

ABSTRACT BOOK

ESA RN 16 MID-TERM CONFERENCE

Health and health care in Europe:
between **inequalities** and new **opportunities**



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Introduction

Health is one of the most important goods for individuals and societies. That is why discussion about health and health care should be treated as crucial. The goal of our conference is to gather together scholars who are conducting research in the field of health and health care. We are going to tackle problems of inequalities and focus on new opportunities for addressing them. Sociology has been concerned with inequality from its very beginnings. Inequality means the uneven distribution of goods. One of the most important goods is health, but social factors such as education, employment status, income level, gender, ethnicity, and age influence health status and access to care.

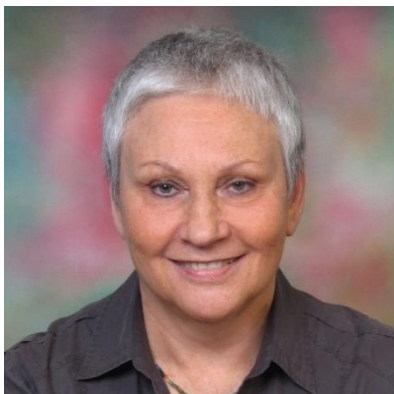
The task of policy makers is to reduce inequalities, which means giving everyone the same opportunities to lead a healthy life. But the task for sociologists is to research and explain what does, or could, cause inequalities and to propose solutions. We know that education, employment status, income level, gender and ethnicity and other factors have a great impact on life expectancy and quality of life. In modern Europe all these social factors are fueled by migration, political tribulations and the neoliberal economy. Value crises, risk, and individualism do not help. Developments in medicine, in medical technology and biotechnology, new treatments and new procedures, and many other things which become an opportunity to cure and care, can be a source of further inequalities. That is why involving social science, in particular sociology, in the discourse about health and health care is important.

Plenary lectures

Health care, public health and social determinants of health. Sociological interpretation of possible links and their consequences for health .

ZOFIA SŁOŃSKA

The problem of social determinants of health came into being in the consciousness of international medical communities as a result of recognizing lifestyle as the main factor determining the variability in the health status of contemporary, developed societies. This fact took place in 1974 and was related to the dissemination in developed countries of the results of the so-called Lalonde's Report. This report provided scientific evidence that undermined the key role of healthcare and attributed it to lifestyle. It was the first step towards the birth of health promotion in 1986, a new field of public health, based on the concept of multi-factor health determinants and multi-sectoral collaboration. The sociologists played a significant role in the emergence and development of this field in the world. The institutionalization of health promotion, despite its popularization, turned out not to be so simple. Among other things, because there were and are attempts to medicalize it, and thus to give up interdisciplinary and intersectoral cooperation. The subject of the lecture will be the analysis of key problems related to the implementation of the interdisciplinary approach in health care and public health, as well as the involvement of medical institutions in intersectoral cooperation to reduce the negative impact on health of non-medical factors, including social ones.



Zofia Słowska is a PhD in sociology, academic researcher and lecturer, currently retired. In years 1991-2002 she worked as an assistant professor and a head of the Department of Health Promotion and in years 2002-2020 a deputy head at the Department of Epidemiology, Cardiovascular Disease Prevention and Health Promotion, the National Institute of Cardiology in Poland. Between 2006-2018 she was a member of the Polish Government Population Council. In 1991, she was employed as a consultant for health promotion in the World Health Organization, Regional Office for Europe, Copenhagen. In years 1993-2002 she cooperated with WHO as a national health promotion WHO counterpart for Poland and in years 1995 to 2002 as a member of the European Committee for Health Promotion Development. Since 2010 she was elected a member of the executive Board of the European Society for Health and Medical Sociology (ESHMS) and currently is the vice president of this organization. Her research areas of interest are: sociology of health and medicine, public health, including health promotion, social epidemiology and health literacy. She is an author and co-author of many national and international research projects, including the awarded in 2012 the European Health Award 'the European Health Literacy Survey (HLS-EU)' as well as more than 100 peer-reviewed Polish and foreign scientific publications, including monographs, collective works and articles in scientific journals and the Encyclopedia of Sociology (illness/disease/sickness, pol. *choroba*, vol. 1; health, pol. *zdrowie*, vol. 4, 1998).

Expanding the institutional perspective on population health

PIET BRACKE

In social epidemiology and in public health research an individualistic bias prevails, even when focusing on health inequalities. Income, education, social class, ethnicity, and gender are often considered to be social characteristics of individuals instead of indicators of broader institutional contexts and processes that affect population health. The latter have been the realm of health sociology for some decades, and, recently, important contributions to the development of an institutional perspective attest to this enduring sociological gaze. These contributions on social transformation and population health mainly focus on health care systems or welfare regimes, and on social inequalities in health.

I argue for a more thoroughgoing "institutional turn" in the sociology of health to further develop a macro-sociology of health and illness. An institutional perspective should not only include social institutions directly related to health and welfare policy, nor should it focus solely on health inequalities.

The potential of a broader institutional approach to population health is illustrated with reference to public health issues characteristic for the latter stage of the epidemiological transition: mental health, and preventive behaviour. We hope to illustrate how the diverse associations, across time and space, between these public health issues, and education, gender, and age as institutions, reflect the enduring impact of social transformations on population health.



Piet Bracke (°1961) is a full professor at the department of sociology of Ghent University, Belgium. He focuses on population health and health services use from an institutional perspective. Core research themes are mental health, stigma, professional care seeking, medicalization, and preventive behaviour. Presently, his research group focuses on mental health and the Covid19 pandemic, on stigma, professional care seeking and ethnicity, on medicalization theory and medication use, and on vaccination hesitancy from a cross-national comparative perspective. Piet Bracke is a former president of the ESHMS (2010-2014).

Special Session: What do we know about COVID-19 pandemic so far?

Organized by: Maria Świątkiewicz-Mośny (Institute of Sociology, Jagiellonian University)

The COVID-19 Social Monitor – Monitoring the Social and Public Health Impact of the Pandemic

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The COVID-19 pandemic challenges society in an unknown way and people experience a substantial change of their daily lives and activities. The COVID-19 Social Monitor (www.zhaw.ch/wig/covid-social-monitor) is a population-based online panel survey which aims to inform the public, authorities, and the scientific community, and to produce evidence for research purposes about changes in population health and behaviour during the COVID-19 pandemic. Starting in the second week of the “lockdown”, we regularly survey 2,000 representatively selected participants in the three language regions of Switzerland and assess several established indicators of well-being, physical and mental health, activities, health care, employment, and health behavior. Based on detailed information about the impact of the pandemic and its containment measures on the population, problems can be identified early and understood better. In the presentation we show how this extraordinary situation affected psychological well-being, social isolation and loneliness, the non-take-up of health services, work productivity, and how the subjectively perceived risk of suffering of severe COVID-19-related illness varied by regions and over time.

The impact of the COVID-19 pandemic on social vulnerabilities. A research in Lombardy

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The research I propose is part of a broader project of the Italian Society of Sociology of Health about "The impact of the COVID-19 pandemic on social vulnerabilities", and it involves various local and regional Italian bodies. It deals of a quanti-qualitative research that investigates the impact of the Covid-19 pandemic and restrictive measures and lockdown on social vulnerabilities (migrants, indigent, homeless, poor the disabled, LGBT) in Lombardy, the most affected region by mortality and morbidity caused by COVID-19: half of the infections and deaths of Italy are in Lombardy.

My part of this research focuses on some cities (Milan, Brescia, Cremona, Mantua, Pavia) by carrying out ten in-depth interviews aimed at stakeholders of local institutions and the non-profit sector. The topics covered concern: the impact of Covid-19 on the lives and relationships of assisted persons and socio-health workers; the reorganization of services and local policies; the future prospects and change.

Some results

About Covid-19 and vulnerable people the following problems and needs are highlighted:

The multifactorial poverty: work-income; home; school-education; relationships;

Families and single/alone people: requests for help are quintupled (especially food) in the suburbs of the cities;

Invisible and excluded people as irregular migrants, homeless, sex-workers, victims of trafficking, do not have the right to access the benefits allocated by local and national authorities to deal with the coronavirus;

Relationships: Isolation and intensification of social and personal conditions of vulnerable people;

Escalation of conflicts and domestic and gender violence due to the lockdown;

Fear of the "other" as possible contagious. Social distancing is difficult in contexts of usual social proximity (suburbs, neighbourhoods and crowded homes);

Great difficulty for the most fragile families to allow their children to continue school and educational activities due to the lack of personal tools and electronic devices.

With regard to the reorganization of services and local policies, the following emerges:

- a significant activation of local policies and social services in close cooperation with the non-profit sector and a strong and consolidated network of services;
- activation of different tools in multiple languages in order to widespread information on the infection and measures of protection;
- psychological, alimentary, economic support to vulnerable people;
- training courses aimed to social and medical workers and professional;
- educational support (tablets, on-line meetings and lessons, etc.) to children and students;
- accommodation for homeless people: 2000 in Milan;
- spontaneous organization of solidarity among assisted people, social workers and medical professional, civil society.

None of the interviewees look to post-COVID time with confidence and serenity. There is uncertainty and fear towards "a world that has changed and for which we are not prepared". They fear worsening poverty and inequality and rising unemployment. They complain about the uncertainty and contradictory messages coming from national and European institutions. At the same time, the interviewees hope not to lose the skills and knowledge acquired during the lockdown; to enhance the tools and operating methods created and tested; to consolidate the collaborations and good practices activated during the period.

The scarcity of resources during SARS-CoV-2 1st wave and the postpone of elective surgery during the lock down: the general surgeons troubled decision making

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General surgeons are human resources of health institutions who have to practice a code of ethics whose *leges artis* can be affected by scarcity of different types of resources that are not within their reach to solve, as it depends on guidelines established from higher levels, namely their administrations. The SAR-COV2 virus that induced the closure of operating theaters between March and June 2020 and the cancellation of thousands of scheduled surgeries, have impacted on the surgeons professional lives and limited their decision making concerning the best options for their patients. The most critical impact was to find themselves as useless physicians, as they were limited to observe the consequences of not treating critically ill patients on fast growing waiting lists and struggling with the shortages of personal protective equipment (Vlessides, 2020), in a time when it was “important to ensure the ability of surgeons and specialized professionals to function through the pandemic” (Coccolini *et al.*, 2020).

There are rare ethnographic and autoethnographic studies in health institutions that provide knowledge about the difficulties experienced by health professionals in Portugal, due to the diversity of objects and systems complexity, which do not facilitate research in this area (Carapinheiro, 2005). So, “the best way to understand what healthcare professionals are most concerned about is to ask” (Shanafelt, 2020) and to be on their field. This article is based on the elaboration of 40 interviews with general surgeons and field diaries based on operating rooms from five hospitals carried out between March 13th and July 9th, 2020, which approach the problems and concerns regarding the treatment of their patients they dealt with in the most critical period of the pandemic, the conditions in which they had to exercise their work and its relationship with their families.

Session 1: Social, political and scientific controversies about vaccines and immunization policies

Organized by Giampietro Gobo (University of Milan) & Barbara Sena (Unitelma Sapienza University of Rome).

Understanding Vaccine Hesitancy as a Set of Extended Attitudes

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The theoretical objective of this paper is to document vaccine-hesitancy as an extended attitude, at the intersection of individual and structural mechanisms. The empirical objective is to identify a typology of vaccine-hesitant attitudes towards vaccination, starting from the conceptualization of vaccine hesitancy as a set of positions located between complete acceptance of vaccination and complete rejection of vaccination. Drawing on the theoretical understanding of risk and science skepticism in post-modern societies, I consider hesitant attitudes towards vaccination as addressing risks that are induced in our everyday lives by science developments. I conducted K-Means Cluster Analysis on Eurobarometer data from 2019 regarding Europeans' attitudes towards vaccination. According to my results, vaccine hesitancy is an extended attitude, a property of socio-economic and expert systems that generate everyday settings for individuals. I identified four clusters of vaccine-hesitant attitudes. Price hesitation and Effort hesitation are attitudes that result from restricted access to vaccination because of structural constraints, such as low economic capital and healthcare system's deficits. Unexercised pro-vaccination is an attitude manifested by people who grant authority to science and experts to manage health-related risks, even though they did not vaccinate in the last five years. Hardcore anti-vaccination pertains to highly reflexive individuals who dismiss experts' authority because of scientifically derived risks.

