Health and Healthcare Access and Utilization Among Syrian Refugees Migrating to Norway

A Longitudinal Study

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1. Contents

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2. Scientific environment

This research was carried out between 2017 and 2021 at the Department of Global Public Health and Primary Care, University of Bergen. This thesis is part of the CHART-project (Changing Health and healthcare needs Along the Syrian Refugees' Trajectories to Norway) and was initiated by my main supervisor, Professor Esperanza Diaz. During the course of this PhD thesis, I have been a member of NAFALM (the Norwegian Research School in General Practice) and the Health Promotion, Migration and Health (HEMIX) research group.

Funding for this research was initially provided by the Norwegian Medical Association (Legeforeningen) with a three-month grant while I was working as a medical doctor in a refugee health clinic and thereafter by the Research Council of Norway (NFR) with a three-year PhD grant.

The main supervisor of this thesis is Professor Esperanza Diaz at the Department of Global Public Health and Primary Care, Faculty of Medicine, University of Bergen. The co-supervisors are Professor Bernadette Kumar at the Unit for Migration and Health, Norwegian Institute of Public Health, and Associate Professor Eirik Abildsnes, Department of Psychosocial Health, University of Agder.

Two other PhD candidates, Elisabeth Marie Strømme and Wegdan Hasha, have been affiliated with the CHART research project during the study period.

3. Acknowledgements

4. Abbreviations

CHART	Changing Health and healthcare needs Along the Syrian Refugees' Trajectories to Norway
CI	Confidence Interval
DAG	Directed Acyclic Graph
EC	Emergency Care
ESSI	ENRICHD Social Support Instrument
GEE	Generalized Estimating Equation
GP	General Practitioner
GSMERH	The Global Society on Migration, Ethnicity, Race and Health
HUNT	Nord-Trøndelag Health Study
IMDI	The Directorate of Integration and Diversity
IOM	International Organization for Migration
MERH	The Global Society on Migration, Ethnicity, Race and Health
NGO	Non-Governmental Organization
NORCO	Norwegian Cultural Orientation Programme
RR	Risk Ratio
SGTI	Single General Trauma Item
SILS	Single Item Literacy Screener
SRH	Self-rated Health
SD	Standard Deviation
QoL	Quality of Life
UN	United Nations
UNHCR	United Nations High Commissioner for Refugees
WHO	World Health Organization

5. Abstract

5.1 Abstract in English

Background: An unprecedented number of people are on the move today and the health of refugees has become a vital global public health concern. During the migration process, refugees move from one environment to another and can face multiple healthcare challenges along their journey. Yet, how the migration process and the changing risk and protective factors influence refugee health and their use of healthcare services remains poorly understood.

Objective: The overarching objective of this thesis is to explore, describe and analyse (a) the changes in health, Quality of Life and use of healthcare services among Syrian refugees migrating to Norway and (b) the association between these changes and sociodemographic and migration-related factors.

Methods: This thesis is part of the *Changing Health and healthcare needs Along the Syrian Refugees' Trajectories to Norway* (CHART) project. Both quantitative and qualitative methods were used to answer the objective of this thesis. In the quantitative part of the study (papers I and II), a prospective longitudinal design was used. Data were collected among adult Syrian refugees accepted for resettlement to Norway through a self-administered questionnaire repeated at two-time points. The first assessment was conducted pre-arrival in Lebanon in 2017–2018 and the second assessment after one year of resettlement in Norway. Primary outcomes were Self-rated Health (SRH), Quality of Life (QoL) and use of healthcare services (general practitioner [GP], emergency care [EC], outpatient/specialist care and hospitalization). In the qualitative part of the study (paper III), 15 individual interviews were conducted with adult Syrian refugees to capture their experiences in terms of changes in their own health and use of healthcare services after arriving in Norway.

Results: In the quantitative part of the study, 506 Syrians participated in Lebanon and 353 in the follow-up one year later in Norway. In paper I, we found that the percentage of participants reporting good SRH showed a non-significant increase from 58% to 63% from Lebanon to Norway, while mean values of QoL increased significantly. Positive effect modifiers for improvement in SRH and QoL over time included male gender, younger age, low level of social support and lack of residence permit in Lebanon. In paper II, we found that the use of GP and EC increased after resettlement while outpatient/specialist care dropped markedly, and hospitalization rates remained the same. Lack of residence permit and poor SRH prior to resettlement were identified as predictors for the use of healthcare after arrival. After resettlement, higher health literacy, higher education, higher social support and poor SRH and QoL were significantly associated with the use of healthcare services. In paper III, we found that the perceived causes of change in health status seem to be related to the resettlement phase with clear gender differences in the resettlement experience and its impact on health. Participants' perceptions of the caregiver, communication and consultation/interaction time were identified as key factors in the care-access journey in inspiring trust or distrust in the caregiver. A model was developed - The Migrant Sensitive Access Model - to address some of the challenges that came to light from our participants' experiences.

Conclusion: Stability and improvement in health and QoL are the most prominent findings of this thesis, indicating strong resourcefulness and adaptability among the studied group, a prerequisite for successful integration. Likewise, this study confirms that both pre- and post-migration factors have an impact on the health and health service use of refugees and underscore that a combination of migration and a social determinant of health approach is necessary for addressing inequities in health and healthcare access. Awareness should be raised of the most disadvantaged refugees with low social support, low education and poor health literacy who may be more susceptible to health disparities by poorer access to healthcare. Despite universal health coverage after resettlement, access barriers and unmet health needs were

revealed. To enhance healthcare access, efforts should be made to increase trust in the healthcare system and its caregivers. Further, this thesis substantiates that a responsive resettlement process may have important positive health implications and calls for resettlement countries to provide adequate supportive resources upon arrival for all subcategories of forced migrants.

5.2 Abstract in Norwegian

Bakgrunn: Mange mennesker er i dag drevet på flukt, og flyktningers helse har blitt et viktig globalt folkehelseproblem. Under migrasjonsprosessen opplever flyktningene endringer i omgivelser og i livssituasjon. Helsen deres kan under flukt påvirkes av en rekke ulike eksponeringer. Likevel foreligger det i dag lite kunnskap om hvordan migrasjonsprosessen påvirker flyktningers helse, og hvordan de gjennom denne prosessen benytter og opplever bruk av helsetjenester.

Mål: Det overordnede målet med denne avhandlingen er å utforske, beskrive og analysere (a) endringer i helse, livskvalitet og bruk av helsetjenester blant syriske flyktninger som migrerer til Norge og (b) sammenhengen mellom disse endringene og sosiodemografiske og migrasjonsrelaterte faktorer.

Metoder: Avhandlingen er en del av prosjektet *Changing Health and Healthcare Needs Along the Syrian Refugees' Trajectories to Norway* (CHART). Både kvantitative og kvalitative metoder ble brukt for å besvare avhandlingens forskningsspørsmål. Den kvantitative delen av studien (artikkel I og II) benytter et langsgående design med bruk av spørreskjema. Data ble samlet inn fra voksne syriske kvoteflyktninger som hadde fått innvilget bosetting i Norge. Spørsmålene var primært knyttet til egenvurdert helse (SRH), livskvalitet (QoL) og bruk av helsetjenester (fastlege, akuttmottak, poliklinisk/spesialistbehandling og sykehusinnleggelse). Spørreundersøkelsen ble gjennomført to ganger: Første gang før ankomst til Norge, i Libanon fra 2017 til 2018, og deretter etter ett års bosetting i Norge.

I den kvalitative delen av studien (artikkel III) ble det utført 15 individuelle intervjuer med voksne syriske flyktninger for å få mer dybdekunnskap om deres erfaringer med endringer i egen helse og bruk av helsetjenester etter ankomst til Norge.

Resultater: I den kvantitative delen av studien deltok 506 syrere i Libanon og 353 i oppfølgingen ett år senere i Norge. Funn fra artikkel I viser at andelen deltakere som rapporterte om god SRH viste en ikke-signifikant økning fra 58% til 63% fra de var i Libanon til de kom til Norge. Gjennomsnittsverdiene for egenvurdert livskvalitet (QoL) økte betydelig mellom de to undersøkelsestidspunktene. Å være mann, ha yngre alder, lav sosial støtte, eller mangel på oppholdstillatelse i Libanon var alle positive effektmodifikatorer for forbedring av SRH og QoL over tid.

Funn fra artikkel II viser at bruk av fastlege og legevakt økte etter ankomst til Norge, mens poliklinisk/spesialistbehandling falt markert. Sykehusinnleggelse var den samme. Mangel på oppholdstillatelse og dårlig SRH før ankomst ble identifisert som prediktorer for bruk av helsetjenester etter ankomst. Dertil var høy helsekompetanse, høy utdanning, høy sosial støtte og dårlig SRH og QoL signifikant forbundet med bruk av helsetjenester etter ankomst.

Funn fra artikkel III indikerer at flyktningene opplevde at årsakene til endring i helsestatus var relatert til bosetningsfasen med forskjellige utfordringer avhengig av tid etter ankomst. Beskrivelser av hva som påvirker egen helse under og etter migrasjon viste også en tydelig kjønnsforskjell. Deltakernes oppfatning av helsearbeideren, kommunikasjon og tid under konsultasjon ble identifisert som sentrale faktorer for å oppnå tillit til eller forårsake mistillit overfor helsearbeideren. En modell kalt The Migrant Sensitive Access Model ble utviklet for å beskrive noen av utfordringene som kom fram fra deltakernes erfaringer.

Konklusjon: Stabilitet og forbedring av helse og QoL er de mest fremtredende funnene i denne avhandling. Dette indikerer en sterk motstandsdyktighet og tilpasningsevne blant deltakerne, noe som er en forutsetning for vellykket integrering.

I tillegg viser avhandlingen at både faktorer før og etter migrasjon påvirker flyktningers helse og bruk av helsetjenester. Funnene indikerer at en tilnærming som belyser sammenhengen mellom migrasjon og sosiale helseforskjeller er nødvendig for å få bedre kunnskap om ulikheter innen helse og tilgang til helsetjenester. Det er behov for økt bevissthet om helsesituasjonen til de mest vanskeligstilte flyktningene som har lav sosial støtte, lav utdanning og dårlig helsekompetanse ettersom disse kan ha større risiko for å få eller ha helseutfordringer, og ha dårligere tilgang til helsetjenester. Til tross for at flyktningene får universell helsedekning etter bosetting i Norge, viser avhandlingen at de møter hindringer for å kunne ta i bruk helsetjenester og at de har umøtte helsebehov. For å forbedre tilgangen til helsehjelp for denne målgruppen bør det gjøres satsinger på å øke tilliten deres til helsevesen og helsepersonell. Videre får funnene fra avhandlingen fram at en støttende og rask bosettingsprosess kan ha viktige positive implikasjoner på helse. Dette fremhever viktigheten av at mottaksland gir tilstrekkelige støttende ressurser ved ankomst for alle kategorier av flyktninger.

5.3 Abstract in Arabic

ملخص الدراسة

الخلفية:

لقد باتت ظاهرة هجرة اللاجئين وبأعداد غير مسبوقة تشكل مصدر قلق حيوي على الصحة العامة العالمية خلال الآونة الأخيرة. يتمثّل مصدر هذا القلق في أن هؤلاء الأفراد إنما ينتقلون خلال هذه الهجرة من مجموعة عوامل خطر صحية إلى أخرى وهذا بدوره يعرضهم الى مواجهة تحديات رعاية صحية متعددة خلال هذه الرحلة. كيف تؤثر عوامل الخطر المتغيرة هذه على صحة اللاجئ, وماهي خدمات الرعاية الصحية الواجب على مجتمعات التوطين توفيرها له لا يزال غير مفهوم بشكل دقيق حتى الآن.

الهدف:

الهدف الشامل لهذه الدراسة يتركز حول هو إستكشاف ووصف وتحليل:

أ ـ التغيرات في صحة وجودة الحياة لدى اللاجئين السوريين المهاجرين إلى النرويج وكذلك مدى استخدامهم لخدمات الرعاية الصحية المتوفرة لهم في النرويج.

ب ـ الإرتباط بين هذه التغييرات والعوامل الاجتماعية والديموغرافية ومسببات الهجرة.

منهاج البحث:

لقد تم استخدام البيانات الكمية والنوعية للإجابة على هدف هذه الدراسة. في الجزء الكمي من الدراسة (الورقة الأولى والثانية), استخدمنا اسلوب المراقبة الطويلة والتي اعتمدت على الملاحظة المتكررة لتأثير عوامل ومتغيرات مختارة خلال فترة زمنية طويلة نسبياً إمتدت لما زاد عن العام.

لقد قمنا بجمع البيانات بين اللاجئين السوريين البالغين الذين تم قبولهم للتوطين في النرويج وذلك من خلال استبيان تم إجراؤه ذاتياً بما في ذلك التقييمات الذاتية التي تكررت خلال فترتين زمنيتين محددتين. تم إجراء التقييم الأول في لبنان في الفترة 2017-2018 والثاني بعد عام واحد من إعادة التوطين في النرويج. لقد اشتملت النتائج الأولية على الدراسات المتعلقة بالمواضيع التالية: الصحة الذاتية (SRH) ، جودة الحياة (QoL) ، استخدام خدمات الرعاية الصحية والتي تشتمل على خدمات الطبيب العام (GP)، خدمات الرعاية الطارئة (EC)، إضافة الى خدمات الرعاية المتخصصة، والخدمات المشفاياتية (الإقامة في المشفى).

في الجزء النوعي من الدراسة (الورقة الثالثة)، أجرينا 15 مقابلة فردية مع لاجئين سوريين بالغين وذلك من اجل التقاط تجاربهم المتعلقة بالتغييرات التي طرأت على صحتهم بعد وصولهم الى النرويج واستخدامهم خدمات الرعاية الصحية التي قُدمت لهم.

النتائج :

في الجزء الكمي من الدراسة، شارك 506 لاجئا سورياً في لبنان و 353 لاجئا في المتابعة بعد عام واحد من وصولهم الى النرويج. في الورقة الأولى، وجدنا أن النسبة المئوية للمشاركين الذين أبلغوا عن ان صحتهم (SRH) جيدة أظهرت زيادة غير ملحوظة وذلك من 58% إلى 63% فيما بين لبنان والنرويج، بينما زادت وبشكل ملحوظ القيمة الوسطية المتعلقة بمكونات جودة الحياة (QoL). لقد شملت معدلات التأثير الإيجابي لتحسن الصحة (SRH) وجودة الحياة (QoL) مع مرور الوقت الفئات التالية: جنس الذكور، الفئات ذات العمر الأصغر، الفئات ذات الدعم الاجتماعي المنخفض، والفئات التي لم يوجد لديها تصاريح إقامة في بلد العبور. في الورقة الثانية وجدنا أنه وبعد التوطين، ازدياد في خدمات الطبيب العام (GP)، وخدمات الرعاية الطارئة (EC)، بينما وجدنا انخفاض وبشكل ملحوظ في معدلات خدمات الرعاية الصحية التخصصية، في حين بقيت الرعاية الصحية المشفاياتية على نفس المعدل .

قبل التوطين: إن عدم وجود تصاريح إقامة لدى المهاجر في بلد العبور، بالإضافة إلى تدني المستوى الصحي لديه، تم تشخيصه في هذه الدراسة على أنه مؤشر على تلك الرعاية الصحية التي احتاج اليها اللاجئ بعد وصوله الى بلد التوطين. بعد إعادة التوطين: إن ارتفاع الوعي الصحي لدى اللاجئ وارتفاع مستوى التعليم العالي لديه والدعم الاجتماعي المرتفع وانخفاض في مستوى الصحة وجودة الحياة إنما هي عوامل لها ارتباط وبشكل كبير في الحاجة الى خدمات الرعاية الصحية. في الورقة الثالثة، وجدنا أن الأسباب المتصورة للتغيير في الحالة الصحية كانت مرتبطة بمرحلة إعادة التوطين والجنس (ذكر/انثى). لقد تم تشخيص التصورات التي كانت لدى اللاجئ حول الجهه المقدمة للرعاية الصحية وطبيعة التواصل معها وكذلك الوقت، على أنها عوامل مفتاحية في مسألة وجود الثقة أو عدمها في مقدم الرعاية الصحية. لقد قمنا

بتطوير نموذج لمعالجة بعض التحديات التي ظهرت للضوء من خلال تجارب هؤلاء المشاركين؛ إنه النموذج الذي من شأنه المساعدة في بناء علاقة ذات موثوقية بين الجهة المقدمة للرعاية الصحية وطالب الرعاية.

الخلاصة :

يعتبر الاستقرار والتحسن في الصحة (SRH) وكذلك في جودة الحياة (QoL) من أبرز نتائج هذه الدراسة، مما يشير إلى أن سعة الحيلة والقدرة على التكيف لدى المجموعات المدروسة، هو شرط أساسي للاندماج الفعّال والناجح في المجتمع. وبالمثل، تؤكد هذه الدراسة أن كلاً من عوامل ما قبل الهجرة وما بعدها كان لها تأثير على الصحة وخدمات الرعاية الصحية المقدمة للاجئين. لقد أكدت الدراسة أن المزج بين الهجرة والمحدد الإجتماعي للمنهج الصحي ضروري في معالجة أوجه عدم المساواة بين الصحة والرعاية الصحية. يجب رفع مستوى الوعي لدى اللاجئين الأكثر حرماناً والذين يحظون بدعم إجتماعي منخفض، وتعليم منخفض، وأمية صحية ضعيفة والذين قد يكونون أكثر عرضة لعدم المساواة في الرعاية الصحية بسبب ضعف الوصول إلى هذه الرعاية.

على الرغم من توفر التغطية الصحية الشاملة بعد إعادة التوطين، تم الكشف عن وجود حواجز وإحتياجات صحية غير ملباة. لتعزيز الوصول إلى الرعاية الصحية، ينبغي بذل الجهود لزيادة الثقة في نظام الرعاية الصحية ومقدمي الرعاية. علاوة على ذلك، فإن هذه الدراسة اظهرت أن عملية إعادة التوطين سريعة الاستجابة قد يكون لها آثار صحية مهمة، و وعلى هذه فإن بلدان إعادة التوطين مدعوة إلى توفير موارد داعمة وكافية من أجل الوصول لجميع الفئات الفرعية للمهاجرين قسراً.

6. List of Publications

Haj-Younes J, Strømme EM, Igland J, Kumar B, Abildsnes E, Hasha W, Diaz E.
   Changes in self-rated health and quality of life among Syrian refugees
   migrating to Norway: a prospective longitudinal study. Int J Equity Health.
   2020 Oct 27;19(1):188. **(Paper I)**

Haj-Younes J, Strømme EM, Igland J, Kumar B, Abildsnes E, Hasha W, Diaz E. Use
   of health care services among Syrian refugees migrating to Norway: a
   prospective longitudinal study. BMC Health Serv Res 21, 572 (2021). **(Paper
   II)**

Haj-Younes J, Abildsnes E, Kumar B, Diaz E. The road to equitable healthcare: A
   qualitative study on the health experiences of Syrian refugees in Norway.
   Under revision in Social Science and Medicine. **(Paper III)**

7. Introduction

In Syria, I used to be a lawyer; I even had my own law firm. When the war broke out, I did not want to leave Syria, but we had reached a point where we begged for food to survive. I was ashamed…I am not a beggar. Fearing for our lives, my family and I managed to escape to Lebanon. In Lebanon, we were at least safe even though we faced some tough years, living as second-class citizens with no formal rights. We faced difficulties accessing basic healthcare, my wife was pregnant and we lived with the constant worry of what the future would bring. Everything changed when my family and I were accepted for resettlement to Norway. I thank God for my good fortune. When I first arrived in Norway, I did not know anything about Norwegian society but I got a lot of help from others. I did not know how to access healthcare; I felt ashamed and helpless. My friend, who is good at Norwegian, helped me a lot; I probably would not have managed without him. My health has changed since I arrived here; I have gained weight and stay at home a lot. Sometimes I feel depressed. I wish I could go out to work.

- *A Syrian refugee in Norway (April 2020)*

Figure 1. *Art by Palestinian-Syrian artist Imad Alwahibi, with permission from the artist.*

This short vignette of the life of a Syrian refugee in Norway highlights the many layered aspects to a migration trajectory which can affect almost all parts of life, physical and mental health, and social relationships. At every stage of the migration journey, unique experiences act as potential health exposures: from the pre-migration stage in the midst of conflict and war to living in limbo in a transit setting to starting a new life after resettlement in the host country. It also gives an insight into the challenges migrants experience when accessing and utilizing healthcare throughout the migratory path with barriers to care at several levels, from the legal barriers in transit to the non-legal barriers after resettlement. The vignette raises many unanswered questions in the field of migration and health: What is the status of migration factors as health determinants? To what degree does health change with migration? How should we address the issue of migration and health in a 21st-century global society? Likewise, the vignette also points to the importance of understanding the factors that counterbalance the health exposures of migrants, such as the inherent resilient factors which act as protective barriers at an individual level and the responsive policies and healthcare systems of the receiving countries at meso and macro levels. The end of the vignette clearly shows how challenging integration into host societies is and how it can result in negative health outcomes, thus linking refugee health with the effects of non-health policies (1).

The study of migration and health can be justified using several arguments. For me, the most central among these is the ethical argument that views health as a fundamental human right (2). The right to the *highest attainable standard of health* as enshrined in the Constitution of the World Health Organization (WHO) as well as the clarion call of the 2030 Agenda for Sustainable Development to *leave no one behind* highlight these views (3). Governments and states are obliged to secure these rights under international convention. Another crucial argument rationalizing the importance of studying refugee and migrant health is the public health argument. Living amid the COVID-19 pandemic, the public health argument becomes even more evident than before. We can now clearly witness what happens when

subpopulations of society are not meaningfully included in public health planning and the impact that has on the rest of society. The public health argument also points to the interdependence of migrant health and public health, where the health of migrants has become a public health goal (4). Lastly, the economic argument lifts the importance of viewing migrant's health as resources for the receiving countries' society, in light of the fact that health is integral to human capital (5). Given the central role good health plays in successful integration into the receiving community, health can also be seen as a driver of integration. Hence, investment in refugee health can be seen as contributing to positive economic growth and development, important for society at large and consistent with national self-interest.

While working as a medical doctor in the wake of the "*2015 summer of migration*" in a refugee health clinic in Kristiansand, I was overwhelmed and astonished by the lack of empirical data to guide policy and clinical work when unprecedented numbers of refugees knocked on our doors. This spurred my interest in this research field and marks the start of my research journey. The main objective of my thesis is to obtain a broader understanding of what factors, exposures and circumstances impact overall health, QoL and the use of healthcare services among refugees migrating to Norway. This threefold focus of the thesis allows a broader understanding of a complex research field. On an overall epistemological and ontological stand, I place this dissertation within critical realism. A critical realist research paradigm focuses on the mechanisms that drive social reality even when they are not directly observable (6), meaning knowledge is a social product not independent of those who produce it (7). This readily aligns with the Biopsychosocial Health Model (8), also used as a foundation in this research, which allows a degree of complexity and holism regarding health in society involving mind, body and social environment.

The background chapter of this thesis is outlined as follows. The first section (8.1) focuses on migration, introducing the concept of migration and discussing important terms and definitions (8.1.1), thereafter discussing migration from both an international perspective (8.1.2) and a Norwegian perspective (8.1.3). Section 8.2

discusses the concept of health, while section 8.3 discusses the connection between migration and health in two subsections: the effect of migration on health (8.3.1) and the effect of migration on QoL (8.3.2). Section 8.4 discusses access and utilization of healthcare services followed by a section on theoretical perspectives on migration and health (8.5). A conceptual framework of the thesis is provided in section 8.6, with the final section discussing research gaps and the rationale for conducting the study (8.7).

8. Background

8.1 Migration

8.1.1 Terminology, concepts and definitions

Migration is often defined as the movement of people between regions or countries (9) and has always been a part of human history shaping the world as we know it today. This definition encompasses any type of movement of people, either across an international border or within a state, for any reason, allowing for great heterogeneity in the causes of migration. The United Nations (UN) defines a migrant as "*someone who changes his or her country of usual residence, irrespective of the reason for migration or legal status*" (10). To explain the different perspectives in migration dynamics, several subsets to the concept of migration are commonly used in research and in political and public discourse. For instance, the term *forced migration* is often used to distinguish between involuntary and voluntary migration. The International Organization for Migration (IOM) defines forced migration as the movement of people due to an element of coercion including a threat to life or livelihood (11) induced by humans or nature. This definition, being a broad umbrella term, includes refugees, asylum seekers, internally displaced persons, persons in an irregular situation and victims of trafficking, among others. Likewise, forced migration may be either documented or undocumented depending on whether migrants' presence in the receiving country is legally sanctioned. The concept of voluntary migration encompasses persons migrating for work, education or family reunification. In Scandinavia, the term immigrant is commonly used instead of migrant, referring to any foreign-born person including both voluntary and forced migrants and sometimes also their children (12).

The traditional dichotomy separating forced and voluntary migration also falls short of acknowledging the nuances in migration experiences as the reasons for migrating might be mixed. Forced migration is however not a legal concept and lacks a unified definition. The terms *refugee* and *asylum seeker* on the other hand are founded in international law and are often used to underline the important political implications

and specific rights that accompany these statuses; for example, the right to protection, non-refoulement and access to healthcare (13). Article 1 of the United Nations Convention relating to the Status of Refugees defines a refugee as "*someone who is unable or unwilling to return to their country of origin owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group, or political opinion*" (13). An asylum seeker is someone whose request for sanctuary has not yet been decided (10), which implies that asylum seekers often travel perilous journeys on their own to find a safe haven to seek asylum. If their application for protection is granted by the destination country, they then take on the status of refugees. This also illustrates the contextuality of the label.

In research, concepts and definitions serve the purpose of classifying complex phenomena as heuristic devices that can help understand, navigate, and study the migration experience and migrant health outcomes. One might argue that specific health exposures and outcomes, more often accompanying subcategories of migrants, can be blurred in wide classifications. Additionally, several explanatory hypotheses revolve around these definitions, such as *the healthy migrant effect* elaborated upon later in this thesis. Conversely, labels and definitions are often politically loaded (14, 15) and the lines are in reality often not that distinct, making rigid classifications impractical and to a certain extent reductionist. The "label" can also change or overlap throughout the migratory path and is dependent on contextual policies, laws and regulations.

Ultimately, it is important to acknowledge the fact that labels, concepts, and definitions are merely tools to help us understand research and policy; they never fully represent the true circumstances of the individual and their life experiences. Similarly, the lack of unified definitions and consensus on classifications points to a complex and continuously evolving research field. To make it easier to understand this research study, I have used classifications based on terms outlined in the glossary of The Global Society on Migration, Ethnicity, Race and Health (GSMERH) and

terms commonly used by the United Nations High Commissioner for Refugees (UNHCR), IOM, and established researchers in the field (16). Since refugees form the principal data source for this study, the term *refugee* is most commonly used. However, I also use the term *forced migrant* as a broader term to include refugees, asylum seekers and persons in refugee-like situations. In terms of the receiving community, Norway and Norwegians in this case, I use the terms *resettlement country population*, *receiving* or *recipient country population* or *destination country* interchangeably. The choice of terminology has been dynamic, iterative and progressive, based on ongoing feedback and discussions within the research group as well as advice from peer reviews throughout the research period.

8.1.2 Salient features, international trends and the 2015 "refugee crisis"

In this section, I describe the salient points of international migration, focusing thereafter on migration in Norway.

Migration, a growing phenomenon propelled by globalization and urbanization, is one of three factors defining population change within a nation, the other two being birth and death. The decision to migrate is influenced by push and pull factors (9). Push factors (e.g. conflict, natural disasters, lack of economic opportunities or several such factors in concert) incite a person to migrate, while pull factors (e.g. opportunities for a better life) attract the migrant to their place of destination (17). This view, however, pays little attention to the migrant's aspirations and desires. Instead, it focuses on structural drivers that influence mobility such as political climate or the existence of transport infrastructure (18). This model has been criticized as being too simplistic, failing to account for modified decisions *en route* (19). That said, the factors affecting the decision to migrate are probably a combination of personal desires, wishes and aspirations and structural push and pull factors. Along the same lines, a more faceted conceptualization divides migration drivers into three different types based on Bronfenbrenner's *Ecological Systems Theory* (20, 21): macro- (e.g. systems of governance, social and economic policies,

war and culture), meso- (e.g. living conditions, poverty and social support) and micro-level (e.g. age, gender) causes.

There are an estimated 281 million international migrants to date, equalling 3.6% of the world's population. This number has grown steadily over the last two decades, with a 49% increase between 2000 and 2017 (22). In 2019, the number of forcibly displaced persons was estimated to be 79.5 million worldwide, of which 26 million were registered as refugees, accounting for 12% of all international migrants (23). Similarly, this number has continuously risen in the last decade, largely due to armed conflict and poverty in low-income countries. Despite this, low-income countries host a large majority (85%) of the world's refugees (23), while only a small number (3%) are hosted in high-income countries, a sharp contrast to what is presented in the media and general public perception.

In 2015, over 1.25 million refugees arrived at the borders of the European Union (EU), an unprecedented and twofold increase from the previous year (24). The three main drivers of this migrant trajectory were the Syrian civil war, the Afghanistan war and the Iraq war (24). The year 2015 is often referred to as "*the year of Europe's refugee crisis*" and "*the long summer of migration*" in the European media. The spike in refugee numbers in the EU was preceded by a steady increase in refugees in the geographical areas surrounding the conflict regions; at the time Europe had managed to remain largely unaffected. However, new migration routes enabled forced migrants to access Greece and Italy by crossing the Mediterranean Sea by boat, causing the initiation of border controls in several European countries. The scenes that played out in 2015 in the EU during the escalating migrant crisis stretched capacities of some of the receiving communities, spurring governments and policymakers to jointly coordinate and respond to the needs of the newly arrived refugee population. The focus was on emergency response including housing, addressing basic health needs and carrying out health assessments upon arrival (25, 26).

The lack of empirical data on several aspects of refugee reception, health and healthcare use became evident and prompted research initiatives to better answer questions and guide policymakers and service providers. This also forms the backdrop and part of the rationale of this thesis. In 2015, several restrictive measures were implemented to reduce the number of forced migrants arriving in Europe. The measures proved to be effective since arrivals in the following years were reduced drastically. In 2019, the European Commission declared the migrant crisis over even though the underlying causes of the crisis have not changed. Today, the share of migrants in the EU is 8.2% compared to its total population, of which 0.6% are refugees (23). Migration remains on the EU's agenda and is expected to be a major force shaping 21st-century global society (27).
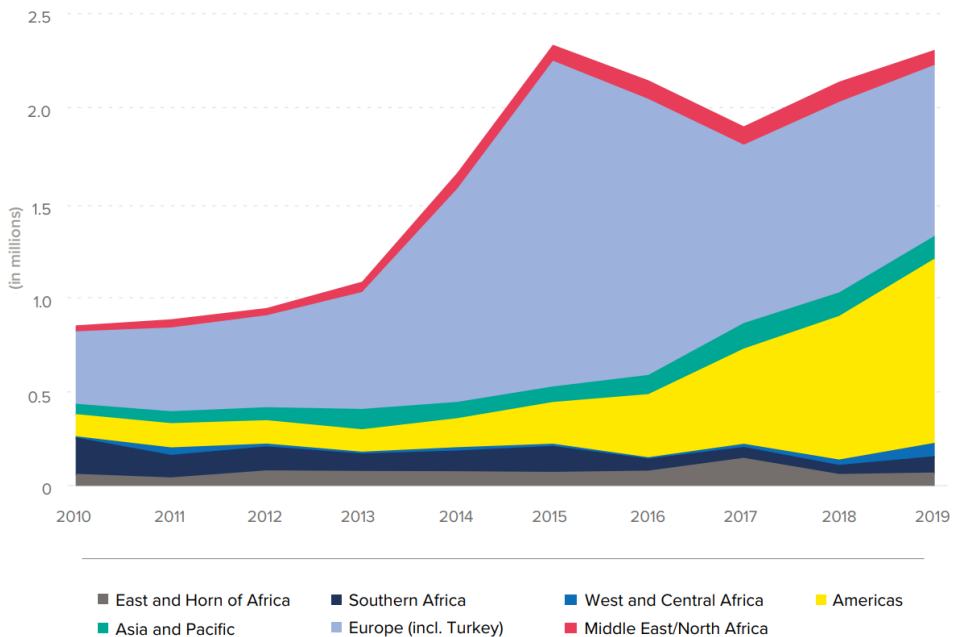
Figure 2. *Asylum applications registered by region, showing the peak in 2015 followed by a decline due to restrictions and thereafter a steady increase. Source: UNHCR Global Trends Report 2019 (23).*

8.1.3 A Norwegian perspective

Even though migration is a long-standing tradition in Northern Europe, Norway is a relatively new destination country. The demographics of migrants to Norway have changed from mainly labour migrants from Europe in the early 1960s to an influx of forced migrants from different regions of the world in recent years. Norway ratified the United Nations 1951 Refugee Convention Relating to the Status of Refugees in 1953 and accepted its 1967 Protocol, receiving a fluctuating number of asylum seekers since. In addition, Norway receives resettlement refugees through the UNHCR annually, a quota regulated by the Norwegian Parliament. Today, 18% of the Norwegian population has a migrant background including Norwegian-born to immigrant parents (12). Of this number, 4.4% has a refugee background (28). The five largest country groups in Norway are migrants from Poland, Lithuania, Sweden, Syria and Somalia (29). The first three groups being mainly labour migrants and the latter two forced migrants. Labour migrants are still by far the largest group of migrants in Norway.

