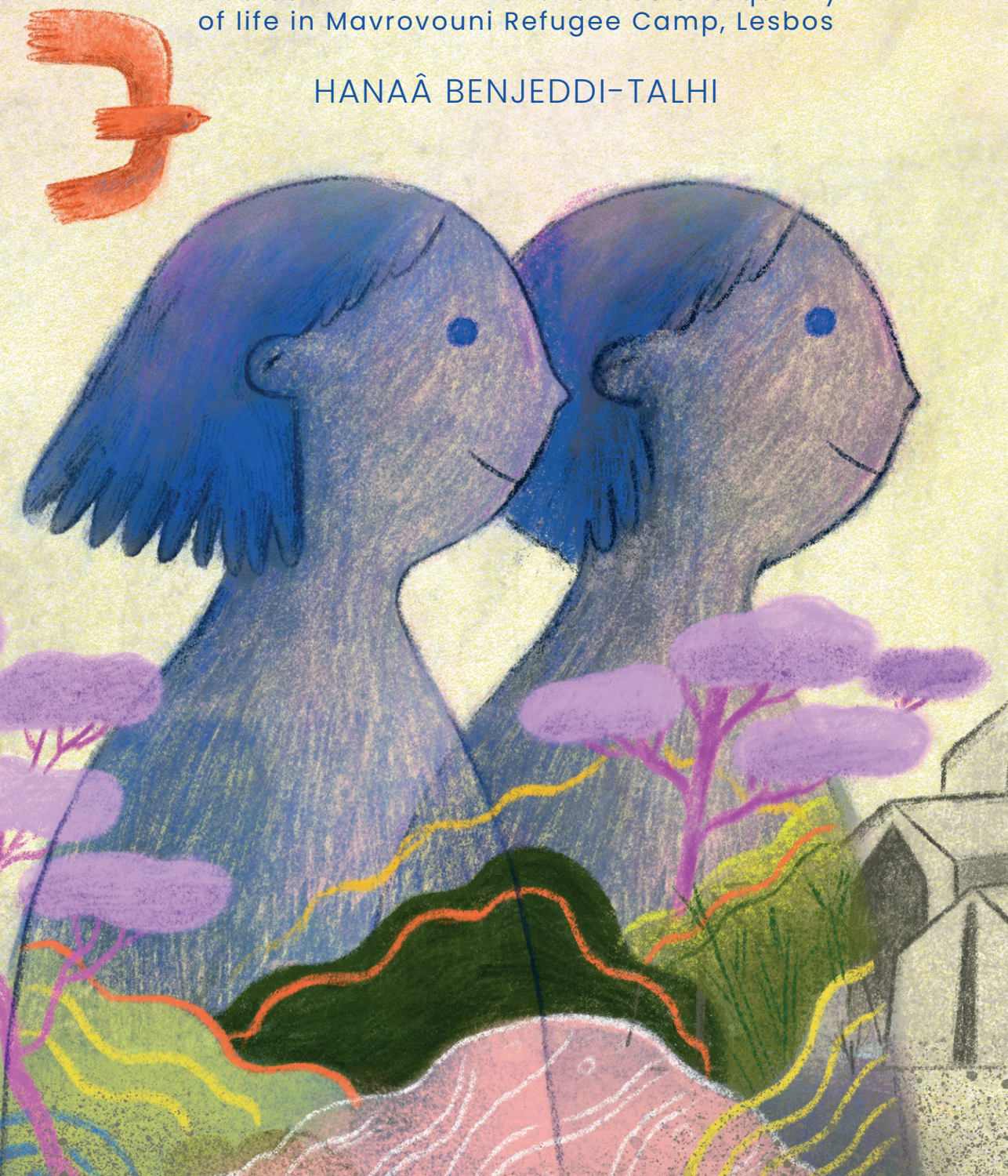
The Health of Displaced Children

Studies on the nutritional status and quality of life in Mavrovouni Refugee Camp, Lesbos

HANAÂ BENJEDDI-TALHI



STELLINGEN

behorende bij het proefschrift

The Health of Displaced Children

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1. De voedingsstatus van vluchtelingenkinderen is gecompromitteerd. *(dit proefschrift)*
2. Eén op de drie alleenreizende vluchtelingenkinderen is ernstig chronisch ondervoed. *(dit proefschrift)*
3. Alle kinderen die verblijven in het grootste vluchtelingenkamp van Europa ervaren een slechtere kwaliteit van leven. *(dit proefschrift)*
4. Hoe langer kinderen in dit vluchtelingenkamp verblijven, hoe slechter hun kwaliteit van leven. *(dit proefschrift)*
5. Morele distress is onlosmakelijk verbonden met het doen van onderzoek naar mensen in nood. *(dit proefschrift)*
6. "The children are always ours, every single one of them, all over the globe; and I am beginning to suspect that whoever is incapable of recognising this may be incapable of morality." – *James Baldwin*
7. "Elk kind in de wereld heeft dezelfde groeipotentie." – *Mercedes de Onis*
8. "Organised science can trigger action." – *Richard Horton*
9. "As you return home, to your home, think of others (do not forget the people of the camps)." – *Mahmoud Darwish*
10. "La vérité n'a pas honte d'être nue. – De waarheid heeft geen schaamte om naakt te zijn." – *papa*

Hanaâ Benjeddi

Amsterdam, 18 september 2026

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Hanaâ Benjeddi-Talhi

This PhD thesis was embedded within the Department of Global Child Health of the Amsterdam UMC, Location AMC, University of Amsterdam, the Netherlands.

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The Health of Displaced Children

Studies on the nutritional status and quality of life in Mavrovouni Refugee Camp, Lesbos

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Voor mijn ouders

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CHAPTER ONE

General introduction

Displaced children worldwide

The worldwide rise in forced displacement has reached unprecedented levels; at the end of June 2024, 122.6 million people worldwide remained forcibly displaced due to persecution, conflict, violence, human rights violations or events seriously disturbing public order, with 40% of them being children.[1,2] Of these 122.6 million people worldwide, 43.4 million classify as refugees. Of the total amount of refugees, 73% originate from five countries: Afghanistan (6.4M), Syria (6.4M), Venezuela (6.1M), Ukraine (6M), and South Sudan (1.5M). Recently, the genocide in the Gaza Strip has led to an increase in the number of Palestinian refugees, totaling 6 million.[3]

Migration is an understudied determinant which influences the health of migrants, host populations and those who remain.[4] Displaced people can be defined in many different ways, depending on their legal status. Table 1.1 gives an overview of the different kinds of terminology used.

Table 1.1: Definitions of displaced people[5]

Asylum seeker	A person who has left their country of origin and formally requested international protection in another state but whose claim to be recognized as a refugee has not yet been decided
Refugee	A person who 'owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group, or political opinion, is outside the country of his nationality, and is unable to or, owing to such fear, is unwilling to avail himself of the protection of that country' - Article 1, 1951 Refugee Convention, Geneva, Switzerland
Unaccompanied minor	A person under 18 years of age who is outside their country of origin and separated from both parents and other adult relatives or legal guardians
Migrant	Umbrella term for a person who moves from one country to another, or within a country, primarily to improve living conditions

Routes of travel to Europe

The Eastern Mediterranean route (EMR) through Greece remains a key entry point for refugees arriving in Europe. The EMR refers to land and sea migration pathways to Europe that lead mainly to Greece, Cyprus, and Bulgaria, with departures predominantly from Turkey and, to a lesser extent, from Lebanon, the Syrian Arab Republic, and more recently Libya.[6] This EMR-route is used largely by people from the Syrian Arab Republic, Afghanistan, Egypt, Turkey, and Eritrea who are escaping armed conflict, political instability, economic deprivation, and increasingly restrictive asylum regimes in neighboring states.

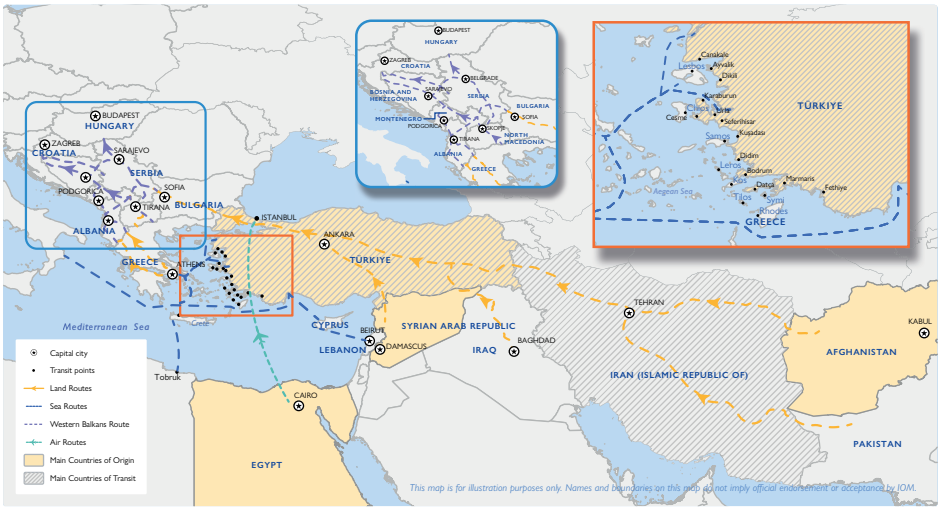


Figure 1.1: Eastern Mediterranean Route map according to the International Organization of Migration (IOM).

While Europe hosts many temporary refugee settlements, accurately estimating the exact number of refugee camps in the region is challenging due to differences in definitions and reporting practices. Greece currently hosts over 30 refugee accommodation centers and 6 Reception and Identification Centers.[7] The island of Lesvos is the main entry point for Greece due to its geographical location, housing one of Europe's largest refugee camps, the Closed Controlled Access Center (CCAC) Mavrovouni, also known as Kara Tepe camp. Established in September 2020 as an emergency response following the fire that destroyed the Moria refugee camp, its population fluctuates between 1,000 and 5,000 individuals, representing diverse demographics from different countries and ongoing humanitarian crises.

The situation concerning displaced people on Lesvos remains controversial. Since the EU-Turkey deal in March 2016, people have been forced to remain on the island awaiting their asylum procedure.[8] This lead to significant overcrowding, which, combined with insufficient resources and asylum capacity, led to inhumane living conditions.[9] These conditions caused violation of basic human rights such as the right to healthcare, the right to housing, and access to the asylum procedure. Numerous governmental and non-governmental organizations, such as Médecins sans Frontiers (MSF), Stichting Bootvluchteling, Kitrinos and Doctors of the World, have provided critical healthcare services, especially to children at CCAC Mavrovouni.

Despite the amount of media attention on the dire living conditions in camp Moria, very little scientific research has been done on the wellbeing of displaced children living on the island. Numerous journalists have reported that children fall ill because of unhygienic living conditions.[10] Violent living conditions, together with pre-existing stress due to e.g. war, lead to severely compromised mental health among the children in camp Moria. MSF coined camp Moria an "open-air "mental asylum"", reflecting the extremity of mental health issues.[11] Suicide attempts were not uncommon among children.[12] NGO health workers report: "More and more of these children stop playing, have nightmares, are afraid to go out of their tents and start to withdraw from life."[13] No formal eduction was available for these children, although several NGO's provided informal eduction to meet the educational needs of these children.

Despite compelling evidence from journalistic resources demonstrating the compromised well-being of displaced children on Lesbos, there was a lack of published scientific evidence on their well-being prior to this PhD project. Our strong belief is that scientific research adds weight and credibility for policy and practice change. That has been the intention of this research project. The research presented in this thesis is based on studies performed in and around the CCAC Mavrovouni on Lesvos, Greece, one of the largest entry points for displaced people in Europe. In addition, we focus on UAM living in designated shelters on the island.

Displaced children at the European borders

Children in refugee camps face significant emotional and physical distress. In 2024, 234,670 first-time asylum applicants were under 18 years old, accounting for 25.7% of the total number of first-time asylum applicants in the EU.[14] The loss of their homes and the dangerous journey are major contributing factors, and they also suffer from physical stress due to harsh conditions and potential physical or sexual violence. An important subset of these children are the group unaccompanied minors (UAMs). An UAM has been defined as a child "separated from both parents and other relatives and is not being cared for by any other adult who, by law or custom, is responsible for doing so', as defined by UN Convention on the Rights of the Child (CRC).[15] They arrive without their parents, often because they

are orphans due to conflict in their home countries, or they are traveling alone with the intention of reuniting with their families later.[16] In 2024, UAMs made up 15.9% of all first-time asylum applicants in the EU under 18 years old.[7]

There is limited research on the health status of displaced children upon their arrival in refugee camps, both globally and specifically at CCAC Mavrovouni. Remarkably, there is significant paucity in the literature on nutritional status of unaccompanied children.[16] In refugee camps, increased prevalence of infections, limited access to essential healthcare (such as vaccinations), and poor hygiene increases the risk for outbreaks such as measles, cholera, and meningitis.[17] In 2017, Hermans et al published a cross-sectional study reporting the disease prevalence in Camp Moria, as one of the few scientific studies published.[18] One study describes the nutritional status of UAMs in camp Moria on Lesbos, showing a prevalence of 24% underweight among 63 UAMs.[19] Other relevant publications are opinion pieces in which attention is drawn to the harrowing situation and in which the effect on aid workers is described.[20]

Nutritional status

Nutritional status is a well-established indicator of overall health and socio-economic conditions in children.[21] Forced migration can both create and worsen nutritional problems: disruption to familiar environments and food sources can lead to acute malnutrition in the short term, while prolonged displacement often results in chronic undernutrition. Hypothetically, nutritional status could improve over time due to arrival to a safer place, yet there is no scientific evidence to prove this.

Relevant anthropometric measurements include weight, height and mid-upper arm circumference (MUAC). For each child, Z-scores can be calculated using World Health Organization (WHO) Anthro-tool for children 0–59 months[22] and WHO Anthro-Plus tool for children aged 6–19 years of age.[23] Commonly calculated Z-scores includes: Length-for-age (LAZ) and weight-for-height (WHZ). The WHO definitions of wasting (weight for height Z-score equal or smaller than -2) and stunting (height-for-age Z-score equal or below -2) are used as parameters of malnutrition. Stunting is caused by prolonged undernutrition, which impairs long-term growth, while wasting occurs due to insufficient nutrition over a shorter period of time.

We aimed to study nutritional health in children on Lesbos for multiple reasons. Firstly, we believed it would give us an understanding of their overall health when entering Europe. Secondly, it informs us whether their nutritional health improves during time in the camp, and therefore whether their important nutritional needs are met to adequately support their development during this transit period. Lastly, we believe it will inform us about the nutritional health of children moving to other parts of Europe, and it gives us a clear image on how compromised their health is and what their overall health need are entering the reception country.

Quality of Life (QoL)

Another important element of the wellbeing of displaced children is their Quality of Life (QoL). The concept of QoL, as defined by the World Health Organization (WHO) refers to "an individual's subjective assessment of their experience of life".[24] QoL is a multifaceted construct encompassing various domains such as physical health, mental health, and social health.[24] Children in refugee camps face many challenges that could potentially affect their QoL: limited access to education, malnutrition, and psychological trauma, which may occur in their home country, while traveling, or during their time in refugee camps.[25] This is especially true for UAMs, who are without the protective presence of family during difficult and dangerous journeys.[16] Despite the additional hurdles they face, research on this group of children is notably limited, even though their QoL is likely to be significantly impacted by these extra challenges. As elaborately reported by journalists, it is probable that the QoL of these children is severely compromised as children say "they have found hell" when describing camp Moria.[11]

Measuring QoL in children living in refugee camps is particularly challenging due to the lack of validated, including cross-cultural validity, tools for children. An additional complicating factor is the fact that children in refugee camps generally speak different languages. There is however a critical need of understanding the important determinants in these children in order to effectively support and improve their QoL. Studying QoL gives us an insight of how children are impacted in their day-to-day life, aiming to capture their subjective experience in a systematic manner.

Research questions

Thee research questions can subdivided in main- and sub-questions:

1. What is known about nutritional status of children living in refugee camps in and around Europe?
   i. What is known about the changes in nutritional status overtime?

2. What is nutritional status of displaced children on Lesvos?
   i. What is the prevalence of wasting and stunting?
   ii. How does their nutritional status develop overtime?
   iii. What is the nutritional status of children traveling without their parents?

3. What is the Quality of Life of displaced children on Lesvos?
   i. What is the Quality of Life of children in CCAC Mavrovouni compared to the reference group?
   ii. What is the Quality of Life of Unaccompanied Minors compared to the reference group?
   iii. What factors are associated with worse Quality of Life?

4. What are the ethical challenges faced by research students?

Anticipated limitations

The following limitations were anticipated in our study. Our biggest challenge was obtaining all the necessary permissions to execute the project in an ethical and scientifically sound manner. For example, securing ethical clearance from an official Greek body. Additionally, the rapidly changing composition of the camp population meant that our data would primarily represent the situation at the time of data collection, potentially not capturing long-term trends or shifts. Another significant challenge we expected to encounter was a substantial loss to follow-up, which is likely be inevitable due to the high mobility of the refugee population, with families being relocated between different camps. This factor was expected to impact the continuity and completeness of our data over time.

Outline of this thesis

In **chapter 2**, the thesis provides a systematic review including meta-analysis of existing research on the nutritional status of children living in refugee camps in and around Europe. The chapter begins by summarizing the current understanding of malnutrition among displaced children by highlighting key studies conducted in Europe and surrounding regions. The chapter identifies significant gaps in the literature, including the lack of longitudinal studies, and limited or absent data from specific refugee camps. Moreover, methodological challenges, such as difficulties in data collection in such research settings are discussed. These insights set the stage for the subsequent chapters of the thesis, which aim to address these gaps and further contribute to the understanding of displaced children's nutritional needs, as one of the most important health child health proxies.

Chapter 3 describes the findings of a prospective cohort study that was conducted between February and August 2023 at CCAC Mavrovouni to assess the nutritional status of children in the camp. Data were collected on demographics, dietary details, and health indicators, with a focus on the prevalence of wasting, stunting, and overweight based on World Health Organization (WHO) criteria. Subgroup analyses for UAMs and breastfed children are presented and the importance of other factors, such as travel duration or duration of residence in camp, influencing nutritional status are explored.

In **chapter 4**, we investigated the QoL of displaced children living in CCAC Mavrovouni and UAMs living in designated shelters on Lesvos, Greece. Using the PROMIS® tool, we quantitatively assessed various QoL domains and compared the results to a reference group. We also aimed to identify associated variables influencing QoL. Additionally, open-ended questions were included to explore qualitative aspects of QoL among UAMs.

In **chapter 5**, we systematically reviewed and quantitatively analyzed all available scientific evidence on the nutritional status of UAMs across the world. The primary aim was to summarize prevalence estimates of key nutrition-related indicators such as prevalence of stunting and overweight, and to explore how these varied by geographical location.

In **chapter 6**, we qualitatively studied the ethical challenges and potential moral distress faced by our researchers at the CCAC Mavrovouni. The research involved conducting three ethics support workshops, where 5 to 10 participants discussed the moral dilemmas they encountered in their work. The sessions were audio-recorded, transcribed, and analyzed using reflexive thematic analysis. We aimed to identify the main themes related to the ethical challenges faced by our researchers.

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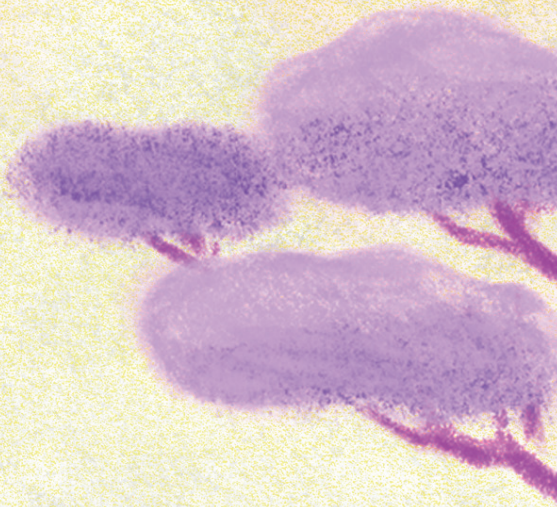
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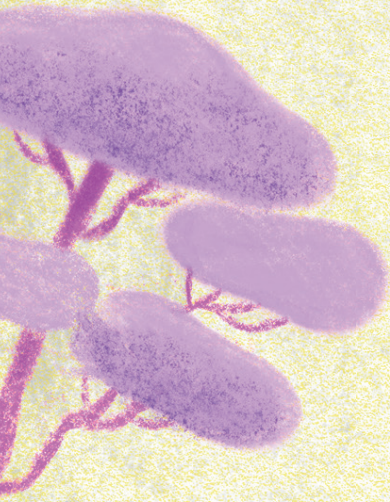


CHAPTER TWO



Nutritional status of refugee children living in temporary settlements in Europe and MENA region: a systematic review and meta-analysis

Hanaâ Benjeddi, Derre Kwee, Mariken Gruppen, Martijn van der Kuip, Michaël Boele van Hensbroek, Marceline Tutu-van Furth



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Abstract

An estimated 41% of all forcibly displaced people are children.[1] Many of these children may live in refugee camps, under poor conditions, for years. The health status of children when arriving in these camps is often not recorded, nor is there a good insight into the impact of camp life on their health. We systematically reviewed the evidence concerning the nutritional status of children living in refugee camps in the European and Middle East and North Africa (MENA) regions. We searched Pubmed, Embase, and Global Index Medicus. The primary outcome was the prevalence of stunting, and the secondary outcome was the prevalence of wasting and being overweight. Out of 1,385 studies identified, 12 studies were selected, covering 7,009 children from fourteen different refugee camps in the Europe and MENA region. There was great heterogeneity among the included studies, which showed that there was a pooled prevalence of stunting of 16% (95% confidence interval (CI) 9.91–22.92%, I^2 95%, $p<0.01$) and of wasting of 4.2% (95% CI 1.82–6.49%, I^2 97%, $p<0.01$).

Anthropometric measurements were done at random points in time during the children's camp period. However, no study had a longitudinal design, describing the effect of camp life on the nutritional status.

Conclusion: This review showed that there is a relatively high prevalence of stunting and a low prevalence of wasting among refugee children. However, the nutritional status of children when entering the camp and the effect of camp life on their health is not known. This information is critical in order to inform policymakers and to create awareness concerning the health of the most vulnerable group of refugees.

Introduction

According to data published in 2022 by the UN Refugee Agency (UNHCR,), for the first time in recorded history, over a hundred million individuals worldwide were forcibly displaced as a result of persecution, conflict, violence, or events seriously disturbing public order.[2] This number has doubled over the last decade. An estimated 41% of all forcibly displaced people are children.[1] Europe and its individual countries have struggled with the high influx of refugees.[3]

This inevitably leads to suboptimal solutions where refugees are offered shelter in temporary settlements. These camps were initially designed to keep people safe during specific emergencies, but emergency situations have become protracted, resulting in people living in camps for years.[4]

Especially for children, migration is a core determinant of health.[5] The conflict that they flee from affects their health and development in a myriad of ways.[6] The health status of children when arriving in refugee camps is often not recorded, nor is there a good insight into the impact of camp life on their physical and psychological health. This insight is of critical importance, since it is known that the effect of health threats in childhood, such as malnutrition, trauma, and poor living conditions, may have a lasting impact on their health and quality of life. This might be carried into adulthood leading to decreased work productivity.[7,8] For example, stunting, defined as having a height for age lower than two standard deviations from the WHO Child Growth Standards median, may cause diminished cognitive and physical development, reduced productive capacity, and an increased risk of non-communicable diseases such as diabetes.[9,10] Suboptimal water, sanitation, and hygiene (WASH) facilities can furthermore lead to poor health.[11]

Documenting the health of children on arrival and during their stay in the camps can be challenging because registration systems are not always in place and health care is provided by many different Non-Governmental Organizations (NGOs). Furthermore, children and their families reside in refugee camps for uncertain amounts of time, moving unexpectedly to other camps which makes assessing the impact of camp life on the health status of these children challenging.[11]

There are risk factors at every stage of a refugee child's journey that lead to compromised health. This can be at the pre-migration level (e.g., violence and food

insecurity), during the journey (e.g., exposure at sea, hunger, trafficking, acute infectious diseases), and in the country of destination (e.g., suboptimal access to health care, discrimination, caregiver's mental health problems).[10]

Literature on the health of children in European refugee camps is thought to be limited, but has not been systematically reviewed. The aim of this paper is, therefore, to systematically review the evidence concerning the nutritional status of children arriving and living in refugee camps in Europe and the MENA region. A better understanding of their health status will be of importance to improve policies and awareness concerning the health of the most vulnerable group of refugees.