Session 2: The social construction of autism

Organized by Alice Scavarda (University of Turin) & Angela Genova (Università Carlo Bo, Urbino)

Neurodiversity movements in cultural and historical context

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The term neurodiversity was coined by Judy Singer in the 1990s, in Australia, as a shorthand for neurological diversity and a description of an empowerment model for autistic and otherwise “neurodivergent” people. As a social movement, neurodiversity spread first in the United States, United Kingdom, and the Netherlands, and is being increasingly recognized worldwide. Neurodiversity movements encompass a diversity of people and perspectives, and autism-related social movements engage with neurodiversity ideas in a variety of ways, prompting many debates about what neurodiversity is and what it means. Drawing on a review of published qualitative research conducted around the world and the author’s own ethnographic research in Italy and the United States, this presentation will unpack the ways that neurodiversity movements contribute to the construction of the contested category of autism. It argues that, although the basic proposition of the neurodiversity concept are universal, the specific language and rhetoric of neurodiversity is more appealing in some contexts than others due to differences in biopolitics, including both understandings of the relationship between body and self and between self and state. Notably, these variations cannot be explained by associating neurodiversity only with Asperger’s, lower levels of support needs, or an anti-support perspective, because indeed many neurodiversity movements include and address people with high levels of support needs. This presentation will conclude with comments on neurodiversity in the context of diagnostic classification changes away from the language of Asperger’s, and include directions for future research.

Autism self-advocacy movement. Case of Poland

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In 1998 the Australian Sociologist Judy Singer described emerging conviction that neurological syndromes like autism are not form of pathology but variant and valuable forms of cognitive differences. Due to that it requires rather acceptance and accommodation than treatment. The Autreat and the rise of this movement was described by Steve Silberman in his book “NeuroTribes: The Legacy of Autism Neurodiversity” in 2015. Polish translation of this book has been published in 2017. Gradually increasing popularity of the term Neurodiversity in such countries as Australia, Great Britain, Scotland and United States is connected with tendency to use a notion Autism Spectrum Condition instead of Autism Spectrum Disorder. The Autistics community prefer the first term because it define Autism as a developmental pattern. This way of thinking is less stigmatizing then the second one. However in Poland medicians and therapists get used to describe autistic traits with the term Autism Spectrum Disorder which is connected with tendency that Autistic have no right to be their-self and should learn how to behave like those who are no autistic. In our research we concentrate on qualitative analyzes of online activity of polish Autistics. We treat blogs of people with ASD, who are connected with Self-Advocacy movement as diaries. In our area of interest are such issues as: Who publishes in Self - Advocacy (people with what specific symptoms of autism spectrum)? What content are published and how? Do Autistics create self-awareness majority, similar to the majority of deaf people? How Autistics define their self? Is there specific polish autism self-advocacy movement? What is the purpose of this movement and how it is realized? Is idea of defining autism as a variant and valuable forms of cognitive differences common among poles with autistic traits who are involved in self-advocacy

movement? What kind of social construction of autism are common among individuals involved in autism self-advocacy movement in Poland? Are we dealing with the emancipation of autistic people? Qualitative analysis was carried out using the QDA MINER program. Preliminary results are interesting but need validation on a larger research group.

Health got graphic! The role of Graphic Medicine in understanding autism

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In the last two decades, comics and graphic novels have been increasingly used in academic research, giving birth to a set of theoretical and methodological approaches included in the so-called Arts-based research. One example is Graphic Medicine, namely the use of comics as a medium to analyse and communicate healthcare issues, around which a community of academics, health care professionals, authors and artists is growing internationally.

People with autism can benefit from Graphic Medicine in a wide variety of ways. Health-related comics dealing with this topic may help patients and caregivers to adjust to their situation, as well as to overcome the stigma related to it. Both the refusal to acknowledge autism (e. g. “you’re lazy”) or the assumption of stereotypes derived from media representations (e.g. “you can’t be autistic if you’re bad at math”) may be challenged by the graphic accounts of living experiences with autism. The purpose of this study was to explore if the use of three selected autobiographical graphic novels would help to understand this condition with visual cues and emotions.

Our analysis highlights the potential of graphic novel as a powerful tool in raising awareness both for those who have no experience with autism and for patients and families by offering the possibility of visualizing other people in similar situations. Lastly, the visual aids accompanying the storyline serve as an engine of reading comprehensively.

Session 3: Making sense of gender and age in the lived experience of chronic illness

Organized by Catarina Delaunay (CICS.NOVA) & Ana Patrícia Hilário (Instituto de Ciências, Universidade de Lisboa)

The body troubled: how chronic illness questions the age and gender categorizations

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Social categorizations of age and gender enable society to order, hierarchy, and make intelligible the transformations of the body, their fluidity and diversity. Chronic disease acts as a lens of these social processes of stabilization and normalization, mostly legitimated by medicine and other institutions. Sick children having to behave “like adults”, degenerative processes that “bring old people back to childhood” or that force adults to “act like the seniors”. These forms of desynchronization and cleavage between body, age and status are particularly interesting for analysing these categorizations and denaturalizing them. Based on an anthropological research carried out in France, our presentation questions how a chromosome anomaly may reframe the childhood/adulthood boundaries and the gender positions. We explore the experience of growing-up of women and girls having a Turner syndrome. This syndrome is due to the partial or complete lack of one of two X-chromosomes, and its most frequent symptoms are small size, malfunction of the ovaries, failure to develop during puberty and other related pathologies. The presentation shows how this process of growing-up with Turner syndrome is embedded in a temporal perspective affecting bodily experience: the cut temporality of the syndrome itself; the rhythms of growth, often medicalized through hormones, which do not correspond to social and medical standards (i.e. size or puberty); the long term of filiation disrupted by partial or total infertility. These three temporal dimensions give rise to

experiences of subordination and liminality, due to the cleavages between bodily condition, age and gender categories, and social status. They also reveal the normativity of these social categorizations in contemporary French society.

“You eat like a girl!”: men, masculinities and chronic illness

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There has been a growing interest in the study of masculinity and its intersection with health, and this work adds to this literature by focusing on men's accounts of autoimmune diabetes. For many researches, the starting point has been men's disadvantage in health, a trend that has been explained with the thesis that “masculinity is bad for men's health” which implies that men engage in “unhealthy” practices in order to demonstrate masculinity. More recently, critical perspectives on the study of men's health have challenged such assumption and this work aimed to further problematize masculinity in relation to health and illness. Diabetes has been selected as a case study because it is a chronic condition that has an impact on everyday practices that are deemed as important for masculinity construction but, unlike other health conditions, it might leave some room for compensatory practices. This work is based on 40 in-depth interviews conducted with young/adult diabetic men from working/middle class backgrounds. The main result of the study is that health and gender might intersect in complex ways and that men might respond to the emasculating threat posed by illness not only by engaging in “unhealthy” practices. From the analysis of the empirical material it emerged that men can re-signify and embody health practices in order to fulfil or redefine dominant ideals of masculinity. More specifically, three different modes of understanding and self-disciplining diabetic male bodies have been identified and will be discussed: the “Diabetic Quantified Self,” the “Athlete,” and the “Free Spirit.”

Dealing with uncertainty in end-of-life care: how healthcare professionals manage discord in palliative care for the elder

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In our talk, we will develop a sociological analysis of the role played by professional management of information about elder patients' end-of-life (EoL) processes in palliative care (PC). We will thus highlight the processes by which PC professionals, in Portugal, manage health information about elder patients in the frame of this type of care. Our analysis relies on data collected through two research projects on PC, both funded by the Portuguese Science and Technology Foundation (FCT), namely data collected in five Portuguese hospitals through an in-depth qualitative approach to the field, based upon interviews to professionals and ethnographic observation. We will present some of the findings in the frame of these projects, namely (i) how managing information about prospective EoL trajectories of aged citizens by healthcare professionals is one of the major challenges in their daily work in PC wards; (ii) how, in these contexts, older patients and their families and members of the healthcare teams tend to have different experiential and personal careers in their relation with disease, the organisation of care and EoL trajectories, whose confrontation at the level of interaction produces complex effects in social processes that occur in daily activity contexts of PC; (iii) the manner through which this tends to engage professionals in actions which are meant to reduce uncertainty and appease disquietude and discord around situations of EoL care.

When age masks and normalizes gender. A sociological approach of personalised care for adolescents and young adults with cancer in France.

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Since the early 1990s, specific programs have been developed to care for teenagers and young adults (“TYA”) with cancer. These dedicated units pursue a dual objective. On the one hand, it is the purpose of making paediatric and adult medicine collaborate in order to propose the treatments that are best adapted not to the age, but to the type of tumour. On the other hand, the support aims to ensure that young people can have a "normal" adolescence in spite of the disease. This paper questions the role played by this normalization of adolescence on the references and practices related to gender in the cancer care of TYA.

The results presented are based on a Phd in sociology conducted at the École des Hautes Études en Sciences Sociales de Paris (under the direction of Philippe Bataille, funded by the Institut National du Cancer). The data was collected during a two years field ethnography in France and England, composed of observations and 50 semi-directive interviews with young patients and professionals. Firstly, these results demonstrate that representations of age make social relationships of race, class and gender invisible inside the services. Then, the communication shows that gender stereotypes are used by professionals to promote the normalization of adolescence (gender workshops, diet, weight, self-presentation, social relationships and sexuality).

Session 4: Chronic illnesses and media: resources, opportunities and online representation

Organized by Andrea Volterrani (University of Rome Tor Vergata) & Angelica Spampinato (University of Rome Tor Vergata)

Online Health Communities and healthcare: between ‘experiential lay expertise’ and social inequalities

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This research, conducted in Italy in 2018, investigated the role of Online Health Communities (OHCs) that address diabetes in supplying and forging health related information to their members. The study was based on 14 semi-structured interviews with Italian OHC administrators, as they were seen to be key actors in this field.

Findings showed that OHCs helped bridge the informational inadequacy that people usually experience with healthcare institutions and professionals, mainly due to lack of time. Indeed, OHCs offer members peer-to-peer expertise which encompasses many tips that are useful to self-manage their conditions (about therapeutic devices, or the management of hypo/hyper-glycaemia, etc.), as well as emotional support.

Findings can be read through Bandura’s social learning theory (1977), by which people can learn by observing other people’s behaviour. Also, socio-material perspectives are useful, in highlighting the specific human-not-human assemblages that exist between members and OHCs, and the relational connections and affective forces that emerge in these assemblages, in which lay knowledge and expertise are created and framed.

However, the unsatisfactory institutional patterns of information, as mentioned above, which was highlighted by the feeling of abandonment and bewilderment reported, also led this ‘experiential lay

expertise’ to individualistic approaches and concerns of potential inequalities, due to social determinants (digital divide among them), informational asymmetry, different individual preferences and different degrees of health literacy and agency.

This helps to understand that the ‘experiential lay expertise’ allowed by OHCs must be studied within the wider healthcare context in order to understand whether they produce desired health outcomes rather than widening social inequalities.

Filling in the gaps: the role of social media in diabetes management

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Recent studies show that there is a growing trend of using social media in the process of chronic care management (Li 2013; Pousti, Urquhart & Linger 2014; Isika, Mendoza & Bosua 2016), transforming it from clinical practice to a more community-based activity (Eysenbach 2008, O’Connor 2010). By building the sense of community, providing emotional support, contributing to patients’ and carers’ empowerment, providing information (Pousti, Urquhart & Linger 2014; Patel et al 2015), social media often fill in the gaps in public policy in the areas of health education and information, as well as professional support. Moreover, there is a growing body of literature reporting the effects of using social media on patients’ behaviour and clinical parameters (Gabarron, %u0139rsand & Wynn 2018). In Poland, however, there were few attempts of scrutinising this topic. Gawel *et al* established that new technologies like social platforms simplify treatment and aid patients in daily diabetic control (2018), also being a source of medical knowledge about the illness, replacing insufficient support from the therapeutic personnel (Nowakowska, Lewartsowska-Zychowicz 2018). This paper aims at determining the roles of social media in chronic disease management among Polish patients, focusing on diabetes, which is one of the most prevalent chronic diseases. The study takes a qualitative case study approach. The data was collected from social media sources, i.e. Facebook and Instagram,

which are the most popular social media platforms in Poland, and encompassed content analysis of discussion groups, fan pages and accounts that raise the issues related to diabetes.