The increase in forced migration to Europe in 2015 also affected the number of refugees and asylum seekers arriving in Norway, with a threefold increase from the previous year (30). Also, in Norway, measures were taken to restrict the arrivals (31) resulting in a record decline in arrivals in subsequent years, following the same trend as the rest of Europe.

The migrant cohort in this thesis consists of Syrian resettlement refugees arriving in Norway in 2018. As of 2019, there are 30 795 persons of Syrian origin living in Norway and 2 500 Norwegian-born to Syrian parents, which makes them the seventh-largest migrant group in Norway (28). Even though migrants from Syria are a relatively new population in Norway, they had the highest growth in both 2016 and 2017 (32). The sizable representation of migrants in Norway and the increasing demographic diversity make the health of migrants an important concern in public health and in society as a whole.

8.2 Self-rated Health and Quality of Life

8.2.1 Terminology, concepts and definitions

There are many definitions of health. One of the most prominent is from the 1948 Constitution of the World Health Organization (WHO) which defines health as a *"state of complete physical, mental and social well-being and not merely the absence of disease or infirmity"* (3). WHO's definition mentions three dimensions of health, namely physical, mental and social. This inclusion of social well-being as a part of health was a key and novel aspect of this definition back then. Although criticized for being utopic (33), WHO's definition of health was somewhat ground breaking when it first appeared in that it diverged from the traditional biomedical definition of health and aligned with a holistic health model. In an attempt to address the criticism levelled against it, the WHO definition of health was modified in the Declaration of Alma-Ata, where it was redefined as *"the highest possible level of health"* (34). Despite its limitations, I adhere to the WHO definition of health in this thesis given its recognition in the literature.

8.2.2 Measurements of Quality of Life

In the shift from a biomedical health paradigm to a more biopsychosocial one, the importance of Quality of Life (QoL) emerged juxtaposed with mortality. With new treatment and interventions extending life, a need to adequately measure the effects of an extended life surfaced that account for aspects other than mortality rates. The definition of QoL has also been a subject of debate but is defined by the WHO as "*an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns*" (35). QoL is a broad concept covering all aspects of life, including non-health-related elements. It can be useful when investigating how exposure impacts psychological, social and economic well-being. Health and QoL can be viewed as distinct concepts where health is only a part of QoL. However, given the intricate relationship between non-health-related factors and health, also in line with the WHO definition of health, I argue that this distinction is not very clear. Nevertheless, most of the literature available on the subject views health and QoL as distinct and separate

concepts, arguing that satisfaction with life is influenced by health but health status explains only a small part of life satisfaction (36). I adhere to this separation in this thesis, albeit recognizing the strong relationship between the two concepts.

8.2.3 Measurements of Self-rated Health

Self-rated health (SRH) is the individual's perception and evaluation of his or her health. SRH measures have proven to be valuable predictors of all-cause mortality and morbidity (37, 38), including in minority populations (39), and is widely used in health monitoring and to research health inequalities. In 1997, Idler and Benyamini wrote: "*We would argue that the global rating represents an irreplaceable dimension of health status and in fact that an individual's health status cannot be assessed without it*" (37). The most common way of measuring SRH is with a single-item question in which the individual is asked to make a general rating of his/her health. The question has been incorporated in many health surveys. Interestingly, the evidence supports SRH as a reflection of an overall pattern of one's health trajectory and not just current level of health (40).

8.3 Migration and health

In this section, I provide an overview of research on migration and health. The two-way relationship between migration and health is complex, involving several determinants that are context-dependent, and can be approached from many angles (14, 41). Additionally, the lack of comparable data due to unclear and varying definitions across studies and countries adds to an already complex research field. Notwithstanding a holistic view of health, I will approach this field by categorizing health into physical and mental followed by QoL for the sake of simplicity and to adhere to the division often included in the available research. I will also try to give an overview of migrants' health in general and thereafter look more specifically into the health of forced migrants.

8.3.1 The effect of migration on health

Previous research supports a robust health advantage among migrants. The UCL-Lancet commission on Migration and Health review from 2018 showed that international migrants have a mortality advantage compared with general populations that persisted across the majority of ICD-10 disease categories (42). The known health advantage among migrants has been explained by *the healthy migrant effect*, derived from *the healthy worker effect* (43), meaning that migrants have a health advantage, especially during the first five to ten years after migration (44). This health advantage exists in comparison with the receiving countries' population and also with the population in the home country. Paradoxically, the phenomenon is found even among migrants with lower socio-economic status than non-migrants in the so-called *migrant mortality paradox* (45). However, few studies in the UCL-Lancet commission review included refugees, asylum seekers and other forced migrants, indicating a gap in the research for these population subsets. Hence, the current evidence base has not been able to proof a health advantage for all subcategories of migrants. It could, therefore, be more appropriate to talk about health advantages in terms of specific migrant flows, embedding them in time and context. The healthy migrant effect has been explained by the selection of healthy individuals, either at an individual level or at the state level, as well as with data artifacts. The most discussed data artifact is the salmon bias, explained as selective return migration of the weak, sick and elderly (46). Evidence supporting remigration bias is however weak (47).

In spite of the evidence pointing towards a positive selection, several studies have shown a deterioration in migrants' health depending on duration of stay in the destination country (48, 49). Common theories explaining this progressive deterioration of health are the *exhausted migrant effect* and *allostatic load*, pointing to reasons for the decline being caused by various post-migration factors and accumulative wear-off (50, 51). However, few studies have investigated the direction of the health trajectory shortly after resettlement (52). Consequently, how quickly the post-arrival decline occurs for the different groups of migrants remains largely unanswered. Some of the most studied factors hypothesized to cause post-arrival

decline include self-perceived discrimination, poor living and working conditions and poor access to healthcare (53, 54). Importantly, many of these factors are indicators of poor integration. Therefore, mere resettlement in a safe country does not necessarily equal improvement in health and well-being. In contrast, greater social integration has been associated with better physical and mental health among refugees (55).

Health among refugees is largely associated with the same factors determining health for other migrants and non-migrants. Still, when reviewing the literature on the health of forced migrants specifically, several factors point to a somewhat different risk profile than migrants in general, indicating determinants more common among refugees. Forced migrants may face specific exposures such as violence, destruction of their homes, exploitation, loss of loved ones, unsafe living conditions and poor or conditional access to healthcare as part of the forced migration experience. This might make some forced migrants vulnerable to certain diseases and health outcomes (56). The concept of vulnerability in this context refers to this heightened risk of exposure to adverse events with potential effects on health (57). However, despite increasing research on the health of forced migrants, conclusive evidence is still lacking. A literature review on forced migrants' health from 2020 concluded that data on forced migrants' physical health status is insufficient (58). Even though the current evidence base is inconclusive, there seems to be a tendency towards poorer physical health outcomes among forced migrants, contradicting the healthy migrant effect (59-62). In addition, there are also some methodological considerations in the current evidence base, which is dominated by cross-sectional studies skewedly distributed on mental health outcomes and infectious diseases. A too narrow focus on mental health hampers a broader understanding of refugee and migrant health. The focus has also been on pathogenic processes in clinical populations, leaving a gap in the research with population-based samples and salutogenic processes. Salutogenesis is introduced and discussed later in this thesis.

With regard to mental health, a substantial body of research indicates increased prevalence rates of mental disorders among refugees and forced migrant populations (63-65). The mental health of migrants after resettlement has historically been described in three stages in the *disillusionment model* (66). The model explains how, shortly after resettlement, the health of migrants seems to be equal to or even better than that of the receiving population. This good health in the first stage is attributed to the *euphoria of arrival*. It is hypothesized that mental health deteriorates in the so-called *nostalgia phase* because of feelings of loss. In this second stage, refugees purportedly face a higher mental health risk. Eventually, *adaptation* takes place (third stage) which means that the health of the migrant approaches the health of the receiving population due to acceptance of the new environment. However, the *disillusionment* model has proven to be too simplistic, failing to sufficiently account for protective factors such as social support and their impact on mental health (67).

8.3.2 The effect of migration on Quality of Life

QoL among migrants is an understudied research field. Most available studies evaluate QoL in relation to disease or treatment (68). However, with regard to refugees, there are more generic non-disease-related studies available. Evidence shows a correlation between flight experiences such as traumatic events and poor access to healthcare and, later, poor QoL (69, 70). Some studies also point to a lower QoL among refugees in high-income countries compared to the non-migrant population (71-73). Findings also suggest a less favourable QoL among migrants experiencing separation and marginalization (74) and, conversely, that subjective integration positively associates with better QoL (75). A systematic review from 2020 of the predictors of QoL among refugees and asylum seekers in high-income countries found that high social support was associated with higher QoL, whereas mental disorders were strongly associated with reduced QoL (76).

One of the most recognized determinants of health is access and use of healthcare services. Hence, this is discussed in the next section (8.4), starting with the definition and concepts (8.4.1), followed by a section on refugees' access and use of healthcare services (8.4.2).

8.4 Access and utilization of healthcare

8.4.1 Terminology, concepts and definitions

Access to healthcare is a complex concept with varying interpretations across the literature. In a nutshell, access to services can be explained as the ease with which a person is able to use appropriate healthcare services in proportion to his/her needs (77). Meanwhile, healthcare utilization refers to the actual use of healthcare services and access is, therefore, a prerequisite for use. Thus, looking only at utilization rates as a proxy for access is insufficient since factors and potential barriers preceding actual use would be lacking. Measuring healthcare access can be difficult, while the use of healthcare services can be measured either by self-report instruments or registers.

8.4.2 Refugees' and other migrants' access and use of healthcare services

Substantial evidence shows that migrants face challenges in accessing and utilizing healthcare during the different phases of migration and upon arrival in the destination country (78). Rights and entitlements vary across the stages of migration and in different destination countries thereby impeding access to care. However, challenges to healthcare access have also been identified in countries where migrants have the same rights and entitlements to healthcare as the resettlement country population. The early stages of resettlement post-migration are particularly vulnerable phases (79). In addition, forced migrants might have different healthcare needs related to the migration experience that are not sufficiently met. Studies have documented a discrepancy between services offered and the care needed by the refugee populations, resulting in unmet needs (80). The fact that poor access and utilization of healthcare contributes to poor health is thoroughly documented. Barriers to healthcare are various and at several levels. Hence, the famous inverse care law that states that "*the availability of healthcare is inverse to the health needs of the population*" (81) is highly relevant among migrant populations.

8.5 Theoretical perspectives on migrant health

8.5.1 A trajectory perspective

The shifting nature of migration requires a dynamic research approach, allowing for the presence of a time axis. In many cases, migration entails sequential changes over time mirroring a process rather than a state or one point in time exposure. Migrants might move several times before reaching their destination and the migration might be circular (82). Therefore, migration trajectories are characterized by spatial dynamics (transit settings) and spatial frictions (detention, not having residence permit, borders) and are seldom a simple unidirectional linear trajectory denoting a move from one country to another (83). Experiences encountered throughout migration, individually or accumulated, might have a persisting influence in later life, sometimes causing health disparities (84). Today, most studies on migration and health are cross-sectional, a design that often fails to sufficiently account for the multiple transformations and temporal dimensions that a migration experience implies. Longitudinal approaches have therefore been recommended to guide empirical migration research, ideally with the use of a life course perspective focusing on critical periods throughout life (85).

8.5.2 Risk and protective factors: Vulnerability and resilience

When describing possible exposures and risk factors along the migratory path, a useful way to get an overview is to broadly categorize the migration experience into stages, namely pre-migration, peri-migration and post-migration (86). Several exposures at different levels (micro, meso, and macro levels) can influence the forced migrant during these stages and cause vulnerabilities that result in poor health outcomes. This has been exemplified in the concept of syndemic vulnerability, explained as health conditions co-occurring in environments of heightened adversity interacting synergistically to generate worse health outcomes than each affliction would likely cause on its own (87). For instance, a forced migrant can be exposed to pre-migration trauma in his/her country of origin, followed by poor living conditions, poor access to healthcare and marginalization in the transit country, and, lastly, post-

migration acculturative stress upon resettlement. This type of trajectory can, in sum, result in deteriorating health. A similar trajectory was highlighted in the introduction to this thesis, with the Syrian father pointing to several difficulties throughout the migratory path, all of which resulted in poor health and well-being. In recent years, there has been a shift in focus from the vulnerabilities caused by pre-migration trauma to factors affecting health after resettlement, commonly referred to as *post-migration stressors* or *acculturative stressors*. Thus, the negative effect of post-migration stress on health has been juxtaposed to the effect of pre-migration trauma (39, 86).

However, in contrast to vulnerability, the concept of resilience is sometimes highlighted as the most important protective factor among forced migrants (88). The resilience of individuals can be explained as better-than-expected trajectories of healthy functioning over time, meaning the ability to cope successfully despite adversity (89). Previous research supports resilience as a key modifying factor that counteracts exposure and vulnerability (90). Family, religion, personality characteristics, ethnic community and social support have been identified as the factors that help build resilience (91). In general, there is need for research on the factors that help maintain resilience among individuals and social groups (92). To be able to map these factors, a salutogenic research approach has proven to be valuable. Antonovsky's salutogenic model is framed around the development of health through health-promoting factors, as opposed to the pathogenic approach which is centred around risk factors and disease (93).

8.5.3 Migration as a determinant of health

In the early 1990s, an inverse social gradient in mortality for coronary heart disease among British civil servants was presented by Marmot, of which only a quarter could be explained by coronary risk factors (94). This study lay the foundation of the social determinants of health, shifting the focus from mere biology to a larger recognition of

the social and economic environment as crucial determinants of health. The WHO defines social determinants of health as "*the conditions or circumstances in which people are born, grow, live, work and age*" (95). This commonly includes access to healthcare, education, literacy, health behaviour and social support. In recent years, several researchers have stressed the importance of recognizing migration as an independent social determinant of health (96, 97). Migration and the migratory path interact with several aspects of life and can therefore both be a consequence of social determinants and a social determinant of health in and of itself. The effect of migration as a determinant of health depends on migration-related factors such as time spent in a transit setting, having a residence permit or not, and whether you have sufficient access to healthcare.

The conceptualization of social determinants of health, based on Dahlgren and Whitehead's model (98), contains various layers that impact health, with biological aspects such as age and gender at the core and several layers such as living and working conditions and socio-economic conditions on top (micro-, meso- and macro-level layers in line with Bronfenbrenner's *Ecological Systems Theory*). The migration experience can cut across all these layers (99).
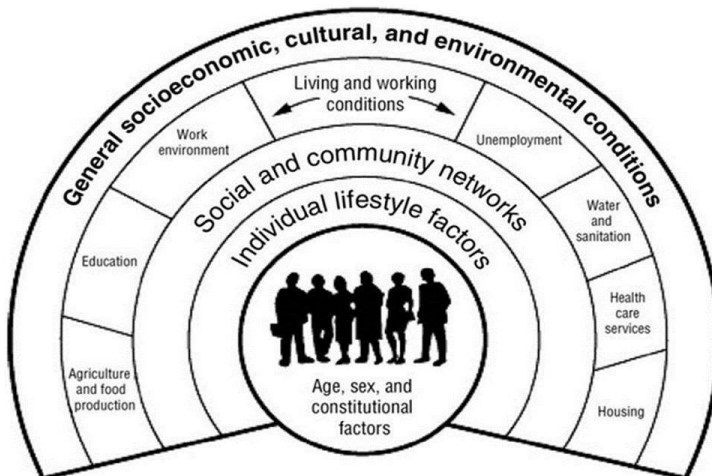
Figure 3. *Social determinants of health. Source: Dahlgren and Whitehead (1991) (98). With permission from the authors.*

8.5.4 Theoretical perspectives on access and use of healthcare

A multitude of conceptualizations attempt to define and categorize the access and use of healthcare services. Such conceptualizations are important for an overview of the kinds of barriers patients face when accessing and using healthcare services. I have chosen to focus on two influential conceptualizations: the Levesque model (77) and Andersen's behavioural model (100). In the Levesque model, barriers to healthcare are divided into those on the provider side and those on the user side. The framework is categorized into five dimensions on the provider side (approachability, acceptability, availability and accommodation, affordability, and appropriateness) and five dimensions on the user side (ability to perceive, ability to seek, ability to reach, ability to pay and ability to engage). This framework allows one to look at both provider- and user-side factors, as opposed to only macrostructural factors such as health system performance and delivery. These individual factors, the doctor-patient relationship, continuity and quality of care, are especially relevant in a refugee setting where language, communication and culture differences are evident.

The Andersen behavioural model suggests that healthcare access and utilization are determined by predisposing, enabling and need factors (100). Predisposing factors can be explained as the predisposition to use health services, including sociodemographic factors and health beliefs. Examples of enabling factors are external facilitators and barriers such as social support. Need is influenced by the actual health status of the individual and his/her self-perceived need for care. From a refugee perspective, one can argue that several factors impacting the use of services are specifically related to the refugee experience.

8.6 A framework for this thesis

Below, I present a framework for this thesis showing how several of the concepts introduced so far can interact to shape the health and QoL of refugees.
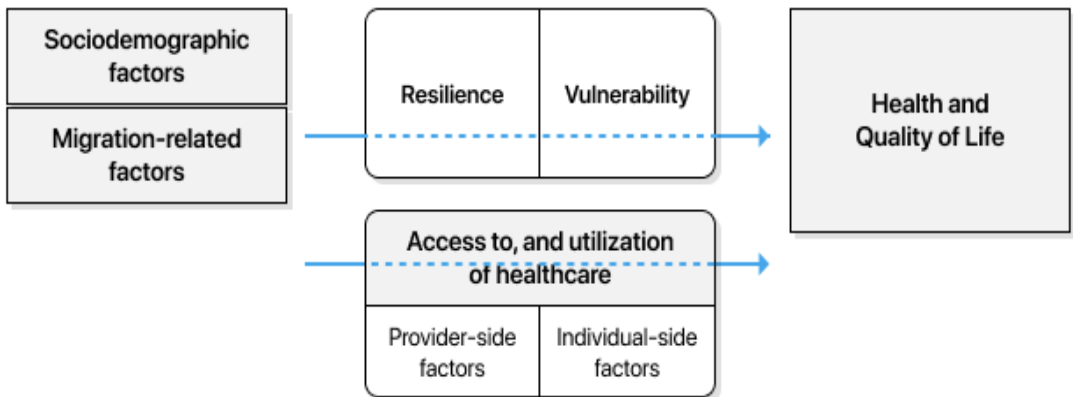
Figure 4. A conceptual framework for the dynamic interaction between migration, health and the use of healthcare services.

8.7 Rationale and challenges that need to be addressed

As discussed in the introduction, studying and understanding refugees' and other migrants' health is important to ensure equity in care, guide policy and inform future arrivals. Despite an increasing evidence base on refugees' and other migrants' health, some important research gaps need to be highlighted and will be underpinned in this section. First, previous research has been overshadowed by a disproportionate focus on mental health and infectious diseases (101), impeding the understanding of other aspects of health and well-being. Specifically, there has been a lack of a multidimensional focus on health, including both physical and mental health, and social environments. Second, in the current evidence base, there is poor knowledge of the effect of the migration experience on health and the use of healthcare services, both short- and long-term effects. The available research often lacks the inclusion of refugees' own perceptions on what shapes and contributes to a decline in health during and after migration. Third, research on the access and use of healthcare focuses on emergency response, entitlements and economic barriers, with few studies on long-time solutions and barriers beyond entitlements and costs.

Additionally, some methodological considerations should also be highlighted. Few studies to date have applied a longitudinal design, hindering the observation of changes in health with time. There is limited research on health trajectories, particularly in the early phase of resettlement, as well as lack of approaches combining longitudinal and qualitative designs. Furthermore, there are other pragmatic challenges in the field of migration and health, such as the lack of unified definitions and cross-culturally validated research instruments and difficulties in getting representative samples. Addressing these challenges is, however, beyond the scope of this thesis. Following the rationale, the principal hypothesis behind this thesis is that factors related to the migration experience influence migrants' health outcomes and access and use of healthcare services.

9. Objectives

9.1 General objective

The overarching objective of this thesis is to explore, describe and analyse the changes in health, QoL and use of healthcare services among Syrian refugees migrating to Norway.

9.2 Specific objectives

The specific objectives can be stipulated as follows:

1. To investigate longitudinal changes in SRH and QoL from a transit setting to after resettlement and to evaluate potential effect modifiers of this change in terms of sociodemographic and migration-related factors. This objective was addressed in the first paper.
2. To investigate longitudinal changes in the use of healthcare services from a transit setting to after resettlement and to study the associations between the use of healthcare services and health, sociodemographic and migration-related factors. This objective was addressed in the second paper.
3. To explore refugees' perceived changes in health status along the migratory path and the access and use of healthcare services. This objective was addressed in the third paper.

10. Material and methods

This thesis uses both quantitative and qualitative research methods to address the overall aim of the study for the purpose of breadth and depth of understanding (102). Combining quantitative and qualitative information gives a broader research perspective by addressing the research questions in multiple ways (102). The first two papers use questionnaire data from a prospective longitudinal study and the third paper uses data from individual in-depth interviews. The qualitative interviews draw upon the quantitative work, allowing a deeper exploration of topics identified as pertinent and unanswered or partly answered in the quantitative data material. In the discussion, data material from both quantitative and qualitative studies is synthesized for a richer understanding. Table 1 gives an overview of the papers and methodology used.

	Paper I	Paper II	Paper III
Research question	How do SRH and QoL change during migration to Norway?	How does the use of healthcare services change during migration to Norway?	What experiences do Syrian refugees have with changes in health and the Norwegian healthcare system?
Research design	Quantitative Prospective Longitudinal	Quantitative Prospective Longitudinal	Qualitative Individual interviews
Study population	Syrian resettlement refugees (16+)	Syrian resettlement refugees (16+)	Adult Syrian refugees with mixed legal status upon arrival, settled in a municipality
N	355	355	15

Time of data collection	T1: August 2017 - April 2018	T1: August 2017 - April 2018	April 2020
	T2: December 2018- December 2019	T2: December 2018- December 2019	
Data analysis	Descriptive and inferential statistics	Descriptive and inferential statistics	Systematic text condensation

Table 1. *Overview of methodological approach, sample and method of analysis for each paper.*

10.1 Changes in Self-rated Health, Quality of Life and use of healthcare services: Quantitative part (papers I and II)

10.1.1 Study design

In the quantitative part of the study, we used a prospective longitudinal design. We collected data from adult Syrian refugees accepted for resettlement to Norway. We used a self-administered questionnaire including self-ratings, repeated at two-time points. The first assessment was conducted pre-arrival in Lebanon in 2017-2018 and the second assessment was conducted one year after resettlement in Norway. Thus, we can compare health outcomes in the transit migration phase with the outcomes in the post-resettlement phase for the same individual. The primary outcome for the first paper was SRH and QoL and the primary outcome for the second paper was the use of healthcare services (General Practitioner [GP], Emergency Care [EC], outpatient/specialist care and hospitalization).

10.1.2 Participants and setting

Syrians in Lebanon

Lebanon, a densely populated upper-middle-income country, hosts the largest number of Syrian refugees per capita in the world, with an estimated 1.5 million Syrian

refugees as of 2020 (103). Despite this large number of Syrian refugees, Lebanon is not a signatory of the 1951 Geneva Refugee Convention relating to the Status of Refugees and its 1967 Protocol and has held on to the notion of not being a country of asylum (104). During the start of the influx of Syrian refugees to Lebanon in March 2011, the Lebanese government held an open border to the Syrians. Registering with the UNHCR allowed Syrian refugees to receive a residence permit in Lebanon granting them a degree of legal protection and access to healthcare. Due to changes in the political climate in Lebanon, the open-door principle was exchanged with closed doors in 2014–2015, and the renewal of residence permits was stopped. Today, a large number of Syrians live unregistered in Lebanon without any form of international protection which renders them particularly vulnerable and marginalized. This number has increased in the last few years, and it is estimated that around 70% of all Syrian refugees in Lebanon have no members in the family with legal residency (105). Life in an undocumented situation is immensely harsh, characterized by poor housing conditions, limited access to healthcare, unemployment, food insecurity and limited access to schooling for minors. As a result, an estimated 90% of Syrian refugees in Lebanon currently live below the extreme poverty line (105).

Access to healthcare for Syrian refugees in Lebanon

The Lebanese healthcare system is highly privatized, fragmented between different providers and largely based on user fees (106). Most hospitals are owned by the private sector. For primary care, most centres are operated by non-governmental organizations (NGOs) with agreements with the Ministry of Public Health (107). Since the quality of services available through the public healthcare sector is poor, patients must resort to private healthcare, which is costly, making healthcare services largely inaccessible for people with limited resources (106). Syrian refugees registered with the UNHCR are eligible for subsidized care under certain conditions. Primary healthcare is provided for a lower fee and some services such as vaccinations

are free of charge. UNHCR covers 75% of the costs for secondary and tertiary care, but only in life-threatening emergencies (107). Despite subsidized care, the cost of treatment remains the main barrier to accessing care for Syrian refugees, both in primary and secondary care (105). For unregistered refugees, healthcare is largely inaccessible.

Resettlement

Resettlement refugees are usually persons registered as refugees by the UNHCR but who cannot be provided a permanent solution in the country they are in. To receive an offer of third-country resettlement, refugees go through an identification process. In Norway, families with children under the age of 18 and vulnerable women are given priority (108). Representatives from Norway are sent on selection missions to interview cases already chosen by the UNHCR through a pre-screening, where identity papers and the need for protection are examined. The UNHCR formally applies for resettlement to the third country, and it is up to the receiving country to decide who will be granted permission.

In Norway

After arrival in Norway, all refugees and asylum seekers are screened for tuberculosis (TB), a procedure required by law. Thereafter, forced migrants are invited to a voluntary general health assessment, recommended to be done within the first three months. Resettlement refugees are provided with a GP immediately upon arrival and have the same rights and entitlements to services as the non-refugee population. Asylum seekers must usually wait for a GP until their claim has been processed and they have received settlement in a municipality. The Norwegian healthcare system offers universal coverage with relatively small out-of-pocket expenses. Primary care with GPs in the front act as gatekeepers to the next echelons of medical care, regulating access to hospitals and specialists.

Data collection

Participants were adult Syrian quota refugees under the UNHCR mandate, accepted for third-country resettlement and residing in Lebanon. The International Organization for Migration (IOM) organized the recruitment in connection with the pre-departure cultural orientation programme approximately four to six months before their journey to Norway. The Norwegian Cultural Orientation Programme (NORCO) is mandatory and includes information on Norwegian culture and society with classes taking four days for adults (16 years and above) and two days for children (8–15 years). The NORCO training sessions are handled by bicultural and bilingual trainers. Three recruitment sessions were held in connection with these classes, in August and October 2017 and in April 2018, respectively, and everyone attending the programme was invited to participate (N=544) (figure 7). The author and main supervisor travelled to Beirut and met with the IOM team to coordinate the data collection and secure an understanding of the questionnaire. During this field trip, efforts were made to understand the pre-migration context of the refugee families, increase visibility of the CHART-project, and anchor the project to both the IOM staff and the participants to increase trust and to minimize later dropout rates. Written informed consent was obtained which included consent to be contacted again after approximately one year's stay in Norway. Even though the questionnaire was designed as a self-report instrument, in cases where participants were illiterate or had low Arabic language proficiency, the questionnaire was read out by the trainers. The author and supervisor administered the questionnaires for the first recruitment in August along with the NORCO trainers who organized the recruitment on their own during the next two sessions.

Figure 5. *Participants, translator, NORCO trainer and research member during data collection in connection with the pre-travel course arranged by IOM. Photo: Jasmin Haj-Younes. With permission from everyone depicted.*

The follow-up recruitment was conducted between December 2018 and December 2019. On arriving in Norway, participants were settled in 134 different municipalities across the country, which created its own challenges when the participants had to be gathered again to fill out the questionnaire a second time. The mode of data collection was therefore deliberately changed from self-administered questionnaires to structured telephone interviews. Participants were presented with the same questions and response alternatives by the author along with two other Arabic-speaking project members. Information on participants' addresses was received through The Norwegian Directorate of Integration and Diversity (IMDI). Thereafter, all the municipalities that had settled any of our participants were contacted for their phone numbers and addresses. A total of 353 interviews were completed over the phone. Among the 506 who completed the baseline survey, 41 did not resettle in Norway, 1 died post-arrival and 111 declined participation or did not reply. In total 153 (30%)

were lost to follow-up and 353 (76%) completed the follow-up survey (figure 7). The reasons for non-response were recorded.
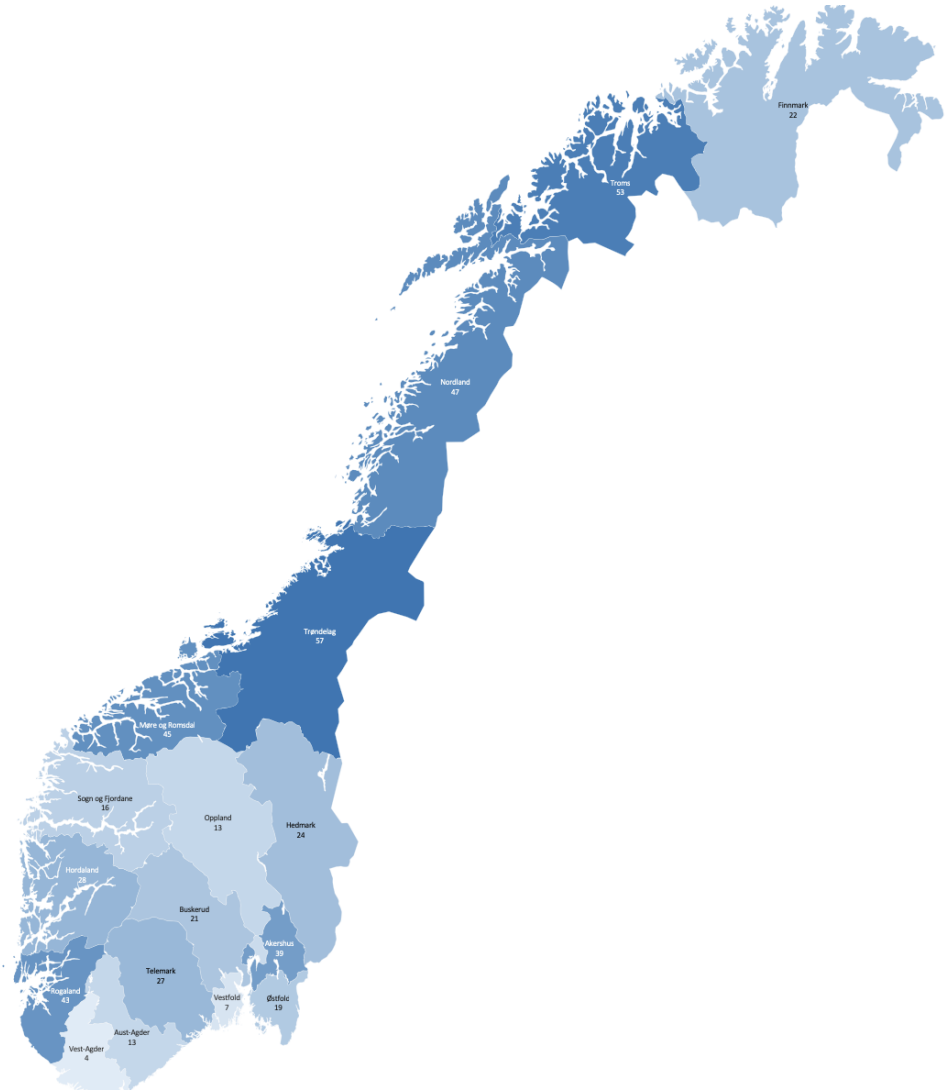
Figure 6. *Distribution of study participants in the counties after resettlement in Norway.*
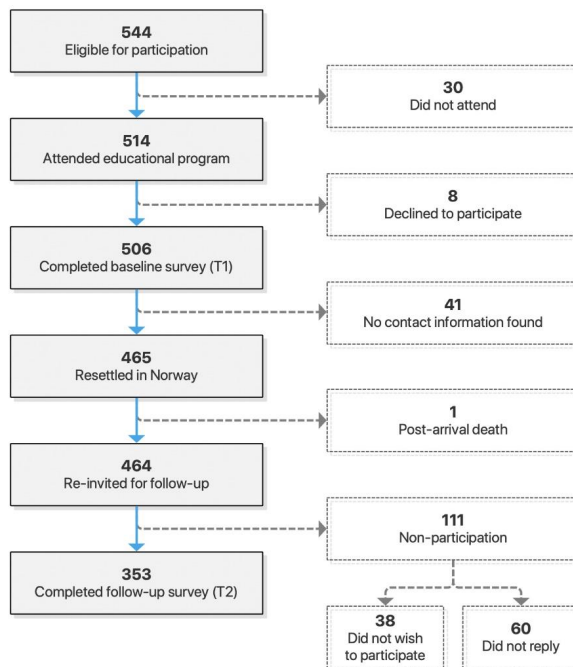
Figure 7. *Flow chart of the recruitment process*

10.1.3 The questionnaire

No available questionnaire could meet the need of the study design and research questions. Therefore, a study-specific context-sensitive questionnaire was developed based on internationally acknowledged and validated instruments as well as questions developed by our research group (see appendix). The full questionnaire contained several sections covering health, including sections not addressed in this thesis. Only the parts included in this doctoral work are discussed here. The questionnaire was divided into four main modules: (1) sociodemographic characteristics, health literacy and social support, (2) migration-related factors, (3) health and QoL, and (4)

utilization of healthcare services. Permission was sought from copyright holders and granted for all the instruments used in the questionnaire.

