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Steger | Ramšak | Łuków | Muzur [Hrsg.]

Equal Access to Healthcare in Socially Diverse Societies

VERLAG KARL ALBER

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Volume 8

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Preface

This volume is the result of the European Union project »Healthcare as a Public Space: Social Integration and Social Diversity in the Context of Access to Healthcare in Europe«, which has been conducted in years 2019–2022 within the framework of the Joint Research Programme »Public Spaces: Culture and Integration in Europe« funded by the Humanities in the European Research Area (HERA) network and the European Commission.

Healthcare is an excellent example of a public space that models the processes of social integration and social equity. In a general sense, healthcare can connect diverse groups of a society under the common idea of health and illness, but also lead to exclusion and segregation of social minorities. Within the framework of the project, research focused on the European normative frameworks concerning equal access to healthcare and their implementation in national healthcare systems and healthcare practice in four European countries: Croatia, Germany, Poland, and Slovenia.

Four research institutions at four European universities contributed to the realization of the project: the Institute of the History, Philosophy and Ethics of Medicine at Ulm University (Germany), the Institute of History of Medicine at the Faculty of Medicine of the University of Ljubljana (Slovenia), the Department of Social Sciences and Medical Humanities at the Faculty of Medicine of the University of Rijeka (Croatia), and the Center for Bioethics and Biolaw at the Faculty of Philosophy of the University of Warsaw (Poland).

Generous support of funding agencies allowed realization of the project and publication of this book. We are thankful to the Humanities in the European Research Area (HERA) network together with the European Commission for approval and funding of the project. We also thank all national funding agencies: Croatian Academy of Sciences and Arts (Croatia), Federal Ministry of Education and Research (Germany), National Science Centre (Poland), and Ministry of Education, Science and Sport (Slovenia) for financing and support of the project during its whole duration. We are also grateful to all authors for contributing to this volume.

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Florian Steger, Mojca Ramšak,
Paweł Łuków and Amir Muzur

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Introduction

Equal access to healthcare for minority groups is one of the major challenges in modern healthcare systems. With regard to various groups that constitute our societies, consideration of their different needs, situations, values, and goals can lead to improvement of their health and contribute to a community, in which individuals can flourish. On the other hand, discrimination in healthcare can lead to further segregation, stigmatization, and exclusion. Race, ethnicity, culture, or sexual orientation in their pluralism are only a few of characteristics of modern societies and have a tremendous impact on participation in medicine and healthcare. They play a role in formulation of healthcare needs, in patient-physician relationship and communication, and in perception of health and illness.[1] The characteristics that constitute diversity can be visible, e.g., race, age or gender, or hidden, e.g., religion, convictions, and sexual orientation, but in many situations they influence the way, in which healthcare is provided. Inadequate legal entitlements, stigmatization, racism, or prejudicial and discriminatory behavior can negatively affect the trust and confidence in healthcare system and lead to negative health outcomes.[2]

Therefore, reduction of health inequalities for minority and vulnerable groups requires careful consideration. On the one hand, access to healthcare can be influenced by structural factors, as it is acknowledged in in the United Nations' International Covenant on Economic,

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[1] Tim Peters, Tatjana Grützmann, Walter Bruchhausen, Michael Coors, Fabian Jacobs, Lukas Kaelin, Michael Knipper, Frank Kressing, Gerald Neitzke: Grundsätze zum Umgang mit Interkulturalität in Einrichtungen des Gesundheitswesens. In: Ethik in der Medizin 26 (2014), pp. 65–75.

[2] Lise G. M. Hanssens, Jens D. J. Detollenaere, Amelie Van Pottelberge, Stijn Baert, Sara J. T. Willems: Perceived discrimination In Primary Healthcare in Europe: evidence from the cross-sectional QUALICOPC study. In: Health and Social Care in the Community 25 (2017), https://doi.org/10.1111/hsc.12353.

Social and Cultural Rights (ICESCR) of 1966. In Article 12 point 1, the ICESCR recognizes »(…) the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.«[3] In accordance with this, point 2 of the Article 12 urges the states that are parties of the Covenant to include steps towards realization of this right, which should include among others: »The creation of conditions which would assure to all medical service and medical attention in the event of sickness.« As recommended by the Committee on Economic, Social and Cultural Rights (CESCR), the goal of the highest attainable standard of health, public health, healthcare facilities, goods and services, as well as programs should contain four elements: availability, accessibility, acceptability, and quality.[4] In the context of non-discrimination, especially the requirements of accessibility and acceptability gain important role. First, health facilities, goods and services should be accessible to »everyone without discrimination«, especially to the most vulnerable or marginalized sections of the population. Second, the dimension of acceptability relates to a respect for medical ethics and cultural background. In particular, all health facilities, goods and services must be: »(…) culturally appropriate, i.e. respectful of the culture of individuals, minorities, peoples and communities, sensitive to gender and life-cycle requirements.« According to the CESCR, the national states have a continuing obligation towards the full realization of the Article 12 of the ICESCR. This obligation is threefold, it includes duties to respect, protect, and fulfill the human right to healthcare. States' duty to respect the right to health concerns refraining from denying or limiting equal access to preventive, curative, and palliative health services for all persons, including among others minorities, asylum-seekers, and illegal immigrants. The duty to protect encompasses an obligation to adopt legislation ensuring equal access to health care. The States are also required to facilitate access to healthcare for individuals and communities, to provide specific rights for the realization of the right to health, and to promote the right to health through creation, maintaining, and restoration of the

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[3] United Nations: International Covenant on Economic, Social and Cultural Rights. Adopted and opened for signature, ratification and accession by General Assembly resolution 2200A (XXI) of 16 December 1966. https://www.ohchr.org/en/professionalinterest/pages/cescr.aspx (accessed on 7.2.2023).

[4] United Nations' Committee on Economic, Social and Cultural Rights: General comment no. 14 (2000): The right to the highest attainable standard of health. (11.8.2000). https://digitallibrary.un.org/record/425041 (accessed on 7.2.2023).

health of the population. This last point contains a specific provision concerning diversity-oriented health services. Namely, States should ensure: »(…) that health services are culturally appropriate and that healthcare staff are trained to recognize and respond to the specific needs of vulnerable or marginalized groups.«

This last point touches on ethical dimension of access to healthcare. It reflects on individual behaviors of all involved in provision of medical care. Equality of access to healthcare involves the ethical responsibility to minimize differences in providing the best healthcare for individual patients without discerning the social minority groups to which they belong. This should occur in congruence with the medico-ethical principles of autonomy, beneficence, non-maleficence and justice[5] and based on the fact, that all humans are bearers of human dignity. In this context, diversity competence becomes one of the central issues of the modern healthcare services. It involves a commitment to appropriate policies and practices to improve the capacity of healthcare organizations and healthcare professionals in the provision of quality healthcare for diverse populations.[6] It aims at improvement of patients' satisfaction and efficiency in provision of medical care, with the overall goal of better health outcomes.

This volume includes twelve contributions from various fields gathered under the common topic of access to healthcare. It is divided into three sections: vulnerable groups, minorities, and healthcare professionals. In their contributions, twenty authors explore the topic of equal access to healthcare from various perspectives: of patients from vulnerable and minority groups, their relatives as well as different medical professions. The chapters of this book present impulses for a debate on one of the central questions of healthcare nowadays: How can participation in modern medicine be provided for all? As is clear from the following contributions, the answer is not straightforward and requires a multifaceted and interdisciplinary consideration of various viewpoints, concerns, and individual circumstances. The following passages shortly describe individual chapters in this volume.

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[5] Tom L. Beauchamp, James F. Childress: Principles of Biomedical Ethics. 8th Edition. New York, Oxford 2019.

[6] Cindy Brach, Irene Fraserirector: Can Cultural Competency Reduce Racial and Ethnic Health Disparities? A Review and Conceptual Model. In: Medical Care Research and Review 57 (2000), pp. 181–217.

In the first section of the volume, the authors examine different factors that influence access to healthcare for vulnerable groups. Belonging to such a group can constitute a relevant obstacle in equal participation in medicine and healthcare services.[7] Vulnerable groups can be especially susceptible to discrimination because of structural determinants such as inadequate provision of healthcare services but also because of limited awareness of healthcare professionals to their particular needs. Moreover, lack of sensitivity to the distinct situation of vulnerable groups, such as women, minors, or individuals from gender and sexual minorities can lead to depersonalizing or paternalistic treatment.[8] Therefore, in focus of the contributions gathered in this section stand questions of special attention to the position of vulnerable groups in the healthcare system.

Discussion about challenges in accessing healthcare first requires a scrutiny of questions related to individual autonomy of patients entering the patient-healthcare professional relationship. Hence, this section opens with Julia Allessandra Harzheim's contribution »The role of Patient Autonomy and Informed Consent for equal access to healthcare: A conceptual inquiry of contemporary bioethical debate«. The author explores various normative dimensions of the concept of autonomy, its development, and links to other conceptions across disciplines, countries and scientific inquiries. Basing her analysis on the results of literature review, Harzheim argues that the contemporary debate on this topic is dominated by the understanding of patient autonomy and informed consent, which mostly originate from Anglo-American discourse in social sciences. This notion is contrasted with the concept of autonomy presented in Kantian philosophy. The author concludes that growing attention to questions of equality and discrimination in different scientific disciplines drives interdisciplinary and pragmatic approach as well as various measures to address and resolve these issues. However, this development also presents conceptual challenges, such as introduction of a new definition of vulnerable and minority groups. Therefore, Harzheim holds that re-assessing the concept of autonomy and its links to informed consent in the contexts of vulnerability and social diversity is crucial for any further scientific pursuit in this topic.

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[7] Erika Gathron: Vulnerability in health care: A concept analysis. In: Creative Nursing 25 (2019), pp. 284–291.

[8] David B. Waisel: Vulnerable populations in healthcare. In: Current Opinions in Anesthesiology 26 (2013), pp. 186–192.

After this analysis of conceptual questions connected to issues of autonomy and access to healthcare for vulnerable and minority groups, the following authors in this section focus on challenges and opportunities for particular vulnerable groups: women, children, and individuals of sexual and gender minorities. Nika Pavlović's contribution »Disparities in women's access to reproductive healthcare« analyses the question of women's access to reproductive healthcare in Croatia, Germany, Poland and Slovenia. Starting with an observation on the influence of various factors on women's health and description of the differences in health systems in these four countries, the author focuses her analysis on challenges and initiatives that aim to reduce disparities in access to healthcare for women in each individual country. The analysis shows similar challenges in all countries under analysis. Issues of pregnancy termination, contraception and access to reproductive healthcare for women form minority groups are observable in all four countries; however, with specific inclinations in particular countries. These specificities result in various strategies towards issues such as gaps in access to healthcare for vulnerable groups, in maternal and newborn healthcare, or in meeting healthcare needs of women with migration or minority backgrounds. In the final section of this chapter, Pavlović turns her attention to the question of access to reproductive medicine in times of COVID-19 pandemic, which in many cases compromised access to reproductive healthcare, especially for vulnerable groups; it also, to various extent depending on the country, contributed to expanding telemedicine, e.g., as a tool used in medical consultations. The author concludes that reproductive health education as well as development of professional normative guidelines are necessary for improvement of the situation.

The issue of access to healthcare for vulnerable groups, this time from the perspective of minors, is continued in Gordana Šimunković and Ivana Borić's contribution »Exercise of children's participatory rights in the healthcare system of the Republic of Croatia«. The authors' focal point in this paper lies on the issue of children's vulnerability and their protection and participation. Opening with a theoretical analysis of the concept of children's vulnerability, the authors then move to an analysis of participatory rights of children in the Croatian healthcare system. This analysis starts with an overview of international and national policy documents regarding child participation in the healthcare system, after which the authors move to the question of how a balance between protection of children and their participation in healthcare can be achieved. On this ground, the authors present the results of an international and national study, on the ground of which they identify components for facilitation of children's participation. In their concluding remarks, Šimunković and Borić postulate to further invest in the promotion and education of children's rights, development of guidelines for the participation of children in the healthcare system which will strengthen the connection between policy and practice, and further exploration of the topic in research.

Although there has been considerable progress regarding the acceptance and protection of individuals of sexual and gender minority, they still suffer from substantial discrimination and disparities regarding their access to healthcare. Therefore, in their contribution, Ann Kristin Augst and Annika Spahn examine LGBATIQ patient's experiences in the German healthcare system. Based on group discussions and interviews conducted with queer patients, the authors endeavor to determine the barriers for LGBATIQ individuals in access to healthcare. Moreover, the authors attempt to identify how discriminatory experiences shape the health of LGBATIQ people in Germany. The chapter begins with an overview of the concept of heteronormativity as a theoretical framework and in relation to socio-political and regulations and individual patient-doctor interactions in Germany. Next, Augst and Spahn present results of their research, according to which stigma and discrimination lead to minority stress, which in turn impacts health of affected individuals. Additionally, actual, or even anticipated, discrimination leads to avoidance of seeking of medical attention, which, correspondingly, impacts health of LGBATIQ individuals. Furthermore, deficient awareness on the side of healthcare professionals concerning specific healthcare needs of this group can lead to inappropriate care or even to treatment errors. In order to improve healthcare of the minority group under consideration, the authors propose in their concluding remarks an increased attention to, and reflection on specific needs of queer individuals, especially in situation of medical encounters with healthcare professionals.

Individual experiences of representatives of vulnerable groups can provide important insights into the limits in provision of healthcare services for them but also into consequences for personal life. In the chapter entitled »Becoming a parent as a lesbian in Poland: an autoethnographic narrative« Marta Lewandowska presents a personal narrative about the perspective of homosexual individuals seeking to have a child in Poland. Based on her personal experience, Lewandowska explores individual ordeal on the way to motherhood – from the decision to become a parent, through exploring clinically supported reproduction options in Poland, to the experiences of pregnancy and birth. The personal story of the author provides a framework for an account of legal and social homophobia, stigma, and discrimination. The author's personal story provides a basis for normative and interpersonal recommendations. Without structural and systemic changes to the regulations and medical practice in Poland, Lewandowska concludes, improvement of the situation of homosexual »parents to be« is impossible. These changes should encompass modifications of the legal status of homosexual individuals in Poland and improvement of access to clinical reproduction methods. Moreover, there is a pressing need for support for homosexual persons; through assistance provided to them, through groundwork on discriminatory perception of this group that is prevailing in the society, and through education about experiences of homosexual persons in Poland, not only for healthcare personnel but also for whole society.

The question of access to healthcare for representatives of ethnic, national, and religious minorities stands in the focus of the second section of this volume. This issue arises often with regard to the subject of migration and healthcare. People with a migration background often have a lower socioeconomic status, work in health-damaging conditions, are unemployed, or live in unfavorable conditions.[9] However, religious or ethnic minorities also often face unfavorable situations in healthcare environment due to language and cultural barriers or their beliefs. This can have a deteriorating result on the health situation of individuals from these groups and is especially threatening if it coincides with structural barriers in accessing healthcare.

With regard to these issues, in the contribution »Provision of healthcare for culturally diverse populations: Insights from a qualitative study on dementia care with the members of the Turkish immigrant community in Germany« Zümrüt Alpinar-Sencan examines the situation of first-generation migrants in Germany in accessing healthcare. Through interviews conducted with caregivers and relatives of people with dementia of Turkish descent living in Germany,

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[9] Bernd Rechel, Philipa Mladovsky, David Ingleby, Johan P. Mackenbach, Martin McKee: Migration and health in an increasingly diverse Europe. In: Lancet 381 (2013), pp. 1235–1245.

the author analyses their experiences on dementia care and expectations for counseling. After opening with remarks on provision of dementia care for culturally diverse populations and on culture's role in healthcare ethics, Alpinar-Sencan moves to presentation of the results of qualitative interviews. These highlight the needs of migrant groups in healthcare situations: from information about disease and its management, through social support, to increased sensitivity to cultural differences of the patients from the healthcare professionals. The interviewees' testimonies distinctly show the role of culture in shaping health-related phenomena. Moreover, apparent become the aspects of the impact of migrant life on the initiation of dementia and the importance of family care. Based on the results of the interviews, Alpinar-Sencan underlines the pressing need for culturally sensitive healthcare, which should contribute to overcoming language barriers and improvement of patient-doctor relationship. Moreover, a migration background can cause and reinforce perception of discrimination in healthcare, which can in consequence lead to worse healthcare outcomes. Therefore, the author argues, there is a moral obligation of culturally responsive healthcare. However, in adopting such an approach, individual needs, perceptions, and identities of patients cannot be ignored.

Considerations of influence of religious beliefs on provision of healthcare, on the example of one particular religious group, are in the focus of Dean Markić and Lada Zibar's contribution »Kidney transplantation in Jehovah's Witnesses – the Croatian perspective«. Based on the specific examples of patients treated at the University Hospital Rijeka in Croatia, the authors describe medico-legal and ethical dilemmas revolving around the questions of patient's autonomy and provision of medical care. Especially in the case or religious convictions, like in the case of Jehovah's Witnesses, the medico-ethical principles of autonomy, beneficence, non-maleficence, and social justice present healthcare professionals with challenges. Markić and Zibar present in their chapter the medical as well as legal and ethical perspective on this issue. The authors point out, that in such specific situations, as the ones presented in their chapter, there is a need for clear-cut guidelines prepared with participation of all stakeholders: national legislators, professional medical societies, and patients' associations. Only through involvement of all interested parties and through inclusion of patients' will and choice, as well as the rights and beliefs of healthcare professionals, every patient's access to the best possible healthcare can be offered and guaranteed.

In the following contribution entitled, »Health status and access to the healthcare system of members of the Roma national minority in the Republic of Croatia«, Suzana Kunac and Aleksandar Racz turn their attention to the challenges experienced by a particular minority group, Roma people, in accessing healthcare in Croatia. In their chapter, the authors aim to systematize and analyze the data on the status, access, and discrimination of Roma. They also attempt to deepen the existing knowledge regarding the approach to health of Roma minority in this country. Analyzing the current situation, the authors state that the health of this minority group is influenced by their living conditions, insufficient nutrition, and poverty. This leads to development of chronic non-communicable diseases at a much younger age than in the general population in Croatia. However, as Kunac and Racz observe, a considerable number of Roma individuals report discrimination in healthcare. In order to counteract discrimination of this group, the authors argue for systematic monitoring of data on the use of healthcare, as well as on discrimination, challenges, and obstacles to the use of health services with consideration to the ethnic groups, to which the patients belong. Such actions, supported by research on this topic, could contribute to elimination of systemic barriers in access to healthcare for Roma individuals and allow members of this group access to healthcare on the same conditions as it is provided for the majority of the Croatian population.

In the third thematic section of this volume, the authors focus on the questions of social diversity and access to healthcare from the perspective of different professional groups: medical doctors, nurses, and social healthcare workers. Recognition and understanding of diversity and equality is essential for the provision of quality healthcare.[10] However, in many situations, lacking education about implications of ethnicity, race, culture, belief, or sexual orientation leads to discrimination and diminished healthcare outcomes. Individual discrimination can occur on the level of personal encounters, i.e. between a healthcare professional and an individual patient. Obstacles

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[10] Lesley Baillie, Milika Matiti: Dignity, equality and diversity: an exploration of how discriminatory behavior of healthcare workers affects patient dignity. In: Diversity and Equality in Health and Care 10 (2018), pp. 5–12.

in such individual encounters have various contexts, e.g. they can stem from factors such as language barriers, different concepts of health and disease, or the presence of racism.[11] In their contributions, the authors in this section present how healthcare professionals view diversity and access to healthcare, what challenges in this regard they observe in their countries and their daily practice, and what solutions they offer.

The chapter »Diversity-sensitive healthcare delivery across Poland's clinical landscapes« by Ewa Nowak, Anna-Maria Barciszewska, Karolina Napiwodzka focuses on the perspective of Polish healthcare practitioners in dealing with patients of diverse national, ethnic and cultural backgrounds. In the center of their investigation stands the question of how health providers rate pro-diversity knowledge and competencies of fellow clinicians in ensuring equitable access to health services for minority groups. In order to answer this question, the authors conducted a survey among Polish clinicians employed in hospitals, medical practices, and non-public units. The results show that respondents generally assessed levels of knowledge, awareness, and competence of their fellow clinicians as medium-high to low. Highest scores received clinicians' competence to identify and distinguish diverse sociocultural identities, awareness of stereotypes circulating among clinicians about patients and vice versa, and attitudes toward factors contributing to health disparities. These opinions are not significantly dependent on age, gender, professional specialties, or length of professional service. However, respondents employed in hospitals or clinics rated diversity related knowledge in their collaborators higher than respondents employed in other healthcare units. Main barriers to socio-culturally competent healthcare, according to the respondents, are lack of time, lack of resources and awareness, and prejudices. According to authors, these results, are to be traced to lack of education in the area of diversity-sensitive healthcare and low professional internationalization. Therefore, the question arises whether Polish healthcare sector is sufficiently equipped to deal with the issue of equal access to healthcare for patients from diverse minority groups.

The perspective of healthcare professionals with regard to care for patients with culturally diverse background is further explored in Bojana Filej, Mojca Poredoš and Boris Miha Kaučič's contribu-

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[11] Nancy Krieger: Discrimination and health inequities. International Journal of Health Services 44 (2014), pp. 643–710.

tion »Educational needs of nurses in intensive therapy units to improve attitudes towards interculturally diverse patients in Slovenia«. The focus of the research presented in this chapter is the issue of cultural competency in intensive care units in Slovenia. The authors begin with presentation of the importance of cultural competencies in healthcare environment. Such competencies are crucial for provision of culturally congruent care through better communication with patients and their relatives and respect of patients' beliefs and values. As cultural diversity is one of the major challenges for modern healthcare, integration of specific training, which is aimed at improvement of cultural competencies is central in patient-oriented healthcare. Against this background, the authors ask the question about the need for the education of nurses in intensive care units with regard to their attitudes towards culturally diverse patients. In order to answer this question, the authors gathered qualitative data from 98 healthcare providers from intensive care units in Slovenia. The results show that participants expressed a relatively strong need for education, especially in group of nurses who perceive themselves as sympathetic towards interculturally diverse patients. Based on these results, the authors postulate implementation of educational contents for self-education to improve the cultural knowledge, skills, and competencies of nurses in the ICU, which can consecutively reduce inequalities in treatment for culturally diverse patients.

Beside lack of sufficient education about implications of social diversity on the question of access to healthcare, communication barriers can be a major obstacle for provision of quality healthcare. Therefore, in their contribution entitled »The importance of improving education of healthcare professionals on communication with minorities – experience with Roma in the Croatian healthcare system«, Sanja Pleština and Sandra Karabatić explore this issue by focusing on miscommunication with family members of a Roma patient, which led to an emotional shock. The authors analyze how communication barriers can be triggered by emotions, stereotypes, and conflicts of values and beliefs. Based on the results of a meeting with representatives of the Council of Roma Minorities of the City of Zagreb, the authors present strategies for better understanding and communication with ethnic and cultural minority groups. The authors especially highlight the need for awareness of individual patient's background, culture, and values. Perception of these unique features builds trust in the patient-physician relationship and improves care in the medical setting.

In healthcare encounters, not only medical doctors and nurses play an important role. Other healthcare professions contribute to the provision of quality medical care for various social groups. Challenges of work with patients from culturally diverse groups from the perspective of social workers are presented in Vanja Branica and Ivana Mošić Pražetina's chapter »Improving access to healthcare for minority groups: qualitative study with social workers in Croatia«. Through qualitative research conducted in focus groups the authors had access to the experiences of this professional group working with culturally diverse patients and to examples of good practice. Among main obstacles in provision of quality healthcare for minority groups, the authors mention communication barriers, administrative procedures, and lack of time for attention to patients' issues. The respondents participating in the research acknowledged the need for improvement of the situation, which could be achieved through increased effort in administrative tasks and procedures, improved cooperation within and between institutions and systems, advocacy for patients' rights and improved communication with patients. The goal of better access to healthcare services, so conclude the authors, should be achieved through inclusion of the concept of cultural diversity in educational programs for social workers and healthcare providers throughout their professional career. Moreover, development of work protocols within a hospital and between hospital social workers, social care system, police, and other state agencies could improve provision of quality healthcare for patients from minority groups.

The contributions to this book make it clear that the challenge of providing equal access to healthcare for minority groups is not a marginal matter but stands in the very center of medicine and healthcare nowadays. The chapters show that attention to this question is important from the perspective of all stakeholders in the healthcare system: from patients from minority groups to healthcare professionals, who include physicians, nurses, social workers, and other professions involved in healthcare environment. Individual ethical reflection on this challenge is important. It can start with realization of individual shortcomings in diversity competency and ways to improve it, through perception of different backgrounds, values, and goals of all involved in the healthcare setting, to better communication, not only through reducing language barriers but also through sharing ideas, thoughts, and feelings. However, this is not enough. The amelioration of the situation requires a systemic approach. Provision of education in cultural competency, enhancement of patients' rights, development of joint strategies against discrimination in healthcare on international and national levels, and further research on the topic, involving both patients and healthcare professionals, are only few but important steps towards the goal of socially inclusive healthcare.

I.

Vulnerable groups

Julia Alessandra Harzheim

The role of Patient Autonomy and Informed Consent for equal access to healthcare: A conceptual inquiry of contemporary bioethical debate

Abstract
In contemporary, increasingly interdisciplinary discourse, so-called »patient autonomy« has been emphasized as a moral as well as a legal right of any individual affected, commonly resulting in autonomy understood as a justified claim to make decisions on grounds of provided information within the encounter between physician and patient. The focus on the pragmatic implementation of such concepts through standardization – »best practice« – has contributed to the increasing relevance of terms like »patient choice« and »informed consent« in contemporary bioethics. In order to ensure their normative force in practice of public healthcare, these concepts have been strongly linked to juridical, political and sociological inquiry and measures. Based upon the assumption that the protection of patient autonomy cannot happen successfully and comprehensively without the awareness of their underlying roots, normative dimensions and limitations, these notions are re-assessed on a conceptual level, resulting in an alternative understanding of autonomy and minority groups.

1. Introduction

The rising significance of a notion of autonomy in the context of bioethical debate referred to as »patient autonomy« and its implementation as a well-entrenched ethical principle for so-called »best practice« in public healthcare are undeniable developments. Drawing back upon ideas to strengthen any individual's free choice in healthcare practice and research, seeking to protect patients against involuntary treatment, this understanding of autonomy has become strongly linked to decision making procedures with an emphasis on »patient choice« and the idea of »informed consent« to ensure its realization in medical practice with the aid of legal authority. The increasing overlap of differing normative implications tied together in the same expression, namely »autonomy«, is a result of growing demands of a more complex and interdisciplinary environment and as such a phenomenon that was to be expected. However, problems arise as soon as conceptual roots and limitations disappear not only in pragmatic debate on the implementation of ethical principles, but go unnoticed even in scholarly debate on patient autonomy, aiming at improving issues of discrimination and injustice in public healthcare. Applying a concept like autonomy as *terminus technicus* in a highly specific or stipulative way only, linking it to other notions or even individual requirements, could result in inadvertent effects on the attempt to improve equal access to healthcare. Therefore, in this work, the problematic link between patient autonomy, patient choice and informed consent on the basis of abilities to process information and participate in rational decision making has been of particular interest. Besides, the tension between individual patient autonomy and requirements of public healthcare, often relying upon generalizable and standardized approaches, has been identified as another problem to be discussed. Lastly, the assumption that informed consent and patient autonomy in their current understanding as entrenched ethical and legal principles are always suitable means to protect every individual and ensure justice and equality in public healthcare is challenged by possible disadvantages they might bring about, resulting in an alternative definition of minority groups. Overall, this study aims to re-assess the conception of autonomy by exploring its various normative dimensions, the development of its usage up to the present day and possible links to other notions across several disciplines, countries and scientific inquiries. Emphasis has been laid upon the comparative evaluation of two main branches in medical ethics defending differing views on autonomy. In identifying and discussing these opponent perspectives, conceptual roots of the term are traced back to Kantian philosophy and a notion encountered less frequently in contemporary bioethical debate. Finally, underlying premises and implications of both stances are carefully examined with regard to possible effects on equality and access to healthcare, illustrated by means of selected examples.

For this purpose, an evaluation of international and interdisciplinary discourse on (in)equality in the context of healthcare, social diversity and minority groups has been conducted, whose procedural details will be explained in part 2 (Methods and Materials). Relevant research literature has been selected and analyzed based upon the following research questions, which will be re-addressed in part 3 (Results): (1) Which methods have been employed in order to survey (un)equal access to public healthcare, and which areas of expertise or subjects of examination have been central for conducting these inquiries? Is there a certain systematic order which could be identified? If so, how have concepts, definitions and terms been applied in the resulting categorization of research? (section 3.1.); (2) Based upon which criteria, e.g. certain features or traits of individuals, has contemporary research on social diversity and minority groups as well as discrimination in healthcare mainly been conducted? As one aim of this study is to accentuate the conceptual links of »patient autonomy« and »informed consent« with pivotal notions in research on minority health and social diversity, the understanding and application of these two concepts is examined against this backgroundand thus embedded into the broader topic of this book (section 3.2.); (3) If the conception of »patient autonomy« has been incorporated into research on social diversity and minority health, how has it been defined, which normative ideas are carried over – and what implications for individual and public healthcare could eventuate, especially with regard to (in)justice and equality? It will be demonstrated that there is a predominant understanding of patient autonomy stronlgy linked to the idea of informed consent in contemporary bioethical debate,mostly emanated from Anglo-American discourse in social sciences and related research areas (section 3.3.1.). This stance, which represents the results of a systematic and international literature review, is contrasted by a different notion, drawing back on conceptions of autonomy according to Kantian philosophy (section 3.3.2.), which is expanded to questions of medical care in the selected material. In the following part 4 (Discussion), the results of this contrastive evaluation are applied to the individual medical encounter between patient and physician first – it is illustrated how and in which way current understandings of patient autonomy could even contribute to inequality and exclusion in certain cases (section 4.1.), thus introducing a different definition of minority groups (section 4.2.). After extending the findings to systematic problems of injustice and discrimination in public healthcare (section 4.3.) and a critical evaluation of the threats just as the undeniable importance of informed consent requirements (section 4.4.), possible limitations of this work and its methodology are provided to the reader in part 5. In the final part (Conclusion), the strong appeal to re-assess fundamental normative concepts like autonomy is reinforced by consolidating the main findings of this work in a condensed and concise summary.

2. Methods and Materials

Methods of this work include both systematic literature review in order to identify and present predominant stances in contemporary bioethical discourse and an additional non-systematic evaluation of several opponent perspectives in order to re-assess concepts, terms and definitions by means of a contrastive, comparative analysis.

2.1. Systematic literature review

In order to identify a corpus of textual material representing the predominant stances on the research questions formulated above, a systematic literature search was conducted in the electronic databases Pubmed, Embase, SpringerLink and Wiley Online Library in a two-step procedure, following the guidelines set forth by the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA 2020). For this purpose, several key words in accordance with the subject of this work had been established, as detailed in Table 1. Based on the two core keywords and additional keywords strongly related to the thematic focal point of the book, here defined as »contextual keywords« or »contextual search strings – stage I«, a large corpus of central texts was identified in a first step. Following an initial reading phase and overview, the search scope was augmented by identifying further search strings as listed in »contextual search strings – stage II«, which appeared most frequently in the literature resulting from the primary search. This way, the usage of the core keywords within the context of social diversity and public healthcare could be examined more comprehensively. The key words were joined by either »AND« or »OR«.

Stage	Algorithm
Core keywords	*»autonomy« (Title/Abstract) AND/OR »informed consent« (Title/Abstract)*
Contextual search strings – stage I	*»minority group*" (Title/Abstract) AND/OR »social diversity« (Title/Abstract) AND/OR »public health care« (Title/Abstract) AND/OR »injustice« (Title/Abstract) AND/OR »justice« (Title/Abstract)*
Contextual search strings – stage II	*»minority health disparit*« (Title/Abstract) AND/OR »medical ethics« (Title/Abstract) AND/OR »ethical tool*« (Title/Abstract) AND/OR »decision making« (Title/Abstract AND/OR »beneficence« (Title/Abstract) AND/OR »paternalism« (Title/Abstract) AND/OR »patient choice« (Title/Abstract)*

Table 1: Search algorithms for the systematic literature search

For inclusion in the initial comprehensive literature review, articles needed to meet the following criteria: 1) abstract available in English or German language, 2) free full text available, 3) date of publication between 1970 and 2022, 4) at least one keyword in either title or text. Articles were excluded if they did not meet the stated inclusion criteria. Thus, a primary corpus of research literature was identified with a total of more than 8000 works, not limited to a specific area or country and therefore including American or English literature as well as works created in Germany or other EU countries, including both qualitative and quantitative research, ranging from the 1970s to having been published only recently in 2022. Research conducted within the last two decades was of particular interest. After a digital screening of the contents for a combination of certain keywords, e.g. the combination of the keyword »autonomy« or »informed consent« with the keyword »minorities« in title or text, the resulting material could be further reduced in size. In total, 2266 texts available in the databases were identified this way. Based on an even more specific content screening for inclusion of additional keywords as presented in table 1 and after the elimination of a huge data redundancy caused by works appearing in multiple databases, a total of 234 full texts and linked bibliographical data were imported into MAXQDA 11 for textual analysis. Relevant text passages were labelled with coding that was generated deductively and inductively. Publications on patient autonomy or informed consent combined with an inquiry on social diversity and minority groups have been preferred in the final selection process in order to keep a strong thematic link to the topic of the book, i.e. social diversity and access to healthcare for minority groups. Finally, based on these criteria and various search procedures, a number of 89 works which appeared to be most significant and cover predominant stances without redundancy was selected to be examined and evaluated manually with due regard to the research questions formulated above, meant to represent the main contemporary understanding of autonomy and informed consent in the context of medical healthcare.

2.2. Non-systematic documentary evaluation

As this work not only aspires to provide an overview of predominant international perspectives on the research questions formulated in the introduction, accessible via systematic literature search in online databases, but constitutes a contrastive conceptual inquiry, not all positions cited in the following parts have been obtained via systematic literature review procedures. A non-systematic documentary evaluation was preferred as an additional methodological approach for representing perspectives rarely discussed in international bioethical discourse, not open to systematic review procedures due to the limitedamount of eligible material.. But not solely the notably small number of texts defending other stances did advise against an exclusively systematic literature review, suggesting this additional methodological approach. Instead, it was deemed necessary for the conduct of a conceptual inquiry and comparative evaluation whose aim was to identify similar notions appearing in various contexts, likely to differ in terms, understanding and application. Relevant research material applying diverging terms whilst nonetheless referring to genuinely similar underlying notions might have gone unnoticed in a purely systematic search procedure. This applies specifically to the notion of autonomy according to Kantian philosophy, which could only be portrayed using a small sample of Continental research literature. The material evaluated for this purpose has been selected manually in order to contrast more common understandings of »patient autonomy« in the field of applied ethics (especially when linked to questions of social justice and equality). Material for this part of the literature evaluation has been selected according to the four criteria of documentary research suggested by John Scott,[1] with an emphasis on the criterion of representativeness and on the criterion of meaning (being understood as a comprehensive hermeneutical approach, allowing the researcher to draw conclusions as interpretation of both analysis of text/style and content). In total, 14 positions cited are not covered by the systematic literature analysis conducted in the databases. These works were chosen manually because they were either judged to constitute significant opposing stances in comparison with the results of the systematic literature analysis, or as they appeared to add new perspectives to the controversies discussed in part 4 (Discussion).

3. Results

3.1. Overview of research literature and categorical evaluation

As a result of the overall examination of the corpus of literature with regard tocore questions of inquiry, aims and methods employed, three different levels of research and their respective features of methodological approaches could be identified.

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[1] John Scott: A matter of record: documentary sources in social research. Cambridge 1990.

3.1.1. Level one: implementation, concrete observation, evaluation

On this level, research is directed to evaluating the concrete benefits and/or issues of particular implementations and healthcare practices observable. In the context of social diversity and medical ethics, this inquiry could, for example, lead to examinations on whether so-called ethical consultants are able to improve healthcare by supporting encounters with the aid of ethical frameworks.[2] A large area of research on this level is committed to investigating how certain features of social diversity, e.g. gender/sex, are likely to influence treatment in a particular setting and according to well defined criteria.[3] Methods include both empirical approaches as well as qualitative methods, e.g. interviews. In this work, level one research comprises not only investigations into individual encounters between physician and patient, but also addresses institutional and governmental measures, e.g. so-called »organizational ethics«[4] or the evaluation of EU legislation in order to systematically improve equality and access to public healthcare,[5] such that the subject of examination is a concrete and particular question which is related to practice.

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[2] Chris Kaposy, Fern Brunger, Victor Maddalena, Richard Singleton: The use of ethics decision making frameworks by canadian ethics consultants: A qualitative study. In: Bioethics 30 (2016), pp. 636–642.

[3] Florence D. Mowlem, Mina A. Rosenqvist, Joanna Martin, Paul Lichtenstein, Philip Asherson, Henrik Larsson: Sex differences in predicting ADHD clinical diagnosis and pharmacological treatment. In: European Child and Adolescent Psychiatry 28 (2019), pp. 481–489.

[4] Christiane Burmeister, Robert Ranisch, Cordula Brand, Uta Müller: Organisationsethik in Einrichtungen des Gesundheitswesens. In: Ethik in der Medizin 33 (2021), pp. 153–158; Patrick Schuchter, Thomas Krobath, Andreas Heller, Thomas Schmidt: Organisationsethik: Impulse für die Weiterentwicklung der Ethik im Gesundheitssystem [Organizational ethics: Impulses for the further development of ethics in the healthcare system]. In: Ethik in der Medizin 33 (2021), pp. 243–256.

[5] Marcin Orzechowski, Marianne Nowak, Katarzyna Bielińska, Anna Chowaniec, Robert Doričić, Mojca Ramšak, Paweł Łuków, Amir Muzur, Zvonka Zupanič-Slavec, Florian Steger: Social Diversity and access to healthcare in Europe: how does European Union´s legislation prevent from discrimination in healthcare? In: BMC Public Health 20 (2020), https://doi.org/10.1186/s12889-020-09494-8.

3.1.2. Level two: meta level – underlying mechanisms, dynamics, interactions

Research conducted on this level is committed to questions, measures and subjects of study which presumably highly affect practical healthcare patterns and are linked to problematic dynamics, but are not directly measurable and accessible; e.g. studies examining patterns and elements of health communication[6] or studies on judgment and decision-making in the context of medical decision making,[7] supposed to bring about a better understanding of how certain mechanisms come to play, interact and actually affect the settings in which discrimination could occur. In recent works, the attempt to detach conceptions like discrimination from highly specialized fields of inquiry like e.g. gender health disparities is made by means an extension to more general concerns of health and equality in medical practice.[8] The conceptual level is of relevance for this type of research; however, concepts are appropriated according to the inquiry and its aims, such that, e.g., the examination of communication in the context of possible biases[9] is not touching the concept of communication and its dimensions, limitations and different understandings in general. On this level, research becomes increasingly interdisciplinary in both methods and materials, which can be regarded as a result of the demands of the subject of examination. This tendency is accompanied by major effects on the terminology as well as underlying conceptual dimensions of scientific works: concepts from one area are made use of in order to assess or even legitimize another. Methods tend to include empirical research, data evaluation or systematic analysis. So-called evidence-based approaches and quantifiable features are of major relevance in the first place, whilst conclusions on a more abstract

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[6] Neda Ratanawongsa, Benyam Hailu, Dean Schillinger: Health Communication as a Mediator of Health and Healthcare Disparities. In: Irene Dankwa-Mullan, Eliseo J. Pérez-Stable, Kevin L. Gardner, Xinzhi Zhang, Adelaida M. Rosario (Eds.): The Science of Health Disparities Research. First Edition. Hoboken 2021, pp. 339–358.