Living with a psychiatric diagnosis - media representation of a prospective thinking about mental disorders

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The dominant convictions about mental illnesses determine a highly stigmatizing context for afflicted individuals to recover and for family caregivers to provide support. An available body of research shows that the content of public discourse on mental health is crucial for positive coping with challenges connected to the therapeutic process to individuals with mental disorders and their relatives. Our initial inquiries suggest that social meanings attributed to psychiatric diagnosis in public discourse in Poland are inconsistent and range from those suggesting incurability through those relativizing illness to those giving hope for a full recovery. We applied Critical Discourse Analysis to analyse leading Polish newspapers and magazines to reconstruct the scenarios and prospects of living with a mental illness, such as schizophrenia or affective disorders, which media reproduce.

Engagement and empowerment in chronic diseases: the role of social media

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Social media have completely changed the way of communicating and relating to the world (Boccia Artieri 2012) and this has had a strong impact also on health (Moorhead, Hazlett, Harrison, Carroll, Irwin, Hoving 2013). Major changes have been observed in many aspects especially in chronic disease: patient-doctor communication, common sense knowledge around diseases, and how to relate to disease and treatment processes. More generally, the way of representing social reality, its mediated construction (Couldry and Hepp, 2017), has changed and the relationship between citizens and health workers has also modified itself (Antheunis M.L., Tates K., Theodoor E.Nieboerb T., 2013). Internet for example, explains the Diabetes Web Observatory, confirms itself as a primary source of information for people with diabetes, and shows how important online communities are for these patients: Half of respondents use the web and social media to confront other patients.

The objective of our research is to understand how social networks can be useful to those who are affected by chronic diseases, not only to create new social networks (Volterrani 2017) but also to improve the way of living the disease and everyday life. In order to do so, the posts and websites of hospitals and patient organisations will be analysed.

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Session 5: Disability in the medical and social perspective

Organized by Dorota Żuchowska-Skiba (AGH Univesity of Science and Technology) & Jakub Niedbalski (University of Lodz) & Mariola Raclaw (University of Warsaw)

Social vs Medical? - Disability Models in Polish Public Discourse

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The ratification of the UN Convention on the Rights of Persons with Disabilities by Poland in 2012 resulted in a change in the definition of disability. Disability has stopped to be defined in terms of individual - medical, and began to be perceived by the social prism as the effect of barriers in the social and cultural environment of people with disabilities. The signing of the Convention obliged Polish legislation to make adjustments to laws, regulations and other legal acts in order to remove provisions that prevent social inclusion in this category of persons. As a result of the implementation of the Convention into the Polish legal system and social policy assumptions, there has been a change in the language describing disability. Over the past eight years, many terms that have been negative and stigmatizing have disappeared from public discourse. The term disabled person has replaced the terms commonly used in the 20th century: invalid, cripple, disabled. As a result of the adoption of the Convention, the concept of disability and disability model have also changed. At the declarative level, disability began to have a social rather than a biological (medical) phenomenon in contemporary Poland. These changes are noticeable, however, many aspects of the functioning of people with disabilities are still embedded in the medical model of disability, e.g. disability certification system. This makes it necessary to investigate whether the declared social model of defining disability translates into the functioning social policy model and social practices that result from applicable legal acts and public programs targeted at this category of people.

The main goal of our speech will be the analysis of public discourse in Poland carried out by means of quantitative content analysis. It will cover, among others, applicable legal acts regulating the functioning of people with disabilities in Poland and public programs targeted at people with disabilities implemented at the central level over the last eight years. This will show the changes in the ways of perceiving and defining disability that have occurred as a result of the provisions of the UN Convention on the Rights of Persons with Disabilities, thanks to which it will be possible to reconstruct and present the current model of disability in contemporary Poland.

Evaluation of the personal health budget programme: experiences and outcomes at two years

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The present paper draws from the experience gained with the project "Social Inclusion and Disability: experimentation paths for the Health Budget" (L-inc), that aims to enhance the direct participation of people with disabilities in the decision-making processes that concern their health and healthcare, through a person-centred care and a personalization of the allocation of economic resources that are designed around their desires and needs expressed in their life projects.

L-inc is a pilot project operating in the Nord of Milan that aims to contribute to the development of a more personalised healthcare in Italy. Personal Health Budgets have been adopted in Holland in 1995 and in England in 2007 (Kremer 2006; Williams et.al. 2014) but it has also been piloted in a number of regions in Italy - Friuli Venezia Giulia and Campania in particular – where this experience was conducted in line with the deinstitutionalization practices that have been realised after the Basaglia law (Starace, 2011).

The methods used in order to achieve this objective imply the ongoing evaluation of the programme, with the aim of examining the realisation of the planned activities and the impact of personal health

budget on the quality of life of the budget holders and on the work of the social actors involved (relatives, healthcare services and community), that might be of support or hinder the health budget process. The results obtained to date suggest a positive outcome of the healthcare personalisation processes, although some critical elements will be addressed during the presentation.

Disability and government in a philosophical perspective

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Disability is a phenomenon that we can consider from different perspectives. I suggest tracing the history of perception of disability with an indication of the perceptions of this phenomenon that dominate in a given period of time. The analysis of changes will be carried out in terms of philosophy, with particular emphasis on the knowledge developed by Michel Foucault. His knowledge in area of government, body, disability and change will be treated as a skeleton to which models of disability will be overwritten. In particular the medical, social disability model and biodiversity model. This review and analysis are to lead to a place where the view on the model of biodiversity will be presented as an opportunity to escape from leadership and exercising government over disabled bodies. The last part of the speech will also present an analysis of the theoretical situation of lack of government in relations between people with disabilities and other members of society.

The relevance of the applied research method for changes in the perception of people with intellectual disability

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Research with the participation of people with intellectual disability (ID) is a challenge for a researcher guided by the emancipatory paradigm. Respect for subjectivity, independence, and self-determination of people with ID is important for the social and civic inclusion of this group. Modern researchers not only provide reliable scientific knowledge but also have the educational task of shaping the image of the examined group in society. Academic activities are therefore an important element in shaping the social perception of people with disabilities. One of the rarely used research methods in Poland is the Photovoice method. It can be classified as participatory research, which strengthens subjectivity and develops the social awareness of the respondents. Thus, it often contributes to a change in the functioning of groups that experience exclusion or discrimination. The respondents become active subjects in the process of generating the image of their community and direct activists in the course of changes. Booth and Booth (2003) noted that the unique features of Photovoice make it particularly suitable for use with people with ID. The combination of the photographic and voice elements of the methodology allows for the participation by people with ID who may lack verbal fluency. However, this method is not free of difficulties and ethical dilemmas. As an example, I will present my own research using the Photovoice method concerning the subjective image of the life of women with intellectual disabilities as mothers.

Personal Assistants of Persons with Disabilities – new opportunities leading to new inequalities?

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The aim of the paper is to explore the impact of introducing Personal Assistants as a support measure for people with disabilities, in relation to inequalities that have arisen alongside the solution. It is based on the analysis of relevant literature dealing with Personal Assistance in Norway and in Poland. In our analyzes, we refer to the "paradox of unintended consequences", a phenomenon described in classical sociological theory (e.g. M. Weber, R. Merton) and present in contemporary sociology (cf. A. Mica). Preliminary analysis suggests that while the implementation of Personal Assistance reduces social exclusion of people with disabilities, it may lead to persistent social inequalities affecting personal assistants, and paradoxically people with disabilities. This is the unintended consequence of the way the service is organised and implemented.

The existing system in Norway is based on the municipal level. Differences between municipalities mean difference in access to Personal Assistance between inhabitants of different municipalities despite the fact that Personal Assistance is a citizen right. In Poland up till now the majority of Personal Assistant services were provided by NGOs via various time-limited projects distributed unevenly throughout the country and leading to precarious working conditions. The solution being implemented now is to be municipality based. Pressures on from Activists with Disability to de-professionalise and de-institutionalise the service (Norway) low pay associated with the profession, and the fact that personal assistants often already belong to groups subject to various forms of exclusion (immigrants, women, long term unemployed, etc) appear to deepen social inequalities.

Session 6: Undesirable consequences of increasing non-expert agency in the neoliberal health care system

Organized by Kadi Lubi, (Health Education Center) & Marko Uibu (University of Tartu)

Patient empowerment or “sick role”? How Italian Breast Unit Care Pathway changes patients and healthcare professionals’ agency.

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Aims

This study explored patients' and professionals' respective roles and care pathways perceptions in an Italian Breast Unit (BU), in order to discuss BU's care pathway support to patient engagement and person-centred care model.

Research Methods

Qualitative methodology supported by different data collection and qualitative tools such as: BU activities observation (ward meetings and professionals practice), official document collection and in-depth interviews. Patients (N = 14) and professionals (N = 15) interviews were analysed using qualitative content analysis approach.

Findings

This study showed that although interprofessional collaboration and patient-centred approach are fundamental in healthcare pathways, the BU patients' caring pathway management had still a mono-professional physician imprint. Patients showed a passive agency, whereas healthcare professionals demonstrated lack of role awareness. Therefore, the patient-centred care pathway process, wherein healthcare team should support patient's engagement (Lee&Lin, 2010), basically clashed with a model of care, still influenced by traditional doctor-patient relationship. The study highlighted that BU patients' behaviors are still resembling of Parsons' sick-role (1951) rather than to a patients' empowerment promoting model, like in chronic disease cases (Varul, 2010). Lastly, the lack of

implemented specialist nurses and psychologist active roles within BUs caring pathway did not facilitate interprofessional collaboration or attenuate patient-doctor relational exclusiveness. This research suggested that Parsons' sick role model is still present in patient-centred healthcare pathways. So, it is required to "rethink" the doctor/professional-patient relationship in order to improve patients' agency; furthermore, a cultural change is required not just to patient but also to healthcare actors and health organisation.

Integrating genomic information into patient decision-making for early breast cancer: Sense-making, responsibility and choice

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The UK NHS has seen significant investment into genomic techniques to predict disease and personalise treatment. This is particularly evident within oncology, where genomic approaches are increasingly mobilised within care pathways to guide treatment decisions, and tailor clinical interventions to individual cancer types. These shifts in the delivery of cancer care, involving complex technologies, data and analysis, coincide with a widening emphasis on patient choice in healthcare (Mol, 2008).

The drive to personalise cancer care makes unique demands on patients, who must invoke and make sense of these novel approaches to make what can often be perceived as the 'right' decision about their treatment (Charles et al, 1998). These weighty decisions for patients involve feelings of responsibility towards clinicians, their families and future selves.

In this presentation, we draw on qualitative interviews with 19 patients, exploring their engagement with a genomic technique (Oncotype DX) adopted within the NHS to guide chemotherapy decision-

making for some early breast cancers. This research aimed to consider how the roles and responsibilities of patients are shifting as genomic medicine reportedly ‘revolutionises’ healthcare. We show how recommendations based on genomic information are interpreted and integrated into individual patient treatment decisions. This occurs alongside a constellation of wider factors, including disease histories, caring responsibilities and fears about cancer and its treatment. We explore some of the demands made on patients by the integration of this technology into care pathways, and how personal interpretations of *Oncotype DX* resonate with societal discourses of excitement and promise for genomic medicine.