Methods

Search strategy

Our systematic review was registered in PROSPERO under number CRD42022369667. For this systematic review and meta-analysis, a medical information specialist, experienced in systematic reviews, searched the following databases from 1990 to August 2022: Embase, MEDLINE, Global Index Medicus. The Global Index Medicus is a WHO database focused on low- and middle-income countries. We used both controlled terms (i.e., MeSH terms in MEDLINE) and free-text terms related to the nutritional status of refugee children (e.g., growth, nutrition, stunting). For full search strategies, see Appendix 2.1. Snowballing and citation coupling was used in order to find additional publications.

Inclusion and exclusion criteria

We included studies that focused on children within the age range from birth up to 18 years of age and that were performed in refugee camps or comparable settings. We defined these settings as "a temporary settlement meant for displaced people." In order to have a more in-depth perspective on this topic, the search was extended to the Middle East and North Africa (MENA) region, because many of the refugee children are originally from this region. In addition, camps in the MENA region might be subsequential stops for refugee families. We had no restrictions on the language, date, or publication status. We aimed to include cross-sectional and cohort studies. We excluded studies that entailed health screenings at recipient countries as well as case studies.

Data extraction

The following information was extracted for each study: author, year of publication, study design, sample size, country or region, and the prevalence of stunting, wasting, and being overweight in percentages including confidence intervals. We chose to include stunting as the main outcome as it is part of the World Health Organization's Global Nutrition Target for 2025, achieving a 40% reduction in the number of children under 5 who are stunted.[12] Table 2.1 shows the PICO framework that was used.

Table 2.1: PICO framework

Population	Refugees or internally displaced children aged 0–18 years
Intervention	Living in a temporary settlement or refugee camps in Europe or MENA region
Control	WHO growth standards[13]
Outcomes	Prevalence of stunting Prevalence of wasting Prevalence of overweight/obese

MENA: Middle East and North Africa, WHO World Health Organization

Data analysis

Two reviewers (H.B., D.K.) independently screened titles and abstracts of all identified articles for eligibility. Rayyan was used as a screening tool.[14] Additionally, the full-text articles of all potentially relevant studies were retrieved, and eligibility was determined independently by two authors (H.B., D.K.). Differences regarding the inclusion were resolved through discussion. We collected data according to protocol. We contacted study authors twice for clarification of (missing) data in included and potentially eligible studies, specifically requesting data on children in mixed patient cohorts or missing data in abstracts where the article was unavailable. We used the most complete and recent paper if multiple papers assessed the same (sub)population.

Quality assessment

Quality assessment was performed by utilizing the Joanna Briggs Institute (JBI) critical appraisal checklist for studies reporting on prevalence data. See Appendix 2.2. We used the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines. This work was exempted from medical ethical

approval as we used data from patients enrolled in studies and trials already approved by relevant ethical committees.

Outcomes

Our primary outcome was the prevalence of stunting. Stunting was defined as a height for age below 2 standard deviations of the WHO Child Growth Standards median.[15] Secondary outcomes included the prevalence of wasting and obesity. Wasting was defined as a weight-for-height ≤ -2 SD of the WHO Child growth standards median. Obesity was defined as a weight-for-height ≥ +2 SD of the WHO Child growth standards median.

Statistical analysis

Statistical analyses consisted of a pooled analysis using Review Manager 5.4.[16] Only the studies that reported a confidence interval were used for this analysis. A forest plot was constructed to meta-analyze the primary outcome looking at the prevalence of stunting as well as the prevalence for wasting. If possible, data was stratified for age in 5 years groups based on the published data. The random effects model was used in the meta-analysis. The $I(^2)$ index was used to assess heterogeneity.

Results

This search strategy yielded a total of 1,397 studies of which the abstracts were screened, leading to 46 articles that were sought for retrieval. From that list, a definite number of 12 was selected based on the full text. Figure 2.1 shows the PRISMA flow diagram. The key reason for exclusion was the fact that the study was done in settings other than temporary refugee settings. Table 2.2 provides details of included studies.

Table 2.2: Characteristics of studies about anthropometry (prevalence in %, 95% CI)

Studies	Location	Sample size	Stunting (%)	Wasting (%)	Overweight (%)
Grijalva-Eternod et al. 2012	Four Western Sahara refugee camps in Algeria	N=1,608	29.1 (26.4–31.9)	9.1 (7.6–10.7)	2.4 (1.6–3.3)
Hossain et al. 2016	Za'atri refugee camp (Jordan) and Domiz refugee camp (Iraq)	N=1,299	16.7 (11.6–23.4) 19.0 (15.8–22.7)	1.2 (0.5–3.2) 4.1 (2.8–6.1)	- -
Grammatikopoulou et al. 2019	Two refugee centres in Drama and Kavala, Greece	N=192	7.3 (4.0–11.9)	4.6 (1.0–12.9)	-
Bilukha et al. 2014	Za'atri refugee camp (Jordan)	N=327	17.0 (11.7–24.0)	1.2 (0.5–3.2)	-
Pehlivanturk-Kizilkan et al. 2020	Turkey	N=97	11.0 (5.9–19.4)	0 (0)	6.0
Walpole et al. 2018	Four refugee camps in Northern Greece	N=177	17.4 (11.9– 24.8)	3.7 (1.4–9.6)	11.1% (6.3–18.9)
Aakre et al. 2016	Algeria	N=111	13.8	8.2	-
Khatib et al. 2009	Ruwayshed and Al-Karamah (Jordan)	N=325	12.0	1.2	-
Kimiagar et al. 1995	9 camps in Iran	N=900	28.23	15.95	-
Abukishk et al. 2021	Jerash and Souf refugee camps in Jordan	N=367	23.8 20.4	- -	18.2 7.14
El Khisawi et al. 2017	Refugee camp Gaza Strip Palestine	N=217	22.6	-	-
Haidar et al. 2017	Al-Jad'ah camp in Iraq	N=1,389	-	25	-

Demographics

A total of 7,009 children were examined in the 12 included studies. Studies were conducted in Jordan (n=3), Greece (n=2), Algeria (n=2), Turkey (n=1), Iraq (n=1), Iran (n=1), Palestine (n=1), and multiple countries combined (n=1). These children lived in 29 different refugee camp settings. None of the studies reported longitudinal data on the development of the children's nutritional status during their stay in the refugee camps, i.e., whether their nutritional status improved or worsened over time.

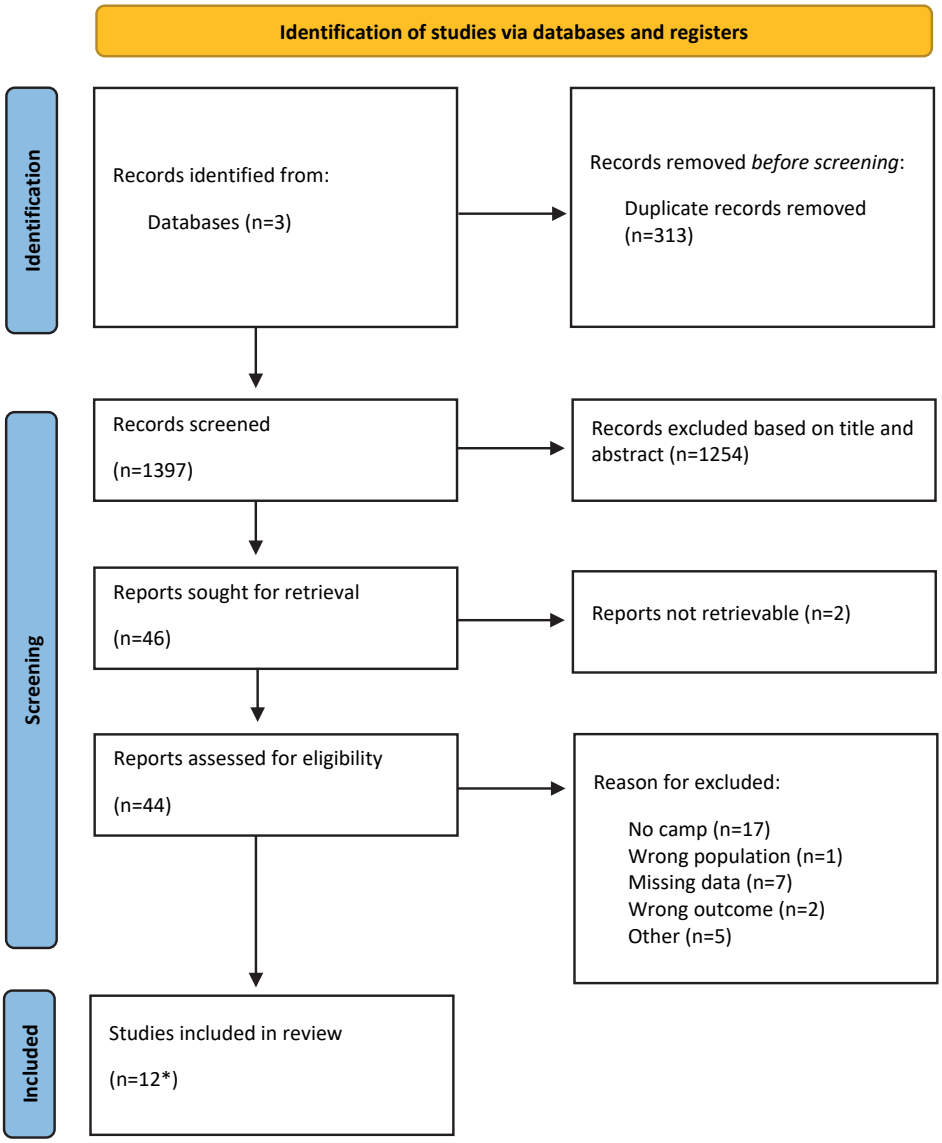


Figure 2.1: PRISMA flow diagram: nutritional status of refugee children living in camps in Europe and MENA region. * All included studies are cross-sectional observational studies.

The most commonly used methodological approach was using weight, height, and age to construct height-for-age and weight-for-height, from which the prevalence of stunting and wasting was determined. Almost all studies used WHO anthropological definitions to determine the level of wasting and/or stunting. The level of stunting ranged from 7.3 (in Drama and Kavala, Greece[17]) to 29% (in Western

Sahara, Algeria[18]). Wasting prevalence ranged from 1.2 (in Za'atari, Jordan[19]) to 5.5% (in four refugee camps in Northern Greece[20]). Figure 2.2 shows the levels of stunting that were reported.

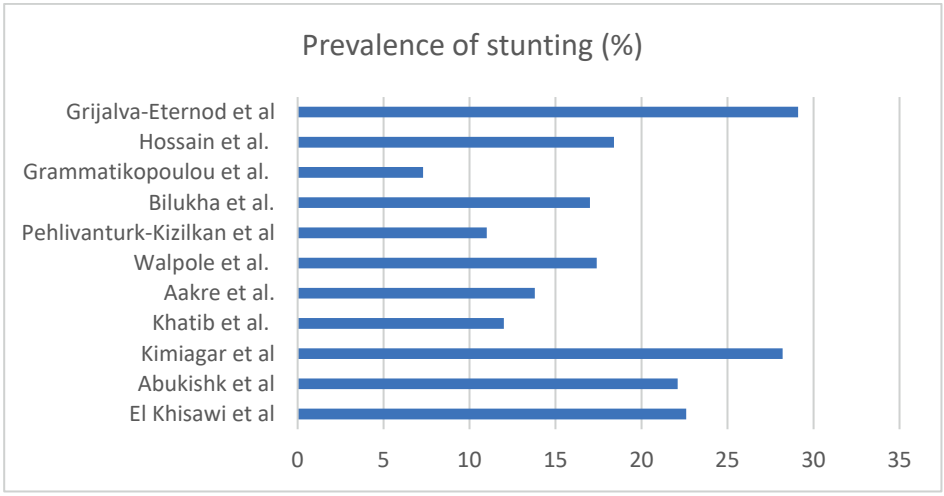


Figure 2.2: Bar chart showing the prevalence of children being stunted.

Meta-analysis

All corresponding authors of these studies were contacted in order to complete the data. Three authors provided us with the relevant confidence intervals needed for the meta-analysis. The pooled prevalence of stunting was calculated to be 16.4% with a 95% CI (9.91–22.92%; I^2 95%), as can be seen in Figure 2.3. There was a high level of heterogeneity, and a random effect was used in the calculation. The heterogeneity was significant between the different studies ($p<0.01$).

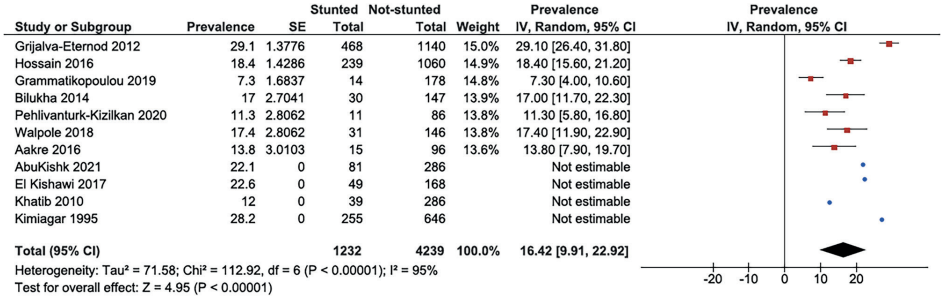


Figure 2.3: Forest plot showing the prevalence of children being stunted. Only the studies that reported a confidence interval were included in the statistical analysis. The blue dots display studies that reported a prevalence without CI or SE.

The pooled prevalence of wasting was calculated to be 4.2% with a 95% confidence interval (1.82–6.49%; I^2 97%), as can be seen in Figure 2.4. For this calculation, there similarly was a very high level of heterogeneity. The heterogeneity was significantly different between groups ($p<0.01$).

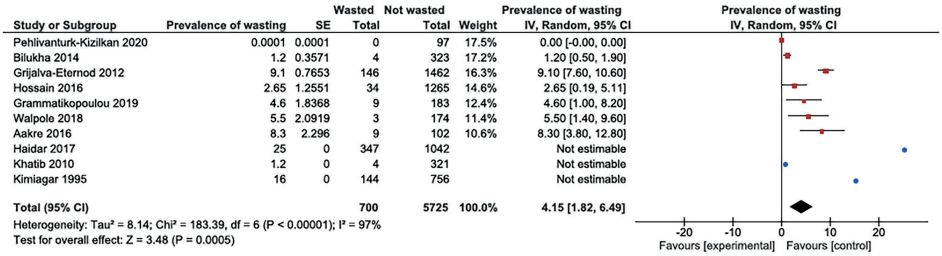


Figure 2.4: Forest plot showing the prevalence of children being wasted. Only the studies that reported a confidence interval were included in the statistical analysis. The blue dots display studies that reported a prevalence without CI or SE.

Discussion

This systematic review showed that there is a pooled prevalence of stunting of 16% and wasting of 4.2% among refugee children living in temporary settlements in Europe and the MENA region. The number of studies that reported on obesity was too low to allow a meta-analysis on obesity. Interpretation of our findings on the prevalence of wasting and stunting can be done in a multitude of ways.

First of all, ranges of prevalence to classify levels of wasting and stunting, for global monitoring of malnutrition by the World Health Organization, have been used since the 1990s.[21] This classification is used as a tool to prioritize action and guide policymakers. Our review shows that, according to these WHO criteria, out of twelve studies, four were classified as having found a "high," six a "medium," and one a "low" prevalence of stunting. The pooled prevalence of stunting in our meta-analysis would be classified as "medium."

Secondly, compared to the average percentage of stunting in Europe, 4.5%,[22] the pooled prevalence of 16% is evidently higher, indicating that children living in refugee camps in Europe and the MENA region are more chronically malnourished when compared to the average child living in Europe.

Conversely, a systematic review that was published in 2021 described the nutritional status of 2,202,869 children (including a small population of refugee children), living in the MENA region,[23] and found a pooled prevalence of stunting of 22% (95% CI 20.4–23.6). Compared to this group, our meta-analysis shows that the average prevalence of stunting among children living in European and MENA refugee camps (16%) is lower. It should however be noticed that this MENA region review comprised of a very heterogeneous set of studies in which stunting prevalence varied between 8.7 and 50%. In addition, it is important to realize that the 95% confidence intervals of the two reviews (MENA and ours) overlap. However, an explanation for a difference in prevalence (22% vs 16%) could be that the study population in the 12 studies in our review either have their origins in a country with a lower prevalence of stunting or that their nutritional status improves during their stay in the refugee camps. If the level of stunting found in our review is higher than the level of their country of origin, it might be hypothesized that children arriving in refugee camps have been subject to long and often very stressful journey and chronic food shortage. An example is the prevalence of stunting among Syrian children (8%), as reported in this systematic review, versus the prevalence of 16% as calculated in our meta-analysis. From our review, however, we cannot exclude the possibility that stunting has worsened in the refugee children during their period living in the camps.

The levels of wasting in the twelve studies included in our review can be graded by making use of the WHO framework for malnutrition and results in the following grades: two having a "high," three a "medium," one a "low," and four a "very low" prevalence of wasting. Stunting therefore seems to be more common in children in refugee camps, whereas wasting is very rare. This could be explained by the fact that refugee children are chronically under stress receiving an inadequate diet during their flee to a safer place which often takes months or years, which leads to stunting, rather than acutely and severely deprived of nourishment. Important to note is also the fact that refugee children frequently are born during the mother's flee, in which period the mother is under stress and might have decreased access to appropriate nutrition. This can lead to intra-uterine malnutrition leading to irreversible stunting in the child's first years of life.[24]

Important to stress again that from the 12 studies included in our review, it is unclear at what point in time the anthropometry was done: on entering the refugee

camp or at random points in time during their stay in the camps. It is important when designing effective health interventions to know if these children enter the camp already being stunted or that they become stunted (or wasted) during their stay in the camps. It is known that children in refugee camps can gain weight, reflected as decreasing levels of wasting, during their stay in the camp, as seen in a study done in a large refugee camp in Myanmar where Rohingya refugee children and their families reside.[25] Despite differences in refugee camps, causes of malnutrition and the effect of stressful circumstances could be similar among camps. We therefore also looked at the prevalence of obesity in the included studies; four studies incongruently reported on this, and this parameter therefore was not included in the meta-analysis.

Limitations

Firstly, the limited number of studies was identified. However, we had a strong search strategy making it unlikely that relevant studies were missed.

Secondly, in designing the review strategy, we became aware that it was challenging to define the concept of a "refugee camp." Different terms were used in the literature to describe temporary settlements for refugees. The additional complexity is that these temporary settlements turn into long-term solutions, with which the definition of a refugee camp becomes unclear. However, we minimalized this shortcoming by reaching a consensus by discussion in case of doubt (to in- or excluded a study).

Thirdly, next to the challenge of finding a clear definition of a refugee camp, these camps also differ in the way they are set up. There can be differences in terms of WASH facilities, health facilities, and other available services. This limits the generalizability of our study.

Conclusion

Our review provides evidence for a deprived nutritional status among refugee children living in camps in Europe and the MENA region, as expressed by relatively high levels of stunting. The data in this systematic review does not only contribute to Sustainable Development Goal (SDG) number tree, good health, and well-being: it also contributes to SDG number 16, which aims to promote a peaceful and inclusive society. Our findings highlight the important need for future research

to not only assess the health status of children when entering a refugee camp, but also focus specifically on the effect of camp life on the health and nutritional status of refugee children and how it can be improved.

Acknowledgements

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Authors' contributions

H.B. and D.K. wrote the main manuscript text. MK helped with the statistical analysis. All authors reviewed the manuscript.

Data availability

The data that supports the finding of this study are available from the corresponding author, HB, upon reasonable request.

Ethical approval

No ethical approval was required as the review concerns data from previously published studies.

Competing interests

The authors declare no competing interests.

Data availability statement

The data that supports the finding of this study are available from the corresponding author, HB, upon reasonable request.

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Appendix 2.1

Search terms

1. Refugees - Refugees [MeSH] OR Refugee Camps [MeSH] OR Refuge* [tiab] OR Refugee Camp* [tiab] OR Refugee cent* [tiab] OR Refugee settlement* [tiab] OR Reception facilit* [tiab] OR Identification center* [tiab] OR displaced person [tiab] OR IDP [tiab] OR asylum seeker [tiab] OR Migrant [tiab] OR Immigrant [tiab]
2. Children - Infant [MeSH] OR Child [MeSH] OR Minor [MeSH] OR Child Development [MeSH] OR unaccompanied minor [tw] OR child*[tw] OR schoolchild*[tw] OR infan*[tw] OR pediatri*[tw] OR paediatr*[tw] OR neonat*[tw] OR toddler*[tw]OR boy[tw] OR boys[tw] OR boyhood[tw] OR girl[tw] OR girls[tw] OR girlhood[tw] OR youth[tw] OR Adolescent [tw] OR Teen [tw]
3. Europe + MENA-region + Turkey - Austria OR Belgium OR Bulgaria OR Croatia OR Cyprus OR Czech Republic OR Denmark OR Estonia OR Finland OR France OR Germany OR Greece OR Hungary OR Ireland OR Italy OR Latvia OR Lithuania OR Luxembourg OR Malta OR Netherlands OR Poland OR Portugal OR Romania OR Slovakia OR Slovenia OR Spain OR Sweden OR Turkey OR Algeria OR Bahrain OR Djibouti OR Egypt OR Iran OR Iraq OR Jordan OR Kuwait OR Lebanon OR Libya OR Morocco OR Oman OR Qatar OR Saudi Arabia OR Palestine OR Syria OR Tunisia OR United Arab Emirates OR Yemen
4. Anthropometrics - Nutritional Status [MeSH] OR Child Nutrition Disorders [MeSH] OR Nutritional inadequacy [tiab] OR Malnutrition [tiab] OR Stunting [tiab] OR Wasting [tiab] OR GAM [tiab] OR SAM [tiab] OR Growth [tiab] OR Underweight [tiab] OR Overweight [tiab] OR Height [tiab] OR Weight [tiab] OR Anthropometric [tiab] OR height-for-age [tiab] OR HAZ [tiab] OR weight-for-height [tiab] OR WAZ [tiab] OR weight-for-age [tiab] OR WFA [tiab] OR Height-for-age [tiab] OR HFA [tiab] OR BMI [tiab] OR BMIZ [tiab] OR MUAC OR mid-upper arm circumference [tiab] OR skinfold thickness [tiab] OR head circumference [tiab] OR waist circumference [tiab].