[7] Robert M. Hamm: Medical Decision Scripts: Combining Cognitive Scripts and Judgment Strategies to Account Fully for Medical Decision Making. In: David Hardman, Laura Macchi (Eds.): Thinking: Psychological Perspectives on Reasoning, Judgment and Decision Making. Hoboken 2003, pp. 315–345.

[8] Maximiliane Hädicke, Claudia Wiesemann: Was kann das Konzept der Diskriminierung für die Medizinethik leisten? [What can the concept of discrimination provide for medical ethics?]. In: Ethik in der Medizin 33 (2021), pp. 369–386.

[9] Ratanawongsa, Hailu, Schillinger: Health Communication (Note 6), here p. 346.

and conceptual level are rather inferences from the phenomenon observed. Otherwise, terms and definitions are made use of in a technical and pragmatic way in order to conduct the examination according to relevant determinants and salient features, c.f. the not otherwise specified notion of »trust« as a key element within the identification of relevant components of successful communication.[10]

3.1.3. Level three: conceptual level – re-assessing concepts, terms and definitions

Works in the context of social diversity and public healthcare which address the underlying terms, definitions and concepts applied within research conducted on level one and two could be categorized as »conceptual inquiry« of research. In contrast to the aforementioned types of research, concepts, definitions and terms, their contextual relations and their application in the sciences, methodologically as well as regarding their normative implications, are themselves subject of inquiry. Differently put, assumptions necessary to conduct research on level one or two are not taken as starting points for other, more specific inquiries, nor are they to be inferred after the collection of data – instead, they are re-assessed by means of an inverse analytic procedure. Not the question how a certain inquiry could be carried out in an effective manner and according to already established premises and goals of evaluation is central to the examination, but the question what underlying notions are subject to most inquiries, in which aspects they differ from one another, make use of same terms and which implications they thereby involve. Consequently, these works are highly sensitive to otherwise – necessarily so – neglected dimensions of concepts and terms applied, questioning their implicit semantic and genuinely normative content as well as possible effects on research conducted on level one or two. They thus serve as a potential corrective and reflexive means to complete, support and accompany other research. This article aims at conducting a level three examination of relevant notions, dimensions and implications of »autonomy« and »informed consent«, first as applied within the medical encounter, then with special regard to research on public healthcare and minority health disparities. For this purpose, selected literature which could be attributed to level three research will be

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[10] Ratanawongsa, Hailu, Schillinger: Health Communication (Note 6), here p. 341.

discussed in the scope of the work, partly with the aid of evaluation of research work conducted on level one or two.

3.2. Research on Social Diversity and Minority Health: The relevance of Patient Autonomy and Informed Consent

Research on social diversity and minority health in the context of public healthcare primarily challenges questions of justice and equality regarding the distribution of access to medical care, its quality and possible disparities. On the basis of what has been defined as, for instance, »social diversity«, »minority groups« or »minority health«, these inquiries on possible inequalities grounded their most eminent determinants in individual, so-called socially salient features, which have been identified as socioeconomic status, geographic aspects, ethnicity or race in the past.[11] Similarly, in recent debates on health disparities, socially salient features like race and ethnicity, gender identity and sexual orientation and religion or belief are highlighted and examined with regard to their correlation with unequal access to public healthcare.[12] In order to investigate, measures on a national level, e.g. through the American National Institute on Minority Health and Health Disparities,[13] the European legislation[14] or institutional measures[15] have been subject to such examinations with the above mentioned terms and features serving as relevant criteria according to which a systematic analysis could be conducted. Research on these questions, aiming at bringing about a better understanding and detection of relevant features, patterns, and dynamics, could be

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[11] Eliseo J. Pérez-Stable, Jennifer Alvidrez, Carl V. Hill: Definitions, Principles, and Concepts for Minority Health and Health Disparities Research. In: Irene Dankwa-Mullan, Eliseo J. Pérez-Stable, Kevin L. Gardner, Xinzhi Zhang, Adelaida M. Rosario (Eds.): The Science of Health Disparities Research. First Edition, Hoboken 2021, pp. 1–2.

[12] Orzechowski, Nowak, Bielinska, et al.: Social Diversity (Note 5), here p. 1.

[13] Pérez-Stable, Alvidrez, Hill: Definitions, Principles (Note 11), here p. 1.

[14] Orzechowski, Nowak, Bielinska, et al.: Social Diversity (Note 5).

[15] Robert Ranisch, Annette Riedel, Friedemann Bresch, Hiltrud Mayer, Klaus-Dieter Pape, Gerade Weise, Petra Renz: Das Tübinger Modell der »Ethikbeauftragten der Station«: Ein Pilotprojekt zum Aufbau dezentraler Strukturen der Ethikberatung an einem Universitätsklinikum [The Tübingen model of the »ethics delegate of the ward«: A pilot project to set up decentralized structures for ethics advice at a university hospital]. In: Ethik in der Medizin 33 (2021), pp. 257–274.

attributed to what has been referred to as level one or level two research, oftentimes making use of empirical evidence, qualitative interviews and systematic analysis. »Social minority groups«, as a first conclusion, have first and foremost been defined by sociologically salient features and, on the grounds of these, they are *eo ipso* regarded as threatened in maintaining their autonomy: in the context of healthcare by either other individuals, institutional or governmental restrictions, or the medical professional, who is portrayed as a potential source of paternalism by design and *ex professo*. With regard to medical ethics and healthcare, it is especially the concept of so-called »patient autonomy« which has received wide ranging attention from international and interdisciplinary discourses. »Patient autonomy«, in this context, is commonly defined as constrained power to exert influence within a treatment or decision making process; it is rarely subject to examinations itself, but serves as a component that shall be increased in order to enable access to proper healthcare, avoid unnecessary or inadequate treatment as well as discrimination by institutions or medical professionals. In their work, Moulton and King[16] are referring to the study once conducted by J. A. Glover,[17] which is identifying the »(…) current chief medical officer (…)«[18] of a certain public health region as »the only significant predictive facto[r]«[19] for healthcare disparities detected in the context of the study – aside from socioeconomic well-being. Additionally, evaluating another study on geographic disparities,[20] they summarize that »(…) physician recommendations (…) to the patient were major driving forces of these variations, rather than clinical need or patient preference.«.[21] Based on this, they proceed to claim that:

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[16] Benjamin Moulton, Jaime S. King: Aligning Ethics with Medical Decision-Making: The Quest for Informed Patient Choice. In: The Effects of Health Information Technology on the Physician-Patient Relationship. In: Journal of Law, Medicine and Ethics 38 (2010), pp. 85–97.

[17] J. Alison Glover: The Incidence of Tonsillectomy in School Children. In: Proceedings of the Royal Society of Medicine 31 (1938), reprinted in: International Journal of Epidemiology 37 (2008), pp. 9–19.

[18] Moulton, King: Aligning Ethics (Note 16), here p. 85.

[19] Moulton, King: Aligning Ethics (Note 16), here p. 85.

[20] John E. Wennberg, Alan Gittelsohn: Small Area Variations in Health Care Delivery: A Population-Based Health Information System Can Guide Planning and Regulatory Decision Making. In: Science 182 (1973), pp. 1102–1108.

[21] Moulton, King: Aligning Ethics (Note 16), here p. 85.

> As a result, over the last three decades, medical ethicists have shifted from guiding physicians to focus on beneficence and improving patient health (…) toward a more subjective and patient-centered' practice, which also prioritizes patient autonomy in medical decision making.[22]

In contemporary bioethical and sociological discourse, any patient's autonomy is widely regarded as a highly desirable and morally required, yet still unduly omitted basis of their right to be treated equally – in comparison to either other patients, or within a strongly hierarchical medical encounter.[23] Patient autonomy thus not only serves as a legitimate basis for claims to equal access but is also regarded as manifestation of an equal and just public healthcare system on an individual level: In such a system, patient autonomy could unfold without restrictions and limitations imposed on said autonomy, e.g. by systematic or individual discrimination. Furthermore, patient autonomy is frequently interpreted as individual freedom and independence within a community, finding expression in not only right to participation but even relative power in decision making, in particular within the medical encounter.[24] Patient autonomy is, moreover, discussed as an individual capability which needs to be proven, exercised and increased in order to improve equality and care for the individual affected – resulting in the vague yet complex notion of so-called »informed consent«,[25] which will be of major relevance for this work. Stavroula Tsinorema notes that: »The idea of ›informed consent‹ is well entrenched in medical care (…) and forms an outstanding feature of bioethical reasoning. It is taken to signify a paradigm shift from a discredited model of medical paternalism in medical ethics.«[26] This way, patient autonomy has mainly been captivated in its active and relative dimension in the context of decision-making procedures from the perspective of either patient or physician.

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[22] Moulton, King: Aligning Ethics (Note 16), here p. 85.

[23] Mark Sullivan: The New Subjective Medicine: Taking the Patient´s Point of View on Health Care and Health. In: Social Science and Medicine 56 (2003), pp. 1595–1604.

[24] Moulton, King: Aligning Ethics (Note 16), here p. 86.

[25] Moulton, King: Aligning Ethics (Note 16), here p. 86.

[26] Stavroula Tsinorema: Consent and autonomy in contemporary Bioethics. In: Annuaire International Des Droits De L'Homme 8 (2016), pp. 229–244, here p. 233.

3.3. The concept of Patient Autonomy: Terms, definitions and normative claims

In the course of the literature analysis, differing notions of autonomy appearing in the specific context of healthcare as »patient autonomy« could be attributed to one of the two general conceptions elaborated below.

3.3.1. Autonomy as individual right to rational decision making: defying paternalism

As Stavroula Tsinorema is highlighting in her work committed to more recent understandings of autonomy in medical healthcare and their reliance upon other notions and concepts: »Overall, in international documents there has been a gradual shift toward specification of detailed processes of consent and a close link to right-based discourse coupled with appeal to the principle of individual autonomy.«[27] This observation fits the hypothesis arrived at in this work after an analysis of research on the topic. The distinction between legal and moral dimensions is blurred, legal passages make use of the word referring explicitly to moral dimensions when justifying a decision and vice versa. Within this broad notion, patient autonomy is generally portrayed as a moral as well as a legal right and a justified claim to make decisions voluntarily and rationally after having beenprovided with all relevant information through an act or procedure summarized as »informed consent«. For the physician and the institution of healthcare, the act of obtaining such informed consent from the person treated is a legal obligation, with only few exceptions, e.g. emergency treatment or the loss of consciousness – which can challenge the motivation of both physician and patient to interact in a more immediate, genuinely interpersonal process. Indeed, as Moulton and King rightly criticize, in many healthcare settings »(…) legal informed consent requirements have reduced (…) to obtaining a patient's signature on a written form, which is rarely read and even less frequently understood.«[28] If, within this branch of research literature, problematic aspects of concepts like autonomy are discussed, they especially

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[27] Tsinorema: Consent and autonomy (Note 26), here p. 232.

[28] Moulton, King: Aligning Ethics (Note 16), here p. 90.

address the controversy about how much information should be revealed to the patient so they can act autonomously, and under which circumstances, or to which degree, the disclosure of information is desirable and hence morally justified: »Health services research (…) reveals a consistent pattern of inadequate information disclosure and low patient comprehension and retention.«[29] In other cases, the possibility that a patient´s cognitive capacities are impaired enough to question the integrity of personhood and autonomy are discussed;[30] here, the immediate link to the ability to grasp, being informed and making decisions rationally is most obviously accepted as an implicit premise. Possible limitations of any individual's autonomy and the problematic results for patients in suspicion of lack of such capacity are already addressed.[31] In the context of medical settings in international medical ethics discourse, autonomy has additionally been directly related to so-called patient centered decision making or patient choice and even the notion of general beneficence, as opposed to otherwise dominant paternalism of physicians and maleficence.[32] However, the link between patient autonomy and beneficence as opposed to physician authority, or paternalism, is not consistently portrayed in research literature. Moulton and King, for example, claim that an inadequate amount of patient autonomy could pose a threat toward so-called beneficence: »Whilst the shift toward autonomy is well represented in the literature and ethical guidelines (…), physicians have yet to strike the ideal balance between absolute patient autonomy and beneficence.«[33] Within their work, they argue that too much disclosure of information would ultimately coerce the patient

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[29] Moulton, King: Aligning Ethics (Note 16), here p. 87.

[30] Rebecca S. Dresser: Life, Death and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law. In: Arizona Law Review 28 (1986), pp. 373–405; Rebecca S. Dresser, John A. Robertson: Quality of Life and Non-Treatment Decisions for Incompetent Patients: A Critique of the Orthodox Approach. In: Law, Medicine and Health Care 17 (1989), pp. 234–244; Ronald Dworkin: Life's Dominion. New York 1993, pp. 218–237.

[31] Katrina Hauschildt, Raymond De Vries: Reinforcing medical authority: clinical ethics consultation and the resolution of conflicts in treatment decisions. In: Sociology of Health and Illness 42 (2019), pp. 307–326, here p. 315 and 319.

[32] Kunal Bailoor, Thomas Valley, Chithra Perumalswami, Andrew G. Shuman, Raymond DeVries, Darin B. Zahuranec: How acceptable is paternalism? A survey-based study of clinician and non-clinician opinions on paternalistic decision making. In: AJOB Empirical Bioethics 9 (2018), pp. 91–98.

[33] Moulton, King: Aligning Ethics (Note 16), here p. 85.

into making a medical treatment decision without the support of the physician and medical expertise, in which cases »(...) the pendulum has swung too far. The unmitigated rise of autonomy can result in the decline of beneficence.«[34] The two notions of autonomy and beneficence have also been described as conflicting in many cases from the perspective of clinicians and so-called »best practice«.[35] The relative »authority« of patient or physician has become the epicenter of a lively debate in the context of clinical decision making: As Katrina Hauschildt and Raymond De Vries portray within their work,[36] the alleged rivalry between »Patient vs. physician autonomy«[37] is seen as a huge issue, with physician authority, often equaled with physician autonomy, contributing to injustice because it supposedly reduces the autonomy of the patient. It is argued that, even in cases where ethical consultants are involved in solving ethical conflicts, they still tend to seek the expertise of clinicians and thereby reinforce medical authority, albeit in a far subtler way, into the encounter.[38] Thus, the increase of patient autonomy is still regarded as an effective and desirable measure for a just medical environment within most bioethical and sociological research literature. In case this approach is rejected, objections refer to hierarchical encounters by design and necessity, emphasizing possible outcomes if the role of the medical professional and their expertise were neglected: the underestimation of medical expertise and guidance could lead to overwhelm of patients not prepared and skilled enough to understand medical treatment options to the degree necessary for decision making.[39] Additionally, it is considered preferable for medical ethics to train physicians who are in charge and enabled to perform decisions *ex professo* in being virtuous instead of trying to limit their influence.[40]

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[34] Moulton, King: Aligning Ethics (Note16), here p. 85; Ruth R. Faden, Tom L. Beauchamp: A History and Theory of Informed Consent. Oxford, New York 1986.

[35] Hauschildt, De Vries: Reinforcing medical (Note 31), here p. 319.

[36] Hauschildt, De Vries: Reinforcing medical (Note 31), pp. 307–236.

[37] Hauschildt, De Vries: Reinforcing medical (Note 31), here p. 319.

[38] Hauschildt, De Vries: Reinforcing medical (Note 31), here p. 317.

[39] Hauschildt, De Vries: Reinforcing medical (Note 31), here p. 319; Sharon R. Kaufmann: Ordinary Medicine: Extraordinary Treatments, Longer Lives, and Where to draw the Line. Durham 2015.

[40] Hauschildt, De Vries: Reinforcing medical (Note 31), here p. 319; Howard Brody: The Healer's Power. New Haven 1992.

3.3.2. Kantian autonomy as an inherent status sui generis

Whilst the focus of most recent and international research on the topic has been laid upon structural and generalizable measures after evaluating collective data and general tendencies, which resulted in fields like »organizational ethics«[41] or tools like »ethical frameworks«[42] applicable to medical decision making as a standard procedure, only few scholars have offered an alternative yet non-arbitrary perspective on ethical decision making and justice in healthcare by drawing attention to more direct, immediate and genuinely interpersonal concepts of high relevance for any doctor-patient relationship. Aside from virtue ethics, which can be re-assessed e.g. by means of Aristotelian concepts in a fruitful way ,[43] those approaches are mostly based upon Kantian ethics. Here, the aforementioned definitions and especially the strong link or even interdependence with concepts like informed consent are not denied; meanwhile, in contrast to the notion of autonomy explained in Section 3.3.1., they are not adopted as a premise or a conclusion to arrive at but discussed as possibly problematic. With regard to its social as well as individual dimensions, autonomy has largely been portrayed as an expression or requirement of individual freedom in the sense of independence and self-empowerment, almost exclusively without referring to genuinely social aspects. Thomas Sören Hoffmann, for instance, notes that: »›Autonomy‹ is one of the keywords of modern ethics and its orientation on the realization of freedom (...)«, subsequently stating that »(...) misunderstandings appear as soon as the original sense of ´autonomy´ as the rational self-legislation of human action is confounded with mere formal self-determination or even mere arbitrariness.«[44] In his work on autonomy, the Kantian notion including the dimension of limitation of individual autonomy, resulting from its essentially interpersonal nature, are elucidated and then applied to relevant examples within medical healthcare practice. The crucial question for him seems to be the relationship between autonomy and what he refers to as

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[41] Burmeister, Ranisch, Brand, Müller: Organisationsethik (Note 4); Schuchter, Krobath, Heller, Schmidt: Organisationsethik: Impulse (Note 4).

[42] Kaposy, Brunger, Maddalena, Singleton: The Use (Note 2).

[43] Marcus Knaup: Virtues: foundations for medical ethics? In: European Journal for Person Centered Healthcare. 3 (2015), pp. 108–112.

[44] Thomas S. Hoffmann: On the Relation of Autonomy, Self-Determination and Arbitrariness. In: Imago Hominis 23 (2016), pp. 189–198, here p. 189.

the German equivalent of »care« (»Fürsorge«),[45] which ideally seeks to form a complementary and not competing concept in medical healthcare – especially being aware that individuals tend to heavily rely upon others in situations, in which they are seeking medical help and need treatment. Indeed, the quest for autonomy cannot be extended to public healthcare without questioning this premise of mere self-determination, and similarly its connection with other alleged requirements in order to be considered an autonomous living being. In her work, Stavroula Tsinorema adverts to complex underlying premises and problematic links, criticizing that:

> (…) Only where this capacity [note: the capacity to have a distinctive character and act out of a sense of identity with one's values (individuality)] exists over a continuous period of time (…) does one have the required abilities so as to claim a right for autonomy.[46]

Aside from the stipulation of autonomy as a legal or moral right on the basis of certain abilities (implying a dependency of autonomy on said abilities as a prerequisite), it is the disconnection of this idea from social dimensions which seems highly debatable in comparison with her own notion of autonomy. She thus proceeds to clarify that:

> (…) Kantian autonomy is not a ›value‹ or a ›right‹. Autonomy is necessarily attributed to the will of each and every moral agent, qua member of the human community. (…) Put differently, autonomy means responding to moral reasons. It is not merely an individual right or a value, but a structural feature of moral agency and is, as such, presupposed by all rights and duties. Rights stem from (moral) autonomy. (…) Kant does not ground moral requirements on some prior value, or some valuable feature to be found in other human beings. Rather, he turns the relation the other way round: something has value because it is morally required.[47]

This means, amongst other things, that individual autonomy cannot be thought without autonomy of others, for it is constituted by a shared moral endeavor to respect other beings in their autonomy, famously formulated as the Categorical Imperative in Kantian phi-

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[45] Hoffmann: On the Relation (Note 44), here p. 191.

[46] Stavroula Tsinorema: The Principle of Autonomy and the Ethics of Advance Directives. In: Synthesis Philosophica 59 (2015), pp. 73–88, here p. 80.

[47] Tsinorema: The Principle (Note 46), here p. 82.

losophy,[48] and thus forms individual autonomy in relation to all other human beings.[49] Although this relational aspect sets limits for individual autonomy, it is therefore a genuinely social and interpersonal, not at all separating idea.[50] Autonomy is nonetheless an absolute, not a relative, individual status and an inherent property or, in Latin, »proprium«,[51] independent from abilities and capacity for performance – instead, it results from higher moral and shared principles, and every human being is an autonomous being qua member of the moral community.[52] Assuming that autonomy is indeed, as Kant put it, the ground of the dignity of human nature and every rational nature,[53] it seems even more problematic to couple dignity to aspects of so-called competence, control and voluntary rational decision making, additionally relying upon alternatives open to the individual having to perform the choice within the medical healthcare setting. This stance is contrasted by more comprehensive notions; e.g. by Jan P. Beckmann, who is clarifying that, according to Kantian conceptions, the capacity to make decisions rationally and thus be an autonomous being is an inherent property[54] which can be violated, just like human dignity – but which cannot be taken away, get lost or be considered decreased, even in the case of significant impairment and loss of decision making abilities.[55] Therefore, any human being is autonomous sui generis, instead of in possession of, more or less, autonomy; the autonomous decision is a manifestation of inherent autonomy and ought not to be confused with a prerequisite or requirement.[56]

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[48] Immanuel Kant: Grundlegung der Metaphysik der Sitten [Foundation of the metaphysics of morals]. In: Akademie der Wissenschaften (Hg.): Immanuel Kant: Gesammelte Schriften [Collected Writings], AA Bd. IV. Berlin, here p. 450.

[49] Jan P. Beckmann: Autonomie: Aktuelle ethische Herausforderungen der Gesellschaft [Autonomy: Current ethical challenges of society]. Freiburg, München 2020, here pp. 21–23.

[50] Beckmann: Autonomie (Note 49), here pp. 21–23.

[51] Beckmann: Autonomie (Note 49), here pp. 21–23.

[52] Tsinorema: The Principle (Note 46), here p. 82.

[53] Kant: Grundlegung (Note 48), here p. 436.

[54] Beckmann: Autonomie (Note 49), here p. 21.

[55] Beckmann: Autonomie (Note 49), here pp. 21–22.

[56] Beckmann: Autonomie (Note 49), here p. 22.

4. Discussion

4.1. Patient Autonomy and Informed Consent in individual medical encounters

Two notions of patient autonomy and their links to so-called informed consent have been discussed above. The way in which especially the reliance of the latter upon the quest for »rational decision making« and the actual cognitive ability to do so could affect public healthcare in such a way that it possibly results in less equal access shall be illustrated by means of selected examples in this section. In the context of dementia, so-called advance directives based upon what is coined »precedent autonomy«[57] in the form of legal instructions or designating someone on behalf, a proxy, are seen as legitimate solutions to ethical questions of treatment options under certain conditions. However, as a measure of so-called post-competence seemingly ensuring self-determination and control of one's own life before loss or decrease of the ability to make choices rationally could occur, notions like precedent autonomy likewise reveal some limitations of underlying normative and philosophical grounds, e.g. regarding the idea of personhood, which is sometimes taken to be discontinuous on the basis of cognitive changes. In her work, Stavroula Tsinorema challenges such views and contrasts them with the Kantian notion of autonomy; as a conclusion, she states:

> (...) when obvious harm to the contemporary patient's well-being will be a consequence of the application of the advance directive, those making the decision ought to scrutinize carefully whether and to what extent the author of the directive anticipated and considered the effects now occurring. As Onora O'Neill puts it, quoting Bernard Williams, ›we should not put too much weight on the fragile structure of the voluntary‹.[58]

Whilst Stavroula Tsinorema is highlighting the necessity to re-assess the current situation through the perspective of the »author of the directive«, i.e. the »previously competent patient«,[59] thereby putting

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[57] Ronald Dworkin: Autonomy and the Demented Self. In: The Milbank Quarterly 64 (1986), pp. 10–14.

[58] Tsinorema: The Principle (Note 46), here p. 86; Onora O'Neill: Questions of Life and Death. In: The Lancet 372 (2008), pp. 1291–1292.

[59] Tsinorema, The Principle (Note 46), here p. 86.

less emphasis on the voluntary, represented by the current will or agreement of the patient, this stance is debatable and highly objected in other contexts. In a qualitative study on informed consent and its effect on research in the context of dementia,[60] the authors conclude that their inquiry on research ethics raises the question:

> (…) whether the current prevailing emphasis on the cognitive aspect of autonomous decision making, i.e., comprehension, may be too one-sided, and to what extent the ›volitional‹ aspect in giving consent should be given greater consideration.[61]

At first glance, this conclusion appears to be in direct opposition to what Stavroula Tsinorema is arguing for in her work cited above. And indeed, the aspect of the so-called voluntary dimension of autonomous decision-making is where both works essentially differ from one another. Yet, this observation ought to be examined more carefully than initially suggested: In essence, it is not the rejection or promotion of the voluntary which is crucial for the authors´ critique. Instead, both works coincide with regard to one misunderstanding of current notions and approaches to implementation of patient autonomy: that is, the generalized assumption that being autonomous is reliant upon cognitive competence and maintained by the ability to consent on the basis of information. As Stavroula Tsinorema puts it in her work on advance directives: »Moral autonomy does not involve empirical abilities to function independently, or lack of dependence on continuous medical intervention, or freedom from physical or cognitive deterioration«.[62] They thus both challenge the value and unquestioned application of conceptions like informed consent and their link to autonomy, albeit in a different way and for different reasons. In their qualitative study on informed consent and dementia mentioned above, the authors come to conclude that, whilst both demented patients as well as caregivers did not comprehend the information provided to them, with the latter being unaware of their incomplete understanding, and the demented individuals

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[60] Holger Schütz, Bert Heinrichs, Michael Fuchs, Andreas Bauer: Informierte Einwilligung in der Demenzforschung. Eine qualitative Studie zum Informationsverständnis von Probanden [Informed consent in dementia research. A qualitative study on the information comprehension of subjects]. In: Ethik in der Medizin 28 (2016), pp. 91–106.

[61] Schütz, Heinrichs, Fuchs, Bauer: Informierte Einwilligung (Note 60), here p. 92.

[62] Tsinorema, The Principle (Note 46), here p. 86.

partly being aware of their inability to comprehend,[63] it seemed to be of less relevance for the demented persons to fully grasp the consent documents, and participation served as a coping strategy for dealing with their diagnosis.[64] Finally, they do see a threat for demented patients and other groups not deemed »competent« in the situation assessed to be systematically and by necessity excluded from research, and hence from possible progress on questions regarding the underlying illness and treatment options, stating that: »This might result in exclusion of dementia patients from research, as capacity for understanding and decision making are often equated with the ability for rational decision making.«[65] Consequently, this work illustrates how the tension between respecting every individual´s autonomy and dignity in an attempt to avoid unequal outcomes ought not always to be as obvious as it is e.g. within organ donation or similar allocation issues in public healthcare systems. Instead, questions of (in)justice and equal access to healthcare already arise within the context of research itself.

4.2. Re-definition of Minority Groups in the light of the findings

On the basis of the critical revision of autonomy and its links to informed consent, an attempt to re-define so-called minority groups is made. When Onora O´Neill scrutinizes: »If some persons are more autonomous than others, will informed consent procedures be more important for them? Or will they, on the contrary, be more important for those with limited autonomy?«,[66] there are two key aspects worthy of being considered in identifying minority groups which are entailed within these questions. As already stated, the stance that individuals can be more or less autonomous than others is rejected in this work; however, they can be able to act autonomously and live in coherence with their autonomy to a greater or lesser extent, dependent on themselves as well as their environment. Assuming that the integrity of any patient's autonomy is indeed not only the legitimization, but the teleological foundation for any other measure, e.g. legal

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[63] Schütz, Heinrichs, Fuchs, Bauer: Informierte Einwilligung (Note 60), here p. 92.

[64] Schütz, Heinrichs, Fuchs, Bauer: Informierte Einwilligung (Note 60), here p. 92.

[65] Schütz, Heinrichs, Fuchs, Bauer: Informierte Einwilligung (Note 60), here p. 92.

[66] Onora O'Neill: Informed consent and public health. In: Philosophical Transactions of the Royal Society 359 (2004), pp. 1133–1136.

or institutional implementations in healthcare practice, and those patients supported by informed consent requirements in protecting their autonomy are supposed to form the majority, all others would, by logical necessity as well as according to conventional stipulations of discrimination or disadvantage, form the minority group a conclusion arrived at through this so-called »qualitative approach«. If informed consent procedures are indeed more important – as in: relevant – for some compared to others, which group can be identified as suffering from disadvantage or even systematic exclusion according to current understandings of autonomy and the partly hidden, premises already outlined above; i.e.: links between autonomy and cognitive abilities in decision making scenarios? Most commonly, constellations in which informed consent requirements are considered to be problematic instead of protective are summarized as »hard cases« in scholarly discourse, implying a comparatively small number of individuals affected in comparison to all other, »normal« or »easy« cases. This implicit assumption is rarely addressed; however, Onora O'Neill is clarifying that:

> The hard cases are numerous and intractable. Many patients cannot consent to medical treatment because they are too young, too ill, too disabled or too demented to understand the information that they would have to grasp to make an informed choice.[67]

She has thereby already outlined four out of various possible features, in coherence with the concept of social diversity and socially salient features in the context of decision making, which could prevent informed consent requirements to unfold their supposedly beneficent effect – given the premise of the capability to understand relevant information is accepted, and leaving many other possible features aside. Likewise, Jan P. Beckmann is emphasizing that the misunderstanding of autonomy as a capacity to make decisions rationally and participate in decision making procedures could result in questioning the autonomy of large groups of citizens, like e.g. young children, very ill or disabled individuals,[68] thereby criticizing a statement of the German Ethics Council from 2016 which defined autonomy essentially as capability to discuss and deliberately make decisions

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[67] O'Neill: Informed consent (Note 66), here p. 1133.

[68] Beckmann: Autonomie (Note 49), here p. 22.

in their medical treatment.[69] The traits or circumstances mentioned above as unfavorable in the context of autonomy and decision making are not only vague, but partly even constitute causal factors to seek treatment in public healthcare institutions, e.g. regarding patients considered »too ill« to consent. Consequently, calling these constellations »hard cases« would render most cases »hard cases« – and the number of patients possibly affected by this requirement in a way which is likely to unfold negative effects on their treatment unexpectedly high. In fact, this approach to identifying individuals who are suffering from disadvantages due to consent requirements could lead to a quantitatively large group which can, but must not, be part of more common definitions of minority groups according to socially salient features like ethnicity, gender or belief which already contribute to problems of injustice and exclusion. Likewise, this approach to identifying individuals suffering from disadvantages due to consent requirements could lead to a quantitatively large group, e.g. all cognitively impaired and demented patients, which can, but must not, be part of those commonly regarded as »privileged group« e.g. for being well educated, wealthy and natives, possessing no socially salient feature in accordance with predominant definitions of social minorities. On the basis of a concept of autonomy dependent on informed consent, the identification of minority groups in public healthcare would yield a completely different result which is extremely hard to grasp or quantify at all.

4.3. Expanding the results to systematic problems of access to public healthcare

But which relevance do the notions of autonomy and consent discussed above and the way in which they differ from one another unfold for concrete medical healthcare practice and questions on justice, equality and social diversity or minority groups? The question of access to healthcare, especially public healthcare, and comprehensive notions of autonomy reconcilable with collective and social needs has been of minor interest in most research evaluated. And yet, it is especially the quest for any individual's autonomy in the form of

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[69] Deutscher Ethikrat: Patientenwohl als ethischer Maßstab für das Krankenhaus [Patient welfare as an ethical standard for the hospital]. Berlin 2016, here p. 38.

so-called informed consent which is potentially in conflict with public healthcare and guidelines, rules or other measures which need to be generalizable and applicable for all individuals possibly affected. Or, as Stavroula Tsinorema puts it: »A large area where informed consent procedures cannot be validly invoked is that of public health, where policies address groups or the whole of the population. (...) Public health is an area where consent requirements have limited application.«[70] It thus seems adequate and necessary to examine the definition and application of notions like the link of autonomy with patient or individual choice and informed consent especially in the context of public health and social diversity: Which challenges does public healthcare research face with regard to patient autonomy and eliciting consent? Which challenges could these notions impose in comparison to contexts like decision making settings? Onora O'Neill claims that:

> During the past 25 years, medical ethics has concentrated largely on (...) the treatment of individual patients. This focus permits a view of medical provision as a (quasi-) consumer good, whose distribution can be or should be contingent on individual choice. The approach cannot be extended to public health provision.[71]

She proceeds to open up a strict distinction between so-called individualist vs. public healthcare:

> Most uses of theories of justice in public healthcare have addressed distributive issues, such as the just distribution of clinical care. Discussions of healthcare allocation decisions (...) are discussions of the just distribution of a good that can be made contingent on individual choice.[72]

The assumption that the personal medical encounter is so very distinct from public healthcare and can be treated and examined just as differently and independently shall be questioned, being specifically aware of the relational and interactive components of both: Just as there would be no individual autonomy without others constituting it, there could be no individual treatment environment without other patients, physicians and public healthcare. More important, however, are the implications resulting from such a claim for social diversity

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[70] Tsinorema: Consent and autonomy (Note 26), here pp. 6–7.

[71] O'Neill: Informed consent (Note 66).

[72] O'Neill: Informed consent (Note 66), here p. 1133.

in the context of public healthcare: The emphasis put upon so-called patient choice relies upon more than the hidden assumption that the patient is able and willing to make a choice within an already given medical encounter. First, the discussion of patient choice requires that said patient has been able to access healthcare institutions – and ideally a suitable one, according to their individual needs and preferences. As access to certain healthcare procedures is not evenly and equally distributed, as many studies already cited suggest, the patient's dependence on influential factors like e.g. socioeconomic, geographical or other resources is thus ignored in most discussions evolving around patient autonomy and patient choice in medical encounters without incorporating public healthcare backgrounds. Moreover, the term »individual choice« implies that treatment alternatives are known and open to the patient. In this context, it seems worth mentioning that in more recent and systematic research on possible sources and patterns promoting injustice, inquiries have shifted towards including aspects of knowledge, drawing back to conceptions of Miranda Fricker[73] and subsequent developments of notions like epistemic injustice.[74] In the case of testimonial injustice, it becomes obvious how defining injustice as undue neglect of a person in their »role as a knower« and their »capacity to contribute to knowledge« can lead to problematic conclusions for persons not considered cognitively competent. By arguing about any justified, proportional amount of »credibility« which can be attributed to a person who has to defend their position by rational arguments, these theories draw back on formerly criticized definitions of autonomy, relying on capability or competence. Hermeneutical injustice, on the other hand, can be a result originating in different patterns, cultural habits, or language; consequently, some individuals may not be sufficiently included into contemporary research and healthcare measures because of a lack of possibilities to express their suffering adequately, or the treating medical person being unable to interpret them adequately for various reasons. Through the concept of epistemic injustice, albeit not ideal in itself, the gap between individual medical encounters, systematic

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[73] Miranda Fricker: Epistemic injustice: Power and the ethics of knowing. Oxford 2007.

[74] José Medina: The relevance of credibility excess in a proportional view of epistemic injustice: Differential epistemic authority and the social imaginary. In: Social Epistemology 25 (2011), pp. 15–35.

issues of discrimination and public healthcare is bridged comprehensively.

4.4. The significance of Informed Consent for justice in public healthcare: a critical revision

Tracing the historical origins of the requirement for informed consent, its roots can be detected in the Nuremberg Code shortly after WWII in 1947, where it is explicitly mentioned as a requirement in the context of research in order to prevent abuse of individuals in the name of research, putting emphasis on the dimension of the voluntary and the cognitive abilities to agree.[75] Despite all the flaws discussed above, the concept of autonomy just as the implementation of informed consent as part of public healthcare procedures are not to be rejected as a whole, as this could open the door for a different form of arbitrariness – being legitimized and exerted not only by individuals within particular encounters, but instead by legislation and governmental measures themselves. It is undebatable that the implementation of informed consent procedures as such have contributed largely to secure individual rights – and protect individual autonomy. The issues lie deeper, when it comes to how informed consent procedures are implemented into medical practice and which other notions they rely upon. Even if individual autonomy is a notion often misunderstood, and individual patient choice can prove to be problematic, it is essential especially for public healthcare decisions to not neglect such principles of »best practice« completely by idealizing contemporary moral ideas and social imaginary. Conceptions form and guide our interactions according to our ideas about ourselves, others finally what we consider good and right – impacting how we approach issues of justice in public healthcare system and according to which criteria we attempt to identify exclusion and discrimination. More precisely, if it has been a generally accepted and unquestioned duty to worship life as such, every kind of assistance in suicide seems eo ipso morally despicable, and individuals affected are prone to undertake harmful suicide attempts instead of seeking medical advice; and if e.g. binary

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[75] Paul Weindling: The Origins of Informed Consent: The International Scientific Commission on Medical War Crimes, and the Nuremberg Code. In: Bulletin of the History of Philosophy 75 (2001), pp. 37–71.

ideas of sex and gender have as of yet fundamentally shaped not only our own ideas of ourselves, but also those of our environment and of being a part of society as human being, this understanding could just as well serve as an obstacle to tackling pre-existing injustice in the form of prejudices. In the context of social diversity and equal access to public healthcare, it seems admittedly counterintuitive to question a standardized approach to largely systematic dynamics contributing to injustice. This stance is well portrayed with Onora O´Neill's claim:

> Because there are no obligations to do the impossible (›ought implies can‹), informed consent cannot be ethically required for the provision of public goods [note: public health included]. (…) For example, clinical care itself has to be provided to standards and formats that are also largely fixed and uniform (…). The public provision of healthcare can reflect democratic process, and thereby certain forms of collective choice; but its basic structures cannot be geared to individual choice.[76]

This statement poses a striking example of how the claim for standardized implementations and procedures could contribute to consolidating pre-existing ideas about values, behavior and justice. Kristie Dotson, on this note, elaborates so-called third order exclusion as follows: »Third-order epistemic exclusion proceeds from the outside of a set of epistemic resources to throw large portions of one's epistemological system into question as a result of the goals of a given inquiry.«[77] In literature on public healthcare, for instance, discussions are extended to the question whether informed consent ought to be invoked and considered ethically valuable or even necessary at all. This stance is expressed by Onora O'Neill when she claims that:

> An adequate ethics of public health needs to set aside debates about informed consent and to consider the permissible limits of just compulsion for various types of public good. It will therefore gain more from engaging with work in political philosophy than with individualistic work in ethics.[78]

Above, Onora O'Neill is even arguing that issues of public concern ought not to be tackled by means of ethical inquiry, but instead examined under the guidance of political philosophy. However, con-

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[76] O'Neill: Informed consent (Note 66), here p. 1135.

[77] Kristie Dotson: Conceptualizing Epistemic Oppression. In: Social Epistemology 28 (2014), pp. 115–138, here p. 129.