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Unworthy Self: Deficits of Agency in Healthkeeping Practices Among Russians Back to the Institutionalized Discounting of Human Life

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As a canon of market society (Sandel 2013) neoliberalism prescribes autonomous individuals to treat their health as a market asset and to care about it out of their agency and with all self-discipline and responsibility. When this expectation meets preventive and patient-centered public medicine one not only reduces budget expenses on healthcare but provides society with health as a political good, both individual and collective. However, this ideal type is quite far from the empirical practice, especially when it touches upon countries with unmaturing market economies. For instance, people in Russia are suffering from so called “investor myopia”: they are inclined to waste their health on short term life achievements instead investing in it and keeping for the future. Health as a guarantee of life in the

future turns out to be discounted as a human resource. Some studies of self-care in Russia argue that Russian patients are lack of agency in health keeping practices and explain the fact by the Russia's paternalistic past. Promotion of personal health responsibility led to undesired absenteeism of selfcare as an ability to be free from paternalistic supervision. Similar outcomes are probable for other post-soviet European countries and states with a high degree of healthcare support.

On the data from Russian Longitudinal Monitoring Survey (RLMS), conducted (by National Research University Higher School of Economics) in 1994-2018, the study analyzes the structure of selfcare practices of Russians and estimates the motivation to care on one's own health among different socio-demographic groups. The results indicate higher rates of investments in individual capitals including health among families with children and young millenials (Radaev, 2020). Quantitatively observed trends are additionally interpreted with the data of 57 in-depth interviews on the self-care meanings, drivers and practices, gathered and processed along with the methodology of grounded theory. The study seeks to suggest an alternative explanation to the low interest of people in Russia to own-self-care. It poses the problem of health care practices in Russia in the realm of discounted value of individual life institutionalized in Russia and projected on the individual subjectivity. Such an approach highlights that the deficits of agency in health keeping practices are anchored in the cultural mindscape that prevents Russians from spending time, money and attention on "unworthy self".

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Crowdsourcing in medicine in the neoliberal era

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The presentation develops an analysis of the emergence of crowdsourcing in medicine in the neoliberal era. There seems to be two lines along which this phenomenon is developing: there are the bottom-up projects initiated by non-institutional actors such as patients, their families, or ordinary citizens; in contrast are the top-down initiatives promoted by an institutional matrix composed of government agencies, universities, for-profit organizations or private social services. While the former is basically directed to the improvement of care and the sharing of experiences and information, the latter headed towards scientific research. The hypothesis we're going to discuss is that each of these manifestations of crowdsourcing in medicine can be read as indicators of the impact that the neoliberal ethos has had and keeps on having on the therapeutic relationship and the practice of scientific research. On one hand, the bottom-up versions of the crowdsourcing approach can be read as a consequence of the lack of trust towards expert knowledges which is implied in the neoliberal dogma of competition. On the other, the top-down trends reveal the secret desire of neoliberal powers to surveil social dynamics through objective data.

Session 7: Health inequalities among the elderly: differences in morbidity, autonomy and quality of life

Organized by Höglinger Marc (Zürich University of Applied Sciences) & Carlander Maria (Winterthur Institute of Health Economics)

Determinants of neglect and self-neglect in Polish community-dwelling older adults

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Neglect and self-neglect are important medical and social problems which are frequently unrecognized or unreported even if each of this phenomena is perceived as the most prevalent type of mistreatment in older age.

The aim of the study was to verify the role of socioeconomic and health status, living arrangement, health damage behaviors, social network (structure, social ties), social support and feeling of loneliness. Special attention has been paid to other forms of abuse (physical, emotional, financial) reported by older people.

The cross-sectional study *Elder neglect and self-neglect* was conducted in Lesser Poland in 2017. Analysis was based on 1635 face-to-face interviews performed among randomly selected individuals from general population .

For the purpose of presented study special instruments have been developed. *Self-Reported Neglect Scale (SRNS)* represented by 12 items considering basic physiological and safety needs and psychological needs. There were three self-neglect scales considered, a subjective and two objective measures related to physical appearance and standards of living arrangements.

The results of structural equation model showed that the strongest direct effect on neglect was observed for abuse then for poor social network and depression. Among others significant determinants of neglect not being married or in partnership and number of geriatric syndromes was found. The strongest predictors of self-neglect were number of geriatric symptoms, poor social network and feeling of loneliness; it means that both medical and social factors are associated with the neglect and self-neglect.

May I go home? Impact of social determinants on admission to a nursing home after hospital discharge of elderly in patients with chronic conditions.

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Aims: Autonomy is an important aspect of quality of life in old age. Most people in Switzerland wish to live and even die in their own home. After hospitalisation the question often arises, whether elderly patients may go home or have to move to a nursing home. The aim of this analysis is to clarify which social factors influence the risk of being admitted to a nursing home after a hospital stay due to chronic diseases.

Research method: The SIHOS-study combined for the first time in Switzerland existing anonymous national inpatient and census data by record linkage. Multivariate logistic regression models included

indicators for social gradient (education), lack of social support (living alone) and a proxy for financial resources (insurance class). Models controlled for sex, age, nationality, year of hospitalisation, severity of illness (Elixhauser index) and mental comorbidity (N=36'427).

Findings. The risk for admission to a nursing home after hospital discharge e.g. due to coronary heart disease was not associated with education but with financial resources: patients with low (OR 1.49, 95% CI: 1.21-1.83) or medium insurance class (OR 1.39, 95% CI: 1.10-1.74) had a significant higher risk compared to highest insurance class. Also living alone increased the risk (OR 1.77, 95% CI: 1.55-2.02) compared to living with others.

Discussion. Returning home after hospitalisation is depending on the social situation of elderly patients in Switzerland. Living alone and low financial resources restrict both the access to the required support at home. Our findings suggest that the health system should provide adequate support for vulnerable patients, thus increasing health equity.

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Informal support of older immigrants in Germany: between self-responsibility and opportunities for healthy ageing

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While immigrants generally seem to be in better health compared to the host population after migration, older immigrant populations experience more health risks compared to the non-migrant elderly. This is caused by cumulative risks throughout the life course due to lower socioeconomic status, harmful working conditions and insecurity. Social networks and informal support are discussed as a major potential of older migrants for healthy ageing in the gerontological literature. This paper investigates the social constructions of informal and public opportunities and challenges of older immigrants in Germany. Policy reports, guidelines and handbooks on ageing and migration

from 2000 to 2019 (42 documents in total) were analysed, following a sociology of knowledge approach to discourse (Keller 2011). Results show that besides public initiatives concerning care, health promotion and social services, informal solutions through social networks are frequently emphasised. Thereby, self-responsibility of older immigrants becomes an essential aspect of reducing health inequalities among the elderly. Self-support and care within the family, however, can put additional stress on family members in lower socioeconomic living situations. The resources of older immigrants such as social support should be valued and supported. Yet, the burden of self-responsibility and care within families deserves increased recognition in order to improve the chances of reducing health inequalities in older age and to strengthen the resources for healthy ageing.

Inequalities in dementia care. Different access to government and community-based resources and its consequences

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Dementia is a democratic disease. No one is immune. Regardless of gender, social class or education everyone has a certain chance to develop the disease. The main risk factor is age. People who belong to higher status live longer, but it does not mean lower status people are not affected in large quantities. Part of the explanation related to heart and vascular system diseases which are also marked as risk factors of dementia (Ramsey, 2017). Resultantly, the last 10-15 years of the average European is spent dealing with a chronic disease, a growing proportion of which, is expected to be dementia. The clinical course of the disease can be more than a decade. Memory declines, spatial and temporal disorientation is also common. Mood swings, as well as conspicuous behavioral changes can arise. The disease goes hand in hand with the gradual loss of self-sufficiency, which is precisely why, individuals with dementia will increasingly depend on informal caregivers / family members. Exclusion is common, which results in hiding on the part of both patients, and their respective caregivers. According to our research program, carried out in

2019 with focus groups of informal caregivers, higher status families have access both government funded resources and community-based programs. It is important to point out that it is not just about financial condition, but relations. On the other hand, lower status families have no access to external support, which means, patients here have much less chance for adequate care, autonomy and quality of life.

Session 8: Incorporating the One Health approach into health care organizations: how does it work?

Organized by Giacomo Balduzzi (University of Eastern Piedmont) & Francesca Zaltron (University of Eastern Piedmont) & Anna Rosa Favretto (University of Eastern Piedmont)

Session 9: Reform policies of European health care systems among state, market and civil society

Organized by Guido Giarelli (University 'Magna Græcia')

Opinions of Polish medical students on the possibility of introducing a sunshine law in Poland

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It has been known for many years that benefits and education provided by the pharmaceutical industry influence physicians' prescribing behavior (Orlowski & Wateska, 1992; Wazana, 2000). Following the U.S. example, many European countries (e.g., France, Slovakia, and Greece) have introduced transparency (sunshine) laws to positively influence the ethics of pharmaceutical industry marketing strategies. These laws require the industry to compile and disclose the benefits they provide to particular physicians. These data are publicly available. Poland does not have such a law, and there is a lack of public debate about whether it should. I will present the results of focus group interviews involving 92 Polish medical students conducted to ascertain their opinions about transparency laws. I will also discuss participants' perceptions of the obstacles to introducing a law in Poland. These include: the resistance of practicing doctors; misuse of disclosed data; a possible decrease (rather than an assumed increase) in patient trust, and; society's lack of preparedness. I will conclude by discussing whether the European Union should consider introducing transparency regulations at the European level or whether it should leave such a decision to member states.

Session 10: Inequalities and informal care: “the voice” of caregivers of chronic illness patients

Organized by Cristina Calvi (Ca' Foscari University of Venice) & Stefania Fucci (University of Parma)

Toxic buildup. Performing gender, parental and caregiving roles by mothers of children with metabolic disorders

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The aim of this paper is to discuss new identities, disrupted biographies and double social roles of mothers whose child was diagnosed with rare metabolic disorder. Drawing from 3,5 year long ethnographic fieldwork among Polish families affected by two such disorders: LCHADD and PKU, this paper will explore the impact of chronic illness on family relations, imposed gender roles and expectations of caregivers responsibilities.

LCHADD and PKU are both effecting body's ability to metabolize nutrients from food. In case of discussed disorders, the only way to avoid severe disability or even death is restrictive diet that should be follow for the rest of persons' life (fat free but high in calories for LCHADD and low in phenylalanine for PKU).

As such, diet becomes fundamental not only in a sense of medical treatment, but it also plays a crucial role in assessing division of responsibilities related to childcare, medical knowledge about disease and household labour. By using ethnographic methodology of combined in-depth interviews with primary caregivers and participatory observation conducted in LCHADD and PKU children homes I was able not only to touch on the impact of the disease on family relations but also to see how gender and parental roles are performed. In families affected by LCHADD and PKU primary caregivers were mostly mothers, who were pressured to assume a double role of both stay-at-home-mom (whose main

job is to feed the child) and also medical expert, trained in composing meals, maintaining medical devices and managing symptoms.

Mothers and fathers's caregiver trajectories

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This oral presentation proposes to explore the manners in which parents of children suffering from type 1 diabetes may experience a “turning point” in their lives at the time of the diagnosis of their child's chronic illness and other forms of biographical bifurcations while they must reorganize their lives in order to respond to their child's needs throughout the illness trajectory and as he/she grows up.

From a qualitative research on children and their families' experiences of chronic illness¹[1], I would like to discuss more specifically some differences which were observed between mothers and fathers' trajectories as caregivers. Mainly visible while the child is in hospital or during medical appointments, mothers are (or make themselves) very available, for example by going on a leave or by quitting their jobs. But outside of the hospital and on a daily basis, it seems like the role of each parents is – if not the same – at least more equal as they work on a new distribution of tasks related to the illness management and to the child's well-being. It would be a mistake to say that the distribution is the same in every family, however. And I will make sure to consider elements such as education level and profession of the parents, social and familial resources and presence of diabetes in the family history, since it seems to have effects on some parents' involvement in the treatment and in the relation to health professionals.

¹ Research conducted in France with children aged from 6 to 14 (23 interviews, as some of them have been regularly met for 2 to 3 years), their parents (18 interviews) and health professionals involved in the illness trajectories (23 interviews). Ethnographic observations were also conducted in two hospitals during hospitalizations, medical consultations, therapeutic education sessions and in day hospital (51 families met).