Appendix 2.2

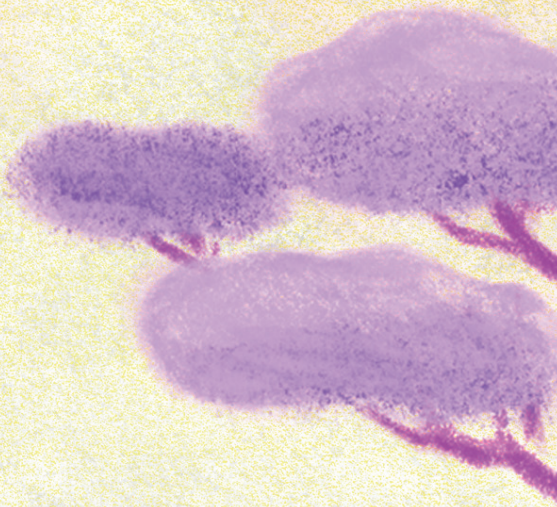
Joanna Briggs Checklist score

Study	Score
Walpole et al.[20]	7
Grammatikopoulou et al.[17]	7
Pehlivanturk-Kizilkan et al.[27]	6
Hossain et al.[19]	8
Bilukha et al.[26]	6
Abukishk et al.[31]	9
Khatib et al.[29]	8
Grijalva-Eternod et al.[18]	9
Haidar et al.[32]	4
Kimiagar et al.[30]	3
El Kishawi et al.[33]	8
Aakre et al.[28]	8





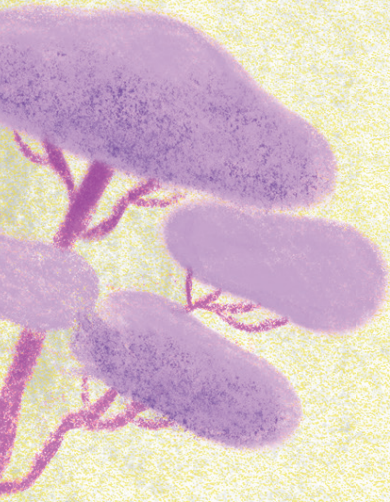
CHAPTER THREE



Nutritional status of displaced children including unaccompanied minors on Lesvos, Greece

Hanaâ Benjeddi, Mariken Gruppen, Sam Post, Arte Groenewegen, Embla Egen, Eirini Samiotaki Logotheti, Zoi Livaditou, Wieger Voskuijl, Marceline Tutu-van Furth, Michaël Boele van Hensbroek, Agis Terzidis*, Martijn van der Kuip*

* Shared authorship



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Abstract

Introduction: The number of displaced people worldwide has reached an unprecedented 120 million, of whom 40% are children. There is limited knowledge about the health of children in refugee camps, particularly regarding their nutritional status. This study examines the nutritional status of 304 displaced children (0–18 years) in Closed Controlled Access Centre (CCAC) Mavrovouni, Lesvos, Greece.

Methods: An observational study was conducted between February and August 2023 at CCAC Mavrovouni. Data collection included demographics, dietary details, health and nutritional status. The primary outcome was the prevalence of wasting, stunting and overweight using World Health Organization (WHO) criteria. We also conducted subgroup analyses for unaccompanied minors (UAMs) separately. Secondary outcomes of our study included the role of breastfeeding and other factors that potentially affect nutritional status.

Results: The overall prevalence of stunting among minors in CCAC at baseline was 11%. 10% of children under five were wasted. Of all children, 5% underweight and 13% were overweight. Nutritional status does not change during their stay in the camp: wasting (improvement in Z-score by 0.2, 95% CI -0.5–0.1), stunting (decrease in Z-score by 0.07, 95% CI -0.2–0.3). There was a significantly higher prevalence of stunting in the UAM sub-group (31%, $p<0.01$). No association was found between breastfeeding and weight-for-height Z-scores under two years old (Z-score difference of 1.3, $p=0.16$), but there was in the larger age group up to five (Z-score difference of 0.82, $p<0.01$).

Conclusions: Our results show that poor nutritional status is prevalent amongst displaced children on Lesvos, highlighting their vulnerability. Our results underline the compromised health and vulnerability of UAMs, with nearly one third of this group being stunted. The unexpected prevalence of overweight highlights complex nutritional challenges.

Introduction

The global increase in forced displacement has reached unprecedented heights, with projections indicating 120 million people in April 2024 (United Nations Refugee Agency - UNHCR),[1] of whom 40% are children. Of the total of 43.4M refugees, 73% originate from 5 countries: Afghanistan (6.4M), Syria (6.4M), Venezuela (6.1M), Ukraine (6M) and South-Sudan (1.5M).[1] Conflict in the Gaza Strip has recently caused a surge in the number of Palestinian refugees (6M). While Europe has many temporary settlements, accurately determining the exact number of refugees in the region is complicated, due to differing definitions and reporting methods.[2] Despite the refugee agreement between the European Union and Turkey in 2016,[3] the Eastern Mediterranean route through Greece remains an important gateway for refugees entering Europe. The Eastern Mediterranean route is a path used by refugees from the Middle East, North Africa, and South Asia to reach Europe. They typically travel through Turkey and cross the Aegean Sea to Greece, often in unsafe boats.[4] Greece hosts over 30 refugee accommodation facilities and 6 so-called Reception and Identification Centers.[5] The island of Lesvos serves as the primary entry point and hosts one of Europe's largest refugee camps, known as Closed Controlled Access Center (CCAC) Mavrovouni and also referred to as Kara Tepe camp. It was established in September 2020 as an emergency response after the Moria refugee camp was destroyed in a fire.[6] Its population fluctuates between 1,000 and 5,000 individuals, reflecting a diverse demographic profile based on countries of origin and the current humanitarian crises.[7] Numerous governmental and non-governmental organizations are instrumental in providing urgent healthcare services, especially for children in CCAC Mavrovouni. To avoid confusion regarding legal terminology related to refugees and migrants, we use the term "displaced children" to describe all children in the camp.

Children face emotional distress on various levels, with the loss of their home and the perilous journey being the most significant factors.[8] There are premigration, peri-migration and postmigration factors impacting their health.[9] Before reaching the shores of Greece from Turkey, many have often attempted to cross the sea multiple times, facing intimidating circumstances. A specific group of these children, known as unaccompanied minors (UAMs), arrive without parents for two main reasons. Some are orphans who lost their parents during conflicts

in their home countries, while others travel alone with plans to reunite with their families later on.

Little has been studied on the topic of health status of displaced children upon arrival at refugee camps, both globally and specifically at CCAC Mavrovouni. Increased exposure to infections, limited access to adequate health care (e.g., vaccinations), and poor hygiene can lead to comprised health.[10] Nutritional status is an established factor that reflects overall health and socio-economic status in children.[11] Forced migration can create and exacerbate compromised nutritional status: the disruption of familiar environments and access to food resources can lead to acute malnutrition in the short term, while long-term displacement often results in chronic undernutrition, in part due to pre-departure stressors.[12]

In order to understand what is scientifically known about the nutritional status of displaced children living in refugee camps in Europe specifically, we conducted a systematic review and meta-analysis, that was recently published.[13] In that review by our group, which encompassed 12 studies and included 7,009 children from 14 refugee camps in and around Europe, we found a pooled prevalence of stunting of 16% and wasting of 4%. Our review also underscored that there is a lack of research on how nutritional status of refugee children may evolve over time, as well as the importance of including potentially associated variables, such as the practice of breastfeeding and being a UAM, in surveys and analyses.[14,15] Only one study describes the nutritional status of UAMs in camp Moria on Lesbos, showing a prevalence of 24 % underweight among 63 UAMs that were included.[16]

This study aimed to examine the nutritional status of children in CCAC Mavrovouni with an additional focus on UAMs. We hypothesized that study participants' overall nutritional status would improve over time in CCAC Mavrovouni. Additionally, we hypothesized that UAMs would exhibit poorer nutritional status.

Methods

Study design and participants

In this study, we conducted an observational study within CCAC Mavrovouni on the island of Lesvos, Greece, as well as within shelters on this island dedicated to care for UAMs. This research project formed part of the Mavrovouni Migrant Child

Health Project, an initiative that aims to investigate the health status of children arriving at CCAC Mavrovouni and the effects of living in the camp on their physical and psychological health. This is a collaboration between the National and Kapodistrian University of Athens in Greece, the University of Amsterdam and the VU University Amsterdam in the Netherlands. Data were collected on working and weekend days, depending on the availability of interpreters. The data collection ran from 9 February 2023 to 14 August 2023. The research facilities were situated within the medical area of CCAC Mavrovouni, in addition to four distinct UAM shelter locations distributed across the island of Lesvos. See Appendix 3.1 for a map of CCAC Mavrovouni.

The primary outcomes were the prevalence of wasting and stunting determined by Z-scores for weight-for-height, height-for-age, and BMI as measured at one point in time during our six-month period of data-collection. Secondary outcomes included comparison of nutritional status between children with families and/or caregivers to UAMs. Other secondary outcomes were comparison of nutritional status between different age categories, malnutrition among breastfed children, the prevalence of malnutrition based on mid-upper arm circumference (MUAC) and the development of nutritional status at follow-up. Evident clinical signs of malnutrition were assessed as another secondary outcome.

Infants, children and adolescents aged 0 to 18 years, were screened for eligibility for inclusion. Age assessment was based on their official asylum documentation which was obtained from the reception and identification administration upon arrival to Lesvos. All children living in CCAC Mavrovouni were eligible for inclusion if they were accompanied by a parent and/or guardian. Informed consent was requested from a parent or legal guardian. For those aged 12 years or older, informed assent was used as a supplementary mandatory component of the enrollment process. UAMs were considered eligible for participation if they were residing in one of the designated shelters serviced by the largest NGO responsible for the care of UAMs in Greece. They facilitate accommodation, food, psychological care and education for UAMs on the island. In the present study, informed consent was obtained with approval from the public prosecutor. Additionally, individuals aged 12 years or older were also required to provide informed assent as a condition for inclusion in the study.

The camp management provided a list featuring potential study participants based on arrival date. Children and their families that had newly arrived were given priority so as to include children as early as possible during their stay in the camp. We aimed to do the baseline measurement within four weeks after arrival. Thereafter, the coordination of appointments was facilitated by a non-governmental organization (NGO) operating within the camp. Emphasis was placed on ensuring equal representation from different countries of origin. The UAMs only had one appointment due to logistical reasons.

In order to arrange follow-up assessments after 3 months, initial contact was established by placing telephone calls to a contact number provided during the first visit. When direct communication was not possible, inquiries were made to the camp management regarding the current location or status of the participants. If the subjects were still residing within the camp, efforts were made to arrange visits to their accommodations. However, if it was determined that they had already left the camp, they were classified as 'lost to follow-up.' Oral informed consent and assent were administratively provided.

Ethics

Ethical clearance for this research project was obtained from the Medical Ethics Committee of the Greek National Public Health Organization (EODY). This was provided in December 2022 under Reference No. 23,702/06–12–2022 (see Appendix 3.2).

Procedures

A questionnaire addressing demographics, general health status, food sources and diet, including information on breastfeeding duration if applicable, was administered by trained research assistants. Interpreters from the camp translated the questions for participants if needed (see Appendix 3.3). Research assistants comprised students in master's-level research degree programs from four academic institutions in the Netherlands and Greece, who had backgrounds in medicine, global health, and disaster management and received preparatory training. The research coordinator conducted quality assessments of the data collection. Interpreters were recruited through collaboration with camp management as well as various NGOs that worked in the camp. They were assessed for eligibility and

underwent training to ensure optimal interpretation. A total of six interpreters provided translation in Arabic, Farsi, Dari and Somali.

Anthropometric measurements were done by trained research assistants at the study clinics making use of a Seca 716 mechanical person scale and Seca 213 stand-alone length meter for weight and a height and a Seca 354 baby scale and Seca 207 baby length meter for the non-standing children (Seca manufactured in Hamburg, Germany). Mid-upper arm circumference (MUAC) was measured using standardized and internationally used methodology.[17] There were no time restrictions for data inclusion.Children were screened for clinical signs of malnutrition, specifically: oedema, pallor, dry skin, dermatitis, dull nails, enlarged thyroid, cracked lips, bleeding gums, xerophtalmia, dull hair, excessive dental caries.[18] A referral pathway to a Greek pediatrician in an academic hospital was established in case referral as deemed necessary.

Data handling, definitions and statistical analysis

The information was securely stored in a Castor cloud database.[19] Using a sample size of 300, a two-sided 95 % confidence interval for a single proportion extended 4.1% from the observed proportion for an expected proportion of 0.16 based on our systematic review and meta-analysis.[13] For each child, Z-scores were calculated using World Health Organization (WHO) Anthro tool[20] for children 0–59 months and WHO Anthro Plus tool for children aged 6–19 years of age.[21] This tool ensures correction for both gender as well as age. The calculated Z-scores were for length-for-age and weight-for-height. These Z-scores were analyzed using SPSS Statistics 28.0.1.1.[22] MUAC Z-scores were obtained using the "Anthro" package in R.[23] The WHO definitions of wasting (weight for height Z-score equal or smaller than -2) and stunting (height-for-age Z-score equal or below -2) were used as parameters of malnutrition.[24] The Mann-Whitney U test was used to assess statistical differences between non-normally distributed data. A paired T-test was used to assess the difference between two Z-scores in the same child over time. To assess the difference in stunting prevalence between two groups of children (accompanied children and UAMs), Fisher's exact test was used. In all analyses, the significance level was 0.05. To explore potential correlations, a multivariable regression test was used to assess the relationships between the dependent variable of Z-score height-for-age at baseline and the following independent variables: the number

of siblings, length of stay in the camp, and travel duration before camp arrival. Multicollinearity was assessed by examining the Variance Inflation Factor (VIF) in the multivariable regression. A VIF greater than 5 was considered indicative of potential issues requiring further investigation. However, no multicollinearity was detected among the included variables.

Results

We enrolled a total of 304 displaced children, aged 0–18 years, residing on the island of Lesvos. Figure 3.1 shows the flow diagram for participant inclusion. Our sample represented 16 nationalities, with the majority (88%) originating from five countries: Afghanistan, Somalia, Palestine, Yemen and Democratic Republic of Congo. Detailed baseline characteristics are presented in Table 3.1.

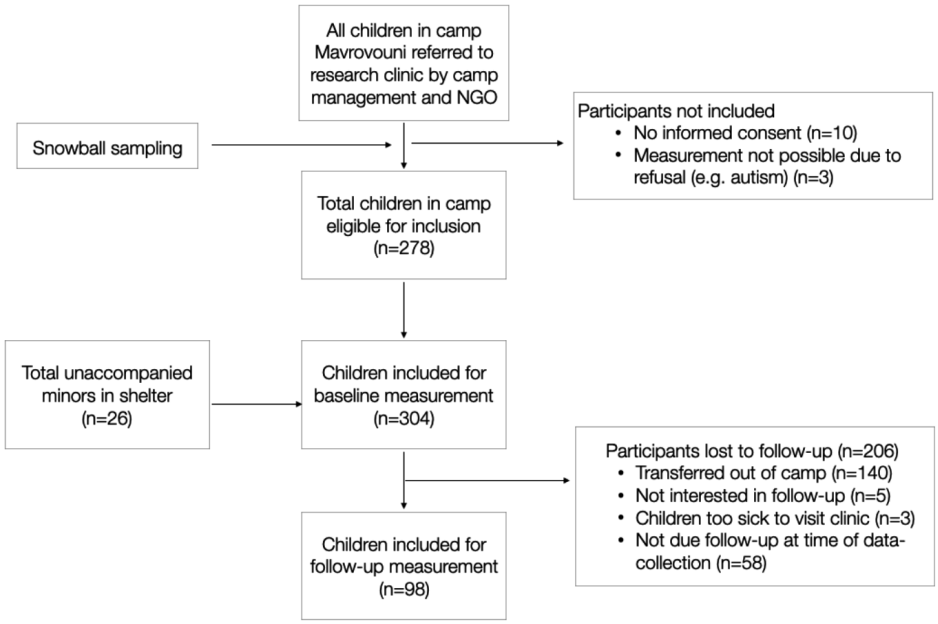


Figure 3.1: Flow diagram for participant inclusion.

Table 3.1: Baseline characteristics

Demographics	0–5 years	6–18 years	Total
Number	110	194	304
Age (mean, yrs)	2.3	10.9	7.9
Gender: female (%)	55	52	54
Country of origin based on asylum papers (%)			
Afghanistan	55	60	58
Somalia	11	10	10
DR Congo	8	9	8
Palestine	7	7	6
Eritrea	6	4	5
Other	14	11	12
Siblings (%)			
No siblings	27	3	12
1 sibling	23	19	21
2 siblings	28	29	29
3 or more siblings	22	49	19
Chronic disease [1] (%)	10	12	12
Vaccinated (%)	90	95	93
Currently breastfed (%)	40	0	14
Travel information	**0–5 years**	**6–18 years**	**Total**
Travel duration before arrival (median and range in mo)	8 0–72	7 0–108	7 0–108
Months in CCAC Mavrovouni (median and range in mo)	5 0–125	5 0–66	5 0–125
Resided in refugee camp before (%)	9	19	16
UAMs	1 child (1%)	25 children (13%)	26 (9%)

[1] Chronic diseases that were reported include skin conditions, epilepsy, autism, anemia, solitary kidney and developmental delay.

Table 3.2 shows the prevalence of malnutrition among different age groups. On enrollment, the 0–5 years old age group had the greatest prevalence of stunting. Longitudinally, there were no statistically significant changes in wasting (increase in Z 0.2, 95% CI -0.5–0.1) or stunting (decrease in Z 0.07, 95% CI -0.2–0.3). We found that, upon arrival, 19% of children in the 6–18 year age group were overweight, which decreased over time to 2%. MUAC scores, collected for 83 children under 5 years of age, showed a median Z-score of 0.66. Based on MUAC scores, only one child was at risk of malnutrition and no children showed moderate or severe malnutrition.

Among the subgroup of UAMs, stunting was especially prevalent (31%) as compared with 9% among accompanied children ($p<0.01$). Moreover, there was a difference in Z-scores of 0.86 for height-for-age between these two groups ($p<0.05$) (Figure 3.2).

Table 3.2: Percentages of malnutrition at baseline subdivided by age group

	Stunting[1] (N, %, 95% CI)	Wasting[2] (N, %, 95% CI)	Underweight[3] (N, %, 95% CI)	Overweight[4] (N, %, 95% CI)
0–6 months (N=17)	1 (6%, 0–17%)	1 (6%, 0–28%)	0 (0%, 0–19%)	0 (0%, 0–19%)
0.5–2 years (N=36)	5 (14%, 2–26%)	1 (3% (0–14%)	0 (0%, 0–19%))	4 (11%, 1–21%)
2–5 years (N=53)	8 (15%, 5–25%)	9 (17%, 7–27%)	3 (6%, 0–12%)	0 (0%, 0–6%)
6–18 years (N=198)	18 (9%, 5–13%)	n/a	11 (6%, 2–9%)	37 (19%, 13–24%)
Total (N=304)	32 (11%, 7–14%)	11 (10%, 5–16%)*	14 (5%, 2–7%)	41 (13%, 10–17%)

[1] Height-for-age Z-score equal or below -2.
[2] Weight for height Z-score equal or smaller than -2.
[3] For children 0–5 years defined as Z-score weight-for-age < -2; for children 5–18 years defined as Z-score BMI < -2.
[4] For children 0–5 years defined as Z-score weight-for-age > 2; for children 5–18 years defined as Z-score BMI > 1.
* Percentage calculated for children under five.

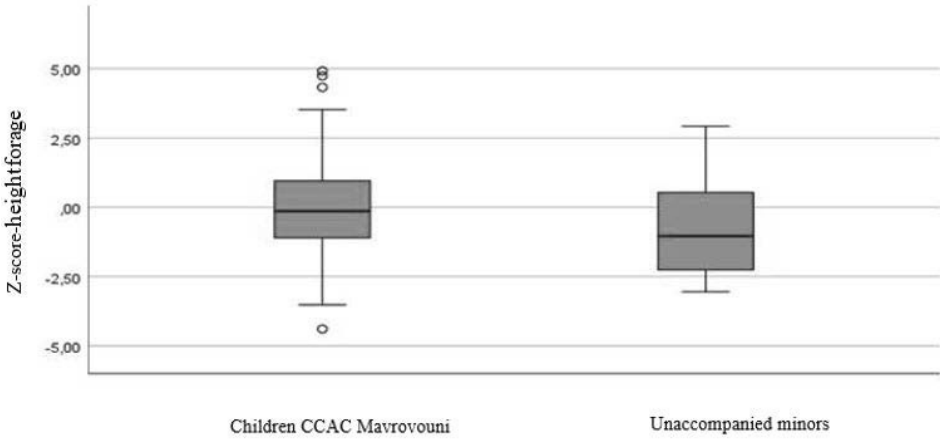


Figure 3.2: Boxplot reflecting the statistically significant difference in Z-score height for age between the group of accompanied and UAMs.

We compared the nutritional status of children under two years old who were breastfed versus those who were not. Children who were breastfed demonstrated a non-significant higher WHZ (median Z-score for weight-for-height (Z-score difference of 1.3, p=0.16). Noteworthy is that children in our study population were breastfed up to the age of four years old. Comparing children in this age group does give a statistically significant difference in Z-score between breastfed children, Z-score 0.44, vs non breastfed children, Z-score -0.38 (Z-score difference of 0.82, p<0.01).

Of the accompanied children, 254 (90%) were found to have the food distributed in camp as their main source of nutrition. The remainder reportedly consumed

food from other sources. At the time of our study, the food was distributed once a day at 14:00 and included items such as pasta and rice.

A multivariable regression showed no significant associations between Z-score height-for-age at baseline and the following variables: number of siblings (β=0.06, 95% CI -0.06–0.2, p=0.3), length of stay in the camp (β=-0.08, 95% CI -0.02–0.004, p=0.2), and travel duration before camp arrival (β=0.1, 95% CI -0.001–0.02, p=0.7). There was also no significant difference in Z-score height-for-age at baseline and reported presence of chronic disease.

In terms of clinical signs of malnutrition, 36 (12%) children showed excessive dental caries. Dry, scaly skin was observed in 15 (5%) of the children. No children showed evidence of nutritional edema.

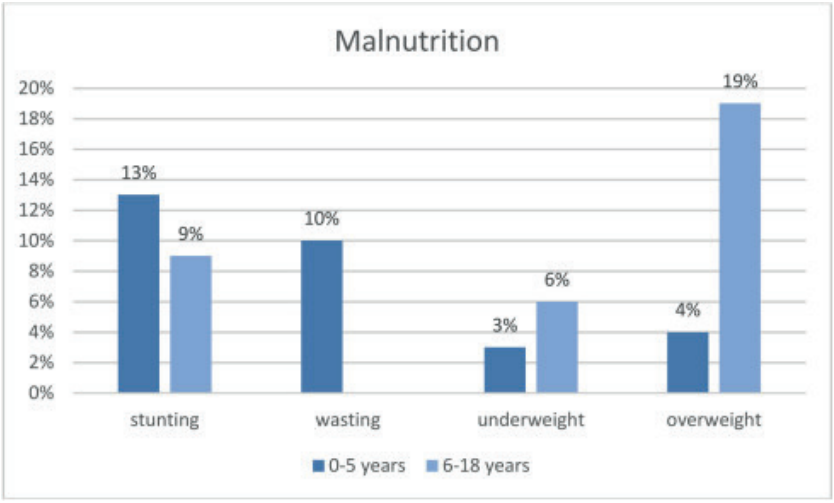


Figure 3.3: Percentages of malnutrition at baseline subdivided by age group.

Discussion

This study focuses on the nutritional status of children living in one of Europe's largest refugee camps. The research aims to provide insight into the well-being of this vulnerable group of children.

We believe that it provides important tools to inform policies and raise awareness about their health. This gap in the literature may be in part due to the fact that

research in a refugee camp – particularly among minors – involves navigating numerous practical challenges, including logistical difficulties, ethical considerations, and the fragile living conditions of a highly vulnerable pediatric population.

We found a prevalence of 11% of stunting. 10% of children under five were wasted. Of all children, 5% underweight and 13% were overweight. The percentage of stunted children is lower compared to the numbers reported in our meta-analysis among displaced children living in refugee camps in Europe and the MENA region, which showed a pooled prevalence of 16%.[13] By contrast, we observed a higher rate of wasting of 10%, compared to 4% in the systematic review. One possible explanation is that our sample consists of children who have recently arrived at a European refugee camp, unlike the studies in our review, which involved children in Northern Greece or long-term refugee camps in the MENA region. The higher percentage of wasting may reflect the difficult and insecure food situation during the fleeing period.