[78] O'Neill: Informed consent (Note 66), here p. 1133.

cerns of public health are not a question of tracking down »the permissible limits«, as what is permissible is not, by principle, morally justified – nor are they to be treated according to the premise »ought implies can«, which paradoxically argues for the consolidation of established dynamics if no easily accessible solution is in sight. Instead of rejecting concepts like autonomy and informed consent in the context of public health concerns, or rather: throwing large portions of our epistemological system into question as a result of the inquiry, the underlying normative grounds must be re-assessed and separated from other intentions and influential factors – especially as research becomes increasingly interdisciplinary. Whether »(...) informed consent procedures [are] required because they provide a degree of assurance that patients are not deceived or coerced in the course of clinical practice«[79] in every case is, indeed, questionable at best. In most literature examined which portrayed autonomy in accordance with or even as synonym with patient choice and the right to be informed and consent, underlying legal, institutional and political motivation and dynamics affecting the rise of this tendency in international and interdisciplinary discourse as well as on institutional level, independently from whether in support or in objection to this principle, have failed to be addressed. The underlying premise that implementations like e.g. ethical councils or law are not impacted by e.g. political, economic, institutional, e.g. accreditation, or other incentives note genuinely resulting from the quest to protect the individuals affected is rarely discussed. Yet, this assumption needs to be scrutinized carefully for every particular claim in question: For institutional as well as governmental measures or healthcare policies are meant as a means to an end – justice – and not a means in themselves.

5. Limitations

In order to contribute to research on public healthcare, social diversity and minority groups in a fruitful way, a short remark on the scope and the limitations as well as the aim of this work is considered advisable. With regard to the chosen methods and the selection process of relevant material, which has been conducted systematically

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[79] O'Neill: Informed consent (Note 66), here p. 1133.

as well as non-systematically, it is crucial to clarify that this work does not claim to provide an exhaustive or even representative overview of research in these areas or the application and understanding of concepts like autonomy and informed consent across disciplines. The relevancy of the literature that has been chosen manually in order to contrast other stances has been subject to specific selection criteria which were deemed suitable for this inquiry; consequently, these works should be regarded as indispensable for illustrative purposes but non-comprehensive. The specific examples chosen in »Discussion« seemed qualified in order to unveil potentially problematic dimensions of the notion of autonomy in actual medical practice – and yet, they should not be considered the only relevant or even the most relevant scenarios, as views on this selection will differ. Furthermore, the concept of autonomy and its links to informed consent represent only few of many ideas highly relevant for equality in public healthcare and worthy of being re-assessed according to what was termed level three research – conceptual inquiry. At this point, it seems necessary to highlight that this work does not promote the prioritization of either kind of inquiry, e.g. level three research, over other ones. Instead, any possible competitive understanding of this categorization, which was supposed to serve as a helpful methodological frame for carrying out this study, is rejected. Overall, this work aspires to provide an alternative approach to questions of (in)justice in the context of public healthcare, rather re-assessing underlying and implicit normative concepts and claims than examining more specific dynamics in healthcare practice. Resulting in a different approach to identifying minority groups on the basis of a qualitative rather than a quantitative understanding, it could help to amplify the scope of pre-existing, undeniably valuable inquiry. Similarly, whilst the question of actual access to public healthcare is addressed within this work and unfolds enormous relevance within the examination of autonomy and informed consent, the definition has been extended to »adequate access« and »access to (adequate) healthcare/treatment options/decision making process«.

6. Conclusion

Scholarly debate on equality and prevention of discrimination in public healthcare flourishes in various fields of science, leading to a more interdisciplinary and pragmatic approach to questions of (in)justice as well as possible measures to determine, quantify and combat existing discrimination issues. However, this generally approvable tendency likewise poses unanticipated conceptual challenges, which could result in a problematic influence of well entrenched normative principles like patient autonomy and informed consent on healthcare practice. By affecting certain individuals negatively and in an inadvertent manner, they are thus introducing a new definition of minority groups, as has been elaborated in this work. The underlying concepts and terms in question, most notably autonomy and dignity, can be traced back to genuinely philosophical grounds. In an attempt to implement such notions in medical practice, they nowadays find their resonance in corresponding moral claims and legal rights, with the latter originally supposed as a means to protect the former. However, as disciplines and terms increasingly overlap and are made use of in order to examine issues like discrimination, otherwise necessary methodological combination does affect those concepts in their core aspects and understandings – such that, for instance, the line between informed consent and patient choice as a an ethically desirable procedure vs. a legal measure to protect either patients´ rights or physician and institutions becomes blurred and teleological aspects disappear behind investigations targeting at increasing efficiency. So, why is re-assessing autonomy and its links to informed consent in the context of social diversity and public healthcare crucial for further inquiry? First, the unreflected usage of complex terms like autonomy shall not serve to falsely imply a thorough normative ground in order to justify problematic behavior or structural issues, thereby consolidating already established dynamics especially difficult for so-called minority groups. Secondly, because direct links to informed consent could possibly exclude or at least negatively affect many patients systematically from either access to healthcare, research on their underlying illness, or, in the case of individual medical encounters, adequate access to treatment options. Lastly, it is philosophical investigation which ought to accompany more pragmatic and empirical inquiries, e.g. in the field of applied ethics, in order to prevent any misalliance or even abuse of moral notions and conceptions. Therefore, scientific endeavours ought to take these fundamental normative implications into consideration whilst continuing to conduct research on level one or two, e.g. empirically based research in line with the so-called evidence-based medicine (EBM) movement in general. These branches of research do not pose any rivalry for conceptual inquiry, but ideally seek to complement one another in a wholesome way. When John Worrall, with regard to the relevance of empirical research, is stating that: »In order to start to resolve this mess, we need to go ›back to the basics‹; and that means turning to the philosophy of science«,[80] the same conclusion is held to be pivotal for inquiries on social diversity and minority groups in the context of public healthcare.

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[80] John Worrall: Evidence: philosophy of science meets medicine. In: Journal of Evaluation in Clinical Practice 16 (2010), pp. 356–362, here p. 356.

Nika Pavlović

Disparities in women's access to reproductive healthcare

Abstract
The health system characteristics sometimes can respond the needs of some population groups more widely than others. Women are more disadvantaged than men in some points of access to healthcare. Reproductive healthcare, as an important aspect of every woman's life is sometimes more difficult to access due to geographical, financial, cultural and social barriers, moral stigmas and prejudices. The chapter provides an insight into diversities, benefits, good practice and successful program implementations related to access to reproductive healthcare in four-member states of European Union: Croatia, Germany, Poland and Slovenia. Different solutions are offered according to the scope and severity of the problem in each country. Countries are trying to overcome existing obstacles at the state, local and institutional levels by drafting instructions and guidelines in comparison to current regulations. The desire to progress and overcome disparities in women's access to reproductive healthcare was recognized in all observed countries while the development of telemedicine was most prominent in the COVID-19 pandemic.

1. Introduction

Being in good health is an advantage. As a major determinant of quality of life, well-being and social inclusion, good health also contributes to both, social and economic growth. However, many factors affect the health status of one population and can be addressed by regional or national health policies. Obstacles in access to healthcare services include expenses, distance, waiting times, lack of cultural sensitivity and discrimination leading to inequalities in healthcare which ultimately represent a burden on individual's health and a loss of productivity and costs associated with social protection systems.[1] Weaknesses and benefits of health systems are country-specific.[2] Doričić et al. investigated diversity competency as well as access to healthcare in four states, Croatia, Germany, Poland and Slovenia.[3] Despite the fact that all four are EU members, selected countries have different health organization. Differences in socio-cultural demography as well as variety in economic developments also contribute these diversities. The authors studied hospital internal documents on improving access to healthcare for minorities and estimated there is a need for advancement in application of specific hospital policies.

By observing four states, Croatia, Germany, Poland and Slovenia, according to Eurostat data from 2014, most common reasons for unmet healthcare needs were long waiting lists, followed by high cost and distance or transportation.[4] A key component of person's fundamental right to health is access to healthcare and all citizens must be provided accessible, proper and effective services.[5] There are significant differences in women and men considering health and disease.[6] Because they are more aware of their health status, women use healthcare services more frequently. On the other hand, men are often more covered by private insurance than women what is a

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[1] Eurostat: Unmet health care needs statistics: Statistics Explained (2021). https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Unmet_health_care_needs_statistics (accessed on 7.2.2023).

[2] Rita Baeten, Slavina Spasova, Bart Vanhercke and Stéphanie Coster: Inequalities in access to healthcare. A study of national policies. Brussels 2018.

[3] Robert Doričić, Marcin Orzechowski, Marianne Nowak, Ivana Tutić Grokša, Katarzyna Bielińska, Anna Chowaniec, Mojca Ramšak, Paweł Łuków, Amir Muzur, Zvonka Zupanič-Slavec, Florian Steger: Diversity competency and access to healthcare in hospitals in Croatia, Germany, Poland, and Slovenia. In: International Journal of Environmental Research and Public Health 18 (2021), https://doi.org/10.3390/ijerph182211847.

[4] Eurostat: Unmet health (Note 1).

[5] European Union Fundamental Rights Agency: Inequalities and multiple discrimination in access to and quality of healthcare. Publications Office of the European Union 2013. https://fra.europa.eu/sites/default/files/inequalities-discrimination-healthcare_en.pdf (accessed on 7.2.2023).

[6] Franziska Prütz, Birte Hintzpeter, Laura Krause, Anke-Christine Saß: How are the women in Germany? The Women's Health Report of German Federal Health Reporting. European Journal of Public Health 30 Supplement 5 (2020), https://doi.org/10.1093/eurpub/ckaa166.1313.

financial obstacle in access to healthcare.[7] Furthermore, by observing the access to reproductive healthcare in selected countries, common problems can be detected. The states face those challenges differently. Referring to main obstacles, positive and successful examples of their reduction are discussed below.

2. Method

The research was based on scanning the literature and analyzing currently available secondary data, collected in order to gain insight into the differences, advantages and successful implementation of programs and ideas of access to reproductive healthcare in four selected European countries, members of the European Union, Croatia, Germany, Poland and Slovenia. To extract required information, the databases Web of Science, PubMed, Google Scholar as well as major search engines related to European and national legislation were used. The inclusion criteria covered all available literature according to the topic with search terms »disparities in access to healthcare«, »inequality in access to healthcare«, »women access to healthcare«, »minorities access to healthcare«, »good practice in access to reproductive healthcare«, »successful implementation in access to reproductive healthcare«. All search terms included every observed country individually. The targeted population were all women in need of reproductive healthcare living in selected countries. Due to differences in the severity of each issue and better overview of good practice, the chapters are divided according to countries.

3. Differences in health systems

The purpose of every health system is to preserve and improve health. However, funding of those health systems can vary considerably between countries.[8] Before pointing out the differences in access to reproductive healthcare in selected countries, the principles of their health systems should be recalled.

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[7] European Union Fundamental Rights Agency: Inequalities (Note 5).

[8] Martina Sopta, Marko Bešker: Funding health system in Croatia. 20th International Scientific Conference »Economic and Social Development« Prague, 27–28.4.2017.

The Croatian healthcare system refers to a combination of Bismarck and Beveridge financing model which is based on solidarity. The health needs of the entire population are financed from separate income of those who are employed. Insured people can select additional insurance for a number of free services. Primary healthcare is most commonly used care which includes women's health.[9] The mandatory health insurance in Croatia provides access to primary and specialist inpatient and outpatient care as well as access to medicines.[10] Germany healthcare system refers to Bismarck financing model and is observed globally as one of the best healthcare systems.[11] It offers a wide number of health services especially in hospital and ambulatory care with short waiting times.[12] Everybody is obligated to have statutory health insurance which is funded through insurance premiums. It includes principle of solidarity and self-governance.[13] Poland faced many reforms in post-communist era and after 2015 polish healthcare sector included program for better coordination between primary and specialist care, ambulatory and inpatient care as well as formation of health needs maps. Polish government's aim to increase public health financing by 2024 is also one other opportunity to improve healthcare system. Yet there are still ongoing problems that could be solved by holistic approach and a good strategy.[14] There have been important organizational changes in Slovenia's health system. As a state with highest per capita Gross Domestic Product (GDP) in the region of central and eastern Europe, Slovenia implemented

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[9] Sopta, Bešker: Funding health (Note 8).

[10] Aleksandar Džakula, Dorja Vočanec, Maja Banadinović, Maja Vajagić, Karmen Lončarek, Iva Lukačević Lovrenčić, Dagmar Radin, Bernd Rechel: Croatia health system review. In: Health systems in transition 23 (2021). https://apps.who.int/iris/handle/10665/348070 (accessed on 7.2.2023).

[11] Reinhard Busse, Miriam Blümel, Franz Knieps, Till Bärnighausen: Statutory health insurance in Germany: a health system shaped by 135 years of solidarity, self-governance, and competition. In: The Lancet 390 (2017), pp. 882–897.

[12] Miriam Blümel, Anne Spranger, Katharina Achstetter, Anna Maresso, Reinhard Busse: Germany health system review. In: Health systems in Transition 22 (2020). https://eurohealthobservatory.who.int/publications/i/germany-health-system-review-2020 (accessed on 7.2.2023).

[13] Institute for Quality and Efficiency in Health Care (IQWiG): Health care in Germany: The German health care system. (6.5.2015, updated 8.2.2018). https://www.ncbi.nlm.nih.gov/books/NBK298834/ (accessed on 7.2.2023).

[14] Christoph Sowada, Anna Sagan, Iwona Kowalska-Bobko: Poland: health system review. In: Health Systems in Transition 21 (2019). https://apps.who.int/iris/handle/10665/325143 (accessed on 7.2.2023).

statutory health insurance and provided almost universal health coverage with co-payments. The access to services is generally good.[15]

In 2011, the Council of Europe Committee of Ministers adopted the »Istanbul Convention on Preventing and Combating Violence against Women and domestic violence«. Croatia signed the Convention in 2013 and ratified 5 years later, in 2018. Germany signed earlier, in 2011 and ratified 6 years later, in 2017. Poland signed the Convention in 2012. and declared its »in accordance with the principles and the provisions of the Constitution of the Republic of Poland«. They ratified the Convention in 2015.[16] Slovenia signed the Convention in 2011 and ratified it in 2015.[17]

4. Overcoming disparities in women access to reproductive healthcare

4.1. Croatia

According to the »National Development Strategy 2030« developed in 2018, Croatia could become »competitive, innovative and secure country of recognizable identity and culture, a country of preserved resources, quality living conditions and equal opportunities for all«. The Strategy includes strengthening the position of Croatian minorities, the unity of homeland and emigrant Croatia as future goals. It also includes the improvement of healthcare by development of quality and affordable healthcare for vulnerable groups. Demographic revitalization and a better position of the family are also highlighted as relevant goals in the Strategy. In the last few decades, Croatia has been accompanied by negative demographic trends, which is one of its biggest challenges. Accordingly, Croatia has decided to continue

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[15] Tit Albreht, Katherine Polin, Radivoje Pribaković Brinovec, Marjeta Kuhar, Mircha Poldrugovac, Petra Ogrin Rehberger, Valentina Prevolnik Rupel, Pia Vracko: Slovenia health system review. In: Health System in Transition 23 (2021). https://apps.who.int/iris/handle/10665/330245 (accessed on 7.2.2023).

[16] Balogh Lídia: The Ratification Status of the Council of Europe's Istanbul Convention Among EU Member States. In: MTA Working Papers 7 (2020), pp. 1–22.

[17] Council of Europe Portal: Grevio – The first report by the Republic of Slovenia on the implementation of the Council of Europe Convention on preventing and combating violence against women and domestic violence (Istanbul Convention). https://rm.coe.int/grevio-inf-2019-15-eng/pdfa/1680989a54 (accessed on 7.2.2023).

to improve the situation of families, children and youth as well as the consistent implementation of women's and mothers' rights to early childhood security. Demographic policy includes increasing fertility rates, return and arrival of young people with families. Regarding to horizontal priorities, Croatia will develop a society without discrimination based on race, ethnicity, religion, gender, sexual orientation, national or social origin and disability, where all citizens have equal status and equal opportunities to exercise their rights and benefits.[18] One other example of good practice is the co-financing of medically assisted insemination in the city of Osijek[19] and in city of Makarska in 2022[20]. Almost all European countries, except Belarus, Ireland and Switzerland, provide some kind of financial assistance for assisted reproductive technology (ART). From all observed countries Slovenia is the only one that fully financially covers treatments and has the highest ART utilization rates.[21]

One of the most important public health problems in Croatia is cervical cancer. Therefore, in 2007 Croatia introduced HPV vaccination, in 2012 a »nation-wide screening program for cervical cancer« and in 2016 a »nation-wide HPV vaccination program« led by the Croatian National Institute of Public Health.[22] Vaccination against HPV infection is free and optional until the age of 25.[23] As

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[18] Republic of Croatia: National Development Strategy 2030. In: Official gazette 13 (2021). https://narodne-novine.nn.hr/clanci/sluzbeni/2021_02_13_230.html (accessed on 7.2.2023).

[19] City of Osijek Osijek-Baranja County Republic of Croatia. https://www.osijek.hr/postupak-isplate-novcanog-iznosa-sufinanciranja-troskova-medicinski-pomognute-oplodnje/ (accessed on 7.2.2023).

[20] City of Makarska Split-Dalmatia county. https://makarska.hr/novosti/grad-makarska-od-1-sijecnja-sufinancira-troskove-medicinski-pomognute-oplodnje (accessed on 7.2.2023).

[21] Patrick Präg, Melinda C. Mills: Assisted reproductive technology in Europe: usage and regulation in the context of cross-border reproductive care. In: Michaela Kreyenfeld, Dirk Konietzka (Eds.): Childlessness in Europe: Contexts, causes, and consequences. Cham 2017, pp. 289–309.

[22] Ivan Sabol, Nina Milutin Gašperov, Mihaela Matovina, Ksenija Božinović, Goran Grubišić, Ivan Fistonić, Dragan Belci, Laia Alemany, Sonja Džebro, Mara Dominis, Mario Šekerija, Sara Tous, Silvia de Sanjosé, Magdalena Grce: Cervical HPV type-specific pre-vaccination prevalence and age distribution in Croatia. In: PLoS One 12 (2017), https://doi.org/10.1371/journal.pone.0180480.

[23] The Croatian Institute of Public Health: Vaccination against human papilloma virus (24.11.2021). https://www.hzjz.hr/aktualnosti/cijepljenje-protiv-humanog-papiloma-virusa-hpv-2018-2019/ (accessed on 7.2.2023).

a part of the EU project »Live Hello« in Croatia, a summer public health campaign »No cuddling without attention« is held every year across the country as part of sexual health education.[24] Furthermore, Croatia participates every year in the World AIDS Day with public health activities such as »I love health«.[25] The HIV epidemic in Croatia is at a relatively low level and since 2015 it has been also declining. There are successful community testing programs with a developed network of voluntary and anonymous testing centers and a sexually transmitted disease testing project at the »Afternoon Clinic« for vulnerable populations.[26]

A woman can legally request an abortion in Croatia. Demographic indicators show a steady trend of depopulation and declining fertility rates. Accordingly, the number of abortions is also in constant decline. Abortions in Croatia are performed by health professionals in authorized health institutions in accordance with the rules of the profession. Likewise, data on abortions outside authorized institutions are not known.[27] The practice of conscientious objection by providers in reproductive healthcare services include abortion, contraceptive prescriptions and prenatal tests. Not only as a part of laws, conscientious objection is also globally included in medical ethical standards which scope vary from country to country.[28] Conscientious objection is a part of the Croatia national legislation and health professionals are entitled to inform patients on their decision as well as give

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[24] The Croatian Institute of Public Health: Sexual health – summer campaign »No cuddling without attention« (14.7.2021). https://www.hzjz.hr/sluzba-promicanje-zdravlja/spolno-zdravlje-ljetna-kampanja-nema-mazenja-bez-pazenja-2/ (accessed on 7.2.2023).

[25] The Croatian Institute of Public Health: World AIDS Day 2021 Campaign (1.12.2021). https://www.hzjz.hr/aktualnosti/kampanja-povodom-svjetskog-dana-aids-a-2021/ (accessed on 7.2.2023); The Croatian Institute of Public Health: I love health. https://huhiv.hr/volim-zdravlje/ (accessed 7.2.2023).

[26] Josip Begovac: Ending HIV epidemic in Croatia. In: Infektološki glasnik 39 (2019), pp. 48–49; Tatjana Nemeth Blažić, Jasmina Pavlić: Epidemiologija HIV/AIDS-a u Hrvatskoj i rad centara za besplatno i anonimno savjetovanje i testiranje na HIV [Epidemiology of HIV/AIDS in Croatia and the work of centers for free and anonymous HIV counseling and testing]. In: Infektološki glasnik 33 (2013), pp. 27–33.

[27] Ina Starčević, Darko Ropac: Abortion Statistical Data in Croatia--Some Characteristics and Comparison. In: Društvena istraživanja, 27 (2018), pp. 345–362.

[28] Christina Zampas, Ximena Andión-Ibanez: Conscientious objection to sexual and reproductive health services: international human rights standards and European law and practice. In: European Journal of Health Law 19 (2012), pp. 231–256.

them information and refer them to another health professional.[29] A surgical and medical abortion are both legal in Croatia.[30] By using the IT tool »Smart Health«, Croatian Health Insurance Fund gives an overview of institutions in the Republic of Croatia that provide abortion services.[31] In 23 European countries including Croatia, Germany, Poland and Slovenia, purchases behind-the-counter for emergency contraception are allowed from 2013.[32] Among others, Croatia has developed several prevention programs such as: »Croatian National Program for prevention of HIV/AIDS 2011–2015«, »Program to promote breastfeeding in Croatia« and the »National Program for Roma«.[33] In general, Roma population have significantly lower health status in all European countries. Among other barriers, they are facing disparities in access to sexual health and reproductive health services.[34] The example of good practice was also seen in »Health Education of Roma in Osijek-Baranya County« implemented by the Ministry of Health and Social Welfare in cooperation with local authorities to educate and raise awareness of Roma people about reproductive health, safe motherhood and family planning.[35] One of important activities in fight against Roma poverty was to improve their access to healthcare through health campaigns, information and more frequent presence of health workers in Roma settlements. The

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[29] Ana Borovečki, Sanja Babić-Bosanac: Discourse, ethics, public health, abortion, and conscientious objection in Croatia. In: Croatian medical journal 58 (2017), pp. 316–321.

[30] Natalija Vuletić, Jelena Ivandić, Nataša Smajla, Marko Klarić, Herman Haller: Medical termination of unplanned pregnancy. In: Liječnički Vijesnik 142 (2020), pp. 222–229.

[31] Croatia Health Insurance Fund: Search engine for contracted health care contents in the Republic of Croatia. https://hzzo.hr/zdravstvena-zastita/zdravstvena-zastita-pokrivena-obveznim-zdravstvenim-osiguranjem/trazilica (accessed on 7.2.2023).

[32] Chelsey Yang: The inequity of conscientious objection: Refusal of emergency contraception. In: Nursing Ethics 27 (2020), pp. 1408–1417.

[33] Sopta, Bešker: Funding health (Note 8).

[34] Robert Doričić, Marcin Orzechowski, Marianne Nowak: International Conference Healthcare as a Public Space: Social Integration and Social Diversity in the Context of Access to Healthcare in Europe: September 5th and 6th 2019, Rijeka, Croatia. In: Jahr – European Journal of Bioethics 11 (2020), pp. 283–286.

[35] Niall Crowley, Angela Genova, Silvia Sansonetti: Country Report on Croatia: Empowerment of Romani Women within the European Framework of National Roma Inclusion Strategies (2013). https://www.europarl.europa.eu/RegData/etudes/etudes/join/2013/493020/IPOL-FEMM_ET(2013)493020_EN.pdf (accessed on 7.2.2023).

Roma health should constantly be monitored due greater exposure to some diseases related to their living conditions. Roma life expectancy is about one third shorter than other populations and by improving the awareness of reproductive health and access of Roma women to education would greatly enhance their health.[36] Roma women in Croatia have a low frequency of gynecological examinations with an emphasis on adolescent pregnancies and a high abortion rate, which are primarily spontaneous. One of the specific goals in the »Croatian National Plan for Roma Inclusion (2021–2027)« is to improve Roma health with effective, equal access of Roma to quality health services especially access to reproductive healthcare. The activities will promote and improve access to examinations and consultations related to sexual and reproductive health services. Furthermore, the project »Equality, inclusion, participation and integration of Roma through health care – JUPI ZDRAV (2023–2027)« aims to improve the reproductive health of Roma women.[37] As concerning refugee-migration crisis in 2015/2016, international organizations such as International Red Cross gave big effort to assist migrants with access to healthcare.[38] Croatia and Germany are also among 11 European Union countries as a member of the UN LGBTI Core Group.[39] The overview of main challenges regarding disparities in women access to reproductive healthcare in Croatia as well as most important solutions and interventions are provided in Table 1.

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[36] Maja Štambuk: How do Croatian Roma live. Zagreb 2005.

[37] Croatian Government Office for Human Rights and the Rights of National Minorities: National Roma Inclusion Plan for the period from 2021 to 2027.

[38] Sunčana Roksandić Vidlička: Criminal offences against people's health. In: Leo Cvitanović, Davor Derenčinović, Ksenija Turković, Maja Munivrana Vajda, Marta Dragičević Prtenjača, Aleksandar Maršavelski, Sunčana Roksandić Vidlička (Eds.): Kazneno pravo posebni dio [Criminal law special part]. Zagreb 2018.

[39] United Nations LGBTI Core Group. https://unlgbticoregroup.org/members/ (accessed on 7.2.2023).

Croatia	**Challenges**	**Solutions and interventions**
	Gaps in healthcare for vulnerable groups	National Development Strategy 2030
	Negative demographic trends	Co-financing medically assisted insemination (Osijek, Makarska) Financial assistance for ART
	Breastfeeding and pumping	All baby-friendly maternity hospitals, Program to promote breastfeeding in Croatia
	Gaps in maternal and newborn healthcare	International Project IMAgiNE EURO
	Cervical cancer – public health problem	HPV vaccination (introduced in 2007)
		Nation-wide screening program for cervical cancer (2012)
		Nation-wide HPV vaccination program (2016)
		Health campaign: »No cuddling without attention« – sexual education (part of EU project Live Hello)
	HIV problem	Public health activities »I love health« – World AIDS Day
		Prevention program: Croatian National Program for prevention of HIV/AIDS 2011–2015
		»Afternoon Clinic« – voluntary and anonymous testing centers
	Conscientious objection in case of abortion	Surgical and medical abortion are legal
		IT tool »Smart Health« – an overview of institutions providing abortion services
		Emergency contraception purchase behind-the-counter allowed in 2013

		Health professionals with conscientious objection must refer patients to another health professional
	Health and reproductive health of Roma women	National Programme for Roma
		Health Education of Roma in Osijek-Baranya County and health campaigns
		Croatian National Plan for Roma Inclusion (2021–2027)
		Equality, inclusion, participation and integration of Roma through health care – JUPI ZDRAV (2023–2027)
	Women with disabilities	National Strategy of Equalization of Opportunities for Persons with Disabilities (2017–2020)
	Access to healthcare for migrants	International Red Cross actions
	Reporting undocumented migrants for treatment	Full access to maternal care, screening, midwifery and curative services

Table 1. An overview of main challenges and interventions regarding inequalities in women's access to reproductive healthcare in Croatia

4.2. Germany

As considered a liberal state, German women have the right to abortion. Nevertheless, the number of professionals who perform the procedure is declining due to conservative and religious views. As Polish women go to Germany for abortions due to fear of strict Polish law, German women on the other hand seek help in Netherlands.[40] Vulnerable groups of women in Germany such as adolescents, undocumented immigrants or women with lower socioeconomic status, sometimes address to telemedicine abortion outside of formal health

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[40] Céline Miani, Oliver Razum: The fragility of abortion access in Europe: a public health crisis in the making. In: Lancet 398 (2021), p. 485.

sector due to empowerment or disempowerment.[41] Although they have free access to contraception as German women, refugee women have high family planning needs.[42] All regular immigrants in Germany have access to healthcare equal to other citizens that is guaranteed by law. A study conducted on 6702 immigrant women confirmed that there are no health inequalities in obstetric and perinatal health outcomes compared to native Germans, while by observing their educational status there is a difference.[43] Furthermore, all migrant women in Germany have access to maternal care, screening, midwifery and curative services. Healthcare providers can treat undocumented migrants but have an obligation to report them latter to the Immigration Office. In practice, this type of procedure deters migrants and other vulnerable women from accessing services due to fear of deportation or stigma.[44] Reporting of undocumented migrant women is required by health professionals in Croatia, Germany and Slovenia, while in some countries it includes the discretion of health providers.[45] The Robert Koch Institute has been involved since 2021 as a national and international partner of the WHO in the fight against viral hepatitis and the elimination of hepatitis (especially hepatitis B and C)

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[41] Kristina Killinger, Sophie Günther, Rebecca Gomperts, Hazal Atay, Margit Endler: Why women choose abortion through telemedicine outside the formal health sector in Germany: a mixed-methods study. In: BMJ Sexual and Reproductive Health 48 (2022), pp. 6–12.

[42] Melisa G. Inci, Nadja Kutschke, Sara Nasser, Sara Alavi, Ingar Abels, Christine Kurmeyer, Jalid Sehouli: Unmet family planning needs among female refugees and asylum seekers in Germany – is free access to family planning services enough? Results of a cross-sectional study. In: Reproductive Health 17 (2020), https://doi.org/10.1186/s12978-020-00962-3.

[43] Matthias David, Theda Borde, Silke Brenne, Babett Ramsauer, Wolfgang Henrich, Jürgen Breckenkamp, Oliver Razum: Obstetric and perinatal outcomes among immigrant and non-immigrant women in Berlin, Germany. In: Archives Gynecology and Obstetrics 296 (2017), pp. 745–762.

[44] Veronika Flegar, María Dalli, Brigit Toebes: Access to Preventive Health Care for Undocumented Migrants: A Comparative Study of Germany, The Netherlands and Spain from a Human Rights Perspective. In: Laws 5 (2016), https://doi.org/10.3390/laws5010009.

[45] Konstantina Davaki: Access to maternal health and midwifery for vulnerable groups in the EU. European Parliament's Policy Department for Citizens' Rights and Constitutional Affairs (2019). https://www.europarl.europa.eu/RegData/etudes/STUD/2019/608874/IPOL_STU(2019)608874_EN.pdf (accessed on 7.2.2023).

as well as the containment of HIV.[46] It is a strategy that contributes 2030 Agenda for Sustainable Development.[47] The report »Health Situation of Women in Germany« prepared by Federal Health Reporting together with many experts from Robert Koch Institute, gives up-to-date information on women health status, health behavior and healthcare. Furthermore, the »German Prevention Act (PrävG)« from 2015 explains how health promotion and health prevention could help reducing social and gender inequalities in health. It regulates for the first time that statutory health insurance services should take gender-specific characteristics into account.[48] The overview of main challenges regarding disparities in women access to reproductive healthcare in Germany as well as most important solutions and interventions are provided in Table 2.

Germany	**Challenges**	**Solutions and interventions**
	Incidence of bacterial sexual transmitted infections	The Center for Sexual Health Freiburg (CSHF) established[49] (Feiburg, Bochum, Berlin, Frankfurt am Main
	Family planning	Financial assistance for ART
	Gaps in maternal and newborn healthcare	International Project IMAgiNE EURO
	Migrant women – unmet family planning needs	Telemedicine

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[46] Robert Koch Institute: WHO Collaborating Center for viral hepatitis and HIV (25.5.2021). https://www.rki.de/EN/Content/Institute/International/WHO_CC_viral-hepatitis_HIV/WHO_CC_viral-hepatitis_HIV_node.html;jsessionid=68F0688C844565FA63638A2C650219D9.internet112 (accessed on 7.2.2023).

[47] World Health Organization: Global Health sector strategy on viral hepatitis 2016–2021. https://www.emcdda.europa.eu/system/files/attachments/9478/WHO-HIV-2016.06-eng.pdf (accessed on 7.2.2023).

[48] Robert Koch Institute: Health Situation of Women in Germany: Summary and conclusion. Berlin 2020.

[49] Matthias C. Müller, Susanne Usadel, Stefan Zimmermann, Andreas Fahrhöfer, Winfried C. Kern, Ulrike Hoffmeister, Siegbert Rieg: Closing Sexual Health Service Gaps with a New Service Model in Germany: Performance of an on-Site Integrated, Cross-Sectoral, Low Threshold Sexually Transmitted Infections/HIV Counseling and Treatment Service. In: Frontiers in Public Health 10 (2022), https://doi.org/10.3389/fpubh.2022.793609.

		Complementary family planning services – free of charge
	Reporting undocumented migrants for treatment	Full access to maternal care, screening, midwifery and curative services
	Viral hepatitis and HIV	WHO: Global Health sector strategy on viral hepatitis 2016–2021 – Robert Koch Institute
	Health Situation of Women in Germany	the report up-to-date information on women health
	Social and gender inequalities in health	German Prevention Act (PrävG) 2015.
	Women with disabilities	National Action Plan to Implement the UN Convention on the Rights of Persons with Disabilities (2011–2021)
	Declining health professionals performing abortion	Emergency contraception purchase behind-the-counter allowed in 2013
		Free contraception
		Telemedicine abortion

Table 2. An overview of main challenges and interventions regarding inequalities in women's access to reproductive healthcare in Germany

4.3. Poland

Development of health policy programs in Poland arise in 2010 and several, that included women's reproductive health, were evaluated positively in 2016 and 2017. Programs included infectious diseases (detection and vaccination against HPV and hepatitis C detection), reproductive health (infertility, in vitro and perinatal and mother and child care and reproductive health education), neoplasms in women (cervix, breast) and birth defects.[50] Lack of reproductive health education, which is an important aspect of public health, can lead to risky sexual behavior. A survey on reproductive knowledge on more than 20,000 Polish women showed satisfying knowledge but lower knowledge among women with lower educational status and living in small centers. Nowadays, reproductive health education is crucial due to personal protection and early sexually active adolescents, depending on the country. There are no special trainings in Poland for this age group and education in Polish schools are not always held by trained professionals.[51] The Health Programme under the Norwegian Financial Mechanism 2014–2021 with its objective »Improved prevention and reduced inequalities in health« included the reduction of inequalities in health, implementation of certain health services by telemedicine and e-health as well as education on healthier lifestyle.[52] Poland was the second country after the Soviet Union to legalize abortion in the event of endangering the pregnant women's life, incest or rape in 1932. The Law was expanded in 1956 and included medical and social reasons. Changes took place in 1990 with the arrival of democracy. The woman had the right to choose and, in most cases the reasons were »difficult living conditions«. The consent of three medical experts has been introduced. In 1993, abortions could no longer be performed on social grounds.[53] Today, Poland's law on abortion is one of the most rigorous across Europe.[54] The frequency of abortion performance is mostly related to culture, economic sta-

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[50] Patrycja Kurowska, Anna Królak, Wojciech Giermaziak: Health policy programs realised in Poland in 2016–2017. In: Roczniki Państwowego Zakładu Higieny 69 (2018), pp. 209–217.

[51] Damian Warzecha, Iwona Szymusik, Bronislawa Pietrzak, Katarzyna Kosinska-Kaczynska, Janusz Sierdzinski, Nicole Sochacki-Wojcicka, Miroslaw Wielgos: Sex education in Poland – a cross-sectional study evaluating over twenty thousand polish women's knowledge of reproductive health issues and contraceptive methods. In: BMC public health 19 (2019), https://doi.org/10.1186/s12889-019-7046-0.

[52] The Norwegian Ministry of Foreign Affairs: PL-Health- Norwegian Financial Mechanism 2014–2021. https://zdrowie.gov.pl/uploads/pub/pages/page_973/text_images/Programme%20Agreement%20PL-HEALTH.pdf (accessed on 7.2.2023).

[53] United Nations: Abortion policies: a global review. https://www.un.org/en/development/desa/population/theme/policy/AbortionPoliciesAGlobalReview2002_Vol3.PDF (accessed on 7.2.2023).

[54] Julia Hussein, Jane Cottingham, Wanda Nowicka, Eszter Kismodi: Abortion in Poland: politics, progression and regression. In: Reproductive Health Matters 26 (2018), pp. 11–14.

tus, religion and law in each country.[55] In 2020, due to the Polish Constitutional Tribunal decision, abortion is allowed only if woman's life is endangered or in case of rape.[56] The physicians in Poland hesitate to perform an abortion due to legal responsibility, fear of real indication or unemployment because their contracts often depend on conservative hospital policy. They refuse to provide abortions in public hospitals and offer the same service private. Older physicians have sometimes more decision-making power than younger ones.[57] Women from countries with strict abortion laws, such as Poland, that have no access to medical abortion, sometimes purchase such drugs online from foreign countries. Due to lack of sexual education in schools, telemedicine became a possible alternative for informing patients. Some polish organizations help to facilitate contact with clinics in foreign countries which again is limiting for women with lower income.[58] Women with disabilities as high-risk group sometimes face challenges in access to healthcare services.[59] »Polish Strategy for Persons with Disabilities 2018–2030« is a comprehensive national policy framework emphasizing family before all. The Polish Government also introduced »Program for People with Disabilities and their Integration with the Society«. »National Action Program for Equal Treatment 2013–2016« considered activities in all areas including access to healthcare.[60] Croatia also introduced »National Strategy of Equalization of Opportunities for Persons with Disabilities

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[55] Bojana Pinter: Medico-legal aspects of abortion in Europe. In: The European Journal of Contraception and Reproductive Health Care 7 (2002), pp. 15–19.

[56] Kornelia Zaręba, Krzysztof Herman, Ewelina Kołb-Sielecka, Grzegorz Jakiel: Abortion in Countries with Restrictive Abortion Laws—Possible Directions and Solutions from the Perspective of Poland. In: Healthcare 9 (2021), https://doi.org/10.3390/healthcare9111594.

[57] Atina Krajewska: Revisiting Polish Abortion Law: Doctors and Institutions in a Restrictive Regime. In: Social and Legal Studies 31 (2021), pp. 409–438.

[58] Zaręba, Herman, Kołb-Sielecka, Jakiel: Abortion in Countries (Note 56).

[59] Agnieszka Wołowicz, Magdalena Kocejko, Kamila Ferenc: Women with disabilities and access to gynaecological services in Poland. In: Disability and Society 37 (2020), pp. 386–405; Agnieszka Wołowicz-Ruszkowska: How Polish Women with Disabilities Challenge the Meaning of Motherhood. In: Psychology of Women Quarterly 40 (2015), pp.80 – 95.

[60] United Nations Department of Economic and Social Affairs Disability: Disability Strategies and Action Plans by Country/Area. https://www.un.org/development/desa/disabilities/strategies.html (accessed on 7.2.2023).

(2017–2020)«,[61] Germany presented their »National Action Plan to Implement the UN Convention on the Rights of Persons with Disabilities (2011–2021)«,[62] and Slovenia their »Action Programme for Persons with Disabilities 2014–2021«[63]. Polish Ministry of Health additionally helped in the reduction of health inequalities by following the examples of other EU states and created maps of health needs that provide crucial information in healthcare.[64] The overview of main challenges regarding disparities in women access to reproductive healthcare in Poland as well as most important solutions and interventions are provided in Table 3.

	Challenges	**Solutions and Interventions**	
Poland	HPV	Detection and vaccination	Health policy programs in 2016–2017
	Hepatitis C	detection	
	Reproductive health	Infertility, in vitro Perinatal care and mother and child care	

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[61] The Government of the Republic of Croatia: National Strategy for Equalization of Opportunities for Persons with Disabilities 2017–2020. https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2019/10/Croatia_National-Strategy-of-Equalization-of-Opportunities-for-Persons-with-Disabilities.pdf (accessed 7.2.2023).