Module 1: Sociodemographic characteristics, health literacy and social support

To map a sociodemographic background, we asked questions on age, gender, primary language spoken, number of children, marital status, years of education, health literacy and social support. We used the Single Item Literacy Screener (SILS), a single question designed to identify persons needing help understanding health-related material with answers ranging from 1 to 5 (109). To conceptualize social support, we used the ENRICHD Social Support Instrument (ESSI), a 7-item instrument with a 5-point response scale measuring social support (110) that has previously been validated among Syrian refugees (111).

Module 2: Migration-related factors

To conceptualize the migration experience, migration-specific questions were developed. We asked about time since flight from Syria, time in transit, multiple transit countries, residence permit in Lebanon, whether migrating alone or with family, and trauma exposure. Trauma exposure was assessed with the Single General Trauma Item (SGTI), validated in refugee populations (112).

Module 3: Health and Quality of Life

SRH was used as an indicator of health in this research. The SRH-item is a single validated question with a 5-point response scale. To assess QoL we used the WHOQOL-BREF, which is a widely used cross-culturally validated instrument measuring four dimensions: physical health, psychological health, social relationships and environment (113). Answers were given on a 5-point Likert scale. The scale has been validated in Arabic (114) and among refugee populations (115) and has been used among Syrian refugees in previous research (116).

Module 4: Utilization of healthcare services

The utilization of healthcare services was measured using two questions based on questions from the Nord-Trøndelag Health Study (HUNT): "*During the last 12 months, have you visited any of the following: a general practitioner, emergency care, outpatient care, specialist care (yes/no)*" and "*Have you been admitted to the hospital in the last 12 months? (yes/no)*".

Variable definitions

Variable group	Explanation	Data level	Paper I	Paper II
Sociodemographic 13 items	Age	Continuous	Independent	Independent
	Gender	Binary	Independent	Independent
	Marital status	Binary	Independent	Independent
	Number of children	Continuous	Independent	Independent
	Primary language spoken	Binary	Independent	Independent
	Education	Continuous	Independent	Independent
	Health literacy	Continuous	Independent	Independent
	Social support (7 items)	Binary	Independent	Independent
Migration-related 4 items	Time since the flight from Syria	Continuous	Independent	Independent
	No residence permit in Lebanon	Binary	Independent	Independent
	Migrating alone to Lebanon	Binary	Independent	Independent
	Trauma exposure	Binary	Independent	Independent
Health status 29 items	Self-rated health	Binary	Dependent	Independent
	Quality of Life: Physical (8 items) Psychological (6 items) Social relationships (3 items) Environmental (8 items)	Continuous	Dependent	Independent

Use of healthcare services 2 items	Use of GP, EC, outpatient/specialist care, and hospitalization	Binary	-	Dependent

Table 2. *Overview of exposure variables and covariates*

Translation

The complete questionnaire, apart from the WHOQOL-BREF instrument (validated Arabic version already available), went through a translation process according to the standards of cross-cultural research. The translation process was based on Wild et al. (*Principles of Good Practice for the Translation and Cultural Adaptation Process for Patient-Reported Outcomes (PRO) Measures*) (117).
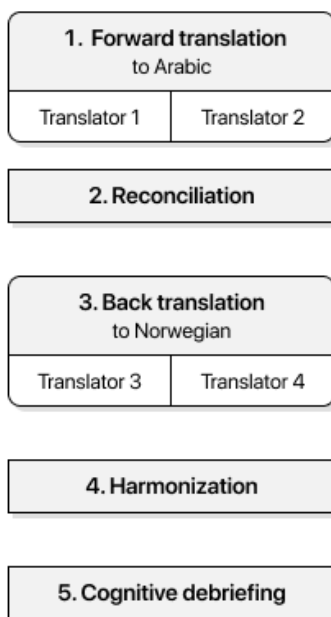
Figure 8. *Questionnaire translation process*

The questionnaire was put through two independent forward translations by highly qualified professional translators, one with a medical background (medical doctor) and one without. The back translations were performed by two other professional translators not involved in the first step. In the harmonization process, the questionnaire was discussed with the author and the translators for quality control. A small pilot study with 6 respondents was subsequently performed where the respondents had the opportunity to comment on linguistic comprehensibility and cultural acceptability. Several minor alterations were made based on this process.

10.1.4 Sample size and power calculation

The sample size was calculated using McNemar's test for repeated measurements of the same individuals over time. The calculations were done on one of the main outcomes, poor SRH based on estimates from pre-war Syria (118). To be able to detect a change in prevalence of poor SRH from 10% to 20%, if accounting for a 20% attrition rate with a 5% probability of type 1 error (p<0.05) and a power of 0.80, it is necessary to recruit 250 individuals. We ended up with a higher number than required due to changes in the study plan as a consequence of political climate and policy change during the course of data collection. Initially, we were supposed to recruit refugees through the EU relocation scheme established in 2015 (119) from Greece and Italy, in addition to recruiting in Lebanon, to compare participants subjected to different migration trajectories. However, these routes were closed in September 2017 after the scheme ended and we subsequently increased recruitment in Lebanon.

10.1.5 Data analysis

After data collection, the data were entered in the management software twice, Excel at baseline and EpiData at follow-up, followed by automatic error detection features and manual checks to ensure quality. The quantitative data material was analysed by the author in close collaboration with a statistician, supervisors and co-authors.

For papers I and II, baseline characteristics were analysed as counts and proportions for categorical variables, medians and interquartile ranges (IQR), and means and standard deviations (SD) for continuous variables. Differences in characteristics between the participants and the loss to follow-up group were analysed using χ^2-statistics and independent group's t-tests.

For papers I and II, longitudinal data were analysed using generalized estimating equations (GEE) in long format with two observations per individual and "wave" as a binary covariate to evaluate change in outcome from baseline to follow-up. The GEE method accounts for the non-independence of repeated data from the same subject. For binary outcomes, we applied a log-link and binomial distribution and reported exponentiated regression coefficients as risk ratios (RR) with 95% confidence interval (CI). For continuous outcomes, we applied an identity link and Gaussian distribution and reported regression coefficients (B) with 95% CI.

In paper I, potential effect modifiers for change in outcomes over time were evaluated by stratifying by various characteristics measured at baseline in Lebanon (gender, age, ethnicity, marital status, education, health literacy (SILS), social support (ESSI), time in transit, multiple transit countries, residence permit in Lebanon, migrating alone) and by incorporating interaction terms between the covariates and wave in the GEE models to test for significant differences in change over time for different subgroups. Adjusting for confounders in the GEE models was deemed unwarranted since the same individuals were assessed twice.

In paper II, we used log-binomial regression analysis to evaluate factors (pre- and post-resettlement) associated with the use of healthcare services in Norway. We reported risk ratios with 95% CI in two models: (1) unadjusted and (2) adjusted for potential confounders for the total effect of each characteristic on the outcome based on results from a directed acyclic graph (DAG) (see figure 14 in the Discussion section) (120). DAGs are useful when identifying potential confounding factors and

in minimizing the risk of over-adjustments (121). When using a DAG, the researcher visually maps the hypothesized causal relationships between exposure, outcome and other covariates. The DAG was constructed using the software DAGitty v.3.0. In cases where convergence was not achieved in log-binomial regression analysis, Poisson regression was used with robust error variance (122).

Missing values were handled through list-wise deletions. An alpha value of 0.05 was considered statistically significant. Internal consistency for questionnaire instruments was estimated with Cronbach's alpha. We analysed the data using STATA/IC software, version 16.0 (StataCorp LLC, Texas, USA).

10.2 Syrian refugees' experience with changes in health and use of healthcare services during migration: Qualitative part (paper III)

10.2.1 Study design

The qualitative study explores refugees' health status and perceived change in health status with migration, as well as their health experiences in Norway. We used a design with semi-structured individual interviews with adult Syrian refugees.

10.2.2 Interviewers role, background and preconceptions

One can never achieve neutrality in the exploration and interpretation of phenomena. All findings are negotiated through my voice, and hence my background and social characteristics are an integral part of this study. My Syrian background allowed me to approach the study with some cultural insight. However, I am also influenced by a non-Syrian frame of reference by virtue of being born and raised in Sweden. Moreover, having a medical background with clinical experience with patients from refugee backgrounds influenced my pre-study beliefs. For instance, I have witnessed patients who have newly arrived in Norway, reflected upon their health status and some of the challenges they face upon arrival, including unmet health needs. These

experiences have shaped my understanding and impacted all aspects of this research project. Understanding some of these pre-study preconceptions has been important to position myself with the context of this study.

10.2.3 Study setting, participants and data collection

Fifteen in-depth telephone interviews in Arabic were conducted in April 2020. We used purposive sampling targeting maximum variation to ensure sample diversity in terms of age, gender, educational background and geographical location in Norway. The sampling method included the identification of eligible participants through networks in combination with snowballing. Syrian nationals who arrived in Norway after 2010 as asylum seekers, refugees or as family reunification to a refugee family member were considered eligible. The participants were not derived from the sample of the quantitative study. At the time of the interviews, all participants had refugee status and had received settlement in municipalities. The interviews were based on a semi-structured interview guide with open-ended questions with additional probes for deeper exploration (see appendix). The length of the interviews ranged from 30 to 60 minutes and were conducted by phone due to the ongoing COVID-19 pandemic.

10.2.4 Data analysis

The interviews were recorded, transcribed verbatim, translated by a professional translator and cross-checked against the original recordings by the author. Data were deemed as sufficient based on the concept of information power (123), including the concepts of sample and research question specificity, use of established theory, quality of dialog and analysis strategy. We used an inductive iterative approach when analysing the data using Systematic Text Condensation (124). Analysis was initially performed by the author, supervised by Eirik Abildsnes, and thereafter independently analysed by Esperanza Diaz. Nvivo software was used to manage the data.

10.3 Ethical considerations

During the study recruitment process, we had to consider some very specific ethical issues given the heightened vulnerability many of our participants were experiencing. Additionally, with hot political topics such as migration, there is always the risk of misuse of information which could enhance stereotypes and fuel the anti-migrant political and public discourse. Conversely, it is vital that refugees are represented in scientific research and not systematically excluded due to their vulnerable background or the fear of increasing the stigma attached to their refugee status. Seagle et al. recommend three key areas that would provide a supporting structure to the ethical framework developed to guide research on refugees: *engage, educate* and *empower* (125). To engage with stakeholders, community leaders and community members throughout the investigation, to educate investigators on topics such as cultural competence and ethics, and to ensure that participants fully understand that participation is voluntary is of the utmost importance. In terms of our research, we travelled to the recruitment site to secure an understanding of the project among all stakeholders, including training with all data collectors. All recruitment sessions started with information on the study communicated orally and with emphasis on the voluntariness of the project and its independence from the resettlement process and authorities. Also, the participants had already been granted refugee status, had gone through the UNHCR selection scheme and had received a residence permit in Norway before study enrolment. To secure the relevance of the study outcomes, we involved a Syrian user representative as part of the reference group that we regularly sought advice from. Additionally, we had close contact with the refugee population, both clinically in medical practice, as well as with the Syrian refugee community in Bergen and Kristiansand. Ethical approval was obtained from the Regional Committees for Medical and Health Research Ethics (REC) of South East Norway (ref. no. 2017/377). Informed consent was obtained from all participants. Data were de-identified and stored on a secure server.

11. Main results

In this section, I present a synopsis of the results of the three papers.

11.1 Paper I

Do the health status and QoL of resettlement refugees improve or decline shortly after resettlement? If so, what modifies this change? Where do the QoL scores stand in comparison with the Norwegian population and with international samples?

In the first study, we investigated changes in SRH and QoL pre- and post-resettlement in Norway. The study cohort had a median age of 34 years and 49% were males. Participants had an average of eight years of schooling and three out of four respondents were married (75%). Most of the participants had been migrants for approximately five years at baseline. A majority had high health literacy (56%) and approximately one third (35%) had high social support.

In the GEE-analysis, we found that the percentage of participants reporting good SRH showed a non-significant increase from 58% to 63% from Lebanon to Norway, while mean values of all four QoL domains increased significantly; the physical domain from 13.7 to 15.7, the psychological domain from 12.8 to 14.5, social relationships from 13.7 to 15.3, and the environmental domain from 9.0 to 14.0. Trajectories of SRH showed that most participants rated their health as good and kept this view of their own health at both time points (46%) while 17% showed an improvement in SRH from Lebanon to Norway (figure 9). In the effect modification analysis, we found that positive effect modifiers for improvement in SRH and QoL over time included male gender, younger age, low level of social support in Lebanon and lack of residence permit in Lebanon. When comparing data from our participants with the Norwegian population and international reference points of QoL, we found that the social relationship and environment domain of QoL surpassed the levels of Norwegian and international reference scores after resettlement (figure 10).
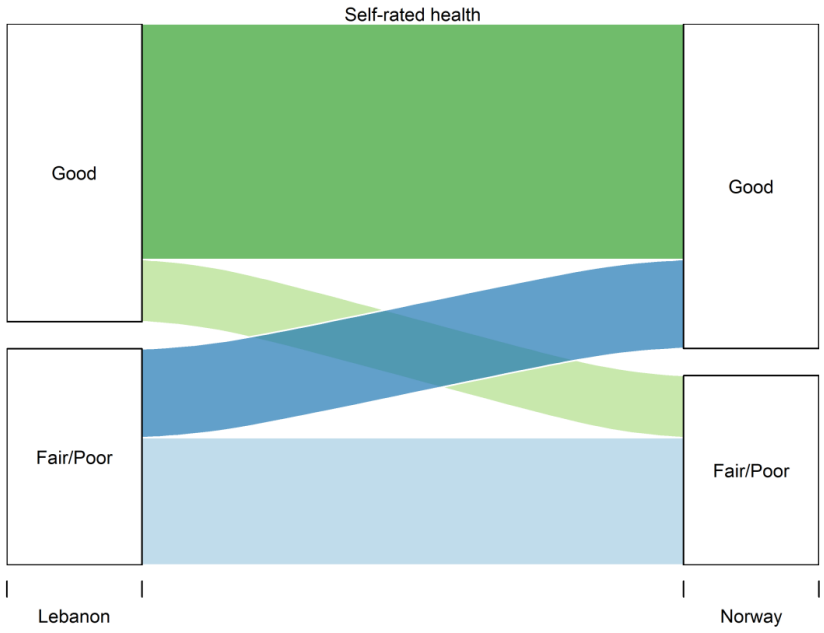
Figure 9. *Sankey chart showing trajectories of SRH from baseline to follow-up.*
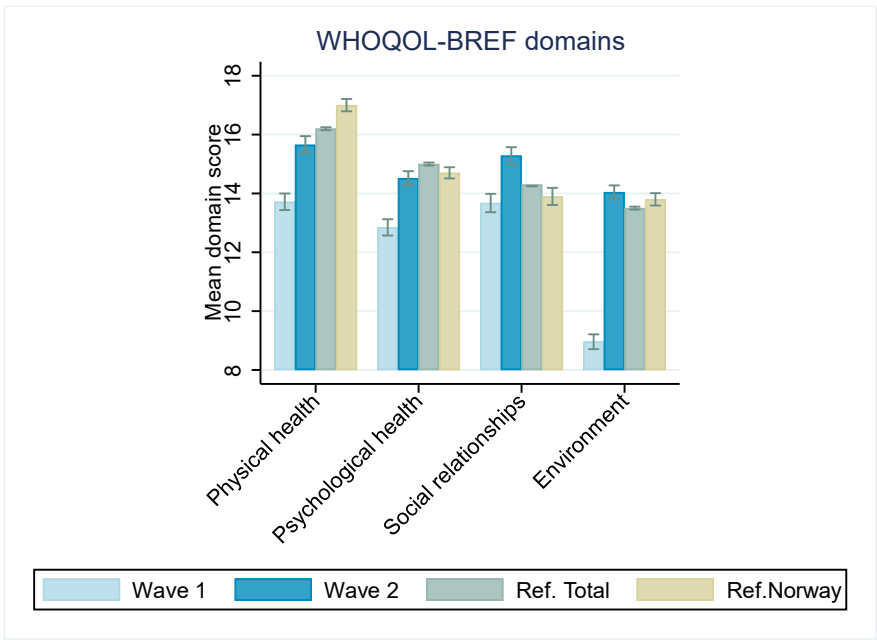
Figure 10. Mean (SD) scores for the continuous outcome (WHOQOL-BREF four domain scores, range 4–20) from baseline to follow-up compared with data from the WHOQOL-BREF field trials from Skevington, Lofty & O'Connell (2004), both Ref.Total and Ref.Norway are retrieved from this paper. Error bars represent 95% CI.

11.2 Paper II

Does the use of healthcare services among resettlement refugees change pre- and post-resettlement? If so, what are the factors in the pre-arrival context that can predict later use of care? What are the factors associated with use after resettlement?

In the second study, we investigated changes in the use of healthcare services (GP, EC, outpatient/specialist care and hospitalization) pre- and post-resettlement in Norway in the same cohort of Syrian refugees resettling from Lebanon to Norway.

Of the 353 participants, 33% visited a GP in Lebanon, 32% visited outpatient/specialist care, 16% were hospitalized, and 10% used EC in the 12 preceding months at baseline. In Norway, the use of a GP increased to 85% and the use of EC to 18%, while hospitalizations remained the same and outpatient/specialist care visits dropped to 16%. In figure 11, we present Sankey charts showing trajectories of healthcare service use. Most participants did not use EC, outpatient/specialist care or hospital care either at baseline or at follow-up. Hence, the biggest change in trajectory is the increase in the use of a GP from pre-arrival to after resettlement.
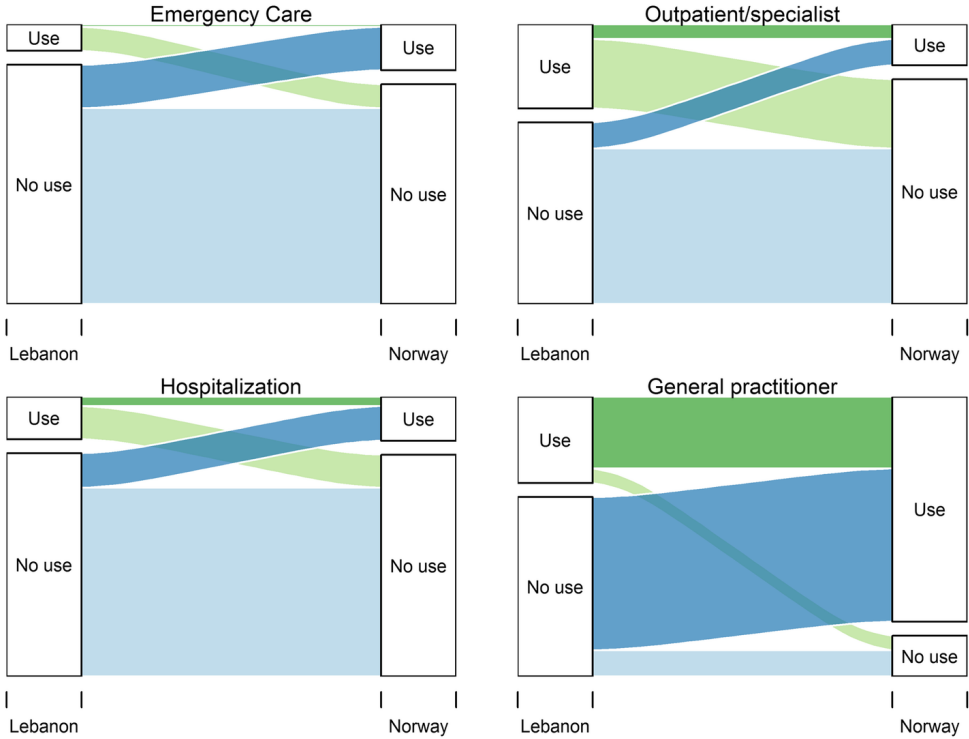
Figure 11. *Trajectories of healthcare utilization from baseline to follow-up*

In the regression analysis, we found no significant associations between pre-arrival sociodemographic factors and the use of healthcare services at follow-up, except for higher age. With regard to health status pre-arrival, we found that poor SRH was significantly associated with increased risk of EC use after arrival and lower scores in the social relationships' domain of QoL (i.e. poorer social relationships) were significantly associated with EC use after arrival. With regard to migration-related factors, not having a residence permit in Lebanon was significantly associated with EC use after arrival.

When in Norway, higher age was still significantly associated with the use of EC services and hospitalization. Likewise, increased health literacy was significantly associated with the use of a GP and EC and hospitalization. Similarly, high social support (ESSI) was significantly associated with increased risk of EC use, use of outpatient/specialist care and hospitalization, and an increasing education level was

associated with hospitalization. When looking at health status, we found that poor SRH was significantly associated with EC use and hospitalization. Generally, lower scores in the different QoL dimensions were associated with higher use of services. However, higher scores in the environmental domain of QoL were significantly associated with the use of a GP (see table 3 in paper II for details).

11.3 Paper III

How do refugees experience changes in health pre- and post-resettlement and what is their experience with healthcare service use in Norway?

In this study, we were able to shed light on many of the how questions arising in the two previous papers. The aim of the study was twofold: to explore perceived changes in health status among Syrian refugees as well as their own experiences with access and use of healthcare services pre- and post-resettlement. We identified three main themes that summarize the factors that emerged during the interviews: *changes in health and well-being*, *expectations* and *trust.* The first theme deals with perceived health status change where primarily three trajectories were represented in our material: no perceived change, feeling of an improvement in health status and, lastly, feeling of a health decline. Decline in health was commonly attributed to unemployment and a sedentary lifestyle among males, while women pointed to role overload with difficulties balancing cultural identity and new responsibilities outside the home after resettlement. In contrast, the perception of an upturn in health was frequently attributed to relief, security, improved living standard and easier access to different types of services. We also found that the types of health challenges varied with the resettlement phase.

The two other themes, *expectations* and *trust*, address refugees' experiences with the Norwegian healthcare system and the healthcare encounter. Based on the data on healthcare access represented in the two themes, a conceptual model was developed

(figure 12). The conceptual model outlines a pathway from expectations of healthcare to experiencing trust or distrust in the system and its providers by key elements along the way. We have highlighted three elements in this proposed pathway—*perception of caregiver*, *communication* and *time*—grounded in our data. These elements can either serve as barriers or facilitators to achieving trust. The point of the model is to highlight how different parts of the care-access process interact to reach the endpoint of either fulfilled or unmet healthcare needs, and the parallel process of healthcare seeking and acculturation. As shown from our data, negative experiences from healthcare seeking can amplify an already existing feeling of separation from society leading to more distancing, which in turn can have an impact on how health needs are met and the use of regular and alternative healthcare services. In contrast, positive experiences follow a positively reinforcing root based on trust and integration. A positive experience enhances trust and motivates further use of the healthcare system which in turn strengthens the acceptance of the Norwegian system and society.

Figure 12. *The Migrant Sensitive Access Model*

11.4 Summary of key findings

Paper I	• Overall health remains stable and QoL improves during the first year in Norway. • Persons with poor socioeconomic conditions (i.e. no residence permit and poor social support) in transit experience a larger increase in health and QoL after arrival.
Paper II	• Pre-arrival factors such as undocumented status, poor social relationships and poor SRH predict healthcare service use after arrival. • High health literacy, education level, social support and good living conditions in the resettlement country are associated with healthcare use. • A large majority (85%) visited the GP in the first year after arrival.
Paper III	• Changes in health status were gender-related. Males attributed a decline in health to unemployment and a sedentary lifestyle, while women pointed out role overload and stress as the main causes of their health decline. • Health and healthcare access is dynamic, closely interrelated to the acculturation process, and informed by pre-migration and migration experiences. • Refugees face many barriers beyond entitlements and costs. Many of these barriers can be bridged by achieving a trustful relationship with the healthcare system and its caregivers. • The conceptual model we offer—The Migrant Sensitive Access Model—highlights the key factors that shape the healthcare experience of refugees, resulting in either trust in or distrust of the healthcare system.

Table 4. *Overview of key findings from the three papers*

12. Discussion

In this section, I first discuss the main findings of this study by placing them in a broader context with emphasis on what we have learned (12.1), followed by a discussion on methodological considerations (12.2).

12.1 Main findings

Paper I described how the health and QoL of Syrian refugees improved after resettlement in Norway, with larger improvement among men, the young, and persons with poor socioeconomic conditions in Lebanon. In paper II, we found that peri-migration factors such as undocumented status and poor SRH predict later healthcare use. We also found that persons having an advantage in terms of health literacy, education and social support make use of healthcare services more than their non-privileged peers after resettlement. In paper III, we saw that changes in health and use of healthcare services before and after migration are dynamic and intricately linked to acculturation. We identified the perceived causes for change in health status post-arrival, as well as salient features in the care-access journey, and introduced a framework to healthcare providers to address these challenges.

In the background section to this thesis, I presented different theoretical frameworks which will be used to interpret and discuss our findings. With the use of theoretical perspectives, the importance of having a trajectory perspective in migration and health research was underlined, to document shifting challenges across time. Secondly, the importance of recognizing the personal and social resources counterbalancing vulnerability through a risk and protective factors perspective was highlighted, with a focus on salutogenesis. Lastly, I emphasized the value of viewing migration as a health determinant grounded in several levels affecting health, with micro-, meso- and macro-level factors leaning on both Dahlgren and Whitehead's social determinants of health model (98) and Bronfenbrenner's ecological systems theory (21), to highlight that an attempt to address migrant health determinants needs to be multidimensional and interdisciplinary.

12.1.1 What happens to refugees' health and their use of healthcare services after arrival?

Consistent with the exhausted migrant theory, our pre-study hypothesis was that the health of refugees will most likely decrease over time after third-country resettlement. However, data on the health status of refugees shortly after resettlement is scarce and we had poor information on what happens in the early post-migration stage. We expected to capture some of the effect of post-migration stressors, posited to be particularly high after resettlement (126, 127). On the other hand, in view of the risk and protective factors perspective, we also anticipated a health impact of protective factors. In what direction the sum of all these factors would lead us was yet to be explored.

A theoretical view

Findings of an overall health improvement in the early post-migration stage may be explained by structural factors at meso- and macro levels. First, the dramatic improvement in environmental factors such as the standard of living, access to healthcare and having enough money to meet needs etc., are probably strong contributing factors to better health. This is supported by the fact that the environmental domain showed the largest improvement out of the four health domains of QoL among our participants. Moreover, this is presumably enhanced by a supportive resettlement programme upon arrival. The resettlement programme—resettling refugees under the UNHCR mandate—is a well-organized process aimed to quickly establish refugees in the receiving community by securing access to a GP, language programme and housing at an early stage. This is in sharp contrast to the resettlement process encountered by refugees who were previously asylum seekers arriving in Norway on their own. Several studies support the notion of refugees arriving as asylum seekers having worse health outcomes than their resettlement refugee counterparts. For instance, a German study found that asylum seekers presented with mental and behavioural disorders nine times more often than

resettlement refugees (128). Additionally, prolonged asylum decisions and lack of refugee status have proven to be detrimental to health (129, 130), showing a mental health disadvantage in refugees with temporary residence protection and stringent reception upon arrival (1). Hence, we may be reaping the fruits of stability and predictability, of reducing the stress of uncertainty by quick determination of legal status, of providing quick settlement in the municipality and avoiding temporary housing, as well as facilitating access to care by quick attainment of a GP. All of which the resettlement programme includes.

Secondly, I argue that individual factors at the micro level may play a role in the stability and improvement of our participants' health trajectory. *Resilience*, denoting inherent resilient factors and resources among the participants' buffering stressors (89), and temporary *euphoria* after arrival as explained in the disillusionment model are two such factors (66). The fact that all domains of QoL increased points to overall improvement across different aspects of life and health. This may be indicative of a strong capacity for adaptability and coping among the studied refugee group. The young median age of our cohort probably also boosts this adaptability. In terms of euphoria of arrival, this model when first launched was based on the mental health trajectory of migrants. However, given the strong interlinkage between different forms of health in line with a holistic and biopsychosocial understanding, one can assume that the euphoria of arrival also affects other health domains. On the other hand, evidence supports a rather short euphoric stage, showing that refugees with a length of stay of 10–12 months had higher rates of depression than those arriving earlier (131).

In view of the healthy migrant/exhausted migrant theory, over half of the refugees in our cohort rated their health as good at baseline (58%), corresponding to levels measured in Syrian adults residing in pre-war Syria (55.3%) (118). In contrast, in the general Norwegian population, over 70% rated their health as good (132). Although differences in demographic composition between cohorts make direct comparison challenging, it appears that our cohort did not have an evident health advantage when

compared with either their home country population or the recipient country population. While our quantitative findings only look into the first year post-resettlement, qualitative findings may imply a later health decline or at least changes in the type of challenges met with emerging social exclusion and economic difficulties later into resettlement.

The changes in healthcare utilization documented in paper II probably reflect changes in healthcare system structures at the macro level, and the move from a highly privatized healthcare sector in Lebanon to universal health coverage in Norway. However, some of the findings could imply factors other than system change. We found that refugees with better socioeconomic conditions after resettlement utilize healthcare services more than their unprivileged counterparts. The fact that socio-economic status (SES) plays a vital role in the access and utilization of healthcare services is well known. Unemployment, economic disadvantage and poverty have repeatedly been shown to hamper access and use of healthcare services (133). In contrast, having high health literacy and educational level facilitates healthcare-seeking behaviour and use of healthcare services, including uptake of health information (134). What is interesting in terms of our cohort is that we are seemingly dealing with two different health determinants: migrant background and socio-economic status. This is in line with evidence supporting the notion of migrant background and low socio-economic position being two independent risk factors for poor health (135). Even though this thesis cannot fully disentangle the interaction between these two sets of health determinants and their full effect on health, the interlinkage of the two concepts should be acknowledged and underlined. This echoes with the concept of syndemic vulnerability mentioned in the background section of this thesis, where refugees and other migrants are at risk of concomitant and harmfully interacting forms of health adversity (87).

The high rates of GP use (85%) after arrival may be explained by the fact that in some Norwegian municipalities, the general health assessment upon arrival is

performed by a GP. Despite having a separate question for the general health assessment, we assume some participants might have had difficulties distinguishing between the two alternatives as both entail contact with a primary care doctor. Another possibility is that some refugees were derived to a second visit by the GP at the first encounter for their general health assessment. Nonetheless, it is important to acknowledge the key opportunity GPs have in responding to the need of the refugee patient in early resettlement as the first point of contact. What is important to highlight, however, is that even though care is seemingly accessed, quality of care cannot be guaranteed, meaning whether the care received is effective and if needs are adequately met (136). This is stressed in the findings from the qualitative part of this thesis that accentuates the importance of trust, communication, and time in the doctor-patient relationship to ensure healthcare access and reducing unmet healthcare needs.

An empirical view

Relating our findings to the wider literature, I have sought to identify key longitudinal studies that look at changes in health in the first years after resettlement. Much of the identified literature supports a decline in health. For instance, studies show increasing rates of psychiatric morbidity after one year of resettlement among refugees from near-conflict settings (137, 138) and a gradual decline in overall health five years into resettlement (139). A Canadian study focusing on when the decline occurs showed a rapid decline in physical and mental health in as little as two years after arrival (52). However, results pointing in the opposite direction also exist. Data from an Australian longitudinal study on humanitarian refugees showed no significant change in overall health three years after resettlement, i.e. a stable health trajectory (140) in line with our findings on SRH. Additionally, a long-term follow-up of Vietnamese refugees to Norway showed decreasing rates of mental distress over time (141). However, none of the available studies identified for comparison include a pre-arrival assessment. Hence, we are not really able to compare changes in health pre- and post-arrival with any other study. Notably, the discrepancy in results in the available research underscores the importance of talking about specific refugee waves contextualized to the situation they are in, as well as adhering to precise definitions of

participants (asylum seeker, resettlement refugee, family reunification, etc.) and disaggregating data when possible, to understand what mechanisms drive change in health status.

Although there are a couple of longitudinal studies assessing the health of refugees, there is a profound scarcity of studies assessing healthcare use among refugees longitudinally. Contextualizing the findings on healthcare utilization has therefore proven to be complicated. Longitudinal studies from Canada showed that the health status of recent migrant arrivals declines towards that of the non-migrant population, while healthcare utilization increases with the duration of stay (142, 143). However, the data is more than 10 years old and the studies are not refugee specific.

