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UNIVERSITÉ
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FACULTÉ DE MÉDECINE
Institut de santé globale

Mortality gap associated with mental disorders in the Czech Republic

PhD Thesis

Version 1.5

Student Name:

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Names of supervisors:

Professor Yasser Khazaal MD, PhD

Professor Emiliano Albanese MD, PhD

Geneva, Switzerland

March 2020

1. Acknowledgment

Firstly, I would like to thank my supervisors, Professor Emiliano Albanese who provided me with the tremendous support throughout the PhD program, gave multiple feedbacks and assistance, helped in formulation of research idea, developing methodology and putting research into the context, revised manuscript drafts and inspired for overall professional development in the area of global mental health; and Professor Yasser Khazaal for sharing rich clinical and research experience that helped to put work into clinical and public health context, for kind sustainable assistance in development of project's methodology and interpretation of results.

I would like to acknowledge a pivotal role of the team at the Public Mental Health Programme of the National Institute of Mental Health (Czech Republic) and its head Dr Petr Winkler as well as the institute director Professor Cyril Höschl for creating a unique momentum and leading forward the research agenda in mental health of central eastern Europe, making possible wide international collaboration and implementation of innovative ideas. I am also grateful to all international experts and researchers who shared their invaluable views on mental health service development, all interviewees who agreed to take part in the qualitative study to share their experiences of stigma and discrimination.

On behalf of coauthors of published papers I would like to express our gratitude to: the Institute of Health Information and Statistics of the Czech Republic for kindly providing data and important advice on working with data as requested.

Additional support and assistance was provided by a number of colleagues representing a variety of organizations (in alphabetical order): Daniel Chisholm (World Health Organization), Dana Chrtkova (National Institute of Mental Health, Czech Republic), Anna Kågström (National Institute of Mental Health, Czech Republic), Professor Ellenor Mittendorfer-Rutz (Department of Clinical Neuroscience, Karolinska Institutet (Stockholm, Sweden), Karolina Mlada, (National Institute of Mental Health, Czech Republic), Professor Norman Sartorius (Association for the Improvement of Mental Health Programmes), Professor Graham Thornicroft (Kings College London), Marketa Vitkova (National Institute of Mental Health, Czech Republic).

I am very grateful to Professor Antoine Flahault for the amazing opportunity of being a part of the Institute of Global Health, for his kind attitude, openness and dedication to the provision of education. I am grateful to Lemlem Girmatsion and Natalie Bot for taking care of the program logistic and providing managerial support when it was needed. It was an honour for me to take part in the programme of the University de Geneve.

Some elements of work were done with financial support from the Ministry of Education, Youth, and Sport under the National Program of Sustainability 1 program (project number LO1611), UNIGE for providing financial support allowing open access publication of the key paper.

Last but not least, I am grateful to all other colleagues and coauthors who spent long hours in the office in our attempts to move project further.

2. List of publications

Below is the list of publications, submitted manuscripts, and oral communications produced during the study period, all of which are in the field of global mental health, most directly related to the thesis topic. The 20 publications include 14 papers published in peer-reviewed journals with impact factor, and one book chapter.

2.1. Original article(s) related to the thesis

The backbone of this PhD thesis is a set of five coherent and closely interrelated original, peer-reviewed scientific papers, all of which were written and submitted by the PhD candidate, and that are already published in relevant scientific journals.

For the **first paper** the PhD candidate analyzed data collected within the framework of Mental Health Atlas of the Department of Mental Health and Substance Abuse, World Health Organization (WHO). This paper was conceived and written by the PhD candidate, and was published in BJPsych International during the first year of the PhD, in 2016.

The **second paper** is a broad review article complemented by a structured experts survey on mental health care in central and eastern Europe, which was published in Lancet Psychiatry in 2017.

The **third paper**, published in the Lancet Public Health in 2018, is the central publication of this thesis, which reports the main results on excess mortality in people with mental disorders from a large, nation-wide record-linkage, population-based study conducted in the Czech Republic. The PhD candidate conceived, designed, and conducted this pioneering study in collaboration with mental health experts and statisticians from the National Institute of Mental Health (in Klecany (Czech Republic), under the joint guidance of his PhD supervisors (Prof. Albanese and Prof. Khazaal).

The **fourth paper** was published in Social Science and Medicine in 2018, and is based on the results of a mixed-methods study in which the PhD candidate explored stigma and discrimination associated with schizophrenia in the Czech Republic, from the perspective of their family members.

The PhD candidate is the first author of all these four main publications, and he is also one of authors of the WHO report on “Culture and reform of mental health care in central and eastern Europe” (web link). This high level WHO report is the **fifth publication** of this PhD thesis. The WHO report outlines the key points and recommendations made by participants to a workshop on culture and reform of mental health care in central and eastern Europe, which was held on 2–3 October 2017 in Klecany, Czechia. The PhD candidate was one of the main organizers of this workshop, which objective was to improve understanding of the key cultural aspects that impact and drive mental health-care reform in the central and eastern European region, through an evidence-based approach largely based on the work conducted and data collected by the candidate during his PhD, in collaboration with the National Institute of Mental Health in Klecany (Czech Republic) and his two academic supervisors from the Department of Psychiatry, and Institute of Global Health at the Faculty of Medicine of the University of Geneva, Switzerland (Prof. Albanese and Prof. Khazaal).

Article 1

Title: State of mental healthcare systems in Eastern Europe: do we really understand what is going on?

Authors: Krupchanka D, Winkler P

Journal: BJPsych International

URL: https://doi.org/10.1192/S2056474000001446

Article 2

Title: A blind spot on the global mental health map: a scoping review of 25 years' development of mental health care for people with severe mental illnesses in central and eastern Europe

Authors: Winkler P*, Krupchanka D*(*-equal contribution), Roberts T, Kondratova L, Machů V, Höschl C, Sartorius N, Van Voren R, Aizberg O, Bitter I, Cerga-Pashoja A, Deljkovic A, Fanaj N, Germanavicius A, Hinkov H, Hovsepyan A, Ismayilov F, Ivezic S, Jarema M, Jordanova V, Kukić S, Makhashvili N, Šarotar B, Plevachuk O, Smirnova D, Voinescu B, Vrublevska J, Thornicroft G

Journal: The Lancet Psychiatry

URL: https://doi.org/10.1016/S2215-0366(17)30135-9

Article 3

Title: Mortality in people with mental disorders in the Czech Republic: a nationwide, register-based cohort study

Authors: Krupchanka D, Mlada K, Winkler P, Khazaal Y, Albanese E

Journal: Lancet Public Health

URL: https://doi.org/10.1016/S2468-2667(18)30077-X

Article 4

Title: Experience of stigma and discrimination in families of persons with schizophrenia in the Czech Republic

Authors: Krupchanka D, Chrtkováa D, Vítkováa M, Munzel D, Čihařováa M, Růžičková T, Winkler P, Janoušková M, Albanese E, Sartorius N

Journal: Social Science & Medicine

URL: https://doi.org/10.1016/j.socscimed.2018.07.015

Article 5

Title: Culture and reform of mental health care in central and eastern Europe: workshop report.

Authors: WHO Regional Office for Europe, the WHO Collaborating Centre on Culture and Health at the University of Exeter (United Kingdom) and the National Institute of Mental Health (Czechia).

Journal: WHO report

URL: http://www.euro.who.int/en/publications/abstracts/culture-and-reform-of-mental-health-care-in-central-and-eastern-europe-2018

2.2. Published articles not directly related to the thesis

During his PhD, the candidate has established, nurtured, and cemented several international collaborations in the field of global mental health. These collaborations encompass a variety of studies and investigation of various kinds which results have been widely and effectively disseminated. The PhD candidate is the first author of eight and a co-author of five out of the 15 publications listed below, which were published in peer-reviewed, indexed scientific journals, all during the PhD period, and above and beyond the five publications presented in the previous section of this PhD thesis.

Article 1

Title: What are the training needs of early career professionals in addiction medicine? A BEME scoping review

Authors: Damien K, Adam A, Arya S, Indave I, Krupchanka D, Wood E, Cullen W, Klimas J

Journal: The Best Evidence Medical Education (BEME) Collaboration Journal

URL: https://bemecollaboration.org/Reviews+In+Progress/training+needs+of+early+career+professionals+in+addiction+medicine/

Article 2

Title: Closing the gap between training needs and training provision in addiction medicine

Authors: Arya S, Delic M, Ruiz B, Klimas J, Papanti D, Stepanov A, Cock V, Krupchanka D

Journal: BJPsych International

URL: https://doi.org/10.1192/bji.2019.27

Article 3

Title: Factors associated with health service utilisation for common mental disorders: a systematic review.