[62] Bundesministerium für Arbeit und Soziales: »Our path to an inclusive society« The National Action Plan 2.0 of Germany's Federal Government for the UN Convention on the Rights of Persons with Disabilities (UNCRPD). https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2021/12/NAP-2.0_English.pdf (accessed 7.2.2023).

[63] Republika Slovenija Ministarstvo za delo, družino, socialne zadeve in enake možnosti: Akcijski program za invalide 2014–2021 [Action program for the disabled persons 2014–2021]. https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2019/11/Slovenia_Action-Programme-for-Persons-with-Disabilities-2014-2021.pdf (accessed 7.2.2023).

[64] Tomasz Holecki, Piotr Romaniuk, Joanna Woźniak-Holecka, Adam R. Szromek, Magdalena Syrkiewicz-Świtała: Mapping Health Needs to Support Health System Management in Poland. In: Frontiers in Public Health 6 (2018), https://doi.org/10.3389/fpubh.2018.00082; Jan Olminski, Milena Koziol, Kinga Bartolik, Maps of Health Needs and their use for policy making. In: European Journal of Public Health 30 (2020), https://doi.org/10.1093/eurpub/ckaa166.1275.

		Reproductive health education	
	Neoplasms in women	cervix, breast	
	Birth defects	In general	
	Family planning	Financial assistance for ART	
	Gaps in maternal and newborn healthcare	International Project IMAgiNE EURO	
	Risky sexual behavior in rural areas due to low knowledge	The Health Programme under the Norwegian Financial Mechanism 2014–2021 Telemedicine and e-health	
	Reduction of health inequalities	Maps of health needs with health information	
		Improved prevention and reduced inequalities in health	
	Rigorous abortion law – only if life-threatening or rape	Polish organizations help patients to build contacts in foreign countries	
		Emergency contraception purchase behind-the-counter allowed in 2013	
	Woman with disabilities Communication: health professional – patient with disabilities	Polish Strategy for Persons with Disabilities 2018–2030	
		Program for People with Disabilities and their Integration with the Society	
		National Action Program for Equal Treatment 2013–2016, 2022–2030	

Table 3. An overview of main challenges and interventions regarding inequalities in women's access to reproductive healthcare in Poland

4.4. Slovenia

After conducting an analysis of the health system in 2015, Slovenia decided to reorganize the primary healthcare which resulted with several models of good practice.[65] Various health examinations related to reproductive care such as visits to a gynecologist, cervical cancer screening, prenatal care and family planning are part of primary healthcare. Slovenia has made progress in terms of service and population coverage as well as financial protection. Unmet needs for medical services in Slovenia like diagnostic examinations due to financial reasons are the lowest in the European Union. It is the result of good strategic policies and political commitment.[66] There are several documents regulating equal treatment in Slovenian healthcare. However, there are still sensitive groups and minorities with difficult access to the health system, such as illegal residents, asylum seekers, temporary workers, Roma and especially Roma women.[67] Health of Roma population, as the largest ethnic minority in Slovenia, primarily depends on their way of life. Additionally, their way of life varies on the region in which they live.[68] Due to many obstacles within their minority, such as family position, lower education, unemployment, poverty and communication with health professionals, Roma women are vulnerable group above all. They have equal access to public healthcare system as well as other inhabitants. Despite those equal rights with even elements of positive discrimination, they do not use them enough in practice. Several actions have been taken to increase health literacy and empowerment related to the access of Roma women to healthcare in Slovenia. »The National Conference on the Health of Roma People« in 2009 discussed the health of Roma women. They addressed on better information of Roma women on reproductive health, the importance of preventive gynecological examinations, different approach and health promotion of Roma women in relation to their culture. Regardless their free access to healthcare, which is defined by law, Roma women rarely cooperate

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[65] Vesna Kerstin Petric, Pia Vracko: Primary healthcare reform in Slovenia – focus on changing population needs. In: European Journal of Public Health 27 (2017), https://doi.org/10.1093/eurpub/ckx186.098.

[66] World Health Organization: Integrated, person-centerd primary health care produces results: case study from Slovenia. https://apps.who.int/iris/bitstream/handle/10665/336184/9789289055284-eng.pdf (accessed on 7.2.2023).

[67] Mojca Ramšak: Equal treatment in healthcare irrespective of racial or ethnic origin in the EU and Slovenia. In: Medicine, Law and Society 13 (2020), pp. 67–92.

[68] Victoria Zakrajšek, Tatjana Krajnc-Nikolić: Use of health services by Roma in the health care system of Slovenia. In: European Journal of Public Health 28 (2018), https://doi.org/10.1093/eurpub/cky218.174.

with prevention programs and rarely come to gynecologists after childbirth. Good practice was implemented in Trebnje Health Centre where medical staff established positive communication with local Roma people.[69]

Small regional hospitals in Slovenia offered a wide range of specialist services, rarely performed due to demand. It has been proposed to reduce the number of hospitals that offer such services or even shut down certain departments. In order to ensure the quality and safety of such complicated medical procedures, mandatory ones are determined, while hospitals took additional steps through networking in relation to specialization and regionalization, individually. The exchange of specialists at primary and secondary levels was included. A Slovenian prevention program »Together for health« identifies barriers to access to healthcare, reduces health inequalities and acts on integration of vulnerable populations.[70] In the second half of the 20th century, a strong women's and feminist movement was expressed in Slovenia, protecting the pro-choice, including the right to abortion. The Slovenian public health system is well-developed and protects vulnerable groups such as women and children. Vulnerable groups are provided to direct access to gynecologists, health and sexual education in schools as well as access to contraception. As a result, Slovenia has a low abortion rate.[71] Through the Program »Metabolic and congenital factors of reproductive health, childbirth III« (2014–2019)«, Slovenia strengthen and promoted the holistic health of the whole family in the prenatal period. The »CARE project (2014–2020) «, coordinated by the National Institute for Health, Migration and Poverty in Rome, together with partners from Croatia, Slovenia, Italy, Greece and Malta, aimed to improve the health of migrants through networking of experts. Main project goals included identifying best practices for enhancement of migrant health literacy and reduction of health inequalities. Project »MOST (2017–2020)« gave a community-based approach to health promotion and reduction of

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[69] Marjeta Logar, Danica Rotar Pavlič, Alem Maksuti: Standpoints of Roma women regarding reproductive health. In: BMC Women's Health 38 (2015), https://doi.org/10.1186/s12905-015-0195-0.

[70] Valentina Prevolnik Rupel: Thematic Report on Inequalities in access to healthcare: Slovenia. https://ec.europa.eu/social/BlobServlet?docId=20347&langId=en to promote (accessed on 7.2.2023).

[71] Mirjana Ule: Social inequalities in women's health in Slovenia. In: Slovenian Journal of Public Health 51 (2013), pp. 72–74.

health disparities in local communities. Slovenian national survey on lifestyle, attitudes, health and sexuality provided insight in sexual behavior, education attitudes and health in Slovenia. International project in collaboration with 15 states »IMAgiNE EURO: Improving MAternal and Newborn carE in European Region« included all observed countries, Croatia, Germany, Poland and Slovenia. The results discovered gaps that were later used for better coordination and improvement of quality care.[72] The overview of main challenges regarding disparities in women access to reproductive healthcare in Slovenia as well as most important solutions and interventions are provided in Table 4.

	Challenges	**Solutions and Interventions**
Slovenia	Unmet needs for medical services	Reorganization of primary healthcare in 2015
	Barriers to access to healthcare	Prevention program »Together for health«
	Specialist services shut down in small regional hospitals	The exchange of specialists at primary and secondary level
	Negative demographic trends	Full financial assistance for ART
	Roma women – health literacy	Trebnje Health Centre – positive communication of medical staff with Roma people
	Women with disabilities	Action Programme for Persons with Disabilities 2014–2021
	Access to abortion	Health and sexual education in schools
		Access to contraception
		Emergency contraception purchase behind-the-counter allowed in 2013

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[72] National Institute of Public Health: Programs. https://www.nijz.si/sl/programi-in-projekti (accessed on 7.2.2023); Universidade Europeia: Project: IMAGINE EURO https://www.europeia.pt/content/files/improving_maternal_newborn_care_in_the_euro_region_(imagine_euro).pdf (accessed on 7.2.2023).

	Help women in prenatal period	Program »Metabolic and congenital factors of reproductive health, childbirth III« (2014–2019)
	Migrant women health literacy and inequalities	CARE project (2014–2020) – networking of experts
	Reporting undocumented migrants for treatment	Full access to maternal care, screening, midwifery and curative services
	Health disparities in local communities	Project MOST (2017–2020) – community-based approach to health promotion
	Gaps in maternal and newborn healthcare	International Project IMAgiNE EURO

Table 4. An overview of main challenges and interventions regarding inequalities in women's access to reproductive healthcare in Slovenia

5. Access to reproductive healthcare during COVID-19 pandemic

The onset of the COVID-19 pandemic led to changes in access to healthcare such as access to maternity provision, access to contraception and abortion. Many states have decided to switch to telemedicine in order to reduce the risk of transmitting COVID-19. It was a disadvantage for those who do not speak the language or do not have IT sources. Restrictions mostly affected vulnerable groups such as poor women, women with disabilities, Roma women, undocumented migrants, adolescents, trans and non-binary people, and women at risk of domestic violence. It is familiar how government policies on abortion differ from state to state.[73] The new restrictions included delays or denial of abortion for women living with people having COVID-19 symptoms. Germany and Slovenia delayed abortions

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[73] Clare Wenham: The gendered impact of the COVID-19 crisis and post-crisis period. http://www.europarl.europa.eu/supporting-analyses (accessed on 7.2.2023).

for symptomatic women or women tested positive. Some countries expanded counselling and medical abortion through telemedicine, e.g. Germany, but most abortions are rather performed surgically.[74] Polish women used to travel to Slovakia and Germany for abortion procedure, due to strict Polish law. Since pandemic outbreak and closed borders, increased demands for medical abortion pills were noticed.[75]

Health professionals used different practice recommendations and guidelines on reproductive health service provision to reorganize the health service in COVID-19 pandemic what mostly referred to utilizing telemedicine, community/home based or self-care.[76]

6. Conclusion

In order to prevent diseases and secure the quality of life, it is necessary to provide everyone good and prompt healthcare. By examining the disparities in access to reproductive healthcare in four observed countries, similar problems were detected. Access to abortion, emergency contraception and access to reproductive healthcare for vulnerable and minority women were the main issues, specific to each country. It was noticed how each observed country makes efforts to overcome the existing obstacles most easily. With the arrival of the COVID-19 pandemic, different telemedicine services were developed, which most countries accepted to some extent. Implementation of reproductive health education as well as specific guidelines, projects and national programs led by professionals serve positively as a bridge to proper reproductive healthcare access.

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[74] Caroline Moreau, Mridula Shankar, Anna Glasier, Sharon Cameron, Kristina Gemzell-Danielsson: Abortion regulation in Europe in the era of COVID-19: a spectrum of policy responses. In: BMJ Sexual and Reproductive Health 47 (2021), https://doi.org/10.1136/bmjsrh-2020-200724.

[75] Robert Koch Institute: Health Situation (Note 48).

[76] Lemi B. Tolu, Garumma Tolu Feyissa, Wondimu Gudu Jeldu: Guidelines and best practice recommendations on reproductive health services provision amid COVID-19 pandemic: scoping review. In: BMC Public Health 21 (2021), https://doi.org/10.1186/s12889-021-10346-2.

Gordana Šimunković, Ivana Borić

Exercise of children's participatory rights in the healthcare system of the Republic of Croatia

Abstract
The most suitable approach to children as a vulnerable group is to combine protection and assistance based on information shaped through their participation according to age and cognitive abilities. Such an approach is not adequately reflected in the practices of different countries, including Croatia, despite being established in documents such as the Convention on the Rights of the Child. By observing children in the healthcare system, it has been established that their vulnerabilities intersect, i.e. different areas of vulnerability support one another and consequently increase the vulnerability. This paper deals with the exercise of children's participatory rights in the Croatian healthcare system by giving an overview of children's status and their vulnerabilities, as well as an overview of the relationship between protection and participation. Based on such a review and the results of the first research on the children's participation in the healthcare system in Croatia, this paper provides recommendations for fostering children's participation in the Croatian healthcare system.

1. Introduction – Vulnerability of children

A child's development can be seen as the outcome of a dynamic process during which an individual is formed through the interaction of his or her genetic heritage and the experience with the environment. In this dynamic process, an individual encounters are among the factors that can positively or adversely affect him or her. Predisposition, tendency or susceptibility to stress and a subsequent negative outcome may be considered vulnerability, despite the fact that vulnerability is a dynamic concept without a uniquely accepted definition.[1]

Vulnerability is contextual and socially conditioned and depends on the specific culture and society, but also on the dominant political ideology. Singh, Eghdami and Singh define vulnerability as the consequence of social inequalities rooted in gender, race, social class, culture, nationality, age and other power relationships.[2] Also Pitkin Derose, Escarce, Lurie point out that vulnerability is shaped by multiple factors, including political and social marginalization and lack of socio-economic and social resources.[3] Larkin argues that the concept of vulnerability may entail danger, risk, threat, potential problems, feeling of helplessness, need for protection and support;[4] while some authors make a distinction between ethical vulnerability – defined from the outside, i.e. attributed by others; and emic vulnerability – experience of vulnerability defined from an individual's perspective.[5]

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[1] Annelies Heijmans, Benfield Greig: Vulnerability: a matter of perception. Disaster Management Working Paper 4. London 2001, here pp. 1–17; Pranee Liamputtong: Researching the Vulnerable. A Guide to Sensitive Research Methods. London 2007; Mary Larkin: Vulnerable groups in health and social care. London 2009; Georg Frerks, Jeroen Warner, Bart Weijs: The Politics of Vulnerability and resilience. In: Ambiente & Sociedade Campinas 14 (2011), pp. 105–122; Paul Shitangsu: Vulnerability Concepts and Its Application in Various Fields: A Review On Geographical Perspective. In: Journal of Life and Earth Science 8 (2013), pp. 63–81; Maria de Lourdes Peroni Manzoni, Alexandra Timmer: Vulnerable groups: The promise of an emerging concept in European Human Rights Convention law. In: International Journal of Constitutional Law 11 (2013), pp. 1056–1085; Christina Zarowsky, Slim Haddad, Vinh-Kim Nguyen: Beyond »vulnerable groups«: contexts and dynamics of vulnerability. In: Global Health Promotion 20 (2013), pp. 3–9; Kate Brown: Vulnerability and Young People – Care and Social Control in Policy and Practice. Bristol 2015; Benjamin Wisner: Vulnerability as Concept, Model, Metric, and Tool. In: Oxford Research Encyclopedia of Natural Hazard Science 2016, pp. 1–51; Dearbhail Bracken-Roche, Emily Bell, Mary Ellen Macdonald, Eric Racine: The concept of ›vulnerability‹ in research ethics: an in-depth analysis of policies and guidelines. In: Health Research Policy and Systems 15 (2017), https://doi.org/10.1186/s12961-016-0164-6.

[2] Sapam Ranabir Singh, Mohammad Reza Eghdami, Sarbjeet Singh: The Concept of Social Vulnerability: A Review from Disasters Perspectives. In: International Journal of Interdisciplinary and Multidisciplinary Studies 1 (2014), pp. 71–82.

[3] Kathryn Pitkin Derose, José J. Escarce, Nicole Lurie: Immigrants and Health Care: Sources of Vulnerability. In: Health Affairs 26 (2007), pp. 1258–1268.

[4] Larkin: Vulnerable groups (Note 1).

[5] Judith Spiers: New perspectives on vulnerability using etic and emic approaches. In: Journal of Advanced Nursing 31 (2000), pp. 715–721; Larkin: Vulnerable groups (Note 1); Mary de Chesnay: Vulnerable Populations: Vulnerable People. In: Mary de

The dynamic relative concept of vulnerability has brought up the difficulty of determining which groups are vulnerable or more vulnerable than others; however, when it comes to children, there is a clear consensus. Vulnerability has been associated with children for centuries, and has only relatively recently emerged as the key concept in developmental childhood studies.[6] Children are generally perceived as the most vulnerable social group, as they are more dependent on the help and care of others than adults.[7] Their vulnerability is the outcome of the interaction of individual, i.e., cognitive, emotional and physical capabilities, personal circumstances, and environmental factors, i.e., factors within family and within community, that compound dynamically over time[8]. On the level of individual factors – such as age, disability, ethnic minority, immigrant background etc. – different ages contain different needs that require the support of adults to a greater or lesser extent. Infants depend on caregiving while middle school age children can benefit from education away from the home environment. In this sense, Masten and Gewirtz argue that vulnerability can also change as a function of development, as there are general periods of increased vulnerability during development.[9] On the level of environmental factors – such as material deprivation, exposure to violence, child care services etc. – childhood cannot be seen as a universal category, even when it entails the same time period and similar geographical space. For example, growing up and childhood can be a completely different experience for children living in rural and urban settings, for children from poor and rich families. Such, almost endless, variations in individual childhood experiences lead to different possibilities, priorities and limits of what is possible,

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Chesnay, Barbara Anderson (Eds.): Caring for the Vulnerable. Perspectives in Nursing Theory, Practice and Research. Burlington 2016, pp. 3–19.

[6] Kate Brown, Kathryn Ecclestone, Nick Emmel: The many faces of vulnerability. In: Social Policy and Society 16 (2017), pp. 497–510.

[7] Liamputtong: Researching the Vulnerable (Note 1); Ann S. Masten, Abigail H. Gewirtz: Vulnerability and Resilience in Early Child Development. In: Kathleen McCartney, Deborah Phillips (Eds.): The Blackwell Handbook of Early Childhood Development. Malden, Oxford, Melbourne 2006, pp. 22–43; Larkin: Vulnerable groups (Note 1); Brigid Daniel: Concepts of Adversity, Risk, Vulnerability and resilience; A discussion in the context of the ›child protection system‹. In: Social Policy and Society 9 (2010), pp. 231–241; Brown: Vulnerability and (Note 1).

[8] OECD: Changing the Odds for Vulnerable Children: Building Opportunities and Resilience, OECD Publishing, Paris, 2019, https://doi.org/10.1787/a2e8796c-en.

[9] Masten, Gewirtz: Vulnerability and Resilience (Note 7).

appropriate or expected. Speaking of variations, it should be pointed out that certain vulnerability factors overlap, support one another and/or lead to additional factors, thereby increasing the initial vulnerability, which is also referred to as intersections of vulnerability.[10]

Vulnerable individuals and groups are often denied or hindered – or not enabled – to participate fully in public and political, and often private life.[11] If we see children as weak, immature and incompetent, i.e., more vulnerable, which has been the dominant experience of children for a long time, then we will necessarily focus more on protection and help, and less on encouraging self-determination, self-regulation and participation. In modern western societies, the image of the child is changing, and child is perceived more through his potential and competence, which also affects the reduction of the general experience of vulnerability.[12] The preoccupation with the assumption of children's vulnerability – and consequently the focus on protection – reduces the opportunities for children to experience challenges and to develop coping strategies. In this way we can deprive them of acquiring certain competencies and deny them the active exercise of their rights.[13]

This paper focuses on children in the healthcare system in Croatia, i.e. children who are faced with health challenges, whereby children are considered persons from 0 to 18 years of age in accordance with the Convention on the Rights of the Child. Children in healthcare is one of the groups that are experiencing low levels of participation.[14] It is estimated that children account for 19 %, according to the authors' calculation based on data for the 0–19 age group,[15] in the total share of population in 2020 in the Republic of Croatia, i.e.

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[10] Yochay Nadan, Jill E. Korbin: Cultural Context, Intersectionality, and Child Vulnerability. In: Childhood Vulnerability 1 (2018), pp. 5–14; Zarowsky, Haddad, Nguyen: Beyond »vulnerable groups« (Note 1).

[11] Larkin: Vulnerable groups (Note 1).

[12] Brown: Vulnerability and (Note 1).

[13] Tony Newman, Sarah Blackburn: Transitions in the Lives of Children and Young People: Resilience Factors. Scottish Executive Education Department, Edinburgh, 2002.

[14] Ivana Jeđud Borić: Evaluation of legislation, policy and practice on child participation in the European Union (EU). Country report: Croatia. European Commission, Directorate-General for Justice and Consumers 2015. https://data.europa.eu/doi/10.2838/52052 (accessed on 7.2.2023).

[15] Croatian Bureau of Statistics: Population estimates (2020). https://www.dzs.hr/Hrv_Eng/Pokazatelji/Procjene%20stanovnistva.xlsx (accessed on 7.2.2023).

approximately 740,000 people, which is a decrease compared to previous years. According to the last available census, in 2011 there were 896 605 children aged 0–18 (DZS, 2013) in Croatia, which accounts for approximately 20 % of the total population in the same year. Through primary, secondary and tertiary healthcare, their coverage in the health system can be monitored by number of visits and/or hospitalizations. Thus, in the preventative protection of infants and preschool children, a total of 243,523 children and a total of 299,346 screenings[16] were recorded for 2019 in the area of healthcare protection of infants and preschool children, with acute upper respiratory tract infections being dominant when it comes to diseases and conditions in the area of healthcare protection of infants and preschool children. Primary health care for sick school-age children is carried out by general/family medicine physicians, while preventative and specific healthcare is carried out by school medicine physicians as part of the activities of the Institute of Public Health.[17] According to the authors' calculation based on the data for the last five years, an average of 316,662 children attend primary schools per year, while 155,119 children attend regular secondary schools.[18] At the same time, 118,319 primary school pupils and 38,757 secondary school pupils are covered

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[16] Croatian Institute of Public Health: Croatian Health and Statistical Yearbook for 2018. Zagreb 2020.

[17] Croatian Institute of Public Health: Croatian Health (Note 16).

[18] Croatian Bureau of Statistics: Communication 8.1.2. Primary schools end of school year 2019/2020 and start of school year 2020/2021. Zagreb 2021; Croatian Bureau of Statistics Communication 8.1.2. Primary schools end of school year 2018/2019 and start of school year 2019/2020. Zagreb 2020; Croatian Bureau of Statistics: Communication 8.1.2. Primary schools end of school year 2017/2018 and start of school year 2018/2019 Zagreb 2019; Croatian Bureau of Statistics: Communication 8.1.2. Primary schools end of school year 2016/2017 and start of school year 2017/2018. Zagreb 2018; Croatian Bureau of Statistics: Communication 8.1.2. Primary schools end of school year 2015/2016 and start of school year 2016/2017. Zagreb 2017; Croatian Bureau of Statistics: Communication 8.1.3. Secondary schools end of school year 2019/2020 and start of school year 2020/2021. Zagreb 2021; Croatian Bureau of Statistics: Communication 8.1.3. Secondary schools end of school year 2018/2019 and start of school year 2019/2020. Zagreb 2020; Croatian Bureau of Statistics: Communication 8.1.3. Secondary schools end of school year 2017/2018 and start of school year 2018/2019 Zagreb 2019; Croatian Bureau of Statistics: Communication 8.1.3. Secondary schools end of school year 2016/2017 and start of school year 2017/2018. Zagreb 2018; Croatian Bureau of Statistics: Communication 8.1.3. Secondary schools end of school year 2015/2016 and start of school year 2016/2017 Zagreb 2017.

by physical examinations.[19] Among residential care recipients, children accounted for around 1 % in 2019 (total N = 826 for ages 0 to 19; among which 45 % with limited mobility; 34 % bedridden, 1 % dying; 20 % other).[20] In the total number of examinations in permanent and temporary specialist offices, according to the authors' calculation, children accounted for 14 % (N = 1,525,428 for ages 0 to 19),[21] and 15 % in total hospital morbidity and hospitalizations (N = 96,886 for ages 0 to 19).[22] In the total hospital morbidity and hospitalization of children, respiratory diseases and certain perinatal conditions were dominant, with the trend applying equally to the previous two years. The data are provided in order to gain insight into the population, which is the topic of this paper.

The aim of this paper is to answer the question of how participatory rights of children in the healthcare system, especially in the healthcare system of the Republic of Croatia, are exercised. It will be shown that with the existence of international and national policy frameworks and the recognition of the importance of participation, in the desire to protect the most vulnerable, participation is not sufficient in its balance for protection. In the further text, after information about method and materials, an overview of the status of children's participation in basic policy documents were given. First is given an overview of the basic policy documents for child participation from international level and on the level of Republic of Croatia. Afterwards is given an overview of the basic policy documents relevant to the child participation in the healthcare system. Separate chapter discus relationship between protection and participation of children to which is followed by a chapter with an overview of international research on the topic of children's participation in the healthcare system and the chapter with review of the study on participation of children in the Croatian healthcare system.

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[19] Croatian Bureau of Statistics (Note 15).

[20] Croatian Institute of Public Health: Croatian Health and Statistical Yearbook for 2019. Zagreb 2021.

[21] Croatian Institute of Public Health: Croatian Health (Note 16).

[22] Croatian Institute of Public Health: Croatian Health (Note 16).

2. Method and materials

In order to answer to the aim of the paper, a review of secondary data was made. The secondary data included researches on the topic of participation for the Republic of Croatia and for the international level. Special attention is given to the first wider research on the participation of children in the healthcare system in the Republic of Croatia as part of a larger research on participation of children from vulnerable groups. Also, the review of policy documents relevant to the participation, especially in the field of health, was made.

3. Participation of children

Basic principles of participatory rights of children are embedded in international policy documents and in the policy documents of the Republic of Croatia giving a framework in which the participatory rights of children in the healthcare system are built upon. The starting points for participatory rights can be found in the Convention on the Rights of the Child, where the defined rights of children are generally divided into three groups.[23] Children's participatory rights are defined in the most straightforward way in Article 12, which states that »the child has the right to express [his or her] views freely in all matters affecting [him or her]«. In addition to Article 12, which is considered »synonymous with child participation« by authors such as Hart[24] and Verhellen[25] and the UN Committee on the Rights of the Child, children's participatory rights also refer to other key civil rights such as the right to freedom of expression (Article 13), the right to freedom of thought, conscience and religion (Article 14), the right to freedom of association (Article 15), access to information (Article 17) and the right to protection of privacy (Article 16). The UN's Committee on the Rights of the Child in their General Commentary

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[23] UN General Assembly: Convention on the Rights of the Child (20.11.1989). https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child (accessed on 7.2.2023).

[24] Roger A. Hart: Children's Participation: From Tokenism to Citizenship. New York 1992.

[25] Eugeen Verhellen: Children's rights: Education and academic responsibilities. In: Philip D. Jaffé (Ed.): Challenging Mentalities: Implementing the United Nations Convention on the Rights of the Child. Ghent 1998.

of Article 12 of the Convention on the Rights of the Child defines child participation as a:

> (...) widespread practice which appeared in recent years, and which has been broadly conceptualised as participation, although the term itself is not used in Article 12. The expression has evolved and is now widely used to describe a continuous process which involves the sharing of information and dialogue between children and adults based on mutual trust, in which children can learn how their views and the views of adults are both taken into account and form the outcome of this process.[26]

Based on the Convention on the Rights of the Child, the Recommendation of the Committee of Ministers to member States on the participation of children and young people under the age of 18,[27] contains recommendations for implementing right to be heard. The Recommendation stated that the right to be heard and taken seriously is fundamental to the human dignity and healthy development of every child and young person. The European Commission's recommendations on investing in children and breaking the vicious circle of disadvantaged children recognize the participation of children as one of the three pillars on which action strategies should be based in order to be successful.[28] Furthermore, participation of children is first of the six thematic areas in the EU Strategy on the Rights of the Child[29] presented as participation in the EU's political and democratic life.

Evaluation of legislation, policy and practice on child participation in the European Union shown that the legislative arrangements relating to child participation vary considerably across the EU and that

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[26] UN Committee on the Rights of the Child (CRC): General comment No. 12 (2009): The right of the child to be heard (20.7.2009). https://www2.ohchr.org/english/bodies/crc/docs/advanceversions/crc-c-gc-12.pdf (accessed on 7.2.2023).

[27] Council of Europe: Committee of Ministers, Recommendation CM/Rec(2012)2 of the Committee of Ministers to member States on the participation of children and young people under the age of 18 (28.3.2012), https://www.refworld.org/docid/506981802.html (accessed on 7.2.2023).

[28] European Commission: Commission Recommendation of 20 February 2013 – Investing in children: breaking the cycle of disadvantage. https://eur-lex.europa.eu/legal-content/EN/ALL/?uri=CELEX%3A32013H0112 (accessed on 7.2.2023).

[29] European Commission, Directorate-General for Justice and Consumers: EU strategy on the rights of the child, Publications Office, 2021, https://data.europa.eu/doi/10.2838/313794 (accessed on: 7.2.2023).

gap between legislation and practice often exists[30]. Croatia has a good legislative framework for respecting children's rights in general,[31] but it has been noted that there is a lack of systematic investment in children in accordance with the needs and international guidelines.[32] It is the same with participation of children. Participatory rights are reflected in Family Law Act, Law on Education in Primary and Secondary Schools and Social Welfare Act. The most common forms of child participation are consultation in decisions affecting children and collaboration in shared decisions with adult[33]. Children's right to participation is one of the special goals of the National Plan for the Rights of the Children in the Republic of Croatia for the 2022–2026.[34] Some of the measures related to the participation includes education for experts in the educational system, creation of a procedure for the inclusion of children in the development and adoption of public policy and establishing children's cities councils. We can expect that the new one currently in developmental stage will also nurture that direction. While improvement of children's participation in Croatia[35] and good standardization of participation through legislative and strategic documents are evident,[36] there is also a lack of clear mechanisms for their monitoring, as well as a lack

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[30] Laurie Day, Barry Percy-Smith, Sandy Ruxton, Katharine McKenna, Katy Redgrave, James Ronicle, Tricia Young: Evaluation of legislation, policy and practice of child participation in the European Union (EU) –
Final Report. Luxemburg 2015. https://data.europa.eu/doi/10.2838/45596 (accessed on 7.2.2023).

[31] Paul Stubbs, Siniša Zrinščak: Ulaganje u djecu – kako nadvladati zamku deprivacije – Hrvatska [Investing in children – how to overcome the deprivation trap – Croatia]. Brussels 2014.

[32] Zdenko Babić: Ulaganja u djecu kao visokoisplativa socijalna investicija [Investing in children as a highly profitable social investment]. In: Paediatria Croatica 64 (2020), pp. 53–62.

[33] Jeđud Borić: Evaluation of legislation (Note 14).

[34] Ministry of Labour, Pension System, Family and Social Policy: The National Plan for the Rights of the Children in the Republic of Croatia for the 2022–2026 period. Zagreb 2022.

[35] Paul Stubbs, Siniša Zrinščak: ESPN Thematic Report on Progress in the implementation of the 2013 EU Recommendation on »Investing in children: Breaking the cycle of disadvantage – Croatia«. Brussels 2017.

[36] Ivana Jeđud Borić, Anja Mirosavljević, Nivex Koller-Trbović, Ana Širanović, Sandra Car, Barbara Kušević: Poštujmo, uključimo, uvažimo. Analiza stanja dječje participacije u Hrvatskoj [Let's respect, include, and honor. Analysis of child participation in Croatia]. Zagreb 2017.

of sanctioning mechanisms for non-compliance with provisions and measures, and a lack of or an insufficient number of child-friendly legislative information concerning children.[37]

4. Participation of children in healthcare

When we look at the healthcare system, we can notice an increasing focus on inclusion and participation of children observed in public policies at international level but also at national levels.[38] At the level of the Republic of Croatia basically coverage of participation of children exist within the documents relevant for the patients in general without special emphasis on children. Participatory rights are embedded in the Guidelines of the Committee of Ministers of the Council of Europe on child-friendly healthcare, where »child-friendly healthcare« refers to »healthcare policy and practice that are centered on children's rights, needs, characteristics, assets and evolving capacities, taking into account their own opinion«. The Guidelines define participation as:

> (…) the right to be informed, consulted and heard, to give their opinions independently from their parents and to have their opinions taken into account. It implies the recognition of children as active stakeholders and describes the process by which they take part in decision making. The level of child participation depends both on his or her age, evolving capacities, maturity and on the importance of the decision to be taken.[39]

Furthermore, the Guidelines also state how child participation in the healthcare system can be achieved through three levels of par-

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[37] Jeđud Borić, Mirosavljević, Koller-Trbović, Širanović, Car, Kušević: Poštujmo, uključimo (Note 36).

[38] Jenny Baston: Healthcare decisions: a review of children's involvement. In: Paediatric Nursing 20 (2008), pp. 24–26; Adam Davies, Duncan Randall: Perceptions of Children's Participation in Their Healthcare: A Critical Review. In: Comprehensive Pediatric Nursing 38 (2015), pp. 202–221; Ingrid Larsson, Carin Staland-Nyman, Petra Svedberg, Jens M Nygren, Ing-Marie Carlsson: Children and young people's participation in developing interventions in health and well-being: a scoping review. In: BMC Health Services Research 18 (2018), https://doi.org/10.1186/s12913-018-3219-2.

[39] Council of Europe: Guidelines on child-friendly health care (21.9.2011). https://rm.coe.int/168046ccef (accessed on 7.2.2023).

ticipation: 1. Individual decision making, whether this be lifestyle choices or involvement in medical decision making. Implementation will require accessible information, clinical staff able to communicate with children and measures for mediation when differences occur; 2. Children should be given the opportunity to provide feedback on their experience after they have used services. Implementation will require the development of assessment of both patient-reported outcome and patient-reported experience and different methods of involving them in the process individually and with peers; 3. With increasing maturity and capacity, children should be involved in the policy/planning process for the services they use. Implementation will require appropriate training/learning opportunities to enable them to participate in this process, for example understanding priority setting.

The Council of Europe Strategic Action Plan on Human Rights and Technologies in Biomedicine 2020–2025[40] provides specific consideration on children and pediatric population, underlining that changes in the perception of the decision-making capacity in children are prompting reconsideration of the balance between protection and respect for autonomy. A specific session is dedicated to strengthen children's participation in the decision-making process on matters regarding their health.

In the Croatian healthcare system, fostering the idea of participation can be observed indirectly, especially in the Law on the Protection of Patients' Rights and also in the principles of protecting patients' rights, such as the principle of humanity, which includes ensuring respect for the patient as a human being, and ensuring the right to physical and mental integrity of the patient and protection of the patient's personality, including respect for his or her privacy, attitudes, and moral and religious beliefs. Therefore, integrity cannot be respected while participation is neglected. Provisions of the Law on the Protection of Patients' Rights, which are focused on the right to co-decide, the right to information, and the right to accept or refuse a particular procedure, will be the most conducive to fostering participation, while, in the context of this paper, it should be noted that the right to information is emphasized separately »with regard to age, education and mental abilities« without special emphasis on

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[40] Council of Europe: Strategic Action Plan on Human Rights and Technologies in Biomedicine 2020–2025. https://rm.coe.int/strategic-action-plan-final-e/1680a2c5d2 (accessed on 7.2.2023).

children. Healthcare provider codes of conduct, e.g. the Code of Ethics of Nurses,[41] the Code of Medical Ethics and Deontology,[42] have incorporated elements of participation also without specific emphasis on children. It has been more than a decade since it was observed that the Law on the Protection of Patients' Rights was not harmonized with the Convention on the Rights of the Child, failing to emphasize the possibility and need for the active role of minor patients in health decisions.[43]

5. Relationship between protection and participation of children

In the light of the aforementioned policy documents which, among other things, exist to protect children, it is important to consider the relationship between protection and participation. The balance between protection and participation would be the best solution than can rich the whole society for a long term but it seems that we are still struggling with that balance in everyday practice. Increased focus from society in order to ensure adequate protection of children is reasonable given the fact that children are not responsible for their vulnerability and are more dependent on the help and care from others. Contrary to the dominant perception of children as immature and incompetent, which leads to a significant focus on protection and assistance, we seek to perceive children through their potential and competencies, which helps encourage their self-determination, self-regulation and participation. Tisdall notes that children who are perceived as vulnerable are often prevented from participating

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[41] Assembly of the Croatian Chamber of Nurses: The Code of Ethics of Nurses. Zagreb 2005.

[42] Code of Medical Ethics and Deontology, Official Gazette of Croatia No 55/08; Amendments to the Code of Medical Ethics and Deontology, Official Gazette of Croatia No 139/15.

[43] Gordana Pelčić, Anamarija Gjuran-Coha: UNESCO, bioetika i dijete [UNESCO, bioethics and the child]. In: Jahr 1 (2010), pp. 63–68.; Gordana Pelčić, Neda Aberle, Goran Pelčić, Inge Vlašić-Cicvarić, Darko Kraguljac, Ivica Benčić, Anamarija Gjuran Coha, Silvana Karačić: Croatian Children's Views towards Importance of Health Care Information. In: Collegium antropologicum 36 (2012), pp. 543–548.

precisely under the guise of their protection.[44] Thus, it seems that children are sometimes overprotected in the name of their best interests, but essentially at the expense of their interests, presenting an ethical and a professional challenge. In modern society, especially in Western countries, public discourses emphasize the perspective and the »voices« of vulnerable and marginalized social groups, such as ethnic and racial minorities, people with disabilities, children, etc.[45] On the other hand, Aldridge states that while declaratively a lot of attention is paid to hearing children's voices' in everyday practice, children's perspectives are still not considered a priority, nor are they given the same importance as the perspective of adults.[46] Children who are perceived as more vulnerable, e.g., children with disabilities, children who are patients, children in alternative care, do not have the same access to services nor the same opportunities to participate, preventing them from accessing social, educational, political and cultural life. Furthermore, children are often perceived only as passive beneficiaries of various interventions created and carried out by adults, and their opinion is generally not taken into account in policy and intervention development.[47] Children's vulnerability, related with the scope of protection and participation, stems not only from their lack of competence but from the lack of power and the social position through which they can exercise their rights. Participation itself can make children vulnerable – which again requires protection – as they expose their perspective, i.e., their opinions, ideas and suggestions to adults who still hold more power and are able to punish them if they express opposing views. Lansdown argues that continuous

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[44] E. Kay M. Tisdall: Conceptualising children and young people's participation: examining vulnerability, social accountability and co-production. In: International Journal of Human Rights 21 (2016), pp. 59–75.

[45] Jelena Marković: Je li etično etički istraživati s djecom? Neka etička pitanja u istraživanju folklorističkih i kulturnoantropoloških aspekata djetinjstva [Is it ethical to do research with children? Some ethical issues in researching the folkloristic and cultural-anthropological aspects of childhood]. In: Etnološka tribina 31 (2008), pp. 147–165.

[46] Jo Aldridge: Participatory Research: Working with vulnerable groups in research and practice. Bristol 2015.

[47] Faye Mishna, Beverley J. Antle, Cheryl Regehr: Tapping the Perspectives of Children-Emerging Ethical Issues in Qualitative Research. In: Qualitative Social Work 3 (2004), pp. 449–468; Sharon Bessell: Participation in decision-making in out-of-home care in Australia: What do young people say? In: Children and Youth Services Review 33 (2011), pp. 496–501.

dependence on adults, the lack of power and relative vulnerability make children more susceptible to manipulation and exploitation.[48] In the context of participation of children, when it comes to vulnerable groups of children, the term »seldom heard children« is used:

> The term »seldom heard« refers to groups of people who do not have a collective voice and are often under-represented in consultation or participation activities. »Seldom heard young people« are young people whose voices are not heard in decisions that affect them and/or who are not benefitting from services designed to meet their needs. Seldom heard young people are not a homogenous group, and the term »seldom heard« when used in the current context, may best be seen as an umbrella term which encompasses groups of great diversity and complexity that have in common their isolation from both mainstream and targeted participatory activities.[49]

6. International researches in participation of children in healthcare

The balance between protection and participation is also the challenge in the healthcare system where we can find increased interest of the research community in the involvement of various segments of participation of children. Research covers segments from emphasizing the benefits of participation, overview of the state of children's participation in everyday healthcare practice to factors influencing participation.