The prevalence of overweight, mainly found in the older children, was an unexpected but concerning finding. This percentage exceeds WHO's 'high' cut-off value, 10%, of public health significance.[25] This prevalence could be explained by the double burden of malnutrition.[26] The percentage of overweight could be explained by *in utero* exposure to maternal undernutrition and relatively high levels of stunting earlier in life, that set the stage for later nutritional challenges such as overweight.[27] This is in line with the Barker hypothesis and reflects the nutritional status of the mother.[28] Not only does this impose risks for the individual in the short term, it also increases the risk of non-communicable diseases (e.g. diabetes type II, hypertension and stroke) later in life with all due consequences on a societal level.[29] Furthermore, the large difference in the prevalence of stunting between UAMs and accompanied children is particularly noteworthy, further emphasizing the vulnerability of UAMs. This observed prevalence of stunting (31%), exceeds the 'very high' cut-off value, 30%, set by the WHO for public health significance,[25] underlining its alarming importance. Notably, UAMs are known to misreport their age, a behavior often driven by the wish for protective measures.[15] This tendency introduces a potential underestimation of the true amount of stunting in the researched group. The difference in stunting between accompanied and UAMs could be explained in different ways. Firstly, it could be hypothesized that UAMs have worse living conditions in the country of origin that make them travel alone

in the first place. Secondly, they lack the protection of family which affects both their short- as well as long-term health, including food security. Thirdly, as the cause of stunting includes a myriad of factors – the explanation for this high level of stunting will likely involve decreased access to healthcare, inadequate nutrition, worse sanitation, and broader socioeconomic dimensions.[30]

Another subgroup analysis underscores the ongoing positive nutritional association with breastfeeding. Breastfeeding within refugee camps continues to be an insufficiently studied topic.[31] Our observed higher mean Z-score for weight-for-height among breastfed children shows the protective effect of breastfeeding against undernutrition. This difference is non-significant and might be due to small sample size. Despite the circumstances of breastfeeding mothers, children might be better off in terms of their weight. This finding underscores the significance of promoting and supporting breastfeeding practices, especially in emergency settings like refugee camps.

The non-significant improvement of all malnutrition indicators over time indicates an improvement of nutritional status during their stay in camp. The only other prospective study on this topic involved Rohingya refugee children living in refugee camps in which nutritional status was assessed cross-sectionally twice.[32] This study found significant improvements in acute and micronutrient malnutrition among Rohingya children in makeshift settlements, likely due to the scale-up of nutritional services. An explanation could be that relative safety and stability have a positive impact on nutritional status. However, our findings regarding follow-up data were not statistically significant, which means that they should be interpreted with caution. While our measurements provide insights into the overall nutritional status, we lack information regarding micronutrient levels. It is possible that there is a net positive caloric balance resulting from the consumption of energy-dense but nutritionally unbalanced food provided by the food line. More thorough research is required to address this issue.

While our study has yielded very relevant findings, the following limitations should be taken into consideration. Firstly, the relatively small sample size in our study poses a constraint on the generalizability of our findings. Furthermore, the rapidly changing composition of the camp population means that our results mostly reflect the situation at the time of data-collection. A notable challenge encountered in our

study was the substantial loss to follow-up which was inevitable due to the high mobility, namely families being moved from one refugee-camp to the other. Lastly, factors such as previous healthcare access, socioeconomic status, migration path, and availability of family support may influence both exposure and the outcomes observed. Due to the complexity of these factors and their interactions, they were beyond the scope of our study's objectives and were not included in our analysis.

It is vital for policymakers and humanitarian organizations to acknowledge that displaced children arriving in Europe often do so with a compromised nutritional status, adding an additional layer of vulnerability. UAMs represent a notably vulnerable subgroup, experiencing greater nutritional challenges and additionally having less support from a parental figure. Protecting the health of these children and ensuring access to adequate nutrition is crucial for their development.

Conclusion

In conclusion, this study represents an examination of the nutritional status of children in a European refugee camp, contributing valuable insights to an under-explored research field. The nutritional status of displaced children in camp Mavrovouni is compromised, with 11% being stunted, 10% wasted in children under five, and 13% overweight overall The positive association between breast-feeding and weight-for-height Z-scores suggests that promoting breastfeeding can improve nutritional outcomes. This research not only contributes to the academic understanding of child health in refugee contexts but also provides actionable insights for policymakers, humanitarian organizations, and healthcare providers.

Ethics committee approval

Ethical clearance for this research project was obtained from the Medical Ethics Committee of the Greek National Public Health Organization (EODY). This was provided in December 2022 under Reference No. 23702/06-12-2022 (see Appendix 3.2).

Role of funding source

This study was funded by Stichting Weeshuis der Doopsgezinden and Stichting Steun Emma. The funders of the study had no role in study design, data collec-

tion, data analysis, data interpretation, writing of the report or decision to publish the report.

CRediT authorship contribution statement

H. Benjeddi: Writing – original draft, Visualization, Validation, Supervision, Software, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. M.P. Gruppen: Writing – review & editing, Supervision, Project administration, Data curation. S.A. Post: Data curation. A.D. Groenewegen: Data curation. E.B.K. Egen: Data curation. E. Samiotaki Logotheti: Data curation. Z. Livaditou: Supervision, Data curation. W.P. Voskuijl: Validation, Methodology, Formal analysis. A.M. Tutu-van Furth: Writing – review & editing, Supervision. M. Boele van Hensbroek: Writing – review & editing, Validation, Supervision, Funding acquisition, Formal analysis, Conceptualization. A. Terzidis: Supervision, Project administration, Conceptualization. M. van der Kuip: Writing – review & editing, Validation, Supervision, Formal analysis.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper. The author is an Editorial Board Member/Editor-in-Chief/Associate Editor/Guest Editor for this journal and was not involved in the editorial review or the decision to publish this article.

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Appendix 3.1


MEDICAL AREA
FIRST ISOLATION AREA
SECOND ISOLATION AREA
BLUE ZONE
1ST ZONE
YELLOW ZONE
2ND ZONE
LOGISTICS
ΧΑΤΖΗΣΤΑΜΑΤΙΟΥ ΠΑΝΑΓΙΩΤΗΣ
Εμπορικό Τολυκατάστημα
RED ZONE
3RD ZONE
GREEN ZONE
4TH ZONE
ΣΑΒΒΑΣ ΔΗΜ. ΚΑΡΑΓΕΩΡΓΙΟΥ Α.Ε.
ΕΦΑΜ Α.Ε

Appendix 3.2

ΕΘΝΙΚΟΣ ΟΡΓΑΝΙΣΜΟΣ
ΔΗΜΟΣΙΑΣ ΥΓΕΙΑΣ

Αγράφων 3-5, Μαρούσι
Τ.Κ. 15123
Τηλ. 2105212000
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Πληροφορίες:
Επιτροπή Ηθικής και Δεοντολογίας
ΕΛΕΥΘΕΡΙΑ ΣΙΑΡΕ , 2105212040

Ε.Ο.Δ.Υ.
ΚΠ 2018 / 2023 - 23/01/2023

Προς :

Κοσμήτορα Σχολής Επιστημών Υγείας,
Καθηγητή κ. Εμμανουήλ Πικουλή

Ιατρική Σχολή Πανεπιστημίου Αθηνών

Θέμα:Απάντηση στην υπ' αριθ. 23702/06-12-2022 αίτηση

Σε συνέχεια της υπ' αριθ. 23702/06-12-2022 αίτηση της κας HanaaBenjeddiπρος την Επιτροπή Ηθικής & Δεοντολογίας και κατόπιν του 2ου/16-12-2022 πρακτικού της Επιτροπής το οποίο εγκρίθηκε από το υπ' αριθ. 25298/23-12-2022 απόσπασμα πρακτικού της 7ης/22-12-2022 συνεδρίασης του ΔΣ του ΕΟΔΥ, σας ενημερώσουμε ότι έχει εγκριθεί.

Ο Πρόεδρος ΔΣ ΕΟΔΥ

ΑΚΡΙΒΕΣ ΑΝΤΙΓΡΑΦΟ
Προϊστάμενος Γραμματείας
α.α.
Ναυσικά Παπαθανασίου

Θεοκλής Ζαούτης

Εσωτερική Διανομή :

Γραφείο Γραμματείας Προέδρου
Προϊστάμενος Διεύθυνσης Επιδημιολογικής Επιτήρησης & Παρέμβασης για Λοιμώδη Νοσήματα
Γραφείο Γραμματείας Αντιπροέδρου - Μεταδοτικά Νοσήματα
Γραφείο Γραμματείας Αντιπροέδρου - Μη Μεταδοτικά Νοσήματα
Αυτοτελές Τμήμα Διοίκησης
Προϊστάμενος Διεύθυνσης Επιδημιολογίας και Πρόληψης μη Μεταδοτικών Νοσημάτων και Τραυματισμών
Επιτροπή Ηθικής και Δεοντολογίας

Appendix 3.3

Mavrovouni Migrant Child Health Project - version 19.91

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1. First visit - Demographics

Number	Question	Answers
1.1	Informed consent	◯ Yes ◯ No
1.2	Informed assent	◯ Yes ◯ No
1.3	Date of visit	[ ] [ ] [ ] *(dd-mm-yyyy)*
1.4	Date of birth	[ ] [ ] [ ] *(dd-mm-yyyy)*
1.5	Age	[ ]
1.6	Gender	◯ Female ◯ Male
1.7	Siblings (alive)	[ ]
1.8	Country of origin	◯ Afghanistan ◯ Albania ◯ Algeria ◯ Andorra ◯ Angola ◯ Antigua and Barbuda ◯ Argentina ◯ Armenia ◯ Australia ◯ Austria ◯ Azerbaijan ◯ Bahamas ◯ Bahrain ◯ Bangladesh ◯ Barbados ◯ Belarus ◯ Belgium ◯ Belize

- Benin
- Bhutan
- Bolivia
- Bosnia and Herzegovina
- Botswana
- Brazil
- Brunei
- Bulgaria
- Burkina Faso
- Burundi
- Cabo Verde
- Cambodia
- Cameroon
- Canada
- Central African Republic
- Chad
- Chile
- China
- Colombia
- Comoros
- Democratic Republic of the Congo
- Republic of the Congo
- Costa Rica
- Cote d Ivoire
- Croatia
- Cuba
- Cyprus
- Czech Republic
- Denmark
- Djibouti
- Dominica
- Dominican Republic
- Ecuador
- Egypt
- El Salvador
- Equatorial Guinea
- Eritrea
- Estonia
- Ethiopia
- Fiji
- Finland
- France
- Gabon
- Gambia
- Georgia
- Germany
- Ghana
- Greece

- ◯ Grenada
- ◯ Guatemala
- ◯ Guinea
- ◯ Guinea-Bissau
- ◯ Guyana
- ◯ Haiti
- ◯ Honduras
- ◯ Hungary
- ◯ Iceland
- ◯ India
- ◯ Indonesia
- ◯ Iran
- ◯ Iraq
- ◯ Ireland
- ◯ Israel
- ◯ Italy
- ◯ Jamaica
- ◯ Japan
- ◯ Jordan
- ◯ Kazakhstan
- ◯ Kenya
- ◯ Kiribati
- ◯ Kosovo
- ◯ Kuwait
- ◯ Kyrgyzstan
- ◯ Laos
- ◯ Latvia
- ◯ Lebanon
- ◯ Lesotho
- ◯ Liberia
- ◯ Libya
- ◯ Liechtenstein
- ◯ Lithuania
- ◯ Luxembourg
- ◯ Macedonia
- ◯ Madagascar
- ◯ Malawi
- ◯ Malaysia
- ◯ Maldives
- ◯ Mali
- ◯ Malta
- ◯ Marshall Islands
- ◯ Mauritania
- ◯ Mauritius
- ◯ Mexico
- ◯ Micronesia
- ◯ Moldova
- ◯ Monaco

- Mongolia
- Montenegro
- Morocco
- Mozambique
- Myanmar (Burma)
- Namibia
- Nauru
- Nepal
- Netherlands
- New Zealand
- Nicaragua
- Niger
- Nigeria
- North Korea
- Norway
- Oman
- Pakistan
- Palau
- Palestine
- Panama
- Papua New Guinea
- Paraguay
- Peru
- Philippines
- Poland
- Portugal
- Qatar
- Romania
- Russia
- Rwanda
- Saint Kitts and Nevis
- Saint Lucia
- Saint Vincent and the Grenadines
- Samoa
- San Marino
- Sao Tome and Principe
- Saudi Arabia
- Senegal
- Serbia
- Seychelles
- Sierra Leone
- Singapore
- Slovakia
- Slovenia
- Solomon Islands
- Somalia
- South Africa
- South Korea

- ◯ South Sudan
- ◯ Spain
- ◯ Sri Lanka
- ◯ Sudan
- ◯ Suriname
- ◯ Swaziland
- ◯ Sweden
- ◯ Switzerland
- ◯ Syria
- ◯ Taiwan
- ◯ Tajikistan
- ◯ Tanzania
- ◯ Thailand
- ◯ Timor-Leste
- ◯ Togo
- ◯ Tonga
- ◯ Trinidad and Tobago
- ◯ Tunisia
- ◯ Turkey
- ◯ Turkmenistan
- ◯ Tuvalu
- ◯ Uganda
- ◯ Ukraine
- ◯ United Arab Emirates
- ◯ United Kingdom
- ◯ United States of America
- ◯ Uruguay
- ◯ Uzbekistan
- ◯ Vanuatu
- ◯ Vatican City
- ◯ Venezuela
- ◯ Vietnam
- ◯ Yemen
- ◯ Zambia
- ◯ Zimbabwe

1.9	Months in camp	
1.10	Camp before	◯ Yes ◯ No
1.11	Months on the road	
1.12	Phone number for follow-up	
1.13	Current location Camp	

1.14	Is there any other relevant demographic information?	

2. First visit - Health information

Number	Question	Answers
2.1	Chronic disease	◯ Yes ◯ No
2.2	Chronic Disease	☐ Asthma ☐ Epilepsy ☐ Diabetes ☐ HIV ☐ Other, namely
2.3	Chronic disease specified	
2.4	Medication	
2.5	Vaccinated	◯ Yes ◯ No ◯ Unknown

3. First visit - Breastfeeding

Number	Question	Answers
3.1	Is the child currently being breastfed?	◯ Yes ◯ No

3.2	If breastfeeding, what is the mother's age?	
3.3	If not breastfeeding anymore, what was the duration of breastfeeding	☐ 0-3 mo ☐ 4-6 mo ☐ 7-12 mo ☐ > 12 mo ☐ Unknown ☐ N/A
3.4	In the country of origin, do new mothers breastfeed or prefer a different feeding option?	◯ Prefer breastfeeding ◯ Prefer formula
3.5	Answer the questions below only if mother is currently breastfeeding.	
3.6	Have you received any information about breastfeeding from the camp? If yes, from whom?	
3.7	Safety breastfeeding	☐ Yes ☐ No
3.8	Where do you breastfeed?	☐ At home (container, tent) ☐ A specific designed space for breastfeeding ☐ Other
3.9	Do you feel that you have an adequate diet to breastfeed?	☐ Yes ☐ No
3.10	Do you have enough water to breastfeed?	◯ Yes ◯ No

4. First visit - Diet

Number	Question	Answers
4.1	Food sources	☐ Foodline ☐ Bought from store or market ☐ Donations NGOs

		☐ Combination of above
4.2	What does the child eat on a typical day?	☐ Biscuits ☐ Breast Milk ☐ Cereals and Cereal Products ☐ Eggs ☐ Fats and Oils ☐ Fish and Sea Foods ☐ Fruits ☐ Meats ☐ Milk and Milk Products: Fresh/fermented milk, cheese, yogurt, or other milk products ☐ Pasta ☐ Poultry ☐ Pulses / Legumes / Nuts and Seeds ☐ Rice ☐ Roots ☐ Sugars / Honey and Commercial Juices ☐ Vegetables ☐ Miscellaneous ☐ Unknown
4.3	If breastfeeding, what does the mother eat on a typical day?	☐ Biscuits ☐ Breast Milk ☐ Cereals and Cereal Products ☐ Eggs ☐ Fats and Oils ☐ Fish and Sea Foods ☐ Fruits ☐ Meats ☐ Milk and Milk Products: Fresh/fermented milk, cheese, yogurt, or other milk products ☐ Pasta ☐ Poultry ☐ Pulses / Legumes / Nuts and Seeds ☐ Rice ☐ Roots ☐ Sugars / Honey and Commercial Juices ☐ Vegetables ☐ Miscellaneous ☐ Unknown
4.4	How does the child eat?	☐ Fed by adult ☐ Child feeds self, supervised by adult ☐ Child feeds self, supervised by older children ☐ Child feeds self, unsupervised

		☐ Fed from common plate or bowl ☐ Child exclusively breastfed
4.5	Number of meals	

5. First visit - Physical exam

Number	Question	Answers
5.1	Body weight	kg
5.2	Height	cm
5.3	MUAC	mm
5.4	Clinical malnutrition	☐ Oedema ☐ Pallor (pale) ☐ Dry, scale skin ☐ Dermatitis ☐ Pale or dull nails ☐ Enlarged thyroid ☐ Cracked lips ☐ Bleeding gums ☐ Xerophthalmia ☐ Dull/thin/sparse hair ☐ Excessive dental caries ☐ None

6. Follow-up 3 mo - Demographics 3 mo

Number	Question	Answers
6.1	Date of visit	*(dd-mm-yyyy)*

7. Follow-up 3 mo - Health 3 mo

Number	Question	Answers
7.1	Any health events in the past 3 months (since previous assessment (eg severe illness, admissions, AB courses, extra food supplementations received)?	

8. Follow-up 3 mo - Diet 3 mo

Number	Question	Answers
8.1	Food sources	☐ Foodline ☐ Bought from store or market ☐ Donations NGOs ☐ Combination of above
8.2	Diet	☐ Biscuits ☐ Breast Milk ☐ Cereals and Cereal Products ☐ Eggs ☐ Fats and Oils ☐ Fish and Sea Foods ☐ Fruits ☐ Meats ☐ Milk and Milk Products: Fresh/fermented milk, cheese, yogurt, or other milk products ☐ Pasta ☐ Poultry ☐ Pulses / Legumes / Nuts and Seeds ☐ Rice ☐ Roots ☐ Sugars / Honey and Commercial Juices ☐ Vegetables

		☐ Miscellaneous ☐ Unknown
8.3	Eating	☐ Fed by adult ☐ Child feeds self, supervised by adult ☐ Child feeds self, supervised by older children ☐ Child feeds self, unsupervised ☐ Fed from common plate or bowl ☐ Child exclusively breastfed
8.4	Number of meals	

9. Follow-up 3 mo - Physical examination 3 mo

Number	Question	Answers
9.1	Body weight	kg
9.2	Height	cm
9.3	MUAC	mm
9.4	Clinical malnutrition	☐ Oedema ☐ Pallor (pale) ☐ Dry, scale skin ☐ Dermatitis ☐ Pale or dull nails ☐ Enlarged thyroid ☐ Cracked lips ☐ Bleeding gums ☐ Xerophthalmia ☐ Dull/thin/sparse hair ☐ Excessive dental caries ☐ None

10. Follow-up 6 mo - Demographics 6 mo

Number	Question	Answers
10.1	Date of visit	☐☐☐ *(dd-mm-yyyy)*

11. Follow-up 6 mo - health 6 mo

Number	Question	Answers
11.1	Any health events in the past 3 months (since previous assessment (eg severe illness, admissions, AB courses, extra food supplementations received)?	☐

12. Follow-up 6 mo - Diet 6 mo

Number	Question	Answers
12.1	Food sources	☐ Foodline ☐ Bought from store or market ☐ Donations NGOs ☐ Combination of above
12.2	Diet	☐ Biscuits ☐ Breast Milk ☐ Cereals and Cereal Products ☐ Eggs ☐ Fats and Oils ☐ Fish and Sea Foods ☐ Fruits ☐ Meats

		☐ Milk and Milk Products: Fresh/fermented milk, cheese, yogurt, or other milk products ☐ Pasta ☐ Poultry ☐ Pulses / Legumes / Nuts and Seeds ☐ Rice ☐ Roots ☐ Sugars / Honey and Commercial Juices ☐ Vegetables ☐ Miscellaneous ☐ Unknown
12.3	Eating	☐ Fed by adult ☐ Child feeds self, supervised by adult ☐ Child feeds self, supervised by older children ☐ Child feeds self, unsupervised ☐ Fed from common plate or bowl ☐ Child exclusively breastfed
12.4	Number of meals	

13. Follow-up 6 mo - Physical examination 6 mo

Number	Question	Answers
13.1	Body weight	kg
13.2	Height	cm
13.3	MUAC	mm
13.4	Clinical malnutrition	☐ Oedema ☐ Pallor (pale) ☐ Dry, scale skin ☐ Dermatitis ☐ Pale or dull nails ☐ Enlarged thyroid ☐ Cracked lips ☐ Bleeding gums

- [ ] Xerophthalmia
- [ ] Dull/thin/sparse hair
- [ ] Excessive dental caries
- [ ] None





CHAPTER FOUR

Assessing quality of life in displaced children on Lesvos using PROMIS: a mixed methods study

Hanaâ Benjeddi, Kirsten de Groote, Morgan McKnight, Jonne Feitsma, Mariken Gruppen, Zoi Livaditou, Lorynn Teela, Agis Terzidis, Michael Boele van Hensbroek, Martijn van der Kuip, Marceline Tutu van Furth, Lotte Haverman

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Abstract

Introduction: Due to the ongoing global refugee crisis, around 400 million children are currently displaced. We investigate domains of quality of life (QoL) in two groups of displaced children; children living with their caregivers in Closed Control Access Centre (CCAC) Mavrovouni and unaccompanied minors (UAMs) in designated shelters on Lesvos, Greece.

Methods: A mixed-methods study using PROMIS® to quantitatively assess domains of QoL compared to a reference group by using a one-sample Wilcoxon sign-rank test. Associated variables were identified by multivariable linear regression analyses. Open questions were added to UAMs to qualitatively identify elements influencing QoL.

Results: A total of 111 children (N=94) and UAMs (N=17) participated. Children across all age groups showed significantly worse scores in various domains compared to the reference group. The youngest group (1–4 years) report more Depressive symptoms but better peer relationships, while the 5–18 year groups reported higher levels of anger, anxiety, depressive symptoms, and pain behavior. Adolescents (8–18 years) reported higher scores on meaning and purpose. A longer duration in camp was associated with higher scores on anxiety and depressive symptoms. UAMs mention separation from family as negatively influencing their mental health. They mention future goals, hope and social support as central to their sense of meaning and purpose.

Conclusion: Displaced children report high levels of anger, anxiety, pain behavior, and depressive symptoms, a prolonged stay in the camps even worsens these outcomes. This underscores the need for tailored interventions to enhance the overall well-being of this vulnerable population.

Introduction

Child refugees make up 40% of the displaced population, which amounted to 122 million in April 2025.[1] Five countries account for 73% of the total amount of displaced people: Afghanistan (6.4 million), Syria (6.4 million), Venezuela (6.1 million), Ukraine (6 million), and South Sudan (1.5 million).[2] A surge in Palestinian refugees has occurred as a result of the ongoing conflict in the Gaza Strip (6 million).[3] Many displaced people have traveled from countries with damaged health systems, enduring months or even years without access to healthcare while facing ongoing risks of violence and exploitation.[4]

Refugees typically enter Europe by crossing borders through countries on the EU's external edge, often arriving via land or sea routes. Greece, due to its geographical location, remains an important entrance point for people entering Europe. Upon arrival, many are registered and directed to designated reception facilities, especially if they are traveling with family. Families are often housed in Closed Controlled Access Centres (CCACs), which are secure reception centers designed to manage accommodation while their applications are processed. These centers aim to provide shelter, basic services, and a structured environment with restricted entry and exit under certain conditions. All fleeing children arrive at CCACs, but children without parents or guardians, unaccompanied minors (UAMs), are cared for in state-facilitated shelters. These shelters are run by a Greek Non-governmental Organization (NGO) and provide beds, food, and education for the children.

Children face unique challenges during displacement which can significantly impact their quality of life (QoL). Reasons for this include factors such as lack of education, malnutrition and psychological trauma in the country of origin, during travel or during stay in camp.[2] That is in particular the case for UAMs, as they lack the protection from family during challenging and hazardous journeys. Research in this group of children is particularly scarce despite the fact that their QoL is presumably negatively affected by the myriad of additional challenges that they encounter.[5] To date, there is little empirical data that quantifies or explores how the unique stressors for displaced children translate into measurable QoL deficits. This lack of focused research prevents the development of tailored interventions or policies aimed at safeguarding the health and well-begin of all displaced children.

Measuring QoL in children living in refugee camps is challenging due to the lack of validated, including cross-cultural validity, QoL tools for children. An additional complicating factor is the fact that children in refugee camps generally speak different languages. There is a crucial need of understanding QoL of these children in order to highlight the problem, draw attention to and in the end effectively support and improve their QoL.