Authors: Roberts T, Miguel Esponda G, Krupchanka D, Shidhaye R, Patel V, Rathod S

Journal: BMC Psychiatry

URL: https://bmcpsychiatry.biomedcentral.com/articles/10.1186/s12888-018-1837-1

Article 4

Title: Satisfaction with psychiatric in-patient care as rated by patients at discharge from hospitals in 11 countries

Authors: Krupchanka D, Khalifeh H, Abdulmalik J, Ardila-Gómez S, Armiya'u A, Banjac V, Baranov A, Bezborodovs N, Brecic P, Čavajda Z, de Girolamo G, Denisenko M, Dickens H, Dujmovic J, Ergovic Novotny D, Fedotov I, Fernández MA, Frankova I, Gasparovic M, Giurgi-Oncu C, Grahovac T, James BO, Jomli R, Kekin I, Knez R, Lanfredi M, Lassman F, Mehta N, Nacef F, Nawka A, Nemirovsky M, Ola BA, Oshodi Y, Ouali U, Peharda T, Razic Pavicic A, Rojnic Kuzman M, Roventa C, Shamenov R, Smirnova D, Smoljanic D, Spikina A, Thornicroft A, Tomicevic M, Vidovic D, Williams P, Yakovleva Y, Zhabenko O, Zhilyaeva T, Zivkovic M, Thornicroft G, Sartorius N.

Journal: Social Psychiatry and Psychiatric Epidemiology

URL: https://link.springer.com/article/10.1007/s00127-017-1366-0

Article 5

Title: Experience of stigma in the public life of relatives of people diagnosed with schizophrenia in the Republic of Belarus

Authors: Krupchanka D, Kruk N, Sartorius N, Davey S, Winkler P, Murray J

Journal: Social Psychiatry and Psychiatric Epidemiology

URL: https://link.springer.com/article/10.1007%2Fs00127-017-1365-1

Article 6

Title: Long-term hospitalizations for schizophrenia in the Czech Republic 1998–2012

Authors: Winkler P, Mladá K, Krupchanka D, Agius M, Kar Ray M, Höschl C

Journal: Schizophrenia Research

URL: https://doi.org/10.1016/j.schres.2016.04.008

Article 7

Title: The Role of Insight in Moderating the Association Between Depressive Symptoms in People With Schizophrenia and Stigma Among Their Nearest Relatives

Authors: Krupchanka D, Katliar M

Journal: Schizophrenia Bulletin

URL: https://doi.org/10.1093/schbul/sbw024

Article 8

Title: Equal access for all? Access to medical information for European psychiatric trainees

Authors: Gama Marques J, Pantovic Stefanovic M, Mitkovic-Voncina M, Riese F, Guloksuz S, Holmes K, Kilic O, Banjac V, Palumbo C, Nawka A, Jauhar S, Andlauer O, Krupchanka D, Pinto da Costa M.

Journal: Psychiatry Research

URL: https://doi.org/10.1016/j.psychres.2016.02.015

Article 9

Title: Experience of stigma in private life of relatives of people diagnosed with schizophrenia in the Republic of Belarus

Authors: Krupchanka D, Kruk N, Murray J, Davey S, Bezborodovs N, Winkler P, Bukelskis L, Sartorius N

Journal: Social Psychiatry and Psychiatric Epidemiology

URL: https://link.springer.com/article/10.1007%2Fs00127-016-1190-y

Article 10

Title: Satisfaction with psychiatric in-patient care across 11 countries: Final report of the IDEA-study (inpatient discharge: experiences and analysis)

Authors: Krupchanka D, Khalifeh H, Thornicroft G, Sartorius N, IDEA research group

Journal: European Psychiatry

URL: https://doi.org/10.1016/j.eurpsy.2017.02.294

Article 11

Title: Chapter: Discrimination and Stigma.

Authors: Krupchanka D, Thornicroft G

Book: The Stigma of Mental Illness - End of the Story?

URL: https://www.springer.com/gp/book/9783319278377

Article 12

Title: The Young Psychiatrists' Network: between past and future.

Authors: Krupchanka D, Los T

Book: BJPsych International

URL: https://doi.org/10.1192/S2056474000001148

Article 13

Title: Self-help internet-delivered Low intensity Cognitive Behavioral therapy in the treatment of depression: a Review.

Authors: Burkauskas J, Zalyte G, Krupchanka D, Neverauskas J.

Journal: Biological Psychiatry and Psychopharmacology

URL: http://biological-psychiatry.eu/wp-content/uploads/2015/07/BPP2015_17_1_Review.-Julius-Burkauskas-et-al..pdf

Article 14

Title: Proposals to the National action plan to implement the provisions of the Convention on the rights of persons with disabilities in Republic of Belarus

Authors: Krupchanka D, Kruk N, Khmelnitskaya E, Minkevich K, Aizberg O, Drozdovskij S, Evsegneev R

Journal: Psychiatry, Psychotherapy and Clinical Psychology (journal in Russian)

URL: http://psihea.recipe.by/ru/?editions=2017-tom-8-n1&group_id=item_0&article_id=line_0

Article 15

Title: Qualitative research in medicine and public health

Authors: Kharkova O, Kholmatova K, Kuznetsov V, Grjibovski A, Krupchanka D

Journal: Human Ecology (journal in Russian)

URL: https://www.cabdirect.org/cabdirect/abstract/20173030605

3. Abstract in English

Background: The burden of mental and substance use disorders, and mental health-related stigma is remarkably high in Central and eastern Europe. However, evidence is extremely scarce and largely insufficient to advocate for and inform policy actions and health system reforms and development.

Aim: The overall goal of this PhD was to stimulate and inform an evidence-based reform of mental health systems and services in Central and eastern Europe. Our objectives included the identification of the main mental health research gaps and priorities in the region, the quantification of the specific burden associated with mental disorders in the Czech Republic focusing on the mental health mortality gap, and the exploration of the associated stigma.

Methods: We used a mix of quantitative and qualitative methods to (1) analyse changes in mental health care provision using WHO Mental Health Atlas data; (2) conduct a literature review on 25 years mental health care development; (3) set up, explore, describe and analyze nation-wide routinely collected health data; (4) deterministically link registries of mental health inpatient discharges and causes of death, and assess standardized mortality ratio and causes of deaths; (5) explore the nature of stigma-related burden on families of people diagnosed with schizophrenia.

Results: We identified several pending challenges in mental health care development in the region, and a wide evidence gap. We conceived and described newly developed record linkage procedures and processes across existing data sets and registries to inform and stimulate further research. We linked prospective data of 283,618 individuals, and found that, compared with the general population, people with mental disorders had up to three-times higher mortality, varying by age and cause of death. Further, we found that stigma and discrimination were present at all levels of respondents' lives, suggesting its pervasive nature, which we summarized across three main thematic domains: (1) general lack of understanding and misconceptions about mental illness; (2) structural discrimination and paucity of governmental and public support systems; (3) burden of “pervasive and unlimited” care and inability of independent living.

Conclusion: Key recommendations for policy- and decision makers were formulated, disseminated, and communicated to the leading group of the Czech mental health-

care reforms and to the public also at a purposely organized high-level WHO regional workshop, and the subsequent publication of a comprehensive report on “Culture and reform of mental health care in CEE”.

4. Abstract in French

Contexte : Le fardeau des troubles mentaux et de la toxicomanie, ainsi que de la stigmatisation liée à la santé mentale, est remarquablement élevé en Europe centrale et orientale. Cependant, les données probantes sont extrêmement rares et largement insuffisantes pour plaider en faveur d'actions politiques, de réformes et de développement des systèmes de santé et pour les étayer.

Objectif : L'objectif général de ce doctorat était de stimuler et d'informer une réforme des systèmes et des services de santé mentale en Europe centrale et orientale, fondée sur des données probantes. Nos objectifs comprenaient l'identification des principales lacunes et priorités en matière de recherche sur la santé mentale dans la région, la quantification de la charge spécifique associée aux troubles mentaux en République tchèque en se concentrant sur l'écart de mortalité en santé mentale, et l'exploration de la stigmatisation associée.

Méthodes : Nous avons utilisé un mélange de méthodes quantitatives et qualitatives pour (1) analyser les changements dans l'offre de soins de santé mentale en utilisant les données de l'Atlas de santé mentale de l'OMS ; (2) effectuer une analyse documentaire sur 25 ans de développement des soins de santé mentale ; (3) mettre en place, explorer, décrire et analyser les données de santé collectées régulièrement à l'échelle nationale ; (4) établir un lien déterministe entre les registres des sorties des patients hospitalisés pour des raisons de santé mentale et les causes de décès, et évaluer le taux de mortalité standardisé et les causes de décès ; (5) explorer la nature de la charge liée à la stigmatisation pour les familles des personnes diagnostiquées comme schizophrènes.

Résultats : Nous avons identifié plusieurs défis en suspens dans le développement des soins de santé mentale dans la région, ainsi qu'un large manque de preuves. Nous avons conçu et décrit des procédures et des processus de couplage de dossiers nouvellement développés dans les ensembles de données et les registres existants afin d'informer et de stimuler la poursuite des recherches. Nous avons couplé les données prospectives de 283 618 personnes et avons constaté que, par rapport à la population générale, les personnes souffrant de troubles mentaux avaient un taux de mortalité jusqu'à trois fois plus élevé, variant selon l'âge et la cause du décès. En outre, nous avons constaté que la stigmatisation et la

discrimination étaient présentes à tous les niveaux de la vie des personnes interrogées, ce qui suggère sa nature envahissante, que nous avons résumée à travers trois domaines thématiques principaux : (1) manque général de compréhension et idées fausses sur la maladie mentale ; (2) discrimination structurelle et manque de systèmes de soutien gouvernementaux et publics ; (3) fardeau des soins "omniprésents et illimités" et incapacité à vivre de façon indépendante.