Involvement in decision-making brings a range of benefits for children in the healthcare system, such as maintaining a sense of control over their own life,[50] a higher level of self-determination and

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[48] Gerison Lansdown: The realisation of children's participation rights – Critical reflections. In: Barry Percy-Smith, Nigel P. Thomas (Eds.): A Handbook of Children and Young People's Participation. Perspectives from Theory and Practice. London, New York 2010, pp. 11–23.

[49] Cathy Kelleher, Mairéad Seymour, Ann Marie Halpenny: Promoting the Participation of Seldom Heard Young People: A Review of the Literature on Best Practice Principles (2014). https://arrow.tudublin.ie/cgi/viewcontent.cgi?article=1026&context=aaschsslrep (accessed on 7.2.2023), here p. 24.

[50] Ingrid Runeson, Inger Hallström, Gunnel Elander, Göran Hermerén: Children's Participation in the Decision-Making Process During Hospitalization: an observa-

power,[51] but also a better health outcome.[52] A research in Sweden has shown that children tolerate medical treatments more easily when they feel their opinions are respected.[53] Capurso, Di Castelbianco & Di Renzo emphasize the importance of recognizing the emotions, thoughts and concerns of children in the healthcare system, especially children admitted to hospitals for treatment.[54] Precisely because of this complexity of children's feelings and thoughts, the authors emphasize the importance of talking to children and respecting their perspective.

Based on research conducted in pediatric departments in the Netherlands, Schalkers et al. concluded that health professionals do not use the expression »participation of children« in everyday practice; however, the ideas on which participation is based are perceived as an essential part of their work.[55] The participants stated that the participation of children in decision-making in the healthcare system is complex and limited by numerous factors. They also expressed the need for greater participation of children in the evaluation of healthcare services. Gilljam et al. emphasize the importance of measuring children's participation in the healthcare system in order to provide more precise data on where investments are needed to encourage children's participation.[56] The authors have developed an instrument (Child participation in Health Care – ChiPaC), which was pilot-tested, and showed an adequate level of reliability and

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tional study. In: Nursing Ethics 9 (2002), pp. 583–598; Baston: Healthcare decisions (Note 38).

[51] Isabelle Aujoulat, Fabrizio Simonelli, Alain Deccache: Health promotion needs of children and adolescents in hospitals: A review. In: Patient Education and Counseling 61 (2006), pp. 23–32.

[52] Priscilla Alderson, Katy Sutcliffe, Katherine Curtis-Tyler: Children's competence to consent to medical treatment. In: Hastings Center Report 36 (2006), pp. 25–34.

[53] Runeson, Hallström, Elander, Hermerén: Children's Participation (Note 50).

[54] Michele Capurso, Federico Bianchi di Castelbianco, Magda Di Renzo: »My Life in the Hospital«: Narratives of Children with a Medical Condition. In: Continuity in Education 2 (2021), pp. 4–25.

[55] Inge Schalkers, Cathleen S. Parsons, Joske F.G. Bunders, Christine Dedding: Health professionals' perspectives on children's and young people's participation in health care: a qualitative multihospital study. In: Journal of Clinical Nursing 25 (2016), pp. 1035–1044.

[56] Britt-Mari Gilljam, Susann Arvidsson, Jens M Nygren, Petra Svedberg: Child participation in health care (ChiPaC)-Development and psychometric evaluation of a self-report instrument for children's participation in health care. In: Journal of Clinical Nursing 29 (2020), pp. 107–118.

validity to assess children's participation in the healthcare system. Four components of participation of children are measured by the instrument: involvement, trust in professionals, taking control and understanding information. The questionnaire is adapted to children aged 6–12 and the authors note it can be used both in individual work with children in the healthcare system, but also as an instrument to improve the quality of childcare at the level of the healthcare system in general.

Coyne investigated the attitudes of children, parents and nurses about the participation of children in healthcare in England.[57] She concluded that both children and adults understand the importance of participation and the perspective of children. Nurses say that participation of children depends on the age of the child and his or her understanding of the disease. They believe that children should be allowed to participate with the permission of the parents. Coyne underlines the importance of nurses in encouraging children to become active partners in making decisions on their own healthcare from the very beginning of treatment.[58] In evaluation of the legislation, policy and practice of child participation in the European Union, Day et al. state that children generally have fewer opportunities to participate in developing, planning and reviewing healthcare services.[59] Legislation in EU Member States is predominantly concerned with safeguarding the ability of children to give informed consent to medical procedures. Furthermore, a general view was that opportunities to participate in decisions about their care were limited, i.e. children reported that in practice doctors usually talk to their parents, while ignoring them. Also, children often are not aware of what support and activities exist in the healthcare system nor do they know how to access them.

Children are recognized as holders of rights; however, in everyday practice the participation of children in healthcare remains relatively limited.[60] Davies and Randall state, based on the analysis of

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[57] Imelda Coyne: Children's Experiences of Hospitalization. In: Journal of Child Health Care 10 (2006), pp. 326–336.

[58] Imelda Coyne: Children's participation in consultations and decision-making at health service level: A review of the literature. In: International Journal of Nursing Studies 45 (2008), pp. 1682–1689.

[59] Day, Percy-Smith, Ruxton, McKenna, Redgrave, Ronicle, Young: Evaluation of legislation (Note 30).

[60] Davies, Randall: Perceptions of Children's (Note 38); Noreen M. Clark, Belinda W. Nelson, Melissa A. Valerio, Z. Molly Gong, Judith C. Taylor-Fishwick, Monica

various research in the area of participation of children in the healthcare system, that many children are excluded from decision-making, among other things because of the protective role of parents, as well as the belief that a child cannot adequately decide and act on his or her own best interests.[61] Children's ability to make decisions and to participate in making decisions about medical care and treatment depends more on the attitudes of parents and health professionals than on the capacity of the child,[62] and it is important to bear in mind that children always have the right to express their views, regardless of whether adults assess the child is competent to do so.

The right to express an opinion, established in Article 12 of the Convention on the Rights of the Child, is a fundamental right of the child, irrespective of the assessment of the child's competence. The estimated lack of competence to express opinions does not invalidate the children's right to express their opinions regardless. Participation of children in decision-making in the healthcare system is a complex issue, precisely because of the primary protective role of adults, i.e., parents and health professionals, but also because of perceptions and attitudes towards children as a vulnerable group. Therefore, Coyne and Harder advocate for a situational assessment of the individual child and his or her situation, and for the decisions to be made by adults and children together, all the while respecting the children's rights and opinions.[63] In fact, it is about finding the balance between protecting the child and fostering autonomy, taking into account the child's best interests.[64] Exactly what Strategic Plan on Human Rights and Technologies in Biomedicine 2020–2025 emphasizes recogniz-

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Fletcher: Consideration of shared decision making in nursing: A review of clinicians' perceptions and interventions. In: The Open Nursing Journal 3 (2009), pp. 65–75; Marjo Virkki, Tarja Heino Tolonen, Tapio Koskimaa, Eija Paavilainen: Children as decision-makers in health care – An integrative review. In: Clinical Nursing Studies 3 (2014), pp. 47–54.

[61] Davies, Randall: Perceptions of Children's (Note 38).

[62] Eva K. Mårtenson, Astrid M. Fägerskiöld: A review of children's decision-making competence in health care. In: Journal of Clinical Nursing 17 (2008), pp. 3131–3141.

[63] Imelda Coyne, Maria Harder: Children's participation in decision-making: balancing protection with shared decision-making using a situational perspective. In: Journal of Child Health Care 15 (2011), pp. 312–319.

[64] Annagrazia Altavilla, Ritva Halila, Maria-Andriani Kostopoulu, Laurence Lwoff, Katrin Uerpmann: Strengthening children's participation in their health: the new initiative of the Council of Europe. In: Lancet, Child & Adolescents Health 5 (2021), pp. 237–238.

ing that balance as a challenge when considering that children's rights are situated within a larger set of parental rights and responsibilities which also focus on their best interests.

When it comes to the participation of children in the healthcare system, there are parallel perspectives: user and children's perspectives. Furthermore, changing positions and power relations between adult professionals and children who are patients – users – are also taken into account. In doing so, professionals – adults – are no longer the sole holders of knowledge and skills, and beneficiaries – children – are not solely responsible for the existing problems, but may in turn be regarded as »experiential professionals«.[65] In that sense we speak of »child-centred care« which entails critical consideration of the child's perspective in all situations while ensuring collaboration with the family.[66] Furthermore, this concept also implies changes in the attitudes of healthcare professionals and changes in everyday practice of working with children in healthcare. In this regard, investment in additional education of healthcare professionals is also needed.

Some authors also emphasize that children can participate in different ways[67] and that participation is multidimensional,[68] while it is important, especially in the healthcare system, to consider not only the child's verbal but also the non-verbal statements. It is particularly important that healthcare professionals do not judge the children who choose not to participate or who choose simply to passively

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[65] Gabi Čačinovič Vogrinčič, Nina Mešl: Uspostavljanje suradnog odnosa u socijalnom radu [Establishing a cooperative relationship in social work]. In: Gabi Čačinovič Vogrinčič, Leonida Kobal, Nina Mešl, Miran Možina (Eds.): Uspostavljanje suradnog odnosa i osobnog kontakta u socijalnom radu [Establishing a cooperative relationship and personal contact in social work]. Zagreb 2007, pp. 3–49.

[66] Gail Davison, Martina Ann Kelly, Richard Conn, Andrew Thompson, Tim Dornan: How do children and adolescents experience healthcare professionals? Scoping review and interpretive synthesis. In: BMJ Open 11 (2021), https://doi.org/10.1136/bmjopen-2021-054368.; Karen Ford, Annette Dickinson, Tineke Water, Steven Campbell, Lucy Bray, Bernie Carter: Child Centred Care: Challenging Assumptions and Repositioning Children and Young People. In: Journal of Pediatric Nursing 43 (2018), pp. 39–43.

[67] Angela A. Quaye, Imelda Coyne, Maja Söderbäck, Inger K. Hallström: Children's active participation in decision-making processes during hospitalisation: An observational study. In: Journal of Clinical Nursing 28 (2019), pp. 4525–4537.

[68] Anna Stålberg, Anette Sandberg, Thomas Larsson, Imelda Coyne, Maja Söderbäck: Curious, thoughtful and affirmative—Young children's meanings of participation in healthcare situations when using an interactive communication tool. In: Journal of Clinical Nursing 27 (2018), pp. 235–246.

observe.[69] In this respect, Ehrich et al. emphasize certain requirements for ensuring participation of children in the healthcare system when it comes to relevant stakeholders, i.e., healthcare professionals, parents and children: knowledge, self-confidence, imagination, and trust.[70] The authors state that healthcare professionals are very knowledgeable about medical conditions and diseases, but they lack the skills to enable them to communicate with children and parents. The key principle in sharing information is that such information is aligned with the child's age and capacity for understanding so that the child can understand the information and respond to it. Many adults, including those in the healthcare system, express interest and desire to involve children to a greater extent and to enable children's participation. They, however, often lack the knowledge and the tools to do so.[71]

7. Participation of children in healthcare in Croatia

Research on the participation of children in the Republic of Croatia is sparse, with a rising trend in the last five years. The research on participation of children in the healthcare system, however, is almost non-existent. Existing ones cover part of the participative elements such as need for healthcare information.[72] The most relevant research is the analysis of child participation in Croatia by Jeđud Borić et al.,[73] as well as the overview of participation in the context of the report

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[69] Barbara Rogoff, Ruth Paradise, Rebeca Mejía Arauz, Maricela Correa-Chávez, Cathy Angelillo: Firsthand learning through intent participation. In: Annual Review of Psychology 54 (2003), pp. 175–203.

[70] Jochen Ehrich, Massimo Pettoello-Mantovani, Simon Lenton, Lilly Damm, Jeffrey Goldhagen: Participation of Children and Young People in Their Health Care: Understanding the Potential and Limitations. In: Journal of Pediatrics 167 (2015), pp. 783–784.

[71] Imelda Coyne: Children's Experiences of Hospitalization. In: Journal of Child Health Care 10 (2006), pp. 326–336; Lilly Damm, Ulrike Leiss, Ulrike Habeler, Jochen Ehrich: Improving care through better communication: understanding the benefits. In: Journal of Pediatrics 166 (2015), pp. 1327–1328.

[72] Pelčić, Aberle, Pelčić, Vlašić-Cicvarić, Kraguljac, Benčić, Gjuran Coha, Karačić: Croatian Children's Views (Note 43).

[73] Jeđud Borić, Mirosavljević, Koller-Trbović, Širanović, Car, Kušević: Poštujmo, uključimo (Note 36).

on investments in children[74]. The last major research on participation of children was focused on vulnerable groups of children,[75] and separately covered the children in the healthcare system[76]. Part of the results from that recent study on participation of vulnerable groups of children in Croatia will be given as it follows to illustrate best practices. First, the overall results will be presented, followed by a more detailed presentation of the results obtained in the case study on participation of children in healthcare in Croatia.

»Participation of Vulnerable Groups of Children« is a comprehensive study undertaken by UNICEF Office for Croatia in the 2018–2020 period.[77] The purpose of the study was to gain extensive knowledge on the participation of children from vulnerable groups in Croatia, i.e. Roma children, children without adequate parental care, children with disabilities, children in the healthcare system, children in the justice system, refugee and migrant children, children affected by poverty and children from isolated areas, including the information on existing attitudes, opportunities, barriers and enabling factors for the participation of children. The study combined both quantitative and qualitative data within four main components, three of which are based on empirical research: 1. conceptualization and description of children's vulnerability in respect to their participatory rights; 2. attitudes of the general public and professional from education, healthcare, justice and social welfare sectors regarding the participation of children from vulnerable groups; 3. situational overview of the participation of children from selected vulnerable groups, and information on both the constraints and enabling factors identified through eight case studies; and 4. designing a model of inclusion and participation of children in the process of study implementation – research – and the development of recommendations. A total of 1,774 participants were involved in this study, 232 of which were children and 1,542 adults.

Overall results showed that vulnerability of children is a relative rather than a real, i.e. static, concept or characteristic, since it occurs

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[74] Stubbs, Siniša: Ulaganje u djecu (Note 31); Stubbs, Zrinščak: ESPN Thematic Report (Note 35).

[75] Ivana Borić, Arijana Mataga Tintor: Participacija ranjivih skupina djece [Participation of vulnerable groups of children]. Zagreb 2021.

[76] Gordana Šimunković, Marina Grubić: Participacija djece u sustavu zdravstva [Participation of children in the health system]. Zagreb 2021.

[77] Borić, Mataga Tintor: Participacija ranjivih (Note 75).

as a result of external, i.e. structural, factors, personal characteristics and social processes that can make people vulnerable, excluded and marginalized. Certain groups suffer from intersecting vulnerability to the extent that their vulnerability is almost general. Children from vulnerable groups are often prevented from participating precisely under the guise of their protection, so it seems that adults sometimes overprotect children in the name of their best interests, with the result being quite the opposite. Vulnerable groups of children participate to a lesser degree in various aspects of their lives, i.e. from family and school to the wider community, and mostly participate »inwards«, i.e. within their own, often closed and protected microenvironment. The scope and the reach of participation of children from vulnerable groups outside of their families is very narrow. Most of the children from vulnerable groups have no experience of participating in student councils, and the few who were included felt marginalized and perceived their participation as merely for appearance's sake. Participation of children is not truly practiced and is at best limited, more often individual, and rarely collective. Furthermore, professionals emphasize gender inequality and the disadvantaged position of girls, who have fewer rights and opportunities to participate.

»Study on participation of children in the healthcare system«, as the first wider study on this topic in the Republic of Croatia, focused on finding answers to the participation of children in the healthcare system, at the same time giving children space for participation through the expression of opinions and experiences in segments directly related to them, with the potential to influence a change in their conditions – fostering the participation of children.[78] The study included 74 people – 26 children, 7 young people, 21 parents, 20 professionals – from three different institutions/organizations – a clinical hospital center, a hospital, an association of citizens – who participated in interviews and focus groups. The key criterion for participation in interviews and focus groups was having a health condition that required treatment over a long period of time, thus requiring more frequent contacts with the healthcare system. The research also included an analysis of the available public data – websites and documents accessible through them – of the institutions/organizations covered. Interviews and focus groups have affected the experience of vulnerability, the exercise of children's

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[78] Šimunković, Grubić: Participacija djece (Note 76).

rights, the participation of children in different aspects of their lives and the potential and barriers to participation. The analysis of the website and available documents included an overview of information about participation, i.e. how much it informs, how much it encourages opinions, involvement in decision-making, proposing activities, etc., and sought to understand clear and hidden values related to the field of research.

The research showed that key factors contributing to the vulnerability of the child in the healthcare system at the individual level are those related to the specific difficulty with which the child is faced, i.e. mental health difficulty and/or contributing causes for such difficulty, physical illness, and its characteristics, including symptoms and consequences. Structural factors contributing to vulnerability are the specificities regarding the organization of different systems in the community. Such factors are:

1. too slow and partially effective cooperation between systems, e.g. health and education, health and social care, which is necessary to address the cause of the problem;
2. the location of the mechanisms needed to address the causes in the domain of other systems, e.g. a mechanism which would enable the professionals in a health institution to mandate the parent of a child with mental health difficulties to go to therapy or school for parents, rather than to just advise them to do so;
3. taking over segments from the domains of other systems, e.g. social system, justice system, etc., due to their inadequate functioning, e.g. an aggressive child stays in the hospital for a longer period of time because adequate accommodation needs to be found;
4. lack of adequate supervision of professionals providing services to children;
5. insufficient number of professionals to provide services to children, e.g. to provide adequate number of individual and group therapies, to provide information and/or psychological support for physical illness;
6. lack of knowledge of individual professionals, e.g. in the school system, on how to access and assist the child;
7. lower interest of psychopharmacological companies regarding children, which means that upon arrival in the hospital the child cannot receive the first medicine of choice or that the existing

medicine must be »broken« because it is not available in the dose for children;

8. disregarding the recommendations of one system within another system, e.g. providing a teaching assistant to a child with ADHD who was recommended to stay in school, enforcing boundaries in working with such children, placing them in a separate class.

The intersections of vulnerability happen when individual factors overlap with structural factors, where children with mental health difficulties are perceived as more vulnerable and different, mostly due to the specific nature of their difficulties, but also due to the difficulties of growing up in dysfunctional families. Professionals working with children with mental health difficulties also express a higher level of vulnerability compared to the professionals caring for children with chronic physical illnesses due to the limited resources available in the work – as stated above: lack of supervision, lack of support tools for children, etc.

All participants of the research agreed on the importance of participation of children – children should be informed, listened to, asked for an opinion and involved in decision-making; however, opinions on the level of children's participation differ. Children with mental health difficulties perceive their participation as inadequate – in family, school and healthcare – while most of their parents' state that their children are overly involved and have too many rights. Professionals also emphasize the importance of the family environment in encouraging and limiting the participation of children. Children faced with a physical chronic disease do not see a greater need for participation in the healthcare system. They would like to be provided with more information, but they are satisfied with the fact that doctors mostly talk to their parents. Most research participants in proposals and recommendations for the improvement of participation in the healthcare system highlight the importance of informing children during treatment and of improving the communication skills of healthcare professionals.

Elements resulting from the study, as well as elements enabling and facilitating participation are the following:

1. the sensibility of the individual, institution/organization, system and community regarding the needs of the child and respecting the child as a significant actor in the process of growing up;
2. the use of personal and professional skills that enhance participation, e.g. communication skills;
3. the use of knowledge about the importance of participation and its position in the context of children's rights;
4. the organization of the system to provide an environment for participation, e.g. time availability, availability of human resources.

The following elements are part of good practice:

1. informing the child about a particular service within a health institution in the course of diagnosis and/or treatment, e.g. information about the condition, expectations from hospitalization, expectations from a specific procedure, elements of the diagnosis and/or treatment, expectations from the diagnosis and/or treatment, the benefits and/or risks, etc.;
2. providing the child with the space to ask questions and express opinions, e.g. providing information, having available person(s) to provide information and taking into account the child's opinion, etc.;
3. encouraging participation, e.g. via the website of the institution/organization that fosters participation, by ensuring a supportive environment, organizing a group of children/young people who will act with a specific objective, including participation;
4. providing options, e.g. order of activities, introduction of psychopharmaceuticals, use of certain types of anesthetics, topics in psychotherapeutic work, etc.

8. Conclusion and recommendations

In relation to the situation at the international level, the Republic of Croatia is in the process of rising in terms of children's participation in the healthcare system. In recognizing the importance of participation and the differences in levels of participation, it coincides with some international research. Participation in everyday practice is recognized up to a certain level, with its insufficient emphasis in policy documents. The healthcare system of the Republic of Croatia generates additional factors that contribute to the child's vulnerability, disrupting the balance between protection and participation.

For children in the health system, participation has three important values: intrinsic value for the children themselves in terms of improving their competences and self-esteem; instrumental value in terms of improving interventions for children based on their actual needs and the value in terms of promoting children's rights to participate in all aspects of their lives.[79] In order for the participation of children in the healthcare system in Croatia to be more extensive and meaningful in accordance with the specified values, it is necessary, above all, to further invest in the promotion and education of children's rights at all levels of education. Accordingly, research by Šimunković and Grubić[80] indicated that the participants agreed on the importance of children's participation, but also that opinions on the level of participation differ among children, experts and adults. Information about what participation is and how it is realized should go to children and adults, where in the group of adults special attention will be given to experts from different sectors. In this way, the understanding of all parties will be achieved as to what is expected when fostering participation and enable its greater practice. This is also in accordance with the findings of research from the international level, which indicate that participation depends on the attitudes of parents and health workers.

Education on children's rights and especially the education on the exercise of children's participatory rights is particularly important when it comes to the education of healthcare professionals, among other things, also due to the intersection of vulnerability. Thereby, in addition to introducing the topics on children's rights and participation in formal education programs, additional education in the framework of lifelong education should also be provided, especially education focused on methods and ways of working with children. This is in line with expressed interest and desire of adults to involve children to a greater extent and to enable children's participation but, they,

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[79] Bessell: Participation in decision-making (Note 47).

[80] Šimunković, Grubić: Participacija djece (Note 76).

however, often lack the knowledge and the tools to do so including communication skills.[81]

The case study in Croatia clearly separates the factors that promote participation and factors which contribute to vulnerability. Therefore, the guidelines for the participation of children in the healthcare system, which would include the mentioned factors, should be developed in cooperation with healthcare professionals and the children who have experienced hospitalization and treatment. Such guidelines can be a good reminder for the implementation of participation, which will also strengthen the connection between policy and practice. Similar materials focused on everyday participation of children in the healthcare system are found in European countries, as stated by Wood, Turner, Shaw.[82] In Croatia, two similar publications have been published in the last year, both aimed at professionals working with children in different fields.[83] However, there are no specific guidelines for the healthcare system. The purpose and the profit of developing such guidelines is at least threefold: »value driven« in terms of promoting children's rights, children's perspective and participation in the healthcare system, »practical« in terms of creating specific tools for working with children in everyday practice, and »participatory« through the involvement and cooperation of healthcare professionals and children in the development of the guidelines.

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[81] Coyne: Children's Experiences (Note 71); Šimunković, Grubić: Participacija djece (Note 76); Pelčić, Aberle, Pelčić, Vlašić-Cicvarić, Kraguljac, Benčić, Gjuran Coha, Karačić: Croatian Children's Views (Note 43).

[82] Damian Wood, Gill Turner, Fiona Straw: Not Just a Phase: A Guide to the Participation of Children and Young People in Health Services (2010). https://www.rcpch.ac.uk/sites/default/files/RCPCH-not-just-a-phase-2010.pdf (accessed on 7.2.2023).

[83] Ivana Borić, Arijana Mataga Tintor: Smjernice za kvalitetnu participaciju djece u javnim politikama i odlučivanju [Guidelines for quality participation of children in public policies and decision-making] (2020). https://www.unicef.org/croatia/media/4971/file/Smjernice%20za%20kvalitetnu%20participaciju%20djece%20u%20javnim%20politikama%20i%20odlučivanju%20.pdf (accessed on 7.2.2023); Ivana Borić, Arijana Mataga Tintor, Davorka Osmak Franjić: Smjernice za sudjelovanje djece i mladih u savjetodavnim tijelima, radnim grupama i na sastancima. [Guidelines for the participation of children and young people in advisory bodies, working groups and meetings] (2021). https://www.unicef.org/croatia/media/8831/file/Smjernice%20za%20sudjelovanje%20djece%20i%20mladih%20u%20savjetodavnim%20tijelima,%20radnim%20skupinama%20i%20na%20sastancima.pdf (accessed on 7.2.2023).

Participation of children in the healthcare system in Croatia – or lack of it – should certainly be further explored through more active involvement of children, following the examples of similar research from other countries,[84] especially in the use of modern digital tools[85].

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[84] Sonya Clarke: An Exploration of the Child's Experience of Staying in Hospital from the Perspectives of Children and Children's Nurses using Child-Centered Methodology. In: Comprehensive Child and Adolescent Nursing 45 (2021), pp. 105–118.

[85] Loni Ledderer, Anne Møller, Antoinette Fage-Butler: Adolescents' participation in their healthcare: A sociomaterial investigation of a diabetes app. In: Digital Health 5 (2019), https://doi.org/10.1177/2055207619845448; Stålberg, Sandberg, Larsson, Coyne, Söderbäck: Curious, thoughtful (Note 68).

Ann Kristin Augst, Annika Spahn

»Doctors don't listen to us or the things we need.« Experiences of heteronormative healthcare and its aftermath for LGBATIQ patients in Germany

Abstract
This chapter investigates factors that contribute to the substandard health situation of lesbian, gay, bisexual, asexual, trans, intersex and queer (LGBATIQ) people in Germany. The focus here lies on the somatic health of LGBATIQ people facing heteronormativity within the German healthcare system as a whole. We offer three interconnected explanations: minority stress, (anticipated) discrimination leading to avoidance of the healthcare system, and lack of affirmative and empirically based healthcare. In order to analyze queer patients' experiences, we conducted qualitative interviews with trans and asexual patients. In this chapter, we analyze the findings from our interviews on three levels: the macro level, e.g. socio-political regulations concerning access to healthcare, the micro level, e.g. doctor-patient interaction, as well as the meso level, e.g. workflows in doctor's offices. In closing, we want to discuss in which way access to healthcare for LGBATIQ people can be improved.

1. Introduction

It is an established fact that lesbian, gay, bisexual, asexual, trans, intersex and queer (LGBATIQ) people not only have specific healthcare needs that differ from cisgender and heterosexual patients but that their health is overall considered to be worse. What has not been established, however, is which factors contribute to that situation. This chapter, therefore, analyzes the healthcare situation of LGBATIQ people in Germany by conducting qualitative interviews with queer patients about their experiences of healthcare. It mostly focuses on general health concerns that are not specific to LGBATIQ people like preventative medical check-ups, and not, e.g., transition-related care. We want to look specifically at the daily clinical practice by general practitioners as well as specialists etc. and discuss in what way LGBATIQ people face discrimination and other obstacles to equal access and quality of healthcare and how these experiences of discrimination shape the health of LGBATIQ people in Germany. Our sample consisted of trans patients, some of whom also identified as lesbian or bisexual, and asexual patients, a lot of whom also identified as trans and non-binary. Therefore, we analyzed patients with various sexual orientations and genders.

The focus of this chapter lies on heteronormativity[1] within the German healthcare system as a whole. It will analyze the macro level, e.g. socio-political regulations concerning access to healthcare, the micro level, e.g. doctor-patient interaction, as well as the meso level, e.g. workflows in doctor's offices. The chapter wants to shed light on social practices as well as regulations and laws (e.g. § 2b SGB V). Concluding, we want to discuss in which way access to healthcare for LGBATIQ people can be improved.

1.1. Heteronormativity as a theoretical framework

For this chapter, we work with a theoretical understanding of heteronormativity as a social power relation in which heterosexuality and the associated binary gender relation and understanding are considered the norm, and deviations are sanctioned.[2] In most modern

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[1] Judith Butler: Gender Trouble. Feminism and the Subversion of Identity. New York, London 2007.

[2] Adrienne Rich: Compulsory Heterosexuality and Lesbian Existence. In: Signs. Women: Sex and Sexuality 5 (1980), pp. 631–660; Monique Wittig: The Straight Mind and Other Essays. New York 1992; Michael Warner: Introduction. In: Michael Warner (Ed.): Fear of a queer planet. Queer politics and social theory. Minneapolis 2004, pp. VII–XXXI; Christine M. Klapeer: Vielfalt ist nicht genug! Heteronormativität als herrschafts- und machtkritisches Konzept zur Intervention in gesellschaftlichen Ungleichheiten [Diversity is not enough! Heteronormativity as a concept critical of domination and power for intervention in social inequalities]. In: Friederike Schmidt, Anne-Christin Schondelmayer, Ute B. Schröder (Eds.): Selbstbestimmung und Anerkennung sexueller und geschlechtlicher Vielfalt. Lebenswirklichkeiten, Forschungsergebnisse und Bildungsbausteine [Self-determination and recognition of

Western societies, it is assumed that every person with a uterus and vulva is a woman, that every woman is heterosexual who is also imposed with a certain gender role, which never changes. The lynchpin of heteronormativity is the hierarchical gender binary and the assumption that everyone is cisgender.[3] Judith Butler showed that all three categories, sex, gender, and desire, are social constructs and do not necessarily need to be linked.[4] In a heteronormative society, heterosexuality is constantly reproduced as natural and normal, while LGBATIQ people face discrimination. Heteronormativity is interwoven into the fabric of society – and all of its institutions, including medicine. But it is more than a power structure that imposes pressure upon individuals to be cisgender and heterosexual – it is also upheld by individuals and institutions.[5]

Heteronormativity affects everyone: On the one side, LGBATIQ people are marginalized by heteronormativity, including all those whose bodies, genders, sexual and romantic orientations, and/or forms of romantic relationships do not conform to dyadic, cisnormative binary, allonormative, amatonormative, and normative heterosexuality (see Table 1 – Glossary of terms), even if they do not identify as LGBATIQ themselves. People who belong to these groups are often discriminated against, persecuted, or erased.[6] On the other

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the diversity of sexual orientation and gender. Realities of life, research results and educational modules]. Wiesbaden 2015, pp. 25–44.

[3] Nina Degele: Heteronormativität entselbstverständlichen. Zum verunsicherenden Potential von Queer Studies [Questioning heteronormativity. On the unsettling potential of Queer Studies]. In: Freiburger Frauenstudien 17 (2005), pp. 15–39; Bettina Kleiner: Heteronormativität (7.7.2016). https://www.gender-glossar.de/post/heteronormativitaet (accessed on 7.2.2023).

[4] Butler: Gender Trouble (Note 1).

[5] Nadine Rose: Subjekte der Macht bei Judith Butler und Michel Foucault. Machtvolle Diskurse, Subjektivierungen und Widerstand als Ausgangspunkt für eine rassismuskritische Perspektive in der Migrationsforschung [Subjects of power in Judith Butler's and Michel Foucault's work. Powerful discourses, subjectifications and resistance as a starting point for a racism-critical perspective in migration research]. In: Julia Reuter, Paul Mecheril (Eds.): Schlüsselwerke der Migrationsforschung. Pionierstudien und Referenztheorien [Key works of migration research. Pioneer studies and reference theories]. Wiesbaden 2015, pp. 323–342.

[6] Peter Wagenknecht: Was ist Heteronormativität? Zur Geschichte und Gehalt des Begriffs [What is heteronormativity? On the history and content of the term]. In: Jutta Hartmann, Bettina Fritzsche (Eds.): Heteronormativität. Empirische Studien zu Geschlecht, Sexualität und Macht [Heteronormativity. Empirical studies on gender, sexuality and power]. Wiesbaden 2007, pp. 17–34, here p. 17.

side, endosex, cisgender, alloromantic and -sexual, and heterosexual people are privileged by heteronormativity and remain unmarked in terms of being »natural« or »normal«.[7] However, heteronormativity also has a normative effect on them, for example, in the fear of being mistaken for non-heterosexual or transgender, which entails certain behaviors that emphasize the heterosexuality and cisgendering of the individuals.

1.2. Heteronormativity in the German healthcare system

For Germany, limited research into the health status of LGBATIQ people has been done. While some groups, like men who have sex with men, have been studied quite well, others, like intersex or asexual people, have been overlooked so far. The heterogeneity between – and within – the different subgroups of the queer community calls for an internal differentiation of healthcare needs.[8] Existing international studies document that LGBATIQ persons have a worse health status and enjoy poorer health and healthcare than heterosexual cis people.[9] Generally, health concerns for LGBATIQ people can be categorized in two ways: Firstly, they have the same health concerns as the

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[7] Sabine Hark: Heteronormativität revisited. Komplexitäten und Grenzen einer Kategorie [Heteronormativity revisited. Complexities and limitations of a category]. In: Barbara Paul, Lüder Tietz (Eds.): Queer as… – Kritische Heteronormativitätsforschung aus interdisziplinärer Perspektive [Queer as… – Critical heteronormativity research from an interdisciplinary perspective]. Bielefeld 2016, pp. 53–72, here p. 60.

[8] Kathleen Pöge, Gabriele Dennert, Uwe Koppe, Annette Güldenring, Ev B. Matthigack, Alexander Rommel: Die gesundheitliche Lage von lesbischen, schwulen, bisexuellen sowie trans- und intergeschlechtlichen Menschen [The health situation of lesbian, gay, bisexual, transgender and intersex people]. In: Journal of Health Monitoring 5 (2020), pp. 1–30.

[9] Gabriele Dennert, Gisela Wolf: Zugangsbarrieren im Versorgungssystem als gesundheitspolitische Herausforderung [Access barriers in the care system as a health policy challenge]. In: Femina Politica 1 (2009), pp. 47–58; Wiebke Fuchs, Dan Christian Ghattas, Deborah Reinert, Charlotte Widmann: Studie zur Lebenssituation von Transsexuellen in Nordrhein-Westfalen [Study on the living situation of transsexuals in North Rhine-Westphalia]. https://www.lsvd.de/fileadmin/pics/Dokumente/TSG/Studie_NRW.pdf (accessed on 7.2.2023); BVT* – Bundesvereinigung Trans*: Policy Paper des Bundesverbandes Trans*: Trans*-Gesundheitsversorgung. Forderungen an die medizinischen Instanzen und an die Politik [Policy Paper of the Trans* Federal Association: Trans* Health Care. Demands on the medical authorities and on politics] (2017). https://www.bmfsfj.de/resource/blob/120620/0c5e19af792f13569e13407bf0bbf825/trans-gesundheitsversorgung-bv-trans-data.pdf

rest of the population: They too have toothaches, need vaccinations, and need to have their check-ups for cancer prevention. In regular healthcare, LGBATIQ people are often subjected to discrimination and sometimes violence. Secondly, they have specific healthcare concerns, for example, Hormone Replacement Therapy (HRT) for trans people or HIV prevention for men who have sex with other men (MSM).

We propose that the worse health status of LGBATIQ people has three reasons. Firstly, they experience discrimination, causing minority stress additionally to daily life stressors.[10] Minority stress affects the physical and mental health of minority groups.[11] People who experience minority stress often use coping mechanisms that affect their (somatic) health, like smoking, self-harm, risky sexual behavior and not taking care of their health. It is important to note, however, that it is not being queer that leads to depression, self-loathing, and suicidality but the discrimination and stigma LGBATIQ people face.[12]

(accessed on 7.2.2023); Pöge, Dennert, Koppe, Güldenring, Matthigack, Rommel: Die gesundheitliche Lage (Note 8).

[10] Ilan H. Meyer: Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations. Conceptual issues and research evidence. In: Psychological Bulletin 129 (2003), pp. 674–697.

[11] Tina Dürrbaum, Frank A. Sattler: Minority Stress and Mental Health in Lesbian, Gay Male, and Bisexual Youths: A Meta-Analysis. In: Journal of LGBT Youth 17 (2010), pp. 298–314.

[12] David Deschamps, Bennett Singer: LGBTQ stats. Lesbian, gay, bisexual, transgender and queer people by the numbers. New York 2017; Niels Graf: Substanzkonsum unter LSBT*: Zwischen erhöhter Prävalenz und Defizitorientierung [Substance use among LGBT*: Between increased prevalence and deficit orientation]. In: Stefan Timmermanns, Maika Böhm (Eds.): Sexuelle und geschlechtliche Vielfalt. Interdisziplinäre Perspektiven aus Wissenschaft und Praxis [Diversity of Sexual Orientation and Gender. Interdisciplinary perspectives from science and practice]. Weinheim 2020, pp. 274–290; National LGB&T Partnership: #LBTWomensHealth18 Facts and Figures. https://nationallgbtpartnership.org/lbtwh/lbtwh18-facts-and-figures/ (accessed on 7.2.2023); Martin Plöderl: Suizidrisiko bei LSBTI* [LGBTI* suicide risk]. In: Stefan Timmermanns, Maika Böhm (Eds.): Sexuelle und geschlechtliche Vielfalt. Interdisziplinäre Perspektiven aus Wissenschaft und Praxis [Diversity of Sexual Orientation and Gender. Interdisciplinary perspectives from science and practice]. Weinheim 2020, pp. 291–306; Pöge, Dennert, Koppe, Güldenring, Matthigack, Rommel: Die gesundheitliche Lage (Note 8); Laetitia Zeemann, Nigel Sherriff, Kath Browne, Nick McGlynn, Massimo Mirandola, Lorenzo Gios, Ruth Davis, Juliette Sanchez-Lambert, Sophie Aujean, Nuno Pinto, Francesco Farinella, Valeria Donisi, Marta Niedźwiedzka-Stadnik, Magdalena Rosińska, Anne Pierson, Francesco Amaddeo, Health4LGBTI Network: A review of lesbian, gay, bisexual, trans and intersex (LGBTI) health and healthcare inequalities. In: European Journal of Public Health 29 (2019), pp. 974–980.

Secondly, LGBATIQ people do not necessarily need to experience discrimination from doctors and other health professionals[13] – anticipating discrimination is enough to diminish trust in the medical system[14]. Often, trans people anticipate misgendering and deadnaming at the doctor's office.[15] This leads to LGBATIQ people not or seldom seeking medical help, especially for preventive medical examinations like dental check-ups or gynecological care. In the case of acute symptoms, getting late or no medical attention can lead to worse health outcomes. Thirdly, doctors and other medical professionals are not equipped to deal with the healthcare of LGBATIQ people in an affirmative way.[16]

Although not perceived as a crisis by many societal groups beyond those concerned, such inadequate treatment constitutes a critical dimension of virtually untackled inequality – not only – in the German healthcare system, leading to tangible and/or unresolved – albeit treatable – health problems for those affected by it. From this perspective, LGBATIQ healthcare is an overall ethical issue that warrants a discussion about social inequality.