The migration experience

We found that poor peri-migration conditions impact both health change and healthcare use after arrival. This aligns with previous research showing that the stable conditions experienced after resettlement greatly exceed the living in limbo conditions in transit (144) and, as previously mentioned, that uncertain legal status has proven to have a detrimental effect on health (130). Hence, the great relief of having documented status seems to have a strong positive health impact among our participants. In terms of healthcare use, the lack of recognized documentation in a country complicates the availability of healthcare and one can assume that acute and/or chronic diseases left uncared for contribute to higher use of care post-resettlement. Consequently, securing minimum acceptable living conditions for refugees in transit countries should be a priority concern globally.

Gender

In the quantitative data, we found a stronger improvement in health among men than women. In addition, qualitative findings show that the reasons for perceived change in health status are gender-related. These findings cohere with a recent longitudinal study on Australian refugees which shows that post-migration stressors have different trajectories depending on gender (145). Thus, our findings call for greater awareness

of the impact of gender on the migration experience and its relation to later health outcomes, a research field that to date has been poorly covered (146, 147).

Health access, acculturation and relationship with caregiver

Acculturation at both population and individual levels is believed to shape patterns of refugee health and morbidity (148), posited to be a poorly explored factor that impacts healthcare access (149). Our findings in paper III show that acculturation is strongly linked to the access and use of healthcare services, both of which follow somewhat parallel trajectories.

Despite universal health coverage with no economic or legal barriers to healthcare, findings from paper III revealed barriers to healthcare resulting in unmet health needs and alternative health-seeking behaviour. Trust emerged as a fundamental part of the care-access journey for our participants. Enough trust in the services is a prerequisite for reaching out, and a trustful relationship with the caregiver is pivotal to further acceptance and maintenance of service use. Findings align with a string of literature supporting patient-centred culturally-sensitive healthcare (150).

In addition, moving beyond the healthcare system, several findings from all three papers of this thesis advocate for the importance of non-health policies and their effect on health. This is in line with previous longitudinal research on migrants showing that limitation on employment is a strong risk factor for depression, particularly among men (53). This points to the significance of a holistic understanding of health in line with the theoretical model on Social Determinants of Health introduced earlier in this thesis. While the effect of a major life transition on health is inevitable, this effect can be modified by supportive resources and policies. This is also in line with WHO's *Health in All Policies* approach, calling upon ministries to take efficient action on the social, economic and environmental determinants of health (151).

Returning to the vignette of the Syrian father at the start of this thesis, I checked up on how he was since our conversation a year before. His answer confirms the

importance of viewing the determinants of health at all levels as an integral part of refugee health in the resettlement process.

During the last couple of months, I have been working as a salesman in the local grocery store. You know that I am a lawyer, but I am happy to just have a job. I am glad to be the provider of the family. I feel healthy and relieved. At least now I have hope and maybe one day I will be able to work in my profession.

- *A Syrian refugee in Norway (May 2021)*

Figure 13. *The CHART logo. The CHART logo was designed by a Syrian refugee. He explained how the logo reflects the migration experience of many refugees, as they cross water and climb mountains to reach their final goal. In the end, there is an icon of a refugee getting a job, going to work, being a part of society—a symbol of successful integration and probably also of good health.*

12.2 Methodological considerations

In this section, I first discuss the methodological considerations of the quantitative part of the study (12.2.1) and thereafter address the qualitative part (12.2.2).

12.2.1 Quantitative part

The overall strengths of the quantitative part of this study include a longitudinal study design, with a unique pre-arrival assessment following a cohort of refugees crossing international borders. Participation at baseline was almost complete, followed by a high response rate at follow-up. In addition, the use of mainly validated instruments in Arabic, many of which have previously been used among Syrian refugees, and a homogenous sample in terms of country background add to the strengths of this study. However, all research is encumbered with methodological limitations. I will approach the discussion on limitations by first describing the study design and then assessing its internal and external validity.

Study design

We used a prospective longitudinal design with a pre-arrival assessment, which to our knowledge is a novel contribution to the research field. However, in view of the migrant trajectory perspective and life-course epidemiology, one can argue that a one-year follow-up is too short (85). Preferably, we should have had more information from the pre-migration stage, including from childhood into adulthood, and a longer follow-up into resettlement. Of course, this poses methodological challenges beyond the scope of this study. With regard to sampling, this study lacks an overall sampling frame. We relied on non-probability sampling due to the non-existence of registries on which we could base a random sample. Furthermore, we do not have a control group, a commonly used methodology in migrant research (152). Having a group with a similar background not exposed to migration was deemed methodologically unfeasible given the situation in Syria during study commencement. However, in retrospect, another more viable possibility could have been to have a comparison group with Syrian refugees remaining in Lebanon that were not selected for third-country resettlement to compare health trajectories with. Initially, the study plan was to recruit refugees through the EU relocation scheme. This would have allowed the comparison of different migration trajectories. However, this was not possible after the EU relocation scheme ended in September 2017. Noticeably, the feasibility of our research has been highly linked to the international and national political environments around migration.

Internal validity

Internal validity relates to drawing conclusions about the source population. There are mainly three sources of systematic error important to consider in observational studies relevant to internal validity: selection bias, information bias and confounding (153).

Selection bias

The identification of individuals being in need of third-country resettlement by the UNHCR, in collaboration with the receiving country, naturally affects the profile of the participants included in the quantitative part of this study (154). The selection profile emphasized by the Norwegian government in the country chapter of the *UNHCR Resettlement Handbook* (108) includes families with children under the age of 18, women and girls at risk and persons with health needs. Hence, the selection on vulnerability criteria might cause an over-representation of persons with poor health in our sample. Given the explained selection process, the Syrians recruited to our study may not represent the Syrians residing in Lebanon, but probably represent other Syrian resettlement refugees in Norway. Selection bias could possibly have affected prevalence estimates such as percentage points and means, but effects on association measures such as risk ratios (RR) and regression coefficients are more unlikely (155). Almost all participants invited at baseline commenced with the study, and the response rate at follow-up was high (76%). This decreases selection bias and strengthens validity. Additionally, we performed a sensitivity analysis with comparison between our participants and the loss-to-follow-up group, finding significant differences only in the health literacy variable.

Information bias

Information bias occurs during data collection. Observational studies relying on self-report are generally prone to information bias caused by the inaccurate recall of past events that may produce misclassification. Misclassifications can either be non-differential (random) or differential (non-random) (156). A non-differential classification error happens when the information is incorrect but is the same across

the study population. In our study, there is a possibility of non-differential misclassification, particularly in terms of the variable health literacy assessed by SILS. This instrument has, to our knowledge, not been validated in a refugee population with poor language skills before. We have relied on previous research showing a strong correlation between SILS score and S-TOFHLA (which is often used as golden standard) and research supporting SILS as possible predictors or screeners of health literacy (109, 157, 158). However, these references lack sufficient information on minorities and persons who do not speak the majority language of the country and/or have poor language skills. This type of error may result in an underestimate of the true strength of an association. In addition, non-differential misclassification may have affected the question on healthcare utilization as we did not assess frequencies of contact with the healthcare services; we used only yes/no answers for at least one contact. Because of this we are unable to separate between frequent users and persons who have only used the service once. This may have diluted the effects and given RR estimates closer to 1. Moving on to differential misclassification, this can occur when the information is incorrect and differ in the study population. As we made a deliberate choice to change the assessment method between the first and the second points of data collection to prevent attrition, we introduced the possibility of interviewer bias and, theoretically, the possibility of differential misclassification. In addition, the interviews may have had an impact on how the participants answer the questions and their desire to please the interviewer known as social desirability bias (159).

Confounding

Confounding, referring to the effect of an exposure being mixed up with the effect of another variable, is a constant challenge in observational studies. When confounding is present, the confounding variable must be associated with the exposure, in addition to being a risk factor of the outcome, but cannot be an intermediate step in the causal pathway (156). In paper II, we looked for associations between different exposure variables, both in transit and after arrival, and healthcare utilization. DAGs were used to address confounding and to avoid the mistake of over-adjustments. The main outcome was the use of healthcare services at data collection point 2 (in Norway). In

the regression analysis, we made a model for each exposure variable and adjusted for the relevant confounders for each model as outlined in the DAG. For instance, for the total effect of health literacy at baseline on use of health services in Norway, age, gender and education were potential confounders, while SRH at baseline was considered a mediator and not adjusted for (figure 14). However, DAGs are merely tools and rely on the knowledge of the researchers. Thus, the possibility of confounding is minimized but not eliminated. Contrary to over-adjustment, the lack of data may lead to unknown or unmeasured confounding, known as residual confounding (160). For example, we did not include data on dietary habits, alcohol use, smoking and physical activity that might impact healthcare use. However, we had information on SRH and QoL that we interpreted as participants' overall health status.
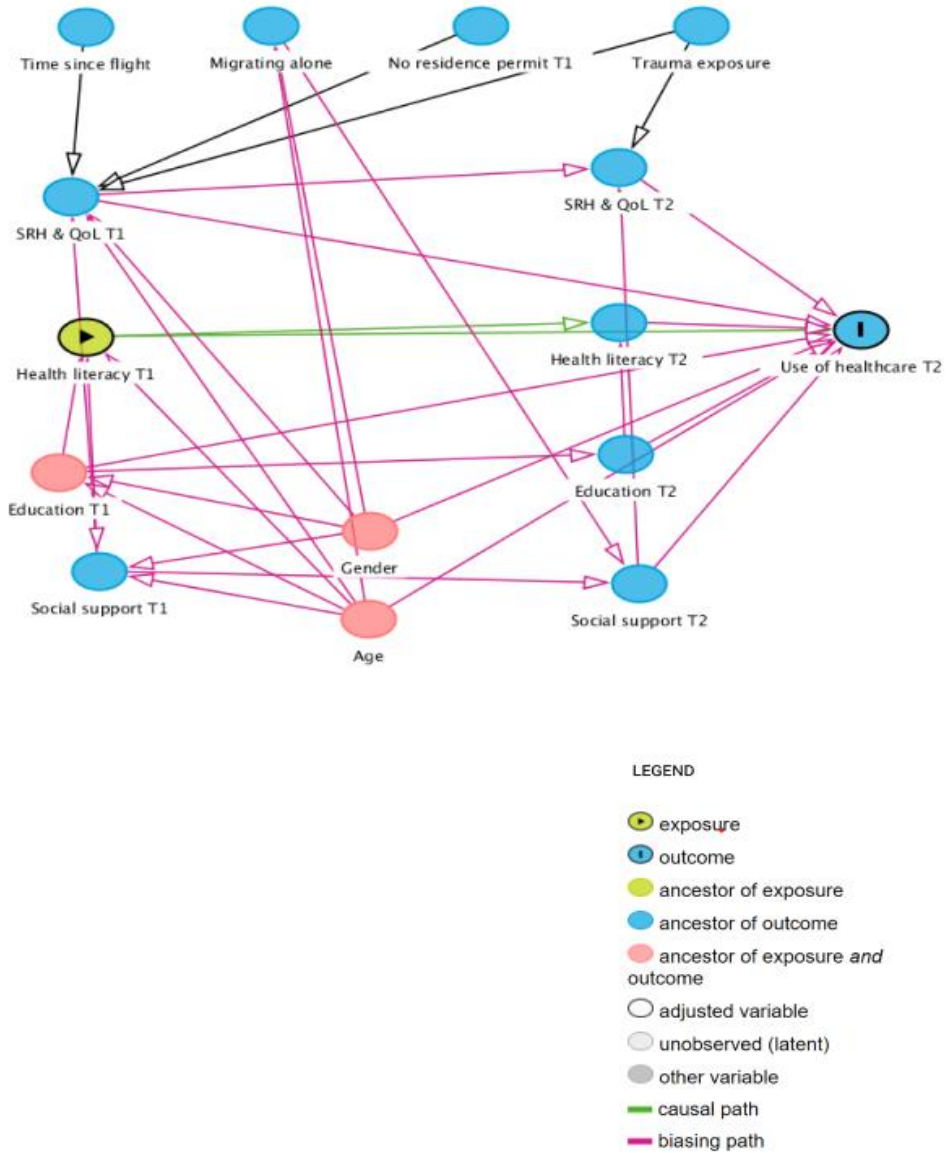
Figure 14. *Directed acyclic graph (DAG) of a model of causality depicting healthcare use at follow-up as outcome and health literacy at baseline treated as exposure.*

External Validity

External validity, or generalizability, is to apply your conclusion to another population. We believe our study results may be generalizable to other Syrian refugees selected for third-country resettlement to other Nordic countries. Generalizability is strengthened by the fact that we assessed approximately 12% of Syrian resettlement refugees arriving in Norway in the given period (2017–2018) (161) and had a low attrition rate. However, generalizability to other subsets of forced migrants should be done with caution. Diversity in the migration trajectory, in part based on legal status throughout the journey, might include other types of risk factors that our participants do not necessarily face. This is particularly evident in terms of refugees initially arriving as asylum seekers.

12.2.2 Qualitative part

To evaluate the trustworthiness and rigour of qualitative research, the most recognized quality criteria are the concepts of *credibility, dependability, transferability, confirmability* (162) and *reflexivity* (163). I discuss the trustworthiness of the qualitative part based on the aforementioned criteria ahead.

Credibility, dependability, transferability and confirmability

C*redibility*, denoting the truth value and appropriateness of the research (164), refers to the steps taken to ensure the accuracy of the findings. The use of an established method of data generation, a sample that reflected diversity and the fact that all the interviews were conducted in Arabic with a Syrian dialect add to the credibility. This probably helped increase the trust between the participant and researcher through familiarity, as well as minimize information lost in translation. Triangulation was performed to secure a maximum variation sample from different geographical regions in addition to investigator triangulation by securing two independent data analysis. Even though we used purposive sampling to achieve a diverse sample, we did not ask about legal status when arriving in Norway (asylum seeker, quota refugee, family reunification) to ensure diversity in migration trajectories, nor have we included any single persons (never married). This may imply a limitation since perspectives related

to young single persons were probably not adequately explored. Judging from the data, we achieved diversity in migrant background and legal status even if we did not directly ask for this during sampling. Adhering to a well-known data generation and analysis process, with individual interviews analysed with Systematic Text Condensation, strengthens both the *credibility* and the *dependability* of the research. The use of telephone instead of face-to-face interviews could contribute to apprehension in the interview situation and loss of non-verbal communication. On the other hand, the use of telephone interviews allows for more anonymity. For example, in cases where participants were dissatisfied with the healthcare system, they valued this anonymity as it made them talk more freely. *Dependability* refers to the process of accurately selecting, justifying and applying research methods and strategies (165). Many of the steps taken to ensure credibility also contributes to the dependability of the study. *Transferability* addresses the range and limitations of the application of study findings (163). Hopefully, the description of the study is thorough enough for the reader to assess the transferability of the findings to other settings. I argue that several aspects of the findings can be relevant to other refugees if contextualized. However, the nature of this research makes it highly dependent upon receiving countries' policies and regulations. *Confirmability* addresses neutrality and to what degree findings are based on the data analysis. Keeping field notes, having two independent analyses and peer debriefing with supervisors throughout the study period helped increase this factor.

Reflexivity and positionalities

Reflexivity and positionalities involve several social characteristics that are context-related (163). The process of self-reflection on my social identity and position in this research started at the beginning of the study and has been an ongoing process. Because of my Syrian background, many participants referred to me as their fellow national, at times saying, "You know how it is in our country". I tried to avoid this situation because I wanted them to elaborate on the question as to not lose important information. I could not relate to the distinct "insider-outsider" divide commonly referred to in minority research (166). In contrast, I perceived my position as fluid, with many layers, influenced by several other factors apart from nationality, language

and country. Although I share a cultural background with the participants, my ideas, expressions and values are also shaped by a western frame of reference. This bicultural base has influenced positionality, the interaction with the participants and my interpretation of the findings.

13. Conclusions

In this thesis, we have followed a cohort of Syrian refugees from a conflict-near setting in Lebanon to their arrival in a safe welfare state, Norway. We have witnessed how the refugee cohort keeps a stable health trajectory, while QoL shows a strong improvement after one year of stay in Norway. This stability and improvement in health and QoL is the most prominent finding of this thesis. A finding that highlights strong resourcefulness and adaptability.

Moreover, this study underpins the impact of peri-migration conditions on future health and health service use, calling for recipient countries to secure needs being efficiently met at an early stage among refugees living with limited formal rights prior to arrival.

While receiving countries may have limited opportunities to impact conditions in the peri-migration phase, these possibilities increase post arrival. Findings from this thesis underscores the importance of good socio-economic conditions on health service use. This may be important protective factors to improve access and utilization of healthcare services for refugees with poor resources and could be promising targets in future health interventions.

To address inequities in healthcare in recipient countries with universal health coverage, it is important to understand how barriers other than entitlements and affordability come into play in the care-access journey.

14. Future perspectives

14.1 Recommendations for policy and practice

Good health is a prerequisite for successful integration and our results support a good starting point. However, how to sustain this witnessed improvement in health and QoL is an important follow-up question. This study implies that a quick resettlement process has important positive health implication. Mitigating post-migration stress by providing adequate supportive resources upon arrival, including access to healthcare services and a GP at an early stage, can be viewed as a health investment, with a positive impact on acculturation. An early investment that probably has a long-term benefit. This aligns with previous research, suggesting that the biggest gains in integration are made in the first year (167). Even though the resettlement programme designed for resettlement refugees seem to have factors that buffer some of the post-migration stressors, this is not the case for other subcategories of forced migrants such as asylum seekers. Thus, there might be a health gain in securing some of the benefits included in the resettlement programme to other subcategories of migrants in line with WHO's Health in All Policies approach.

While our quantitative results support a health improvement within the first year after resettlement, qualitative findings indicate a later health decline attributed to mainly two factors: barriers to healthcare access and the health effects of non-health policies such as unemployment.

In terms of healthcare access, efforts should be made to increase diversity sensitive care, specifically among GPs given their important role as the first port of call for refugees. Here, The Migrant Sensitive Access Model may be useful in reflecting the views of the refugees themselves. Securing an early and continuous relationship with a GP while at the same time increasing knowledge among caregivers in primary healthcare to be able to respond to this task appropriately is recommended. Consistent with well-known migration theories and supported by our qualitative findings, efforts

should be made to raise awareness among caregivers that a later health decline might occur. Hence, a health assessment a couple of years into resettlement could be beneficial to catch the long-term effects of migration. In addition, awareness should be raised of the most disadvantaged refugees (with lowest SES) that might have more barriers to healthcare along the lines of a social determinant of health perspective. Low SES in combination with a migration experience could possibly enhance the likelihood of health disparities consistent with syndemic vulnerability. Along the same lines, social support, education and health literacy can be viewed as protective factors and could be targeted in future interventions aiming to increase access to healthcare and health equity. Finally, we should consider evaluating self-perceived unmet health needs in the health assessment upon arrival as a means to secure early access to healthcare.

In terms of the effect of non-health policies on refugee health, this matter calls for a coordinated response at several levels. Securing acceptable conditions in transit countries is an international concern and should be prioritized globally. After resettlement, receiving countries should secure both short-term and long-term responses with a holistic approach, recognizing that the health of refugees is determined by multiple factors outside the direct control of the healthcare sector. Working to achieve the right to the "*highest attainable standard of physical and mental health*" includes access not only to healthcare but also to the underlying determinants of good health.

Lastly, our findings revealed a clear gender perspective that has been poorly explored in previous research. Employment among men seems to be a health investment, while for women accounting for role overload could be a health investment. This needs to be explored further. However, I recommend greater awareness of the impact of gender in the migration experience and in the resettlement programme and potentially the validation of gender-specific interventions (145).

14.2 Recommendations for future research

In future research, I suggest more knowledge on salutogenic processes among refugee populations to understand what mechanisms drive the witnessed improvement in health and how to sustain it. In the same vein, furthering the understanding of protective factors among refugees may be important both for the studied group as well as other populations exposed to adversities.

Longitudinal research with longer follow-up time including a multidimensional understanding of health could provide important answers regarding changes in health pre- and post-migration. Preferably with the inclusion of forced migrants exposed to different migration trajectories with different background and legal status. Longitudinal research on the healthcare utilization of refugees and other migrants is almost non-existent to date. Such research could offer important knowledge on healthcare use and access trajectories and will probably equip us to address inequities in healthcare access better.

Given the complexity of the research field, interdisciplinary approaches with standardized monitoring of health variables and strong support from the refugee communities are recommended to enhance the representativeness of research findings.

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16. List of appendices

Part A - Papers

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    Paper II

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Part B - Ethical approval and informed consent

    Ethical approval from the Regional Committees for Medical and Health
    Research Ethics (REC) of South East Norway and amendments

    Informed consent form used at baseline (English)[1]

    Informed consent form used at follow-up (English)

Part C - Questionnaires

    CHART Questionnaire 1 used at baseline (English)

    CHART Questionnaire 2 used at follow-up (English)

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[1] Informed consent forms, questionnaires and the interview guide are available in Arabic upon request.

PART A - PAPERS

RESEARCH   **Open Access**

Changes in self-rated health and quality of life among Syrian refugees migrating to Norway: a prospective longitudinal study

Jasmin Haj-Younes[1*] , Elisabeth Marie Strømme[1], Jannicke Igland[1], Bernadette Kumar[2], Eirik Abildsnes[3], Wegdan Hasha[1] and Esperanza Diaz[1,2]

Abstract

Background: Forced migrants can be exposed to various stressors that can impact their health and wellbeing. How the different stages in the migration process impacts health is however poorly explored. The aim of this study was to examine changes in self-rated health (SRH) and quality of life (QoL) among a cohort of adult Syrian refugees before and after resettlement in Norway.

Method: We used a prospective longitudinal study design with two assessment points to examine changes in health among adult Syrian resettlement refugees in Lebanon accepted for resettlement in Norway. We gathered baseline data in 2017/2018 in Lebanon and subsequently at follow-up one year after arrival. The main outcomes were good SRH measured by a single validated item and QoL measured by WHOQOL-BREF. We used generalized estimating equations to investigate changes in outcomes over time and incorporated interaction terms in the models to evaluate effect modifications.

Results: In total, 353 subjects participated in the study. The percentage of participants reporting good SRH showed a non-significant increase from 58 to 63% RR, 95%CI: 1.1 (1.0, 1.2) from baseline to follow-up while mean values of all four QoL domains increased significantly from baseline to follow-up; the physical domain from 13.7 to 15.7 B, 95%CI: 1.9 (1.6, 2.3), the psychological domain from 12.8 to 14.5 B, 95%CI: 1.7 (1.3, 2.0), social relationships from 13.7 to 15.3 B, 95%CI: 1.6 (1.2, 2.0) and the environmental domain from 9.0 to 14.0 5.1 B, 95%CI: (4.7, 5.4). Positive effect modifiers for improvement in SRH and QoL over time include male gender, younger age, low level of social support and illegal status in transit country.

Conclusion: Our results show that good SRH remain stable while all four QoL domains improve, most pronounced in the environment domain. Understanding the dynamics of migration and health is a fundamental step in reaching health equity.

Keywords: Self-rated health, Quality of life, Refugees, Transients and migrants

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Introduction

We are witnessing a time in which forced migration is surging and the need to ensure protection, health, and wellbeing of people on the move is ever so vital. This sentiment is echoed in the Sustainable Development Goals of *leaving no one behind* [1]. In every stage of the migration process (pre-migration, during migration and after resettlement) impact on health and wellbeing is inevitable [2, 3]. Possible health risks and potential protective factors influence the health outcomes of the migrant, and there is an ongoing attempt to identify the relevance of each of these factors [4].

Populations at risk of poor health and health care disparities are generally considered as being vulnerable [5]. Migrants may encounter several barriers to health care because of their legal status and due to economic and social marginalization. Forced migrants differ from other types of migrants in that they are survivors of persecution, violence, and war - factors that might add to their health vulnerability. Hence, it remains unclear if the selection described in the 'healthy migrant effect' that postulates migrants' health advantage compared to both citizens in the home country and in the host country holds true for refugees and other forced migrants [4, 6]. The accumulation of stressors leading to deterioration in migrants' health over time have been explained by the 'exhausted migrant theory' [7]. Others have suggested that the migration experience in itself could be the cause of this deterioration [8] addressing the very act of migration as a social determinant for migrants' health [9].

Despite forced migrants' exposures to stressful events, there is also increasing evidence of positive mechanisms like post-stress growth, described as positive changes following adversity [10], and resilience, which is characterized by the ability to exhibit a stable health trajectory in difficult times [11]. Consequently, both adverse conditions rendering forced migrants susceptible for health disparities and the sources of resilience and growth must be considered in attempting to understand migrant health [12]. Furthermore, these factors need to be understood in synergy with contextual factors as well as embedded in a life trajectory, highlighting the different migration stages [13].

Although the body of evidence in terms of morbidity and mortality of migrants in host countries is growing, research on forced migrants throughout their often long journeys continues to be scarce [4], and has largely been limited to cross-sectional designs [14]. Also, previous research on forced migration has focused mainly on mental health [2, 15], often centered on negative health outcomes, predominantly in torture and trauma victims. Knowledge of overall and general health in non-clinical refugee populations remains insufficient.

Self-rated health (SRH) has proven to be a valuable predictor of all-cause mortality and morbidity [16, 17], including in minority populations [2], and is widely used in health monitoring and to research health inequalities. Quality of life (QoL) is considered a fundamental construct in public health that reflects complete wellbeing, going beyond old paradigms viewing health as merely the absence of disease [18].

Migration is a global, multifaceted, and dynamic phenomenon in which the migration experience in itself constitutes an important segment of the health trajectory [8, 9, 13]. In line with recommendations to address multiple phases of the migratory process [3] we aimed to assess general health among Syrian refugees following their health trajectory from a transit setting to after resettlement using a salutogenic approach. Specifically, our research questions are: 1) how does SRH and QoL of forced migrants change from the transit phase to the early resettlement phase? 2) Which factors (sociodemographic, social support, and migration related) can be identified as modifiers of change? As a second aim, we sought to compare our participants QoL-scores with international samples of QoL used as reference points against which we can interpret our findings. We hypothesized that our cohort of forced migrants would have a stable or decreasing health status after resettlement, as a consequence of post-migration stressors such as acculturation stress, poor access to healthcare, cultural discontinuity, loss of social support and perceived stigma and discrimination [2, 3, 19].

Methods

Data for this study were from the CHART project (*Changing health and healthcare needs among the Syrian refugee trajectory to Norway* [20]), designed with a trajectory perspective to investigate refugee health over time. The reporting follows the STROBE statements for cohort studies.

Study design and participants

This is a prospective longitudinal study assessing adult Syrian refugees under the UNHCRs international protection mandate admitted for resettlement to Norway at two time points. Baseline measures were gathered through a self-administered survey in Arabic in Lebanon between August 2017 and April 2018 in collaboration with the International Organization for Migration (IOM). Inclusion criteria were Syrian nationals from 16 and above attending mandatory pre-departure educational activities in the given time period, a total of 514 persons. Exclusion criteria were unaccompanied refugee minors between 16 to 18 years and severe mental disorder. However, no one was excluded based on mental health. The questionnaire was distributed during class

time under the supervision of trained bilingual staff with cultural competence, available to assist persons with low health literacy, illiteracy or low Arabic language proficiency, and to pick up signs of mental distress in case of re-traumatization. Participants were compensated with the approximate equivalent of $10 USD after completing the baseline questionnaire. After arrival in Norway, the study participants were settled in 134 different municipalities throughout the country. Hence, follow-up measures were gathered through telephone interviews by Arabic-speaking study personnel. The Norwegian Directorate of Integration and Diversity and the municipalities' immigration units provided contact information for the participants after resettlement. A total of 506 eligible subjects were accepted to participate (98%) in the study at baseline, out of whom 464 (92%) were confirmed resettled in Norway and 353 of 464 (76%) followed-up (Additional file 1).

Dependent variables

In this study, we use two indicators for health as main outcomes: SRH and QoL. We have applied a salutogenic approach that is reflected in the selection and categorization of variables.

Self-rated health

As a proxy for general health, SRH was assessed using the single-item question: How do you consider your health at the moment? This question is answered using a five-point response scale from very poor to very good. The item was dichotomized into a binary measure distinguishing between Good and Very Good compared with Very poor, Poor and Neither. The SRH measure has shown reliability and validity among Arabic speakers and within refugee populations [14, 21].

Quality of life

QoL was measured using the WHO Quality of Life Scale (WHOQOL-BREF). The WHOQOL-BREF was selected because it was developed as a transcultural instrument and has demonstrated good psychometric properties, reliability, and validity among Arabic speakers [22]. The instrument comprises 24 items measuring four domains; physical health (seven items), psychological health (six items), social relationships (three items) and environment (eight items). The physical health domain entails questions on pain, medical treatment, energy, sleep, mobility and capacity. The psychological domain includes questions on concentration, self-esteem, meaningfulness and positive and negative feelings and thoughts. The social domain focuses on satisfaction with relationships, practical social support and sex-life. The environmental domain pertains to questions on safety and security, access to healthcare, financial recourses and physical

environment. Each item is rated on a 5-point Likert scale with a higher score denoting a better QoL on the corresponding domain. Raw scores were transformed creating domain scores within the range of 4–20 by multiplying the average of the items in each domain by four, in accordance with instructions from the manual. Cronbach's alpha for the total scale for the present sample is 0.8.

Independent variables

Sociodemographic variables

The questionnaire included sociodemographic variables such as age, gender, mother tongue, marital status, number of children and years of schooling. We also inquired on migration related factors such as time since flight from Syria, time since arrival in Lebanon, number of transit countries before arriving in Lebanon, migrating alone or with family, and residence permit in Lebanon. In addition, we assessed Health Literacy through the single-item literacy screener (SILS): "How often do you need help reading written material from your doctor or pharmacy?" Possible responses are: Never (1), Rarely (2), Sometimes (3), Often (4), and Always (5). Scores higher than 2 point to difficulties with reading health-related material. We created a binary measure and used the variable *high health literacy* defined as responses ≤2.

Social support

Perceived social support was measured with The ENRICHD Social Support instrument (ESSI), a short validated self-report measure that assesses the four defining elements of social support: emotional, instrumental, informational, and appraisal with 7 items [23]. A total score is the sum of all items with higher scores indicating better social support. We created a binary measure for high social support defined as having answered > 2 on at least two of the seven items and a total score of > 18 based on the definition of low-social support by the ENRICHD investigators [23]. ESSI has previously been validated among Syrian refugees [24]. Cronbach's alpha for the present sample is 0.85.

Questions not already validated, such as demographic questions and migration related questions went through a translation process based on the ISPOR principles of good practice guidelines [25]. We included the following steps; two independent forward translations, reconciliation of the forward translation into one translation, back translation, harmonization, cognitive debriefing among a group of 6 respondents and proof reading.

Statistical analysis

Descriptive data were presented as frequencies and percentages for categorical variables and as median with inter-quartile range (IQR) for continuous variables. Sensitivity analyses between the participants and the loss to

follow up group were conducted using χ^2-statistics and independent group's t-tests. We analyzed the longitudinal data using generalized estimating equations (GEE) in long format with "wave" as a binary covariate to evaluate change in outcome from baseline to follow-up. The GEE method accounts for the non-independence of repeated data from the same subject. For binary outcomes we applied a log-link and binomial distribution and reported exponentiated regression coefficients as risk ratios (RR) with 95% CI. For continuous outcomes we applied an identity link and Gaussian distribution and reported regression coefficients (B) with 95% CI. To view our results in relation to other populations, we presented mean values of the WHOQOL-BREF domains together with mean values from Skevington et al. [26]. Their research is based on a sample of 11,830 adults from 23 countries across the globe, including Norway. We compare our sample with both the total sample of 11,830 subjects as well as with only the Norwegian sample of 1047 subjects, separately. To evaluate potential effect modifiers for change in outcomes over time we stratified by various characteristics measured at baseline in Lebanon (gender, age, ethnicity, marital status, education, level of health literacy, level of social support (ESSI), time in transit, multiple transit countries, residence permit in Lebanon, migrating alone) and incorporated interaction terms between the covariates and wave in the GEE models to test for significant differences in change over time for different subgroups. Missing values were handled through list wise deletions. An alpha value of 0.05 was considered statistically significant. We analyzed the data using STATA/IC software, version 15.1, (StataCorp LLC, Texas, USA).

Results

A total of 353 subjects completed both assessments (baseline and follow-up) resulting in an attrition rate of 24% (Additional file 1). The most common reasons for loss-to-follow-up from Lebanon to Norway was not answering the phone/unreachable after a minimum of three attempts and declining participation. Apart from higher health literacy among respondents (56% versus 45%), no statistically significant differences in characteristics were seen between responders and non-responders (Additional file 2).

Demographics at baseline

The overall median age of the cohort was 34 years (IQR 27–41), and 49% were males (Table 1). Participants had an average of 8 years of schooling and three out of four respondents were married (75%). Most of the participants had been migrants for approximately five years at baseline. A majority had high health literacy (56%) and approximately one third (35%) had high social support.