Conclusion : Des recommandations clés à l'intention des responsables politiques et des décideurs ont été formulées, diffusées et communiquées au groupe de tête des réformes des soins de santé mentale en République tchèque et au public, également lors d'un atelier régional de haut niveau organisé à dessein par l'OMS, et la publication ultérieure d'un rapport complet sur "La culture et la réforme des soins de santé mentale dans les PECO".

5. Outline

Context. Although epidemiological evidence is extremely scant, Central and Eastern Europe (CEE) is the world region with the estimated highest burden of mental, behavioral and substance use disorders. The data on the epidemiology and social contexts of mental disorders in the region are insufficient and inadequate to inform policy actions and health system reforms. We urgently need more and better evidence because local policy makers and politicians who committed to plan and implement a comprehensive mental health care reform and nation-wide anti-stigma campaigns recognized the importance of evidence-based decisions to identify priorities, and to inform the design and scale up of culture-sensitive and context-appropriate interventions and structural national-level actions.

Hypotheses to be worked out. Our contention at the beginning of this research endeavor was that the lack of system-level and epidemiological evidence on mental health care and mental health related burden required a comprehensive literature review and expert consultation to shape an actionable research agenda grounded on robust analyses of publicly available, routinely collected health data from the region. We identified several gaps in the evidence from the CEE region worth studying. We focused on two central yet complementary topics in public mental health: premature mortality among people with mental disorders, and stigma and its burden on families of people with mental disorders. The hypotheses under investigations were: (1) there is an increased mortality associated with mental disorders in the Czech Republic; (2) there is high and pervasive burden mental health-related stigma in families of people with severe mental disorders.

Original research conducted to address our hypotheses. We aimed to understand the research priority in mental health in the region and subsequently explore the burden associated with mental disorders in the Czech Republic in terms of mortality gap and mental health related stigma to inform further policy actions.

Specific objectives and project stages:

1. to understand key changes in mental health care provision in the region of CEE in comparison to other European countries, based on publicly available WHO Mental Health Atlas data;

2. to summarize and analyze existing evidence and collect expert opinions about the past 25 years of development and the current state of mental health care practice in countries of CEE;
3. to identify key research priorities;
4. to collect relevant information on available Czech nation-wide routinely-collected health data suitable for epidemiological investigations on mental health burden;
5. to provide a comprehensive description of the available nation-wide database according to the existing international guidelines: (1) the register of inpatient discharges and (2) the causes of death registry;
6. to link the aforementioned databases, clean and manage the data, and create a data repository and dictionary to allow the planned statistical analyses, to facilitate further cross-linkage with other relevant databases, and allow future *bona fide* uses of the data set;
7. to estimate mortality ratios and causes of death for people with mental and behavior disorders and compare these figures with those of the Czech general population;
8. to understand stigma-related challenges for family members of persons living with schizophrenia and to define 'what matters most' to individuals under the threat of stigma in the Czech context;
9. based on all generated evidence to: (1) inform policy in the CEE region, as well as ongoing national mental health-care reforms in the Czech Republic; (2) to provide recommendations to decision- and policy-makers on reduction of stigma-related burden in families and inform an anti-stigma campaign undertaken in the framework of the national mental health reform in the Czech Republic.

5.1. Materials and methods:

Addressing objective 1, we analyzed trends in institutional care between 2011 and 2014 by calculating percentage changes in the numbers of in-patient care facilities and mental hospital beds. For the sake of comparison, we extracted data for the CEE and 15 member states of the European Union (EU15).

Addressing objective 2, we did a systematic review of both indexed and grey literature in all regional languages, and complemented this with an expert consultations focusing on 24 countries, and last 25 years.

Addressing objective 3, based on the findings and conclusions from the previous two steps, we identified the two key priority areas for country-level research: premature mortality and mental health-related stigma.

Addressing objective 4 to 7, we explored, described and analyzed existing nation-wide routinely collected health data sets. We used international guidelines and standards and linked data from the available Czech nation-wide health registries to calculate standardized mortality ratios (SMR) and causes of deaths among people with mental disorders in comparison to the Czech general population. Built upon the deterministic linkage of data, we did a nationwide, register-based, retrospective cohort study using routinely collected health data from two nationwide registries in the Czech Republic: the register of inpatient discharges (from Jan 1, 1994, to Dec 31, 2013) and the causes of death registry (from Jan 1, 1994, to Dec 31, 2014). We first identified all individuals discharged from mental health institutions with WHO International Classification of Diseases tenth edition (ICD-10) diagnoses of mental and behavioural disorders (from 1994 to 2013). We then did a deterministic individual-level linkage of these data with all-cause mortality data for the whole period (1994–2014). SMRs and 95% confidence intervals (CI) were calculated for the year 2014, comparing deaths in people with mental disorders discharged from psychiatric hospitals with deaths in the general population.

Addressing objective 8, we conducted a qualitative study using semi-structured in-depth interviews with relatives of patients diagnosed with schizophrenia in the Czech Republic. Initial respondents were identified through local mental health services and users' organizations with a consecutive chain-referral sampling. Transcribed narratives were thematically analyzed within a pre-developed four-level thematic framework to comprehensively identify experiences of stigma and discrimination in all areas of the respondents' lives.

Addressing objective 9 and 10, we formulated key recommendations for policy- and decision makers that were communicated to the leading group of the Czech mental health-care reforms as well as to the wider audience by contributing to the WHO workshop and subsequent report on “Culture and reform of mental health care in CEE”. A workshop was initiated and convened at the National Institute of Mental Health in Klecany (Czech Republic) to establish and summarize the key cultural drivers of mental health care and its reform; to identify relevant research areas that address cultural aspects of mental health care and its reform; and to recommend aspects of culture through which research and further understanding can influence policy and practice in CEE.

5.2. Results

The analysis of the data from WHO Mental Health ATLAS confirmed the anticipated paucity of data and regional evidence required to inform mental healthcare development and reforms and supporting advocacy campaigns. Our analysis exposed several gaps and suggested specific research questions warranting further exploration. First, the resources allocated to mental health across the region is disproportionately low compared to the burden of neuropsychiatric disorders. Second, despite the multiple calls for deinstitutionalisation, mental healthcare in the majority of Eastern European countries is still dominated by centralized, large psychiatric hospitals and institutions. Based on the data, a set of directions for future service development in the countries of Eastern Europe were suggested.

The review on the topic of mental health-care development in the region revealed a number of barriers across and within countries. We prepared specific profiles for each country, and made them available as supplementary publication materials. Acknowledging county variations, our review identified key barriers requiring further actions. These include low number of epidemiological research, general lack of interest in mental health care and its underfunding, institutional nature of mental health care, poor policy implementation and mental health law enforcement, poor involvement of service users into policy-making process, and a huge burden on patients and their family of mental health stigma and discrimination.

We successfully conducted the planned nationwide, register-based cohort study on excess mortality in people with mental disorders in the Czech Republic. The final study population comprised 283,618 individuals, 3,819 of them died in 2014, corresponding to a mortality risk more than two folds higher than that of the general population in the same year (SMR estimate 2.2; 95% CI 2.2–2.3). Moreover, differences in SMR estimates across ICD-10 diagnostic groups were substantial, with the highest SMR for substance use disorders (3.5; 95% CI 3.4–3.7) followed by schizophrenia, schizotypal, and delusional disorders (2.3; 2.1–2.5), personality disorders (2.3; 2.0–2.6), neurotic, stress-related, and somatoform disorders (1.8; 1.6–1.9), and mood (affective) disorders (1.6; 1.5–1.7). The distribution of causes of deaths varied across diagnostic groups, but cardiovascular disorders were a leading cause of death in all diagnostic groups.

Experience of stigma and discrimination from 25 diverse family members of persons living with schizophrenia spanned all levels of respondents' lives (macro-, meso-, micro-, and intro-level). The overarching themes were: (1) general lack of understanding and misconceptions about mental illness; (2) structural discrimination and paucity of governmental and public support system; (3) burden of “pervasive and unlimited” care and inability of independent living. Based on these findings on the nature of stigma, we could formulate a set of recommendations for policy-makers.

Finally, participants from Armenia, Belarus, Czechia, Hungary, Latvia, Lithuania, Poland, Romania, the Russian Federation and Ukraine who convened to a purposely organized regional WHO workshop were our findings were presented and discussed. We wrote a high-level report of the workshop under the auspices of the WHO. The report is accessible on the WHO website, is available in English and was translated in Russian. The report provides recommendations of methods and approaches from the humanities and social sciences to address cultural drivers of mental health systems and services reforms in CEE. There was a large consensus that a person-centred approach is indispensable in these reforms, and that the voices of those with mental disorders and/or psychosocial disabilities should no longer be silenced, and communication among stakeholders at all levels and across sectors be promoted and fostered. Such efforts towards inclusion and collaboration are vital to the development of effective and empowering mental health care systems across the region.