Mothers of girls with Turner Syndrome: from caregivers to managers of knowledge

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Turner Syndrome (hereinafter TS) is a genetic condition that affects only girls and involves a partial or complete absence of an X chromosome. Some characteristics of TS include short stature, ovarian failure, and as a result sub- or infertility. Girls with TS are put on estrogen replacement therapy and growth hormone treatment. My presentation will be based on ethnographic research with girls with TS and their mothers. The main tools that I used were in-depth interviews and participant observations. My presentation aims to show that mothers-caregivers of girls with TS are managers of health and knowledge. They carry the burden of management of the disease and work for redefinition of the ‘after-diagnosis’ reality. The diagnosis of TS is technically simple and certain, via genetic testing. However, its consequences are, as mothers say, unexpected. The role of a mother and caregiver means then constant negotiating and re-inventing one’s role in relation to the unexpected. Mothers of girls with TS indicate, that one of the most important and painful consequences of the disease is infertility. They are obliged to manage the knowledge of the disease and the infertility in particular. The question of what to tell children and when to tell them the truth about TS is a recurring topic in my interviews. What is revealed and what is hidden constitutes the specific work of mothers-caregivers.

Giving ‘voice’ to parental experiences of caring for a child who suffers from chronic pain

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Although there are some studies on the caring experiences of parents of a child with a chronic illness, limited research has been conducted with parents of children who suffer from chronic pain. This paper intends to offer insights on the parental experiences of caring for a child with chronic pain. A qualitative approach was developed. Semi-structured interviews were conducted with parents of children and young people with sickle cell disorder who suffer from chronic pain. In addition, the draw, write and tell technique was developed with children and young people. The findings show how the uncertainty of chronic pain, in particular the timing and severity of pain, disrupts the family daily living and negatively impact on the biographies of parents. Caring for a child with sickle cell disorder who suffers from chronic pain has changed the identity of these parents. The findings also outline how the caring experiences of these parents are marked by their gender, ethnicity and socio-economic status and demonstrate the extent to which these social axes influence the care offered to these children and young people.

Participatory research: a way to reach hidden carers

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This paper introduces a research on young carers in the Italian context. The issue of caregiving performed by children is described. It typically begins when one family member has a chronic illness or disability. There are many factors associated with the issue of absence of alternatives, among the most important are: insufficient aid from social and lack of health services and financial resources. The group of young carers are fragile and hidden in Italy, especially they are without any legal or social recognition. Thus, inasmuch as carers are hard to reach, studying this phenomenon might pose a particular challenge. In this view, a participatory research was designed. Former young carers were involved in the research at the same level as researcher, that is co-researchers. This approach provided a steering group with them and researcher. Within the group co-researchers shared their experiences on caregiving. The Steering group implemented a mixed-method research with the aim to realize a framework and to explore the phenomenon. The tools of research were carried out by the group. In addition steering group developed data analysis using experiential knowledge. The research highlights how children and teenagers are involved in informal family work often relegated to women, instead of being perceived within the traditional concept of childhood. In addition, participatory research had the power to “give the voice to the voiceless”. Co-researchers had some benefit from this process: they restored their identity. Thus, participatory research developed a personal transformation in co-researchers and promoted a desire for social change.

Transition of care from pediatric to adult services: a second biographical disruption for parents of chronically ill adolescents

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Most of caregivers take care of their partners or their parents. This presentation focus on other caregivers, less studied : the parents of chronically ill children. As for their children, the onset of the disease is a biographical disruption for these parents : their lives are transformed and has to be organised around the child's care and appointments. Some parents even stop working to devote themselves totally to it. As the transition from pediatric to adult services occurs, physicians ask parents to "step back" to allow their children to be more independent in managing their illness. This movement may call into question their identity and provoke a second biographical disruption. This paper is based on the analysis of 30 in-depth interviews conducted with parents of children with chronic illnesses who were about to transit towards adult services. The findings show that some parents perceived the transition as a rupture at three levels : as parents, as parents of a sick child, and as caregivers. This rupture can be expected, allowing parents to regain their prior social identity, or feared; in this latter case, parents feel anxious at the idea of no longer knowing how to position themselves both as parents and as caregivers, as the contours of these two roles are often blurred. These different experiences of transition were modulated by the parents' different resources (relationship with medical institution, experience of their child's illness, and social background).

Session 11: Excellences and Obstacles Implementing Interprofessional Care within Health and Educational Settings: Are healthcare professionals ready to commit?

Organized by Barbara Sena (Unitelma Sapienza University of Rome) & Enrico De Luca (Sapienza University of Rome) & Silvia Cataldi (Sapienza University of Rome)

Session 12: The Medicalization of Human Reproduction in a Global Society: Gender, Inequalities and Social Change

Organized by Lia Lombardi (University of Milan)

Making decisions during childbirth: an analysis of real-time interactions between women and midwives

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Based on 37 real-time audio/video-recordings within two English NHS hospital midwife-led units, this paper explores how decisions are made during labour and birth for ‘low risk’ women. Drawing on questionnaire data, we explore the associations between women’s antenatal expectations (e.g., who they think *should* and who they think *will* make the decisions during labour, themselves or practitioners) and their postnatal accounts of how decisions were actually made. This analysis is set alongside conversation analysis of recordings which establish how decisions (1,347 across the 37 births) are initiated (e.g via assertion, requests, option-listing, offers and open questions) and followed up, and by whom (women, midwives). We find that while women generally want and expect to be involved in decision-making in advance of the birth, most decision-making is midwife- rather than woman-led and initiated by strategies such as assertion and recommendation, especially at the first decision-point (though this varies by type of decision being made e.g pain relief, vaginal examinations, fetal monitoring). Postnatal questionnaire data also indicate that although women reported being less involved in decision-making than they had anticipated antenatally, they were nonetheless generally satisfied with various aspects of the birth experience. The paper raises questions about the capacity of midwives to offer choice and women to make

choices, that is, for ‘shared decision-making’ in a context where national guidelines for intrapartum care exert a strong influence on how birth takes place.

Medicalisation of Abortion in Poland

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The process of medicalisation of abortion in Poland began with the introduction of the law on the admissibility of abortion in 1956. The aim of the communist government was to limit granny midwives procedures and replace such folk medicine with scientific medicine. Since then doctors men have performed the safe procedures (Kuźma-Markowska 2017). Indeed, women's mortality was reduced as a result of unsanitary procedures outside hospitals, but the phenomenon was not reduced. Because contraception was not available in pharmacies, abortion was the main birth control measure for a long time (Kulczycki 1999).

After the fall of Communism the new government limited access to treatments for social reasons in 1993. Currently, abortion is allowed in three cases: when the mother's life or health is at risk, when there is a suspicion of an incurable child disease or fetal deformity, and when a punishable act has been found, rape. In my study on social meanings of abortion (Maciąg 2019), I proved that as a result of the ban, some women make abortion at home. This means partial demedicalisation or auto-medicalisation, but there is often a need for medical intervention, and the hospital procedure is recorded as "missed abortion" or "miscarriage". Doctors men control the phenomenon and participate in an ethical discussion on the access of treatments. Some gynecologists perform illegal procedures for women with good material situation. Other doctors are experts pro-life movements: there is a social debate about abortion as a result of fetal impairment, called "eugenic abortion". Its subject is moral justification for medical selection and human improvement.

The imaginary on intrafamilial surrogacy: some data from an Italian research

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The opportunities for insemination and childbearing offered up by contemporary medically assisted reproduction technologies have opened up landscapes which were unimaginable in the past and given previously unthinkable opportunities to those who cannot or do not wish to have children in the traditional manner, in other words through heterosexual coitus. Over time, the intrafamilial donation option – i.e. the opportunity to bring a child into the world thanks to family members donating gametes or even carrying the child – has gradually become more popular. In Italy, this practice is prohibited by law, but it is discussed especially among those seeking to have children and interpreting intrafamilial surrogacy as a last chance. The aim of this paper proposal is to understand whether it is possible to make at least a rough sketch of the social imaginary about intrafamilial surrogacy. In order to do so, I will refer to three sources of information: scientific literature on the wider issue of intrafamilial donation – although it is rather scarce on certain matters, especially in Italy; the analysis of posts about intrafamilial donation present in some open/public social forums that deal in general with problems related to procreation; part of the *Medically Assisted Procreation and Surrogacy: the new social imaginaries* survey conducted in Italy in late 2017 on a sample of 360 subjects from 24 to 45 years old. The principal aim of that survey was to understand whether there could be said to be a social imaginary around medically assisted reproductive technologies. The survey also investigated the issue of intrafamilial surrogacy, albeit in less depth.

Women's experience of infertility and treatment process in turkey: socio-cultural aspects.

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This study focuses on the women's experiences of infertility and assisted reproductive treatment (ART) process' socio-cultural aspects. First aim is investigating experiences of infertile women with a focus on ART regarding causes of infertility and various strategies of having a child. Second is understanding infertility and treatment experiences with reference to socio-cultural aspects such as, cultural meaning of infertility and having a child, transition and change of social structures regarding infertility and treatment, social pressure and support, role of kinship structure, couple relations, and economic aspect. The study data were collected primarily from İzmir and Manisa which were in Western Turkey and popular for infertility treatment. Data were conducted by means of semi structured in-depth interviews which were conducted with 27 women who had been in the process of treatment. Findings illustrate that many women firstly try nonmedical ways, then start to engage with ART. Women reported that they were subjected to social pressure by their spouse's family members because of cultural attribution to having a child. Some women mentioned that despite advances in treatment, false beliefs in society about infertility have not changed. It is seen that women tend to hide treatment process from their relatives and men were mostly supportive in the process. Women, mostly low-income, reported that treatment costs negatively affect their budget. Few women have thought about adoption, foster family or voluntary childlessness. Results were discussed in terms of sociological aspects of reproductive health in Turkey.

Exploring the co-construction of gendered identities and reproductive technologies: the case of IVF beneficiaries and their embryos in vitro

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Despite social changes in recent decades, female adulthood remains associated with the social construction of motherhood, which is increasingly postponed, while the incapacity to “naturally” reproduce is still marked by a social stigma that many women try to hide. Infertility is increasingly subject to biomedicalisation (through the integration of highly technoscientific interventions in reproductive medicine) as the condition is pathologised (i.e. defined as a disease by the WHO) and medical expertise becomes progressively hegemonic. Assisted Reproductive Technologies (ART) always involve the medicalization of women’s bodies, regardless of the origin of the infertility problem (female or male), and women are under greater pressure, hoping for a successful pregnancy. It is therefore women who speak about ART treatments, either when participating in infertility associations’ online discussion forums (where men are almost entirely absent), or when responding to interview or testimony requests (for academic research or media reports), as studies shows. This paper draws from an ongoing research project on expert and lay meaning-making of human embryos in vitro, both in ART and stem-cell research. It is built upon the analysis of 25 in-depth interviews and on the results of an online survey with 85 respondents, both conducted to a diverse sample of IVF beneficiaries (single or in a relationship, heterosexual or homosexual, with or without a previous medical diagnosis of infertility). We aim not only to highlight how existing gender expectations affect the use and social meanings of reproductive technologies, but also to demonstrate how these technologies shape and re-shape gender itself.

Between the public and the intimate throughout the involvement in the parental project: (dis)engagements and gender dynamics among map beneficiary couples

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The development of reproductive technologies, along with being integrated in the process of medicalization of pregnancy, is also linked with structural social changes that have occurred in recent decades. Namely, the connectionist paradigm emerges as a dominant normative reference in the organization of relationships between individuals, including the relationship of intimate nature between members of a couple. The individuals' social trajectories are composed of affective/sexual projects that succeed each other (and in articulation with other types of projects). Within this myriad of projects, the conception of a child constitutes a more robust, authentic project – a long-lasting object of involvement of two partners and which overlaps the remaining ones. Particularly in the context of medically assisted reproduction, allowing the conception of an embryo outside the mother's womb, the couple is involved in a parental project whose engagement encompasses continuous tests of commitment from both partners – whether in terms of its duration (the beginning of treatment until the succeeded pregnancy) or of the different stages of treatment and consecutive attempts to achieve the (always uncertain) pregnancy. Based on in-depth interviews and an online survey conducted with MAP beneficiaries (heterosexual or homosexual) in an ongoing research project, the aim is to examine the dynamics that are built among partners. From a pragmatist perspective, particular focus is placed on gender differences that emerge in how the parental project is experienced by the couple's members and how oscillations between engagements and disengagements likely to occur throughout the therapeutic trajectory are judged among themselves.