Table 1 Sociodemographic and migration related factors at baseline, $N = 353$

SOCIODEMOGRAPHIC FACTORS		
Gender (n, %)		
Women	181	51
Men	171	49
Age in years (median, IQR)	34	27–41
Mother tongue (n, %)		
Arabic	335	95
Kurmanji	15	4
Marital status (n, %)		
Married	265	75
Living with partner among married	260	98
Number of children (median, IQR)	4	3–5
Education in years (median, IQR)	8	6–10
High health literacy[a] (n, %)	195	56
High social support[b] (n, %)	123	35
MIGRATION RELATED FACTORS		
Time since flight from Syria at baseline in years (median, IQR)	5	4–6
Time since arrival in Lebanon at baseline in years (median, IQR)	5	4–5
Been in other transit country before Lebanon (n, %)	20	6
No residence permit in Lebanon at baseline (n, %)	242	69
Migrating alone to Lebanon (n, %)	55	16

[a]High health literacy defined as scores ≤ 2. [b]High social support defined as > 2 on at least two of the seven items and a total score of > 18

Changes in health from baseline to follow-up and comparison to other populations

Table 2 presents the main outcomes at baseline and follow-up. More than half of the respondents rated their health as good at baseline with a non-significant increase at follow-up RR, 95%CI: 1.1 (1.0, 1.2), $P = 0.072$. In the QoL domains, the highest domain scores were observed in physical health and in social relationships. Both domains showed a statistically significant increase at follow-up from 13.7 to 15.7 B, 95%CI: 1.9 (1.6, 2.3) and from 13.7 to 15.3 B, 95%CI: 1.6 (1.2, 2.0), respectively. The lowest scores at baseline were observed in questions relating to the environment followed by the psychological domain but these also increased at follow-up, from 9.0 to 14.0 B, 95%CI: 5.1 (4.7, 5.4) and from 12.8 to 14.5 B, 95%CI: 1.7 (1.3, 2.0), respectively. Overall, all the QoL scores were significantly higher in the follow-up assessment.

In Fig. 1, we compare changes in mean values with data from the international field trials of the WHOQOL-group, using both the sum of all field countries' mean QoL-scores as well as Norwegian QoL-scores as reference points, separately [26]. At baseline,

Table 2 Changes in prevalence (%) in dichotomous outcome (SRH) and mean (SD) score for continuous outcome (WHOQOL-BREF four domain scores, range 4–20) from baseline to follow-up, *N* = 353

Self-rated health	Baseline		Follow-up		Change	*P*-value
	N	n (%)	N	n (%)	RR (95% CI)	
Good SRH	349	203 (58)	351	222 (63)	1.1 (1.0, 1.2)	0.072
Quality of life (WHOQOL-BREF)	Baseline		Follow-up		Change	
	N	Score (SD)	N	Score (SD)	B (95% CI)	
Physical health (Domain 1)	353	13.7 (2.7)	353	15.7 (2.8)	1.9 (1.6, 2.3)	< 0.001
Psychological health (Domain 2)	353	12.8 (2.7)	353	14.5 (2.3)	1.7 (1.3, 2.0)	< 0.001
Social relationships (Domain 3)	353	13.7 (3.0)	352	15.3 (2.8)	1.6 (1.2, 2.0)	< 0.001
Environment (Domain 4)	353	9.0 (2.4)	353	14.0 (2.2)	5.1 (4.7, 5.4)	< 0.001

Abbreviations: *RR* Relative risk. *CI* Confidence interval. *SD* Standard deviation

mean values for the physical, psychological and environmental domains were significantly lower than both international and Norwegian reference scores but improved to nearly the same levels at follow-up. The social relationship domain matched the international and Norwegian reference scores at baseline and surpassed these levels at follow-up.

Effect modifications

Risk ratios and regression coefficients from stratified models with test for effect modification are reported in Table 3. We found a statistically significant improvement in the proportion of good SRH among men, but not among women, with a statistically significant interaction effect by gender. The improvement in social relationships (domain 3) and environment (domain 4) was also significantly larger in men. We also observed an interaction by age in the psychological domain (domain 2) with statistically significant improvement only among participants < 40 years of age. For marital status, the only statistically significant interaction was observed in the environmental domain (domain 4), with larger improvement among those who were married. When stratifying on level of social support (ESSI), there was a significantly stronger improvement among those with low social support at baseline in SRH and in the psychological and environment domain (domain 2 and 4). In terms of having a residence permit in Lebanon or not, statistically significant improvement in good SRH and social relationships (domain 3) was seen only among participants with no residence permit at baseline.

In Additional file 3, prevalence of good SRH and mean scores for the QoL domains at baseline and follow-up with stratification on variables showing statistically significant effect modification are reported. Here we can see that participants with low social support at baseline
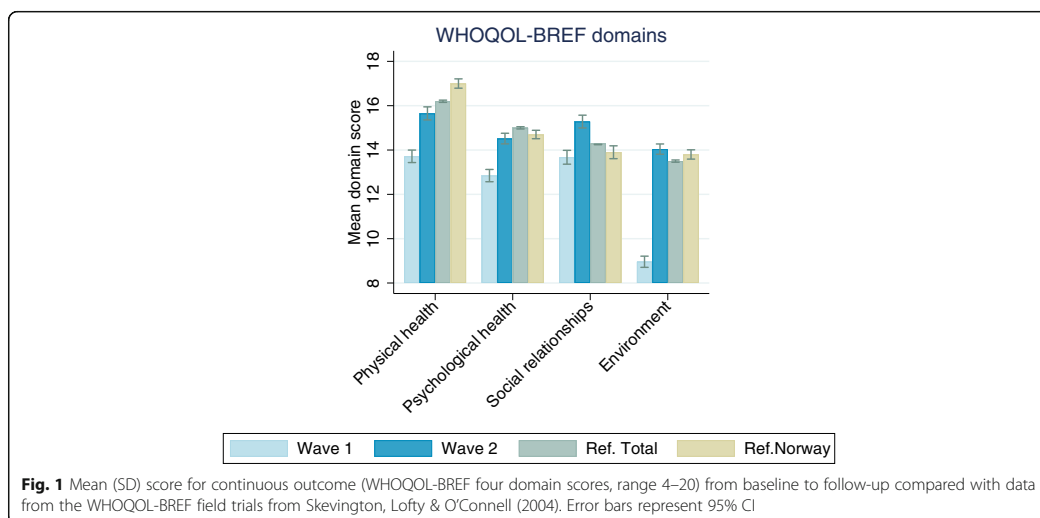

Fig. 1 Mean (SD) score for continuous outcome (WHOQOL-BREF four domain scores, range 4–20) from baseline to follow-up compared with data from the WHOQOL-BREF field trials from Skevington, Lofty & O'Connell (2004). Error bars represent 95% CI

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Table 3 Effect modification of change in dichotomous outcome (SRH) and continuous outcomes (four domains of WHOQOL-BREF) by selected sociodemographic and migration-related variables using interaction terms in generalized estimating equations, N = 353

	Good SRH		Physical health		Psychological health		Social relationships		Environment	
	RR (95% CI)	P	B (95% CI)	P	B (95% CI)	P	B (95% CI)	P	B (95% CI)	P
Gender										
Male	1.2 (1.1, 1.4)		2.2 (1.7, 2.7)		1.9 (1.3, 2.4)		2.1 (1.5, 2.6)		5.5 (5.0–5.9)	
Female	1.0 (0.6, 1.1)		1.7 (1.2, 2.1)		1.5 (1.1, 1.9)		1.2 (0.6, 1.7)		4.7 (4.2, 5.1)	
Interaction test		0.04*		0.157		0.293		0.027*		0.023*
Age										
< 40 years	1.1 (1.0, 1.2)		2.1 (1.8, 2.5)		1.9 (1.5, 2.3)		1.6 (1.2, 2.1)		5.1 (4.7, 5.5)	
≥ 40 years	1.1 (0.9, 1.4)		1.3 (0.5, 2.1)		0.9 (0.1, 1.6)		1.4 (0.7, 2.1)		5.0 (4.3, 5.7)	
Interaction test		0.793		0.056		0.016*		0.533		0.677
Marital status										
Married	1.1 (1.0, 1.3)		2.0 (1.6, 2.5)		1.8 (1.4, 2.2)		1.5 (1.0–1.9)		5.2 (4.9, 5.7)	
Other	1.0 (0.9, 1.1)		1.6 (1.0, 2.2)		1.2 (0.6, 1.9)		2.1 (1.3, 2.8)		4.5 (3.8, 5.2)	
Interaction test		0.478		0.243		0.121		0.202		0.048*
High social support (ESSI)										
Yes	0.9 (0.8, 1.1)		1.5 (0.8, 2.1)		0.8 (0.2, 1.4)		1.4 (0.8, 1.9)		4.4 (3.9, 5.0)	
No	1.2 (1.1,1.3)		2.2 (1.8, 2.6)		2.1 (1.7, 2.5)		1.7 (1.2, 2.3)		5.4 (5.0, 5.8)	
Interaction test		0.01*		0.062		0.001*		0.337		0.006*
Residence permit in Lebanon										
Yes	0.9 (0.8, 1.1)		1.8 (1.2, 2.4)		1.5 (0.8, 2.2)		1.0 (0.2, 1.7)		5.0 (4.4, 5.5)	
No	1.2 (1.1, 1.3)		2.0 (1.6, 2.4)		1.7 (1.3, 2.1)		1.9 (1.5, 2.4)		5.1 (4.7, 5.6)	
Interaction test		0.026*		0.519		0.614		0.035*		0.642

Statistically significant results are marked with an asterisk ($p < 0.05$). Abbreviations: SRH = Self-rated health. P = p-value. RR = Relative risk. CI = Confidence interval. B = beta coefficient

also had low levels of good SRH, psychological health, social relationships and environmental factors with a subsequent increase in each of these variables at follow-up.

Changes in the main outcomes did not differ by level of education, health literacy, time in transit or if migrating alone or with family (not shown in table).

Discussion

Our study used longitudinal data to examine changes in SRH and QoL among Syrian refugees at two stages of their migration path. Overall, we found that SRH remained stable while QoL increased significantly in the short follow-up period of one year. Furthermore, our results suggest that gender, age and factors connected to the situation in transit (social support and residence permit in transit country) are important effect modifiers of change in SRH and QoL. The generally positive outcomes from this study lend credence to the notion of refugees' inherent health resources stimulating growth and resilience [27]. A positive subjective health outcome is an essential means to successful integration, at the same time as successful integration enables good health [28].

Over half of the refugees rated their health as good at baseline (58%). This finding corresponds to levels of SRH measured in Syrian adults residing in pre-war Syria (55.3%) [29] and is also similar to previous findings on SRH among forced migrants resettled in high income countries, ranging from 58 to 64% [30, 31]. In contrast, in the general Norwegian population, over 70% rated their health as good [32]. Thus, we postulate that our cohort of forced migrants do not have an evident health advantage when compared with their final host population, which contradicts the healthy migrant effect/paradox [4, 6]. Notably, the SRH level increased marginally but non-significantly after only one year in resettlement.

Additionally, we found that the pre-arrival QoL scores for physical health, psychological health, and environment were rated significantly lower than the mean scores from the WHOQOL-BREF international field trials [26]. The physical and psychological domain improve significantly after resettlement but remain lower than international reference scores. In the environmental domain, mean QoL-scores surpass the levels of international reference scores after resettlement. Only a few previous studies have explored the concept of QoL specifically in forced migrants. Some of them found low

scores in the environmental domain [33, 34] while others did not [35], but comparison is impeded by heterogeneity in the samples, apparent differences in migrant legal status and differences in countries' reception schemes upon arrival. In our study, the lowest ratings at baseline were seen in the environment domain, which contains facets on financial resources, safety and security, accessibility of healthcare services and physical environment. Low scores could be attributed to circumstances observed in refugee settlements where unstable living conditions and poor provision of health services are prevalent. Our finding that all three domain scores: physical, psychological, and environment, improved after one year's stay in the host country supports this theory. In addition, supportive resources upon arrival and favorable integration policies might have contributed to outweigh the effect of post-migration stressors [13].

The social relationship domain scores were lower than international reference scores at baseline but exceeded both international and Norwegian reference scores at follow-up [26]. Even though migration is a main cause of family disruption, most participants in our sample were resettled together with other family members, which might partially explain the high scores in social relationships. Some studies have reported favorable social relationships scores among forced migrants [35, 36] while others found results pointing in the opposite direction [37]. A high social capital has been identified as an important protective factor for poor mental health outcomes [38] and in sustaining refugee resilience and acculturation in the resettlement process [39].

We found stronger improvement in SRH and two out of four QoL domains among men compared to women. These gender-related differences are comparable with evidence from previous research reporting worse health outcomes for female refugees [2, 30]. A gender-gap in SRH-measures has for long been conceptualized by researchers and has been attributed to a combination of biological and socio-behavioral differences [40]. In addition to known gender differences in SRH, the migration experience most likely affects men and women differently [3]. In the psychological domain, there was a larger improvement among younger participants, aged less than 40. This supports the notion of greater resilience seen in younger refugees [2, 41]. Moreover, we found that participants with low social support while in Lebanon had stronger improvement in SRH and QoL. Since there is a strong correlation between social support, SRH and QoL at baseline and their baseline measures were much lower than participants with high social support, this improvement indicates a larger "catch-up" for a group with an inferior starting point. It also means that within the right circumstances, an increase in SRH and QoL can be achieved regardless of

your starting level of social support. The same catch-up phenomenon was seen for the ones who did not have a residence permit in Lebanon. Again, both these findings could point to internal resources in the refugee population enabling adjustment and growth after adversity. Contrary to our expectations, education - a social determinant of health, was not identified as a positive modifier of improvement. This could be attributed to the negative effect of losing your status prevailing over the protective effect of education [2]. Only a few migrated without family (16%) and it is possible that this small number made us unable to detect significant interactions for this variable.

Strengths and limitations

The main strength of our study is the unique pre-arrival assessment that enabled us to trace refugee health outcomes before and after arrival to the host country using a longitudinal design. To our knowledge, this is a novel contribution to the research field allowing us to shed light on the sequential changes in health in a people moving from completely disparate settings. Secondly, we have a high response rate. In joint, the use of only validated instruments and a high response rate supports the internal validity of the study.

However, our findings should be interpreted in the context of the following limitations. Primarily, since there are no available registers on forced migrants during migration, we cannot state to which degree our sample is representative for the target population. This lack of an overall sample frame is a common limitation to observational studies on migrant health [42]. To compensate for this, efforts were put in the design to increase representativeness by inviting all the persons from Syria that were to be resettled to Norway in a given time period, as well as having a long recruitment period and recording of non-participation. Another limitation could be the deliberate change in assessment method from mainly self-completed questionnaire at baseline to telephone interviews at follow-up that introduces the possibility of interviewer bias. We used a short follow-up time that gives us important insight into the first phase of resettlement. However, we lack a long-term perspective. Prior research has shown deterioration in health over time [43] which warrants further longitudinal follow-up.

Our findings of an overall healthy cohort of refugees showing improvement in QoL in a short period of time provide important and novel information about a phase of the migration trajectory where little previous knowledge exists. From a clinical point of view, this information can encourage a shift in attention from pathogenesis to salutogenesis [44]. Recognizing positive health outcomes and refugees' inherent health resources

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is important in the developing of interventions to bolster growth, resilience, and adaptation for the general refugee. In a policy-making setting, our findings suggest that women and older refugees should be subjected to a special effort to improve health. Our findings are also important in informing political and public discourse, nuancing the perception of refugees as a group with an inferior health status. We recommend more in-depth research to understand the mechanisms behind this rapid increase in QoL so that it can be sustained.

Conclusion

We found stability in SRH and improvement in QoL in the early resettlement phase of refugees, more in younger age and among men compared to women. In addition, the social relationship and environment domain of QoL surpassed the levels of international reference scores after resettlement. Policy-makers and health care professionals should acknowledge that health of refugees is dynamic and can show rapid improvement after resettlement. To promote health equity and facilitate migration reception and integration, both short-term and long-term health outcomes should be taken into account.

Supplementary information

Supplementary information accompanies this paper at https://doi.org/10.1186/s12939-020-01300-6.

Additional file 1.

Additional file 2.

Additional file 3.

Availability of data and materials
The datasets generated for the present study are not publicly available due to data protection regulations in Norway.

Ethics approval and consent to participate
Ethical approval was obtained from the Regional Committee for Medical and Health Research Ethics of South East Norway (ref. no. 2017/377) and by the International Organization for Migration and was conducted in accordance with the Declaration of Helsinki. Participants provided written consent at baseline and verbal consent at follow-up prior to participation. Participants were recruited to the study after they had been granted refugee status and a residence permit in Norway to avoid any unjustified expectations. Confidentiality was ensured to all participants including those with illegal status in Lebanon. Data were de-identified and stored on a protected server. Permissions to use the validated survey instruments were obtained from all copyright holders.

Consent for publication
Not applicable.

Competing interests
The authors declare that they have no competing interests.

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Use of health care services among Syrian refugees migrating to Norway: a prospective longitudinal study

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Abstract

Background: Understanding the differential utilization of healthcare services is essential to address the public health challenges. Through the migration process, refugees move from one set of health risk factors to another and can face multiple healthcare challenges along their journey. Yet how these changing risk factors influence refugees' use of health care services is poorly understood.

Methods: A longitudinal survey assessing health care utilization of 353 adult Syrian refugees was conducted; first in a transit setting in Lebanon and after one year of resettlement in Norway. The main outcomes are the utilization of general practitioner services, emergency care, outpatient and/or specialist care and hospitalization during the previous 12 months. Associations between use of healthcare services and several sociodemographic, migration-related and health status variables at both time points were found using regression analysis. We also analyzed longitudinal changes in utilization rates using generalized estimating equations.

Results: The use of general practitioner and emergency care increased after resettlement while outpatient/specialist care markedly dropped, and hospitalization rates remained the same. Undocumented status and poor self-rated health (SRH) prior to resettlement were identified as predictors for use of health care after arrival. After resettlement, higher health literacy, higher education, higher social support and poor SRH and quality of life were significantly associated with use of healthcare services.

Conclusions: Utilization of health services changes post migration to the destination country and are associated with migration-related and socio-demographic factors. Poor SRH is associated with use of services, both pre-arrival and post-resettlement. Our findings have implications for future resettlements, health care policies and service provision to newly arrived refugees with regard to both health needs as well as delivery of services.

Keywords: Refugees, Migrants and Transients, Health services utilization, Longitudinal

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Introduction

Many countries in Europe have long humanitarian tradition of receiving and resettling forcibly displaced individuals [1] and should provide equitable healthcare services to an increasingly diverse population [2]. Responding to changes in demographics and attaining equity in health can be viewed as a public health investment. However, for many European countries this is hampered by the lack of reliable knowledge of the health status and health needs of forced migrants in the early phase of resettlement [3]. Without adequate information, many resettlement-countries are unable to assess whether services are accessible for forced migrants and if needs are efficiently met [2].

The utilization of healthcare services is a multidimensional process that combines need for, and access to care. In an optimal scenario, use of services should be proportional to ones need [4]. Even though access of and use of services are inter-related, they are distinct parts of the health delivery process where utilization presumes access [5]. Factors related to access to services have been conceptualized in many ways, and commonly includes aspects on both the provider side and the user side such as accessibility, affordability, availability and appropriateness [6]. Both access and use of healthcare services is hence influenced by context, meaning that even where entitlements are formally established and financial barriers are lifted, access and use are influenced by resources required for good health, such as social support, education, and health literacy. Likewise, one might argue that additional factors related to the migration experience affect the use of health care services for forced migrants given the risk of exposure to external factors such as persecution, food insecurity, and violence. Exposures that can shape the forced migrants' health profile and subsequently their need for care [7]. This, however, has scarcely been researched.

The Syrian refugee crisis remains the largest displacement crisis in the world, with 5.6 million registered refugees seeking transient safety in neighboring countries [8]. While in transit, healthcare services are often characterized by high privatization, fragmented between many different providers, making access to care difficult and costly [9]. For undocumented migrants, economic barriers are further aggravated with fear of detention or deportation if seeking healthcare [9]. Upon arrival in Norway, refugees are invited to a general health assessment, and have the same rights and entitlements to services as the resettlement country population. The Norwegian health care system offers universal coverage with relatively small out-of-pocket expenses. The general practitioner (GP) serves as a gatekeeper to secondary care, regulating the access to specialist and hospital care [10]. Primary care services are thus patient-driven while influx into secondary care is managed by healthcare providers.

Through the resettlement process, refugees move from one set of health risk factors to another and can face multiple additional healthcare challenges along their journey. Few studies have focused on this change of context and environment, how it affects subsequent use of health care and whether adverse conditions affecting health and the use of health care services pre-arrival persists post migration. Applying a longitudinal design allowing a trajectory perspective, our study aimed to: (a) describe patterns of health care service use in Lebanon and Norway, (b) identify pre-arrival sociodemographic and migration-related predictors of health care service use post migration and (c) identify post-arrival factors associated with health care service use in the resettlement country.

Methods

Study design, participants, and data collection

This is a two-time points follow-up study which is part of the *Changing Health and health care needs Along the Syrian Refugees' Trajectories to Norway* (CHART) project [11], assessing health of Syrian refugees in Norway. Methods were carried out in accordance with the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement guidelines and with national and European privacy legislation.

In this paper, we focus on persons recognized as refugees by the United Nations High Commissioner for Refugees (UNHCR) accepted for third-country resettlement [1]. The methods have already been described elsewhere [12]. In brief, a baseline self-administered survey was conducted in Lebanon in 2017–2018, followed by a follow-up survey in Norway after one year. A total of 514 Syrian nationals from 16 and above attending the mandatory Norwegian Cultural Orientation Programme (NORCO) in the given period were included in the study in Lebanon. The Arabic baseline questionnaire was distributed during course time under the guidance of cross-culturally responsive bilingual trainers. Follow-up measurements post-arrival were gathered through structured telephone interviews in Arabic. A total of 506 eligible subjects completed the baseline survey (98 %), of which 464 (92 %) were confirmed resettled in Norway and 353 completed the second questionnaire (70 %) (Supplementary Fig. 1).

Dependent variables

The main outcomes for this study are the utilization of a GP, emergency care (EC), outpatient and/or specialist care as well as hospitalization during the previous 12 months. These four main outcomes were assessed through the following questions: 'During the last 12

months, have you visited any of the following: a general practitioner, emergency care, outpatient care, specialist care (yes/no)' and 'Have you been admitted to the hospital the last 12 months? (yes/no)'. Given similarities in outpatient and specialist care in Norway, where the main point is to be assessed by a medical specialist, these two variables were merged into one. The two items are based on questions from The Nord-Trøndelag Health Study (HUNT) [13].

Independent variables

Self-rated health (SRH) was measured as an indicator of the need for healthcare at both time points. We used a validated single-item question: "How do you consider your health at the moment?", with a five-point Likert scale ranging from very poor to very good. The item was dichotomized merging 'very poor' and 'poor' indicating poor SRH versus non-poor SRH. The SRH-item has shown acceptable validity and reliability among Arabic speakers and in refugee populations [14, 15]. Additionally, we measured quality of life (QoL) using the WHO Quality of Life Scale (WHOQOL-BREF), a transcultural instrument previously validated in Arabic [16], which includes a total of 26 questions on physical health, mental health, social relationships, and environment [17]. Each item is rated on a five-point Likert scale with a higher score indicating a better QoL. Raw scores were transformed creating domain scores within the range of 4–20 by multiplying the average of the items in each domain by four, in accordance with the user's manual [17].

Perceived social support was measured with the 7-item ENRICHD Social Support Instrument (ESSI) [18]. A total score is the sum of all items with higher scores indicating better social support. A binary measure for high social support defined as having answered > 2 on at least two items and a total score of > 18 was created, based on the definition of low-social support [18]. ESSI has previously been validated among Syrian refugees [19].

Sociodemographic variables encompassed age, gender, primary language spoken, marital status and level of education. In addition, we assessed Health Literacy through the single-item literacy screener (SILS): "How often do you need help reading written material from your doctor or pharmacy?" With a five-point Likert scale. Scores higher than 2 point to difficulties with reading health-related material. We also inquired on migration-related factors such as time since the flight from Syria, migrating alone or with family, residence permit in Lebanon, and possible exposure to traumatic events with The Single General Trauma Item [20].

The entire questionnaire was in Arabic; it contained questions already translated and validated and those sections that were not went through a standardized translation process [21].

Statistical analysis

We present sociodemographic and migration-related characteristics as counts and proportions for categorical variables, medians, and interquartile ranges (IQR), and means and standard deviations (SD) for continuous variables (Table 1). Selection bias between the cohort and the loss-to-follow-up group was assessed using χ^2-statistics and independent group's t-tests (Supplementary Table 1).

We used a Sankey chart to visualize the changes in use of services before arrival and after resettlement by creating trajectory variables with the proportions going from use to no use and vice versa or no change in outcomes (Fig. 1). Changes in the use of health services from baseline to follow-up were also analyzed using generalized estimating equations (GEE) with data in long format with two observations per individual and "wave" as a binary covariate (Table 2). We applied a log-link and binomial distribution and reported exponentiated regression coefficients as risk ratios (RR) with 95 % CI.

We used multivariate analysis to evaluate factors associated with the use of healthcare services in Norway looking at selected sociodemographic and migration-related factors as well as self-perceived health status and QoL at baseline and follow-up. First, we looked at baseline characteristics in Lebanon as predictors for the use of services after arrival in Norway. Thereafter, we looked at characteristics while in Norway and associations with the use of services in Norway. We used log-binomial regression analysis reported as risk ratios with 95 % confidence intervals in two models; (1) unadjusted (2) adjusted for potential confounders for the total effect of each characteristics on the outcome based on results from a directed acyclic graph (DAG) depicted in supplementary Fig. 2. The DAG was constructed using the software DAGitty [22]. For instance, for the total effect of health literacy at baseline on use of health services in Norway, age, gender, and education were potential confounders, while SRH at baseline was considered as a mediator and not adjusted for. In cases where convergence was not achieved in log-binomial regression analysis, Poisson regression was used with robust error variance (Table 3) [23].

Missing values were handled through listwise deletions. An alpha value of 0.05 was considered statistically significant. We analyzed the data using STATA/IC software, version 16.0, (StataCorp LLC, Texas, USA).

Results

Characteristics of the study population

Sociodemographic characteristics and self-perceived health and QoL of this cohort has been published elsewhere but are stated in Table 1 for the sake of clarity. We included data from 353 participants in the final

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Table 1 Sociodemographic and migration related factors, *N* = 353

SOCIODEMOGRAPHIC FACTORS	BASELINE	FOLLOW-UP
Gender (n, %)		
Women	181 (51)	-
Men	171 (49)	-
Age in years (median, IQR)	34 (27–41)	-
Native tongue (n, %)		
Arabic	335 (95)	-
Kurmanji	15 (4)	-
Marital status (n, %)		
Married	265 (75)	260 (75)
Number of children (median, IQR)	3 (2–4)	3 (2–4)
Education in years (median, IQR)	8 (6–10)	8 (6–9)
High health literacy[a] (n, %)	195 (56)	23 (7)
High social support[b] (n, %)	123 (35)	210 (60)
HEALTH AND QUALITY OF LIFE		
Good Self-rated health (n, %)	203 (58)	221 (63)
Poor self-rated health (n, %)	67 (19)	51(15)
Physical health (WHOQOL-BREF domain 1) (mean, SD)	13.7 (2.7)	15.6 (2.8)
Psychological health (WHOQOL-BREF domain 2) (mean, SD)	12.8 (2.7)	14.5 (2.3)
Social relationships (WHOQOL-BREF domain 3) (mean, SD)	13.7 (2.9)	15.3 (2.8)
Environment (WHOQOL-BREF domain 4) (mean, SD)	8.9 (2.4)	14.0 (2.2)
MIGRATION RELATED FACTORS		
Time since flight from Syria at baseline in years (median, IQR)	5 (4–6)	-
Time since arrival in Lebanon at baseline in years (median, IQR)	5 (4–5)	-
Been in other transit country before Lebanon (n, %)	20 (6)	-
No residence permit in Lebanon at baseline (n, %)	242 (69)	-
Migrating alone to Lebanon (n, %)	55 (16)	-
Length of stay in Norway at follow-up in months (median, IQR)	-	14 (12–15)
Experience of pre-migration trauma (n, %)	135 (40)	-

[a]High health literacy defined as scores ≤ 2 (Likert scale from 1 to 5). [b]High social support defined as > 2 on at least two of the seven ESSI items and a total score of > 18, range for ESSI 0–22.

analysis (supplementary Fig. 1). The respondents did not differ from the loss-to-follow-up group in terms of age or gender but had higher health literacy (supplementary Table 1).

Use of healthcare services and changes in use from Lebanon to Norway

Of the 353 participants, 33 % visited a GP in Lebanon, 32 % visited outpatient/specialist care, 16 % were hospitalized, and 10 % used EC in the 12 preceding months at baseline (Table 2). In Norway, the use of a GP increased to 85 % and the use of EC to 18 % while hospitalizations remained the same and outpatient/specialist care visits dropped to 16 %. In Fig. 1, we present Sankey charts showing trajectories of healthcare service use. Most participants did not use EC, outpatient/specialist care, or

hospital care neither at baseline nor at follow-up. There were 16 % new reports of EC use at follow-up, while 9 % used this in Lebanon but not in Norway. For specialist/ outpatient care, 10 % reported new use while 26 % reported using this in Lebanon but not in Norway. The biggest change in trajectory is the increase in the use of GP from pre-arrival to after resettlement with 58 % new reports of use.

Pre-arrival predictors of use of health care services in Norway

Increasing age was significantly associated with the use of EC services and hospitalization after arrival (Table 3). No other significant associations between pre-arrival sociodemographic factors and the use of healthcare services at follow-up were found. With regards to health
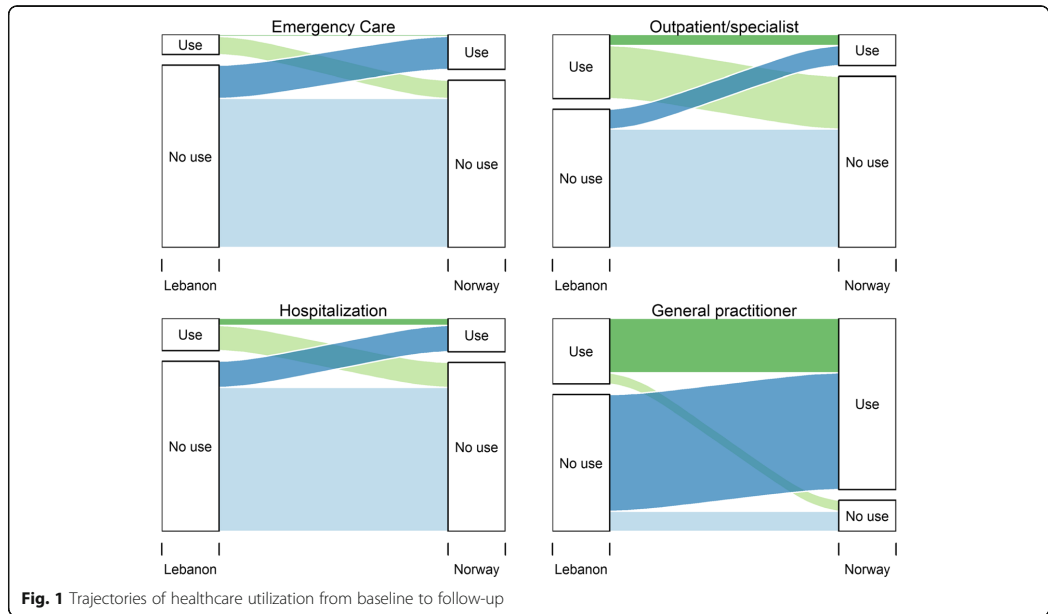
Fig. 1 Trajectories of healthcare utilization from baseline to follow-up

status pre-arrival, we found that poor SRH was significantly associated with increased risk of EC use after arrival, while lower scores in the social relationships' domain of QoL (i.e., poorer social relationships) were significantly associated with use of EC after arrival. With regards to migration-related factors, not having a residence permit in the transit country was significantly associated with the use of EC after arrival.

After-arrival factors associated with the use of health care services in Norway

When in Norway, increasing age was still significantly associated with use of EC services and hospitalization (Table 3). Likewise, increased health literacy was significantly associated with use of GP, EC and hospitalization. Similarly, high social support (ESSI) was significantly associated with increased risk of EC use, use of outpatient/specialist care and hospitalization, and increasing education

level was associated with hospitalization. When looking at health status, we found that poor SRH was significantly associated with the use of both EC and hospitalizations. Generally, lower scores in the different QoL dimensions were associated with higher use of services. However, higher scores in the environmental domain of QoL were significantly associated with use of a GP.