5.3. Conclusion

This PhD thesis is the first, systematic and far-reaching attempt to describe the current situation of mental health care development in the CEE region, rooted on novel and robust epidemiological evidence on mortality and the burden associated with mental disorders in the Czech Republic. We designed and conducted an innovative, nationwide case-register study of mortality among people with mental disorders, and complemented this with an in-depth qualitative study that explored the nature of first-hand experience of stigma burden stimulated further research and provided evidence for reforms in the country and beyond.

6. General introduction

6.1. “The scandal of premature mortality” among people with mental disorders

Excessive mortality among people with mental disorders has been consistently reported across studies attesting from a two- to three-folds higher risk of death compared to the general population (1,2). Some of these figures are comparable to those of heavy smoking related mortality (3). Compared to the general population, men and women diagnosed with severe mental disorders have an average of 20 and 15 years shorter life expectancies, respectively (4). This astonishing life expectancy gap between people with mental disorders and general population is widely known and referred to as **„The scandal of premature mortality“** (5).

According to the Global Burden of Disease (GBD) study, mental behavioral and substance use disorders account for 0.5% of all Years of Life Lost (YLL) (6). However, it is widely recognized that burden related to mental and behavioral disorders is likely substantially underestimated using the GBD approach (7–9). Notwithstanding this underestimation, the burden of neurological and mental health disorders accounted for up to a fourth of the total amount of the Disability Adjusted Life Years (DALYs) in the GBD. This is largely explained by the chronic nature of this group of diseases, clinical onset in early as opposed to late adulthood, by their high prevalence in the general population, and their impact on independence.

The findings of a recent meta-analysis suggest that mental disorders rank among the most substantial causes of death worldwide (10). Moreover, this gap is likely increasing because different from the general population, lifespans in those affected by mental disorders have not increased in recent years (11).

The complex relationship between physical and mental health provides a number of potential explanations for this gap in life expectancy (12,13). The multilevel model of risk for excess mortality in persons with severe mental disorders posits complex interrelationship of factors, at different levels of individual, health system (leadership, financing, information, service delivery, human resources, medications) and social determinants of health (public policies, socio-economic position, culture and societal values, environmental vulnerabilities, social support) (13).

At the individual level these factors span across the disease-related (such as severity of disorder, family history, symptoms/pathophysiology, early age of onset, recency of diagnosis), behavioral (such as tobacco use, poor diet, inadequate physical activity, sexual and other risk behaviours, substance use (alcohol and drugs), and low motivation (e.g., treatment seeking, adherence); at the level of health system they may pertain to issues of mental health leadership (absence of relevant policies and guidelines), financing (low investment in quality care), information (limited health information systems), service delivery (verticalization and fragmentation of health services, lack of care coordination and management, limited access to services), human resources (poor quality service provision, negative beliefs/attitudes of workforce, poor communication), medications (no treatment, polypharmacy, higher than recommended dosages); at the level of social determinants of health explanatory factors may relate to public policies (discriminating policies, low financial protection and limited coverage in health packages, socio-economic position, unemployment, homelessness, low health literacy), culture and societal values (stigma and discrimination in society, negative perceptions about persons with mental disorders), environmental vulnerabilities (infections, malnutrition, access to means of suicide, impoverished or unsafe neighbourhoods), and social support (limited family, social and community resources).(13)

Moreover, all these factors are intertwined, and interrelationships at multiple levels likely contribute towards excess mortality. No single factor alone explains the excess mortality. It is imperative to assess the extent of the mental health-related burden, especially in countries in which evidence is thin or simply inexistent. This information is indispensable to advocate for, motivate and inform policy actions and to delineate specific risk factors and ways to modify them. It is necessary to identify and address barriers for mental health reforms to understand how to deliver evidence-based interventions and effective policies in the real world, taking into account issues of feasibility, acceptability, appropriateness and cultural context. Innovative approaches to research are needed as well as ways to strengthen the voices of service users and their family members.

6.2. “Persistent predicament” of stigma and discrimination:

One of the key barriers to improve care for people with mental disorders is stigma and the discrimination often associated by it. Stigma and discrimination permeate all areas of the lives of people with mental disorders and their families.

Since Goffman's seminal work on stigma (14), research in this field has steadily grown (15). Several conceptual frameworks and perspectives (16), including cognitive (17,18), anthropological (19), and sociological ones coexist (20), implications of power relationships for stigma have also been investigated (21–23).

The social cognitive model of stigma (18,24,25) focuses on three core features of stigma, namely, **stereotypes** (negative beliefs about a group), **prejudice** (agreement with stereotyped beliefs and/or negative emotional reactions such as fear or anger) and **discrimination** (a behavioural consequence of prejudice, such as exclusion from social and economic opportunities). In addition to these three, progressive features, stigma may exist at different levels, from public to label avoidance and structural stigma, through self-stigmatization attitudes that (see Table 1). (26)

	Public stigma	Self-stigma	Label avoidance	Structural stigma
Stereotype (cognitive / knowledge)	*People with mental illness are violent*	*People with mental illness are incompetent*	*People with mental illness are "psycho"*	*People with mental illness are lazy*
Prejudice (affective / emotional)	*Landlord feels scared of Bob because he has a mental illness*	*I am a person with mental illness and therefore incompetent. Who would want to date me?*	*I have a mental illness and am ashamed to be seen as "psycho"*	*I feel disgusted by Joann; if she really wanted a job, she could try harder*
Discrimination (behavior)	*Landlord won't rent apartment to Bob*	*I think "why try" and stop looking for a relationship*	*I don't tell my boss I need time off to see a therapist for fear I will lose my job*	*Funding cuts for employment programs in mental health*

Table 1. A matrix for understanding the complexity of mental health-related stigma (source: Sheehan, Nieweglowski & Corrigan 2017).

The mechanisms of stigma are complex, pervasive and interchangeable, with direct and indirect and conscious and unconscious ways of deployment. Stigma has been defined as a “persistent predicament in the lives of persons affected by it” (21) because even after fixing or blockage of one of the mechanisms of discrimination, the pre-existing labelling, stereotypes and prejudices from a group in power tend to persist through alternative pathways (21).

The exact way through which stigma is transformed into negative behavioural actions towards people diagnosed with mental disorders is often difficult to pinpoint. Actual discrimination may occur and be experienced in almost any domains of everyday life, and across levels of social interaction and structure, which are usually grouped into 3 main levels (27):

1. Macro-social level: structural discrimination

A concept of ‘institutional racism’ was offered to describe practices of discrimination and a failure to meet the demands of racial minority groups by institutional practices (28). The very broad governmental and societal structures, practices and functioning may be created in a way that limits life chances of stigmatised groups contributing to society, and acting freely. Superposition of the concept into discrimination associated with mental disorders leads to the formulation of ‘structural’ or ‘institutional’ discrimination (29), which is defined as a type of stigma ‘formed by sociopolitical forces and [which] represents policies of private and government institutions that restrict the opportunities of the groups that are stigmatized’ (18).

The consequences of structural discrimination include a variety of disadvantages that people with mental health conditions and their families face in all areas of their life. Example of structural discrimination include low resource allocation to mental health care that is far beyond the need, disadvantageous legislation and policies, discrimination in education, employment and economic exclusion, unreasonable lack of priority of mental health when compared to the level of its burden, poor access and low quality of health care and treatment, denial in education, employment and other ways of economic exclusion, traditional, media portraits, etc. (27)

Particular example of structural discrimination is the treatment gap for mental, neurological and substance use disorders. Several studies have demonstrated that the majority of people with mental disorders do not have access to treatment (30,31), when only 13.7% of 12-month cases with DSM-IV psychiatric diagnoses in lower-middle-income countries, 22.0% in upper-middle-income countries, and 36.8% in high-income countries receiving treatment (32). For some conditions the treatment gap is even lower, with less than 10% of people with anxiety disorders receiving adequate treatment (33), about 16.5% with major depressive disorders (34), and only 7.1% with substance use disorders (35).

2. Micro-social level: interpersonal discrimination

People with mental disorders experience discrimination in their everyday communications. Individual discrimination is defined as a process taking place in the direct interaction between the stigmatising and the stigmatised person (36). There is a large body of evidence on public attitude towards people with mental disorders. This negative attitude is infamously encapsulated in the ‘not in my backyard’ principle, when people refuse to have contact with or live near a person with serious mental illness as they perceive them as dangerous and unpredictable (37). Discrimination in interpersonal relationship was reported by half of people with mental disorders with the most frequent areas of making or keeping friends (47 %), within families (43 %), in finding or keeping a job (27 %) and in intimate or sexual relationships (23 %) (38). In another study almost 80% of people with depression reported experiencing discrimination in at least one life domain (39). Interpersonal discrimination might be present also in the context of health care. For example, GPs may have higher level of stigma than the general population. In a recent large scale survey conducted in the UK, GPs reported to have more comfort with individuals who are deaf than with people with mental disorders (40).