Session 13: Vaccinations in public discourse

Organized by Paulina Polak (Jagiellonian University) & Maria Świątkiewicz-Mośny (Jagiellonian University)

Vaccination public discourse and religious authority: The case of non-vaccinating ultra-orthodox Jewish mothers in Israel

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The public discourse about vaccination in Israel draws on diverse sources of information. Parents seek information from doctors and nurses, family and friends, and search on-line in scientific journals, social networks, forums, and governmental and alternative sites. Ultra-orthodox Jews in Israel live in closed and segregated communities, at some remove from the influences of modern life. Belief in the knowledge and powers of Jewish religious leaders (rabbis) is deeply grounded in these communities. Most rabbis instruct parents to vaccinate their children, yet there have been outbreaks of measles among "pockets" of unvaccinated children in the ultra-orthodox Jewish population in Israel and elsewhere.

Our research sought to study the role of public and religious discourse in the decision-making process of Israeli ultra-orthodox parents. In-depth interviews were conducted during 2019 with ten Israeli ultra-orthodox Jewish mothers who do not vaccinate their children. The interviewees reported that they do not consult rabbis regarding vaccination, interpret their pronouncements for themselves, and may even fail to heed their instructions. The mothers decided not to vaccinate their children after gathering a good deal of information. They search on-line, use social media, read books, discuss the matter with friends and family, and consult conventional and alternative practitioners. Their search for information, as well as their reasons for not vaccinating, were found to resemble those reported by secular Israeli parents who do not vaccinate their children. This pattern appears to be part of a

widespread recent process whereby religious authority and traditional media are challenged by the internet. information from doctors and nurses, family and friends, and search on-line in scientific journals, social networks, forums, and governmental and alternative sites. Ultra-orthodox Jews in Israel live in closed and segregated communities, at some remove from the influences of modern life. Belief in the knowledge and powers of Jewish religious leaders (rabbis) is deeply grounded in these communities. Most rabbis instruct parents to vaccinate their children, yet there have been outbreaks of measles among "pockets" of unvaccinated children in the ultra-orthodox Jewish population in Israel and elsewhere.

The Ambivalence of Vaccines: Roles of Communication and Social Perception

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We aim to articulate the relationships between people's behavior and their vaccination representations according to social characteristics and the role of social media. We conducted our research using mixed methods including: loosely structured, in depth interviews, and web surveys. Our research showed that participants with a low-level of education, tended to believe myths highlighting conspiracies, while those with higher levels of education considered their more direct contribution to general health. Confidence in these authorities vs doubts about Big-Pharma industries plays a significant role in shaping the people's socio-cognitive representations on the field of vaccinations. Our work underscores how the interconnection among representations, people, experience, universalistic values, doubts about science and many reiterated ambivalent messages of the media and of the web, trigger contradictory positions in most cases. Compared to this, a sociological approach may be useful for identifying the social conditions under which skeptical attitudes towards vaccinations emerge. Scholars should consider this complex interplay of notions coming on one side from medical-clinical experts, and on the other from social media and the meaning-making elaborated

by individuals. Many conclusions could be drawn from these results, by healthcare system and stakeholders in public health, for designing systems and policies to improve vaccination acceptance and direct requests.

Healthcare professionals, distrust of expertise and vaccine hesitancy

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Distrust of expertise represents a great challenge for modern societies. In particular, it creates difficulties for healthcare professionals, given that citizens are arriving at the consultancy room with ready-made diagnoses, internet misinformation and contested attitudes. Vaccine hesitancy epitomizes this contestation: some individuals refuse to vaccinate their children or themselves which leads to low vaccine coverage and risks of disease outbreaks.

I will focus on healthcare professionals and vaccine hesitancy. I will present preliminary findings from a vaccine hesitancy survey (n=1024) and interviews (n=37) with Finnish healthcare professionals. The study makes clear the challenges of healthcare professionals in meeting vaccine hesitant individuals and pays also attention to vaccine hesitancy within the healthcare profession itself. Theoretically the presentation draws from sociology of health and medicine, sociology of professions and science and technology studies.

Moreover, I will introduce an EU Horizon 2020 funded consortium *Addressing Vaccine Hesitancy in Europe* (VAX-TRUST, 2021-2024). The multidisciplinary consortium includes researchers from seven countries: Finland, Belgium, Poland, Czech Republic, Italy, Portugal, and the UK. This initiative targets at equipping healthcare professionals with up-to-date knowledge on vaccine hesitancy. It aims to give professionals tools and support to deal with vaccine hesitancy and related challenges that the contestation of expertise brings simultaneously in many fronts.

Session 14: Coercion in psychiatric cure

Organized by Mario Cardano (Università degli Studi di Torino) & Luigi Gariglio (Università degli Studi di Torino)

Behind the screen of voluntary psychiatric hospital admissions: a qualitative exploration of treatment pressures and informal coercion in experiences of patients in Italy, Poland and the United Kingdom.

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Introduction / aims

Recent studies suggest that coercion is a relational and contextual phenomenon and despite being first described, already more than half a century ago, still little is known about voluntarily admitted patients who experience high levels of perceived coercion on admission to inpatient mental health care. In our analysis we explore forms of treatment pressures put on patients, not only by clinicians, but also by patients' relatives, during admission to psychiatric hospitals in Italy, Poland, and the United Kingdom.

Research methods

Data were obtained via in-depth, semi-structured interviews with patients (N=109) suffering from mental disorders (F20–49). A maximum variation sampling was applied to secure the representation of patients with different socio-demographic and clinical characteristics. The study applied a common methodology to secure comparability and consistency across participating countries. The qualitative data from each country were transcribed verbatim, coded and subjected to theoretical thematic analysis. Szmukler and Appelbaum's hierarchy of treatment pressures has been used as an initial theoretical frame.

Findings

Results of the analysis confirm that patients often come into the psychiatric treatment system not by their own volition, but under pressure from institutional agents: their clinicians or even police. Moreover, they are also pushed into hospital care by their relatives and friends. These findings support the assumption, that legal classifications of involuntary and voluntary hospitalisation do not capture the fundamental distinctions between patients who are and are not coerced into treatment. Our results show that the level of perceived coercion in voluntary patients is ranging from minor to most coercive measures: from ‘persuasion’ and ‘interpersonal leverage’ (categorized as treatment pressures) to ‘threat’, ‘someone else’s decisions’ and ‘violence’ (categorized as informal coercion).

Normality and Pathology in times of COVID-19

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Mental health sociology has questioned the definition used by psychiatry about mental disorder. Specifically, it questions the confused differentiation between normality and pathology.

In this communication we talk, specifically about the agoraphobia disorder, defined in the DSM-5 as fear or intense anxiety of being in open spaces, public transport use or to be in a crowd, among others. It is a disorder, in which it seems complex to discern between the separation of normality and what is a pathology.

Another fundamental sociological contribution of mental disorder consists of understanding the disorders as possible phenomena in history and culture. In this sense, from 15 th March to 21 st of June of 2020, the Spanish government declared the State of Emergency, in response to the coronavirus outbreak, based on a compulsory self-confinement for the Spanish citizens. During those weeks, no citizen could (force majeure exceptions) use public transport, leave the house or to attend any mass events.

With these precedents exposed, the communication that we present has as its objective, to examine the disorder through the narrative experiences of agoraphobic patients, to make visible the fluid and potential fine line that separates normal from pathological in times of social confinement. To achieve this objective, an ethnographic qualitative analysis has taken place between March and June of 2020. A narrative review of entries posted in the groups belonging to the social networking site, Facebook. These groups are used and created by persons with an agoraphobia diagnosis, and are groups selected based on the number of participants and the communication activity. The entries were uploaded to the program Atlas.ti and were codified from a category tree for its analysis. The main results obtained in our analysis indicate that persons diagnosed with the agoraphobia disorder have experienced the compulsory self-confinement by the Covid crisis in the following ways: a) fear to relapse, and get

closer to the pathology extreme, or to abnormality; b) perception of social confinement as an opportunity of a bigger understanding from society; c) feeling of invasion into their pathologic area, which was only theirs before; d) appreciation of agoraphobic life style as an advantage in front of the rest of citizens as consequence of the lifestyle of the confined, and; e) appreciation of the situation as an opportunity to “be normal” in the new confined normality without feeling the social pressure towards a public normality. We conclude that, in a context in which the lifestyle of some people - until now highly pressured by society to go out to the street, a pathologic lifestyle- is transformed into an imposition, it becomes “normal” the concept of pathology as a disorder, a deviation or alteration of normal disposition becomes blurred. In this context, people diagnosed with agoraphobia develop possibilities of changing the hegemonic clinical speech about agoraphobia, to deconstruct the disease that defines them.

Increasing our understanding of the dynamics behind the screen of voluntary admission by identifying different coercive actors, and different levels and forms of treatment pressure and informal coercion is a first step towards reducing the level of coercion during the admission process. We suggest to use the term ‘informal coercion’ in a more restricted way - to practices of pressuring patient into treatment by threatening and deceiving them, by making them believe that they have no choice, and by taking away their power to make an autonomous decision; and furthermore, to reserve the term ‘treatment pressures’ for mild and common techniques of influencing patients’ decision-making process (i.e. offering advice and support in getting professional help or using emotional arguments based on the personal relationship with the patient).

Session 15: Health and its social meanings

Organized by Iwona Taranowicz (University of Wroclaw)

From beneficence to autonomy. Transformation of society – transformation of ethical dilemmas in medicine

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Until 1989, the attitude to patients prevailing in the Czech health system was rather paternalistic. It was based on the Hippocratic approach where the physician – according to his or her best knowledge, abilities, and skills – decides what is good for the patient – the beneficence principle. Since 1990, the country has passed ethical and legal regulations that reflect the requirements of the current society and emphasize human rights, autonomy, and informed consent of the patients. The aim of the report is to determine the ethical dilemmas of the today's medicine from the viewpoint of the Czech doctors, to assign ethical principles to them, and to determine, whether they correspond to the social changes. The research was based on various methods. At first, doctors of specialized education (n=62) defined the ethical dilemmas of their practise. The dilemmas then formed a questionnaire, where physicians (n=42) marked the most important dilemmas of the current medicine, or they added their own dilemmas. The respondents identified a total of 36 ethical dilemmas in 517 answers. The most frequent (n=96 answers, i.e. 18.6 % from the total answers) dilemmas were as follows – 1) who is to

get preference when providing expensive health care, 2) treatment of very old patients, 3) possibility of euthanasia, 4) excessive paperwork. All 36 dilemmas applied in majority the principle of justice, followed by autonomy and nonmaleficence; the least applied principle was beneficence. The hierarchy of ethical principles has changed, and the ethical dilemmas of the Czech doctors correspond to the social changes.

Meanings of health in a context of increased health risk

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In this paper, we propose to investigate health and its social meanings in a specific health context of “*increased health risk*”. Childhood cancer survivors, because they face a large spectrum of late effects related to cancer treatment, including life-threatening conditions such as second cancer or cardiovascular diseases, live with such an increased health risk. Indeed, epidemiological studies show that 70% of them have a health condition at the age of 35 years old.

A peer-based qualitative research study was conducted by the members of a patients’ association, in collaboration with two sociologists. The interview guide covered knowledge of risks and perceptions of health and tertiary prevention, including screening and attendance to long-term follow-up clinics. A total of 28 interviews were made. Peer-researchers were involved in the design of the qualitative study, created the interview guide, conducted the interviews, participated to the analysis of data.

Collective analysis of the interviews showed that individuals living with an increased health risk after childhood cancer rarely wanted to engage in individual screening prevention. Furthermore, if individuals who had already experienced late effects (second cancer, cardiac disease) wanted to know more about the origin of their past conditions, they did not want to be aware about their future risk of having another life-threatening disease. Indeed, they solely wanted to give a sense of coherence to their life trajectory by understanding the etiology of their past diseases.