For this study, we choose to use PROMIS item banks. PROMIS provides adaptable, relevant measures of health and well-being that could accommodate the perspectives of participants from diverse backgrounds. The use of PROMIS ensures that QoL assessments are methodologically robust, and due to their international approach hopefully also sensitive to the unique lived experiences of children in refugee settings. Furthermore, in order to address potential language barriers, trained interpreters are engaged to translate the questionnaires into the children's respective mother tongues, thereby enhancing the accuracy and reliability of responses.

Therefore, the general objective of this study was to assess QoL of a group of displaced children, existing of children living with their caregivers in CCAC Mavrovouni as well as of UAMs living in designated shelters, both operating on the island of Lesvos in Greece. Initially, we compared the entire child population to a reference group. Subsequently, we explored variables associated with QoL. To further enhance our understanding of the results, we included qualitative data in our analysis.

Methods

This research project was the outcome of a collaborative effort involving academic institutions from Greece (Kapodistrian University of Athens) and the Netherlands (University of Amsterdam and VU University Amsterdam). The QoL assessment was part of a larger study also focusing on nutritional status of this same group of displaced children.

Quantitative study: part one

The first part of this study consisted of a cross-sectional study assessing domains of QoL of displaced children (children living in CCAC Mavrovouni and UAMs) living on Lesvos.

Participants

Between 9 February and 1 August 2023, children were invited to complete patient reported outcome measures (PROMs) in different ways.

Inclusion criteria were age 1–18 years old and ability to provide oral informed consent, according to age and legal representation, and ability to complete PROMIS assessment. Exclusion criteria were significant cognitive impairment or severe communication difficulties despite interpreters.

Children living in CCAC Mavrovouni

Children, aged 1–18 years, with parents or guardians residing in CCAC Mavrovouni were eligible to participate in this study.

Children in CCAC Mavrovouni were referred to the research clinic by the camp management with support from a Greek Non-governmental Organization (NGO). Snowball sampling, by means of camp management referrals, was performed to attempt to achieve equal representation of the countries of origin. Country-of-origin representation was monitored via camp registration records, which provide precise data on nationalities present. This allowed the study team to track percentages and actively strive for equal country-of-origin representation in the study, ensuring that our sample mirrored the camp's demographic composition as closely as possible.

Informed consent was obtained from all parents and/or guardians of the children that were included in the study, and if the child was ≥12 years also from children themselves. Oral informed consent was deemed most appropriate, considering that illiteracy was common. Secondly, oral consent was considered less intimidating in a setting where people face hostile legal procedures.

Unaccompanied minors (UAMs)

UAMs live in separate shelters on Lesvos; three of these shelters were visited for study participation. UAMs were referred to the research team by the psychologist working at UAM shelter. In this group, snowball sampling was done by this psychologist. Informed consent for the UAMs was officially provided by the UAMs and the public prosecutor. Under Greek law, the Public Prosecutor is responsible for ensuring that the child's best interest are considered in all legal proceedings involving unaccompanied minors.

Study procedure

A research assistant conducted the questioning orally in English, and an interpreter facilitated translation to participants and/or their parent(s). Subsequently, responses were translated back into English and entered into on the KLIK website (www.hetklikt.nu) by the research assistant.[6]

Interpreters were thoroughly trained and received the questions in English on paper to ensure consistency. This method was chosen to ensure uniformity and prevent potential biases from the use of different translation methods. Due to many missing translations in specific domains, we used English versions with trained interpreters for consistency and scientific rigor.

Measurements

Socio-demographics

A socio-demographic questionnaire including age, gender, country of origin, duration of stay in residency or camp, stay in previous residency or camp, number of months on the road, and the presence of a chronic disease was completed. The questionnaire was uploaded to a secure cloud software system, Castor EDC.[7]

PROMIS pediatric measures

The Patient-Reported Outcomes Measurement Information System (PROMIS®) was used to measure different domains of QoL. PROMIS is based on Item Response Theory,[8] which makes it possible to use Computerized Adaptive Testing (CATs). With CATs, questions are presented to the participant based on their previous answer. Irrelevant questions are therefore left out and this leads to minimal participant burden.[9]

PROMIS domains utilized in this study were chosen following a workshop involving a panel of experts (LH, MBvH, MG, MM, MTvF, AS, LK, HB) with expertise in global health, child psychology, pediatrics, and psychiatry. Several of these experts had previously worked with children in camp Moria on Lesvos in Greece. Important outcomes were identified, after which the appropriate and applicable PROMs were chosen. We chose the following domains; sleep disturbance, depressive symptoms, anxiety, anger, peer relationships, cognitive functioning, positive affect, meaning and purpose. Age-appropriate questionnaires for each group, ranging from 1 to 18 years, were chosen. For children aged 1–4 years, the Early Childhood Parent Report Item Bank was utilized.[10] For ages 5–7 years, the Parent Proxy was utilized,[11] and for ages 8–18 years, the Self-Report Item Banks were used.[12] Appendix 4.1 shows the measures per age group.

Specific questions from the chosen measures were intentionally left out, as they were deemed inappropriate and possibly triggering in this research group. To assess possible differences in accuracy of assessment due to the changes in the CAT procedure, we sample-wise compared standard error (SE; representing reliability) of the original CAT administration with the SE of the same CAT with the item(s) removed post-hoc. The questions 'people will remember me when I die', 'I was worried I might die', and 'I worried that something might happen to my parents or guardian' were considered too sensitive for this context. During the administration of the CAT these questions were skipped by the interviewer by selecting any response category. All responses on these items were subsequently removed (i.e. made missing) and T-scores were recalculated using the online PROMIS Scoring Service.[8] Additionally, the question 'I expect to have a family in the future' was considered too sensitive for use with UAMs, therefore the responses to this item was removed only for UAMs prior to recalculating T-scores. As PROMIS items are calibrated on the same scale, scores remain comparable even when not administering all items.

The collected data was anonymized and securely stored online through the research website of the KLIK PROM portal (https://www.hetklikt.nu/). The KLIK PROM portal complies with the privacy regulation (GDPR) and continuously make adjustments to comply with increasingly strict privacy regulations.[6] For children aged 2–7 years, the questionnaire was filled in by a parent/guardian proxy. In the age group 8–18 years, self-reporting was utilized. For all PROMIS pediatric measures,

responses were solicited using a 5-point Likert scale ranging from 1 = "never") to 5 = "almost) always", except for the domains meaning and purpose (ranging from 1 = "not at all" to 5 = "very much") and cognitive functioning (ranging from 1 = "none of the time" to 5 = "all of the time"). The CAT automatically stopped when the standard error of the estimate (SE) was ≤3.2 (90% reliability) and/or a maximum of 12 items was administered. PROMIS scores were calculated by transforming the item scores into a T-score ranging from 0 to 100. For all pediatric measures, higher scores represent more of the construct (e.g., more sleep disturbance or a better positive affect).

Statistical analysis

Statistical analyses were performed using IBM SPSS Statistics 28.0.1.1.[13] Descriptive analyses were performed for socio-demographics. Comparison to US norm population was done by comparing PROMIS T-score medians to medians described in literature[14] using a one-sample Wilcoxon sign-rank test. r≥0.5 was considered a large effect size. T-score medians were compared to a median of 50 if there was no comparison median available in literature. In addition, to assess which variables were significantly associated with physical, mental and social health, multivariable linear regression analyses were conducted for each PROMIS domain. The following variables were included as independent variable, based on literature, expertise and experience of the research team: presence of parent/caregiver, gender, age, months in refugee camp, travel duration before arrival at CCAC Mavrovouni or UAM shelter (in months). We assessed multicollinearity by looking at the variance inflation factor (VIF) of the multivariable regression. We considered a VIF >5 to be impactful and require further investigating. No multicollinearity was present for the included variables. Variables were considered to be associated with the PROMIS domain when the p value < 0.05. We reported unstandardized regression coefficients (B) for each multivariable linear regression. In case data was not normally distribute, is was log transformed.

Qualitative study: part two

The second part of this study was qualitative and only performed among UAMs.

Participants and study procedure

The qualitative part of this study consisted of open ended questions that were asked subsequent to the PROMIS measure (Appendix 4.2). This qualitative section had the purpose of enriching and contextualizing our quantitative findings.

The interviews were conducted by researchers KG, HB, and AG, PhD students and healthcare professionals. When needed, the questions were translated by interpreters to the UAMs' native language. Permission was asked verbally in order to record the interview.

We purposefully chose to alternate interviewers to enhance depth and quality of the interview. There was no relationship between interviewers and the participants prior to study commencement. The participants were aware of the interviewers' roles and the purpose of the study. Participants were selected using convenience sampling method. Participants were approached face-to-face by the psychologist of the UAM shelter in which they stayed. Data was collected in the UAM shelter of residence. The interviews lasted approximately ten minutes each and the duration of the interview was announced at the start of each interview. The interview duration was kept short to make it feasible for this vulnerable population, as they are often fatigue and due to time constraints due to school obligations or other planned activities. Participants did not review transcripts.

Data analysis

Data were collected by three interviewers (KG, HB and AG) who used voice recorders and field notes as a data capture method. The voice-recorded interviews were transcribed non-verbatim by researcher KG. Non-verbatim transcription was chosen due to the fact that children often were interviewed in their second or third language, and non-verbatim transcription was a more appropriate method of capturing the essence of what they said. Data was coded by one coder (HB). Deductive codes were based on the domains of the PROMIS questionnaire; depending on the thematic relevance, additional questions were posed for each PROMIS domain, although not every domain was necessarily addressed. The inductive codes emerged from the interview transcripts after discussion between researchers (KG, HB and AG). The themes were both identified in advance based on the PROMIS domains and emerged inductively from the interview data. ATLAS.ti software was used to manage and analyze the data.[15] Participants were

not involved in checking the findings. Participant quotations were included to illustrate key findings. Each quotation was identified by a participant number to maintain anonymity.

Results

A total group of 111 children comprised 94 children (aged 1–18) and 17 were UAMs (aged 9–18). Table 4.1 summarizes the socio-demographics. UAMs and children differ on all characteristics, except for the presence of a chronic disease.

Table 4.1: Socio-demographics of study population including p-values for difference between the two groups

Demographics			
	Children in CCAC Mavrovouni (N=94)	Unaccompanied minors (N=17)	
	Median (range)	Median (range)	p-value
Age in years	9.00 (2–18)	17.27 (9–18)	<0.001
	N (%)	N (%)	
Gender (female)	36 (38%)	13 (77%)	0.004
Chronic disease (present) *	12 (13%)	4 (24%)	0.245
Country of origin based on asylum papers			<0.001
Afghanistan	72 (77%)	3 (18%)	
Somalia	4 (4%)	11 (65%)	
Haiti	1 (1%)	0	NA
Palestine	13 (14%)	0	NA
South Sudan	1 (1%)	0	NA
Yemen	3 (3%)	0	NA
Syria	0	1 (6%)	NA
Kenya	0	1 (6%)	NA
Bulgaria	0	1 (6%)	NA
Travel information			
	Median (range)	Median (range)	
Travel duration before arrival (months)	9 (0–108)	3 (0–24)	0.005
Duration of residence (months)	2 (0–12)	4 (0–72)	<0.001
	N (%)	N (%)	
Resided in refugee camp before	11 (12%)	16 (94%)	<0.001

* Self-reported chronic conditions included skin conditions, epilepsy, autism, anemia, solitary kidney, developmental delay.

Most UAMs originated from Somalia (n=11; 64.7%), while most children in CCAC Mavrovouni originated from Afghanistan (n=72; 76.6%). The median duration of the journey in months from the children's native country to reach Lesvos was shorter for UAMs (Mdn 3.00 months) compared to children with parents/guardians (Mdn 9.00 months).

Comparison to US general population

Table 4.2 shows the comparison in PROMIS T-scores between the total group of displaced children living on Lesvos and the reference group, a representative sample of the US general population. The 1–4 year age group exhibited poorer scores on Depressive Symptoms (p=0.004) and higher scores on peer relationships (p=0.005) compared to the reference group. In the 5–7 year age group, there were worse scores for the domains Anger (p=0.008), Anxiety (p=0.047), Depressive Symptoms (p=0.010), Pain Behavior (p<0.001), and Sleep Disturbance (p=0.015) relative to the reference group. Similarly, the 8–18 year age group scored significantly worse for anger, anxiety, depressive symptoms (p<0.001), and pain behavior (p = 0.018), positive affect (p=0.001), and cognitive functioning (p=0.004) compared to the reference group. Surprisingly, they reported significantly better outcomes in the domain of meaning and purpose (p=0.004).

Associated variables with PROMIS domains

Table 4.3 presents the unstandardized regression coefficients from the ANCOVA analysis on PROMIS domains among all displaced children the were included. Key findings are that age is significantly associated with more sleep disturbance (B=1.21*), and pain behavior (B=1.23*). Positive affect is negatively correlated with age (B=-1.31*). Being a UAM was related to a higher meaning and purpose (B=10.30*) as well as Positive Affect (B=8.46*).

Months in camp is significantly associated with more anxiety (B=12.35**) and more depressive symptoms (B=12.67*) and lower positive affect (B=-16.52**).

Removal of sensitive questions

Removing sensitive items from the CAT post-hoc had negligible effects on the accuracy of assessment which we tested on a sample basis for the Fear Proxy PROMIS questionnaire (mean difference: 0.22, SE difference: 0.59).

Table 4.2: Comparison PROMIS T-scores in study population compared to US reference population

PROMIS Item Bank	Median (SD)	US general population mean (SD)[14]	p-value	Effect size (r)
Early Childhood: 1–4 years (parent report)				
Higher domain scores reflect poorer functioning				
Anger and Irritability (N=25)	49.5 (12.5)	50 (10)*	0.840	-.04
Anxiety (N=25)	50.9 (6.3)	50 (10)*	0.493	.14
Depressive Symptoms (N=25)	52.5 (6.5)	50 (10)*	0.004	.57
Sleep Disturbance (N=25)	51.7 (10.5)	50 (10)*	0.545	.12
Higher domain scores reflect better functioning				
Positive Affect (N=25)	54.6 (11.7)	50 (10)	0.861	.04
Peer Relations (N=25)	59.5 (7.12)	50 (10)	0.005	.57
Parent proxy: 5–7 years (parent report)				
Higher domain scores reflect poorer functioning				
Anger and Irritability (N=16)	54.6 (15.4)	43	0.008	.66
Anxiety (N=15)	48.5 (7.4)	43	0.047	.51
Depressive Symptoms (N=16)	51.0 (9.6)	44	0.010	.65
Pain Behavior (N=16)	21.7 (16.1)	13	<0.001	.90
Sleep Disturbance (N=16)	55.0 (12.5)	49	0.015	.61
Higher domain scores reflect better functioning				
Positive Affect (N=16)	44.3 (10.8)	49	0.234	-.30
Peer Relationships (N=16)	50.7 (10.4)	49	0.756	.08
Pediatric 8–18 years (child report)				
Higher domain scores reflect poorer functioning				
Anger (N=68)	51.7 (11.1)	44	<0.001	.54
Anxiety (N=67)	54.2 (9.0)	42	<0.001	.82
Depressive Symptoms (N=66)	54.5 (10.1)	45	<0.001	.66
Pain Behavior (N=69)	30.0 (10.4)	32	0.018	.29
Sleep Disturbance (N=69)	51.4 (12.0)	50	0.098	.20
Higher domain scores reflect better functioning				
Meaning and Purpose (N=62)	56.0 (9.9)	50*	0.004	.36
Positive Affect (N=63)	40.0 (11.1)	49	0.001	-.41
Peer Relationships (N=63)	48.3 (9.7)	48	0.476	-.09
Cognitive Functioning (N=67)	46.7 (7.8)	50*	0.004	-.35

* Median 50 was used as reference median was missing from literature.

Table 4.3: ANCOVA analysis for relevant variables

	Anger (N=65)	Anxiety (N=64)	Depressive Symptoms (N=63)	Pain Behavior (N=66)	Sleep Disturbance (N=66)	Meaning and Purpose (N=59)	Positive Affect (N=60)	Peer Relationships (N=60)	Cognitive Functioning (N=64)
Covariates	B	B	B	B	B	B	B	B	B
UAMs ▪	-5.4	-3.0	0.1	-9.4*	-2.7	10.3*	8.5*	5.2	4.7
Gender‡	0.7	-5.0	-1.7	-1.2	3.0	3.2	-3.7	-2.1	2.8
Age	0.3	-0.2	0.6	1.2*	1.2*	-0.5	-1.3*	-0.4	0.6
Months in camp°	9.3	12.4**	12.7**	-1.7	8.2	-2.3	-16.5**	-9.4	-3.3
Travel duration°	1.2	-1.2	3.6	-1.9	3.6	-1.7	0.6	-0.4	2.1

▪ Reference group is children accompanied by parents/guardians, ‡ reference group is female, * $p<0.05$, ** $p<0.01$.
° Data log transformed as data was not normally distributed.

Results from qualitative study

This analysis is centered on a selection of the most robust themes that emerged from the interviews, namely: depressive symptoms, peer relationships, and meaning and purpose. Fifteen interviews were done among UAM aged 9–18 years who also completed the PROMIS item.

Depressive symptoms

Several reasons for experiencing *Depressive Symptoms* were given. UAMs reported on sadness being caused by asylum procedures, departure of their friend, or remembering their past.

> *I feel sad when I remember [name], it was one of the children that was here from Africa, from Congo and left the island.* – 9 years, UAM from Congo.

Episodes of loneliness were caused by missing their parents, a plausible cause of their experience of this emotion as they are unaccompanied with parents in their country of origin or after loss of their parents.

> *Sometimes when I see families, I feel like I am unlucky that I don't have this kind of life.* – 17 years, UAM from Bulgaria.

It is remarkable that we found significantly higher levels of Depressive Symptoms in the age categories that UAMs belonged to. Curious to know what helped UAMs to cope with this, we asked them what mechanisms they used in their lives. It was noticable to some minors mentioned praying.

> *Yes and forget everything. Before I was feeling that my chest is like I can't breathe. But when I go to the sea, or go to a place lonely or pray, everything is finished. Talk and then everything is finished, to myself.* – 17 years, UAM from Somalia.

Others valued being alone, going out with a friend, or activities such as football or listening to music. This indicates the diversity of emotional management between individuals, ranging from solitude to engaging in activities, and is based on personal preferences. Despite the hypothesis that high levels of Meaning and Purpose among UAMs could be a coping mechanism, negative experiences are not neglected or ignored. One minor mentioned as a coping mechanism how they acknowledge negative past experiences:

> *Even if I think negative, negative things happened to me, I experienced it. That's why I never like to think about the negative things, because it influenced me a lot, myself and my life as well. That's why I prefer to be strong and positive.* – 15 years, UAM from Afghanistan.

Another minor reported on similar development of a mindset after having to deal with certain experiences. Acknowledging past negative experiences is very much part of their experience.

> *I came here to achieve my goals. I crossed that sea alone. […] From the day that I left, there are some things I will never know. […] But I know that I'm a strong person. And I just see my goal, I know that it's going to take a long time.* – 17 years, UAM from Somalia.

Peer relationships

The importance of having family was a recurring theme raised by the UAMs, which is expected from children that have left their family behind or lost their family at home or along the way. One of the UAMs biggest goals that gave their purpose in life was family reunification.

> *The big goal and wish for me, I try to bring my family in the future. And can also live with them again, and join them. And doing something so that they also come here.* – 15 years, UAM from Kenya.

Participants described that being separated from their family was difficult for them and that they miss them. In addition, they explained that the absence of their family affected them and evoked different emotions (e.g., loneliness, sadness).

> *I am feeling lonely, because I am not with my parents.* – 17 years, UAM from Somalia.

Not all UAMs feel the purpose of reuniting with family—some so regret their decision to travel alone and having left their family behind. One minor felt regret for coming to Greece without their family, a reflection that is of particular significance for this group of children.

> *I regret like, why did I come here without my family?* – 17 years, UAM from Kenya.

All of these statements indicate a pattern that highlights the important role that family plays in many of the UAMs' lives and the possible negative impact of their absence on their QoL. When experiencing these emotions, the participants indicated that, instead of their missing family, friends can offer support and reliability. One minor emphasized the importance of having a friend when missing their family.

> *The meaning of a friend is someone who becomes behind you when you miss your family.* – 11 years, UAM from Somalia.

Participants indicated the high added value that friends can offer to their well-being and of support on UAMs' QoL.

When asked what a good friend means to them, UAMs answered:

> *A friend can be a shoulder to cry on. You speak with them to be calm and comfortable. To share something with them.* – 15 years, UAM from Afghanistan.

> *The one who knows everything from you and even if you don't tell him, he can understand from your face.* – 17 years, UAM from Kenya.

> *A good friend is when you are sad, that person that moves to you, bonds with you, understands you, listens to you. Even if the person doesn't have anything, he tries to make you happy. Tell me that if today is a bad day, tomorrow is going to be better.* – 17 years, UAM from Somalia.

Meaning and purpose

It is remarkable that UAMs score particularly high in the quantitative part of our study on the domain of Meaning and Purpose. When asked about contributions to Meaning and Purpose in life, UAMs provided a multitude of descriptions such as setting and achieving goals. Most UAMs reported their goal is to have a job in the future, and other minors explicitly mentioned they valued education.

> *My goal is first of all being healthy and I'm not that kind of person that says I want to be rich and that. So like a normal job, with my family next to me, my mother, my father has passed away. Also, I want to help people.* – 17 years – UAM from Somalia.

Other ambitions that UAMs mentioned included being healthy, family reunification, helping others, and contributing to society. Obtaining independence to provide for themselves was also valued by some of the participants.

> *I want to be someone who works hard and does not depend on anyone. And I can pay for everything myself.* – 17 years, UAM from Kenya.

UAMs attributed having hope for the future as means to not remember their past. This does suggest that being hopeful may serve as a mechanism to cope with their past experiences.

> *I think it is meaningful, that I am alive and doing what I want to. [.] Achieve my goals, that gives meaning.* – 17 years, UAM from Afghanistan.

One participant regained hope after leaving their past behind and having the opportunity to rebuild their life in UAM shelters' residence.

> *I didn't have any dreams, any hopes. My life was finished when I was with my parents. I just prayed to God to bring me a good family. [.] Now I feel very well, full of hope.* – 17 years., UAM from Kenya.

Discussion

This study presents an understanding of QoL of displaced children on Lesvos. Compared to the US general population, the children aged 5–18 years old exhibited higher levels of Anger, Anxiety, Pain Behavior, and Depressive Symptoms. A prolonged stay was associated with higher scores on Anxiety and Depressive Symptoms. We strived to minimize all forms of bias through our scientific measures, despite the significant challenges of executing this study in a refugee camp.

This study revealed significant distinctions in mental health, represented by the domains of Anger, Anxiety, and Depressive Symptoms between the displaced child population and the US reference group. This aligns with Karadag and Ogutlu's (2021) examination of psychiatric symptoms in a sample of 62 Syrian child refugees aged 12–16 in a Turkish refugee camp, reflecting high levels stress, depression and anxiety.[16] These results are consistent with prior research indicating heightened emotional states among Sudanese refugee children in Ugandan refugee camps.

Notably, 45.6% of the children, along with their parents, recognized a tendency to easily develop irritation or anger following displacement as refugees.[17] Problems in mental health may be attributed to limited resources and disruptions in the normal structure within the refugee context compared to the current study's reference group. The results regarding Depression, Anxiety and Sleep Disturbance align with previous studies, as both Jakobsen,[18] who reviewed several studies using self-reporting instruments, and Montgomery,[19] using the HSCL-25 questionnaire. Both found higher levels of Depression, Anxiety and Sleep Disturbance among minor refugees and asylum seekers compared with the general population in the country of research.

Sleep disturbance is described as a potential indicator of mental health disorders, such as depression and anxiety disorders. Morales-Muñoz and Gregory,[20] describes the bidirectional relation between sleep and mental health, already detectable in childhood.