Stigma and discrimination transferred also from people with mental disorders to their companions and relatives, and discrediting them is described in the literature as “courtesy stigma” (41), “associative stigma” (42), “stigma by association” (43) or “family stigma” (44). This can affect children, parents, siblings and spouses (45), and evidence demonstrates that the phenomenon is present across cultures and continents, regardless of nationality, educational level, and social class (46–52). The burden of stigma in families leads to practices of hiding ill relative, concealing diagnosis, refusing help and avoiding contact with the external world, with perilous repercussions on help-seeking behaviors that may cause delays in treatment and increase emotional burnout (53). Some family members may decide to distance themselves from their relatives, which contribute to an increased number of divorces and decreased number of years of marriage. People with mental disorders are then left to live in a ‘broken family’ (47,54) either with some social contacts or in loneliness.

3. Intrapersonal level: anticipated discrimination and self-discrimination

Experience of both structural and individual discrimination, repeatedly throughout the life of a person with diagnosis of mental disorders, contributes to internalization of ‘spoiled identity’, anticipated discrimination, self-stigma and self-discrimination. Results of the INDIGO study showed anticipated discrimination was reported more frequently than experienced acts of discrimination and not necessarily associated with it (55). Although the exact mechanisms of internalisation of stigma are not clear, several explanations have been suggested. The concept of ‘moral experience’ (or “what is most at stake for actors in a local social world”) may explain pervasion of stigma inside the personal world of an individual (20). Previous knowledge, self-prejudice and attitude as well as agreement with stereotypes by persons with mental disorder may play a role in its internalization too, decreasing self-esteem and self-efficacy (16,56).

6.3. Central and Eastern Europe as a “blind spot on the global mental health map”

The GBD data revealed that CEE is the region with the world’s highest level of DALYs (6) and YLLs due to mental, behavioral and substance use disorders (57). Notably, YLLs were found to be critically high when compared to other world regions. This may be partly explained by the high prevalence of substance use and substance use disorders (57,58). Yet, country level evidence from this CEE region is extremely patchy (59).

Most of the available evidence on disproportionate mortality associated with mental disorders comes from Scandinavia, Western Europe, North America, Asia and Australia with no studies from CEE (10). Issues of generalizability may exist because of the potential differences across the determinants, diagnostics and treatments of mental disorders and in systems responsiveness between countries and world regions. However, the causal role on standardized mortality ratio (SMR) of substance use disorders (opiate use - 14.7 (60), amphetamine – 6.2 (61), alcohol – 6.68 (62)) and anorexia nervosa (5.86 (63)) followed by other conditions (acute and transient psychosis – 4.7, bipolar disorder – 3.3 (64), schizophrenia – 2.5 to 4.6 (64,65) depression (1.52) (66) is plausible and may therefore be ubiquitous. Nevertheless, there is almost no epidemiological data on country- and region-specific mortality among people with mental disorders, neither on risks factors distribution and associations with differential mortality.

A recent study on the treatment gap for mental disorders performed in the Czech republic showed that access to care is limited in the country, presenting similar figures to those available from the rest of the world: 61% of people with affective disorders do not have access to care, raising to 93% for those with alcohol use disorders. (67)

Finally, evidence on mental health related stigma is extremely limited in CEE comparing to the rest of Europe. The limited evidence that exists seems to indicate that it is more frequent and more severe in comparison to stigma in England (68), but the content of the differences and experience of those under threat of stigma remain largely unknown.

6.4. Strengthening evidence base, capacity and political will for mental health reforms

Evidence from the CEE region is a key to advocate for and inform local action, and may also allow unprecedented comparisons across cultures and geographic regions that may provide further insight into the underlying mechanisms of lower life expectancy among people with mental disorders. We maintain that good quality research on the anticipated excess mortality due to mental ill health, and on the potential underlying mechanisms is crucial to advocate for and inform health promotion, disease prevention, policy and health systems responses aimed at addressing the ethical and moral implications of the existing life expectancy gap in people with mental disorders.

The aim of this work was two-fold: first, to study the excess annual mortality associated with mental and substance use disorders in the Czech Republic, and second, to understand the underlying stigma and discrimination faced by families of people with schizophrenia. The overall goal was to provide decision and policy makers with a unique evidence-base to design, develop, plan and implement mental health, national strategies, and a health and care services structural reform. Because our work required the creation of a rich, comprehensive and nationwide representative data repository, a secondary but extremely important aim of this work was to facilitate international, comparative research, and hypothesis generation and testing in future collaborative studies in the CEE region.

This is the first study of this kind conducted in country of CEE, with potential great relevance for the ongoing mental health care reform in the Czech Republic, which ultimate aim is to improve the quality and duration of life of people with mental disorders, and to reduce the impact of mental disorders on those affected, their families and society at large.

7. Articles

7.1. Article 1. “State of mental healthcare systems in Eastern Europe: do we really understand what is going on?”

Methods: We derived data from WHO Mental Health Atlas (WHO-MHA) 2011 and 2014 (WHO, 2011, 2014b) on basic statistics available for the majority of Eastern Europe countries. Where data were unavailable in the WHO-MHA 2014, we referred to the 2011 database to make comparisons possible. To analyse trends in institutional care between 2011 and 2014 we have calculated percentage changes in the numbers of in-patient care facilities and mental hospital beds. For the sake of comparison, we extracted data for the countries of Eastern Europe and 15 member states of the European Union (EU) before its enlargement in 2004 (EU15).

Role of the candidate: initial idea of the paper, data extraction and analysis, drafting the manuscript, submission of the paper to the journal and working on the revision.

7.2. Article 2. A blind spot on the global mental health map: a scoping review of 25 years' development of mental health care for people with severe mental illnesses in central and eastern Europe

Methods: with a focus on 24 countries of CEE and last 25 years of mental health care for people with severe mental illnesses, we performed a scoping literature review and extensive expert consultations to draft country profiles and overview the situation in the region. This involved use of a broad search strategy to identify relevant studies; selection of studies according to inclusion and exclusion criteria; charting the data; collating, summarizing, and reporting the results; and placing particular emphasis on consultations with relevant experts. We therefore included articles that focused on: mental health services (inpatient, outpatient, primary care, community and residential services for people with severe mental illnesses); epidemiological studies of population mental health; policy and legislation; involvement of user and family members in service delivery and planning; resource availability and allocation, and economic evaluations of complex interventions; quality and duration of training for mental health specialists (including the availability of education for mental health care development, such as health-service research, psychiatric epidemiology, mental health economics); and studies on mental health-related stigma among the general population and current or future health-care professionals.

To triangulate the findings from the literature review, and to address the anticipated lack of literature, the review was complemented by an expert survey. Expert reports were collected by country collaborators who approached up to five experts in their countries.

Role of the candidate: initiating the project, writing the study protocol and preparing instruments, coordinating literature review, identifying, collecting and analyzing data received from country experts, leading discussions on key messages and conclusions, drafting the manuscript and supplementary materials, assisting with submitting paper to the journal and working on the revision.

7.3. Article 3. Mortality in people with mental disorders in the Czech Republic: a nationwide, register-based cohort study

Methods: We did a nationwide, register-based, retrospective cohort study using routinely collected health data from two nationwide registries in the Czech Republic: the register of inpatient discharges (from Jan 1, 1994, to Dec 31, 2013) and the causes of death registry (from Jan 1, 1994, to Dec 31, 2014). We first identified all individuals discharged from mental health institutions with ICD-10 diagnoses of mental and behavioural disorders (from 1994 to 2013). We then did a deterministic individual-level linkage of these data with all-cause mortality data for the whole period (1994–2014). Standardised mortality ratios (SMRs) and 95% Cis were calculated for the year 2014, comparing deaths in people with mental and behavioural disorders discharged from psychiatric hospitals with deaths in the general population.

Role of the candidate: coming up with the initial idea for the study, initiating the project, writing the protocol, working with agencies to obtain and proceed data, engaging external experts and collaborators, obtaining ethical permission for the project, coordinating and supervising work of data analyst, drafting the manuscript and supplementary materials, submitting paper to the journal and working on the revision.

7.4. Article 4. Experience of stigma and discrimination in families of persons with schizophrenia in the Czech Republic

Methods: We conducted a qualitative study based on semi-structured in-depth interviews with relatives of patients diagnosed with schizophrenia in the Czech Republic. Initial respondents were identified through local mental health services and users' organizations with a consecutive chain-referral sampling. Transcribed narratives were thematically analyzed within a pre-developed four-level thematic framework to comprehensively identify experiences of stigma and discrimination in all areas of the respondents' lives.

Role of the candidate: coming up with the initial idea for the study, initiating the project, writing the protocol, obtaining ethical permission for the project, coordinating and supervising work of data collector, analysis of translated data, drafting the manuscript and supplementary materials, submitting paper to the journal and working on the revision.

7.5. Article 5. Culture and reform of mental health care in central and eastern Europe: workshop report

Methods: The WHO Regional Office for Europe, the WHO Collaborating Centre on Culture and Health at the University of Exeter (United Kingdom) and the National Institute of Mental Health (Czechia) convened a workshop on culture and reform of mental health care in central and eastern Europe on 2–3 October 2017 in Klecany, Czechia. The aim of this workshop was to improve understanding of the key cultural aspects that impact and drive mental health care reform in the central and eastern European region. Participants consisted of 31 professionals in diverse fields from Armenia, Belarus, Czechia, Hungary, Latvia, Lithuania, Poland, Romania, the Russian Federation and Ukraine. Based on a workshop a report was produced that outlines the key points and recommendations made by participants in relation to this objective.