This study provides data on the ways of thinking and perceiving health in a specific health context.

Ethnic differences in searching for health information: A test of the extended social diversification hypothesis

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Ethnic disparities in health exist in every multicultural society. These disparities are also evident in how people search for health information. The current study examined the extended social diversification hypothesis while decomposing the disadvantaged minority based on size of localities they reside in. The study contends that disadvantaged minorities residing in small localities have less health-related social capital than other groups since they have limited access to advanced health services. Therefore, they are expected to be motivated more than other groups to acquire this type of social capital by searching for health information. Using data from the Israel Social Survey 2017, the study found that minorities residing in small localities are more likely than other groups to search for three particular health information topics and for information on disease prevention, thus partially supporting the extended social diversification hypothesis. This finding signals a major need to improve the public health services in small localities populated by disadvantaged minorities.

Ignorance, resistance and irresponsibility? The reasons why women refrain from taking breast cancer screening

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Despite the promotion of breast cancer screening programs, there were only 6 countries in 2016 in EU reaching the recommended target of 70-75% of invited participants. The aim of the research was to examine the reasons why a relatively big number of women refrain from taking part in the breast cancer screening procedure. The research investigates whether and how existing habits might influence breast cancer screening related decision-making and whether the communication should address low awareness or any other influencing factors.

Data was collected with semi-structured in-depth interviews among nine Estonian women who have received the invitation but have not participated during the procedure. For data analysis, the thematic textual analysis was performed.

The findings revealed that the social meanings related to the reasons why women refrain from taking breast cancer screening might be misleading and not related to the low level of knowledge or resistance to the medical system. Women's final decision to refrain from breast cancer screening might have habitual (i.e. existing, routine and unconscious ways of visiting and communicating with physicians), practical (i.e. everyday aspects and arrangements) and emotional (i.e. different (health) beliefs, fears and cognitive aspects) reasons and the shift in this public perception might need change in order to change the situation.

Participation in oncological preventive examinations and beliefs regarding the importance of prevention and responsibility for health. Considerations in the context of social inequalities.

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Poland belongs to the countries with the highest cancer mortality rates. It is estimated that compared to 2006, in 2025, the number of deaths caused by cancer in Poland will increase by 1.5 times. In this context, the participation of healthy people in preventive examinations is of particular importance. We will present the results of a sociological study carried out in 2018 on a population of 898 healthy adults (without "cancer" diagnosis) residents of Wrocław (the capital of Lower Silesia). A quota sample was used. As a research tool, a proprietary interview questionnaire with a high level of standardization was used.

The paper presents the results of analyzes regarding:

Frequency of respondents' participation in preventive examinations related to the following cancers: colon, skin, female (breast and cervical) and male (prostate and testicular)

The health beliefs of the respondents about a) responsibility for general health and the impact of their lifestyle, the likelihood of "cancer"; b) the impact of prevention on the individual's overall health and the importance of cancer prevention.

Correlation of respondents' participation in oncological preventive examinations and health beliefs and socio-demographic variables (sex, age, education, mother's and father's education, marital status and number of children, income level, and assessment of the material situation) was examined.

Correlation between the frequency of participation in oncological preventive examinations and examined health beliefs.

Therefore, the participation of respondents in oncological preventive examinations will be analyzed in the context of discourse regarding social inequalities and the socio-cultural perspective, by showing the correlation of participation in preventive examinations on health beliefs as a cultural construct, which is one of the forms of social awareness of laypeople.

„I am monitoring... so I am healthy” Consequences of the dynamic expansion of self-tracking for health

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In our presentation we will discuss issue of using self-tracking applications and other devices to monitor own health. Numerous advantages and disadvantages of this self-monitoring for health have been identified in the scientific literature. It has also been shown that the development of this technology has an effect on shifting the understanding of the "health care" term, which now must now include the fact that patients become specialists of their bodies as they can measure different aspects of it. In our presentation we will discusses the concept of "*self-tracking* culture" - demonstrating that its actors are not only people involved in *Quantified Self* social movement but also physicians, health care institutions and sometimes even employers. We will show difference between “voluntarily” and “pushed by healthcare providers” *self-tracking*. We will present sociological interpretations of this phenomenon. In the conclusions, potential areas of sociological research concerning *self-tracking* will be shown.

Health, drug use and rights – a case study from Poland

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Władek, who has used drugs for many years, has been fighting for accessible substitution treatment in the Pomeranian region of Poland. He became known in the media in 2008 when he wrote a letter to therapists from other cities asking for their support in developing a local substitution program. His hometown, Gdańsk, had only offered long-term abstinence programs for opioid-type substance dependencies. To receive buprenorphine, Władek had to travel to Kraków (almost 600 km away) or acquire the drug illegally, which ipso facto would criminalise his therapy (Kołodziejczyk 2009). His letter went viral and reached the President of Gdańsk and the Parliamentary Committee on Health, among others.

In his request, Władek made a claim to his rights as a patient and demanded access to harm reduction services by demonstrating his vulnerable position (i.e. sick without access to substitution treatment), but he also expressed criticism of the living conditions of people who use drugs, the criminalisation of their behaviours, and inequalities in access to healthcare (Piótrek 2009):

"Why am I not treated as a sick person in my own city, while I could receive help, for example, in Kraków? Why are people like me forced to acquire a medicine illegally, by breaking the law, while in other places you can get it without problems?".

Władek's struggle for substitution treatment started even earlier, in 2007, when he tried to establish an association to introduce substitution services in his region. Although they were unsuccessful in creating the organisation, their voices demanding harm reduction programs initiated further discussions in Poland on the right to health in the context of drug use.

Using this story as a starting point to reflect on the meanings attributed to health, the presentation will show how the categories of health and patient rights mobilise actions in the field of harm reduction and drug use. Based on existing data as well as on my own qualitative research carried out within the EUROPACH – *Disentangling European HIV/AIDS Policies: Citizenship, Activism and*

Health project, I will show how, in the context of criminalization of drug use and stigmatization of drug users, the reference to health in activism can be seen as a strategy to go beyond dominant social discourses, which construct drug use and people who use drugs through the moral and criminal lens.

Sexual health among older adults: vitality, sexuality and asexuality of an aging body. Qualitative study results

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In Western culture, sexual health was associated with the ability to procreate, combined with self-control and distancing oneself from sexuality. Sexual activity other than for procreation was considered an illness. Currently, sexuality at an older age is increasingly commonly considered part of a senior's satisfying life, an important factor in their health and well-being. A sexually healthy older person is one who can express their sexuality without fear, in the physical, mental and social realms (Marshall 2011).

The purpose of the presentation is to reflect upon the sexual desires, practices, and attitudes of senior citizens understood individually and socially, based on subjective factors and social and cultural ideas (stereotypes, social convictions). An important part of this presentation focuses on empirical data, to wit, an analysis of 403 in-depth, individual interviews conducted between 2012-2014 with men and women who were 60 or older from Polish cities and rural communes. The outcomes are also based on an analysis of the content of Polish guidebooks addressed to senior citizens. The research shows that senior citizens are perceived as asexual beings. An old man or woman seeking sexual adventures was judged negatively in a moral, social, aesthetic and medical sense. While the sexual activity of the respondents is gradually being treated less like something sinful and shameful, there still exists a "double standard in aging" - the different standards for women and men. Menopause is the end of femininity for the woman.

Session 16: Explaining variation in health inequalities from a comparative institutional perspective: innovative theoretical approaches and empirical studies

Organized by Katrijn Delaruelle (Ghent University, Belgium)

The Changing Subjective Well-being Enhancing Effect from a College Degree in China: A HAPC Analysis

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Aims: This paper aims to explore how the Chinese's subjective well-being (SWB) changed in the past two decades and examine the relationship between subjective well-being and higher education under a dramatically changing macro socioeconomic context in China.

Methods: We utilized nine waves cross sectional data from the Chinese General Social Survey (CGSS) 2003-2015 and adopt the hierarchical Age-Period-Cohort model to evaluate how the well-being and returns to higher education change with age, period, and cohort in an age of increasing economic inequality and educational expansion.

Findings: First, the subjective well-being of people with higher education is always higher than that of people without higher education. Second, there is a U-shaped relationship between age and subjective well-being. Subjective well-being gradually declines after the age of 20, but from 55-60 years old, individual's subjective well-being begins to rise. From 2003 to 2015, the subjective well-being of individuals gradually increased, but the subjective happiness of young cohorts was lower than that of older generations. Third, the return on subjective well-being of higher education decreases with age and period, but the return on subjective well-being in younger cohorts is stronger than in older cohorts.

Relationship between social ties and precarious employment on mental health.

A cross-regional study among Italian workers.

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Drawing on the second wave of the European Health Interview Survey (EHIS 2015) data, this paper shall analyse the stress-buffering role played by social ties in moderating the impact of precarious employment conditions on Italian workers' mental health.

Literature has found that precarious employment conditions act as social determinants on both physical and mental health, the latter by enhancing the level of uncertainty in one's life and thus threatening one's internal locus of control. The stress-buffering model states that the negative outcomes of stressful circumstances (e.g. damaged self-esteem, lack of sense of belonging, inability to appraise the situation) could be moderate by specific aspects of social support.

In this study, social ties are measured using two variables as proxies of *instrumental support* and one variable as proxy of *matter*ing, which concerns the perception of being an object of other people attention, and it is positively associated with self-esteem and with one's notion of having a meaningful life, both key elements of mental health. The latter is measured using the Patient Health Questionnaire (PHQ-8), 8-item depression screener, which covers a subset of the negative mental health dimension. We expect findings to allow us to understand to what extent social support could moderate the impact of precarious employment conditions on Italian workers' mental health, and if the stress-buffering effect of social ties could bridge the current gap between North and South of Italy in terms of both health care services efficiency and employment patterns, moderating the existing inequalities.

Cancer screening and the primary care system: screening overuse and inequalities in screening uptake

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Objectives: This study examines the role of the primary care system in shaping cancer screening inequalities, in the context of broader income inequalities. We hypothesise that a weaker primary care system and lower healthcare gatekeeping favour higher screening uptake among higher-income individuals, and increase screening inequalities.

Methods: We analyse data from the European Health Interview Survey (2014), using multilevel logistic regressions to analyse cervical, breast and colorectal screening participation among individuals ($N_{\text{cervical}}=99,794$; $N_{\text{breast}}=52,065$; $N_{\text{colorectal}}=112,268$) nested in 30 European countries.

Results: Results suggest that, (1) average cervical and breast screening uptake levels are around 70% while colorectal screening is 26%, (2) most individuals screen within the past year indicating over-consumption, (3) in countries with a higher Gini index, cervical and breast screening is higher among higher-income individuals, (4) countries with weaker primary care systems and lower gatekeeping have higher uptake levels in cervical and breast screening and a larger gap between lower and higher-income level individuals.

Conclusion: When implementing cancer screening strategies, the role of the primary care system in shaping inequalities should be considered against the backdrop of broader societal levels of inequality, particularly in cervical and breast cancer screening as this study highlighted. Weaker primary care and lower gatekeeping may involve higher healthcare commodification and favour screening inequalities driven by a two-fold process of over-consumption among wealthier individuals and under-consumption among poorer individuals. Such association was not observed in colorectal screening as lower screening uptake levels may contribute to inhibiting healthcare consumerism.

From cancer screening participation to consumption participation: influence of the neo-liberal market and commodification of health on inequalities in screening uptake

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Background: Institutional factors have often been ignored by public health research in the assessment of cancer screening programs and their impact on inequalities in screening uptake. A more critical approach is suggested.

Aim: This study investigates under which institutional conditions the organisation of cervical and breast cancer screening programs can result in lower levels of inequalities in screening uptake: a more welfare state or a more neo-liberal oriented context.

Methods: A two-level multilevel design with women ($N_{\text{cervical}}=89,550$; $N_{\text{breast}}=59,180$) nested in 29 European countries was used to analyse data of the second wave of the European Health Interview Survey. The institutional orientation was measured using the decommodification index and out-of-pocket expenditure as a percentage of GDP.