Discussion

This study provides data on health care utilization before and after resettlement assessed at two different locations and time points following the journeys of the same participants and therefore incorporates factors from the pre-arrival context as possible predictors for later use. We find that not having a residence permit and having poor health status pre-arrival predict the use of services after resettlement. Poor SRH was significantly associated with use of services both in Lebanon and in Norway

Table 2 Changes in healthcare service utilization from Lebanon to Norway

	Baseline		Follow-up		Change	
	N	n (%)	N	n (%)	RR (CI)	p-value
Variable						
General Practitioner (yes)	345	112 (33)	353	300 (85)	2.6 (2.2–3.1)	< 0.001
Emergency care (yes)	343	34 (10)	352	62 (18)	1.7 (1.2, 2.7)	0.005
Outpatient/Specialist (yes)	346	109 (32)	353	55 (16)	0.5 (0.4, 0.7)	< 0.001
Hospital (yes)	346	55 (16)	352	56 (16)	1.0 (0.7, 1.4)	0.991

Abbreviations: RR = Relative risk. CI = Confidence interval.

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Table 3 Associations between sociodemographic characteristics, health status and migration related factors at baseline and follow-up and use of emergency care, outpatient/specialist services and hospitalizations at follow-up

	General Practitioner at T2		Emergency care at T2		Outpatient/Specialist care at T2		Hospitalization at T2	
	RR (CI 95 %)	ARR (CI 95 %)	RR (CI 95 %)	ARR (CI 95 %)	RR (CI 95 %)	ARR (CI 95 %)	RR (CI 95 %)	ARR (CI 95 %)
Sociodemographic factors at T1								
Gender								
Male (reference)	1	1	1	1	1	1	1	1
Female[A]	1.09 (0.99, 1.19)	1.09 (0.99, 1.19)	1.10 (0.70, 1.73)	1.34 (0.83, 2.08)	0.84 (0.52, 1.37)	0.81 (0.50, 1.33)	0.85 (0.53, 1.36)	1.01 (0.62, 1.64)
Age (years)[B]	1.00 (0.99, 1.00)	1.00 (0.99, 1.00)	1.03 (1.01, 1.05)**	1.04 (1.02, 1.06)**	1.01 (0.98, 1.03)	1.01 (0.98, 1.03)	1.03 (1.01, 1.05)*	1.03 (1.01, 1.05)*
Education (continuous)[C]	0.99 (0.99, 1.01)	1.00 (0.99, 1.01)	0.93 (0.87, 1.00)*	0.95 (0.90, 1.01)	0.98 (0.91, 1.06)	0.98 (0.91, 1.06)	0.96 (0.90, 1.04)	0.98 (0.92, 1.05)
Health literacy (continuous)[D]	1.01 (0.98, 1.05)	1.01 (0.98, 1.05)	0.99 (0.84, 1.18)	0.89 (0.73, 1.10)	0.95 (0.79, 1.15)	0.91 (0.74, 1.13)	1.07 (0.90, 1.27)	0.97 (0.80, 1.19)
Social support (categorical)								
Low social support (reference)	1	1	1	1	1	1	1	1
High social support[C]	1.02 (0.92, 1.12)	1.00 (0.91, 1.11)	1.18 (0.72, 1.93)	1.46 (0.86, 2.47)	1.24 (0.73, 2.13)	1.35 (0.77, 2.35)	1.22 (0.72, 2.05)	1.56 (0.90, 2.70)
Health status and Quality of life at T1								
Self-rated health (categorical)								
Moderate to good SRH (reference)	1	1	1	1	1	1	1	1
Poor SRH[E]	1.03 (0.92, 1.14)	1.05 (0.95, 1.16)	1.72 (1.06, 2.77)**	1.72 (1.06, 2.78)*	1.43 (0.83, 2.47)	1.36 (0.77, 2.43)	1.17 (0.65, 2.08)	1.05 (0.60, 1.84)
Quality of life (continuous)								
Physical health (WHOQOL–BREF domain 1)[E]	0.99 (0.99, 1.00)	0.99 (0.97, 1.01)	0.98 (0.90, 1.06)	0.99 (0.90, 1.08)	0.96 (0.88, 1.05)	0.96 (0.88, 1.06)	0.98 (0.90, 1.07)	0.99 (0.91, 1.09)
Psychological health (WHOQOL–BREF domain 2)[E]	1.00 (0.99, 1.02)	1.00 (0.99, 1.02)	1.04 (0.95, 1.13)	1.05 (0.96, 1.15)	0.99 (0.91, 1.09)	0.99 (0.90, 1.09)	0.99 (0.90, 1.08)	1.00 (0.91, 1.11)
Social relationships (WHOQOL–BREF domain 3)[E]	0.99 (0.98, 1.00)	0.99 (0.98, 1.01)	0.94 (0.88, 1.01)	0.93 (0.88, 0.99)*	1.04 (0.95, 1.13)	1.06 (0.96, 1.16)	0.94 (0.88, 1.01)	0.95 (0.89, 1.01)
Environment (WHOQOL–BREF domain 4)[E]	0.99 (0.97, 1.00)	0.99 (0.97, 1.01)	0.96 (0.88, 1.06)	0.98 (0.89, 1.08)	1.03 (0.93, 1.13)	1.05 (0.94, 1.17)	0.89 (0.80, 0.99)*	0.93 (0.84, 1.03)
Migration related factors								
Time since flight from Syria (continuous)[C]	0.98 (0.97, 0.98)*	0.97 (0.94, 1.01)	0.97 (0.80, 1.17)	0.94 (0.80, 1.11)	0.99 (0.80, 1.23)	0.98 (0.80, 1.22)	1.01 (0.81, 1.26)	0.97 (0.79, 1.20)
No residence permit in Lebanon[C]	1.12 (1.00, 1.25)*	1.10 (0.99, 1.25)	1.95 (1.06, 3.60)**	2.72 (1.39, 5.31)**	1.05 (0.62, 1.81)	1.04 (0.61, 1.79)	0.62 (0.38, 1.00)	0.74 (0.45, 1.22)
Migrating alone to Lebanon[C]	0.66 (0.38, 1.13)	0.67 (0.39, 1.16)	1.25 (0.32, 4.83)	0.64 (0.24, 1.72)	1.16 (0.45, 3.01)	3.15 (0.64, 15.4)	1.31 (0.59, 2.92)	1.04 (0.54, 2.07)
Trauma exposure before resettlement in Norway[C]	0.96 (0.88, 1.05)	1.05 (0.96, 1.15)	0.77 (0.48, 1.24)	1.49 (0.95, 2.32)	0.84 (0.51, 1.39)	1.16 (0.69, 1.93)	0.57 (0.34, 0.94)*	1.63 (0.98, 2.71)
Sociodemographic factors at T2								
Gender								
Male (reference)	1	1	1	1	1	1	1	1
Female[A]	1.06 (0.97, 1.16)	1.06 (0.97, 1.16)	1.13 (0.71, 1.80)	1.28 (0.81, 2.00)	0.86 (0.52, 1.42)	0.88 (0.53, 1.46)	0.86 (0.53, 1.41)	0.96 (0.59, 1.57)
Age (years)[B]	1.00 (0.99, 1.00)	1.00 (0.99, 1.00)	1.03 (1.01, 1.05)**	1.04 (1.02, 1.06)**	1.01 (0.99, 1.03)	1.01 (0.99, 1.03)	1.03 (1.01, 1.05)**	1.03 (1.01, 1.05)**
Education (continuous)[F]	1.00 (0.99, 1.01)	1.02 (0.99, 1.04)	0.96 (0.90, 1.02)	1.05 (0.92, 1.19)	1.02 (0.96, 1.10)	1.11 (0.99, 1.25)	1.03 (0.96, 1.10)	1.19 (1.08, 1.31)**

Table 3 Associations between sociodemographic characteristics, health status and migration related factors at baseline and follow-up and use of emergency care, outpatient/specialist services and hospitalizations at follow-up (Continued)

	General Practitioner at T2		Emergency care at T2		Outpatient/ Specialist care at T2		Hospitalization at T2	
Health literacy (continuous)[G]	1.07 (1.03, 1.12)*	1.06 (1.02, 1.1)*	1.37 (1.08, 1.74)*	1.28 (1.02, 1.61)*	1.24 (0.96, 1.60)	1.21 (0.93, 1.59)	1.61 (1.25, 2.06)**	1.59 (1.25, 2.01)**
Social support (categorical)								
Low social support (reference)	1	1	1	1	1	1	1	1
High social support[H]	1.02 (0.93, 1.12)	1.04 (0.94, 1.14)	1.69 (1.02, 2.80)*	1.82 (1.11, 2.98)*	1.82 (1.05, 3.18)*	1.83 (1.04, 3.24)*	1.75 (1.02, 3.00)*	1.83 (1.06, 3.16)*
Health status and Quality of life at T2								
Self-rated health (categorical)								
Moderate to good SRH (reference)	1	1	1	1	1	1	1	1
Poor SRH[I]	0.99 (0.87, 1.13)	0.99 (0.86, 1.14)	2.17 (1.35, 3.47)*	1.92 (1.15, 3.20)*	1.81 (1.05, 3.13)	1.88 (1.03, 3.43)*	2.93 (1.84, 4.66)**	2.49 (1.49, 4.15)**
Quality of life (continuous)								
Physical health (WHOQOL–BREF domain 1)[I]	1.00 (0.98, 1.01)	0.99 (0.98, 1.01)	0.90 (0.85, 0.94)**	0.91 (0.84, 0.97)**	0.90 (0.85, 0.96)*	0.89 (0.84, 0.95)**	0.87 (0.83, 0.92)**	0.88 (0.82, 0.94)**
Psychological health (WHOQOL–BREF domain 2)[I]	1.02 (1.00, 1.04)*	1.02 (0.99, 1.04)	0.87 (0.81, 0.93)**	0.89 (0.84, 0.98)*	0.94 (0.85, 1.04)	0.96 (0.84, 1.09)	0.89 (0.82, 0.98)*	0.89 (0.80, 0.99)*
Social relationships (WHOQOL–BREF domain 3)[I]	1.00 (0.98, 1.01)	0.99 (0.98, 1.01)	0.93 (0.86, 0.96)*	0.91 (0.86, 0.96)*	0.92 (0.86, 0.99)*	0.90 (0.86, 0.99)*	0.88 (0.83, 0.93)**	0.90 (0.84, 0.97)**
Environment (WHOQOL–BREF domain 4)[I]	1.04 (1.02, 1.06)**	1.04 (1.02, 1.05)**	1.06 (0.96, 1.17)	1.08 (0.96, 1.21)	1.03 (0.93, 1.15)	1.01 (0.89, 1.15)	1.06 (0.96, 1.18)	1.06 (0.91, 1.23)

A: adjusted for age. B: adjusted for age and gender. C: adjusted for age and gender. D: adjusted for age, gender, social support at T1 and education at T1. E: adjusted for age, gender, social support at T1 and trauma exposure. F: adjusted for age, gender and education at T1. G: adjusted for age, gender, social support at T1, education at T1 and health literacy at T1. H: adjusted for age, gender, social support at T1 and trauma exposure. I: adjusted for age, gender, social support at T1, SRH and QoL at T1, time since flight from Syria, no residence permit at T1 and trauma exposure. Significant results with $P < 0.05$ are marked with an asterisk. Significant results with $P < 0.01$ are marked with two asterisks

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suggesting a stable association along the migration path. For the post migration stage, we find a significant association between the use of healthcare services and increasing health literacy (SILS), high social support (ESSI), education and poor QoL. These factors did not seem to influence future health care behavior while in transit, suggesting phenomena subjected to change with time and context. Also, we find an increase in GP and EC use after resettlement and a decrease in outpatient/specialist care while hospitalization rates do not change pre- and post-resettlement, probably mirroring the health care system in the country of stay at each period.

Use of GP services more than doubled pre- and post-resettlement. This rate (85 %) is slightly higher than that of the resettlement country population in Norway, where 75 % reported use of GP in the last 12 months in population-based data [24]. Comparing numbers between surveys is encumbered with uncertainties, but we believe some of the differences in GP utilization between our sample and the resettlement country population can be explained by the fact that in some Norwegian municipalities, the general health assessment upon arrival is performed by a GP. Despite having a separate question for the general health assessment, we assume some participants might have had difficulties distinguishing between the two alternatives as both entails contact with a primary care doctor. Another possibility is that some refugees were derived to a second visit by the GP at the first encounter for their general health assessment. In any case, it is important to acknowledge the key opportunity GPs have in responding to the need of the refugee patient in early resettlement as the first point of contact. Previous studies have argued that refugee primary care services might reduce unnecessary EC use [25], showing that refugees who receive a health assessment shortly after arrival will be less likely to have an acute care visit in this period [26]. Furthermore, we found an increase in EC use from 10 % before arrival to 16 % after resettlement, which is similar to the utilization rates of the resettlement country population [27].

On the other hand, the use of outpatient/specialist care dropped from 32 % in Lebanon to 16 % in Norway. This decrease might be explained at the system level, since outpatient/specialist care services in Norway require a referral, usually from a GP, while other routes are available to access such care in Lebanon given a highly privatized health sector. When comparing with population-based data from the Norwegian population, 36 % reported having had contact with outpatient/specialist care the last 12 months [24]. A number twice as high as that of our population, but not adjusted for morbidity, so potential under-or overuse is not possible to determine with certainty. Furthermore, some of our respondents might have been referred by their GPs to

secondary care, but still waiting for their appointments with a specialist at the time of the follow-up survey. However, the doctor-patient interaction is key in identifying patients needing a referral [28]. Previous research has shown that not speaking the same language is associated with decreased symptom reporting, fewer referrals to specialist care [29] and shorter consultation time [30], which also could explain our results. An inverse socioeconomic gradient in terms of utilization of outpatient/specialist care has also been documented in Norway [31] that confirms privileged groups are those that avail most of services [32]. However, utilization of GP and hospital admissions, which is easier to access, was found to be equitable [33]. Similarly, a systematic review across Europe showed that outpatient visits for specialized care were generally used less often by migrants [34]. In our sample, hospital admissions did not change pre- and post-resettlement, which could point to hospital admissions having similar access thresholds across countries.

Finding pre-migration predictors for use of health care in Norway can be of key importance to adequately prepare health services to the new migrant population. One novel finding in this study is that not having a residence permit in the transit country and having poor social relationships in transit was associated with higher use of emergency care the first year after resettlement. Generally, the lack of recognized documentation in a country complicates the availability of healthcare and one can assume that acute and/or chronic diseases left uncared for contribute to higher use of care post-resettlement. Hence, securing minimum acceptable living conditions for refugees in transit countries should be a priority concern globally.

The strongest correlation we found was the one between poor SRH and health care utilization, signifying the concordance between need for care and use of care. Perceived poor health status seems to be a stable factor as it holds for both pre-arrival health status and after resettlement, even though the association after resettlement is stronger. While the association between health need and health care utilization is well-known [35], our study highlights the stability of this association along the migration trajectory. Post-migration, we found associations between use of services and higher health literacy, higher education, higher social support (ESSI), and low levels of QoL. High health literacy drops from 56 % in Lebanon to only 7 % in Norway, pointing to challenges with a new language and a different health care system, while high social support (ESSI) somewhat unexpectedly increases from 35 % in Lebanon to 60 % in Norway. This increase might be explained by the fact that most quota refugees are resettled as families and some are re-united with extended family members preceding them to the resettlement country. Easier access to online

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communication and established support networks upon arrival can also explain this increase. Why persons with high health literacy, higher education and high social support have increased probability of use while in Norway but not in transit is difficult to answer but we assume these factors become more important in a context where there is universal health coverage, and no economic barriers to health care.

For the concept of social support and social relationships, we found associations pointing in opposite directions. Poor social relationships measured with WHOQOL-BREF while in Lebanon was associated with use of EC after arrival. When in Norway, high social support (ESSI) was associated with use of EC, outpatient/specialist care and hospitalizations. Likewise, poor social relationships (WHOQOL-BREF) were associated with outpatient/specialist care and hospitalizations. We believe some of this can be explained by measurement differences in social support instruments, not capturing the exact same phenomenon. The social relationships domain in WHOQOL-BREF as part of QoL only consists of three questions (satisfaction with relationships, satisfaction with support from friends and satisfaction with sexual relationships) and has the concept of satisfaction in it while ESSI consist of 7 questions and asks directly if you have someone available to talk to, receive advice, emotional support, receive help with daily chores etc. without assessing satisfaction.

The environmental domain of QoL describes feeling of safety, satisfaction of living place, enough money to meet needs, and satisfaction with transportation. Interestingly, we found that higher scores in this domain were associated with use of a GP. This also confirms the inverse care law [32].

Strengths and limitations

Working with a cohort with similar background arriving at the same time minimizing influence of contextual factors as well as a high response rate and the use of validated instruments add to the strengths of this study. However, certain limitations need to be considered when interpreting our data. We did not assess frequencies of contact with the healthcare services, only yes/no for use at least once. Because of this we are not able to separate between frequent users and persons who have only used the service once. This study has an explorative nature with a high number of statistical tests, which increases the risk of Type 1 error. We can therefore not rule out that some of the significant results are chance findings, especially those with p-values close to 0.05 (marked with one asterisk in Table 2). In addition, the variable health literacy is assessed with only one question (SILS) which is limited and has to our knowledge not been validated in a refugee population with poor language skills upon

resettlement. Moreover, we deliberately changed mode of data collection from self-completion to structured interviews between the two time points which can introduce a possibility of interviewer bias, but in that way, we achieved a high response rate. Further, we should ideally have had a longer follow-up time to better assess changes with time. However, previous research has highlighted that we especially lack data on the first 5 years after resettlement [36]. Last, utilization of care is not equal with appropriate care or equality in quality of care, which we are unable to evaluate with the current study design.

Despite these limitations, we believe our findings add important knowledge to the field of health services research for refugees, a group that is understudied in health system research. Based on our findings, we encourage resettlement countries to enhance primary care services in providing diversity-sensitive care given their role as first port of call. Possible under-use of specialist/outpatient care among refugees and reasons for such differences warrants further research. People with undocumented status before arrival should be subjected to extra awareness to secure healthcare needs being effectively met at the primary care level. Social support and health literacy can be possible targets for future interventions to enhance accessibility of care. In conclusion, the use of healthcare for refugees clearly changes from the pre-and-post resettlement phase. Apart from entitlements and need, health care utilization is impacted by sociodemographic factors and migration-related factors.

Supplementary information

The online version contains supplementary material available at https://doi.org/10.1186/s12913-021-06571-5.

Additional file 1

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on previous versions of the manuscript. All authors (JHY, EMS, JI, EA, BK, WH and ED) read and approved the final manuscript.

Availability of data and materials
The datasets generated and/or analysed during the current study are not publicly available due to data protection regulations in Norway but are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate
 We obtained ethical approval from the Regional Committee for Medical and Health Research Ethics of Norway (ref. no. 2017/377) and consent from the International Organization for Migration. Informed consent was obtained from all subjects. Confidentiality was ensured to all participants and data were de-identified and stored on a protected server.

Consent for publication
Not applicable.

Competing interest
The authors declare that they have no competing interests.

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Paper III: The road to equitable healthcare: A conceptual model developed from a qualitative study of Syrian refugees in Norway

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Abstract

Background: Refugees in high-income countries face barriers to healthcare access even when they have the same rights and entitlements as the host population. Disadvantages in healthcare access contribute to differences in health outcomes and impact acculturation. This study explores perceived changes in health status and experiences with the Norwegian healthcare system of Syrian refugees living in Norway, using a trajectory perspective.

Methods: We conducted 15 semi-structured interviews in April 2020 among purposefully recruited adult refugees from Syria resettled in Norway. Interviews were carried out in Arabic and analysed with Systematic Text Condensation using NVivo software. We used Lévesque's access model and Edberg's migration trajectory perspective as theoretical frameworks. A conceptual model was developed – The Migrant Sensitive Access Model - that highlights the factors contributing to a positive versus negative healthcare journey.

Results: Findings were summarized under three main themes: *changes in health and well-being, expectations*, and *trust.* Perceived changes in health status and attributed causes for change were related to the resettlement phase, gender, and were highly informed by pre-migration and migration experiences. The users' perception of the caregiver, communication, and time were identified as key factors in the care-access journey in inspiring trust or distrust in the caregiver.

Conclusion: Syrian refugees in Norway appreciate the Norwegian healthcare system but are impeded in their access to care. Many of the barriers can be bridged during the doctor-patient interaction with a diversity sensitive caregiver. The model we propose gives a comprehensive overview of key areas determining the healthcare experience of this population. The results of this study can be useful to policymakers and healthcare providers when addressing disparities in healthcare access for forced migrants.

Keywords: Access to healthcare, health status, refugees, migrants and transients, health equity, public health, qualitative research

Introduction

With an unprecedented number of people on the move, the health of forced migrants has become a vital global public health concern (1). While the right to health and access to healthcare is embedded in a number of international laws and agreements (2), protecting these rights in practice remains a challenge. Resettlement countries are obliged to secure health systems that deliver appropriate and equally accessible services. Yet, forced migrants in high-income countries are often at a disadvantage when accessing the healthcare they are legally entitled to, despite resettling in welfare states with publicly funded health services.

Healthcare inequities are found when there are preventable systematic variations in access caused by socio-economic conditions, migrant status, or ethnicity (3). Measuring access to healthcare is, however, complex. Access relates directly to the need of the patient and the use of health services should be proportional to this need. Hence, proxies for access such as healthcare utilization, time until treatment, and mortality rates are often used (4). Prior research has found that migrants in several high-income countries display different patterns of healthcare utilization than the non-migrant population, representing both overuse and underuse (5-7). Similarly, the use of healthcare services also varies depending on the reason for migration and length of stay in the receiving country (8). These differences may indicate inherent barriers to access. However, measuring access through utilization rates and indicators cannot sufficiently answer questions on satisfaction, if needs are met, and the quality of care received. Forced migrants may be at particular risk of having unmet needs and receiving poorer quality of care due to numerous obstacles such as language and communication barriers, low health literacy, sociocultural norms, lack of trust and perceived discrimination (9, 10). For instance, disparities in referral rates based on migrant background could indicate poorer quality of care (11). While socio-economic status can account for much of the documented differences in healthcare utilization, previous research point to migrant background as an independent risk factor for health disparities (12).

Insufficient access to healthcare has been identified as one of several concurrent post-migration stressors causing progressive deterioration of health (13) and, subsequently, in the loss of the health advantage as outlined in the *healthy migrant theory* (14). While the relationship between health and acculturation is not fully understood, it is generally recognized that good health is both an essential element for integration and an outcome of successful integration (3, 15). Hence, the healthcare system can either amplify or weaken this process. Given its fundamental role in both short- and long-term health outcomes, healthcare access is acknowledged as a key social determinant of health and the reduction in inequities as a principal element in health system performance (13).

Studies on forced migrants' access to healthcare often fail to sufficiently integrate the different factors affecting the migrants' health in the different phases of their life course: preceding and accompanying migration and after resettlement (16). The home-country setting, including the healthcare system, plays a role in shaping migrants' perceptions and expectations of the receiving country's healthcare system. During migration and in transit settings, healthcare access is often limited and scattered and may be accompanied by fear of detention or deportation. Upon resettlement, the values of the caregiver and migrants' health beliefs, among other factors, influence migrants' perceptions of the health services being reliable and acceptable, impacting future healthcare behaviour.

Forced migrants in Norway have the same rights and entitlements to benefits and welfare services as the non-migrant population. The Norwegian healthcare system offers universal health coverage with small out-of-pocket expenditures. Primary care with GPs in the front act as gatekeepers to the next echelons of medical care, regulating access to hospitals and specialists. A large majority of forced migrants in Norway meet their GP within the first year after arrival, often as their first point of healthcare contact (17). Interpreters are available for patients with poor language proficiency.

Current research largely focuses on describing the barriers to healthcare forced migrants face regarding restricted rights to entitlements, covering temporary post-migration stressors such as resettlement challenges, often from the provider's perspective. Few studies have focused on settled refugees where many of the temporary challenges are eliminated. There is also lack of research on the migration trajectory, exploring the process from arrival to later resettlement, and the multifaceted correlation between past migration experiences and future healthcare access. The aim of this study, therefore, is to explore settled Syrian refugees' perceived health status, health status change, and experiences with the Norwegian healthcare system post-migration, employing a migrant trajectory perspective. In doing so, the research allows for exploring the nexus between health and healthcare access among forced migrants in relationship with the acculturation processes.

Theoretical framework

We used Lévesque et al.'s conceptualization of access to healthcare as a theoretical input to support the research (18). This framework integrates the attributes of both providers (supply side) and individuals (demand side), each identified by five dimensions. The five dimensions on the provider side are: approachability, acceptability, availability and accommodation, affordability, and appropriateness. The five dimensions on the user side are: ability to perceive, ability to seek, ability to reach, ability to pay, and ability to engage. The model also adds a time perspective and presents each dimension sequentially, attempting to mirror the patient's healthcare journey. However, many

of the stages of the model are inter-related, and the movement between the stages is continuous and fluid. Healthcare access is defined as *"the opportunity to reach and obtain appropriate health care services in situations of perceived need for care"* (5).

The migrant trajectory perspective is based on Edberg et al.'s work (19), drawn from a socio-ecological model, which explains that while several factors contributing to refugee health disparities have been identified, the interaction of these multiple contributing factors is seldom considered. In all stages of the migrant trajectory (pre-, peri- and post-migration), factors add on and interact to shape later healthcare behaviour, operating together as a dynamic system over time. We adopted this framework to emphasize how the migration experience informs later healthcare access, impacted by geography and time.

1. Methods

Study design and participants

This study is part of a larger study titled *Changing Health and health care needs Along the Syrian Refugees' Trajectories to Norway* (CHART) which investigates health among Syrian refugees in Norway. We conducted 15 semi-structured in-depth telephone interviews with adult Syrian refugees (seven men, eight women) in April 2020. Participants were between 24 and 68 years of age (average 47 years), settled in seven different municipalities (both rural and urban) at the time of the interviews. Their length of stay in Norway ranged from 1 to 9 years (average of 4.5 years). The sociodemographic characteristics of the participants are presented in Table 1.

Table 1. Sociodemographic characteristics (insert table here)

Data collection

We identified the participants through contacts in the Syrian community with subsequent snowballing (20) and proceeded with purposive sampling to ensure diversity in characteristics and background (gender, age, education, geographical location, and years of stay in Norway). For instance, we started in the city of Bergen where we have an established network within the Syrian community and approached relevant participants directly. Eight participants were recruited this way. We then asked participants already enrolled if they knew a Syrian refugee living in a rural area, or some of the other characteristics we were looking for to ensure diversity. Seven participants were recruited this way. We selected Syrian nationals who arrived in Norway after 2010 as asylum seekers, refugees, or family reunification to a refugee family member. All participants were settled in a

municipality, which gave them equal rights to entitlements as Norwegian citizens. We developed questions based on knowledge from previous quantitative research (21) and used an interview guide with open-ended questions with additional probes for deeper exploration. All interviews were conducted by the first author (JHY) who is fluent in the first language of the participants (Arabic) and shares their Syrian background. The interviewer is a female medical doctor pursuing a Ph.D., with experience of working in a refugee health centre. JHY was not familiar with any of the participants before the study. The interviews were carried out during the start of the COVID-19 pandemic, providing the rationale for the choice of interview method. The second author is an experienced qualitative researcher (EA), and the third (BK) and fourth (ED) authors are established researchers in the field of migrant health. The research team on this study thus offers a range of perspectives.

We developed an interview guide covering three main themes:

1) Changes in health during migration and after arrival in Norway.

2) Experiences with the healthcare system after arrival in Norway.

3) Trust and distrust in the healthcare system and healthcare providers.

The interview protocol is provided in Appendix A. The interviews lasted approximately 40 minutes (range: 30-60 minutes). All the refugees who were contacted gave their consent and participated and no one dropped out from the study. After completing the interview, participants were offered a 150 NOK gift card as a token of appreciation for their time. Interviews were audio recorded, transcribed verbatim, translated by a professional translator, and cross-checked against the original recordings by the first author. Transcripts were not returned to the participants for comments or corrections. We judged the information power from the data as sufficient based on the concepts of sample and research question specificity, use of established theory, quality of dialog, and analysis strategy (22). The broad, exploratory cross-case analysis called for a sample large enough to create sufficient information power. The sample of participants was established with specific aspects of variation in mind. With support from theoretical frameworks as well as strong and clear communication in the participants' first language, we regarded the information power in the transcribed interviews as sufficient to perform adequate analysis.

Data analysis and developing the model

We analysed the data using an inductive iterative approach, using Systematic Text Condensation (23), a method well-suited to thematic cross-case analysis. The analysis followed a four-step process: (i) reading the transcripts repeated times to familiarize with the data (ii) identifying text units (units of meaning) relevant to our aim and encoding them with codes derived from the data (not

determined a priori or mapped to the theoretical models) (iii) interpreting, condensing and abstracting similarly coded text units for a common meaning, and (iv) summarizing the content within the coded groups into descriptions of the participants' perspectives and experiences. We used the theoretical frameworks as «analytical lenses» throughout the analysis. From the thematic analysis, we were able to identify factors that impact the care-access journey of our sample, providing the framework for the conceptual model developed in this study. Data were initially analysed by JHY, supervised by EA, and thereafter independently analysed by ED. The process of data analysis was regularly discussed within the research team and all the authors participated in the final analysis. Consensus on final theme categorization was reached as a team. We used NVivo software to manage the data.

Ethical considerations

We obtained ethical approval from the Regional Committee for Medical and Health Research Ethics-South East Norway (ref. no. 2017/377). Participants were briefed verbally on the study and subsequently received electronic written informed consent in Arabic. Participants gave verbal confirmation of having read the informed consent form and of their participation prior to the commencement of each interview. Data was stored on a protected server.

2. Results

This research aimed to explore forced migrants' perceptions of their health and potential changes in their health with migration as well as experiences with the Norwegian healthcare system. We identified several important aspects related to health and access to healthcare and present these as three themes: *changes in health and well-being, expectations,* and *trust*. We then used the data to elaborate a conceptual model that highlights factors that contribute to the care-access journey of forced migrants. To understand experiences with healthcare access, it is important to first gain insight into the participants perceived health status and healthcare needs (24). Thus, we start by presenting the first theme relating to changes in health and well-being along the migratory path, followed by two themes that deal with health care access more specifically. The concept of acculturation is reflected across the data. Quotations are assigned pseudonyms.

Changes in health and well-being: A process

Initial stressors after arrival

Several participants described the challenges they face in terms of their health and healthcare needs depending on the length of stay in Norway. For many the initial period after arrival was characterized by mental stress over the status of their asylum application. Decline in health was attributed to

stressful lives in the refugee reception centres and struggles with non-permanent housing. In addition, challenges with language barriers, understanding a new culture, or difficulties navigating and negotiating a new societal and healthcare system were highlighted. Participants mentioned numerous types of stressors, often pointing to the sum of stressors as the reason for the perceived decline in health. However, amid this chaos, participants also emphasized positive feelings, of having hope for a better future for themselves and their families, of new opportunities, and the feeling of safety. One participant shared how the initial period after arrival was mentally stressful, so much so that her distress manifested in physical symptoms:

> *"Ever since I came to Norway, maybe because of mental pressure and stress, and because we were in an asylum center for several months waiting for a residence permit with a lot of thinking and so on, I began to have problems with my stomach and it only got worse, it started with a burning sensation in the upper abdomen and it made me unable to sleep..." (Leena, female, aged 31 years)*

The effect of non-health policies on health, as exemplified in the above quote, was frequently mentioned. Some participants emphasized how external factors, such as change in climate, environment, and food culture affected their health in various ways. Strange food and the inability to buy desired food due to either lack of accessibility or lack of money meant for many a drastic change in dietary habits. One participant elaborated on this explaining that she wanted to eat vegetables as she used to do in Syria, but expensive vegetables and a low income made her unable to keep a healthy diet. Another participant described the additive stressors of initial arrival by highlighting non-permanent housing in addition to food insecurity resulting in physical symptoms:

> *"… when I first came, I was healthy and eventually I started not eating. The food was strange for us, we were in a shock somehow, we lived in an asylum center too, but steadily my body became slim and I felt that when I was walking I couldn't feel my own body…" (Sana, female, aged 49 years)*

Geographical location in Norway influences service provision, and rurality impacts several services including healthcare, with implications on the ability to reach healthcare. This was highlighted by some participants who explained how living remotely influenced their social well-being, with limited public transport and longer distances to schools, the GP office, and hospitals in addition to poor support from persons with similar background. For some participants, the Norwegian climate and clean air were perceived as having a positive impact on their health. For a few others, however, the cold climate was a negative, as it caused body pain, joint pain, and dry skin. The importance of

language proficiency on health was highlighted by two older participants that explained how they asked for permission to attend Norwegian classes as this had an impact on their social well-being, even though they were exempted from this due to age. Language was important both in non-health related arenas, as well as in healthcare, pertaining to the ability to perceive and reach healthcare.

New challenges in the later resettlement period

After the initial arrival period, the shock and emergency response of being new seem to resolve, and a better understanding of the country's societal structure facilitates everyday life including healthcare access. However, new challenges relating to social exclusion and exclusion from the labour market appeared with accompanying health effects. Male participants in particular described their mental and physical struggle with unemployment and inactivity leading to weight gain and an unhealthy lifestyle.