Role of the candidate: advocating for and shaping the initial idea of having an expert meeting on the topic, preparing the first draft of the agenda, identifying and engaging experts and partners, participation in all discussions, presenting evidence from own research, participation in formulation of meeting recommendations, supervising work of the person drafting a report and revising it in collaboration with other partners.

8. Conclusions and perspectives

Despite the slight progress in some Eastern European countries, the development of mental healthcare in the region remains slow and ineffective. Our analysis of the WHO Mental Health Atlas data (69) suggests that there are several challenges in mental health care, and that the needs of people with mental disorders remain largely unmet. The resources allocated are scarce, and services are either absent, inadequate, or inequal particularly at the community level. Rehospitalization rates in the country are worryingly high (70). Although our study extended evidence on the excess mortality associated to mental disorders from western countries to the CEE region, one of the key conclusions we arrived at is that there is an urgent need to provide stronger evidence to advocate and inform mental health reforms in the regions.

Over the past decades, CEE countries have experienced major sociopolitical and economic transformation. Mental health care has evolved in the context of important societal changes, including centralised economies being displaced by market-oriented economies, and health insurance replacing state-funded health care. The review of 25 years development of mental health care yielded 12,785 papers reflecting the situation in countries (71). We examined 464 full texts and used 183 articles to compose reports for each country in the region strengthened with analysis of 62 experts' consultations. In terms of mental health services, the 25-year period after 1989–91 has seen some positive developments in community and social psychiatry, in which recovery is promoted and enhanced via the establishment of community service networks. This route has been difficult, however, and several barriers and challenges are still pending.

The number of psychiatric beds in the region has decreased substantially in all CEE countries over the past 25 years. However, this decrease has rarely been accompanied by adequate development of community services, and institutionalisation continues to occur in long-term care facilities. Except some, sporadic exceptions, mental health care across the region remains geographically centralized, around main cities, and largely based on psychiatric hospitals, instead of psychiatric beds in general hospitals. Moreover, the infrastructures of psychiatric hospitals have dramatically deteriorated over time, and in most cases instead of providing healthcare services these large facilities tend to substitute community and housing services. Systems of outpatient psychiatric care, which were already relatively well developed during the Soviet period, continue to function. However, this care is often limited to the prescription of medications and its integration and cooperation with other services of both mental and general health care is malfunctioning, and rare across non-health sectors including social, housing and employment services.

In some countries, networks of community care are well developed and integrated into the mental health system. Examples of excellent community projects, facilities, and services exist all over the region, although countries differ in the proportion of their affected populations that have access to these services. Cases of highly developed community services are certainly not limited to the region's higher-income countries. These projects often have problems with sustainability, scaling up, and integration into mainstream mental health care systems, especially in terms of statutory funding. Presently, good quality community services are available to only a fraction of people who need them in the region. The infrastructure that exists, besides psychiatric hospitals and outpatient care which are largely limited to providing shelter and medications, can be largely attributed to the enormous efforts of enthusiastic individuals and organisations, rather than to strategic development and political dedication on the part of governments.

The vast majority of countries in the region have developed and approved a specific mental health policy. However, these policies remain largely unimplemented, and changes have been more cosmetic than structural. Similarly, legislation has been improved across the region but is reportedly rarely enforced in practice.

All countries in the region have unjustifiably underfinanced mental health systems. Although exact numbers are unavailable, the proportion of health-care budgets allocated to mental health is estimated to be around 3% (equivalent to US$18·7 per person) in most CEE countries. The lack of information also applies to human resources, which should be allocated according to the best available evidence to make the most effective use of available specialists. Nowadays, a considerable proportion of mental health professionals are working in hospital settings. This lack of investment not only hinder progress but also causes frustration and an inevitable demotivation and inertia in the healthcare workforce.

Epidemiological studies on the prevalence of severe mental disorders are rare, and those that exist are often not rigorous to be published in international journals. Therefore, the basis for decision making to allocate resources is not clear, and there is a high risk that the already limited mental health budgets of countries are being spent ineffectively, inefficiently, and unequally.

Self-help groups and service user organisations for people with severe mental disorders exist almost in all countries of CEE. However, involvement of service users in mental health care development continues to be rare across the region. The voices of service users and their families, despite being increasingly raised, at present seem not to have gained sufficient strength to overcome the structural discrimination and huge disparities between mental and general health care. These voices are not only silent but often silenced, through various forms of human rights violations that are difficult to document and report.

There seem to be many anti-stigma activities mentioned across the region, but they rarely include thorough evaluation and therefore are not reported to the scientific community. There are indications that levels of stigma among both the public and health-care professionals are alarmingly high, but empirical evidence is limited to very few studies. The same observation seems to apply to stigma among family members, even though families bear a substantial part of the disease burden and provide care to a large proportion of people with severe mental disorders; however, the evidence is almost exclusively anecdotal.

"*The problem is, however, that in absence of a political will to invest in the infrastructure of mental health promotion and a new type of community-based services, the same priorities as in Soviet times will continue to be funded: psychiatric hospitals, long term care institutions for mentally ill and mentally retarded persons, and pharmacological treatments*." This statement, written by the Lithuanian psychiatrist Dainius Puras, could be the conclusive remark of our review if it were not written almost 20 years ago.

The overall state of mental health care in central and eastern Europe is described as a "blind spot on the global mental health map", and one of the unknown aspects is the mortality gap and other epidemiological data across countries. Production, dissemination and use of this type of evidence for advocacy, decision-making and monitoring progress is crucial to facilitate the transition.

Since Soviet times, many countries of the region were routinely collecting health information data on numerous indicators. However, even if data is available, there is no practice and capability to use it for research purposes. Establishing a practice of rigorously looking into the existing routinely collected health data and doing register-based studies could provide a unique and relatively cheap opportunity to fill the evidence gap. We demonstrated that it is possible to use already available nation-wide health data that have been routinely and systematically collected during the last 25 years. We described the record linkage procedures and processes across registries to inform and stimulate further research in other countries. Our study, published in the Lancet public health, is the first to assess mortality associated with mental and behavioural disorders in CEE using a deterministic linkage of nationwide databases of routinely collected health data.

Using a sample of 283,618 individuals, we showed that, compared with the general population, individuals with a clinical history of mental disorders had up to three-times higher mortality, varying by age and cause of death. Individuals diagnosed with mental disorders died significantly earlier than individuals in the general population. Although the leading cause of death (cardiovascular diseases) was consistent, mortality from other causes markedly varied between the two groups.

The complex association between physical and mental health provides some potential explanations for this gap in mortality. Mental and somatic disorders often co-occur because of shared risk factors and common pathological pathways. Moreover, although chronic diseases can cause or worsen mental disorders because of the associated disability and burden (and through the side-effects of medications), access to care, help-seeking, and adherence to treatment might be poor in people with mental disorders. While poor mental health may affect the detection, diagnosis, and prognosis of both communicable and non-communicable diseases, mental health related stigma and discrimination have detrimental effects on the quality of care and the treatment provided. Finally, poor longitudinal continuity of care, loneliness, unhealthy lifestyle, poor health literacy, absence of health-promoting behaviours, structural issues, and social determinants of health (eg, relative poverty) are among other potential factors contributing to the excess mortality. A combination of all these factors might explain the increased mortality due to different health conditions, including diseases of the nervous, respiratory, and circulatory systems. Some mental and behavior disorders can have indirect effects on mortality. Increased mortality due to severe gastrointestinal diseases might be linked to liver and gastric problems caused by alcohol and other substance use disorders. A direct role of mental and behavioral disorders further contributes to excess death. Schizophrenia and common mental health disorders such as depression, anxiety and substance abuse are the main proximal risk factors for suicide, which is the second leading cause of death in young adults (<30 years) globally. The high mortality due to intentional self-harm in our study is consistent with other findings reported in other studies on high rates of suicide, and unintentional injuries (72). Nonetheless, people with severe and common mental disorders are also disproportionally victims of violence, both psychological and physical, and of homicide. This too may contribute to explain the differences in mortality from external causes of death.

Our findings have relevant implications for the ongoing mental health-care reforms in the Czech Republic. In addition, because we thoroughly described and comprehensively reported the procedures we implemented for the linkage of records across data sets, the methods used in our study could prompt and inform the design of similar epidemiological studies in other CEE countries with existing mental health registries and where research on this topic is still scant.

Stigma and discrimination is one of key factors contributing to disadvantaged situation and excessive mortality associated with mental disorders. To better understand the burden of stigma, we did a comprehensively overview of stigma-related challenges in different areas of life of family members (FMs) of persons living with schizophrenia (PLS) (73). We found that stigma and discrimination were present at all levels of respondents' lives (macro-, meso-, micro-, intro-), suggesting its pervasive nature. Three main topics emerged from our thematic analyses that could be addressed to reduce stigma and discrimination: (1) general lack of understanding and misconceptions about mental illness in general population; (2) structural discrimination and paucity of governmental and public support systems; (3) burden of “pervasive and unlimited” care and inability of independent living. Although it was beyond the scopes of our study to explore potential interventions, our findings demonstrate that a multisectoral approach must be endorsed to tackle the complex mechanisms that lead and reinforce stigma and discriminatory attitudes of across contexts, settings, and situations, and at the individual, group and institutional levels.