Heteronormativity in medicine includes violence against LGBATIQ people by doctors and medical staff, as well as objectification, traumatization, and humiliation in medical contexts. On a structural level heteronormativity in medicine can look like the pathologization of queer sexualities, relationships, genders, and bodies and resulting efforts to change these, e.g., conversion therapy, and epistemic

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[13] FRA – European Union Agency for Fundamental Rights: Being Trans in the European Union. Comparative analysis of EU LGBT survey data. https://fra.europa.eu/sites/default/files/fra-2014-being-trans-eu-comparative-0_en.pdf (accessed on 7.2.2023), here p. 41.

[14] Stephen Whittle, Lewis Turner, Ryan Combs, Stephenne Rhodes: Transgender EuroStudy. Legal Survey and Focus on the Transgender Experience of Health Care. https://www.ilga-europe.org/sites/default/files/Attachments/transgender_eurostudy.pdf (accessed on 7.2.2023), here p. 60.

[15] Luisa Kcomt, Kevin M. Gorey, Betty J. Barrett, Sean E. McCabe: Healthcare avoidance due to anticipated discrimination among transgender people. A call to create trans-affirmative environments. In: SSM – Population Health 11 (2020), pp. 1–8.

[16] Malin Houben, Gabriele Dennert, Muriel González Athenas, Constance Ohms: Gesundheit »jenseits der Mann/Frau-Binarismen«. Bedarfe an eine nicht-normative Versorgung in Bezug auf Körper, Geschlecht und sexuelle Orientierung [Health »beyond male/female binarisms«. Needs for non-normative care related to body, gender, and sexual orientation]. In: Max Nicolai Appenroth, María do Mar Castro Varela (Eds.): Trans & Care. Trans Personen zwischen Selbstsorge, Fürsorge und Versorgung [Trans & Care. Trans people between self-care, care and provision]. Bielefeld 2019, pp. 103–123; Whittle, Turner, Combs, Rhodes: Transgender EuroStudy (Note 14).

violence – meaning that queer people are not seen as experts for themselves. More subtle forms of heteronormativity can include taking a patient's medical history and only asking questions that assume the patient is cisgender and heterosexual, e.g., »Do you have a boyfriend?«.

2. Methods and Materials

In order to analyze the reasons for LGBATIQ patients' deficient physical and mental health we decided to conduct different forms of qualitative interviews with queer people, whose names we have pseudonymized for this publication to preserve their anonymity. The aim is to let queer patients speak about their experiences in and expectations of healthcare. Hence, this is a sociological study and as such, there is no obligation for an ethics statement or evaluation. Qualitative interviews are particularly suitable for openly inquiring about situational interpretations or motives for action, and for collecting everyday theories and self-interpretations in a differentiated and open manner.[17] Immersion in the lifeworld of those affected makes it possible to capture the subjective views of marginalized groups.[18] Furthermore, another advantage of qualitative interviews is that one gets a holistic picture[19] of the reality of the interviewees' lives: Even if the interviewees and the associated results can only be compared to a limited extent, it is still possible to obtain a comprehensive portrait of the interviewees, which can also be of social significance beyond the individual case.[20]

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[17] Christel Hopf: Qualitative Interviews [Qualitative interviews]. In: Uwe Flick, Ernst von Kardorff, Ines Steinke (Eds.): Qualitative Forschung [Qualitative research]. Reinbek bei Hamburg 2008, pp. 349–360, here p. 350.

[18] Arnulf Deppermann: Interview als Text vs. Interview als Interaktion [Interview as text vs. interview as interaction]. In: FQS – Forum Qualitative Sozialforschung/ Forum: Qualitative Social Research 14 (2013), Art. 14, here para. 5.

[19] Siegfried Lamnek, Claudia Krell: Qualitative Sozialforschung [Qualitative social research]. Weinheim 2016, here p. 323.

[20] Lamnek, Krell: Qualitative Sozialforschung (Note 19), p. 323.

2.1 Types of interviews and their analysis

For our diverging Ph.D. projects, we chose different kinds of interview methods: To analyze asexual patients' experiences with healthcare, Annika conducted one group discussion with asexual activists. Questions in the group discussion included if the participants had come out to their doctors, which experiences they had had in healthcare, and if they were ever offered conversion therapy. Kristin conducted individual interviews with trans people in Germany regarding their experiences with regular, i.e. non-transition-specific healthcare. She asked the interviewees about »good« and »bad« examples of interactions with medical staff due to gender presentation and perception, problems they encountered within the German healthcare system, and what improvements they would like or need to see.

Group discussions, as used by Annika, are not a standardized or rigidly defined method. They are qualitative procedures in which a group of about 5–15 people discusses a stimulus or question given by the researchers.[21] The focus of the research also lies on the group dynamics and interactions during the discussion to analyze the constitution of opinions and orientational patterns of the group.[22]

Annika analyzed the conducted group discussion on asexual patients' experiences in healthcare with Jan Kruse's so-called integrative basic procedure (in German: *Integratives Basisverfahren*), which is a form of reconstructive research. The *Integratives Basisverfahren* is, in essence, a (micro-)linguistic approach to analysis, in which one does not approach a text with a singular method of analysis, but the other way around: during the open, (micro-)linguistic analysis of a text, one arrives at the integrative application of specific analytic heuristics, like metaphor analysis, positioning analysis or an analysis of arguments, which fit the research objective and methodology in order to analyze the central structures of meaning in a process of progressive abstraction.[23]

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[21] Philipp Mayring: Einführung in die qualitative Sozialforschung [Introduction to qualitative research]. Weinheim, Basel 2002.

[22] Ralf Bohnsack: Rekonstruktive Sozialforschung. Einführung in qualitative Methoden [Reconstructive social research. Introduction to qualitative methods]. Opladen, Farmington Hills 2014.

[23] Jan Kruse: Qualitative Interviewforschung. Ein integrativer Ansatz [Qualitative interview research. An integrative approach]. Weinheim, Basel 2015, here p. 463.

To investigate trans people's experiences within the German healthcare system, Kristin conducted problem-centered interviews.[24] The problem-centered interview is a survey method that focuses on the interviewee's experiences, perceptions, and reflections on a very specific problem. Based on a guideline, open questions are asked, thus no fixed dimensions or categories – in the form of so-called items – are queried in the problem-centered interview. Hence, this interview type differs from quantitative methods but has a higher degree of structuring than narrative interviews. The leading questions of the problem-centered interview have on the one hand the function to give impulses for a free narration – narratives – of the interviewee, but should on the other hand also enable the interviewer to link to the narratives of the interviewee and to relate the interview to the problem. Accordingly, they are divided into narrative-generating and understanding-generating communication strategies. In this respect, the problem-centered interview also differs from the narrative interview, in which the narrative and inquiry phases are strictly separated. Andreas Witzel[25] suggests that the analysis of the problem-centered interviews should be based on the principles of Grounded Theory[26]. The theoretical presuppositions, which have already been incorporated into the interview guide, now need to be explicated and specified. This is done during open, selective, and axial coding.[27] Grounded Theory aims to capture and explain an as-yet-unknown phenomenon. This makes it clear that an evaluation is particularly suitable if the research question is very open and explorative. Grounded Theory is a research paradigm, which pursues the goal of developing an object-anchored theory from the collected

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[24] Andreas Witzel: Das problemzentrierte Interview [The problem-centered interview]. In: Gerd Jüttemann (Ed.): Qualitative Forschung in der Psychologie. Grundlagen, Verfahrensweisen, Anwendungsfelder [Qualitative research in psychology. Basics, procedures, fields of application]. Weinheim 1985, pp. 227–255.

[25] Andreas Witzel: Auswertung problemzentrierter Interviews. Grundlagen und Erfahrungen [Evaluation of problem-centered interviews. Basics and Experiences]. In: Rainer Strobl, Andreas Böttger (Eds.): Wahre Geschichten? Zur Theorie und Praxis qualitativer Interviews [True stories? On the theory and practice of qualitative interviews]. Baden-Baden 1996, pp. 49–76, here p. 65.

[26] Kathy Charmaz: Constructing Grounded Theory. Los Angeles, London, New Delhi, Singapore, Washington DC 2014.

[27] Charmaz: Constructing (Note 26).

data. The research process is not linear: the different phases of data collection and evaluation take place in parallel or alternate.[28]

2.2. Sample

The group discussion Annika conducted took place during a larger meeting of asexual people and activists in Germany in 2019. The participants did know each other from this meeting, but many of them had not met before the previous day. The group consisted of 12 participants, who were female, nonbinary, genderfluid, genderqueer, or gender questioning. Most of the participants were students or in their professional training. All but one participant self-identified as asexual or on the asexual spectrum.

The problem-centered Interviews Kristin conducted took place between 2019 and 2021 in different cities in Germany. The part of the sample we are taking a closer look at for this article consists of five trans people, who are (trans) feminine, (trans) masculine, or genderqueer. The youngest participant was 28 years old, and the oldest was 40 years of age. The interviews and the group discussion were conducted in German; we translated the quoted bits for this article and edited them for clarity. All names are of course pseudonymized.

3. Preliminary Results and Findings

Our data shall exemplify and illustrate the perception of discrimination queer people face within the German healthcare system and how these – potential – patients deal with it. We analyze asexual patients as an example of the diversity of sexual orientation and trans people's experiences as an example of gender variance.

3.1. Asexual people's experiences in healthcare

The participants in the group discussion express similar critiques of medicine as the general public. They want doctors to listen to them and their needs:

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[28] Charmaz: Constructing (Note 26).

> Sasha (25): »A big problem, I would say, is that therapists and doctors don't listen to us or the things we need. They just do what they think is best.«

The participants recounted multiple situations when they were not taken seriously by doctors and therapists. As cis women, trans men, and non-binary individuals they not only experience allonormativity but also sexism and transphobia. We want to argue that their marginalized position means they are affected more by medical discrimination and that it has specific effects on their health and healthcare in comparison to heterosexual and cisgender patients.

So what kind of experiences do asexual patients have in medicine? One big aspect of being an asexual patient is being confronted with normative assumptions by medical staff. The participants recounted two key questions to illustrate that problem. One question almost every participant said they had been asked by medical staff was »Could you be pregnant?«:

> Gabrielle (25): »Well, I think especially those of us who are femme presenting have all been asked ›Are you pregnant?‹ – ›No‹ – ›Are you sure?‹ – ›Yes‹. Everyone has had this experience where they weren't believed. ›Are you really sure? Do you use protection?‹ – ›No, but I'm really sure I'm not pregnant‹.«

The problem here is not the question itself. It's that the participants anticipate they were not believed their answer, because doctors assumed that every patient is sexually active and did not understand why someone would not want or use protection and still could not be pregnant. For medical staff, the possibility of being pregnant seems to be tied to a patient's physical ability rather than their actual sexual practices. The second question is usually posed during gynecological check-up examinations:

> Bastian (26): »A lot of gynecologists don't ask whether you have penetrative sex, but they use a different question like ›Do you have a boyfriend?‹. This question has a lot of normative assumptions: one, that you're in a heterosexual relationship, two, that you and your partner are both cisgender, three, that you are only sexually active when you are in a romantic relationship, four, that when you are in a relationship you have to be sexually active. These are a lot of misconceptions in one sentence.«

The »Do you have a boyfriend« question is, as Bastian analyzes, a proxy for a lot of different information the doctor is trying to get from their patient. Being asexual means not fitting into the human norm in doctors' minds. It also means not fitting into standard forms, like the depression questionnaire, which includes a question on libido. Maxi (30) recounts instead of checking one of the given answers writing in her own answer »I have never had an interest in sexuality and I don't want to change that« because that is the only way she could make herself visible.

Charlie (28) remembered one exchange with his doctor who assumed that everyone was – or wants to be – sexually active, which is why she pitied Charlie for not needing protection. Rami told the group how once her doctor almost did not prescribe her antidepressants because they would lower her libido even more – something that she did not mind. It was much more important to her to get the medication. When doctors accepted that some patients have not been sexually active yet, they still assumed that they would be in the future. Like Jagoda's (34) doctor who could not examine her internally because of Jagoda's vaginismus and then told her to come back once she had sex – which she never did. The normative assumption around being sexually active and other norms around romantic relationships even lead some doctors to pressure their asexual patients, as another participant mentions:

> Ola (33): »I had this gynecologist once who told me that if I was in a relationship I would have to have sex.«

The last section showed the implication of normative assumptions by healthcare staff. Now on to the question if the participants come out to their medical providers and what experiences they have with that. Rami told the group she tried to come out to her gynecologist, who did not believe her:

> Rami (24): »My gynecologist still doesn't believe me to this day that I'm asexual and that I'm not sexually active. Every time I see her she asks the same questions – and I have just given up. So I'm like ›yes sure, protection, works perfectly‹.«

Because her gynecologist does not believe her, Rami states that she has given up on explaining herself and pretends to be using protection – implying she is sexually active. Rami also thought about coming out to her therapist but described being afraid of his reaction to the term »asexual«. As a consequence, Rami decided not to come out to doctors anymore:

> Rami: »My maxim now is: no coming out to doctors, period.«

Sasha tells the group they were currently looking for a new therapist but were afraid that they would not find an appropriate one because their identity would be questioned and problematized. This refers to another problem asexual people face at the doctor's office. Oftentimes, asexuality is still understood as a medical or psychological problem. For example, Maxi talks about when she was a patient at a psychiatric hospital, she told her therapist that she was asexual but that the asexuality was not a problem. However, the therapist posed further questions, which Maxi felt as violating her boundaries. She felt as though the therapist was pushing asexuality as a topic of therapy and as something possibly treatable onto her. Maxi also recounted that asexuality was part of the therapist's report after the stay in the psychiatric hospital ended and remarked that a patient's heterosexuality would not be part of such a report. Rami is afraid that something similar would happen to her:

> Rami: »For me, the biggest problem would be if you said, my asexuality is not a problem – and then you were ignored or asked about it relentlessly – that would be very bad.«

Nina (26) also recalls experiences with doctors where her asexuality was framed as a phase, something she would grow out of to become sexually active and heterosexual. In the accounts of the participants, their marginalized gender and their asexuality intersect to make their accounts of themselves seem unreliable to doctors. Some of the participants had doctors or therapists suggest or hint at conversion therapies. All of the participants who experienced this, strongly and aggressively made clear that they were not interested in such treatment.

> Bastian: »My therapist asked me once if I wanted help with my asexuality. She hinted that I could be asexual because of past trauma or something like that. I stated clearly that I didn't want or need that. With that, the topic was dropped.«

Bastian also talks about experiencing a doctor looking for a medical explanation of their sexual orientation, suggesting Bastian should have their hormone status looked at. For doctors, asexuality seems to be a symptom of an underlying condition and/or something treatable, not a sexual orientation in its own right.

How do these experiences shape asexual patients' relationship with medicine and healthcare? They develop coping mechanisms, the first of which is humor. So when Rami was asked about a possible pregnancy, she answered that the only possibility would be if she was pregnant with Jesus' sibling. Jagoda had a similar strategy, joking that she had been pollinated by wind.

Nina has a different coping strategy. She is asexual and in a relationship with an allosexual partner and they are sexually active with each other. Even though they do not have penetrative sex, she still sometimes needs gynecological care.

> Nina: »Before visiting a gynecologist, I always think beforehand about how and what I will tell them. With my relationship situation, I have to explain a lot in order to get a diagnosis that actually fits. It's quite complicated and pretty embarrassing for me.«

Bastian told the group that they did not have the patience or strength to explain asexuality to doctors or speak up if they feel mistreated. So they chose to change doctors if they acted negatively. That means that Bastian has often changed doctors. They also expressed having difficulties making appointments and consequently often delaying necessary doctor's visits by weeks or months. One of their coping mechanisms with this stress is that they already know that they need a period of rest after any doctor's appointments and plan accordingly. Bastian is also in psychological therapy and reports having great difficulties finding a good therapist. The one they found rarely has open appointments for them:

> Bastian: »I only have one therapy appointment a month at the moment. That's not enough but it's better than nothing. It is a compromise I have to make to be at least treated by a trustworthy therapist.«

For Bastian, to receive good quality healthcare means to find a therapist who accepts Bastian's trans identity. To receive this Bastian had to compromise and got fewer appointments as would be necessary. For Bastian, this also means putting up with discrimination in order to receive medical care at all:

> Bastian: »I sometimes have the feeling that I had to put up with discriminatory behavior.«

For asexual people, doctor's visits are stressful, complicated, and embarrassing which is why they prepare well beforehand. Many also experience anxiety, not knowing how their doctor will react when they come out. Some participants report having trust issues with medicine and, as a consequence, some of them, like Kay (32), have not seen a doctor in years:

> Kay: »I haven't been to a gynecologist for around four years, since I self-identify as asexual. I just didn't see the need and couldn't bring myself to go to a check-up appointment. This is also because I have difficulties finding doctors who take me seriously and who are patient and gentle.«

Nina also stresses how she is disillusioned by the medical system and does not believe doctors want to help her.

Lastly, we want to draw attention to how asexual patients conceptualize good medical care. The participants do not only talk about negative experiences but, as activists, analyze them as normative and discriminatory practices. In the same vein, they express requirements for good and affirming medical care. For example, Jagoda had an appointment with a gynecologist which she describes as good:

> Jagoda: »He said, he had heard of asexuality before, but he didn't know exactly what it was. I brought a leaflet which he took to read and learn more. I was delighted.«

Bastian counts themselves lucky for having a therapist who only tried to problematize asexuality once and not again after Bastian asked her to. When Gabrielle found a new therapist, she decided to have her coming out as asexual at the start of the therapeutic relationship.

> Gabrielle: »So I thought I will let her know from the start to see how she reacts. She said ›Ok, I have heard of that, but I would need to inform myself further‹. I believe that this is the best possible answer by a healthcare provider.«

The therapist also agreed to hand out leaflets to other potentially asexual patients to help them. This means: It is vital for asexual patients to be taken seriously by their medical providers. Affirmative medical care for asexual people is not a difficult new approach but means that doctors should be willing to learn more about asexuality and question their assumptions about sexuality. These measures alone would build trust in asexual patients.

3.2. Trans people's experiences in healthcare

The problems trans people face – and the interviewees describe – within the German healthcare system are somewhat similar to the issues described by the asexual patients. Yet, not coming out to doctors or medical staff is often not an option. A certain degree of congruency between the photo and the gender designation stored on the health insurance card, and therefore within the patients' file, and the appearance of a patient is generally assumed. »Mismatches« lead to confusion among medical staff:

> Lena (30, genderqueer): »I was sitting in the waiting room, being called by the receptionist who just entered the room: ›Mrs. Galanti?‹. I stood up and answered, ›That's me.‹ The receptionist looked at me questioningly and repeated, ›Mrs. Galanti?‹ I answered again, standing right in front of the doctor's receptionist, ›That's me.‹ This exchange was repeated one more time. Then I entered the treatment room and the doctor asked, ›Mrs. Galanti?‹, looking surprised. And yet again I answered – slightly annoyed at this point –, ›That's me!‹.«

Lena, assigned female at birth, asserts that they are often »read as male«. They called the described situation exemplary: medical staff questioning Lena's identity, which is why they have to claim it insistently. Lena detailed that they feel being held responsible for irritating the staff – and sometimes other patients. Thus, it is not the practice's internal processes that are questioned, but the fitting of Lena's name – meaning gender designation – to Lena's appearance. Lena and Emil (33, trans man) formulate the wish that patients should be called by their first and last names only – without a gendered title.

Robyn (28, trans woman) also recounted being misgendered while being called into the treatment room – from the waiting area – because her health insurance card was taken as a starting point for the gendered salutation.

> Robyn: »I haven't changed my health insurance card yet. Then it's just always Mr. and then I just get in there and then everyone is like ›Huh?‹«

She stated that she is usually gendered – hence addressed – correctly in face-to-face interactions with medical personnel. Before an x-ray was performed, Robyn was asked »Could you be pregnant?«, which was, in this case, a »validation« of Robyn's passing, but also a possible invisibilization of her medical history. Chris (32, genderqueer) recalled mixed experiences with medical staff and doctors: In the community practice that they usually visit for primary care, the physicians tend to have limited information regarding transitions and trans-specific healthcare and/or needs. However, most of them are described to make up for it by listening carefully and taking thorough notes, without asking superfluous or intrusive questions. And the employees are noticed to behave in an extremely professional manner, too:

> Chris: »I had an ECG. And then she said, ›Please uncover your upper body. Also your bra.‹ And when she turned around to me and there were only the scars [from mastectomy], she didn't make a face. She didn't let on anything.«

Still, one of the doctors of that joint practice Chris came into contact with due to an emergency consultation confronted Chris with her psychopathological views. Chris recalled that she tried to explain their stomach issues with their – voluntary and self-determined – mastectomy holding it responsible for gender identity problems and the stomach issues deriving from those.

Unsurprisingly, avoidance is also an issue within the trans community when it comes to healthcare. Sophie (40, trans woman), whose partner is an MD, has stopped seeing doctors who are not involved in her transition process since starting HRT. She omits preventive examinations to avoid reliving her coming out again. Robyn also shuns »uninvolved« doctors unless it is absolutely necessary. Emil tries to refrain from outing situations like these by limiting his »medical contacts«:

> Emil: »I have two or three doctors with whom I must have regular contact. Actually only two, namely the gynecologist and the endocrinologist. I actually avoid everything else.«

He elaborated that this is not due to bad experiences, but the reluctance to explain himself time and again.

> Emil: »Because the explanation usually already starts in the initial situation, not in the treatment room.«

He highlighted another factor why doctor's offices are not considered particularly welcoming for most trans people during the interview: open waiting areas. Emil blames a specific kind of architecture, the open design of some practices, which results in a lack of privacy, for the fact that there all other patients directly know your »diagnosis« if you have to come out at the front desk to explain why your appearance, the so-called »Passing«, and the picture on your health insurance card or the gender in your file seem incongruent.

Uninformed/not sufficiently informed physicians as well as medical staff are also an issue for trans people. Robyn researches doctor's offices in a Facebook group for trans people, trying to find sensitized physicians and minimizing bad experiences. And Emil reported that his gynecologist was unfamiliar with hormones that are supposedly atypical in gynecological practice, namely testosterone.

> Emil: »She was insecure about certain interactions between HRT and vaginal suppositories containing estrogen, which is why she had to consult Dr. Google.«

These findings suggest that education and awareness might be the key to improving healthcare for trans people.

4. Discussion

It is well documented that LGBTAIQ people have worse mental and physical health in comparison to heterosexual and cisgender people. We put forward three interlocking causes, that are all rooted in heteronormativity. (1) Stigma and discrimination lead to minority stress and unhealthy coping mechanisms, which in turn impacts health.[29] (2) Actual or anticipated discrimination in the medical system leads to avoidance. In both our samples participants described delaying or not seeking necessary medical help because of the – anticipated – reaction of medical staff to their queer way of being. (3) Healthcare professionals lack knowledge about LGBATIQ people's specific healthcare needs. Deficient awareness can lead to physicians asking encroaching and inappropriate questions, not knowing how to properly deal with their queer patients.[30] And/or – this would be the worst-case scenario – to treatment errors. Even though some physicians seek to inform themselves: In one example, the doctor seems genuinely interested and wants to read up; in the other, the doctor has to google to be able to help her patient acutely.

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[29] Meyer: Prejudice (Note 10); Dürrbaum, Sattler: Minority Stress (Note 11).

[30] Makini Chisolm-Straker, Logan Jardine, Cyril Bennouna, Nina Morency-Brassard, Lauren Coy, Maria Olivia Egemba, Peter L. Shearer: Transgender and Gender Nonconforming in Emergency Departments. A Qualitative Report of Patient Experiences. In: Transgender Health 2 (2017), pp. 8–16.

Heteronormativity is fundamentally ingrained in medicine. With our data, we can show that heteronormative assumptions play a weighty role in doctor-patient interactions, thus on a micro-level. These can look like normative assumptions about gender identity or sexual activity, or epistemic violence[31] when queer people are not believed when talking about their experiences and identities. On the meso level, we found examples of architecture and questionnaires which embarrass LGBATIQ people and make them invisible or – equally crucial – overly visible. On the macro level, one big issue is the continued medicalization of queer identities, bodies, genders, sexualities and lives[32] and attempts at conversion therapies. All in all, queer lives still seem to be unintelligible[33] and unreadable to the medical system. It is still necessary to come out to a medical provider because overall, all patients are assumed to be heterosexual and cisgender[34]. At the same time, it is not guaranteed for LGBATIQ people to have accepting doctors and therapists, causing anxiety and stress in queer patients. Some patients even opt not to come out at all to medical staff, but not all queer people are able to do that.

Structural stigma can manifest in organizational policies that are not affirming of queer identities and/or providers' knowledge deficits about queer people's health needs.[35] Queer bodies and experiences are not normal within medicine.[36] They irritate routines and presumptions about norms and standards. At the same time, the idea of gender-specific medical measures and/or prevention (§ 2b SGB V) suits only particular gender identities and – up to a certain point – people who engage in particular sexual practices: In the German healthcare

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[31] Miranda Fricker: Epistemic Injustice. Power and the ethics of knowing. Oxford 2010.

[32] Annika Spahn: Frigidität 2.0. Aktuelle Medikalisierungen von A_sexualität [Frigidity 2.0. Current medicalizations of a_sexuality]. https://www.gender-blog.de/beitrag/medikalisierungen-von-asexualitaet (accessed on 7.2.2023).

[33] Butler: Gender Trouble (Note 1).

[34] Markus P. Bidell, Lara M. Stepleman: An Interdisciplinary Approach to Lesbian, Gay, Bisexual, and Transgender Clinical Competence, Professional Training, and Ethical Care. Introduction to the Special Issue. In: Journal of Homosexuality 64 (2017), pp. 1305–1329, here p. 1314.

[35] Chisolm-Straker, Jardine, Bennouna, Morency-Brassard, Coy, Egemba, Shearer: Transgender (Note 30); Kcomt, Gorey, Barrett, McCabe: Healthcare avoidance (Note 15).

[36] Jamie L. Feldman, Joshua M. Goldberg: Transgender Primary Health Care. In: International Journal of Transgenderism 9 (2006), pp. 3–34, here p. 6.

system, special gender-specific preventive examinations are covered by the statutory health insurance with reference to the gender entry. For example, statutory health insurance only pays for prostate cancer screenings for people who are registered as male. All others with a prostate must pay for this service themselves, if it is made available to them at all. That is, the health insurance card is elementary in many cases as the key to these services. Therefore, it poses a problem for some queer patients.[37] Heteronormative perspectives also come into play when it comes to sexual health: The costs for a chlamydia test are only covered by the statutory health insurance up to the age of 25 and only once a year. This does not only affect queer people, but people who engage in certain sexual practices and/or queer living situations (Table 1) might be more dependent on regular control of sexually transmitted infections (STIs).

There are tangible consequences for LGBATIQ people and their health from experiencing heteronormativity in medicine. While some may find numerous ways to cope with difficult situations, others need to change doctors frequently, plan rest periods to recover from discriminatory doctor's visits, or plan if, what, and how they will tell their healthcare providers about their identity. Our research suggests that some have to make compromises to receive the treatment they need, e.g. getting too few therapy sessions with a competent therapist or putting up with discrimination in order to get healthcare at all. And at last, some queer people either delay important doctor's visits for weeks or months or even do not seek medical help at all.

5. Conclusion

Queer people represent an underserved group in need of comprehensive healthcare. Our preliminary results have shown multiple explanations for the worse mental and physical health of queer people. We have also shown that the general criticized position of the patient as inferior is even more so for marginalized people. Therefore, which measures can be taken in order to improve queer people's healthcare? First, medical staff needs to question their normative assumptions:

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[37] Tiffany K. Roberts, Corinne R. Fantz: Barriers to health care for the transgender population. In: Clinical Biochemistry 47 (2014), pp. 983–987.

Not every person is cisgender, and not every person is heterosexual. Consequently, questions about sexuality and gender need to be posed openly, directly, and without embarrassing the patient. Assumptions about sexual orientation, gender identity, behavior, or anatomy should be avoided[38] and sensitive questions should be asked in private spaces only[39].

In our data, it was shown that especially trans, intersex, and non-binary persons would prefer to be invoked or approached by their first and last names only, without any gendered form of address involved.[40] Using their preferred names and/or pronouns that might differ from their legal documents hits the same notch. Another step should be incorporating queer-inclusive language on intake forms and assessment tools as well as promoting a welcoming environment within the doctor's office.[41] This includes adding »queer imagery«, e.g. pictures of a pregnant trans man[42] or a lesbian couple, and content on patient education and marketing materials as well as providing education to staff to promote medical competence in serving queer patients.[43] Queer-friendly treatment regimens and protocols must be implemented to sensitize all healthcare practitioners. »Physical exams should be structured based on the organs present rather than the perceived gender of the patient.«[44] Queermed Deutschland for

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[38] Alison B. Alpert, Eileen M. Chichoskikelly, Aaron D. Fox: What Lesbian, Gay, Bisexual, Transgender, Queer and Intersex Patients Say Doctors Should Know and Do. A Qualitative Study. In: Journal of Homosexuality 64 (2017), pp. 1368–1389, here p. 1377.

[39] Chisolm-Straker, Jardine, Bennouna, Morency-Brassard, Coy, Egemba, Shearer: Transgender (Note 30), here p. 14.

[40] D. Brienne Hagen, M. Paz Galupo: Trans* Individuals' Experiences of Gendered Language with Health Care Providers. Recommendations for Practitioners. In: International Journal of Transgenderism, 15 (2014), pp. 16–34.

[41] Annika Spahn, Lena Ellenberger: Sexuelle und geschlechtliche Vielfalt in der Gynäkologie [Diversity of sexual orientation and gender in gynaecology]. In: Marcel Hackbart (Ed.): Gesunde Vielfalt pflegen [Maintaining healthy diversity]. Vol. 2. Göttingen Waldschlösschen 2021, pp. 79–95.

[42] Ann Kristin Augst: Quo vadis, (Gender) Medizin? Denkanstöße zur (Regel-) Gesundheitsversorgung von trans Personen [Quo vadis, (gender) medicine? Thought-provoking impulses on (regular) health care for trans people]. In: amatom. ein Magazin von kritischen, jungen Mediziner*innen 31 (2018), pp. 11–12.

[43] Augst: Quo vadis (Note 42); Kcomt, Gorey, Barrett, McCabe: Healthcare avoidance (Note 15), here p. 6.

[44] Feldman, Goldberg: Transgender (Note 36), here p. 8.

example offers a checklist to examine whether a doctor's office is queer-friendly or not.[45]

Heteronormativity, as discussed earlier, does not only impact queer people's lives. The proposed measures would also benefit cisgender and heterosexual patients. For example, not every person who is not sexually active is asexual – and vice versa. By just asking if someone is sexually active and accepting the answer as valid without pressuring patients, a lot of pressure is taken from sexually inactive patients. Inferring sexual practices from relationship status can also lead to a bias in the case history of non-queer people. And assuming that certain organs are present because a person has a certain gender entry, like assuming a person who is listed as a woman always has ovaries and a uterus, instead of eliciting the *status quo*, like questioning if a patient of any gender marker could be pregnant, could also lead to poorer care for cis persons. Still, queer people are a minority, facing discrimination inside and outside the healthcare system. They are a vulnerable group that must be given the attention they need to adapt and improve their healthcare. Social disadvantage often leads to health inequalities, so action is urgently needed. The optimal provision of healthcare and prevention services to sexual and gender minorities requires providers to be educated, reflected and attentive – as every healthcare professional should be.

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[45] Queermed Deutschland: Ein Leitfaden für den Umgang mit Patient*innen [A guide to dealing with patients]. https://queermed-deutschland.de/leitfaden-fuer-den-sensibilisierten-umgang-mit-patientinnen/ (accessed on 7.2.2023).

Allo-normativity	Allonormativity is a social norm that assumes that every person wants to have sex or feels sexual attraction toward others. Sexuality is therefore seen as normal and necessary. Allonormativity is part of heteronormativity and leads to discrimination against asexual people.
Amato-normativity	Amatonormativity is a social norm that assumes that every person wants to have a romantic relationship or falls in love with other people. Romantic love is therefore seen as normal and necessary. Amatonormativity is part of heteronormativity and leads to discrimination against aromantic people.
Asexual	An asexual person does not experience sexual attraction.
Aromantic	An aromantic person does not experience romantic attraction.
Bisexual	A bisexual person is attracted to more than one gender.
Cis	»Cis« is the opposite of »trans«. The adjective is used to express that a person identifies with the gender they were assigned to at birth based on genitalia.
Endosex/ Dyadic	Dyadic or endosex refers to a person who is not intersex, that is, whose body fits into the medical norm of male or female bodies.
Gender-queer	Genderqueer is an umbrella term for a person who does not fit into the gender binary norm. It can also describe the gender identity of a person who identifies as both female and male (simultaneously or alternately) or neither female nor male. Thus, genderqueer cannot be clearly distinguished from the term »non-binary«.
Intersex	An inter(sex) is a person whose physical sex (for example the genitals or the chromosomes) cannot be assigned to the medical norm of »unambiguously« male or female bodies, but lies in a spectrum in between.

Non-binary	Non-binary refers to a person who does not (or not to 100 %) identify as male or female, but rather, for example, as both at the same time, between male and female, or as neither male nor female.
Queer	Queer is an umbrella term that refers to anyone who does not fit into society's norms around gender and sexual orientation, including lesbian, gay, bisexual, asexual, and aromantic, as well as trans, non-binary, and intersex people and anyone who is questioning their identity.
Trans	A trans person is someone who identifies with a different gender and/or expresses gender identity differently from the gender that they were assigned at birth. The term »trans« can cover many gender identities, e.g. transsexual, transgender, gender variant, non-binary or genderqueer, only to name a few.

Table 1: Glossary of terms

Marta Lewandowska

Becoming a parent as a lesbian in Poland: an autoethnographic narrative

Abstract
This chapter is an attempt to achieve an in-depth understanding of the actual situation of homosexual couples in Poland who decide to have a child. In Poland, infertility treatment is available only to male-female couples, and discriminatory attitudes towards homosexual persons are widespread. Using the method of autoethnographic narration, through a personal narrative that describes our experience of becoming parents as a lesbian couple, I discuss the legislation, norms and micro-practices which constitute discrimination of non-heterosexual persons in access to reproductive healthcare services. In conclusion, I provide some recommendations concerning both the normative, i.e., legal and ethical regulations, and the interpersonal – especially in relation to the cultural competences of healthcare professionals – levels to ensure non-discrimination and equal access to reproductive healthcare services for LGBTQIA+ persons.

1. Background

According to the European Convention on Human Rights, men and women of full age have the right to marry and form a family; they must not be subjected to arbitrary interference with their privacy and family, and they have the right to equal access to public services in their country.[1] National interpretations of these rights differ in terms of legislation, cultural norms, policies and practices. The crucial

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[1] European Convention on Human Rights, as amended by Protocols Nos. 11, 14 and 15, supplemented by Protocols Nos. 1, 4, 6, 7, 12, 13 and 16. https://www.echr.coe.int/Documents/Convention_ENG.pdf (accessed on 7.2.2023).

differential aspects are the definitions of marriage and family. The Constitution of the Republic of Poland claims, in contrast to the European Convention's less static definition, that marriage is a union of a man and a woman.[2] The Polish Act on Infertility Treatment of 2015 restricts access to infertility treatment to only male-female couples.[3]

This paper is an attempt to undertake an in-depth discussion of the actual situation of homosexual couples in Poland who decide to have a child. This will be achieved by a self-reflective narrative which offers not only a personal perspective but also helps understand what it feels like to be a homosexual person seeking to have a child in a particular social and legal environment. The social context of such a decision is well-illustrated by the statistics, which reveal that over 30 % of Polish citizens agree with the statement that homosexual persons pose a threat to everything that is good, moral, and normal within society, and are also a threat to the Polish family.[4] More recent research shows that attitudes towards homosexual persons in Polish society are getting worse.[5]

The majority of children raised in homosexual families in Poland come from previous heterosexual relationships. Lesbians who decide to become parents while already in a relationship achieve this with donor semen from an acquaintance. This procedure is carried out outside the healthcare system. Non-heterosexual parents who seek clinical assistance with conceiving can thus be considered a minority within a minority.

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[2] 2 Konstytucja Rzeczypospolitej Polskiej z dnia 2 kwietnia 1997 [Constitution of the Republic of Poland of 2 April 1997]. In: Journal of Laws of the Republic of Poland (1997), no. 78, item 483, with amendments. Translation: http://www.sejm.gov.pl/prawo/konst/angielski/kon1.htm (accessed on 7.2.2023).

[3] 3 Ustawa z dnia 25 czerwca 2015 r. o leczeniu niepłodności [Act of 25 June 2015 on Infertility Treatment]. Consolidated text. In: Journal of Laws of the Republic of Poland (2020), item 442.

[4] Paulina Górska, Małgorzata Mikołajczak: Postawy wobec osób homoseksualnych [Attitudes towards homosexual people]. Warszawa 2014, here pp. 2–3. http://cbu.psychologia.pl/wp-content/uploads/sites/410/2021/02/Postawy-wobec-oso%CC%81b-homoseksualnych-PG-MM-ST-poprawiony.pdf (accessed on 7.2.2023).

[5] Paulina Górska: Efekt »tęczowej zarazy«? Postawy Polaków wobec osób LGBT w latach 2018–2019 [»Rainbow plague effect«? Attitudes of Poles towards LGBT people in 2018–2019]. Warsaw 2020, here pp. 2–5. http://cbu.psychologia.pl/wp-content/uploads/sites/410/2021/02/LGBT_2018_2019_final.pdf (accessed on 7.2.2023).

2. Autoethnographic narrative as a method

This chapter relies on the method of autoethnographic narration, in which a self-reflective story connects to wider socio-cultural and political insights.[6] Through a personal narrative on our experience of becoming parents as a lesbian couple, I will discuss the legislation, norms and micro-practices which constitute discrimination of non-heterosexual persons in access to reproductive healthcare services.

The autoethnographic method is recognized and applied in research on the LGBTQIA+ community and in family research.[7] It helps to explore specific and personal experiences in a heteronormative milieu, such as lesbian couples' attempts to conceive a child with the use of donor semen from a sperm bank. With its reflexivity and subjectivity, this method provides a detailed insight into the multi-layered experience of intersectional discrimination.

Of course, this method is limited due to its lack of representativeness. I am not claiming that the experiences of other lesbian parents are similar to ours, although I am convinced that the questions and dilemmas we have faced are comparable. We may differ in the decisions we have made as well as the importance and emotions we attach to them.

One of my biggest concerns while working on this topic was and still is the privacy and well-being of the people involved in my experience. My partner, with whom I shared the crucial parts of this experience, was the first reader of each paragraph I wrote. Many of the details I put into the text emerged from our conversations and shared memories. Nevertheless, the most important figure to whom I was referring in each sentence I wrote was our daughter. She is almost four years old now. We are not going to hide from her the story of how she came into the world, but it is crucial that the information she receives is suitable for her age. This will be a long and delicate process. While writing this paper, I very often imagined her reading it as a 12-year-old person as I think that this is the age at which she would be able to read this text by herself and understand it; this was a kind of benchmark for me in deciding what and how to write. I hope we will prepare her

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[6] Tony E. Adams, Jimmie Manning: Autoethnography and family research. In: Journal of Family Theory and Review 7 (2015), pp. 350–366; Stacy Holman Jones: Autoethnography. In: George Ritzer (Ed.): The Blackwell Encyclopedia of Sociology. Malden, Oxford, Carlton 2007, pp. 355–357.