Results: Firstly, lower out-of-pocket expenditure and higher decommodification were correlated with more Pap smear and mammography screening uptake. Furthermore, results of the logistic regression models demonstrated that the organisation of a screening program, lower out-of-pocket expenditure and higher decommodification were related with lower educational and income inequalities in screening uptake. However, the organisation of a screening program was associated with higher screening inequalities both in a context of low decommodification and high out-of-pocket expenditure.

Conclusion: Government intervention by organisation of screening programs does not necessarily ameliorate a society's screening condition, as in a neo-liberal context it leads to higher inequalities in screening uptake and possibly overconsumption among the higher educated and richer women. In order to have lower levels of inequality, the organisation of a screening program should be combined with a redistributing state policy.

Session 17: International Mobility of Health professionals: pathways, gender and discrimination processes

Organized by: Francesca Sirna (CNRS, CNE, EHESS-Institut Convergence Migrations) & Simeng Wang (CNRS, CERMES3, EHESS-Institut Convergences Migrations)

Digital revolution on health care. What implication for medical professionalism?

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Sociology of professional groups have partially neglected the impact of the digital revolution on medical professionalism: beyond the studies focused on the changes that have affected the doctor-patient relationship, in the literature there are few research studies aimed at evaluating the effects of the technological development on professionalism.

However, some considerations can be done starting from the main results of studies and research concerning the use of technology in the most diverse contexts and situations, often carried out to evaluate the outcome in terms of improved well-being for users.

In this paper we will try to interpret this literature focusing on some conceptual categories (knowledge, practices, intra and inter-professional relationships, regulation and threats to professional autonomy) traditionally used in the study of professional groups. The aim is to understand how and to what extent the implementation of ICT can impact on medical professionalism.

Mind the Gate: general practitioner's attitudes towards depressed patients with diverse migration backgrounds

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Our study investigates (a) whether there are differences in general practitioners' (GPs) attitudes towards native Belgian patients, Belgian born patients with Moroccan roots and patients with an asylum seeking background who all express symptoms of major depression, and (b) whether these differences depend on GPs' familiarity with patients with a migration background (i.e. participation in cultural competency training and interethnic relationships). A quasi-experimental video vignette study was performed among 404 Flemish (Belgium) GPs, who were each randomly assigned to one of three hypothetical scenarios. Participants were asked to give a subjective evaluation of the patient in terms of trustworthiness, therapy adherence and treatability. The results provide evidence of a provider bias towards patients with a migration background. While GPs regard Moroccan-Belgian as less trustworthy and less able to adhere to medical recommendations than native Belgian patients, they also hold more pessimistic views on a potential recovery of asylum seeking patients. In addition, we find that cultural competency training might alter GPs' attitudes of patients with an asylum seeking background in a positive way. Summarized, our research highlights the need to target stereotypes among healthcare professionals for interventions designed to reduce ethnic disparities in healthcare use and health status.

REMEDI – Assessing general practitioners’ recommendations to patients with mental health problems and diverse migration backgrounds through a mixed-methods design: Methodological insights

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The REMEDI project extends on the results of the Mind The Gate project which focused on differences in general practitioners’ (GPs) attitudes towards native Belgian patients, Belgian born patients with Moroccan roots and patients with an asylum seeking background who all express symptoms of major depression. The purpose of the REMEDI project is to (a) investigate contextual variation in GPs’ recommendations to these patients and (b) to examine how these differences can be tackled. Because of its regional diversity, Belgium provides an excellent case-study to investigate whether the reliance on stereotypes and unintentional discrimination is likely to be context-dependent. An innovative mixed-method design will be applied to assess possible discrimination in GPs’ clinical recommendations. Quantitative data will be collected by performing a quasi-experimental video vignette study among GPs and GPs in training. They will each get assigned to one of three hypothetical scenarios and asked to give a subjective evaluation of the patient in terms of treatability and referral. The qualitative part entails a combination of semi-structured interviews and focus groups with GPs, focusing on their personal experiences and perception of treating patients with mental health care problems and a migration background and of their personal experiences with tools (such as intercultural mediation) to overcome possible barriers in treating these patients. The ultimate goal is to eliminate accessibility barriers to specialized mental healthcare services for minority patients by identifying and interpreting attitudes of GPs and by translating them into constructive knowledge and a training tool that will eradicate unconscious stereotyping.

Session 18: Open Session

Organized by: Natalia Ożegalska-Łukasik (Institute of Sociology, Jagiellonian University)

Preventive examinations in times of economic crisis and economic expansion

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Health behaviour, according to Alonso (1993), consists of four separate dimensions. One of them is detection, which includes regular medical examinations in order to reveal and monitor health problems. The frequency of regular preventive examinations use is influenced by a great deal of socio-demographic conditions and health care system. Each adult inhabitant (18+) of the Czech Republic is entitled to regular preventive medical check at a general practitioner ones every two years. This check is wholly covered by the health insurance and insured person must pay no extra charge for this service. The aim of this work is to compare the use of regular preventive examinations at the GPs in times of economic crisis (2010) and economic expansion (2019) in the Czech Republic. Comparison was based on data gained from the biggest Czech health insurance company, which insures about 60 % of Czech inhabitants. Hypothesis was based on that if regular preventive examinations at the GPs are wholly covered by insurance company without need of additional charge from insured person, there will be no effect of economic cycle on use of these examinations. However, preliminary results suggest there was an increase in the use of regular medical examinations by 5% (from 15.0% in 2010 to 20.0% in 2019). There will be necessary to proceed more detailed analysis of growth of preventive check number to be able to find out in which age categories was recorded the highest growth, eventually in which sex it was.

Violent Deaths of Infants under 1 Year of Age: Are the Aggressors Male or Female?

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Modern society still perceives men through the lens of gender stereotypes, i.e. as the representatives of the “stronger” sex carrying attributes such as order, analytical thinking, radical and aggressive approach, master, sadism, conquest. Women, on the other hand, are rather viewed as victims, subordinate persons, dependent, in need of love and strong relationships (Pon%u011B%u0161ický, 2004), and they are still regarded as the guardians of the hearth.

The aim of the report is to reveal the gender ratio of the perpetrators of violent deaths of infant under 1 year of age – are the main aggressor men (fathers, stepfathers) or women (mothers)?

The method of choice was a retrospective analysis of all the autopsy reports (n=259) of infants who died suddenly, unexpectedly, and violently before reaching the 1st year. The autopsies were done at 4 forensic medicine laboratories between 2007 and 2016 in the Czech Republic. In 41 cases, the child’s death was caused by hostile conduct. The violent death of infants under 1 year of age was more frequently caused by women – mothers (73%).

The finding may be explained as follows: 1) in almost all cultures, men engage in out-of-home activities, while women spend more time with children; 2) it is not possible to estimate the impact of the social background, i.e. the symbolic male dominance and female submissiveness as a result of habituation; 3) with respect to gender stereotypes, it is not correct to presume that women and men are biologically programmed for different roles in their relationship to children.

The impact of adapted physical activity on elderly’s wellbeing: sociological perspectives

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Our paper proposes a comparison between three European countries' (France, Italy and Belgium) policies concerning adapted physical activities, sports and well-being. Particular attention will be paid to sports practices adapted to the elderly population and to the positive effects of concrete institutional intervention tools. Moreover, our presentation will focus on the impact that adapted physical activities produce on elderly's perception of quality of life, especially in presence of chronic diseases and other experiences of sickness and pathology: we'll try to follow the marks of a new institutional culture that enhances the relationships between physical well-being and ageing processes.

Our presentation will be structured around the following main axes: the impact of sport promotion policies on welfare models; the impact that these policies have on education systems (caregivers); the transformations that sports induce in daily life of people affected by chronic diseases; the existence of regulatory provisions aimed at specifically promoting the adoption of sports practices in the preventive and therapeutic fields.

We'd like to focus on existing policies and experiences related to adapted physical activity, trying to investigate how the territorial and administrative organization in these different countries influences the application of the regulatory provisions relating to adapted physical activity. Our theoretical analysis will try to delineate sports activities both as a tool useful to institutional policies aimed at guaranteeing the right to health and as a determining factor to be applied for health equity.

Prevalence of depression and associated factors in Spain. A sociological analysis from the National Health Survey 2017

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Aims and objectives. Depression has become an important issue of public health in recent years in Spain, and this has led to increases in total expenditure on health. This communication presents an analysis of the prevalence of depression in Spanish society, as well as the influence of sociodemographic factors on its presence.

Research methods. To do the analysis we draw upon several variables included in the National Health Survey in Spain (2017), a cross-sectional household survey of a representative sample of the population of Spain 15 years and older (23,089 individuals) and the population under 15 years (6,106 individuals).

Main findings. 10.8% of the individuals presented a mental disorder. The most frequent mental disorders were depression and chronic anxiety, both with the same rate (6.7%). Women's depression rates are twice as high as men's (9.2% and 4% respectively). The prevalence of depression is 2.5 more frequent among those who are unemployed (7.9%) than among those working (3.1%), and that figure reaches 30% among disabled people. The National Health Survey in Spain can provide essential outcomes to examine and understand the impact and the factors associated with depression in the social structure.

Ethnic differences in subjective influence of social media on health: a test of the social diversification hypothesis

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Social media has become a dominant source of health information. This emphasizes its importance for health-related decision making. Health information found on the Internet was found influencing health behavior. However, the empirical evidence on the effect of health-related information found on social media is scarce and limited to qualitative findings. Moreover, rare are the studies that investigate ethnic differences in such effect.

The current study intends to understand the differences between the majority and minority groups in Israel regarding their perception of being influenced by health information found on social media using social diversification hypothesis. The data for the study was collected through telephone survey. Logistic regression models were employed to analyze the data. It was found that Arab social media users are more likely than Jewish users to report that health information found on social media has caused them to stop or decrease smoking, appoint to medical tests, and purchase private health insurance. In addition, Arab social media users are more likely than Jewish users to report being influenced by health information on social media in a large number of domains. These findings point to the excessive need of investment in public health in localities populated by ethnic minorities.

Poster session

Disabled People in European Countries and their Experiences of Discrimination

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The aim of social activity of disabled people initiated in the second half of the twentieth century was social inclusion of disabled people and promotion of anti-discrimination solutions. At this time too, the issues of disability were introduced to academic discourse and political debate. Nowadays, there is an urgent need to evaluate the effectiveness of these actions. In the context of such evaluation, this article is an attempt of assessment of the scale of discrimination against disabled people in Europe based on data from the European Social Survey. The analysis was focused on three essential questions:

- what is the percentage of disabled people who declare their own belonging to a group discriminated against in separate European countries?
- what proportion of these disabled people indicate their disability as the main source of discrimination?
- Is disability itself (controlling for influence of other characteristics) a significant predictor of a sense of discrimination?

The analysis concerns 17 European countries that were covered in survey in 2002 and 2016.

Doctors as „poverty managers” in the Poland's health care system

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Since 1998, a series of reforms was introduced in Poland's health care system, ostensibly aiming to prevent profligacy and secure quality care for patients. The economisation, however, failed to deliver on its promise. In the context of persistently underfunded and understaffed public health care system, hospital management do increasingly become „poverty managers,” burdened with the task of balancing between conflicting medical and financial expectations. Some researchers went as far as framing this as a situation where a „financial diagnosis” precedes, and sometimes even replaces the medical one (Charkiewicz 2009). A series of practices of resourcefulness have been reported aiming at improving the financial condition of hospitals while maintaining their basic function of providing care. They range from clearly unethical conducts (unnecessary hysteroscopy) through ambiguous ones (keeping patients in beds over the weekend) to apparently benign ones (diagnosis optimisation). My aim in this paper is to explore the perception and everyday attempts to resolve such dilemmas on the part of junior doctors. I will do it with a series of IDIs. The choice of junior doctors as my group of respondents is based on the hypothesis that this one of few categories within the system that combines genuine on-the-ground knowledge of its workings with the critical gaze of a newcomer. This is also one of few categories of health care employees whose protests combine short-term demands based on self-interest with long-term demands based on a vision of public good.

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