This is relevant because anti-stigma campaigns are ongoing in the Czech republic (see below).

Recent stigma research has suggested that to understand the experience of stigma it is necessary to understand what is “at stake” under the exposure to stigma and discrimination in a specific cultural context. In other words, what is threatened by stigma is a person's ability to participate actively and achieve “what matters most” in society to reach “full status” or “personhood” (19). In our study the overarching theme of the desire to “live independently as a productive member of society,” expressed as an issue across all domains by FMs, highlights that in the Czech Republic, too, this value reflects “what matters most” and what is “at stake” as a result of stigma and discrimination. Somewhat counterintuitively, the issue of marriage and stigma as a threat to marital prospects was not mentioned by respondents of the current study, which might be explained by a value change in Czech society that occurred after the fall of communism. This issue could be explained as a consequence of the values shift happening in the Czech society that followed the international trend of deinstitutionalization and decreased value associated with marriage (74).

All the evidence generated during the PhD was presented at the WHO regional workshop on culture and reform of mental in central and eastern Europe (CEE). The workshop’s scope and purpose covered the exploration of both negative and positive cultures of mental health – that is, factors that function as barriers to or enablers of reform. Participants’ presentations shed light on historical and cultural drivers of reform, highlighted examples of reform processes and lessons learnt, and outlined methodologies for examining culture as relevant to mental health care reform in CEE. Presentations were followed by plenary and small-group discussions to further explore the issues raised by the invited speakers. The following key points were agreed among participants: (1) the normative culture of institutionalized mental health care spans social, clinical and political realms; (2) mental health services and practitioner education are almost exclusively biological in their orientation, and social approaches to care are neglected; (3) high levels of stigma and discrimination deter the disclosure of mental health problems and limit the acceptability of deinstitutionalizing mental health services.

Participants recommended methods and approaches from the humanities and social sciences to address these cultural drivers in CEE. They agreed that these could inform a more people-centred approach to reform by amplifying the voices of those with mental disorders and/or psychosocial disabilities, and by fostering communication among stakeholders at all levels. Such efforts towards inclusion and collaboration are vital to the development of effective and empowering mental health care systems across the region.

Presented findings are particularly important in the context of the ongoing mental health-care reforms in the Czech Republic (75,76). Mortality and its monitoring over time have been included among the key preliminary indicators of the proposed mental health national plan in the country to closely monitor progress in quality of mental health care. Data will be routinely collected to assess the development of mental health-care services.

Findings on stigma and discrimination were used to inform the Czech national program on the reduction of mental health-related stigma. We developed a set of recommendations for policy-makers aimed at reducing ignorance and prejudice amongst the public and professionals, improving health and social services—including employment, housing and community integration—and the provision of family support.

Because of the scarcity of epidemiological evidence from other countries in CEE, further research is needed to inform and propel mental health promotion, disease prevention, and policy and health-systems responses aimed at closing the life expectancy gap in people with mental disorders and addressing the largely unmet mental health needs in the region. CEE is a very special region when it comes to mental health and mental health care. Unfortunately, mental health in these countries has not received enough attention from global mental health community and too often was forgotten by local policy and decision makers or reforms were rather cosmetic and not addressing needs of people in need.

It is our hope that the situation will change in the visible future with the evidence elucidating the gap between needs and provision of care. Implementation of the updated WHO Comprehensive mental health action plan 2013-2020 extended till 2030 (77), WHO Global Strategy to Reduce the Harmful Use of Alcohol (78), WHO/UNODC International Standards for the Treatment of Drug Use Disorders (79), Global Strategy on Human Resources for Health: Workforce 2030 (80) and other tools can be helpful in guiding countries towards longer and healthier lives of people with mental disorders.

The Sustainable Development Goals (SDGs), adopted by all UN Member States provide further opportunity to improve prevention and care as many targets are directly related to mental health, what is reflected in targets 3.4 (By 2030, reduce by one third premature mortality from non-communicable diseases through prevention and treatment and promote mental health and well-being), 3.5 (Strengthen the prevention and treatment of substance abuse, including narcotic drug abuse and harmful use of alcohol) and 3.8 (Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all). Mental health also intersects and influences most of the other SDGs, such as poverty eradication (SDG 1), nutrition (SDG 2), education (SDG 4), women's empowerment (SDG 5), decent work (SDG 8), sustainable cities (SDG 11), sustainable consumption (SDG 12), climate change and disaster recovery (SDG 13), peaceful and just societies (SDG 16) and partnerships (SDG 17).

The famous quotation that "there is no health without mental health" has recently been changed to "there is no sustainable development without mental health" (81) and, indeed, countries need to work harder is they are serious about universal health coverage and future of its citizens where no one is left behind.

This PhD gave me the opportunity to design and conduct a comprehensive and pioneering research program. We disseminated a large set of remarkably novel findings that extends evidence from western countries to the CEE region. We paved the way to future research and work in a region of the world where the impact of poor mental health on both individuals and societies is greatest. But, most of all, we have demonstrated that population sciences can significantly contribute to propel ambitious policy and political agenda that are firmly grounded in global principles and a robust evidence base.

It was a great pleasure to work with all colleagues and partners involved and I hope my participation in the working stream on Social Psychiatry at the National Institute of Mental Health with a support from the University of Geneva has made a significant contribution to future of mental health care in the Czech Republic and in the region of CEE. I have personally learned a lot both as a researcher and as a member of the team putting needs of people at the foremost and believing in the possibility to make the change in constantly changing environment of a very complex field. I would like to finish by expressing once again my deepest and sincere gratitude to everyone involved as acknowledged in the first section of this theses.

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Annex 1. Paper 1

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SPECIAL PAPER

State of mental healthcare systems in Eastern Europe: do we really understand what is going on?

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The article examines the current state of mental healthcare systems in countries of Eastern Europe and derives implications for future research and service development. Analysis of available statistics from the World Health Organization's *Mental Health Atlas* suggests the need for better-quality data collection. Nonetheless, there appear to be insufficient resources allocated to mental health, lack of involvement of service users in policy-making and, to a large extent, systems continue to rely on mental hospitals. Based on the data presented, a set of directions for future reforms was drafted.

Eastern Europe occupies a large part of the European continent. According to the United Nations' definition which we adhere to in the current paper, Eastern Europe consists of 10 countries: Belarus, Bulgaria, Czech Republic, Hungary, Republic of Moldova, Poland, Romania, Russian Federation, Slovakia and Ukraine. It has a total population of nearly 300 million (approximately 150 million without the Russian Federation) (data from http://esa.un.org/unpd/wpp).

The recent fast development of the global mental health movement has increased the attention given to low- and middle-income countries. However, Eastern Europe has been somewhat overlooked by mental health research and practical initiatives (Forsman *et al*, 2014). This is despite the burden of mental and behavioural disorders in the region being one of the highest in the world according to the Global Burden of Disease Study (Lozano *et al*, 2012). According to the World Health Organization (WHO), suicide rates are particularly high (WHO, 2012) and the level of alcohol consumption is enormous and growing (WHO, 2014a).

Eastern Europe went through a political transformation in the 1990s. After the collapse of communism 25 years ago, the countries diverged, pursuing their own paths to development, as well as with respect to the reorganisation and modernisation of their mental healthcare systems. Many positive changes have been achieved but many challenges remain (Füredi *et al*, 2006; van Voren *et al*, 2007; Semrau *et al*, 2011; Dlouhy, 2014).

Methods

The WHO *Mental Health Atlas* (WHO-MHA) 2011 and 2014 (WHO, 2011, 2014b) and the European Health For All database were consulted. After initial screening, we opted to use only the WHO-MHA database, as it seems to be the only one covering details of mental health service functioning. We derived data on basic statistics available for the majority of Eastern Europe countries. Where data were unavailable in the WHO-MHA 2014, we referred to the 2011 database to make comparisons possible.

To analyse trends in institutional care between 2011 and 2014 we have calculated percentage changes in the numbers of in-patient care facilities and mental hospital beds. For the sake of comparison, we extracted data for the countries of Eastern Europe and 15 member states of the European Union (EU) before its enlargement in 2004 (EU15).

Results

General information and data on resources for mental health and institutional care are presented in Table 1.

General information

The majority of Eastern European countries have mental health policies: 77% of countries (compared with 93% in the EU15). However, the involvement of service users and families in the policy-making is markedly worse than in the EU15: there is not a single Eastern European country with full participation of users in policy-making, in contrast to 53.5% of EU15 countries.

Resources for mental health

In both Eastern Europe and the EU15, the proportion of total health expenditure allocated to mental health (3.3% and 7% respectively) mismatches the global burden of disease for neuropsychiatric disorders (21.22% and 29.96% in terms of disability-adjusted life years). However, this difference is especially poignant in Eastern Europe as the total health expenditure per person is almost six times lower than in the EU15 (US$758.78 versus US$4382.53) and the part allocated to mental health is two times lower (3.3 % versus 7%). As a result, the total mental health expenditure per capita is only US$18.7, which is 15.7 times lower than in the EU15 (US$293.7).