Being an UAM was correlated to higher levels of Meaning and Purpose as well as positive affect. It has been described that UAMs develop considerable positive coping skills during migration that can contribute to promoting their wellbeing once in the context of safety.[5] Several reasons for the high levels of Meaning and Purpose among UAMs were provided during the interviews, such as access to education, having goals (e.g. finding a job, and contributing to society) and engaging in daily activities. The positive correlation of Meaning and Purpose and UAMs could be attributed to the access to educational facilities.[21]

Another potential explanation could be that UAMs score higher levels of Meaning and Purpose as a coping mechanism for severe mental distress. This, is particularly striking as the PROMIS outcomes in this age group show significant higher levels of Depressive Symptoms and significant lower levels of Positive Affect. It is possible that reporting a high sense of meaning and purpose in life can, in some cases, serve as a way to avoid confronting traumatic memories.[22] While meaning-making is often viewed as a positive coping mechanism, it can also function as a form of avoidant coping – allowing individuals to focus on future goals or values rather than unresolved trauma, which potentially makes them feeling depressed. Meaning can sometimes offer emotional distance from painful past experiences.

A repeated theme in the interviews, which could explain a higher level of Meaning and Purpose among UAMs, was having friends and hope for a family in the future,

in particular the goal of family reunification, which is often yet uncertain for many children. During the interviews, the importance of social support was reflected in its effect on the other domains of QoL. Multiple UAMs mentioned how the absence of their family evoked different negative emotions (e.g. sadness and loneliness), and thus potentially affected their mental health and QoL. However, UAMs also described how the presence of friends can play an important role in coping with emotions and experiences, and as a source of solace in times of missing their parents. The results of this study and many articles underline the importance of social support and family cohesion to protect mental health of minors.[23,24]

Another noteworthy finding is that a longer duration of residency in the camp and/or shelter is associated with higher scores on the domains of Anxiety and Depressive Symptoms, and a low score for Positive Affect. These correlations emphasize the relation of an extended stay in the camp and/or shelter, indicating a deteriorating trajectory in multiple domains of QoL. It has been described that protracted refugee situations lead to prolonged exposure to physical and emotional stress.[25]

Measuring the QoL of displaced children by means of questionnaires and interviews in the context of a refugee camp was very challenging, and we put a lot of effort to minimize all forms of bias. However, this study had several limitations. This was primarily due to the heterogeneity of the group in terms of background, culture, country of origin, and language.

The cross-cultural validity of diagnostic classifications originating from Western perspectives continues to be a subject of controversy.[26] Another limitation is the small group of UAMs. Moreover, age assessments in this study could be inaccurate as UAMs may falsely report to be younger in order to receive legal protection.[27] In our study, this could have potentially led to misinterpretation of PROMIS outcomes as misreported age can lead to incorrect attribution of QoL relative to developmental expectations, biasing our conclusions.

In the qualitative analysis, we used non-verbatim transcription which might have led to loss of nuance in the data.

Our comparison group, a sample of the US general population, was not entirely ideal due to potential differences in demographic, cultural, and contextual factors. Differences with the control group could exist based on these factors alone,

regardless of displacement. However, it remains the most feasible reference point available for the study. It is important to note that the American reference group also includes clinical patients, which suggests that the findings may actually be more unfavorable if the comparison group was solely the general population. In the reference group, 35% of the children participating in the survey consulted a clinician for a chronic illness diagnosis or treatment within 6 months prior to study enrollment.[25] Additionally, in several domains, there is a difference greater than three points, which is considered meaningful, as a difference of 3 T-score points is generally regarded as a reasonable threshold for comparing groups in most contexts.[28]

Lastly, leaving out inappropriate questions was deemed correct, but could potentially give bias. Our sample-wise analysis showed negligible differences between the results of the questionnaires before and after leaving out these questions.

Children do not belong in refugee camps. Our evidence emphasizes that the duration of a child's stay in a camp should be minimized, with swift relocation to a safe and stable environment. Furthermore, when children do reside in camps, policies should focus on improving shelter conditions, and to ensure access to education and social support, to minimize the negative impact on their quality of life.

Conclusion

In conclusion, this research contributes significantly to the understanding of the QoL of children in refugee camp settings in Europe. All these children report high levels of Anger, Anxiety, Pain Behavior, and Depressive Symptoms. Furthermore, a prolonged stay in the camps worsens these outcomes. The findings provide a foundation for future research and the development of targeted interventions aimed at improving the QoL of displaced children.

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Contributions

All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by Hanaâ Benjeddi, Morgan McKnight, Kirsten de Groote and Jonne Feitsma. The first draft of the manuscript was written by Hanaâ Benjeddi, Kirsten de Groote and Morgan McKnight. All authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Corresponding author

Correspondence to Hanaâ Benjeddi.

Conflict of interest

The authors have no relevant financial or non-financial interests to disclose.

Ethical approval

This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Committee of The Hellenic National Public Health Organization (EODY), Athens, Greece, in December 2022 under Reference No. 23702/06-12-2022 (see Appendix 4.3).

Informed consent

Informed consent was obtained from all individual participants included in the study. Oral informed consent was obtained from the parents and additional informed assent was required for participation if the participant was 12 years or older. Informed consent for the unaccompanied minors was provided by the public prosecutor.

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Appendix 4.1

List of PROMIS Item Bank that were used in each age category

Age group	PROMIS measure
1–4 years	PROMIS Early Childhood Parent Report Item Bank • V1.0 Sleep Disturbance (CAT)[29] • V1.0 Anger/Irritability (CAT)[30] • V1.0 Depressive Symptoms (CAT)[30] • V1.0 Anxiety (CAT)[30] • V1.0 Social Relationships - Peer Relationships (SF 4a)[31] • V1.0 Positive affect (CAT)[32]
5–7 years	PROMIS Parent Proxy Item Bank • V1.0 Sleep Disturbance (CAT)[33] • V2.0 Anger (Scale)[34] • V1.0 Pain Behavior (CAT) • V2.0 Depressive Symptoms (CAT) • V2.0 Anxiety (CAT)[34] • V2.0 Peer Relationships (CAT)[34] • V1.0 Positive affect (CAT)[35] • V1.0 Meaning and Purpose (CAT)[36]
8–18 years	PROMIS Pediatric Item Bank – self reported • V1.0 Sleep Disturbance (CAT) • V2.0 Anger (Scale) • V1.0 Pain Behavior (CAT) • V2.0 Depressive Symptoms (CAT) • V2.0 Anxiety (CAT) • V1.0 Cognitive Functioning (SF 7a) • V2.0 Peer Relationships (CAT) • V1.0 Positive Affect (CAT) • V1.0 Meaning and Purpose (CAT)

CAT, computerized adaptive test; SF, short form.

Appendix 4.2

Interview guide

Opening:
- Introduction researchers and interpreters
- Background information study
- Informed consent

Demographics:
- Age
- Gender
- Country of origin
- Duration of stay in residency or camp
- Stay in previous residency or camp
- Number of months on the road
- Prevalence of a chronic disease

PROMIS® questionnaire with additional open-ended questions within each domain of QoL

Sleep Disturbance:
When participant's answers on the PROMIS® questionnaire indicate sleep disturbance in the past week:
- What is the reason that you sleep poorly/ that you can't sleep/ wake up at night?

Anger:
When participant has experienced anger in the past week:
- What makes you angry?
- Can you give an example of what makes you angry?
- What do you do when you are angry?/ How do you cope with these feelings of anger?

Pain Behaviour:
When participant mentions having experienced pain in the past week:
- What kind of pain did you experience?

Anxiety:

When participant expresses having experienced feelings of anxiety or worries in the past week:

- What makes you feel anxious?
- What makes you feel calm when you are anxious/ worried?
- How do you cope with anxious feelings?

Peer Relationships:

- What does friendship mean to you?
- What is your definition of a 'good friend'?

Positive Affect:

When participant expresses having been happy in past week:

- What are things that make you happy?

Meaning and Purpose:

- What makes your life meaningful?
- What is your biggest dream?
- What is your purpose in life?
- What gives you the power to overcome the obstacles you face in life?

Closing:

- Expression of gratitude for participation
- Opportunity for questions

Appendix 4.3

ΕΘΝΙΚΟΣ ΟΡΓΑΝΙΣΜΟΣ
ΔΗΜΟΣΙΑΣ ΥΓΕΙΑΣ

Αγράφων 3-5, Μαρούσι
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Ε.Ο.Δ.Υ.
ΚΠ 2018 / 2023 - 23/01/2023

Πληροφορίες:
Επιτροπή Ηθικής και Δεοντολογίας
ΕΛΕΥΘΕΡΙΑ ΣΙΑΡΕ , 2105212040

Προς :

Κοσμήτορα Σχολής Επιστημών Υγείας,
Καθηγητή κ. Εμμανουήλ Πικουλή

Ιατρική Σχολή Πανεπιστημίου Αθηνών

Θέμα:Απάντηση στην υπ' αριθ. 23702/06-12-2022 αίτηση

Σε συνέχεια της υπ' αριθ. 23702/06-12-2022 αίτηση της κας HanaaBenjeddiπρος την Επιτροπή Ηθικής & Δεοντολογίας και κατόπιν του 2ου/16-12-2022 πρακτικού της Επιτροπής το οποίο εγκρίθηκε από το υπ' αριθ. 25298/23-12-2022 απόσπασμα πρακτικού της 7ης/22-12-2022 συνεδρίασης του ΔΣ του ΕΟΔΥ, σας ενημερώσουμε ότι έχει εγκριθεί.

Ο Πρόεδρος ΔΣ ΕΟΔΥ

ΑΚΡΙΒΕΣ ΑΝΤΙΓΡΑΦΟ
Προϊστάμενος Γραμματείας
α.α.
Ναυσικά Παπαθανασίου

Θεοκλής Ζαούτης

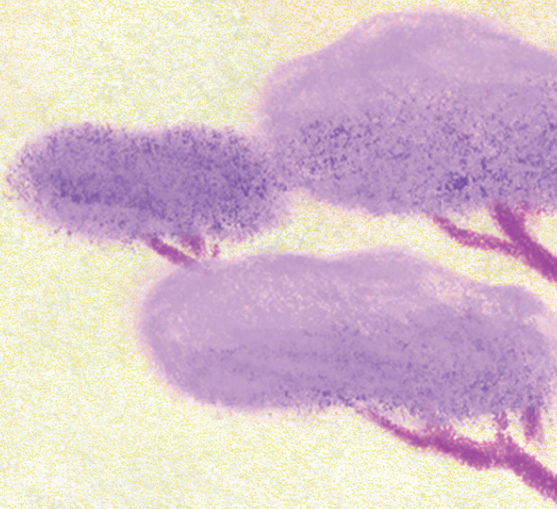
Εσωτερική Διανομή :

Γραφείο Γραμματείας Προέδρου
Προϊστάμενος Διεύθυνσης Επιδημιολογικής Επιτήρησης & Παρέμβασης για Λοιμώδη Νοσήματα
Γραφείο Γραμματείας Αντιπροέδρου - Μεταδοτικά Νοσήματα
Γραφείο Γραμματείας Αντιπροέδρου - Μη Μεταδοτικά Νοσήματα
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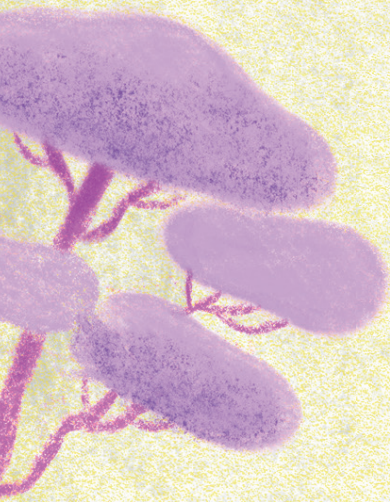


CHAPTER FIVE



Exploring moral distress in research students in a paediatric humanitarian research setting: a qualitative study from the Mavrovouni closed controlled access center, Lesvos, Greece

Hanaâ Benjeddi, Mariana Dittborn, Molly Hirst, Agis Terzidis, Martijn van der Kuip, Mariken Gruppen, Joe Brierley



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Abstract

Moral distress refers to the emotional distress experienced when an individual's moral or ethical beliefs are violated. This concept has been widely studied in a number of disciplines, but limited attention has been given to the moral distress experienced by researchers in the humanitarian setting. This paper aims to explore the ethical challenges and resulting moral distress faced by paediatric humanitarian research students in the Mavrovouni Closed Controlled Access Center, Lesvos, Greece. Based on a qualitative approach, we conducted three ethics support workshops with 5 to 10 participants each, in which they were invited to discuss the moral dilemmas they were experiencing in their research work. Sessions were audio-recorded and transcribed; transcripts were analysed using reflexive thematic analysis. Seven main themes were developed: community and system-level considerations, witnessing and moral responsibility, conflicting duties, participant benefit misconception, coping strategies, cultural aspects, and theories of change. These themes highlight the diverse ethical dilemmas research students face in this field. The results of this study will contribute to the development of support systems for researchers working in sensitive data collection and promote a more sustainable and healthy research practice.

Introduction

Research students from 'The Mavrovouni Migrant Child Health Project', in which nutritional status and the quality of life of children living in one of Europe's biggest refugee camps are assessed, voiced the need for support after experiencing diverse ethical challenges. Lesvos hosts the Closed Controlled Access Center (CCAC), set up in September 2020 as an urgent measure following the fire that destroyed the infamous Moria refugee camp. The camp's population, ranging from approximately 1,000 to 5,000 residents, shifts frequently, mirroring the instability of the conflict zones from which its inhabitants have fled. Camp Moria was known for its inhumane conditions, due to severe overcrowding, lack of hygiene and detoriating mental health among its inhabitants.[1]

Although ethical challenges encountered by humanitarian healthcare workers have been described,[2] the challenges experienced specifically by research students in this context have been little addressed, particularly in the paediatric context. In a systematic review of the ethical challenges of 'field' research in low and middle-income countries,[3] Steinhart and colleagues described the ethical issues reported in the literature, but moral injury, specifically to medical researchers, has rarely been studied or described.[4] It is essential to recognise the vulnerability of the children and families in the refugee centre, especially their ongoing need for basic sustenance and healthcare. The latter cannot always be provided in this setting, and certainly not by researchers in their different roles. Researchers certainly have moral questions about why children and families have been forced into this situation, whether by war or poverty and soon by climate change, none of which they can control, which seems a paradigm set up for moral injury.

Following research abuses, concern for research participants has been the main focus and extensively described, leading to research practices aiming to ensure the protection of all research participants.[5] Additionally, although to a lesser degree, increased attention has been given to the impact of research practices on researchers themselves, with existing research pointing to the need to develop support systems for researchers working in the area of sensitive data collection,[6,7] especially in qualitative research in sensitive topics or with vulnerable populations.[8] However, the focus has been on researchers' safety, emotional distress, and vulnerability,[8] with less attention to the experience of morally challenging situations and the

impact these can have on researchers' well-being and research output. Although researcher safety and wellbeing are best approached as holistic concepts, moral injury specifically has received less focus compared to other types of injury.

While more extensively described in the healthcare and military fields and described in different disciplines, including psychology, psychiatry, social work, philosophy, religious and spiritual studies, the concepts of moral distress and moral injury in the research field have rarely been explored.[4]

There are no agreed definitions for the concepts of moral distress and moral injury, with these terms often used interchangeably. The concept of moral distress was initially described by Jameton in 1984 in relation to student nurses' experiences of distress when "when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action".[9] Moral injury was initially conceptualised in the military context, referring to the emotional distress and a particular type of trauma that an individual experiences as a consequence of their moral or ethical beliefs being violated when "perpetrating, failing to prevent, bearing witness to, or learning about acts that transgress deeply held moral beliefs and expectations".[10,11] Both terms are now used in healthcare to refer to the impact of morally challenging situations on individuals' psychological and spiritual well-being.[12] For example, the British Medical Association adopted an integrated approach,[11] where moral distress is understood as a feeling of unease arising from situations where institutionally required behaviour does not align with the individual's own ethical principles; moral injury occurs when sustained moral distress leads to impaired function or longer-term psychological harm.[13] Witnessing or participating in potentially morally injurious events has been significantly associated with depression, post-traumatic stress disorder and suicidal ideation.[14] Experiencing moral injury can potentially lead to impaired occupational and social functioning.

A better understanding of the ethical challenges faced by research students and the potential for moral distress and moral injury they might experience in this setting is important. Ultimately, supporting researchers better to prevent harm to them will ensure more sustainable and healthy research practices.

Objective

To explore the ethical challenges that paediatric humanitarian researchers working in a European refugee camp face and the impact these experiences have on them.

Methods

An experiential orientation to qualitative study design[15] was chosen to enable in-depth exploration of participants' experiences of ethical challenges in their humanitarian research work practice. Research students from four different universities in the Netherlands and Greece with backgrounds in medicine, global health and disaster management involved in 'the Mavrovouni Migrant Child Health Project' in a European refugee camp, were invited to participate in a series of three ethics workshops. Ahead of the workshops, participants were asked "What are ethical dilemmas that you face during your work as a researcher?" and were invited to share the ethical challenges they experienced, either written ahead of each workshop or verbally during the meeting. We did not provide participants with a definition of "ethical challenge" to allow a more comprehensive discussion without pre-established limits around a concept lacking an agreed definition in healthcare research.[16]

Three workshops were hosted online and were facilitated by two experienced members of a Paediatric Bioethics team from a tertiary children's hospital. Participation in the workshop was entirely voluntary and informed consent from each participant was sought prior to each session, reassuring participation was voluntary and ensuring anonymity and confidentiality of the collected data. Students were assured that declining or withdrawing would have no impact on their academic evaluation or internship opportunities.

All three sessions, with a duration of 45–60 min, were audio-recorded and subsequently transcribed verbatim using an online transcription tool and anonymised. Two authors analysed transcripts independently (MD, HB) following a reflexive thematic analysis approach,[17] following a familiarisation with the data, iterative inductive coding and theme development. Initial codes and themes were then discussed within the team and organised into overarching themes and subthemes.

Results

Participants: out of a total of ten researchers invited to participate, between 5–10 researchers joined each session, with some of them participating in more than one. All participants joined the workshops during their research internships. Participants' included research students with backgrounds in psychology, global health and medicine. Sessions lasted between 45–60 min each. Reflexive thematic analysis of the transcripts led to the development of seven major themes with sub-themes (Table 5.1).

Table 5.1. Themes and subthemes

Main themes	Subthemes
1. Community and system-level considerations	
2. Witnessing and moral responsibility	i. Injustice ii. Discrimination iii. Power imbalances iv. Guilt
3. Conflicting duties	i. Participant welfare ii. Professional boundaries & rules
4. Informed consent and participants' misconception about potential benefits	
5. Coping strategies	i. Emotional support ii. Peer support iii. Privileges and responsibilities
6. Cultural aspects	
7. Theory of change	i. Advocacy ii. Action iii. Giving children a voice

Community and system-level considerations

This theme touched upon the ethical considerations related to the impact of their research work. There were reflections about the short versus long-term effects of the research, as well as local versus international impact. One participant described this in the following manner:

> *You want to create some sort of transformation, some sort of action, action perspective for the people that you work with for the community. In this case, it would be then the people in the camp, the refugee community. And I have had some sort of conflicting things within myself during the time that I was here that the current research that we are doing is of course going to create*

> *hopefully with the, hopefully the impact that we will make, make some change for people in the future, for the people living in the camp later on.* – Participant workshop 1

Researchers grappled with the balance between individual and collective interests, as well as the balance between direct and indirect benefits of the research that they are performing:

> *Say we're not only studying these detailed elements of well-being but trying to describe the whole picture in a more comprehensive picture of a population in a camp and being bold and really looking to see what can we actually really do.* – Participant workshop 1

Participants reflected on how, at times, it felt distressing to know that the research is intended to have long-term benefits but no tangible direct benefit for participants, as illustrated by the following quote:

> *Maybe it even feels now sometimes like a burden for the people that are included because we can give them some information but not always the help.* – Participant workshop 1

Witnessing and moral responsibility

This major theme relates to the moral responsibility and personal impact that researchers felt when witnessing—and feeling unable to change or directly address—the multiple challenges faced by paediatric populations and their caregivers in humanitarian settings. The theme could be further defined into four sub-themes, i.e., different challenges that the researchers witnessed and considered appealed to their own moral responsibility: injustice, discrimination, power imbalances and guilt.

Injustice

This sub-theme delves into the distress researchers encounter when witnessing systemic inequalities and disparities within their research populations, as illustrated by the following quote:

> *And then for me, the feeling, but I go into that camp and I, with that, I feel that I contribute to the system, which I do not completely stand behind. And*

that's the feeling of discomfort that I'm like actually, yeah, or it feels that I'm contributing to a system that doesn't feel right to me in some, yeah, on some levels. – Participant workshop 2

Discrimination

A second important sub-theme that arose was the fact that researchers witness discrimination, feeling that camp residents received worse treatment than themselves as research team members, as illustrated in the following text:

So, at the entrance of the camp, we are not searched, but the residents and visitors are. Just based on how I look, I'm already treated differently. I go there every day and it feels like I am contributing to the inequality in treatment. In the first week, I would make a comment about it and try to suggest that they could scan. – Participant workshop 2

Further highlighting that there should be no discrimination:

We are all humans. Nobody has a stamp that is a refugee, a migrant, or a local, or whatever. – Participant workshop 1

Power imbalances

Researchers frequently mentioned the fact that being a witness to power imbalances also gave significant distress and spoke to their moral responsibility:

Within research people have to decide for themselves really if they want to participate, but is that even possible in a setting like this, if there are so many power imbalances and if people, well, might indeed think that if I do not participate will it have any negative consequences on my asylum procedure. – Participant workshop 1

Guilt

Being a witness to injustice at times brought along a feeling of guilt, questioning their personal opportunities and choices:

Sometimes I feel a bit guilty when I'm spending money on a coffee, while studying or when I'm going out for dinner, while being aware of the current situation in the camp. – Participant workshop 2

Conflicting duties

One prevalent theme revolved around the ethical dilemma of researchers' conflicting duties. Researchers found themselves torn between obligations to the research participants, the broader community, and the scientific community. This overall theme can be subdivided into the following subthemes:

Participant welfare

On the one hand, researchers worried about the potential burden of their research practices on the participants:

> *Sometimes it feels like we are extracting so much data from them, without being able to do something for them right now.* – Participant workshop 1

On the other hand, researchers felt the obligation to provide medical care even though that was beyond the scope of the research.

> *But she was almost five, and she didn't speak. She seemed autistic, and she didn't go to school. And I was talking to her mom and her mom was very concerned about that. It's not the type of chronic disease where she is lacking medication, so she should be urgently transferred to the mainland by using our network of paediatricians. But she is autistic. She has other requirements needed for optimal development.* – Participant workshop 3

Professional boundaries & rules

Researchers sometimes struggled to maintain professional boundaries while maintaining an authentic and genuine human connection in their daily work.

> *We're not providing a service, so there's not a dilemma of them giving us payments or gifts for our service. It's kind of like we're researchers, but we're also humans and think it's perfectly okay to have these kind of connections. It's like we're here and we're in this situation, so I think that as long as we set boundaries…* – Participant workshop 3

Simultaneously, there was a quest for guidance on what was appropriate as a researcher in such a setting.

> *But who makes the boundary, right? And that's what you're saying. Is that something as someone who's new to this should you be told what that is? Should you be able to feel what it is? And if you get it wrong, how can that be right? Because if we're asking you to decide on your own values what should happen, well who can tell you what's right or wrong apart from you? That's the problem. So, what is the set rule of this? What is, you know, what is okay? Are there anything in your world where people say this sort of relationship's okay?* – Participant workshop 3

Informed consent and participants' misconception about potential benefits

Another recurrent theme was 'benefit misconception', where researchers were faced with research participants who had the hope that the research provided some sort of benefit for, e.g., their asylum procedure. Researchers, for example, struggled to obtain unbiased informed consent despite efforts to clarify the actual benefits.