[7] Adams, Manning: Autoethnography and family (Note 6), pp. 350–366.

to receive this information, and giving this text to her to read will be part of the whole and complex process of informing her and helping her adapt to her origins.

There were things of importance in my experience that I decided not to write about. This was mostly because of the concern I had for my relatives and friends. I also do not reveal the names of the personnel and institutions that provided medical and clinical assistance to us in Poland as this might put some of them in danger due to the political and social situation here. I mention by name the Danish clinics we received assistance from because their national and European laws protect them well enough.

3. Our story

3.1. Doubts and fears related to reproduction decisions – before it all began

It took me almost twenty years to make this decision. To become a parent. Many people who consider becoming a parent – or face the fact that they are going to – struggle with fears, questions, and dilemmas. The experience of becoming a parent is very individual as it is based on the psychological structure of a person, their family, and the social environment. It is also based on certain cultural and legal backgrounds. Nevertheless, amongst the variety of individual experiences, there are some aspects of parenthood that appear to be the most common and overwhelming. These aspects may be revealed in questions like: Will the baby be healthy? Will I be a good parent? Is our relationship strong enough for us to make this decision, or am I strong enough to be a single parent? These were not questions I had asked myself before I decided to become a parent. There were two other questions that overshadowed the most obvious ones: Do I have the right to bring a person into the world who will be unsure of some part of their origins? Are we allowed, in moral terms, to consciously expose an innocent child to discrimination and hatred? Will we be able to protect them, or is this even possible?

The first question was the most profound as it considers the identity of a person: What makes us who we are? What are the essential constituents of self, without which it may be impossible to construct a sufficient personhood? Is knowing your genetic origins one of these essential constituents? I cannot say that I have managed to answer these questions. Many lesbian couples resolve this problem by deciding to use semen from an acquaintance donor. Agreements between couples and donors differ: some may put the donor in the position of the father, while others consider him as an »important uncle«, or a friend of the family. These agreements are not always in accordance with Polish law, according to which the mother is the one who gave birth to a child;[8] the father, with all the legal consequences, is the one whose name is put on the birth certificate. Moreover, one cannot register a new-born child without putting the name of the father. The »father« section on the birth registration form must be completed; it cannot be left empty or filled out with »unknown«.[9] The man whose name is on the birth registration form must execute his parental rights and responsibilities, regardless of previous informal agreements between a lesbian couple and him. I strongly believe that when it comes to life and death, love, and parenthood issues, as a Polish poetess described it: »We know ourselves only as far as we've been tested«[10]. Previous bona fide agreements with the sperm donor may not stand if the two parties face real consequences of these agreements. And then there is the law and its execution, which in Poland may have a discriminatory outcome. A profound example of psychosexual orientation-based discrimination is the case X v. Poland in the European Court of Human Rights: four children were taken away from their mother by the decision of the Polish court, the main grounds for which was that the mother engaged in a lesbian relationship after her divorce from the father of the children.[11]

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[8] Ustawa z dnia 25 lutego 1964 r. Kodeks Rodzinny i Opiekuńczy [The Family and Guardianship Code, 25 February 1964]. Consolidated text. In: Journal of Laws of the Republic of Poland (2020), item 1359.

[9] Ustawa z dnia 29 września 1986 r. Prawo o aktach stanu cywilnego [Act on Registry Office Records Act, 29 September 1986]. Consolidated text. In: Journal of Laws of the Republic of Poland (2011), item 1264.

[10] Wisława Szymborska: Moment of Silence. In: Wisława Szymborska: Map. Collected and Last Poems, Clare Cavanagh, Stanisław Barańczak (trans.). New York 2015, p. 34.

[11] Polskie Towarzystwo Prawa Antydyskryminacyjnego: Discrimination in a custody case
based on a mother's relationship with another woman. http://www.ptpa.org.pl/site/assets/files/1915/x_v_poland_information_docx_1.pdf (accessed on 7.2.2023).

While struggling with the final decision, I knew myself well enough to be sure that when it comes to my own family – my spouse and child/children – I am, paradoxically, rather conservative: I want it to be me, my partner, and our child/children. The idea of »third parties« being involved was unbearable. Not only because of the justified fear of possible legal consequences, but also because of my psychological inability to include anyone except my partner in making crucial decisions connected to child rearing. I admire people who create so-called patchwork families. I believe that it is possible to live a happy life in various structures and relations, but a patchwork family is just not my way of doing it.

Once we agreed that an acquaintance donor was not an option, the other possibility for us was to use a sperm bank. A brief research of web content was enough to reveal the options: not only were extended donor profiles available, which offered detailed information about the donor's ancestors, physical and psychological profile, and photographs from his childhood, there was also a non-anonymous donor option. Cryos, one of the biggest sperm banks, helped us to overcome the biggest dilemma: knowing the genetic origins of our child. As we learned after the whole process, our intuitions and concerns about genetic origins matched the consensus in social sciences that overt sperm donation may be considered as a human right of a person born by heterological insemination.[12] Cryos offers a non-anonymous donor option: according to Cryos' procedure and Danish law, a child who is over 18 years of age and who was born thanks to a donor's semen may obtain information that identifies the donor.[13]

The second dilemma and the fears arising from it were strongly connected with our experience as lesbians living in Poland. Both my partner and I had been working as diversity trainers, conducting workshops and leading projects and actions related to equity and inclusion. We were aware of attitudes towards homosexual persons in Polish society. This knowledge did not only come from research and studies. We also worked with many different people, many of whom were employees of local and governmental institutions and non-governmental organizations. We worked with journalists, artists,

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[12] Anna Krawczak: The law versus the need of children born through non-partner donation to know their own genetic heritage. In: Prawo i Medycyna 4 (2017), p. 43.

[13] Cryos: Non-ID Release and ID Release Sperm Donors. https://www.cryosinternational.com/en-gb/dk-shop/private/how-to/how-to-choose-a-sperm-donor/id-release-or-non-id-release-sperm-donors (accessed on 7.2.2023).

social workers, officials, teachers, librarians, students, activists, and so-called leaders from big cities and small villages all over the country. Although we were openly attacked only once – while walking and holding hands on a Warsaw street -almost every day we heard statements filled with misunderstanding and hate, very often from well-educated people who had social influence.

Homophobia in Poland is not only a traditional prejudice – homosexuality considered as a sin, something »against nature«. It nowadays has the appearance of what we call »violence in white gloves«. These attitudes are well described by statements like: »I'm tolerant and non-homophobic, but they should not be so loud and should keep their sexuality in their own homes; it's violation of my freedom if I have to be exposed to two men or women kissing«; or, »I have nothing against homosexuals, but we must not allow children to suffer by living in a family that is not accepted by society.« The quotations are verbatim or almost-verbatim quotations of many of the statements that my partner and I heard when conducting anti-discrimination workshops. For all of my conscious life, my main problem with homophobia has always been that it is hardly ever expressed directly to me. It was, and still is, a strange feeling of incomprehensible distance and mistrust, lost opportunities or relations, and a lack of sympathy. But I am an adult: I have made my decisions to live according to my feelings, desires, and beliefs. I am well equipped to deal with the consequences of my decisions. My child could not decide in what kind of family it would be born, but the consequences for the child could be the same or worse as actually being homosexual. The possible psychosexual orientation of the child has nothing to do with it. It is enough to have two mothers to be discriminated against by association.

Our approach to this problem was to focus on the aspects that we could influence. We could not change the world. We also believed that the most important factor for the child was the immediate environment. Therefore, we directed our efforts towards our families and friends: it took two years of discussions and overcoming crises before we finally felt that all the important people in our life were prepared and that the child would be welcomed by them. My father died five years before this process began. He was a man of principles, the patriarch of the family, a Catholic. He also was a crucial benchmark for me. When we decided to have a child, my mother said, »at least something good came from your father's death. Maybe I'm not a wife anymore, but you will be a mother and I will be a grandma«. Would I have decided to become a parent if my father was still alive? I don't know, but this question provides no relief – it bothers me.

These struggles and hesitation reflected my emotional and intellectual state when approaching the process of becoming a parent. Even though the most important dilemmas and fears were somehow mitigated, I still felt like a person stepping on thin ice. Each challenge or problem, even the smallest one, could become a drama due to fundamental moral issues.

3.2. Getting knowledge – stepping into the underworld

My very first thought in relation to clinically supported reproduction for lesbian couples was the in vitro procedure. This came from common knowledge, such as newspapers and non-professional talks. I am still wondering why this association is so strongly based in the public discourse. I have one intuition: since the in vitro procedure is still recognized by the Catholic church in Poland as something against nature, then associating it automatically with lesbian parenthood makes worse discrimination, namely cross-discrimination, even more likely.

When my partner and I started to think about being parents, we were already aware that if there were no biological obstacles, then the in vitro procedure would not be necessary and we could consider a much easier and cheaper procedure: insemination.

At first, we looked for information about this on Polish websites. There was nothing, or almost nothing. Some web pages had been deleted before our research began. The most useful were American internet forums, where my partner compulsively looked for »success stories« and instructions. However, it was hard to get any practical knowledge from that source because the legal situation in the United States was incompatible with the Polish one. Our internet research was very chaotic and frustrating as most information came from non-professionals, and the names of effective supportive medicines were unrecognizable to us. One of the most confusing pieces of information we found while investigating support possibilities in Poland was that there was a gynecologist, a man, who sold semen and provided insemination in his own practice. The semen allegedly came from students of sport departments, and it was supposed to be very cheap – around 150 euros. We never checked whether that was true. The more we searched, the less we understood.

Our very first conversation about medically supported reproduction was with friends from Love Does Not Exclude, a non-governmental organization committed to introducing marriage equality in Poland. We were given the contact details of a person from another organization whose goal was to support couples who are trying to become parents. I wrote to this person requesting contact, and a couple of weeks later we were invited to her home in the suburbs of Warsaw. In November 2016, late on a Sunday evening, we drove along dark and quite deserted muddy roads to find the place of our meeting. I remember feeling as if I was in a criminal movie. During our phone conversation before the meeting, this activist said it was a pity that we had not done it earlier, before 2015, when the Polish Parliament had adopted the law on infertility treatment. Due to this act, clinically supported reproduction could be offered only to man-woman couples; since that time, she and her organization were not allowed to openly support lesbian couples or single women with clinically supported reproduction. Searching for information and support was hence like stepping into the underworld.

We got a lot of information from this NGO activist. I was overwhelmed and afraid that I would miss something or forget; I tried to make some notes, which was difficult because I was shaking and my body was stiff from tension. She told us that some gynaecologists were trying to help couples like ours. She gave us the name of one of them and told us to be cautious and discreet. We should not go together to the clinic; my partner should not talk too much at the registration desk, especially about our relationship and plans. The next part of the story I know mostly from what my partner told me.

3.3. Clinical support in Poland – being a stranger

When my partner walked into the room where the recommended gynecologist was waiting and explained what she had come for, the physician checked that the doors were properly locked and started to whisper. She told my partner that an option for us was for her to monitor the cycle of my partner and prepare her for home insemination. The procedure of ordering semen from a foreign sperm bank and the insemination itself must be done by ourselves. We visited the clinic several times to monitor my partner's cycle. The monitoring schedule was quite strict, so my partner had an appointment with a different gynecologist almost every time. One of them, instead of whispering, started to write down on a sheet of paper her questions and answers, right after my partner had told her that she had been preparing for home insemination. She also suggested another option that would enable my partner to get clinical insemination: if she brought a man who would sign a document of his parental obligation in the registration office, then my partner could be clinically inseminated in this clinic. This option was meant to be easier, cheaper, and more effective. After a couple of days, my partner went for another appointment at the clinic. She told the gynecologist that we were afraid of the possible legal consequences of involving a man in this process. The gynecologist answered that it could be our friend or someone who was 90 years old, so he would die soon and the problem would be solved. She also mentioned that if my partner decided to use that option, it would be quite good if she and the man, while visiting the clinic, were holding hands or doing other things that would indicate a relationship.

During some visits, my partner did not feel confident enough to inform the physician about the specifics of our situation. She just wanted the monitoring to be done. As the »critical moment« of the cycle approached, she asked the »uninformed« gynecologist when exactly the best moment for successful procreation would be. The physician answered: »Just do it [have intercourse] as often as possible with your husband in the next three days«. My partner did not feel safe enough to explain that this would not work in our situation because we had only one chance of insemination in a cycle. So, our first home insemination had very little chance of success, which we were not aware of at that time.

I was waiting in the car in the clinic's car park while these conversations took place. When my partner came back, she was pale, confused, and her eyes were wide. Usually, it took her some time to be able to talk. One of the hardest moments for me was the time I spent in the car, waiting for my partner to come back from the clinic, and then hearing about the »fake partner and father« option. I was not able to participate in the conversations with the gynecologists; I was not able to support my partner; I felt helpless; I felt like an obstacle in fulfilling our dreams and aspirations. We rejected the »fake father« option, so home insemination was the only way.

We decided to order semen from Cryos, a sperm bank with transparent procedures, a large list of donors with extended profiles, and non-anonymous donor options. The donor we chose was a Danish student of philosophy – like both of us several years previously; we liked the recorded message from him – part of his extended profile; we felt sympathy and some closeness to him. The semen was of high quality; its price was higher because this was a non-anonymous donor with an extended profile, and the list of such donors was shorter. Over €500 for one straw. It was affordable for us. After an e-mail exchange and providing ultrasonograms and other information, we had a phone conversation with a physician from Cryos. When the right time of my partner's cycle was approaching, we finally ordered the semen. It was not €500 but over €2000 because the Cryos website stated that, for the best results, you should order two straws, and there was also a high tax payment and delivery costs. It was a lot for us, but there was no turning back from the process we had started – we would not give up due to the costs.

The semen was delivered to our home by courier three days after we had ordered it. It came in quite a large metal box with stickers on it saying »human tissues«. The courier seemed quite confused giving it to us. The straws in the box were frozen in liquid nitrogen, so steam rose when we opened it. Even though we were well prepared for the procedure by reading instructions and following web forums, it was very stressful, yet still romantic. Ten days later the pregnancy test results dashed our hopes. We repeated the procedure, with cycle monitoring in the clinic, ordering semen and home insemination once again next month, and the results were the same. We could not afford to try again. Not only because of lack of money, but also because of the emotional costs of the uncertainty of acting in the dark without clear instructions about the exact time for insemination.

After our last visit to the fertility clinic, where we faced the truth that we could get no more support there, we called a gynecologist whom we had heard about from friends whom she had helped with their pregnancies with acquaintance donors. She had her own practice and agreed to meet with us. Our first meeting I remember as rather strange. It took us couple more meetings to understand that she was not sure of our intentions. Her liberal attitudes towards abortion brought a lot of hate problems on her, which made her quite suspicious and cautious. Once we were all certain about our intentions and trusted each other well enough, the process accelerated. She strongly advised us against home insemination due to lack of proof of its effectiveness. Her recommendation for us was to choose a clinic where clinical insemination was accessible for homosexual couples, because this way of insemination has been scientifically proven and provides quite successful results.[14]

Since at that time we were certain about our choice – a specific non-anonymous donor from Cryos – we started to look for a clinic. Our first choice was, as suggested by the NGO activist, a Ukrainian clinic. We thought that it would be easier and cheaper to get semen delivered from Denmark and visit Lviv to get clinical insemination there. We were advised by the activist to contact some international medical clinics which have branches in Ukraine. After an exchange of emails and a telephone conversation with one of these clinics, we began preparations for the insemination: filling out documents, collecting the necessary medical test results, etc. We informed the clinic that we wanted to use semen from a Danish sperm bank, so it had to be delivered to the Ukrainian clinic. After a couple of days, we were told that this was possible but that there would be an additional fee. Someone from the Ukrainian clinic told us that there was a man, we got his name, who was able to get semen across the Polish–Ukrainian border. The cost of this service was €1,650, and this was the only way to transfer the semen. It was not explicitly stated, but we understood that this fee was necessary to pay a bribe. We confirmed the price and the name of a man with another Ukrainian clinic. Finally, the Ukrainian option turned out to be not cheap and easy anymore.

3.4. The Danish experience – a breath of fresh air

Our next idea was to find a clinic in Denmark because it would be easy to transfer the semen from Cryos, as Cryos did not have its own clinic. We found Diers Clinic, which was situated in Arhus, the same city as the Cryos sperm bank. We sent documents and test results – HIV test and ultrasonogram. After a phone conversation with a physician from Diers Clinic, we were finally invited to use this clinic's clinical insemination service. Since the clinic has its own sperm bank, with extended donor profiles and a non-anonymous

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[14] Nina Carroll, Julie R. Palmer: A comparison of intrauterine versus intracervical insemination in fertile single women. In: Fertility and Sterility 4 (2001), pp. 656–660.

donor option, we decided to use both services – ordering semen and clinical insemination – in one place. As it turned out, the semen and clinical insemination cost us less than one home insemination with semen from Cryos. With accommodation and travel costs, we spent about €1200 in Arhus.

In parallel with the arrangements with Diers Clinic, we visited our gynecologist at her own practice nearly every week for the cycle monitoring. When ovulation was about to begin, she gave us precise instructions about the time of insemination, and she provided us with a syringe of medicine that we were to inject 24 hours before the insemination procedure. This medicine was supposed to make the time of ovulation more precise and therefore increase our chances of success. My partner injected herself in the stomach while we were on our way to Arhus. This was at noon on a Saturday in October. At noon the next day, we were supposed to show up in the clinic. And that was what we did.

I remember my first impression of the clinic – it did not look medical at all. It was rather cozy and friendly. There was no whispering or other forms of expression connected with our psychosexual orientation. We were treated like all the other clients. At first, this felt a little bit strange – different from all we had experienced so far. No one even said how brave we were or that they admired us. Nothing – just kind and professional interactions. I can only describe it by comparison with the experience of breathing fresh air for the first time, when all your previous experiences had been with polluted air. Surprising and disturbing at first, but purifying and relieving after a while. Before the insemination, I was asked to sign a document confirming my parental responsibility for the child if it were born.

I did so with shaking hands, for this was *the first time* I was legally considered as a potential parent! I participated in the procedure, after which we waited together – lying down, to help the semen reach its goal. Two hours after entering the clinic, we were lying down at the seashore listening to the birds and the waves. We did not talk much – we just looked at the sky and held hands. If there is magic anywhere, it was right there for me.

Ten days later we took a pregnancy test. After two failed attempts at home insemination, we were completely stressed out. When there was no second stripe after two minutes of watching the test, we ran out of the bathroom, devastated. After half an hour, we came back to the bathroom, and the test that we had left on the floor had two stripes on it; however, since it was too late to consider this result as credible, we had to do another test. It was Sunday, so we were unable to buy one and had to wait until the next day. The next test had two stripes within seven minutes; so, we went to take a blood test, and in a couple of hours we were certain – my partner was pregnant.

3.5. Labor and birth – the bitter-sweet taste of privilege

The pregnancy was progressing well, and the fetus was developing fine. For reasons of safety and peace of mind, we decided to continue the pregnancy monitoring with our gynecologist at her own practice. It was expensive but comforting. During one of our visits, she used the word »mothers« while speaking to us. It was the first time somebody called me a mother. I will never forget my heart beating and the overwhelming joy of this moment. This was when I realized that I was not sure whom would I be to the coming baby: Marta? Auntie? Mom? It took me some time to be sure. I finally achieved absolute clarity when I held our daughter in my arms for the very first time: I was her mother.

We began preparing for the birth a couple of months beforehand. We used all resources that were accessible to us. We asked my mother's friend for support, an anesthesiologist who had been working in a gynecology and obstetrics hospital, who gave us a contact to a midwife working in that hospital, and she warned her about our situation. The service of a personal midwife in public hospitals is common practice in Poland – or, at least, in big Polish cities. We knew how much it would cost and what is provided but – even more importantly for us – we were much less stressed by knowing in advance that this person would accept us and our choices. We met with the midwife a couple of times before the date of birth. We discussed the plan of labor and birth, and our midwife informed us about possible attitudes and obstacles from the hospital's personnel. She told us to contact her if we were mistreated in the hospital, and the acquaintance anesthesiologist said the same.

The emotions of the labor and birth themselves were stronger than any fears related to our psychosexual orientation. We came to the hospital one week after the planned birth time as the delivery would be induced. We had our own room, and we spent most of the labor with our midwife. I was able to support my partner during all the labor, and

I was asked to cut the umbilical cord when the baby finally came out. It was tougher than I thought, so I had to cut it several times until it was finally severed. I was not so much interested in the baby, as she was alive and fine. My concern and attention were focused on my partner, who was exhausted and in pain. Our baby was born in the late evening, so I had to leave the hospital. I came back in the morning and that was when I fully experienced the existence of our daughter. Since I was the one with previous experience with newborns, I changed her diapers and did all the other necessary stuff, except for the breastfeeding. Some of the nurses and doctors asked who I was to the mother of the child. I answered that I was her partner. The reaction was usually silence or a quite surprised: »o!«. There were some procedures, like vaccination or the hearing test, for which the guardian was supposed to sign some documents. I was asked once by a nurse to sign a document in the office, at which time my partner was sleeping. I was unsure what to do since I was not a legal guardian according to Polish law. I knew that the nurse was aware of this. She gave me the document and I signed it with my last name. It was easier because my partner, our daughter and I all share the same last name – she has both of our last names. The story of enabling our child to have our last names is long and complicated. There is no place for it in this paper.

4. The privileged

Although we call ourselves – or at least some of us do – the LGBTQIA+ community, we are very diverse. We are Christians, Muslims, Buddhists, non-believers. We differ in terms of social and economic status; we live in different places; we come from various regions; we are of all ages. Some of us experience acceptance and support from our families and direct surroundings; some experience quite the opposite; most of us are somewhere in the middle. In terms of individuality, we have diverse characters, personalities, competences, and appearances. Each of these and many other aspects of our identities put us in specific and incomparable positions in terms of equality and its execution.

When struggling to become parents, my partner and I were about 35 years old; we were supported by relatives and friends; we were quite independent – running our own small businesses and a foundation. We were well educated, with established occupational positions and a quite stable and satisfying income – over the national average wage. Our families were well functioning and established, and we lived in a large city. We spoke foreign languages; we were quite competent in terms of using the internet and searching for information. We were in a large network of non-governmental and activist relations. We personally knew physicians who would support our desires. Both of us had been in psychotherapeutic processes – we were confident of ourselves and our relationship. Our psychological and interpersonal competences were very high – we were teaching others how to develop them. I think that taking away even one of these factors could have put us in a very different position. With no support and a lack of finances or confidence, we would not have overcome the plenitude of crises and doubts. And while I still consider us a minority, I am aware that our approach to parenthood – considering all the other aspects of our situation – came from a privileged position.

Of the over 50,000 children that are being raised in so called »rainbow families« or »families of choice«[15] in Poland, very few are of gay couples[16]. This is mostly due to the impossibility in Poland of legal adoption or surrogacy for gay couples, not to mention social attitudes, which are much more rigid when it comes to raising a child without a mother.

Depending on religious and political orientation as well as respected values and norms, attitudes amongst LGBTQIA+ people towards clinical insemination for lesbian couples differ. On one hand, we could feel support and »good luck« wishes from the community; on the other hand, we sometimes experienced very soft feelings of grief, bitterness, or anger that are hard to recognize and describe. I think these feelings came from people who see us as being in a privileged situation, and what we achieved was considered as unachievable for many other homosexual people. Sometimes the vague and indirectly expressed narrative was that instead for fighting

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[15] Mirosława Makuchowska (Ed.): Sytuacja społeczna osób LGBTA w Polsce. Raport za lata 2019–2020 [The social situation of LGBTA people in Poland. Report for 2019–2020]. Warsaw 2021. https://kph.org.pl/wp-content/uploads/2021/12/raport-maly-2019-2020.pdf (accessed on 7.2.2023).

[16] Joanna Mizielińska, Marta Abramowicz, Agata Stasińska: Rodziny z wyboru w Polsce. Życie rodzinne osób nieheteroseksualnych [Families of choice in Poland. Family life of non-heterosexual people]. Warsaw 2014. http://rodzinyzwyboru.pl/wp-content/uploads/2021/10/Raport_Rodziny-z-wyboru-w-Polsce.-Zycie-rodzinne-osob-nieheteroseksualnych.pdf (accessed on 7.2.2023).

for our rights in an open battle we somehow tried to assimilate with the heterosexual world by pretending to be a »normal family«. But – no matter how hard we try – we are not a »normal family«, and there are so many others who will never be and will not even be able to try.

5. The lesson

Discrimination and inequality have many faces, and that is what our experience has generally revealed. There are structural, systemic, institutional, and individual levels, all of which influence each other. Whilst Polish law does not recognize homosexual couples as families and parents, the support and openness of the medical institution personnel we dealt with felt like we were »partners in crime«; on the other hand, the discrimination we experienced, even if unnecessary for legal reasons, was legitimized. Without structural, systemic, and, most of all, legal changes, I believe it is impossible to improve the situation of homosexual parents and »parents to be« in Poland. The legal changes should consider a wide range of aspects of personal and family life: legalization of same-sex marriages, right to adoption for homosexual individuals and couples, access to clinical insemination for homosexual couples and individuals, non-anonymous donor options, and other enhancements in semen banks.

Equal rights are a necessary condition for social change, but they will not be sufficient. We need organized support for and growth of non-governmental organizations that disseminate non-discriminatory attitudes in society. We need inclusive education on every level. So far, it seems that modern media services like Netflix have the greatest impact amongst young people in terms of acceptance of LGBTQIA+ people.[17] However, streaming platforms will not do

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[17] Bradley J. Bond, Brendon L. Compton: Gay On-Screen: The Relationship Between Exposure to Gay Characters on Television and Heterosexual Audiences' Endorsement of Gay Equality. In: Journal of Broadcasting & Electronic Media 59 (2015), pp. 717–732; Jarel P. Calzo, L. Monique Ward: Media Exposure and Viewers' Attitudes Toward Homosexuality: Evidence for Mainstreaming or Resonance? In: Journal of Broadcasting & Electronic Media 53 (2009), pp. 280–299; Edward Schiappa, Peter B. Gregg, Dean E. Hewes: Can One TV Show Make a Difference? A Will & Grace and the Parasocial Contact Hypothesis. In: Journal of Homosexuality 51 (2006), pp. 15–37; Gary King, Benjamin Schneer, Ariel White: How the News Media Activate Public Expression and Influence National Agendas. In: Science 358 (2017), pp.776 – 780.

the work by themselves, so governments and institutions should be obliged to effect social change. We should work with medical personnel on many levels in terms of their competences and attitudes, but we should also provide internal rules for institutions that lead to consequences for those who discriminate. These rules should be enforced, and we should also provide rules and consequences for institutions themselves. The processes of education, development, and lawmaking should recognize that people have been brought up and educated for years to be prejudiced. We should not judge them but rather support them by delivering information and giving them access to the real, diverse, very human, and emotional life of LGBTQIA+.

The outcome of all these efforts should not be »Oh, you are homosexual, so I should treat you in a special way«; it should be »You are homosexual? So what? You are our client just like anybody else«.

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II.
Minorities

Zümrüt Alpinar-Sencan

Provision of healthcare for culturally diverse populations: Insights from a qualitative study on dementia care with the members of the Turkish immigrant community in Germany

Abstract

Culture plays a crucial role in shaping a person's perceptions towards health-related phenomena. This gains importance in dementia care because the affected individuals become dependent on their caretakers as their faculties associated with self-determination and personhood is jeopardized. There is a danger that not all persons either affected with dementia or their caregivers from minority cultural groups will seek out or find access to care on par with those from the majority culture. The population of first-generation migrants in Germany are reaching an age where they are at risk of developing dementia. This chapter presents a pilot study focusing on the experiences on dementia care and expectations for counseling of caregivers and relatives of people with dementia of Turkish descent living in Germany. The study is based on qualitative research methodology. Seven face-to-face and telephone, semi-structured interviews were conducted. The preliminary analysis revealed four emerging themes: (1) the need for support, counseling and information about the disease and its course, (2) perception of discriminative behavior and neglect from healthcare staff, (3) the impact of migrant life on the initiation of the disease, and (4) the role of family in care. The results highlight the main needs of migrant groups and are further discussed in the context of culturally sensitive care.

1. Introduction

1.1. Migration and dementia

Alzheimer's disease (AD), the most common cause of dementia, is a progressive and irreversible neurodegenerative brain disease that affects cognitive functions, including memory, orientation, planning, language comprehension and judgment.[1] AD/Dementia has recently been conceptualized as a continuum with a long asymptomatic, preclinical phase with the existence of slowly progressing pathological changes.[2] There is no cure for most forms of dementia and those affected become increasingly dependent on caretakers for undertaking activities of daily life. With the progressive worsening of cognitive functions, the disease affects the whole person, jeopardizing the faculties mostly associated with individuality, self-determination, and personhood.

The gradual, progressive, and irreversible nature of the disease raises pressing legal, economic, social, and ethical issues in treatment, support, and care of people with dementia. Family members and caregivers play a crucial role in identifying affected persons' needs or implementing their interests concerning counseling, communication, information, life planning, and care. Ethical issues in dementia and

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[1] Harald Hampel, David Prvulovic, Stefan Teipel, Frank Jessen, Christian Luckhaus, Lutz Frölich, Matthias W. Riepe, Richard Dodel, Thomas Leyhe, Lars Bertram, Wolfgang Hoffmann, Frank Faltraco, for the German Task Force on Alzheimer's Disease: The Future of Alzheimer's Disease: The Next Ten Years. In: Progress in Neurobiology 95 (2011), pp. 718–728; World Health Organization: Dementia (20.9.2022). https://www.who.int/news-room/fact-sheets/detail/dementia (accessed on 7.2.2023).

[2] Reisa A. Sperling, Paul S. Aisen, Laurel A. Beckett, David A. Bennett, Suzanne Craft, Anne M. Fagan, Takeshi Iwatsubo, Clifford R. Jack, Jeffrey Kaye, Thomas J. Montine, Denise C. Park, Eric M. Reiman, Christopher C. Rowe, Eric Siemers, Yaakov Stern, Kristine Yaffe, Maria C. Carrillo, Bill Thies, Marcelle Morrison-Bogorad, Molly V. Wagster, Creighton H. Phelps: Toward defining the preclinical stages of Alzheimer's disease: Recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. In: Alzheimer's & Dementia 7 (2011), pp. 280–292; Silke Schicktanz, Mark Schweda, Jesse F. Ballenger, Patrick J. Fox, Jodi Halpern, Joel H. Kramer, Guy Micco, Stephen G. Post, Charis Thompson, Robert T. Knight, William J. Jagust: Before it is too late: Professional responsibilities in late-onset Alzheimer's research and pre-symptomatic prediction. In: Frontiers in Human Neuroscience 8 (2014), https://doi.org/10.3389/fnhum.2014.00921; Annette Leibing: Situated Prevention: Framing the »New Dementia«. In: Journal of Law, Medicine and Ethics 46 (2018), pp. 704–716.

dementia care are manifold and play out along a broad spectrum including not only the latest stage of the disease, i.e., when the capacity of self-determination is effectively lost, but also the earliest, pre-symptomatic stage, when the distinction between diagnosis and risk information is blurry.[3] Issues involve affected individuals, their families, caregivers, medical professionals, and society at large and include substitute decision-making, receiving and disclosing diagnostic or risk information, future life-planning, and information sharing. Dementia-related ethics is rife with culturally loaded ideas about family responsibilities, the good life, a good death and definitions of personhood. As the affected persons become increasingly dependent on their caretakers, dementia-related healthcare becomes an important context for reflecting healthcare provision for culturally diverse populations.

According to the German Alzheimer's Association around 1.6 million people with dementia live in Germany today, of which approximately 100.000 people have migration background.[4] Germany has the highest immigration rate in Europe.[5] About 20.8 million people living in Germany have migration background. Roughly 2.8 million individuals have Turkish migrant background and they constitute the

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[3] Sperling, Aisen, Beckett, Bennett, Craft, Fagan, Iwatsubo, Jack, Kaye, Montine, Park, Reiman, Rowe, Siemers, Stern, Yaffe, Carrillo, Thies, Morrison-Bogorad, Wagster, Phelps: Toward Defining (Note 2); Schicktanz, Schweda, Ballenger, Fox, Halpern, Kramer, Micco, Post, Thompson, Knight, Jagust: Before (Note 2); Bruno Dubois, Harald Hampel, Howard H. Feldman, Philip Scheltens, Paul Aisen, Sandrine Andrieu, Hovagim Bakardjian, Habib Benali, Lars Bertram, Kaj Blennow, Karl Broich, Enrica Cavedo, Sabastian Crutch, Jean-François Dartigues, Charles Duycaerts, Stéphane Epelbaum, Giovanni B. Frisoni, Serge Gauthier, Remy Genthon, Alida A. Gouw, Marie-Odile Habert, David M. Holtzman, Miia Kivipelto, Simone Lista, José-Luis Molinuevo, Sid E. O'Bryant, Gil D. Rabinovici, Christopher Rowe, Stephen Salloway, Lon S. Schneider, Reisa Sperling, Marc Teichmann, Maria C. Carrillo, Jeffrey Cummings, Cliff R. Jack, Jr: Preclinical Alzheimer's Disease: Definition, Natural History, and Diagnostic Criteria. In: Alzheimer's & Dementia 12 (2016), pp. 292–323.

[4] German Alzheimer's Association: Demenz und Migration: Neues Informationsangebot der Deutschen Alzheimer Gesellschaft in arabischer Sprache [Dementia and Migration: New information service from the German Alzheimer Society in Arabic] (15.3.2021). https://www.deutsche-alzheimer.de/artikel/demenz-und-migration-neues-informationsangebot-der-deutschen-alzheimer-gesellschaft-in-arabischer-sprache (accessed on 7.2.2023).

[5] International Organization for Migration: World Immigration Report 2020. https://publications.iom.int/system/files/pdf/wmr_2020.pdf (accessed on 7.2.2023).

largest migrant group in Germany.[6] These individuals include those, whose parents were migrated from Turkey and who were either born in Germany or came to Germany as a kid – second-generation – or who were born in Turkey and has migrated themselves – first-generation.

The first-generation Turkish migrants came to Germany due to labor migration in the 1960s. Germany recruited workers from Turkey in 1961 as »guest workers«, as well as from other countries, such as Italy, Spain, Greece, Morocco, Portugal, Tunisia and the former Yugoslavia in the 1960, to boom postwar economy after World War II.[7] Due to the global oil crisis, German Government stopped the recruitment in 1973, however many decided to stay, brought their families and became permanent residents, which led to an increase of Turkish – and migrant – population in Germany.[8] The first-generation of Turkish migrants are now reaching an age at which age-related diseases, such as dementia, are more likely to occur. Hence, first-generation Turkish migrants now represent a large potential group for dementia-related healthcare services.[9]

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[6] Ümran Sema Seven, Inka Valeska Braun, Elke Kalbe, Josef Kessler: Demenzdiagnostik bei Menschen türkischer Herkunft – TRAKULA [Dementia diagnostics in people of Turkish origin – TRAKULA]. In: Olivia Dibelius, Erika Feldhaus-Plumin, Gudrun Piechotta-Henze (Eds.): Lebenswelten von Menschen mit Migrationserfahrung und Demenz [Living environments of people with migration experience and dementia]. Bern 2015, pp. 51–87; Federal Ministry of the Interior, Building and Community and Federal Office for Migration and Refugees: 2018 Migration Report: Key Results. Nürnberg: Bundesamt für Migration und Flüchtlinge [Federal Office for Migration and Refugees] (2019). https://www.bamf.de/SharedDocs/Anlagen/EN/Forschung/Migrationsberichte/migrationsbericht-2018-zentrale-ergebnisse.pdf?__blob=publicationFile&v=7 (accessed on 7.2.2023).

[7] Ann-Kristin Tlusty, Hasan Gökkaya, Julia Meyer: Guest Workers in Germany: »Germany Neglected My Parents«. In: Zeit Online (21.11.2019). https://www.zeit.de/gesellschaft/2019-11/gastarbeit-deutschland-nachkommen-vertragsarbeiter-ddr-anerkennung-english?utm_referrer=https%3A%2F%2Fwww.google.com%2F (accessed on 7.2.2023); Federal Ministry of the Interior, Building and Community: Labour Migration (2020). https://www.bmi.bund.de/EN/topics/migration/immigration/labour-migration/labour-migration-node.html (accessed on 7.2.2023).

[8] N.N.: Germany Looks Back at 50 Years of Turkish Immigration. In: The Local (26.10.2011). https://www.thelocal.de/20111026/38441 (accessed on 7.2.2023).

[9] Jessica Monsees, Wolfgang Hoffmann, Johen René Thyrian: Prävalenz von Demenz bei Menschen mit Migrationshintergrund in Deutschland [Prevalence of dementia among people with a migration background in Germany]. In: Zeitschrift für Gerontologie und Geriatrie 52 (2019), pp. 654–660.

1.2. Provision of and access to dementia care for and by culturally diverse populations

Individual and familial immigration is a common cause of cultural diversity in healthcare systems. If the quality of provided dementia care depends on cultural affinity with the majority culture, this may create inequities in access to dementia care. Some studies indicate that there are gaps for minority groups in terms of dementia care access, in knowledge about the disease, and in how to address ethical, social, and practical issues related to dementia care and life planning.[10] A recent qualitative analysis of national dementia plans in Europe has shown that the topic of migration has only a minor role and that there is a lack of services and guidelines addressing the needs of people with migration background.[11] Some experts identified specific issues involving ethnic minority or immigrant groups in Europe. These revolved around communication problems with specific implications for assessments of cognitive function and for diagnosing people with dementia.[12] Recent studies conducted in Europe show that the preva-

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[10] Mary R. Janevic, Cathleen M. Connell: Racial, Ethnic, and Cultural Differences in the Dementia Caregiving Experience: Recent Findings. In: The Gerontologist 41 (2001), pp. 334–347; Dolores Gallagher-Thompson, Nancy Solano, David Coon, Patricia Arean: Recruitment and Retention of Latino Dementia Family Caregivers in Intervention Research: Issues to Face, Lessons to Learn. In: The Gerontologist 43 (2003), pp. 45–51; Jung Kwak, William Haley: Current Research Findings on End-of-Life Decision Making Among Racially or Ethnically Diverse Groups. In: The Gerontologist 45 (2005), pp. 634–641; Hürrem Tezcan-Güntekin, Oliver Razum: Pflegende Angehörige türkeistämmiger Menschen mit Demenz – Paradigmenwechsel von Ohnmacht zu Selbstmanagement [Caring relatives of Turkish people with dementia – paradigm shift from powerlessness to self-management]. In: Pflege & Gesellschaft: Zeitschrift für Pflegewissenschaft 23 (2018), pp. 69–83.

[11] Tim Schmachtenberg, Jessica Monsees, Wolfgang Hoffmann, Neeltje van den Berg, Ulrike Stentzel, Jochen R. Thyrian: Comparing National Dementia Plans and Strategies in Europe – Is there a Focus of Care for People with Dementia from a Migration Background? In: BMC Public Health 20 (2020), https://doi.org/10.1186/s12889-020-08938-5.