> *"My health has worsened, has become a lot worse, but it is not because of the doctors here, we are simply used to work in our home country, you know how it is in Arabic countries and I am a physical worker, not an office worker, but now we have to attend school and are often at home."*
> *(Ammar, male, aged 49 years)*

In contrast, some female participants found the change in their traditional role—from being a homemaker in Syria to being active outside the home in Norway—challenging.

> *"Ever since I came to Norway, I feel I have days when I don't have the capacity to do anything and feel depressed and there are days when I feel good… in Syria, we were not used to being sent to work or go to school, us housewives, not those who work and have jobs, we as housewives… I realized that I get exhausted and depressed at times and I am tired, I can't handle more, but sometimes I pray to God to make us stronger…" (Reem, female, aged 42 years)*

Loss of status and social position, particularly among males, affected mental health, self-esteem, and social well-being negatively. This appeared to be more prominent among the highly educated, experiencing a bigger loss. Overall, there were no clear gender differences in perceived decline or improvement in health trajectories after arrival, however, the attributed reasons for the change were noticeably gender related. Some also correlated past experiences, and exposures pre-migration with their current health status, for example by mentioning physical and mental wounds from the war or poor nutrition over time. Several participants mentioned either having no changes in health or

experiencing an improvement in health after arrival. This perception of an upturn was attributed to relief, security, improved living standard, and easier access to different types of services.

Expectations

Diverging expectations emerged, rooted in the healthcare system known to the participants from their country of origin impacting health beliefs. This was outlined by descriptions and comparisons between the Norwegian healthcare system and the one known from before, here exemplified by a comment from a female participant:

> " …I do not feel that they have as much experience and are as skilful as the
> doctors we have seen in Syria" (Leena, female, aged 31)

Expectations were also shaped by previous experiences, rumours, and anecdotes, in some cases acting as a deterrent to future health seeking. Expectations were not always met. Almost all the participants expected to get painkillers, antibiotics, or other medication when in contact with a healthcare provider. To get "something" was a minimum. One participant reflected on this with an open mind, noting that the way she used to get prescriptions with ease in Syria might not be correct. She explained how it was difficult to not receive what you were used to and how it might affect the elders in their community who were less able to adjust. Another participant, also noting these differences in healthcare systems and cultural beliefs, was unsure about what to think:

> "…but sometimes when you want antibiotics, they [the doctor] won't
> listen, I don't really know if they are the ones being right or if it is just us
> being used to antibiotics…" (Yara, female, aged 64)

Referral to specialists was another subject of mismatched expectations; many participants were used to consulting a specialist without referral in Syria. Hence, the gatekeeping role of the GP was unfamiliar, contributing to unfulfilled expectations.

Another important topic of discussion during the interviews was cultural differences in seeking healthcare. For the participants, when to seek care and the perceived non-acceptance of seeking care for simple conditions such as a fever were significant issues. One father explained that he preferred to seek care when his child had a fever, arguing that he is not a doctor and is afraid his child might suffer severe harm or even die if he does not take action. He explained that if he proceeded to seek care in such a scenario, he would feel bad about breaking Norwegian cultural norms, and "they" would view him as abnormal and disrespectful. This ambivalence on when to seek care appeared to be more prominent among the less educated and the ones with shorter duration of stay.

A majority of participants repeatedly pointed to the long waiting time in both primary and secondary care settings as a major obstacle to accessing healthcare. The waiting time was an unaccustomed experience and, in many situations, it was perceived as problematic.

> *"A difficulty I have seen is, for example, when you are ill and you need to go to the doctor and if they don't find an appointment they make you wait for a week, ten days or two weeks…it's difficulties like these we meet because you somehow manage to recover before you get an appointment." (Reem, female, aged 42)*

Trust and distrust

Most participants trusted the Norwegian healthcare system and Norwegian healthcare providers. This trust is grounded in participants' perception of humane, honest, and respectful treatment from Norwegian healthcare providers and past positive experiences. Several portrayed a process of building trust alongside positive experiences:

> *«You can say that my confidence has changed from when we came to Norway and now. We were used to taking medicine in our home country but here they [the doctors] say no, you do not need it in your situation… maybe the way I reacted was because I was in a new society with cultural differences, but I thought to myself that this was maybe wrong of them… but with time this thought has changed because I have been exposed to several health problems and it has, thank God, gone well. This increased my confidence in them» (Leena, female, aged 31)*

The perception of the caregiver

For some participants, being listened to and being understood were just as important as physical care. This was particularly emphasized among female participants. For some male participants, the providers' skills, and ability to give a prompt diagnosis inspired confidence. One participant explained that the reason he trusted Norwegian doctors was because they were "honest and tell you immediately if there is something wrong". For several participants, the Norwegian healthcare system excels over others because of the humanitarian approach of the system and its caregivers. There is no differentiating between patients based on ethnic background.

> *"…they do not differentiate between Arabs and Norwegians, they treat everyone equally, and they are very kind and do not let you push yourself to cope with things that are beyond what you can handle. If you are in*

pain, they try to make things easier for you, even with when it comes to

just talking, that is, not just with medication." (Dalia, female, aged 24

years)

Both the ability to perceive and the ability to engage in healthcare require trust. The lack of trust in the healthcare system was based on participants' negative experiences, perceived racism and discrimination, poor communication, lack of time, and, to some extent, the perceived inexperience of the healthcare provider. The experiences of racism and discrimination were mixed and occurred in some participants' narratives, often expressed implicitly in statements like "the treatment I received was good considering I am an Arab" and "I am not Norwegian, so I have to wait until I almost die to be able to get treatment". Others highlighted the exact opposite experience, the feeling of being accepted regardless of migrant background. Fear of discrimination in combination with poor communication also appeared in emergency care settings. Several participants described being overwhelmed by difficult questions when contacting pre-hospital emergency care by phone (calling 911). They feared not receiving help if they did not give the right answers. Some participants shared how they had to communicate with the emergency medical dispatcher through their children. A number of participants felt exceptionally vulnerable engaging with an unfamiliar system and not knowing what to say in a time-critical emergency to be able to receive the care that was needed.

"…we called the ambulance and you have to explain things to the

ambulance and answer questions, even a doctor would not have been

able to answer those questions the ambulance is asking, you have to

check the pulse and see how he is breathing, if I knew all those things

then clearly I wouldn't have called." (Ammar, male, aged 49 years)

One participant described his fear of being discriminated against in an emergency setting because of his background. According to him, the first thing the healthcare worker will do is search for your personal identification number and they will know that you are not Norwegian-born. Others reported positive experiences in emergency settings where the ambulance came promptly and they received good treatment at the hospital. In several of these accounts, the person calling the ambulance was fluent in Norwegian (a neighbour, friend, or teacher) and the health problem was well-defined (symptoms of stroke and heart attack).

Communication

Communication emerged as an important topic across the data. Good communication was attributed to the caregivers' abilities to listen and willingness to understand, even with the use of non-verbal communication. Poor communication was related to increased misunderstandings and a poorer

doctor-patient interaction, contributing to distrust. Poor communication was highlighted regardless of the use of interpreters. As one participant explained, when using an interpreter, you must make sure that they understand and deliver your message correctly. For some participants, an interpreter worked well when explaining simple medical conditions. However, for complex and multifaceted medical conditions, where effective communication was fundamental, referring to effective communication being more than mere words, an interpreter was insufficient.

> *"What I have seen are problems with the language. You have to be very competent in the language. Because with interpreters, as I told you, the interpreter does not always give the right picture to the doctor. It's not that if you have a headache, well then you get a pill… this is not where the problem lies, but it is about having special diseases and complex problems and if the doctor does not understand you properly then you will not get the right treatment." (Ali, male, aged 50 years)*

Time

Several participants mentioned time during consultations as crucial in the healthcare experience. Lack of time during the consultation was an obstacle, explaining that consultation with interpreters takes more time, often not accounted for in the appointment scheduling. Participants felt restricted and demotivated to discuss complex problems or mentioning several health issues in the consultation.

> *" I do not feel that I can feel free [to express myself] when I am at the doctor's due to time" (Ali, male, aged 51 years)*

Alternative health-seeking strategies were described when experiencing unmet needs, such as contacting a Syrian doctor outside Norway for advice. Some described seeking out-of-hours care when the waiting time for an appointment at the GP was perceived as too long. The rejection from the healthcare system by negative experiences seemed to be amplified by rejection on other non-health related arenas, such as in education or the labour market, resulting in distrust in the Norwegian system in general. A negative view was often expressed as comparisons, such as "Syrian doctors are better" or "the Syrian educational system is better".

The Migrant Sensitive Access Model

Based on the data on health care access represented in two themes, expectations and trust, a conceptual model was developed (figure 1). The conceptual model outlines a pathway from expectations about healthcare to experiencing trust or distrust in the system and its providers by crucial elements along the way. We have highlighted three elements in the proposed pathway; *the perception of the caregiver, communication, and time*, grounded in our data. These elements can either serve as barriers or as facilitators to achieving trust. In the element we have called the *perception of the caregiver*, we find characteristics participants have identified as important in inspiring confidence and create mistrust. In the *communication* element, participants shared their experiences with what poor and good communication entail. Lastly, the concept of *time* emerged as fundamental in the care-access experience.

The point of the model is to highlight how different parts of the care-access process interact to reach the endpoint of either fulfilled or unmet healthcare needs, and the parallel process of healthcare seeking and acculturation. As shown from our data, negative experiences from healthcare seeking can amplify an already existing feeling of separation from society leading to more distancing, which in turn can have an impact on how health needs are met and the use of regular and alternative healthcare services. In contrast, positive experiences follow a positively reinforcing root based on trust and integration. A positive experience enhances trust and motivates further use of the healthcare system which in turn strengthens the acceptance of the Norwegian system and society.

Figure 1. The Migrant Sensitive Access Model (insert figure here)

Discussion

We explored Syrian refugees' experiences with changes in their own health and access to healthcare services after forced migration to Norway. Our principal findings were categorized into three themes: *changes in health and well-being, expectations*, and *trust*. Our results suggest that health challenges for refugees are deeply intersected with the acculturation process, underpinning the different phases of the post-migration trajectory manifest in different challenges during early, and late resettlement. In early resettlement, participants experienced temporary stressors connected to asylum-seeking and adapting to new environments. Later, challenges relating to social exclusion emerged, centred on the relationship of the migrants with the labour market.

We also identified a gender aspect in the types of challenges met. Some of the female refugees struggled with the transition from being at home in Syria to having many responsibilities outside the home in Norway, while at the same time adjusting to a new culture—a type of role overload and/or role conflict resulting in a change in family dynamics (30). In contrast, male refugees identified

unemployment and inactivity as the main cause of the deterioration in their health. Even though there is a recognition in the literature of the importance of gender differences in shaping migration experiences (31, 32), there is a lack of knowledge on how this affects the resettlement process and its relation to later health outcomes.

Health status change along the migratory path is highly linked with access and use of healthcare services, following parallel trajectories. In the early resettlement period, the **approachability** and **ability to perceive** dimensions in Lévesque's framework were most dominant, with a focus on information and screening from the service side and knowledge of available resources and health literacy on the individual side. In this first dimension, we also find the concepts of expectations, trust, and distrust.

Within the framework of the migration trajectory approach (19), pre-migration and migration experiences as well as sociocultural norms shape the expectations of the receiving country's healthcare system. The concept of expectations draws on a large body of previous theorising within psychological research, placing expectations within the range of cognitive care and context effects (25). This is also in accordance with the **approachability** dimension within Lévesque's framework, which highlights the fact that previous experiences inform one's perception of the healthcare system. Often, high expectations contribute to the feeling of mismatch and, subsequently, disappointment. In our sample, a mismatch in expectations was found in terms of services (lengthy waiting time, referrals to a specialist), in health paradigms (use of antibiotics and painkillers) and in sociocultural norms, as exemplified by the father who was deterred from seeking care because of the fear of how he would be perceived by others. The judged appropriateness to seek care pertains to the **ability to seek** concept that underpins the role of sociocultural factors in accepting the service (18).

Likewise, trust emerged as a core concept in accepting and utilizing conventional health care in our data and is rooted in theories on patient centeredness and cultural competence (26, 27). Enough trust in the services is a prerequisite for reaching out, and a trustful relationship with the caregiver is pivotal to further acceptance and maintenance of service use. A compassionate and empathetic disposition has previously been reported as an important aspect of the healthcare provider to increase a trustful relationship (33). Trust is also a dimension within the concept of social capital and high levels of trust have a positive impact on health and seem to buffer experiences of perceived discrimination (34). Similarly, social capital is fundamental in fostering resilience, a vital salutogenic resource among refugees. Our findings emphasize two aspects regarding trust. First, gaining trust in the Norwegian healthcare system is a stepwise, interactive process, often starting with distrust and gradually shifting to more trust when becoming familiar with the system. Second, a high level of trust

was rooted in positive experiences, good communication, and humane treatment, and not exclusively in increased knowledge of the healthcare system.

On the other hand, distrust was founded in negative experiences including discrimination, lack of time, and poor communication. Manifestation and fear of discrimination and stigmatization based on migrant background were mentioned by some of our participants, especially in emergency care settings where help from Norwegian-speaking friends was commonly necessary. As stated by the World Health Organization, discrimination at individual and institutional levels must be regarded as the fundamental cause of many health problems (35). Evidence suggests that discrimination plays a central role in both physical and mental adverse health outcomes after resettlement (36, 37) and has also been linked to substituting conventional healthcare with alternative healthcare among migrants (38). Additionally, discrimination in the resettlement period has been associated with a negative impact on trust (37, 39). Experiencing discrimination and stigma when accessing care may increase distrust and reinforce negative experiences rendering the healthcare inappropriate, underlined in the final step in the access framework: **appropriateness**.

Healthcare utilization is also influenced by how services are organized and whether they can be reached physically and on time, represented by the **availability and accommodation** dimensions in the access framework. Our participants highlighted waiting times as problematic. Delays in obtaining appointments are recognized as a deterrent to receiving care (18). Long waiting times can be discriminatory and easily implemented and justified since they apply to all patients. Some participants, therefore, viewed the gatekeeping function in healthcare as a point of vulnerability to potential inequity in services, and yet expressed some kind of acceptance of inequity, as exemplified by the participant who pointed out that the care he received was not that bad considering he is an Arab.

The mismatch in expectations and failure to respond in a culturally sensitive way will create unmet needs, which in turn can lead to alternative health-seeking behaviour, as outlined in the last dimensions of the patient journey: **appropriateness** and **the ability to engage**. Despite the increased awareness of cultural sensitivity in recent years, research shows that medical doctors remain largely unprepared due to lack of training and assessment of cultural competence in medical education programmes (40) and call for more training and guidance (33).

Strengths and limitations

Our sample engaged participants from urban and rural areas, from diverse educational backgrounds and with equal gender distribution. We did not use interpreters, allowing direct communication in participants' first language, which most likely had a positive effect on establishing trust and in

increasing the reliability of the data by minimizing information lost in translation. We sought to verify data rigor by including two independent coding procedures and by using two theoretical frameworks to guide our understanding of the findings.

Results should, however, be interpreted keeping in mind the following limitations. Even though we used purposive sampling to achieve a diverse sample, we have not asked about legal status when arriving in Norway (asylum seeker, quota refugee, family reunification) to ensure diversity in migration trajectories nor have we included any single persons (never married). The use of telephone instead of face-to-face interviews could contribute to apprehension in the interview situation and loss of non-verbal communication. On the other hand, the use of telephone interviews allows for more anonymity. The participants' average length of stay in Norway at the time of the interviews was 4.5 years, yielding the possibility of recall bias when describing past events, which in turn may affect credibility. This time aspect, however, enabled us to assess the acculturation process in relation to healthcare access in both early and later resettlement and the gradual transition in between. The model developed is simplified, and we recognize that other factors contribute and interact to shape the care-access journey.

Implications

Findings from this study are highly relevant to understanding forced migrants' experiences and perceptions of the healthcare system. While sociocultural barriers are not generalizable, we believe some of our findings can be relevant for other receiving countries in terms of concepts, given the similar policies governing resettlement and healthcare access in high-income countries across the globe. From a trajectory perspective, gaps and difficulties in healthcare access can be addressed and tailored depending on the resettlement stage. We believe the findings of this study add to the knowledge base of refugee health and can be useful when implementing migrant-sensitive strategies and training for healthcare providers.

3. Conclusion

The road to appropriate healthcare access for a refugee is dynamic, closely interrelated to the acculturation process, and informed by pre-migration and migration experiences. To address inequities in healthcare in countries with universal health coverage, it is important to understand how barriers other than entitlements and affordability come into play in the care-access journey. Many of these barriers can be bridged by achieving a trustful relationship with the healthcare system and its caregivers. The conceptual model we offer – The Migrant Sensitive Access Model - highlights

the key factors that shape the healthcare experience for refugees, resulting in either trust or distrust of the healthcare system.

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Experiences with seeking healthcare

I wonder how you have experienced the contact with the healthcare services after you came to Norway. Can you tell me about the last time you contacted the healthcare services?

- What was the reason behind the need for contact?
- How did you contact the healthcare services? (telephone, webpage, e-consultation, meeting up)
- How did you experience the meeting?
- Did they understand your need?
- Did you receive the help you were looking for?

People have different experiences when they contact the healthcare services, in the way they are met. How has this been for you?

Can you tell me about any such experiences?

- What kind of obstacles have you experienced?
- Do you have any good experiences with the healthcare services? Tell me!
- What has been useful?
- Do you trust that the healthcare services are trying to help you? Tell me!

How has your health been since you came to Norway?

- What has gotten better?
- What has gotten worse?

PART B – ETHICAL APPROVAL AND INFORMED CONSENT

Region:	Officer:	Phone:	Our date:	Reference:
REC South East	Leena Heinonen	22845529	18.04.2017	2017/377 REK South East, Section D
			Your date: 14.02.2017	

Esperanza Diaz
University of Bergen

2017/377 Changing health and health care needs along the Syrian refugees' trajectories to Norway

Responsible for Research: University of Bergen, The Norwegian Centre for Migration and Minority Health (NAKMI)
Project Manager: Esperanza Diaz

We are writing in reference to your Application for Preliminary Approval for the above-mentioned Research Project. The Regional Committee for Medical and Health Research Ethics, Section D, South East Norway, reviewed your Application during its meeting on the 29th of March 2017. The Project was assessed in accordance to the Norwegian Research Ethics Act § 4 2006, and the Health Research Act § 10 2008, for Regional Committees for Medical and Health Research Ethics.

Project summary (as provided by the Project Manager)
The number of refugees living in Norway will soon reach 200.000. Currently, half of the asylum seekers to Norway are from Syria, and most of them obtain permanent refugee status. Little is known about their total burden of disease, how somatic and mental health change during the migration phases and how best to provide adequate health services to this growing group. Among adult asylum seekers and refugees from Syria following different migration paths to Norway, our study aims to investigate their 1) Burden of somatic and mental health problems; 2) Associations between mental and somatic health; 3) Self-reported health (SRH), quality of life (QOL), health care access and unmet healthcare needs; 4) Association between SRH and QOL and health care access and needs. Data will be collected through questionnaires and personal interviews. Our study will provide valuable information for the development of appropriate and equitable health services for asylum seekers and refugees.

The Committee's Considerations
This study is a context-sensitive survey for Syrian and Palestinian refugees aged 16 and upwards. Three groups will be included: 250 Quata refugees in Lebanon, 250 refugees who are waiting in Greece or Italy to come to Norway and 250 refugees who already are in Norway, in Bergen and Kristiansand. The survey data are collected through self-administrated questionnaires, translated to Arabic and repeated within one year. Some of the refugees will be interviewed for the collection of qualitative data. All participants will be asked for informed consent.
The purpose of this project is to study the change in burden of disease, including somatic and mental health and self-perceived health in the different migration phases.

For data collection, the researchers will cooperate with the International Organization for Migration in Lebanon, Greece and Italy. The project is also collaborating with the University of Bristol and the Swedish Red Cross University College for comparison of results collected in other countries.

The Project is a student project, carried out to form the basis for a PhD thesis in Medicine.

The Committee considers that the Project can provide new knowledge about health and disease among the Syrian and Palestinian Refugees and may identify risk factors for negative development of somatic and mental health.

The Committee has no objections to the study as described in the Application Form and the Protocol.

Decision
The Project is approved, in accordance with the Norwegian Health Research Act § 9 and § 33.
The Approval is given on condition that the Project is conducted as described in the Application and the Protocol.

The Approval is valid until 31st of December 2023. The data must be stored as de-identified data, i.e. with identifying information kept separate from the other data. For purposes of documentation, the data should be kept until 31st of December 2028 and deleted or anonymised after this date.

The data must be stored in accordance with the norms of data protection in personopplysningsforskriften chapter 2, and the guide "Personvern og informasjonssikkerhet I forskningsprosjekter innenfor helse- og omsorgssektoren", published by the Norwegian Directorate of Health.

If the Project Manager wants to make substantial changes to the objective, method, schedule or organization of the Research Project, an application must be submitted to the Regional Committee for Medical and Health Research Ethics.

The Project Manager must submit a Final Report to the Regional Committee for Medical and Health Research Ethics when the Research Project is finished.

The Committee's decision was unanimous.

The decision of the Committee may be appealed to the National Committee for Research Ethics in Norway. The appeal will need to be sent to the Regional Committee for Research Ethics in Norway, South-East D. The deadline for appeals is three weeks from the date on which you receive this letter.

With kind regards,

Finn Wisløff
Chair of the Regional Committee for Medical
& Health Research Ethics of South East Norway, Section D

                                                                    Leena Heinonen
                                                                    adviser

CC: Guri.Rortveit@uib.no; bernadette.kumar@nakmi.no
University of Bergen: post@uib.no
The Norwegian Centre for Migration and Minority Health: post@nakmi.no

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK sør-øst	Hege Cathrine Finholt, PhD	22857547	07.08.2018	2017/377/REK sør-øst D
			Deres dato:	Deres referanse:
			02.07.2018	

Vår referanse må oppgis ved alle henvendelser

Esperanza Diaz
Inst Global helse og sammfunsmedisin/NAKMI

2017/377 Endringer i helse- og helsebehov blant Syriske flyktninger på vei til Norge

Forskningsansvarlig: Universitetet i Bergen, Nasjonal kompetanseenhet for minoritetshelse
Prosjektleder: Esperanza Diaz

We are writing in reference to the Project Amendment Application Form dated July 02, 2018 for the abovementioned Research Project. The Chairperson for REC South East D has assessed the amendment form in accordance with section 11 of the Health Research Act 2008.

The Project Manager has applied for the following amendments to the Research Project:
- Nye prosjektmedarbeidere:
  Mahnaj Akter, master student
  Jannicke Igland, Senior engineer
- Innhenting av nye data fra samme utvalgsgrupper
- Oppfølging av samme utvalgsgruppe
- Ny/endret forespørsel om deltakelse og samtykkeerklæring

Review
The Committee has reviewed the amendments has no objections to the proposed amendments as described in the application form.

Decision
The Committee approves the application for amendment to the Research Project, in accordance with section 11 of The Health Research Act 2008.

The project is approved on the condition that it is conducted as described in the Project Amendment Application Form.

Appeals process
The decision of the Committee may be appealed to the National Committee for Research Ethics in Norway. The appeal will need to be sent to the Regional Committee for Research Ethics, Section D, South East Norway, The deadline for appeal is three weeks from the date on which you receive this letter.

Kind regards

Finn Wisløff
Professor em. dr. med.
Leder

Besøksadresse:	Telefon: 22845511	All post og e-post som inngår i	Kindly address all mail and e-mails to
Gullhaugveien 1-3, 0484 Oslo	E-post: post@helseforskning.etikkom.no	saksbehandlingen, bes adressert til REK	the Regional Ethics Committee, REK
	Web: http://helseforskning.etikkom.no/	sør-øst og ikke til enkelte personer	sør-øst, not to individual staff

Hege Cathrine Finholt, PhD
Rådgiver

Kopi til: *Guri.Rortveit@uib.no; bernadette.kumar@nakmi.no; post@uib.no*

Region:	Officer:	Phone		Our date	Reference :
REC South East	Leena Heinonen	22845598		16.06.2017	2017/377 REK South East Section D
				Your date: 28.04.2017	

Esperanza Diaz
University of Bergen

2017/377   Changing health and health care needs along the Syrian refugees' trajectories to Norway

Responsible for Research: University of Bergen, The Norwegian Centre for Migration and Minority Health (NAKMI)
Project Manager: Esperanza Diaz

We are writing in reference to the Project Amendment Application Form dated the 28 th of April 2017 for the abovementioned Research Project. The Chairperson for REC South East D has assessed the amendment form in accordance with section 11 of the Health Research Act 2008. We apologize for the lateness of the reply.

The Project Manager has applied for the following amendments to the Research Project:
- a minor change in the recruitment process

Review
The Committee has reviewed the amendments has no objections to the proposed amendments as described on the application form.

Decision
The Committee approves the application for amendment to the Research Project, in accordance with section 11 of The Health Research Act 2008.

The project is approved on the condition that it is conducted as described on the Project Amendment Application Form.

Appeals process
The decision of the Committee may be appealed to the National Committee for Research Ethics in Norway. The appeal will need to be sent to the Regional Committee for Research Ethics, Section D, South East Norway, The deadline for appeal is three weeks from the date on which you receive this letter.

With kind regards

Finn Wisløff
Chair of the Regional Committee for Medical
& Health Research Ethics of South East Norway, Section D

Leena Heinonen
adviser

CC: *Guri.Rortveit@uib.no; bernadette.kumar@nakmi.no; University of Bergen: post@uib.no*

| **Besøksadresse:** Gullhaugveien 1-3, 0484 Oslo | **Telefon:** 22845511 **E-post:** post@helseforskning.etikkom.no **Web:** http://helseforskning.etikkom.no/ | All post og e-post som inngår i saksbehandlingen, bes adressert til REK sør-øst og ikke til enkelte personer | Kindly address all mail and e-mails to the Regional Ethics Committee, REK sør-øst, not to individual staff |

Informed consent form-questionnaire

'Changing health and health care needs along the Syrian refugees' trajectories to Norway'

Background information:

The University of Bergen together with the International Organization of Migration and the municipalities of Bergen and Kristiansand are conducting a survey to study the health and health care services experiences among Syrian refugees and asylum seekers to Norway. The results from the study will increase our knowledge about the health of refugees in/to Norway and will help us to provide better health care services. This is an invitation for you to participate in this study by answering a questionnaire survey. In case you do not live in Norway already, we ask you for your permission to contact you in Norway again to fill the questionnaire after some months living in Norway.

Participant selection:

All 16 years or older persons at the refugee health centre are invited to participate in this study by answering a self-administered anonymous questionnaire. The questionnaire takes 15-20 minutes to complete, and includes general demographic questions, questions related to health, quality of life, access to healthcare services and unmet healthcare needs.

Confidentiality:

We will not register your name or personal identification number or other directly recognisable type of information in the questionnaire. Information about you that will be collected through the questionnaire will be kept confidential and stored safely. Only the researchers will have access to your information, which will only be used in accordance with the purpose of the study as described above. A code number links your name to your data through a list of names in order to be able to contact you again. The list that can link your name to the code number will be secured, and only the authorised study staff will have access to this list. This study is not linked to any other legal institution and cannot affect your eventual permission or denial to stay in the country.

Rights to refuse or withdraw:

Participating in the Syrian Refugee Health Survey is your choice. You do not have to take part in this research if you do not wish to do so and refusing to participate will not affect your regular health exam or treatment in any way. You may stop participating in the research at any time that you wish without losing any of your rights as a patient here. If you have any questions about this survey, please talk to the person who gave you the questionnaire.

Consent for participation in the study:

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction. I consent voluntarily to participate as a participant in this research. I know that I may refuse to participate or to stop at any time without any loss of health care benefits that I am otherwise receiving.

Date   Date

Respondent Signature   Interviewer Signature

Informed consent form-questionnaire

'CHART- Changing health and health care needs along the Syrian refugees' trajectories to Norway'

Background information:

The University of Bergen is conducting a survey to study the health and health care services experiences among Syrian refugees and asylum seekers to Norway. The results from the study will increase our knowledge about the health of refugees in/to Norway and will help us to provide better health care services. You answered to our questions while you were in Lebanon. This is an invitation for you to participate in this study by answering a similar questionnaire survey once you live in Norway. We also ask you for your permission to contact you in Norway again after one to two years living in Norway to learn how your health is and how the health care system respond to your needs.

Participant selection:

All 16 years or older persons who participated in the CHART study in Lebanon are invited to participate again in this study by answering a self-administered anonymous questionnaire. The questionnaire takes 25-30 minutes to complete, and includes general demographic questions, questions related to health, quality of life, access to healthcare services and unmet healthcare needs plus questions about food security in the household.

Confidentiality:

We will only register your name and other directly recognisable type of information in the questionnaire if you agree that we contact you again. Your personal information will be kept electronically separate from the rest of the information you give us. A code number links your name to your data through a list of names in order to be able to contact you again. The list that can link your name to the code number will be secured, and only the authorised study staff will have access to this list. Information about you that will be collected through the questionnaire will be kept confidential and stored safely, and will only be used in accordance with the purpose of the study as described above. This study is not linked to any other legal institution and cannot affect your eventual permission or denial to stay in Norway.

Rights to refuse or withdraw:

Participating in the CHART Survey is your choice. You do not have to take part in this research if you do not wish to do so and refusing to participate will not affect your regular health exam or treatment in any way. You may stop participating in the research at any time that you wish without losing any of your rights as a patient here. If you have any questions about this survey, please talk to the person who gave you the questionnaire.

Consent for participation in the study:

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction. I consent voluntarily to participate as a participant in this research. I know that I may refuse to participate or to stop at any time without any loss of health care benefits that I am otherwise receiving.

Date   Date

Respondent Signature   Interviewer Signature

PART C - QUESTIONNAIRES

CHANGING HEALTH AND HEALTH CARE NEEDS ALONG THE SYRIAN REFUGEES' TRAJECTORIES TO NORWAY

QUESTIONNAIRE

Thank you for taking part in this study by completing this questionnaire.

The information will be used in research aimed to understand the health situation and improve health care services for refugees. Some of the questions are similar to questions you answer when you attend the health examination. It is important that you answer all the questions on this questionnaire. Please ask if there is something you do not understand. The completed questionnaire should be returned to the person who invited you to the study before you leave.

By answering this questionnaire you accept that we use this information only for the purposes explained to you. All information will be treated in strict confidence.

This survey contains 5 parts. Please answer by putting an X in the box (☐), or answering the open fields (_____) as explained in the text.

Yours sincerely,
The University of Bergen, The Health Care services at the Municipality of Kristiansand, and The Municipality of Bergen and IOM

HEALTH LITERACY SCREENING

1 How often do you need help reading written material from your doctor or pharmacy?

Never	Rarely	Sometimes	Often	Always
☐	☐	☐	☐	☐

BACKGROUND INFORMATION

	Woman	Man
2 Gender:	☐	☐

3 Year of birth: ☐☐☐☐ *(e.g. 1978)*

4 Which country were you born in?

☐ Syria   ☐ Iraq   ☐ Other

_____
Please specify (e.g. Turkey).

5 What language is your native tongue?

☐ Arabic   ☐ Kurmanji   ☐ Sorani

☐ Armenian   ☐ Other

_____
Please specify (e.g. Turkish).

6 What is your ethnicity?

☐ Arab   ☐ Kurd   ☐ Armenian   ☐ Other

_____
Please specify (e.g. Turkish).

7 What is your marital status?

☐ Single   ☐ Separated   ☐ Married

☐ Divorced   ☐ Widowed   ☐ Other

	Yes	No
8 If married, are you living with your partner(s)?	☐	☐

	Yes	No
9 Do you have children?	☐	☐

10 How many children do you have?

☐ 1   ☐ 2   ☐ 3   ☐ 4   ☐ 5 or more

11 How many years of education have you completed altogether? ☐ years
(e.g. 5 years)

12 What was your occupational status in your country of origin?

☐ Employed for wages ☐ Self-employed

☐ Out of work ☐ Homemaker

☐ Student ☐ In the military

☐ Retired ☐ Unable to work

☐ Other

▼

Please explain.

13 When did you flee from your home country?

Year: |____| *(e.g. 2013)*

14 When did you arrive to the country where you are now?

Month and year:

(e.g. November 2013)

15 Did you arrive?

☐ With all immediate family members

☐ With some immediate family members

☐ Alone

	Yes	No
16 Have you stayed in any country (transit) on your way to this place?	☐	☐

17 If yes, in how many countries did you stay for more than a week?

☐ One ☐ Two ☐ Three ☐ More than three

18 If you have stayed in several countries on the way to this place, for how long (in total) did you stay in that country/ those countries?