> *This is another issue, an ethical issue that we have to take in consideration and clarify from the very, very, very beginning that we're not involved in any administrative procedures and nobody's going to take anything off.* – Participant workshop 1

Researchers experienced this as bias in their research:

> *The other thing is that always how you are going to take this sample, let's say, because most of the time people in the camp believe that if they participate, this is a bias always, that if they participate in our research, they are going to take something as an advantage. They are going to think that the procedures, the bureaucratic procedures, the administrative procedures for their asylum will be easier.* – Participant workshop 1

Researchers' coping strategies

Coping strategies emerged as a crucial theme, shedding light on different ways that the researchers personally dealt with the ethical challenges in their research work. They discussed the various strategies employed to manage stress, mitigate emotional impact, and maintain resilience in the face of the challenging ethical dilemmas. The sub-themes that arose from this theme were: emotional support, peer support and using privilege for the good.

Emotional support

Researchers emphasised the need for emotional support as a means to be able to do the work sustainably.

> *You have to take care of your students. They must have psychological support, because many times they will feel like they are doing nothing even if they write all these problems and after that what? Nothing. So, give the psychology support. If we go on and we are not disappointed in what we are doing, we will win.* – Participant workshop 1

Peer support

Much value was placed on having a community to talk about the challenges that were faced, even though they did not bring practical solutions, they did offer some kind of relief:

> *The idea that you can have a space where you might have a facilitated discussion with someone who can help you think through the morality of an issue, even if you can't fix things.* – Participant workshop 1

This is further supported by another researcher who said:

> *I hear how someone who's very experienced deals with that and not just practically or research technically deals with it, but personally deals with it. I think for me that is very important and helps me to not be blocked by an ethical dilemma but to give it a place and to move on.* – Participant workshop 1

Privileges and responsibilities

A repeatedly mentioned coping mechanism for ethical difficulties, especially when it comes to experiencing different opportunities, was to use researchers' own privilege for good.

> *How I personally try to see this is really use, recognising your own privilege and then using it for the good. And that's exactly where this sense of, for me personally, the sense of responsibility comes from saying, well, I have these privileges, so I need to, I have a responsibility to use them to create positive change. And use my privilege to my advantage. So, I definitely, I use the fact that I'm a woman to my advantage, I use the fact that I have a Dutch passport.* – Participant workshop 2

Cultural aspects

Cultural considerations played an important role in shaping the ethical landscape of the research. The transcripts showed the importance of cultural sensitivity, in particular, when, for example, finding the right researcher-participant relationship:

> *I also feel that that's professional distance sometimes is the Western point of view me or Maybe not measured Western but also cultural, that there are cultural differences in that.* – Participant workshop 3

Theory of change

A last theme that emerged when discussing ethical dilemmas in this research setting was the theme concerning theories of change. Researchers critically examined the potential impact of their work and the most effective ways to contribute positively to the research setting so that the research directly affects the local population. Relevant sub-themes were advocacy, action and giving children a voice, with participants highlighting the need for resources and funding to be in place for these actions.

Advocacy

Advocacy was often mentioned as a tool for using the research to truly achieve systemic change.

> *And then if it comes to humanitarian law, I think identifying these issues is very important, to get in contact with a human rights team, following these things up, analysing them, and maybe supporting on individual case level, but also maybe formulating advocacy messages to European and national institutions.* – Participant workshop 1

Action

> *So don't give up. For humanity, for human beings, we have to go on. If we go on and we are not disappointed in what we are doing, we will win.* – Participant workshop 1

Giving children a voice

> *So I think we have to understand that if these children can answer, of course with the parent inside the room, let them speak. The parents could change their answer because of the asylum procedure. So let these children, even five-year-old children, speak. You have to have your ears open and to catch what this child says to you.* – Participant workshop 1

Discussion

This study aimed to explore the ethical challenges faced by paediatric humanitarian researchers, focusing on the context of a European refugee camp. Through qualitative analysis of ethics support session transcripts, several key themes were identified, which enabled consideration of the ethical landscape of this research field.

The factors contributing to the ethical challenges researchers encounter in the refugee environment are multifaceted: witnessing injustice, discrimination, and power imbalances within the research population evoke a sense of moral responsibility. Conflicting duties between researchers' professional roles and genuine human connections further intensify the ethical dilemmas. The balance between individual and collective interests, as well as the long-term impact of research versus some perceived, erroneous, immediate benefit for participants, adds another layer of complexity.

Ethical considerations in research with vulnerable populations and the associated challenges with the informed consent process are widely acknowledged and addressed in international research ethics guidelines.[18] The structural disadvantages experienced by refugees and asylum seekers and the unequal power relationships with the researchers are likely to affect participants' voluntariness to consent. In our study, researchers reflected on the misconception regarding the benefit thought to exist by participants in this setting. Research participant's hope for benefit in this environment, essentially benefit misconception, seems to us to be a version of therapeutic misconception well described in clinical trials, where patients' decision to enrol in research appears to be "based on confusion between the nature of research and of ordinary treatment",[19] potentially invalidating the consent given by participants.[20] Rather than a direct therapeutic benefit, participants perceive some

kind of beneficial factor in their own asylum procedure or in the care of their child. This persists despite specific information to the contrary and repeated clarification from the research team. Research ethics guidance on protecting refugees and asylum seekers participating in research is needed.[18] Alongside addressing both the group's and individual's vulnerability, learning from the work done in relation to the identification and management of therapeutic misconception might offer an additional layer to protect participants and researchers, ensuring the integrity of the whole research process.

In the clinical field, it is well established that ethical dilemmas in which clinicians must deliver treatment that conflicts with their moral viewpoint are harmful and cause accumulative damage to them and their well-being.[13,21,22] Moral distress and moral injury are far less frequently described in the research field, but one could expect the ethical challenges experienced and lack of ability to address the causes to potentially have a negative impact on paediatric humanitarian researchers. While the focus in the research setting has been on researchers' well-being, emotional distress and resilience, we believe that looking at researchers' experiences of ethical challenges through the lenses of the moral distress and moral injury models might offer an opportunity to appropriately investigate, understand, prevent and respond to the problem to ensure both research participants' and researchers' are protected throughout the research process and to avoid harmful consequences to individuals' psychological and physical well-being. Focusing on resilience might imply that the failure is on the individuals suffering from moral distress or injury rather than the institutional and structural constraints leading to these experiences.[13]

Consistent with existing literature on ethical challenges experienced by researchers,[23] participants in our study reported role conflicts, power imbalances and feelings of guilt. Guilt and shame have been described, alongside other emotions, as characteristic emotions of moral injury.[11,24] This suggests that these and other negative emotions should be further explored and addressed as, like healthcare professionals, researchers might be at risk of experiencing moral distress and, if not addressed in a timely way, suffer moral injury if they don't count with appropriate support to address the ethical challenges encountered during fieldwork. Participants acknowledged that existing codes of conduct and guidelines do not address the complexities of their experiences and challenges. Their accounts suggest that peer support and readily available ethics support might offer a more nuanced and contextualised

approach to dealing with these issues. Although limited, evidence suggests that clinical ethics support services can decrease healthcare workers' moral distress.[25,26] Perhaps, together with sound ethical approval and monitoring processes prior to commencing and throughout the research process, researchers working with vulnerable populations or researching sensitive topics should have access to some form of research ethics support to consult when experiencing complex ethical challenges. There is an ethical obligation to ensure that the moral distress that students in these settings experience does not progress to moral injury. Ethically responsible research not only focuses on the wellbeing of the participants, but also offers support to research students that are put in positions of moral distress and potential moral injury.

Lastly, although it is clear that moral support for researchers in these types of humanitarian settings is important, perhaps the experiences of moral injury underscore the urgent need for systemic change.

Despite arguably the novelty of this paper on moral distress among this type of researcher, our study certainly has limitations. Though diverse in academic background, the sample size does not fully represent the spectrum of experiences in paediatric humanitarian research. Additionally, the findings are context-specific to the European refugee camp setting and may not be generalisable to other contexts.

Conclusion

This analysis of support session transcripts provides an exploration of the ethical challenges in paediatric humanitarian research and their impact on the research team. The identified themes, such as participant benefit misconception and witnessing and moral responsibility, highlight the complexity of ethical decision-making and the need for a thoughtful and context-specific approach to navigate the ethical challenges of this field. Acknowledging these challenges is a crucial step towards building ethical research practices that prioritise the well-being of vulnerable paediatric populations in humanitarian settings, ensuring vital research to improve their health is conducted, and securing the well-being of researchers in this field.

Data availability

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

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This research was conducted without any external financial support.

Author contributions

HB conceived the original idea for this project; MD and JB facilitated the workshops, MD and HB analised the data. All authors revised it critically for important intellectual content and approved the final version for publication.

Ethics approval and consent to participate

Ethical clearance for this research project was obtained from the Medical Ethics Committee of the Greek National Public Health Organization (EODY). This was provided in December 2022 under Reference No. 23702/06–12-2022. This study was performed in line with the principles of the Declaration of Helsinki. Informed consent was obtained from all individual participants included in the study. Confidentiality and anonymity of participants were strictly maintained throughout the research process.

Competing interests

The authors declare no competing interests.

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CHAPTER SIX

Discussion and overall conclusion

This thesis aims to contribute to the understanding of the health of displaced children in temporary refugee settlements, specifically children living in the Closed and Controlled Access Center (CCAC) Mavrovouni on Lesvos in Greece. Children form 30% of the world population, yet 40% of all forcibly displaced are under eighteen.[1] Even though the refugee crisis worldwide is one of the biggest themes influencing public health,[2] there is little research done on the health status of children living in refugee camps on, for example, the borders of Europe. Choosing two important proxies of overall child health, we studied the nutritional status and the quality of life (QoL) of these children. Lastly, we investigated what specific ethical issues arise in this field of research. In this chapter, we summarize the key findings that are described in this thesis, compare them with the existing literature and give recommendations for future research.

At the outset, I would like to clearly acknowledge the ethically sensitive context in which this research was conducted. These children and their families are particularly vulnerable to unethical research practices because of their dependent position. The research team was very aware of the sensitive context and has done its utmost best to maintain ethical research practices to protect the participants.

To summarize the aims of this PhD thesis, which were described in the introduction chapter of this thesis, we aimed to capture the overall health status of displaced children in one of Europe's largest refugee camps. The ultimate purpose was to gain understanding about these children's well-being *in order to improve it*. This research was also intended as advocacy material and as a tool to enable change. There was no ulterior motive or gain elsewhere to perform this research. In fact, performing research in a large and controversial research camp has been incredibly challenging and simply would not have been possible without the strong support from our Greek collaborators and our shared motivation to improve the health and quality of life of these children.

Nature published research guidelines, named the TRUST code, to minimise helicopter research and ethics dumping.[3] The code is built around four core values: fairness, respect, care and honesty.[4] Given the complex research setting in CCAC Mavrovouni, the research team made every effort to uphold these ethical principles.

We aimed to protect and minimise burden to research participants, whilst embodying true equality and diversity in our academic collaborations. A few examples of how ethical practice was purposefully upheld in this PhD project:

1. Strong collaboration with Greek partners was cultivated and ensured:
   a. Research students and supervisors were from both Dutch as well as Greek Universities. They were involved from the research design phase through to the execution of the study.
   b. All local students and doctors who actively contributed to the research were purposefully included as co-authors on the relevant publications.
2. Permission from the Medical Ethical Research Committee of the National Greek Public Health Organisation was requested and formally granted.
3. Permission from the Ministry of Migration, ensuring protection of the refugee population, was requested and formally granted.
4. This PhD represents the first step in a long-term collaboration to improve the care for refugee children on an international level.
5. An effort was made to ensure citation diversity by including relevant research that was not widespread and by citing these papers accordingly.

Most important findings:

Nutritional status

Stunting

One of the main WHO Nutrition Targets is to reduce childhood stunting by 40%.[5] Our meta-analysis showed a pooled prevalence in stunting of 16% and our observational study showed a prevalence in stunting of 11%. Both percentages fall in the category 'medium' according to the WHO thresholds of public health significance. According to WHO, categories 'low/very-low' should be aimed at, meaning a prevalence of stunting below 10%.[6] Awareness of the prevalence of stunting in our study population contributes to the awareness and therefore hopefully reduction of stunting.

Our findings are not entirely consistent with other studies. The most relevant comparative publication is the one by Skinner et al.,[7] which is a systemic review on the prevalence of undernutrition among children living in refugee camps *across*

the globe. This review, the most comprehensive and recent published, covered 86 sites and included a total of 36,750 children.

The reported level of stunting amounted 23.8%, as compared to a prevalence in stunting 16% in our review and 11% in our observational study. Another study, looking at the nutritional challenges among African Refugee and Internally Displaced Children, included the nutritional status of 62,242 children. They found levels of stunting varying from 18.8% to 52.1%.[8] We did find lower levels of stunting, however, we must note that the a priori levels of stunting in other parts of the world are higher.[9] In interpreting these differences, we have to take into account that stunting, different from wasting, takes a long (years) time to develop. Our findings, with respect to stunting, may reflect the availability of food before the start of their journey. Another possible explanation may be that the most privileged children have the ability and financial capacity of fleeing conflict, therefore reflecting the group of children that were better off, from a nutrition perspective, in the first place. The crucial information that is still outstanding is how the nutritional status of children in refugee camps *develops overtime*, to compare to their original nutritional status before their travel, and to understand how the journey affects their nutritional status. This information is crucial to understand the impact of forced migration and residence in refugee camps on nutritional status. In our study on Lesvos, we aimed to gain insight in how nutritional status develops overtime in children during their stay in the camp. However, interpretation of our data was affected by the relatively short follow-up period and limited sample size.

Finally, from a prevention point of view, it is important to realise that stunting is a result of a multitude of factors, and often begins as early as in utero and may not always be reversible, interventions should be tailored to address the resulting compromised health, with a special focus on the first 1,000 days (including the period from conception until the age of 2).[9,10] As this period includes pregnancy, pregnant women on the move should be included in interventions.

Wasting

Amongst WHO Global Nutrition Targets, is the goal to reduce childhood wasting to under 5%.[11] Skinner's review showed that the level of global acute malnutrition, defined as a weight-for-height Z-score of < -2, was 7.1% as compared to 4.2% in our review and the highest, namely 10%, in our observational study. Levels of

wasting in the review on African displaced children varied from 0.04–29.3%.[8] Although the levels of wasting are, across all studies, below the levels of stunting, the percentages are still too high as most studies exceed WHO's goal of reduction under 5%.[11] This means that still too many children are exposed to i.e. increased risk of mortality, more infection, compromised neurodevelopment and other long-term health impairments.[12,13]

Acute malnutrition occurs due to a myriad of interconnected factors, of which the following could play a role in the relatively high prevalence of wasting in our study population.

The first factor could be that there is food insecurity, which leads to malnutrition in the *short* term. This food shortage could happen in the country of origin due to conflict, during the journey due to limited resources, and at arrival in the refugee camp in case food is distributed insufficiently and when caregivers solely depend on this resource. Secondly, displaced children are increasingly exposed to poor sanitation and chronic stress, also known contributors to the development of acute malnutrition. Lastly, there is decreased access to healthcare systems for displaced children, leading to a compromised health with its association with acute malnutrition.

Based on the prevalence of wasting that we found, ideally, displaced children arriving to Reception and Identification Centers should be screened for malnutrition. Assuming that our study sample is a representative sample, one in ten children arriving in CCAC Mavrovouni has moderate acute malnutrition and should be offered specific nutritional support. At minimum, all children should have access to their own food. Additionally, in case of moderate acute malnutrition (Z score weight for height between -2 and -3), these children should be offered supplements of approximately 75 kcal/kg/day and should be followed up until nutritional status improves.[14] This kind of nutritional support can be offered community-based and requires no hospitalization as long as there are no complications.

Overweight

In our observational study, the percentage of children being overweight was 13%, which exceeds the 'high' threshold for WHO public health significance.[6] High levels of overnutrition are reported among displaced children in *non-camp* settings

worldwide, as published by Khuri et al., where overall percentages of displaced children being overweight ranged between 9.1–65%. The high levels of overweight could be explained in different ways. Firstly, it could be caused by the shift from a traditional to a Westernized eating pattern, which is typically higher in calories, sugars and fats.[15] Secondly, reduced physical activity and physical stress might lead to weight gain.[16] Barriers that are prevalent in refugee camps could also include lack of safe spaces for play, limited access to recreational facilities, and increased screen time. Thirdly, the possibility that, as described above, the most privileged children have the ability and financial capacity of fleeing conflict, which are in some area's also the children with the highest percentage of overweight. Lastly, socioeconomic challenges in the new environment such as low income, food insecurity, and limited health literacy can lead families to choose inexpensive, energy-dense, and nutrient-poor foods, leading to overweight.[17]

Regardless of the explanation for these high levels of overweight, our findings underline the need for camp settings that enable physical activity. There should also be access to nutrient-dense foods that offer substantive nutritional value beyond mere caloric sufficiency.

General reflections

Although the findings are consistent, it is important to recognize that the children from Skinners review originate from diverse regions worldwide, including large samples from the African and South-East Asian Region, which may limit the comparability of the results. A systematic review on the nutritional indicators among children on the move, which included Internally Displaced People, refugees and migrants, showed that pooled prevalences of stunting vary greatly across regions.[18] Another noteworthy similarity among all these reviews including ours, was that there was great heterogeneity among the included studies, reflecting the diversity backgrounds where children originate form. An I^2 value reflects the heterogeneity in a study with a high value reflecting high heterogeneity. The I^2 in our literature review was 95% and 97% for stunting and wasting, respectively. In another review,[18] the I^2-value was larger than 90% for all nutritional indicators. In other words, global population exhibits substantial variation in stunting prevalence. Even within a single region, or country, the prevalence rates can differ markedly. As previously noted, it would be more insightful to track the nutritional

status trajectory of an individual child over time during a migratory journey. Additionally, one could hypothesize that only the wealthiest children possess the financial resources to migrate, children who rank among the best-nourished in their region.

More research exists on displaced children that are either internally displaced or live in non-camp settings. Even though this group is not a fair comparison to our study population because of the difference in living conditions and phase of their journey, these studies might come close to the reality of children in refugee camps, as they share risk factors for malnutrition such as poverty, food insecurity, limited access to healthcare and infectious diseases. They also do share pre-existing conditions that could lead to chronic malnutrition, such as exposure to violence and trauma, poor living conditions and low vaccine coverage due to conflict.[19]

However, there are a several reasons why these study population should not be compared. Firstly, refugee camps give rise to unique environmental risks for compromised nutritional health. There could e.g. be inconsistent access to food or clean water due to camp policy, as has been exampled in CCAC Mavrovouni.[20] The other important reason is that the measurements are done at another point in time during the journey of a refugee child. Literature suggests that different types of malnutrition exist during different phases in a refugee child's development.[21]

Unaccompanied minors (UAMs)

A particularly vulnerable group are the UAMs, children that travel without legal guardians.[22] Unaccompanied minors exist globally. Geographically, six routes in migration exist for UAMs and there is variance on what is known about UAMs depending on what route they travel:[23]

North Africa to Italy via Libya (Central Mediterranean route), Afghanistan, Syria, Iran to Serbia and Greece via Turkey (Balkan route), Central America to the USA via Mexico, Internal and cross-border displacement in the Horn of Africa, Internal and cross-border labour migration in Southeast Asia, Afghanistan, Bangladesh, Myanmar to Australia via Malaysia, Thailand, and Indonesia. They are especially vulnerable, both due to the situations that have left them unaccompanied (such as war and/or the loss of parents) and because they face additional risks when lacking the protection of close family members leading to negative

health effects on the short and the long term.[24] Accurate numbers of UAMs are missing.[25,26] UAMs are faced with various challenges such as human trafficking,[27] homelessness[28] and sexual and gender-bases violence.[29] With due caution due to our small sample size, we did find a high percentage of 31% of unaccompanied minors being stunted. A previous observational study on unaccompanied minors, a total of 63, in camp Moria showed a prevalence of 24% underweight based on BMI.[30] In this sample, 4.7% was overweight. There was no information reported on levels of stunting, but the levels of underweight do indicate a more compromised nutritional health in this susceptible group of children. It is important to repeat research on nutrition in this group of children to confirm accurate levels of malnutrition. If estimates are correct, the high levels of stunting could be attributed to additional health threats that unaccompanied displaced children experience. There might be early childhood malnutrition and potentially maternal malnutrition leading to early life nutritional deprivation. This nutritional status deficit plays a role in the overall vulnerability of unaccompanied refugee children, as described by Maioli in Figure 6.1. The exposure to stress and adverse conditions could also play a role.[31]

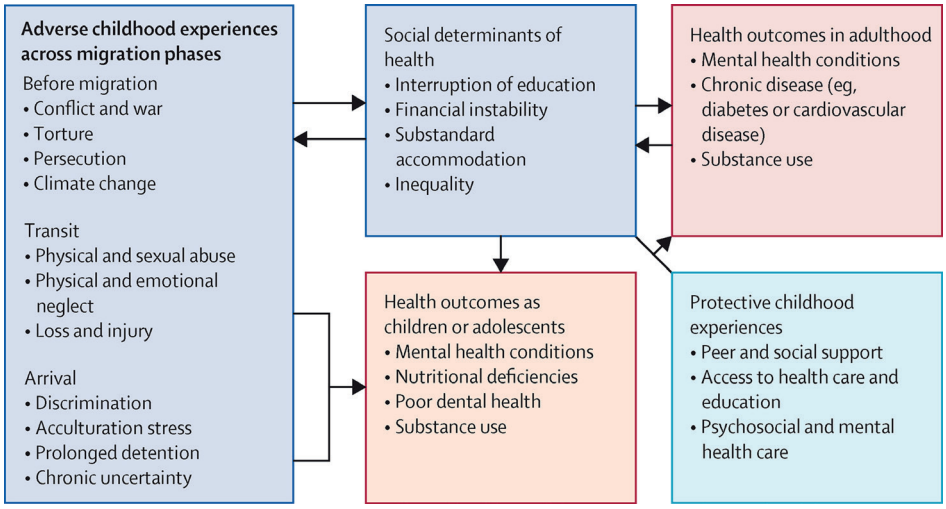


Figure 6.1: Intersection between adverse childhood experiences during migration and social determinants of health, and their long-term effect. Source: Maioli et al., International migration of unaccompanied minors: trends, health risks, and legal protection, The Lancet Child and Adolescent Health.

Future perspectives

Firstly, it is well established that, according to World Health Organization (WHO) standards, the nutritional status of displaced children is compromised. However, the existing literature provides limited insight into how nutritional status evolves over time and the extent to which health-related factors associated with forced migration influence nutritional outcomes. While there is a general understanding of the nutritional background of this population, a more thorough understanding of the progression of nutritional status would be valuable. Such knowledge could inform the development of targeted interventions aimed at improving the health and well-being of displaced children. At a minimum, nutritional status should be routinely assessed by a health professional when refugee children arrive in a new country or are relocated to a new permanent place of residence.

Secondly, it is important to further study groups that are underrepresented in scientific knowledge. UAMs represent a particularly vulnerable subgroup among displaced children, yet they are often challenging to include in research due to ethical considerations and concerns regarding informed consent and protection. Despite these challenges, the limited data available, including findings of this thesis, suggest that the nutritional status of UAMs is severely compromised. This group appears to face greater nutritional deficits compared to their accompanied peers, likely due to increased exposure to food insecurity, lack of adult support, and heightened psychosocial stress. The scarcity of robust data underscores the urgent need for ethically sound research methodologies that can more accurately assess and address the nutritional needs of unaccompanied minors. Nutritional status at arrival in a new country of new place of residence screening should be given particular attention in these children.

Thirdly, the awareness of nutritional deficiencies among displaced children should include overnutrition. Much literature on nutritional status in refugee camps only talks about levels of stunting and wasting, parameters highly relevant in child health. However, overnutrition remains an understudied aspect of nutritional status in this research population, with severe long-term complications if not approached in a right manner.

Quality of Life (QoL) among displaced children

It is broadly known that refugees and migrants experience higher rates of mental health issues, including depression, anxiety, PTSD, and suicide compared to host populations.[32] Numerous newspaper articles have documented the appalling living conditions experienced by individuals in the refugee camps on Lesbos.[33,34] Journalists consistently describe severe overcrowding, with camps such as Moria – originally designed for approximately 3,000 people, often accommodating four to seven times that number. News articles highlighted a severely compromised mental health of children living in this camp, with children attempting suicide.[35,36]

In our study, we carefully chose QoL as our health outcome as it identifies needs and outcomes relevant to the entire child refugee population, not just those with mental health problems. In addition, Quality of Life assessments capture everyday functioning. Displaced children may not develop diagnosable mental health disorders but may still experience significant challenges in daily life, such as difficulties in school, social relationships, or physical health. QoL assessment provides a more comprehensive picture of how children are coping and functioning in their environment.[37] Lastly, QoL captures positive aspects and resilience as part of the assessment in wellbeing, unlike in mental health.