The number of overall mental health staff in Eastern Europe is 2.4 times lower than in the EU15 (47.4 versus 127.2 per 100 000) and there are 1.8 times fewer psychiatrists (8.03 versus 14.13 per 100 000). No Eastern European country reaches the EU15 average level of mental health staff.

Annex 2. Paper 2

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Review

A blind spot on the global mental health map: a scoping review of 25 years' development of mental health care for people with severe mental illnesses in central and eastern Europe

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Just over 25 years have passed since the major sociopolitical changes in central and eastern Europe; our aim was to map and analyse the development of mental health-care practice for people with severe mental illnesses in this region since then. A scoping review was complemented by an expert survey in 24 countries. Mental health-care practice in the region differs greatly across as well as within individual countries. National policies often exist but reforms remain mostly in the realm of aspiration. Services are predominantly based in psychiatric hospitals. Decision making on resource allocation is not transparent, and full economic evaluations of complex interventions and rigorous epidemiological studies are lacking. Stigma seems to be higher than in other European countries, but consideration of human rights and user involvement are increasing. The region has seen respectable development, which happened because of grassroots initiatives supported by international organisations, rather than by systematic implementation of government policies.

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Introduction

2016 marked a quarter of a century since the dissolution of the Soviet Union, which was the symbolic end of communist rule in central and eastern Europe (CEE). For this Review, CEE is defined as the 23 countries included

illnesses. These initiatives have been largely in line with the principles enshrined by the Universal Declaration of Human Rights[6] and Alma Ata Declaration,[7] and included the UN Principles for the Protection of Persons with Mental Illness[8] and later the Convention on the Rights of

Annex 3. Paper 3

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Articles

Mortality in people with mental disorders in the Czech Republic: a nationwide, register-based cohort study

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Summary

Background The region of central and eastern Europe is estimated to have high rates of premature mortality due to mental disorders. However, epidemiological evidence is scarce and insufficient to inform policy actions and health system development. We aimed to assess mortality associated with mental disorders in the Czech Republic.

Methods We did a nationwide, register-based, retrospective cohort study using routinely collected health data from two nationwide registries in the Czech Republic: the register of inpatient discharges (from Jan 1, 1994, to Dec 31, 2013) and the causes of death registry (from Jan 1, 1994, to Dec 31, 2014). We first identified all individuals discharged from mental health institutions with WHO International Classification of Diseases tenth edition (ICD-10) diagnoses of mental and behavioural disorders (from 1994 to 2013). We then did a deterministic individual-level linkage of these data with all-cause mortality data for the whole period (1994–2014). Standardised mortality ratios (SMRs) and 95% CIs were calculated for the year 2014, comparing deaths in people with mental and behavioural disorders discharged from psychiatric hospitals with deaths in the general population.

Findings The final study population comprised 283 618 individuals. 3819 of these individuals died in 2014, corresponding to a mortality risk more than two times higher than that of the general population (SMR estimate 2·2; 95% CI 2·2–2·3). Differences in SMR estimates across diagnostic groups were substantial, with the highest SMR for substance use disorders (3·5; 95% CI 3·4–3·7) followed by schizophrenia, schizotypal, and delusional disorders (2·3; 2·1–2·5), personality disorders (2·3; 2·0–2·6), neurotic, stress-related, and somatoform disorders (1·8; 1·6–1·9), and mood (affective) disorders (1·6; 1·5–1·7).

Interpretation Mortality among people with mental disorders in the Czech Republic is markedly higher than in the general population. Our findings should stimulate and inform policy in the central and eastern Europe region, as well as ongoing national mental health-care reforms in the Czech Republic.

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Annex 4. Paper 4

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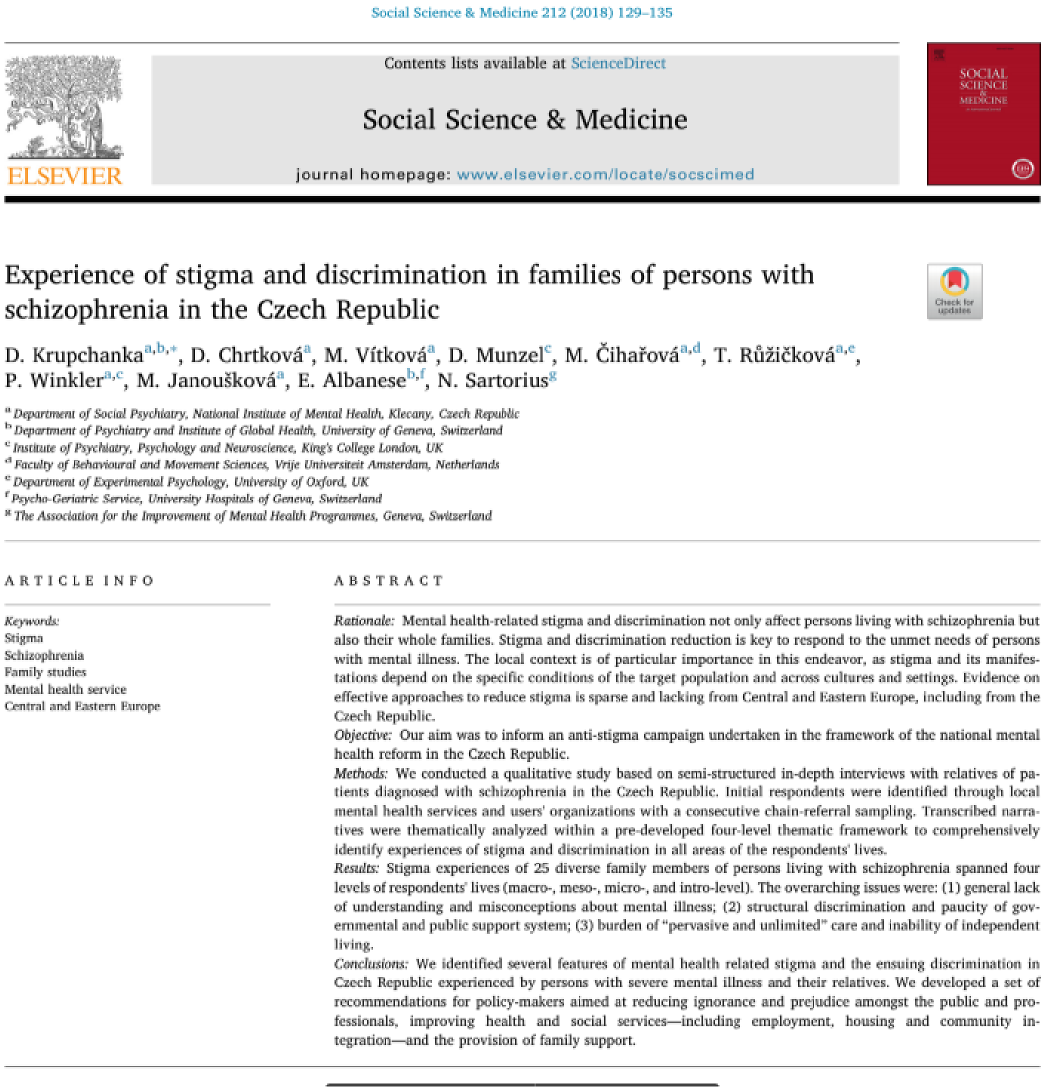

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Experience of stigma and discrimination in families of persons with schizophrenia in the Czech Republic

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ABSTRACT

Rationale: Mental health-related stigma and discrimination not only affect persons living with schizophrenia but also their whole families. Stigma and discrimination reduction is key to respond to the unmet needs of persons with mental illness. The local context is of particular importance in this endeavor, as stigma and its manifestations depend on the specific conditions of the target population and across cultures and settings. Evidence on effective approaches to reduce stigma is sparse and lacking from Central and Eastern Europe, including from the Czech Republic.

Objective: Our aim was to inform an anti-stigma campaign undertaken in the framework of the national mental health reform in the Czech Republic.

Methods: We conducted a qualitative study based on semi-structured in-depth interviews with relatives of patients diagnosed with schizophrenia in the Czech Republic. Initial respondents were identified through local mental health services and users' organizations with a consecutive chain-referral sampling. Transcribed narratives were thematically analyzed within a pre-developed four-level thematic framework to comprehensively identify experiences of stigma and discrimination in all areas of the respondents' lives.

Results: Stigma experiences of 25 diverse family members of persons living with schizophrenia spanned four levels of respondents' lives (macro-, meso-, micro-, and intro-level). The overarching issues were: (1) general lack of understanding and misconceptions about mental illness; (2) structural discrimination and paucity of governmental and public support system; (3) burden of "pervasive and unlimited" care and inability of independent living.

Conclusions: We identified several features of mental health related stigma and the ensuing discrimination in Czech Republic experienced by persons with severe mental illness and their relatives. We developed a set of recommendations for policy-makers aimed at reducing ignorance and prejudice amongst the public and professionals, improving health and social services—including employment, housing and community integration—and the provision of family support.

Annex 5. Paper 5

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