☐ Up to 6 months ☐ 6-12 months

☐ 1 -2 years ☐ More than two years

	Yes	No
19 Were you ever retained against your will during the transit phase?	☐	☐

	Yes	No
20 Do you have a residence permit in the country you are now?	☐	☐

21 How do you consider your health at the moment?

Very poor	Poor	Neither	Good	Very good
☐	☐	☐	☐	☐

22 Have you had or do you have any of the following?
(Put an X on each line under No or Yes. If Yes, please explain.)

	Not familiar with the term	No	Yes	Age first time
22.1 Heart attack/chest pain	☐	☐	☐	22.2 |____| years
22.3 Heart failure	☐	☐	☐	22.4 |____| years
22.5 Other heart disease	☐	☐	☐	22.6 |____| years
22.7 Stroke/brain hemorrhage	☐	☐	☐	22.8 |____| years
22.9 Kidney disease	☐	☐	☐	22.10 |____| years
22.11 Liver disease	☐	☐	☐	22.12 |____| years
22.13 Asthma	☐	☐	☐	22.14 |____| years
22.15 Chronic bronchitis, emphysema or COPD	☐	☐	☐	22.16 |____| years
22.17 Tuberculosis	☐	☐	☐	22.18 |____| years
22.19 Diabetes	☐	☐	☐	22.20 |____| years
22.21 Psoriasis	☐	☐	☐	22.22 |____| years
22.23 Eczema	☐	☐	☐	22.24 |____| years
22.25 Cancer	☐	☐	☐	22.26 |____| years
22.27 Arthritis *Reumatoid arthritis*	☐	☐	☐	22.28 |____| years
22.29 Other joint diseases	☐	☐	☐	22.30 |____| years
22.31 Osteoporosis	☐	☐	☐	22.32 |____| years
22.33 Fibromyalgia or generalized body pain	☐	☐	☐	22.34 |____| years
22.35 Mental health problems you sought help for	☐	☐	☐	22.36 |____| years
22.37 Epilepsy	☐	☐	☐	22.38 |____| years
22.39 Headache	☐	☐	☐	22.40 |____| years
22.41 Abdominal pain/diarrhea	☐	☐	☐	22.42 |____| years
22.43 Allergies	☐	☐	☐	22.44 |____| years

23 Do you suffer from long-term (at least 1 year) illness or injury of a physical or psychological nature that impairs your daily life?

☐ Yes   ☐ No

24 If yes, how would you describe your impairment?

	Slight	Moderate	Severe
24.1 Motor ability impairment	☐	☐	☐
24.2 Vision impairment	☐	☐	☐
24.3 Hearing impairment	☐	☐	☐
24.4 Impairment due to physical illness	☐	☐	☐
24.5 Impairment due to mental health problems	☐	☐	☐

	Yes	No
25 Do you have physical pain now that has lasted more than 6 months?	☐	☐

26 If yes, how strong has your physical pain been during the last 4 weeks?

No pain	Very mild	Mild	Moderate	Strong	Very strong
☐	☐	☐	☐	☐	☐

27 Have you used any of the following medicines?
(Please place only one X for each medication at the answer that best fits your situation.)

	Daily	Weekly	Less than weekly	Not taken during the last 4 weeks
27.1 Drugs for peptic ulcer, gastro-esophageal reflux and digestion	☐	☐	☐	☐
27.2 Antithrombotics (aspirin, warfarin)	☐	☐	☐	☐
27.3 Cholesterol reducing medication	☐	☐	☐	☐
27.4 Medicine for high blood pressure	☐	☐	☐	☐
27.5 Medicine for diabetes mellitus	☐	☐	☐	☐
27.6 Medication for asthma or COPD	☐	☐	☐	☐
27.7 Painkillers, off prescription	☐	☐	☐	☐
27.8 Painkillers, on prescription	☐	☐	☐	☐
27.9 Sedatives	☐	☐	☐	☐
27.10 Tranquillizers	☐	☐	☐	☐
27.11 Anti-depressive medication	☐	☐	☐	☐
27.12 Medication for allergy	☐	☐	☐	☐
27.13 Other prescribed medication, but do not know for what	☐	☐	☐	☐

28 Listed below are symptoms or problems people sometimes have. Please indicate in the appropriate box how much each of these symptoms has bothered or distressed you <u>in the last week</u>.

	None	A little	Quite a bit	Extremely
28.1 Suddenly scared for no reason	☐	☐	☐	☐
28.2 Feeling fearful	☐	☐	☐	☐
28.3 Faintness, dizziness or weakness	☐	☐	☐	☐
28.4 Feeling tense or keyed up	☐	☐	☐	☐
28.5 Blaming yourself for things	☐	☐	☐	☐
28.6 Difficulty falling asleep, staying asleep	☐	☐	☐	☐
28.7 Feeling blue	☐	☐	☐	☐
28.8 Feeling of worthlessness	☐	☐	☐	☐
28.9 Feeling everything is an effort	☐	☐	☐	☐
28.10 Feeling hopeless about future	☐	☐	☐	☐

29 Exposure to a stressful event or situation (either short or long lasting) of exceptionally threatening or catastrophic nature is likely to cause pervasive distress in almost anyone. Examples of such difficult and frightening experiences are: being assaulted, or witnessing other people being hurt or killed.

	Yes	No
Have you experienced any of these or some other terrifying event(s)?	☐	☐

30 The following are symptoms people sometimes experience after hurtful and terrifying events. Please indicate, in the appropriate box, how much each symptom has bothered you <u>in the last week</u>.

	Not at all	A little	Quite a bit	Extremely
30.1 Recurrent thoughts or memories of the most hurtful or terrifying events	☐	☐	☐	☐
30.2 Feeling as though the event is happening again	☐	☐	☐	☐
30.3 Recurrent nightmares	☐	☐	☐	☐
30.4 Feeling detached or withdrawn from people	☐	☐	☐	☐
30.5 Unable to feel emotions	☐	☐	☐	☐
30.6 Feeling jumpy, easily startled	☐	☐	☐	☐
30.7 Difficulty concentrating	☐	☐	☐	☐
30.8 Trouble sleeping	☐	☐	☐	☐
30.9 Feeling on guard	☐	☐	☐	☐
30.10 Feeling irritable or having outbursts of anger	☐	☐	☐	☐

Survey number/ID:

30.11
Avoiding activities that remind you of the traumatic or hurtful event ☐ ☐ ☐ ☐

30.12
Inability to remember parts of the most hurtful or traumatic events ☐ ☐ ☐ ☐

30.13
Less interest in daily activities ☐ ☐ ☐ ☐

30.14
Feeling as if you don't have a future ☐ ☐ ☐ ☐

30.15
Avoiding thoughts or feelings associated with the traumatic or hurtful events ☐ ☐ ☐ ☐

30.16
Sudden emotional or physical reaction when reminded of the most hurtful or traumatic events ☐ ☐ ☐ ☐

HEALTH HABITS

31 Do you smoke? *(Put an X in only one box)*

☐ No, I have never smoked.

☐ No, I quit smoking.

☐ Yes, cigarettes occasionally (parties/vacation, not daily).

☐ Yes, cigar/cigarillos/pipe/shisha (water pipe) occasionally.

☐ Yes, cigarettes daily. Number of cigarettes per day: ☐ 31.1

☐ Yes, cigar/cigarillos/pipe/shisha (water pipe) daily.
Number per day: ☐ 31.2

32 About how often in the last 12 months did you drink alcohol?
(Put an X in only one box)

☐ 4-7 times a week   ☐ About once a month

☐ 2-3 times a week   ☐ A few times a year

☐ About once a week   ☐ None the last year

☐ 2-3 times a month   ☐ Never drink alcohol

Yes   No
33 Did you drink alcohol during the past 4 weeks? ☐ ☐

34 If yes, did you drink so much that you felt very intoxicated (drunk)?

☐ Yes, 3 times or more

☐ Yes, 1-2 times

☐ No

Yes   No
35 Did you use any other type of drug during the past 4 weeks? ☐ ☐

36 How often do you exercise?
(On average. Put an X in only one box)

☐ Never   ☐ 2-3 times a week

☐ Less than once a week   ☐ Nearly every day

☐ Once a week

37 About how many hours do you sit during a normal day?
(Both work hours and leisure time)

About ☐ hours *(e.g. 6 hours)*

HEALTH RELATED QUALITY OF LIFE

	Very poor	Poor	Neither	Good	Very good
38 How would you rate your quality of life?	☐	☐	☐	☐	☐

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
39 How satisfied are you with your health?	☐	☐	☐	☐	☐

	Not at all	A little	A moderate amount	Very much	An extreme amount
40 To what extent do you feel that physical pain prevents you from doing what you need to do?	☐	☐	☐	☐	☐
41 How much do you need any medical treatment to function in your daily life?	☐	☐	☐	☐	☐
42 How much do you enjoy life?	☐	☐	☐	☐	☐
43 To what extent do you feel your life to be meaningful?	☐	☐	☐	☐	☐

	Not at all	A little	A moderate amount	Very much	Extremely
44 How well are you able to concentrate?	☐	☐	☐	☐	☐
45 How safe do you feel in your daily life?	☐	☐	☐	☐	☐
46 How healthy is your physical environment?	☐	☐	☐	☐	☐

	Not at all	A little	Moderately	Mostly	Completely
47 Do you have enough energy for everyday life?	☐	☐	☐	☐	☐
48 Are you able to accept your bodily appearance?	☐	☐	☐	☐	☐
49 Have you enough money to meet your needs?	☐	☐	☐	☐	☐
50 How available to you is the information that you need in your day-to-day life?	☐	☐	☐	☐	☐
51 To what extent do you have the opportunity for leisure activities?	☐	☐	☐	☐	☐

	Very poor	Poor	Neither	Good	Very good
52 How well are you able to get around?	☐	☐	☐	☐	☐

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
53 How satisfied are you with your sleep?	☐	☐	☐	☐	☐
54 How satisfied are you with your ability to perform your daily living activities?	☐	☐	☐	☐	☐
55 How satisfied are you with your capacity for work?	☐	☐	☐	☐	☐
56 How satisfied are you with yourself?	☐	☐	☐	☐	☐
57 How satisfied are you with your personal relationships?	☐	☐	☐	☐	☐
58 How satisfied are you with your sex life?	☐	☐	☐	☐	☐
59 How satisfied are you with the support you get from your friends?	☐	☐	☐	☐	☐
60 How satisfied are you with the conditions of your living place?	☐	☐	☐	☐	☐
61 How satisfied are you with your access to health services?	☐	☐	☐	☐	☐
62 How satisfied are you with your transport?	☐	☐	☐	☐	☐

	Never	Seldom	Quite often	Very often	Always
63 How often do you have negative feelings such as blue mood, despair, anxiety, depression?	☐	☐	☐	☐	☐

Please read the following questions and put an X for each question in the response that most closely describes your current situation.

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
64 Is there someone available to you whom you can count on to listen to when you need to talk?	☐	☐	☐	☐	☐
65 Is there someone available to give you good advice about a problem?	☐	☐	☐	☐	☐
66 Is there someone available to you who shows you love and affection?	☐	☐	☐	☐	☐
67 Is there someone available to help you with daily chores?	☐	☐	☐	☐	☐
68 Can you count on anyone to provide you with emotional support (talking over problems or helping you make a difficult decision)?	☐	☐	☐	☐	☐
69 Do you have as much contact as you would like with someone you feel close to, someone in whom you can trust and confide?	☐	☐	☐	☐	☐

Survey number/ID:

ACCESS TO HEALTHCARE, UNMET HEALTH NEEDS AND KNOWLEDGE OF HEALTH CARE SYSTEM

70 During the last 12 months, have you visited any of the following:
(Please, put an X on each line)

	Yes	No
70.1 Health assessment at arrival to your current living place	☐	☐
70.2 General practitioner	☐	☐
70.3 Another specialist outside the hospital	☐	☐
70.4 Consultation with doctor without being admitted	☐	☐
70.5 Emergency room services	☐	☐
70.6 Chiropractor	☐	☐
70.7 Homeopath, acupuncturist or other alternative treatment practitioner	☐	☐
70.8 Have you been admitted to hospital in the last 12 months?	☐	☐

71 If you did not get the health care you needed after you fled from your country of origin, was the reason that:
(You may choose more than one option.)

☐ I have not experienced unmet health needs

☐ I did not know where to go for treatment.

☐ Interpreters or cultural mediators were unavailable.

☐ I could not afford it.

☐ The problem was not considered urgent enough.

☐ The services needed were unavailable in my location.

☐ Restrictions/limitations of rights to medical care.

☐ I did not trust the local health services.

☐ Other reasons. Please specify below.
▼

_____
_____
Please specify.

72 Do you feel that in your current living place, you or your family members have access to medical care when you are concerned of your health?

☐ Not at all ☐ A little ☐ Moderately ☐ Completely

73 Do you feel that in your current living place, you or your family members have received the medical assistance you need?

☐ Not at all ☐ A little ☐ Moderately ☐ Completely

74 If you have experienced unmet health needs mentioned in previous questions, where were you residing?

☐ I have not experienced unmet health needs

☐ In a transit country (Lebanon, Greece, Turkey)

☐ In Norway

☐ Both in transit country and in Norway

75 Do you currently know where you can find healthcare if needed?

☐ Unsure

☐ No

☐ Yes

THANK YOU FOR ANSWERING THESE QUESTIONS! PLEASE MAKE SURE TO RETURN THIS FORM TO THE PERSON WHO GAVE IT TO YOU BEFORE LEAVING.

CHART – Changing health and health care needs along the Syrian refugees' trajectories to Norway

FOLLOW-UP QUESTIONNAIRE

Thank you for taking part in this study by completing this questionnaire!

The information will be used in research aimed to understand the health situation and improve health care services for refugees in Norway. Most of the questions are the same ones that you answered when you were in Lebanon. It is important that you answer all the questions on this questionnaire once more. Do not hesitate to ask if there is something you do not understand.

Please hand the completed questionnaire back to the person who invited you to the study before you leave

or send it back with the attached envelope in case you are answering from home.

By answering this questionnaire you accept that we use this information only for the purpose explained to you. All information will be treated in strict confidence.

This survey contains 6 parts. Please answer by putting an X in the box (☐), or answering the open fields (_____) as explained in the text.

Yours sincerely,
University of Bergen.

HEALTH LITERACY SCREENING

1 How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?
(This question applies to the situation where you are now.)

Never	Rarely	Sometimes	Often	Always
☐	☐	☐	☐	☐

PART 1 – BACKGROUND INFORMATION

2 Gender:
Woman ☐   Man ☐

3 Year of birth: _____ *(e.g. 1978)*

4 What language is your native tongue?
☐ Arabic   ☐ Kurmanji   ☐ Sorani
☐ Armenian   ☐ Other

_____
Please specify (e.g. Turkish).

5 What is your marital status?
☐ Single   ☐ Separated   ☐ Married
☐ Divorced   ☐ Widowed   ☐ Other

6 If married, are you living with your partner(s)?
Yes ☐   No ☐

7 Do you have children?
Yes ☐   No ☐

8 If yes, how many children do you have?
☐ 1   ☐ 2   ☐ 3   ☐ 4   ☐ 5 or more

9 How many years of education have you completed altogether? _____ years
(e.g. 5 years)

Survey number/ID: _____

10 What is your occupational status in Norway?

☐ Employed for wages ☐ Self-employed

☐ Out of work ☐ Homemaker

☐ Student / introduksjonsprogrammet

☐ Retired ☐ Unable to work

☐ Other
▼

Please explain.

---

11 When did you arrive in Norway?

Day, month and year: ☐☐ . ☐☐ . ☐☐☐☐
(e.g. 14.11.2013 for November 14th 2013)

---

12 Did you arrive?

☐ Alone

☐ With all immediate family members

☐ With some immediate family members

PART 3 – HEALTH STATUS

13 How do you consider your health at the moment?

Very poor	Poor	Neither	Good	Very good
☐	☐	☐	☐	☐

---

14 Have you had or do you have any of the following?
(Put an X on each line under No or Yes. If Yes, please explain.)

	Not familiar with the term	No	Yes	Age first time
14.1 Heart attack/chest pain	☐	☐	☐ ▶	14.2 ____ years
14.3 Heart failure	☐	☐	☐ ▶	14.4 ____ years
14.5 Other heart disease	☐	☐	☐ ▶	14.6 ____ years
14.7 Stroke/brain hemorrhage	☐	☐	☐ ▶	14.8 ____ years
14.9 Kidney disease	☐	☐	☐ ▶	14.10 ____ years
14.11 Liver disease	☐	☐	☐ ▶	14.12 ____ years
14.13 Asthma	☐	☐	☐ ▶	14.14 ____ years
14.15 Chronic bronchitis, emphysema or COPD	☐	☐	☐ ▶	14.16 ____ years
14.17 Tuberculosis	☐	☐	☐ ▶	14.18 ____ years
14.19 Diabetes	☐	☐	☐ ▶	14.20 ____ years
14.21 Psoriasis	☐	☐	☐ ▶	____ years
14.23 Eczema on hands	☐	☐	☐ ▶	14.24 ____ years
14.25 Cancer	☐	☐	☐ ▶	14.26 ____ years
14.27 Arthritis *Reumatoid arthritis*	☐	☐	☐ ▶	14.28 ____ years
14.29 Other joint diseases	☐	☐	☐ ▶	14.30 ____ years
14.31 Osteoporosis	☐	☐	☐ ▶	14.32 ____ years
14.33 Fibromyalgia or generalized body pain	☐	☐	☐ ▶	14.34 ____ years
14.35 Mental health problems you sought help for	☐	☐	☐ ▶	14.36 ____ years
14.37 Epilepsy	☐	☐	☐ ▶	14.38 ____ years
14.39 Headache	☐	☐	☐ ▶	14.40 ____ years
14.41 Abdominal pain/diarrhoea	☐	☐	☐ ▶	14.42 ____ years
14.43 Allergies	☐	☐	☐ ▶	14.44 ____ years

---

15 Do you suffer from long-term (at least 1 year) illness or injury of a physical or psychological nature that impairs your daily life?

☐ Yes ☐ No

---

16 If yes, would you describe your impairment as slight, moderate or severe?

	Slight	Moderate	Severe
16.1 Motor ability impairment	☐	☐	☐
16.2 Vision impairment	☐	☐	☐
16.3 Hearing impairment	☐	☐	☐
16.4 Impairment due to physical illness	☐	☐	☐
16.5 Impairment due to mental health problems	☐	☐	☐

---

17 Do you have physical pain now that has lasted more than 6 months?

Yes	No
☐	☐

---

18 If yes, how strong has your physical pain been during the last 4 weeks?

No pain	Very mild	Mild	Moderate	Strong	Very strong
☐	☐	☐	☐	☐	☐

Survey number/ID:

19 Have you used any of the following medicines?
(Please place only one X for each medication at the answer that best fits your situation.)

	Daily	Weekly	Less than weekly	Not during last 4 weeks
19.1 Drugs for peptic ulcer, gastro-esophageal reflux and digestion	☐	☐	☐	☐
19.2 Antithrombotics (aspirin, warfarin)	☐	☐	☐	☐
19.3 Cholesterol reducing medication	☐	☐	☐	☐
19.4 Medicine for high blood pressure	☐	☐	☐	☐
19.5 Medicine for diabetes mellitus	☐	☐	☐	☐
19.6 Medication for asthma or COPD	☐	☐	☐	☐
19.7 Painkillers, off prescription	☐	☐	☐	☐
19.8 Painkillers, on prescription	☐	☐	☐	☐
19.9 Sedatives	☐	☐	☐	☐
19.10 Tranquillizers	☐	☐	☐	☐
19.11 Anti-depressive medication	☐	☐	☐	☐
19.12 Medication for allergy	☐	☐	☐	☐
19.13 Contraceptives (pills, injections or other methods)	☐	☐	☐	☐
19.14 Other prescribed medication, but do not know for what	☐	☐	☐	☐

20 Listed below are symptoms or problems people sometimes have. Please indicate in the appropriate box how much each of these symptoms has bothered or distressed you <u>in the last week</u>.

	Not at all	A little	Quite a bit	Extremely
20.1 Suddenly scared for no reason	☐	☐	☐	☐
20.2 Feeling fearful	☐	☐	☐	☐
20.3 Faintness, dizziness or weakness	☐	☐	☐	☐
20.4 Feeling tense or keyed up	☐	☐	☐	☐
20.5 Blaming yourself for things	☐	☐	☐	☐
20.6 Difficulty falling asleep, staying asleep	☐	☐	☐	☐
20.7 Feeling blue	☐	☐	☐	☐
20.8 Feeling of worthlessness	☐	☐	☐	☐
20.9 Feeling everything is an effort	☐	☐	☐	☐
20.10 Feeling hopeless about future	☐	☐	☐	☐

21 Exposure to a stressful event or situation (either short or long lasting) of exceptionally threatening or catastrophic nature is likely to cause pervasive distress in almost anyone. Examples of such difficult and frightening experiences are: being assaulted, or witnessing other people being hurt or killed.

	Yes	No
Have you experienced any of these or some other terrifying event(s)?	☐	☐

22 The following are symptoms people sometimes experience after hurtful and terrifying events. Please indicate, in the appropriate box, how much each symptom has bothered you <u>in the last week</u>.

	Not at all	A little	Quite a bit	Extremely
22.1 Recurrent thoughts or memories of the most hurtful or terrifying events	☐	☐	☐	☐
22.2 Feeling as though the event is happening again	☐	☐	☐	☐
22.3 Recurrent nightmares	☐	☐	☐	☐
22.4 Feeling detached or withdrawn from people	☐	☐	☐	☐
22.5 Unable to feel emotions	☐	☐	☐	☐
22.6 Feeling jumpy, easily startled	☐	☐	☐	☐
22.7 Difficulty concentrating	☐	☐	☐	☐
22.8 Trouble sleeping	☐	☐	☐	☐
22.9 Feeling on guard	☐	☐	☐	☐
22.10 Feeling irritable or having outbursts of anger	☐	☐	☐	☐
22.11 Avoiding activities that remind you of the traumatic or hurtful event	☐	☐	☐	☐
22.12 Inability to remember parts of the most hurtful or traumatic events	☐	☐	☐	☐
22.13 Less interest in daily activities	☐	☐	☐	☐
22.14 Feeling as if you don't have a future	☐	☐	☐	☐
22.15 Avoiding thoughts or feelings associated with the traumatic or hurtful events	☐	☐	☐	☐
22.16 Sudden emotional or physical reaction when reminded of the most hurtful or traumatic events	☐	☐	☐	☐

PART 3 – HEALTH HABITS

23.1 Do you smoke? *(Put an X in only one box)*

☐ No, I have never smoked.

☐ No, I quit smoking.

☐ Yes, cigarettes occasionally (parties/vacation, not daily).

☐ Yes, cigar/cigarillos/pipe/shisha (water pipe) occasionally.

☐ Yes, cigarettes daily. Number of cigarettes per day: [____] 23.2

☐ Yes, cigar/cigarillos/pipe/shisha (water pipe) daily.
Number per day: [____] 23.3

24 About how often in the last 12 months did you drink alcohol?
(Put an X in only one box)

☐ 4-7 times a week   ☐ About once a month

☐ 2-3 times a week   ☐ A few times a year

☐ About once a week   ☐ None the last year

☐ 2-3 times a month   ☐ Never drink alcohol

	Yes	No
25 Did you drink alcohol during the past 4 weeks?	☐	☐

26 If yes, did you drink so much that you felt very intoxicated (drunk)?

☐ Yes, 3 times or more

☐ Yes, 1-2 times

☐ No

	Yes	No
27 Did you use any other type of drug during the past 4 weeks?	☐	☐

28 How often do you exercise?
(On average. Put an X in only one box)

☐ Never   ☐ 2-3 times a week

☐ Less than once a week   ☐ Nearly every day

☐ Once a week

29 About how many hours do you sit during a normal day?
(Both work hours and leisure time)

About [____] hours *(e.g. 6 hours)*

PART 4 – HEALTH RELATED QUALITY OF LIFE

	Very poor	Poor	Neither	Good	Very good
30 How would you rate your quality of life?	☐	☐	☐	☐	☐

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
31 How satisfied are you with your health?	☐	☐	☐	☐	☐

	Not at all	A little	A moderate amount	Very much	An extreme amount
32 To what extent do you feel that physical pain prevents you from doing what you need to do?	☐	☐	☐	☐	☐
33 How much do you need any medical treatment to function in your daily life?	☐	☐	☐	☐	☐
34 How much do you enjoy life?	☐	☐	☐	☐	☐
35 To what extent do you feel your life to be meaningful?	☐	☐	☐	☐	☐

	Not at all	A little	A moderate amount	Very much	Extremely
36 How well are you able to concentrate?	☐	☐	☐	☐	☐
37 How safe do you feel in your daily life?	☐	☐	☐	☐	☐
38 How healthy is your physical environment?	☐	☐	☐	☐	☐

Survey number/ID:

	Not at all	A little	Moderately	Mostly	Completely
39 Do you have enough energy for everyday life?	☐	☐	☐	☐	☐
40 Are you able to accept your bodily appearance?	☐	☐	☐	☐	☐
41 Have you enough money to meet your needs?	☐	☐	☐	☐	☐
42 How available to you is the information that you need in your day-to-day life?	☐	☐	☐	☐	☐
43 To what extent do you have the opportunity for leisure activities?	☐	☐	☐	☐	☐

	Very poor	Poor	Neither	Good	Very good
44 How well are you able to get around?	☐	☐	☐	☐	☐

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
45 How satisfied are you with your sleep?	☐	☐	☐	☐	☐
46 How satisfied are you with your ability to perform your daily living activities?	☐	☐	☐	☐	☐
47 How satisfied are you with your capacity for work?	☐	☐	☐	☐	☐
48 How satisfied are you with yourself?	☐	☐	☐	☐	☐
49 How satisfied are you with your personal relationships?	☐	☐	☐	☐	☐
50 How satisfied are you with your sex life?	☐	☐	☐	☐	☐
51 How satisfied are you with the support you get from your friends?	☐	☐	☐	☐	☐
52 How satisfied are you with the conditions of your living place?	☐	☐	☐	☐	☐
53 How satisfied are you with your access to health services?	☐	☐	☐	☐	☐
54 How satisfied are you with your transport?	☐	☐	☐	☐	☐

	Never	Seldom	Quite often	Very often	Always
55 How often do you have negative feelings such as blue mood, despair, anxiety, depression?	☐	☐	☐	☐	☐

Please read the following questions and put an X for each question in the response that most closely describes your current situation.

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
56 Is there someone available to you whom you can count on to listen to when you need to talk?	☐	☐	☐	☐	☐
57 Is there someone available to give you good advice about a problem?	☐	☐	☐	☐	☐
58 Is there someone available to you who shows you love and affection?	☐	☐	☐	☐	☐
59 Is there someone available to help you with daily chores?	☐	☐	☐	☐	☐
60 Can you count on anyone to provide you with emotional support (talking over problems or helping you make a difficult decision)?	☐	☐	☐	☐	☐
61 Do you have as much contact as you would like with someone you feel close to, someone in whom you can trust and confide?	☐	☐	☐	☐	☐

PART 5 – ACCESS TO HEALTHCARE, UNMET HEALTH NEEDS AND KNOWLEDGE OF HEALTH CARE SYSTEM

62 During the last 12 months, have you visited any of the following:
(Please, put an X on each line)

	Yes	No
62.1 Health assessment at arrival to your current living place	☐	☐
62.2 General practitioner	☐	☐
62.3 Another specialist outside the hospital	☐	☐
62.4 Consultation with doctor without being admitted	☐	☐
62.5 Emergency room services	☐	☐
62.6 Chiropractor	☐	☐
62.7 Homeopath, acupuncturist or other alternative treatment practitioner	☐	☐
62.8 Have you been admitted to hospital in the last 12 months?	☐	☐

63 If you did not get the health care you needed after you arrived in Norway, was the reason that:
(You may choose more than one option.)

☐ You did not know where to go for treatment.

☐ Interpreters or cultural mediators were unavailable.

☐ You could not afford it.

☐ The problem was not considered urgent enough.

☐ The services needed were unavailable in your location.

☐ Restrictions/limitations of rights to medical care.

☐ You did not trust the local health services.

☐ Other reasons. Please specify below.

▼

Please specify.

64 Do you feel that in your current living place, you or your family members have access to medical care when you are concerned of your health?

☐ Not at all ☐ A little ☐ Moderately ☐ Completely

65 Do you feel that in your current living place, you or your family members have received the medical assistance you need?

☐ Not at all ☐ A little ☐ Moderately ☐ Completely

66 Do you currently know where you can find healthcare if needed?

☐ Unsure

☐ No

☐ Yes

PART 6 – FOOD SECURITY

The following questions are about the food situation for your household in the past 12 months.

In case you know that your partner is answering this questionnaire, please tell the person who gave you this questionnaire before you fill it.

67 Which of the following statements best describes the food eaten in your household in the past 12 months, that is since [current month] of last year?

☐ You and other household members always had enough of the kinds of foods you wanted to eat.

☐ You and other household members had enough to eat, but not always the kinds of food you wanted.

☐ Sometimes you and other household members did not have enough to eat.

☐ Often you and other household members didn't have enough to eat.

☐ Don't know / refuse to answer (Go to end of module)

Now we present you several statements that may be used to describe the food situation for a household. Please mark with an "x" if the statement was often true, sometimes true, or never true for you and other household members in the past 12 months.

68 You and other household members worried that food would run out before you got money to buy more. Was that often, sometimes or never true in the past 12 months?

☐ Often true ☐ Sometimes true ☐ Never true

☐ Don't know / refuse to answer

69 The food that you and other household members bought just didn't last, and there wasn't any money to get more. Was that often, sometimes or never true in the past 12 months?

☐ Often true ☐ Sometimes true ☐ Never true

☐ Don't know / refuse to answer

---

70 You and other household members couldn't afford to eat balanced meals. Was that often, sometimes or never true in the past 12 months?

☐ Often true ☐ Sometimes true ☐ Never true

☐ Don't know / refuse to answer

Only to answer if you live with children under 18 in your household:

Now we present you a few statements that may describe the food situation for households with children.

71 You or other adults in your household relied on only a few kinds of low-cost food to feed the child(ren) because you were running out of money to buy food. Was that often, sometimes or never true in the past 12 months?

☐ Often true ☐ Sometimes true ☐ Never true

☐ Don't know / refuse to answer

---

72 You or other adults in your household couldn't feed the child(ren) a balanced meal, because you couldn't afford it. Was that often, sometimes or never true in the past 12 months?

☐ Often true ☐ Sometimes true ☐ Never true

☐ Don't know / refuse to answer

---

73 If the child(ren) were not eating enough because you and other adult members of the household just couldn't afford enough food. Was that often, sometimes or never true in the past 12 months?

☐ Often true ☐ Sometimes true ☐ Never true

☐ Don't know / refuse to answer

The following few questions are about the food situation in the past 12 months for you or any other adults in your household:

74 In the past 12 months, since last [current month] did you or other adults in your household ever cut the size of your meals or skip meals because there wasn't enough money for food?

☐ Yes ☐ No ☐ Don't know / refuse to answer

---

75 If yes, how often did this happen?

☐ Almost every month

☐ Some months but not every month

☐ Only 1 or 2 months ☐ Don't know / refuse to answer

---

76 In the past 12 months, did you (personally) ever eat less than you felt you should because there wasn't enough money to buy food?

☐ Yes ☐ No ☐ Don't know / refuse to answer

---

77 In the past 12 months, were you (personally) ever hungry but didn't eat because you couldn't afford enough food?

☐ Yes ☐ No ☐ Don't know / refuse to answer

---

78 In the past 12 months, did you (personally) lose weight because you didn't have enough money for food?

☐ Yes ☐ No ☐ Don't know / refuse to answer

If you have answered "yes" to any one of 73-78, then continue with the questionnaire; otherwise, skip to PART 7 - FOLLOW-UP.

79 In the past 12 months, did you or other adults in your household ever not eat for a whole day because there wasn't enough money for food?

☐ Yes ☐ No ☐ Don't know / refuse to answer

---

80 If yes, how often did this happen?

☐ Almost every month

☐ Some months but not every month

☐ Only 1 or 2 months ☐ Don't know / refuse to answer

Only to answer if there are children under 18 in your household:

81 In the past 12 months, did you or other adults in your household ever cut the size of any of the children's meals because there wasn't enough money for food?

☐ Yes   ☐ No   ☐ Don't know / refuse to answer

82 In the past 12 months, did any of the children ever skip meals because there wasn't enough money for food?

☐ Yes   ☐ No   ☐ Don't know / refuse to answer

83 If yes, how often did this happen?

☐ Almost every month

☐ Some months but not every month

☐ Only 1 or 2 months

☐ Don't know / refuse to answer

84 In the past 12 months, were any of the children ever hungry but you just couldn't afford more food?

☐ Yes   ☐ No   ☐ Don't know / refuse to answer

85 In the past 12 months, did any of the children ever not eat for a whole day because there wasn't enough money for food?

☐ Yes   ☐ No   ☐ Don't know / refuse to answer

PART 7 – FOLLOW-UP

Finally, we would like to ask you for your permission to contact you again for the project in one to two years' time. It is important for us to know how you are doing in terms of health.

If you agree, please provide your personal details below:

Name:

Mobile number:

Email address:

Place:

Date: |__|.|__|.|____|

THANK YOU VERY MUCH FOR ANSWERING THESE QUESTIONS! PLEASE RETURN THIS FORM TO THE PERSON WHO GAVE IT TO YOU BEFORE YOU LEAVE.

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