Our study assessed the quality of life of 111 displaced children in Lesvos, Greece, revealing significantly worse outcomes across multiple PROMIS domains compared to normative U.S. data.[38] Specifically, children aged 1–4 years showed elevated Depressive Symptoms but relatively positive Peer Relationships, while children aged 5–18 years reported significantly higher levels of Anger, Anxiety, Depressive Symptoms, and Pain Behavior. Adolescents (8–18 years) also reported high scores for Meaning and Purpose. Strikingly, longer durations in the camp were associated with worsening quality of life – especially increased Anxiety and Depressive Symptoms, and lower Positive Affect.

Important to note is that our study provides a unique perspective. Firstly PROMIS QoL assessments have never been used in refugee camps before, offering a unique and solid way of measuring QoL in displaced children. Secondly, we have been able to describe the QoL of children as young as one year old. Most other studies use age groups of 12 years and above.[39-44] Because of the PROMIS tool, we have

been able to measure QoL in younger ages as well, in age groups where we found concerning level of impaired QoL.

There have been several studies suggesting that a *prolonged* stay in camp Moria, the camp prior to CCAC Mavrovouni, was associated with a worse mental health status in adults, both with qualitative studies,[45,46] as well as quantitatively.[47] One of the most striking findings in our observational study on QoL of children is that a prolonged stay in camp was significantly associated with a worse QoL on different domains, specifically on the domains Anxiety (higher score), Depressive Symptoms (higher score) and Positive Affect (lower score). Not only is their QoL worse than the control group, but the longer they are in camp, the worse their QoL is. This could initially be explained by the chronic exposure to adverse living conditions in a camp that is not built to be supportive environment for a developing child. However, it could also be that there is psychological coping initially, but that these coping mechanisms wear out over time.

Important to highlight is that in our study, the control group was an American control group. One could argue that this is an unfair comparison, however, this group included clinical patients, which suggests that our findings may actually be more unfavorable if the comparison group was solely the general population.

Future perspectives

It would be beneficial to understand what interventions have a positive effect on one more QoL domains of children living in camps such as CCAC Mavrovouni. An implementation study with specific psychosocial programs or physical health initiatives could give clarity on what supports QoL of these displaced children best.

Lastly but most importantly, our recommendation for future research is to emphasize that, while continued investigation is valuable and important, there is an urgent need to translate existing knowledge into *action*.

Extensive evidence already identifies the factors that support quality of life in children, including access to education, psychosocial support, health services, and protection from harm.

Children do not belong in refugee camps. Our evidence emphasizes that the duration of a child's stay in a camp should be minimized, with swift relocation to

a safe and stable environment. Furthermore, when children do reside in camps, policies should focus on improving shelter conditions, and to ensure access to education and social support, to minimize the negative impact on their QoL.

Ethical perspectives on research among displaced children

Moral injury arises when individuals experience emotional distress due to violations of their moral or ethical beliefs, a phenomenon underexplored among humanitarian researchers.[48] Our study investigates the ethical challenges and resulting moral injury faced by pediatric researchers working in the Mavrovouni refugee camp in Lesvos, Greece, using data from three ethics workshops analyzed through reflexive thematic analysis. The findings reveal seven key themes of ethical dilemmas and aim to inform support systems that foster healthier and more sustainable research practices in humanitarian contexts.

The key principles of medical ethics are Autonomy, Beneficence, Nonmaleficence, Justice.[49] In our perspective, our research findings lead to ethical concerns in most of these domains. It is questionable whether we indeed do no harm by letting children stay in temporary camps such as these for longer periods of time, as our research suggests that their QoL diminishes over time. Justice relates to the fair distribution of resources and care. The poor nutritional status and declining QoL among children raise concerns about whether resources are being allocated equitably and whether the needs of the most vulnerable are being prioritized. Ethical practice would be that children and pregnant women are prioritized in the provision of food resources. We underscore the need for humanitarian and health actors to prioritize interventions that prioritize children's right related to their health and overall wellbeing.

Aside from these rational perspectives, one could consider that moral distress is rather a guide than an inconvenience that we experience. In a world where human suffering is constantly broadcast and live-streamed, it becomes easy to grow desensitized and to suppress our emotional responses just to keep functioning. Yet, I believe it is precisely our moral compass that should alert us and guide us in these moments. We are called to respond to such situations with compassion and take meaningful action to alleviate the suffering of others. For this reason, ethical considerations must be at the heart of our humanitarian efforts, rather than being

treated as a secondary concern. The findings of our study on ethical perspectives in this kind of setting function as a kind of wake-up call for human rights that are being violated, rather than a purely scientific finding.

Overall conclusions

The health of displaced children is significantly compromised in several ways. Firstly, their nutritional status is neglected based on relatively high levels of wasting and overweight. Secondly, their QoL is low on several important domains, and our research shows that duration of stay in camp is significantly correlated with worsened QoL. Lastly, our research emphasizes the complexity regarding ethical issues when doing research with displaced children in such a challenging environment.

In conclusion and most importantly, future research should not only generate new insights but it should reinforce the imperative to act on what is already known. It demands that children's rights, dignity, and wellbeing are systematically prioritized and safeguarded in all policy planning and humanitarian responses.

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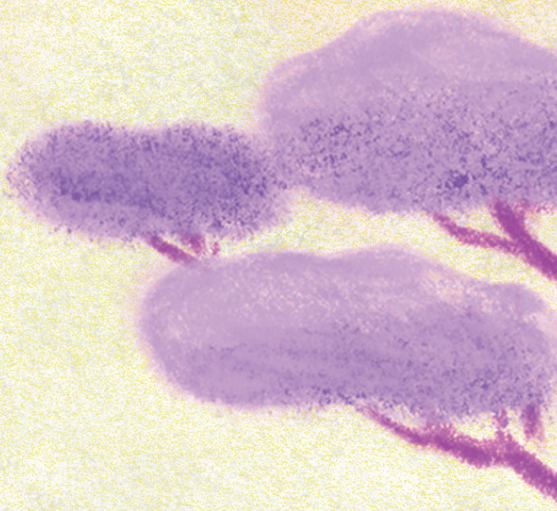
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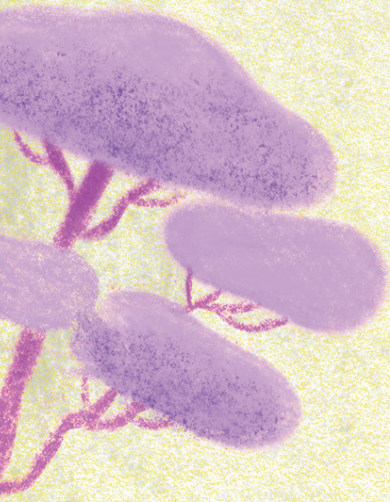




CHAPTER SEVEN



English summary



Main findings

In **Chapter 2**, we systematically reviewed the existing scientific knowledge on the nutritional status of displaced children that live in camps across Europe and the Middle East and North Africa (MENA) regions. From 1,385 identified studies, 12 were included, covering 7,009 children in 14 different refugee camps. Our meta-analysis showed a pooled prevalence of stunting at 16% and wasting at 4.2%, indicating a relatively high rate of chronic malnutrition but a low rate of acute malnutrition among these children.

In **Chapter 3**, we assessed the nutritional status of 304 displaced children aged 0–18 at the Closed Controlled Access Centre (CCAC) Mavrovouni refugee camp in Lesvos, Greece. We found that malnutrition is prevalent. In our research sample, 11% was overall stunted, 10% was wasted among children under five, 5% underweight, and notably 13% overweight, highlighting compromised nutritional status among this group of displaced children. Unaccompanied minors (UAMs) were especially vulnerable, with a significantly higher stunting prevalence of 31%. Our study observed no significant improvement in nutritional status during the children's stay in the camp. Breastfeeding showed a positive association with better weight-for-height scores, in children up to five years old.

In **Chapter 4**, we addressed the quality of life (QoL) of displaced children living in refugee settings on the Greek island of Lesvos, focusing on those in CCACs with caregivers and Unaccompanied Minors (UAMs) in shelters. Using the Patient-Reported Outcomes Measurement Information System (PROMIS) item banks, our study measured multiple QoL domains such as anxiety, depression, and cognitive functioning. The tools were adapted with interpreters to overcome language barriers. A total of 111 children (94 with caregivers and 17 UAMs) participated, showing worse scores in emotional and physical health domains compared to US norms, but surprisingly higher meaning and purpose, especially among UAMs. We found that a longer duration in camp was significantly associated with higher scores on Anxiety and Depressive Symptoms, and lower scores on Positive Affect.

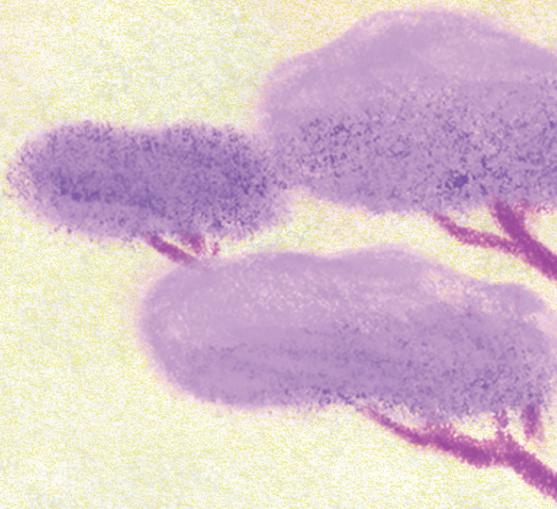
In **Chapter 5**, we explored the moral distress experienced by paediatric humanitarian researchers working in the Mavrovouni Closed Controlled Access Center in Lesvos, Greece. Through qualitative ethics workshops with researchers, our

study identified seven key themes reflecting the complex ethical dilemmas they face, which included community and system challenges, moral responsibility, conflicting duties, misconceptions about participant benefits, coping strategies, cultural factors, and theories of change. Our findings show that without proper support, researchers are at risk of moral distress, underscoring the need for dedicated support systems.

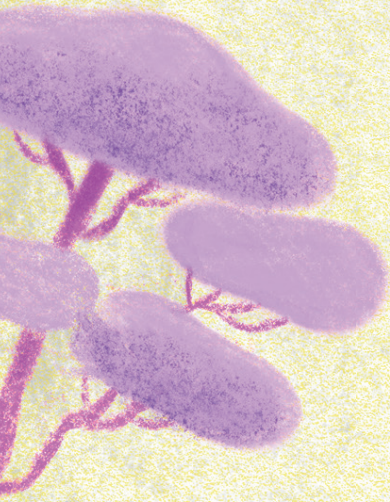




CHAPTER EIGHT



Nederlandse samenvatting



Belangrijkste bevindingen

In **hoofdstuk 2** hebben we systematisch de bestaande wetenschappelijke literatuur op een rij gezet over de voedingsstatus van vluchtelingenkinderen die in kampen wonen in Europa en de regio's Midden-Oosten en Noord-Afrika (MENA). Van de 1.385 geïdentificeerde studies werden er 12 geïncludeerd, die in totaal 7.009 kinderen in 14 verschillende vluchtelingenkampen omvatten. Onze meta-analyse toonde een prevalentie van chronische ondervoeding ('stunting') van 16% en acute ondervoeding ('wasting') van 4,2%, wat wijst op een relatief hoge mate van chronische ondervoeding, maar een lage mate van acute ondervoeding bij deze kinderen.

In **hoofdstuk 3** onderzochten we de voedingsstatus van 304 vluchtelingenkinderen van 0–18 jaar in het Closed Controlled Access Centre (CCAC) Mavrovouni-vluchtelingenkamp op Lesbos, Griekenland. We stelden vast dat acute ondervoeding veel voorkomt. In onze onderzoeksgroep was 11% chronisch ondervoed, 10% van de kinderen jonger dan vijf jaar leed aan acute ondervoeding, 5% had ondergewicht en opvallend genoeg was 13% te zwaar, wat wijst op een verstoorde voedingsstatus binnen deze groep kinderen. Alleenreizende minderjarigen (UAM's) waren bijzonder kwetsbaar, met een significant hoger percentage groeiachterstand van 31% tegenover 11% in de algemene groep kinderen. Onze studie liet geen significante verbetering van de voedingsstatus zien tijdens het verblijf van de kinderen in het kamp. Borstvoeding was positief geassocieerd met betere gewicht-voor-lengte-scores bij kinderen tot vijf jaar.

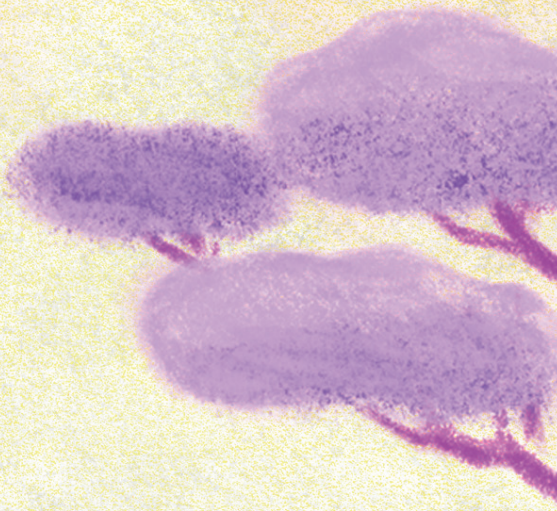
In **hoofdstuk 4** richtten we ons op de kwaliteit van leven (QoL) van kinderen die in vluchtelingenkampen op het Griekse eiland Lesbos wonen, met speciale aandacht voor kinderen in CCAC's met verzorgers en alleenreizende minderjarigen (UAM's) in opvanghuizen. Met behulp van de Patient-Reported Outcomes Measurement Information System (PROMIS) itembanken hebben we verschillende QoL-domeinen gemeten, zoals angst, depressie en cognitief functioneren. De vragenlijsten werden vertaald door tolken. In totaal namen 111 kinderen deel (94 met verzorgers en 17 UAM's), die slechter scoorden op emotionele en fysieke gezondheidsdomeinen vergeleken met Amerikaanse normen, maar verrassend genoeg een hoger gevoel van zingeving, vooral onder UAM's. We ontdekten dat een langere verblijfsduur in het kamp significant geassocieerd was met hogere scores op angst- en depressieve symptomen.

In **hoofdstuk 5** onderzochten we de morele stress die onderzoekers ervaren tijdens hun werk in het CCAC Mavrovouni. Via kwalitatieve ethische workshops met onderzoekers identificeerde onze studie zeven belangrijke thema's die de complexe ethische dilemma's weerspiegelen waarmee zij worden geconfronteerd, waaronder uitdagingen op gemeenschaps- en systeemniveau, morele verantwoordelijkheid, conflicterende plichten, misvattingen over voordelen voor deelnemers, copingstrategieën, culturele factoren en veranderingsmodellen. Onze bevindingen tonen aan dat onderzoekers zonder adequate ondersteuning risico lopen op morele schade, wat het belang van speciale ondersteuningssystemen onderstreept.

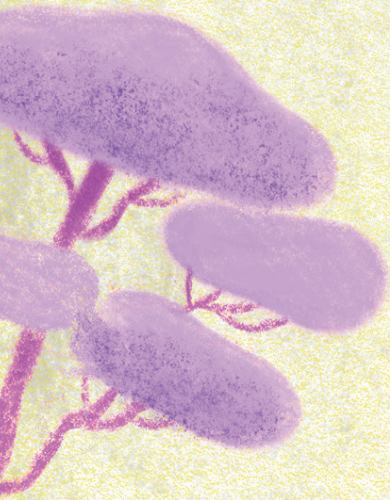




APPENDICES



Co-author affiliations
PhD portfolio
List of publications
About the author
Dankwoord



Authors and affiliations

Joe Brierley | Consultant Paediatric Intensive Care - Director of Bioethics Great Ormond St Hospital (GOSH) for Sick Children, London

Michaël Boele van Hensbroek | Paediatrician and pediatric infectious disease specialist and Head of the Centre for Global Child Health Amsterdam

Mariana Dittborn | Researcher at Paediatric Bioethics Centre, London

Kirsten de Groote | MSc Medicine student and MSc Global Health graduate

Jonne Feitsma | Medical doctor at Utrecht University

Mariken Gruppen | Pediatrician and Rheumatologist at Emma Children's Hospital

Molly Hirst | MSc in science of Bioethics at Harvard Medical School

Zoi Livaditou | Medical Doctor, Kapodistrian University of Athens

Morgan McKnight | Master of Public Health, VU University Amsterdam

Derre Kwee | Master of Medicine, University of Amsterdam

Martijn van der Kuip | Paediatrician and pediatric infectious disease specialist at Emma Children's Hospital, Amsterdam

Lotte Haverman | Head of the research group and clinical pediatric psychologist of the psychosocial department at the Emma Children's Hospital

Marceline Tutu van Furth | Paediatrician and pediatric infectious disease specialist at Emma Children's Hospital, Amsterdam

Lorynn Teela | Coordinator KLIK PROM portal at Emma Children's Hospital

Agis Terzidis | Paediatrician, General Secretary of the board of directors of the Doctors of the World, Greece and head of Master's Program Global Health - Disaster Medicine at Kapodistrian University of Athens

PhD portfolio

PhD student: Hanaâ Benjeddi-Talhi
PhD period: January 2020 – November 2025
PhD supervisors: Prof. dr. M. Boele van Hensbroek and prof. dr. A.M. Tutu – van Furth
PhD co-supervisors: Dr. M. van der Kuip and M. Gruppen

Course	Site	CATS[1]
Basic Epidemiology	LSHTM	10
Basic Statistics for Public Health & Policy	LSHTM	10
Issues in Public Health	LSHTM	10
Principles of Social Research	LSHTM	10
Population, Poverty and Environment	LSHTM	10
Foundations for Health Promotion	LSHTM	10
Ethics, Public Health & Human Rights	LSHTM	15
Current Issues in Maternal and Neonatal Health	LSHTM	15
Approaches to Health Promotion	LSHTM	15
Research Integrity	AUMC	2 ECTS

[1] CATS is the UK's system, with each credit representing 10 hours of work.

Daily supervision of student	Thesis	University
Derre Kwee, BSc Medicine	Health status of displaced and refugee children living in temporary settlements, a systematic review	University of Amsterdam
Daniëlle Konte, BSc Medicine	Quality of Life Measurement Tools for Children Living in Refugee Camps: A Critical Appraisal and Overview of Published Literature	University of Amsterdam
Jonne Feitsma, MSc Medicine	The quality of life of refugee children at Lesvos, Greece	Utrecht University
Morgan McKnight, MSc Global Health	Nurturing Hope Amidst Adversity: Assessing the Quality of Life of Refugee Children in Refugee Camp	Vrije Universiteit Amsterdam
Eva Feijt, MSc Global Health	Unveiling the nutritional challenges of refugee children in greece: insights from parents/guardians living in camp Mavrovouni, Lesbos	Vrije Universiteit Amsterdam
Arte Groenewegen, MSc Medicine	Nutritional status of refugee children in relation to psychosocial health and their duration of residence in CCAC Mavrovouni, Lesvos, Greece	Utrecht University

Daily supervision of student	Thesis	University
Sam Post, MSc Medicine	The nutritional status upon arrival of refugee children at RIC Mavrovouni, Lesvos, Greece	University of Amsterdam
Eirini Samiotaki, MSc Humanitarian and Disaster Management	Breastfeeding and migration: the process of breastfeeding in a crisis situation, the conditions that promote it and the obstacles that breastfeeding mothers face in the Greek refugee camp in Lesvos	Kapodistrian University of Athens
Embla Egen, MSc Global Health	Child Nutrition and Breastfeeding in camp Mavrovouni	Vrije Universiteit Amsterdam
Zoë Tzagkaraki	Systematic review and meta-analysis on the prevalence of malnutrition in unaccompanied refugee minors	Vrije Universiteit Amsterdam

List of publications

This thesis

Benjeddi H, Kwee D, Gruppen M, van der Kuip M, van Hensbroek MB, Furth MT. Nutritional status of refugee children living in temporary settlements in Europe and MENA region: a systematic review and meta-analysis. Eur J Pediatr. 2023 Aug;182(8):3397-3404. doi: 10.1007/s00431-023-04999-x. Epub 2023 May 23. PMID: 37219629; PMCID: PMC10460366.

Benjeddi H, de Groote K, McKnight M, Feitsma J, Gruppen M, Livaditou Z, Teela L, Terzidis A, van Hensbroek MB, van der Kuip M, van Furth MT, Haverman L. Assessing quality of life in displaced children on Lesvos using PROMIS: a mixed methods study. Qual Life Res. 2026 Jan 9;35(2):30. doi: 10.1007/s11136-025-04100-z. PMID: 41511561; PMCID: PMC12789238.

Benjeddi H, Dittborn M, Hirst M, Terzidis A, van der Kuip M, Gruppen M, Brierley J. Exploring moral distress in research students in a paediatric humanitarian research setting: a qualitative study from the Mavrovouni closed controlled access center, Lesvos, Greece. BMC Med Ethics. 2026 Jan 9;27(1):17. doi: 10.1186/s12910-025-01356-5. PMID: 41514254; PMCID: PMC12882611.

Benjeddi H, Gruppen MP, Post SA, Groenewegen AD, Egen EBK, Samiotaki E Logotheti, Livaditou Z, Voskuijl WP, Tutu-van Furth AM, Boele van Hensbroek M, Terzidis A, van der Kuip M. Nutritional status of displaced children including unaccompanied minors on Lesvos, Greece. Journal of Migration and Health. 2026, 13, 100393. doi: 10.1016/j.jmh.2025.100393

About the author

Hanaâ was born on 9 December 1990 in Amsterdam Zuid-Oost, the Netherlands. Hanaâ is the middle child of three, born to two parents who are primary school teachers. She attended the Oostvaarders College, completing her gymnasium education cum laude. During her secondary school years, she was an active participant in the Model United Nations in The Hague, where her passion for international collaboration and global health first started.

In 2008, Hanaâ went on to study Medicine at the Vrije Universiteit in Amsterdam, where she was admitted to the honours program. As the recipient of the ECHO Zorg Award, she had the opportunity to spend a summer at the University of Los Angeles, studying East-West Medicine and the Philosophy of Metaphysics. Her surgical clerkship took her to Paarl Hospital in South Africa. She completed an internship at the World Health Organization headquarters in Geneva.

Throughout her studies, Hanaâ was highly involved with the International Federation of Medical Students Associations (IFMSA). She served not only as President of IFMSA VUmc, but also as a national training coordinator. She was the founder of Humans of Health, a platform dedicated to the personal development of medical students worldwide. Through this initiative, together with fellow students she organized four editions of the Healthcare Leadership Summer School, held in the Netherlands, Portugal, the United States, and South Africa. These events gathered medical students from all corners of the world.

In 2015, she started her first job as ANIOS Paediatrics at the Flevoziekenhuis in Almere. In 2016, Hanaâ moved to London for a year to pursue a Master's in Public Health at the London School of Hygiene and Tropical Medicine. During this year, she also volunteered with the medical mission of Stichting Bootvluchteling on Lesbos, gaining invaluable experience in humanitarian medical care.

In 2018, she began her pediatric residency at the Emma Children's Hospital, during which she also spent four months on Lesbos as a medical coordinator for Boat Refugee Foundation. Motivated by her experiences, she initiated her PhD project to map and improve the health of refugee children on Lesbos, the results of which are presented in this thesis. After completing a clinical rotation in pediatric intensive

care at Great Ormond Street Hospital in London, Hanaâ began her fellowship in pediatric intensive care at the Emma Children's Hospital.

Hanaâ is happily married to Yassir. Together with their two children, Noah and Reem, they live in Bussum.

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en ik hoop dat ons onderzoek werkelijk een verschil zal maken voor de mensen die het nodig hebben.

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شكرا لك يا جدتي العزيزة

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