[12] T. Rune Nielsen, Asmus Vogel, Matthias W. Riepe, Alexandre de Mendonça, Guido Rodriguez, Flavio Nobili, Anders Gade, Gunhild Waldemar: Assessment of Dementia in Ethic Minority Patients in Europe: A European Alzheimer's Disease Consortium Survey. In: International Psychogeriatric 23 (2011), pp. 86–95; Mette Sagbakken, Ragnhild Storstein Spilker, T. Rune Nielsen: Dementia and Immigrant Groups: A Qualitative Study of Challenges Related to Identifying, Assessing, and Diagnosing Dementia. In: BMC Health Services Research 18 (2018), https://doi.org/10.1186/s12913-018-3720-7.

lence of MCI (Mild Cognitive Impairment) and dementia is higher among the immigrant groups compared to the native population.[13] Moreover, these groups are less commonly diagnosed and are less likely to receive a drug therapy for slowing symptom progression or to be placed in a nursing home.[14] As some studies indicate, the insufficiency of the services is due to the language, cultural, religious and ethnic differences between the dominant culture and the persons with migration background.[15]

Access to adequate healthcare services and responsiveness of the provided service to the needs of the person seeking help often generate a challenging situation in culturally diverse societies. Many factors affect inadequate access to care, such as socio-economic background, e.g., type of education, occupation, immigration status, e.g., citizenship, country of origin, permanent residence permit holders, etc., language competence or proficiency, e.g., receiving important information, communication with the healthcare staff, as well as stigma and marginalization, e.g., differences in appearance, different cultural background, accent, etc. Healthcare services that are insensitive to these issues run the risk of reinforcing the perceptions of discriminative behaviors.[16] If these perceptions become prevalent, they can lead to a decrease in trust in medical services, and help-seeking behavior. Adequate access to healthcare is crucial, because poor health reduces people's range of opportunities.[17] Healthcare includes

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[13] Kurt Segers, Florence Benoit, Cathérine Colson, Valérie Kovac, Delphine Nury, Valérie Vanderaspoilden: Pioneers in Migration, Pioneering in Dementia: First Generation Immigrants in a European Metropolitan Memory Clinic. In: Acta Neurologica Belgica, 113 (2013), pp. 435–440; Juliette L. Parlevliet, Özgul Uysal-Bozkir, Miriam Goudsmit, Jos P. van Campen, Rob M. Kok, Gerben ter Riet, Bernd Schmand, Sophia E. de Rooij: Prevalence of Mild Cognitive Impairment and Dementia in Older Non-Western Immigrants in the Netherlands: A Cross-Sectional Study. In: International Journal of Geriatric Psychiatry 31 (2016), pp. 1040–1049.

[14] Lea Stevnsborg, Christina Jensen-Dahm, Thomas R. Nielsen, Christiane Gasse, Gunhild Waldemar: Inequalities in Access to Treatment and Care for Patients with Dementia and Immigrant Background: A Danish Nationwide Study. In: Journal of Alzheimer's Disease 54 (2016), pp. 505–514.

[15] Seven, Braun, Kalbe, Kessler: Demenzdiagnostik (Note 6).

[16] Roberto De Masi: Multiculturalism, Medicine and Health Part 1: Multicultural Health Care. In: Canadian Family Physician 34 (1988), pp. 2173–2177; Kathryn Pitkin Derose, José J. Escarce, Nicole Lurie: Immigrants and Health Care: Sources of Vulnerability. In: Health Affairs 26 (2007), pp. 1258–1268.

[17] Norman Daniels: Health-Care Needs and Distributive Justice. In: Philosophy and Public Affairs 10 (1981), pp. 146–179.

preventive, curative, and rehabilitative services and thus preserves our range of opportunities, which is needed for us to construct our conceptions of a good life.

1.3. Culture's role in healthcare ethics

Culture is a complex term. It is often described as standards if patterns of behavior and a system of beliefs that one acquires as a member of a particular group.[18] Moreover, the group's shared distinctive (cultural and religious) beliefs and values govern the conduct of their life and are exhibited in their rituals, social norms and behaviors.[19] Culture plays a significant role in shaping a person's attitudes towards risky and healthy behaviors and in influencing decision-making with respect to care, treatment and prevention. Therefore, culture has an impact on a person's perceptions of illness, health, responsibility and obligations towards one's family, etc.[20]

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[18] De Masi: Multiculturalism, Medicine (Note 16); Toni Tripp-Reimer, Eunice Choi, Lisa Skemp Kelly, Janet C. Enslein: Cultural Barriers to Care: Inverting the Problem. In: Diabetes Spectrum 14 (2001), pp. 13–22; Matthew W. Kreuter, Stephanie M. McClure: The Role of Culture in Health Communication. In: Annual Review of Public Health 25 (2004), pp. 439–455.

[19] David Miller: The Life and Death of Multiculturalism. In: Elizabeth Goodyear-Grant, Richard Johnston, Will Kymlicka, John Myles (Eds.): Federalism and the Welfare State in a Multicultural World. Kingston 2018, pp. 319–339.

[20] Lucy M. Candib: Truth telling and advance planning at the end of life: Problems with autonomy in a multicultural world. In: Families, Systems, and Health 20 (2002), pp. 213–228; Evelyn Donate-Bartfield, Leonard Lausten: Why Practice Culturally Sensitive Care? Integrating Ethics and Behavioral Science. In: Journal of Dental Education 66 (2002), pp. 1006–1011; Leigh Turner: Bioethics in a Multicultural World: Medicine and Morality in Pluralistic Settings. In: Health Care Analysis 11 (2003), pp. 99–117; Michael Paasche-Orlow: The Ethics of Cultural Competence. In: Academic Medicine. 79 (2004), pp. 347–350; Cornela Betsch, Robert Böhm, Collins O. Airhihenbuwa, Robb Butler, Gretchen B. Chapman, Niels Haase, Benedikt Herrmann, Tasuku Igarashi, Shinobu Kitayama, Lars Korn, Ülla Karin Nurm, Bernd Rohrmann, Alexander J. Rothman, Sharon Shavitt, John A. Updegraff, Ayse K. Uskul: Improving Medical Decision Making and Health Promotion through Culture-Sensitive Health Communication: An Agenda for Science and Practice. In: Medical Decision Making. 36 (2016), pp. 811–833; Brenda Louw: Cultural Competence and Ethical Decision Making for Health Care Professionals. In: Humanities and Social Sciences 4 (2016), pp. 41–52.

Following Kymlicka, culture provides a meaningful context for the range of options people have for implementing their values and preferences, which enable the execution of one's autonomy.[21] This allows one to form and revise one's own conception of a good or fulfilled life.[22] Culture »provides its members with meaningful ways of life across the full range of human activities, including social, educational, religious, recreational, and economic life, encompassing both public and private spheres.«[23]

Cultural membership shapes one's self-identity and provides a sense of belonging (pp. 89–90).[24] According to Taylor, what is central to the person's wellbeing, their notions of a good life (e.g. what is worthwhile, admirable or of value) and the cultural background of the society in which the person grew up informs their self-identity.[25] Cultures provide the conceptual framework that determines which values and life plans or aims inform how a person's conception of good life and self-identity is generated. Thus, insofar as conceptions of a good life inform an individual's health choices, culture and cultural diversity is a remarkably important category for analyzing dementia-related healthcare choices.

The qualitative study presented in this chapter aims to explore the experiences and expectations concerning dementia care and counseling of caregivers and relatives of people with dementia of Turkish descent living in Germany. This is a pressing issue because among the first-generation of migrants in Germany the occurrence of dementia is more prevalent, and therefore, they will likely become a potential group for seeking dementia-related healthcare.

2. Methods

This pilot study is conducted as a part of an international research project funded by the German-Israeli Foundation for Scientific

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[21] Will Kymlicka: Multicultural Citizenship: A Liberal Theory of Minority Rights. Oxford 2013.

[22] John Rawls: Justice as Fairness: A Restatement. Edited by Erin Kelly. Cambridge 2001.

[23] Kymlicka: Multicultural Citizenship (Note 21), here p. 76.

[24] Kymlicka: Multicultural Citizenship (Note 21), here pp. 89–90.

[25] Charles Taylor: Sources of the Self. The Making of the Modern Identity. Cambridge 1989.

Research and Development (G.I.F. grant no: G-1413–119.4/2017). The larger cross-sectional, qualitative study aimed at exploring how various stakeholders' moral and psychosocial attitudes regarding early diagnosis of dementia are embedded in social and cultural contexts in Germany and Israel. The study presented here is based on a qualitative research methodology. Seven face-to-face and telephone, semi-structured interviews with family caregivers and relatives of people with dementia of Turkish descent living in Germany were conducted from March 2020 to November 2021. The study's protocols were approved by the Ethics Committee in the University Medical Center Göttingen (Ref. Nr. 17/12/16). For the interviews, different from guest workers defined in the introduction, first-generation refers to those who were born in Turkey and came to Germany in the recent years to work or to study.

2.1. Recruitment process

The participants were recruited by using flyers and posters in Turkish, which were widely disseminated at collaborative memory clinics, one self-help organization and at one university as well as at supermarkets, mosques, public offices and societies. Also, an online advertisement was placed on one university's announcements' site. Additionally, in order to reach more people, mediators, who are working for special organizations, societies and help-centers for migrants, were contacted. The recruitment of participants was challenging and complicated as a whole. Although this was partly due to COVID-19 pandemic outbreak, people's hesitation to participate in a study played a huge role. Their hesitation was either due to being a foreigner in a country or due to their worry concerning sufficient anonymization, which likely led them to refrain from participating.

2.2. Study design

The interviews were conducted according to semi-structured interview guidelines. The guideline was developed to examine topics related to (a) participants' experiences, knowledge, and assessments of prediction and early diagnosis of dementia; (b) assessment of situations in which predictive results and diagnoses were disclosed; (c) the practical and social impact of these information on participants' lives; and (d) their expectations and experiences in terms of support and information.

2.3. Data collection and analysis

All interviewees were given a description of the study and afterwards they provided written informed consent. Every interviewee was free to withdraw from the study at any point in time. Each received 25€ for their contributions to the study. The interviewees were informed clearly about the procedure, recording, transcription, anonymization, and publications of the results. The interviews were conducted either in Turkish or in German and lasted about 30 to 45 minutes. All interviews were recorded and then transcribed verbatim. Transcriptions were fully anonymized to protect the interviewees' anonymity. Interview transcripts were analyzed following thematic content analysis.[26] The analysis software Atlas.ti™ supported coding and analysis.

3. Findings

In the following, the main findings of the study are presented. There was a homogeneity among the interviewees' expectations and experiences specifically for the need for more information and support at the early stages of the disease and the disease's course. Similar themes were found concerning lack of knowledge of the disease, the impact of living and working conditions on the initiation of the disease, and the importance of family care. A strongly emphasized sense of discrimination was found. The quotations given below are selected to illustrate the range of emerging themes.

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[26] Virginia Braun, Victoria Clarke: Using Thematic Analysis in Psychology. In: Qualitative Research in Psychology 3 (2006), pp. 77–101.

3.1. There is a need for support, guidance and information

Most participants mentioned that neither sufficient help nor information was provided. They therefore gathered all information themselves, for instance via the internet:

> WR2: »No, unfortunately not, no, not at all. I did in the first place, I search [for information on the disease as well as care and support services] on the internet all the time.« (Age: 36–50, caring daughter, second-generation)
>
> MR5: »(…) We had so many difficulties. We educated ourselves and gathered information. We did the research. We didn't get help and we had many difficulties. We obtained a lot of information from these difficulties. (…) When the first symptoms of dementia, such as forgetfulness, wetting himself or having difficulties with the bowel movement, were apparent, we went to the neurology outpatient clinic. They prescribed him with medicines. He [my father] was old, therefore they did not lend assistance. We obtained information on our own. We searched via internet.« (Age: 36–50, caring son, second-generation)

Some participants stated there was not enough aid, support, or guidance from the healthcare staff, while the doctors, for instance, neither had sufficient time nor informed concretely on what to do or how to proceed. Two participants expressed intensely that they were left alone:

> MR5: »As a simple example, I called the health insurance in order to ask about ›what to do‹, ›where to go‹, ›where to get support‹ or ›how to help‹. [I was being told that] ›we do not know that. Ask your doctor.‹ The doctors are like factories [machines], only the important things are taken care of. There cannot be a doctor with sufficient time. There cannot be.« (Age: 36–50, caring son, second-generation)
>
> WR2: »I feel so sad, because there should be more things posted for the relatives and for the sick person. Not any hints were given. Not at all. Also, for what we should pay attention to [in the course of the disease]. (…) Relatives [family members] need information. This could be very helpful. (…) They know the disease; [but], they do not know what to do with it. (…) There had to be more consultations [on what to expect in the course of the disease].« (Age: 36–50, caring daughter, second-generation)

It was also mentioned that sharing the experiences and the obtained information could be very helpful for others, who were in the same situation. This would be helpful to get sufficient information, which should instead be provided by the healthcare personnel, and to get emotional support from others. This idea was brought forward by an interviewee, who gave support to his neighbor, whose husband was diagnosed with early dementia:

> MR5: »I think her [his neighbor, whose husband was diagnosed with early dementia] German is not very good. They are now facing the same difficulty. They are not informed, they [doctors] do not tell much. They [affected neighbors] follow our suggestions: we did this, you should do this, too.« (Age: 36–50, caring son, second-generation)

As one interviewee stated having support through self-help groups, of which the members face the same difficulties and experiencing similar situations, would be quite helpful:

> WR7: »For every disease, it could be very helpful to know that the person is not alone having to face the disease. For instance, my mother-in-law does not partake in any activity and she feels very sad and even a bit embarrassed to be the only one who is affected among her friends. Therefore, joining to such groups [self-help groups], obtaining information from each other and support each other emotionally could be beneficial.« (Age: 36–50, wife of caring son, no information)

Predictive risk information was favored to prepare the family, as the disease burdens the family members, specifically those who are taking care of the affected person. Therefore, right at the beginning a need for support and counseling became apparent:

> MR5: »It [the disease] burdens the family most. We could be informed in advance. There are seminars, educations. We could have participated in those. We did not know that in advance. (…) The family members of the affected could be educated [informed] more in order to better communicate with the affected person and to get psychologically prepared [for the progress of the disease]. That would be very helpful. « (Age: 36–50, caring son, second-generation)

> WR7: »(…) [I]n such a disease not the affected person herself, but more importantly the persons taking care of the affected person should be informed more. The affected person normally forgets the situation [cannot recognize at all] and cannot prepare herself. Those who are close to the affected person should be informed about everything. « (Age: 36–50, wife of caring son, no information)

> WR2: »(…) My mom has dementia and our family suffers very much from it. Uh, I think my mother does not notice anything anymore.

> One [can] say that it [the disease] has arrived. She has her own world. The children suffer. The spouse suffers. Sometimes we are helpless [clueless] with certain things, but yes that's just the way it is, right? « (Age: 36–50, caring daughter, second-generation)
>
> WR3: »(…) For the caretaker, it is a very difficult disease and the caretaker needs to have psychological support.« (Age: 36–50, relative, first-generation)

Getting earlier support and counseling was evaluated positively specifically when the need for preparing advance care directives became apparent to ensure that the affected persons make and carry out their own life decisions. Self-determination was valued by participants as the disease was associated with a diminished capacity for decision-making and hence, loss of control. However, without getting enough support or detailed information at an earlier stage, it is difficult to get prepared for the future, for instance by considering concrete options for care:

> WR2: »Definitely, definitely! We don't have any, but it [advance care directive] would be useful. (…) We were given little information. (…) We were not very well informed by the doctors. That must be changed in any case.« (Age: 36–50, caring daughter, second-generation)
>
> MR5: »We obtained information on that [advance care directives] on our own, too. Whenever we were in the hospital, they were asking us if we had any directives, but it was already too late, the disease was very advanced at that stage and he [my father] would not be able to decide. (…) I would recommend everyone to have an advance care directive, specifically for those who doesn't know German and who are from the same generation of my father while they are still in their right minds.« (Age: 36–50, caring son, second-generation)

An interviewee mentioned that they were informed about having an advance directive during one of their visits not related to dementia. The form was in German and the interviewee translated this document verbally to her mother. However, her mother was irritated and declined to have an advance care directive:

> WR1: »As I started to read the questions, like ›would you like to be connected to the machines?‹, ›would you like to be connected to the respiratory machine?‹, ›would you like to be resuscitated‹, she [my mom] told me that ›I am not that ill, I won't do this. I don't want this.‹ And we let it ride, she didn't want it.« (Age: 51–70, caring daughter, second-generation)

3.2. The disease is not well-known

One of the participants stated that he was not aware before that dementia was a disease. He assumed that his grandfather had the disease; he was not diagnosed with it. The family assumed that it was senility due to advanced age. Generally, among the public, dementia is often known as senility and perceived as something normal rather than as a disease. After conducting some research on the internet on dementia, the participant thought his grandfather had it:

> MR6: »When I saw the announcement [for this study], it mentioned dementia. Up to now, I did not know anything about this disease. (…) I search for dementia on internet considering if one of my relatives could have the disease and I wondered about the disease itself. (…) I surprised to find out that I have a relative in that condition. I didn't know the medical name of the disease.« (Age: 26–35, relative, first-generation)

Other participants also mentioned that not only the disease, but also how it progresses was not well-known:

> WR2: »(…) [M]y mom, many acquaintances, they did not know what dementia is. Many relatives, friends and so many also laughed at her behavior. (…) I find that sad, because dementia is a disease that one [the affected] cannot see for herself. This is a disease and many cannot handle it. They have to be prepared (…) also one has [to show] a little respect for this person; respect in the sense that one should know that it is a disease, which one cannot help it.« (Age: 36–50, caring daughter, second-generation)
>
> WR3: »(…) It would be very helpful to have a booklet or something like that informing the patients' relatives step-by-step about what they could expect to see as the disease progresses.« (Age: 36–50, relative, first-generation)

3.3. Being a foreigner had led to a sense of discrimination

One participant very intensely and frequently stated that they were ignored and that the doctors did not pay enough attention or give sufficient information because his father was old and they were foreigners:

> MR5: »We were left alone. In every respect. Because he was old. Also, because he was a foreigner.« (Age: 36–50, caring son, second-generation)

The same participant stated also concrete examples, where he felt they were treated differently and were discriminated against because they were foreigners. In the last couple of years, the participant's father was an inpatient a couple of times for a couple of days. The nurses were calling him to take care of his father. He had to go to the hospital and sometimes he was finding his father tied up from his hands and feet. He also mentioned that nurses were treating other inpatients differently. For instance, he found once that the diapers were not changed for about 16 to 17 hours. The nurses were changing the patient next door's, he stated, but not his father's. He also suspected that if he was not there to control the care his father received, the nurses would not connect his father to the oxygen tube:

> MR5: »(…) We suffered a lot, [because] they [the nurses] were treating us differently compared to the inpatients next door. (…) Since you are a foreigner, you recognize any different conduct. (…) We had suffered a lot. Different conducts, they look at [treat] my father differently. For instance, if we weren't there, they would not give him the oxygen. [Once] I found that his adult diapers were not changed for sixteen, seventeen hours. (…) They change the one next door. At night, before all went to bed, the nurses check everything. They change the adult diapers, but they would not change my father's. They were changing the next door, but not ours.« (Age: 36–50, caring son, second-generation)

The same interviewee gave another example concerning the provision of healthcare in terms of informing the person seeking help. He mentioned that the healthcare personnel did not show exactly how to make the insulin shots for his neighbor, who had diabetes. The person was about to have a shock due to very high blood sugar level. He stated that the healthcare personnel did not pay enough attention and the person was not informed well enough or sufficiently, even though the person's knowledge of German was well enough to communicate and express herself. However, it was not quite clear if the interviewee was specifically referring to being a foreigner or to the insufficiency of the information provided by the healthcare staff or a mixture of both.

3.4. Living and working conditions have an impact on the initiation of the disease

Some interviewees mentioned that having had to lead a stressful life had negative effects on one's mental health. Some interviewees stressed the difficulties their parents had to face as having to live in a foreign country as a migrant. According to some interviewees, leading a life with changes in one's living and working conditions was among stress factors initiating cognitive decline in one's later life:

> WR2: »I think stress factor also play a very big role [in developing dementia in the later years]. (…) How do I deal with a woman with dementia? How can I help her? What is feasible for her? (…) Also, [I would check for] stress factor. For example, has this woman had much stress in her life? (…) My mother had a lot of stress in her life, a lot.« (Age: 36–50, caring daughter, second-generation)
>
> MR5: »My father came to Germany in 1960s and worked in boiler making industry. Then in mid-1980s he opened a supermarket. His German was super [very good]. However, in 2003, we went bankrupt. With the bankrupt, we had to face psychological distress as a family. Then, he [my father] had a cerebral hemorrhage in 2004. Then, it began [cognitive decline]. Afterwards, he stopped talking in German and generally stopped talking at all.« (Age: 36–50, caring son, second-generation)

3.5. The care is offered by the family members

For all of the participants, it was so natural that the sons or daughters take care of the affected person. It is the family's choice. Mostly, it was expressed by the participants that no one else could take care of their affected parents as they did:

> WR3: »My aunt takes care of her [my grandmother]. My grandmother lives with my aunt and my mom helps my aunt three times a week.
>
> I: Was that the preference of your aunt and your mother? Or did your grandmother earlier told them that she did not want to be placed in a nursing home? Or was that rather the family's choice?
>
> WR3: More of a family choice. (…) For my aunt, taking care of her mother was so natural. Actually, she does not believe anyone else could take good care of her.« (Age: 36–50, relative, first-generation)

Very generally, getting professional support and help was evaluated quite positively. However, placing the affected relatives in a nursing home was quite unlikely:

> WR2: »In our culture, one does not want to be placed in a nursing home willingly. However, it is a relief for the family and one should consider that.« (Age: 36–50, caring daughter, second-generation)

In Germany, the caretaker gets an allowance from the state. Also, a person is sent by the government as well to help in household. Since the mother of one interviewee could not speak German, she was present every time the attendant came. Such help was not evaluated as helpful in particular. This is not only because the affected person trusts her children (in this case, her daughter specially), but also there is the belief that the family knows the affected person better, i.e., not any help coming outside could be beneficial:

> WR1: »Actually, after the disease is recognized, one cannot expect anything. I do not expect anything from my mother. As I am not expecting anything, I am just helping her. What else can I expect for help? Solely, I can expect help from my sister. I do not think there can be any other help or support from outside. I do not think so. There cannot be.« (Age: 51–70, caring daughter, second-generation)

4. Discussion

The findings of the study presented in this chapter demonstrate the experiences and expectations of the participants with migration background regarding dementia care and counseling. Specifically, a culturally sensitive approach to care, the plausible role of culture shaping health-related phenomena, the impact of migrant life on the initiation of the disease and the importance of family care became apparent. In the following, the findings will be discussed and be compared with current studies.

4.1. Need for culturally sensitive care to promote better access and provision of healthcare

Language barriers lead to miscommunication, poorer understanding of the health condition, treatment options, and early termination of care.[27] In cases, where language is a barrier to access to care,

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[27] Tripp-Reimer, Choi, Kelly, Enslein: Cultural Barriers (Note 18).

usually a family member or, wherever possible, a professional staff member acts as an interpreter. However, family interpreters, as part of their cultural background, sometimes act as a protector by not totally informing the person about her condition.[28] Not informing the person accurately can harm the patient-doctor relationship, the person's autonomy, and the demand to keep information confidential.

This was not the case in the pilot study: none of the interviewees, who acted as a translator during the examination, mentioned misleading the affected relatives by hiding the diagnostic information.

Even though only one interviewee strongly emphasized it, having migration background can reinforce the perceptions of discrimination and stigmatization of culturally diverse groups. Such perceptions can lead to less help-seeking behavior, postponement of care and trust in medical services. Therefore, as some argued, culturally sensitive care can be considered a moral obligation.[29] Culturally sensitive care »means an openness for wishes and decisions that can be traced back to a patient's cultural or religious values.«[30] It aims to enhance patient satisfaction by improving the quality and outcome of healthcare services. Effectiveness of healthcare is not only due to individual's lack of information, language and communication difficulties, but also lack of sensitivity of the healthcare personnel for the cultural particularities, e.g., a different understanding of illness and a different way of dealing with it. These barriers hamper the doctor-patient relation, communication and the motivation to seek help and treatment. Culturally sensitive care does not only improve the quality and outcomes of healthcare services for cultural minorities but also promotes the principles of patient autonomy, beneficence and justice.[31] Lack of cultural sensitivity leads to violation of three biomedical principles, namely respect for autonomy, beneficence and justice, since it hinders communication, blocks some patients' ability

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[28] Lucy M. Candib: Truth telling and advance planning at the end of life: Problems with autonomy in a multicultural world. In: Families, Systems, and Health 20 (2002), pp. 213–228.

[29] Donate-Bartfield, Lausten: Why Practice (Note 20); Paasche-Orlow: The Ethics of Cultural Competence (Note 20).

[30] Ilhan Ilkilic: Culture-Sensitive Advance Directives in a Multicultural Society and the Muslim Concept of Death. In: Walter Moczynski, Hille Haker, Katrin Bentele (Eds.): Medical Ethics in Health Care Chaplaincy. Berlin 2009, pp. 89–101, here p. 95 footnote.

[31] Paasche-Orlow: The Ethics of Cultural Competence (Note 20).

to realize their rights to make choices about their own treatment,[32] and diminishes the quality of care. Violation of these principles affects their willingness to seek further help and care, which limits their right to access to an adequate healthcare.

However, in making healthcare culturally sensitive, the danger of stereotyping and overgeneralization should be avoided. Limiting all considerations to culture runs the risk of reinforcing stereotypes about ethnic groups.[33] Attitudes within cultural groups can be diverse due to differing education levels, socio-economic backgrounds, gender, personal experiences, and acculturation or due to assimilation to a culture or cultural community, which can be observed, for instance, in the 3rd or 4th generation of people with migration background.[34] Thus, defining individuals by their cultural identity alone prevents adequate responses to the needs of individuals and their families.

4.2. Culture's role in shaping one's health-related phenomena

If individuals and their families from minority-cultural backgrounds bring their cultural perceptions and attitudes into culturally insensitive clinical settings,[35] culture-specific demands or practices can lead to conflicts between the medical system of the dominant culture and families from non-dominant or minority cultures.[36] For instance, ritual infant circumcision is a traditional religious practice among Jews

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[32] Donate-Bartfield, Lausten: Why Practice Culturally Sensitive Care? (Note 20).

[33] Silke Schicktanz, Sabine Wöhlke: Kulturelle Faktoren bei Entscheidungen zur Therapiebegrenzung. In: Andrej Michalsen, Christiane S. Hartog (Eds.): End-Of-Life Care in der Intensivmedizin. Berlin, Heidelberg 2013, pp. 133–137; Michael Coors, Tim Peters, Ilhan Ikilic: Kulturelle Differenz in der Gesundheitsversorgung [Cultural difference in healthcare]. In: Ethik in der Medizin 30 (2018), pp. 177–179.

[34] Candib: Truth telling (Note 28); Leigh Turner: From the Local to the Global: Bioethics and the Concept of Culture. In: Journal of Medicine and Philosophy 30 (2005), pp. 305–320.

[35] Leigh Turner: Bioethics in a Multicultural World: Medicine and Morality in Pluralistic Settings. In: Health Care Analysis 11 (2003), pp. 99–117.

[36] Robert L. Schwartz: Multiculturalism, Medicine, and The Limits of Autonomy: The Practice of Female Circumcision. In: Cambridge Quarterly of Healthcare Ethics 3 (1994), pp. 431–441; Candib: Truth telling (Note 26); Sawitri Saharso: Feminist Ethics, Autonomy and the Politics of Multiculturalism. In: Feminist Theory 4 (2003), pp. 199–215; Kerry Bowman: What are The Limits of Bioethics in a Culturally Pluralistic Society? In: Journal of Law, Medicine and Ethics 32 (2004), pp. 664–669.

and Muslims. In Germany, the practice was ruled as illegal because it was considered a violation of the child's right to bodily integrity and self-determination. The decision of the court was justified based on children's wellbeing (»Kindeswohl«), which cannot be overridden by parents' right to a religious upbringing of the children. The wellbeing of the child was held by the court in an individualistic and medical context, and not in a broader, culturally informed context, by which the best interest of the child can differ.[37]

In intercultural contexts, where the physician and the patient do not share the same cultural realm, ethical conflicts occur. Some cultural phenomena have ethical relevance because some health-related phenomena vary by culture.[38] For instance, including family members in decision-making can be an expression of traditional moral expectations including the traditional structure of authority within the family or faith and trust in one's family. Influence of family on decision-making might not necessarily be a breach of patient autonomy.[39] Although all the interviewees mentioned the importance of self-determination, making decisions for the affected family member was not seen as a breach of autonomy of the affected person. On the contrary, this showed strong bond of family ties, trust in family in making decisions as well as duty of responsibility of the descent to the parents.

4.3. Impact of migration experience on one's mental health

Having a migration experience is stressful and can affect the health of the person including cognitive decline, which might be due to the living and working conditions.[40] Working conditions, income, unemployment, etc. generated disadvantaged and stressful situations for the first-generation Turkish migrants.[41] This also shows consistency with the pilot study: the negative effects of stressful living and

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[37] Ilhan Ilkilic: Islamische Aspekte der Beschneidung von Minderjährigen Jungen [Islamic aspects of circumcision of minor boys]. In: Zeitschrift für Medizinische Ethik 60 (2014), pp. 63–72.

[38] Ilhan Ilkilic: Interculturality and Ethics in Health Care. In: Ilhan Ilkilic, Hakan Ertin, Rainer Brömer, Hajo Zeeb (Eds.): Health, Culture and the Human Body. Istanbul 2014, pp. 697–709.

[39] Ilkilic: Culture-Sensitive (Note 30), here pp. 89–100.

[40] Seven, Braun, Kalbe, Kessler: Demenzdiagnostik (Note 6).

[41] Seven, Braun, Kalbe, Kessler: Demenzdiagnostik (Note 6).

working conditions were also considered an initiating factor for the cognitive decline.

4.4. Willingness to care for the family

All interviewees mentioned that their affected relatives were taken care by their family members, namely by the affected person's daughters and sons. In Germany, there are well-developed aged-care services, such as residential aged-care facilities and aged-care cash allowance for the families. However, most elderly people with a Turkish immigrant background prefer to stay at home, to be taken care of by their family members and to receive the cash allowance, which might also generate a burden for the family as one study showed.[42] Another study also showed that the elderly Turkish migrants are mostly taken care by their families, however they often do not get professional support.[43] Although preferences in care are dependent on many other factors as well, such as costs, marital status and disease's severity, a Danish nation-wide study also showed that non-western immigrants were less likely to live in a nursing home.[44] There are also studies documenting in intergenerational relationships including the willingness to care for parents.[45] These results show consistency with the findings of the pilot study. However, it was also strongly

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[42] Rosa Brandhorst, Loretta Baldassar, Richard Wilding: The Need for a »Migration Turn« in Aged Care Policy: A Comparative Study of Australian and German Migration Policies and Their Impact on Migrant Aged Care. In: Journal of Ethnic and Migration Studies 47 (2021), pp. 249–266.

[43] Tezcan-Güntekin, Razum: Pflegende Angehörige (Note 10).

[44] Lea Stevnsborg, Christina Jensen-Dahm, Thomas R. Nielsen, Christiane Gasse, Gunhild Waldemar: Inequalities in Access to Treatment and Care for Patients with Dementia and Immigrant Background: A Danish Nationwide Study. In: Journal of Alzheimer's Disease 54 (2016), pp. 505–514.

[45] Helen Baykara-Krumme, Daniela Klaus, Anja Steinbach: Generationenbeziehungen in Deutschland. Ein Vergleich der Beziehungsqualität in einheimischen deutschen Familien, Familien mit türkischem Migrationshintergrund und Aussiedlerfamilien [Intergenerational relations in Germany. A comparison of the quality of relationships in native German families, families with a Turkish migration background and families with emigrants]. In: Josef Brüderl, Laura Castiglioni, Nina Schumann (Eds.): Partnerschaft, Fertilität und intergenerationale Beziehungen Ergebnisse der ersten Welle des Beziehungs-und Familienpanels [Partnership, fertility and intergenerational relationships Results of the first wave of the relationship and family panel]. Würzburg 2011, pp. 259–286.

emphasized that having professional support was quite helpful, and at times quite informative as well. Even though in the current state some were not getting the professional help, they emphasized the importance of it, because they believed that it would relieve the burden a bit. However, most were hesitant to place their affected relatives to a nursing home. Additionally, lack of knowledge concerning the disease, i.e., seeing the disease as a natural course of life, as well as care and help structures was also apparent in the pilot study, which was also the case in another study.[46]

5. Limitations

There are a number of limitations of this study, which should be acknowledged. First, the pilot study is limited by a small sample, where the focus is on the caregivers and family members of people with dementia of Turkish descent living in Germany. Therefore, the findings of the study cannot be applied to the community of caregivers and family members with a Turkish descent or with migration background in Germany. Second, since qualitative research methods were referred to for this study, the validity of the results is based on the selected sample and can neither be claimed to be representative nor generalizable for the broader population.

6. Conclusion

The presented pilot study in this chapter focused on provision of dementia care for persons with migration background. The preliminary analysis of the pilot study revealed four emerging themes, which are the need for support and information, perception of discriminative behavior and neglect, the impact on migrant life on the initiation of the disease and the role of family in care. These findings highlighted some main needs of migrant groups: more information about disease management and social support as well as more accessibility and sensitivity for cultural differences from the healthcare personnel. These findings show consistency with existing studies as discussed above. The concerns participants raised supported in a limited way

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[46] Tezcan-Güntekin, Razum: Pflegende Angehörige (Note 10).

three working hypothesis: (1) the needs of immigrants affected with dementia are not always addressed satisfactorily; (2) this deficit is due to cultural differences; (3) decision-making is family-centered, even though individual autonomy is highly regarded.

The results of the presented study indicate a need for more research on the (plausible) impact of having migration background on shaping the perceptions regarding experiences of being a caretaker and the needs for counseling. Further comparative studies conducted with those without migration background could help to illuminate whether the perceptions of discriminative behaviors or neglect from healthcare personnel are due to having migration background. There is a lack of empirical ethics studies focusing on the influence of ethnic and cultural differences in family members and affected persons' attitudes in the context of dementia-related healthcare. This is at least partly due to lack of sufficient language skills and relevant cultural background knowledge among scholars. Such research would help to develop culture-sensitive guidelines for dementia-related care.

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Kidney transplantation in Jehovah's Witnesses – the Croatian perspective

Abstract
Jehovah's Witnesses are recognized for their blood transfusion refusal. Instead of blood transfusion refusal, they accept organ transplantation. Kidney transplantation is the best modality for the treatment of end-stage renal disease, but in the case of severe perioperative blood loss, blood transfusion is required. Because of the blood transfusion refusal, most of the transplant centers worldwide, including those in Croatia too, refuse to perform kidney transplantation in Jehovah's Witnesses patients. University Hospital Rijeka is the only center in Croatia that performs kidney transplantation in Jehovah's Witnesses and two such transplantations were successfully performed. The legislation in Croatia, as in many other countries, has not recognized some specific conditions related to Jehovah's Witnesses. In this chapter, we present our experience and different ethical and medico-legal dilemmas about kidney transplantation in Jehovah's Witnesses in Croatia.

1. Introduction

The Jehovah's Witness religion was founded in 1872 in Pittsburgh, Pennsylvania, the United States of America. At the moment they have about 8.7 million members worldwide. They identify themselves as Christians, but their beliefs are different from other Christians – orthodox, protestant, catholic. They are recognized for their special door-to-door evangelism, military, and blood transfusion refusal.[1]

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[1] Paul J. Cummins, Federico Nicoli: Justice and respect for autonomy: Jehovah's Witnesses and kidney transplant. In: Journal of Clinical Ethics 29 (2018), pp. 305–312.

Jehovah's Witnesses refusal of blood transfusion is, probably, the most well-known example of a religious-based refusal of medical intervention. The roots of this decision are going after World War II. The Jehovah's Witnesses religion was at the beginning administered by the Watchtower Bible and Tract Society of Pennsylvania (the Watchtower Society). In 1945, the Watchtower Society recommended to their members against blood transfusion and against receiving blood products.[2] In 1967, when the era of transplantation of solid organs started, the Watchtower Society also imposed a ban on organ transplantation. Later, the Watchtower Society revised its guidance on blood transfusion and organ transplantation. They rejected the blood transfusion and use of stored autologous blood, but Jehovah's Witnesses should consult their personal conscience to decide to receive acute normovolemic hemodilution, intraoperative blood salvage and blood fractions as albumins, immunoglobulins or clotting factors. Instead, they still do not accept transfusion of whole blood, red blood cells, platelets, plasma, hemoglobin solution, stored autologous blood and blood donation. Afterward, the Watchtower Society revised its previous statement against organ transplantation and changed it to a matter of personal conscience.[3]

As a consequence of that, most of the Jehovah's Witnesses population refuses transfusion of homologous and autologous blood products.[4] This refusal is based on their interpretation of the Bible. According to their beliefs, acceptance of blood or blood products will forfeit their chance for resurrection and eternal salvation. Most Jehovah's Witnesses accepts crystalloid solutions, synthetic colloid solutions, hemoglobin substitutes as perfluorocarbons or artificial hemoglobin solution, and recombinant proteins as erythropoietin or activated factor VII. The whole blood, red blood cells, platelets and plasma are unacceptable. Individual decisions need to be made regarding the administration of the purified fractions of plasma as immunoglobulins and albumin or solid organ transplants. Addition-

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[2] Cummins, Nicoli: Justice and respect (Note 1).

[3] Cummins, Nicoli: Justice and respect (Note 1).

[4] Cummins, Nicoli: Justice and respect (Note 1); Enrique Lledo-Garcia: Jehovah's Witnesses and bloodless kidney transplants. Considering the ethical dilemmas transplantation urologists may face. In: European Urology Today 33 (2021), p. 43.

ally, patients need to make personal decisions regarding heart or venovenous bypasses, hemodilution or intraoperative red cell salvage.[5]

Methods of renal replacement therapy include hemodialysis, peritoneal dialysis, and as the most efficient method, kidney transplantation. Kidney transplantation is the best treatment modality for patients with end-stage renal disease. Compared to hemodialysis and peritoneal dialysis it offers better survival and quality of life. Despite the improved prognosis after successful kidney transplantation, cardiovascular diseases remain the leading cause of death in this specific population.

Kidney transplantation is a major surgical procedure including performing a vascular anastomosis between major pelvic vessels and graft vessels. At least two vascular anastomoses were performed for each patient and they can be a major source of possible bleeding. Intraoperative and/or postoperative bleeding is a complication that can be found in up to 14 % of kidney transplanted patients.[6] Sometimes severe, life-threatening blood loss can develop which needs blood transfusion as the standard and most effective therapeutic procedure, sometimes along with surgical management.

According to Croatian law, every citizen has the right to access to healthcare, including kidney transplantation, no matter of his/her ethnicity, religion, nationality or social status. In the Republic of Croatia, in the year 2017, there were 3,730 patients on renal replacement therapy.[7] Since 2007 Croatia has been a member of the Eurotransplant. The Eurotransplant is international and non-profit organization responsible for the allocation of donor organs in Austria, Belgium, Croatia, Germany, Hungary, Luxembourg, Netherlands and Slovenia. The membership in Eurotransplant gave to Croatian transplant pro-

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[5] Lledo-Garcia: Jehovah's Witnesses (Note 4).

[6] Mehdi Salehipour, Hesmatollah Salahi, Hamed Jalaeian, Ali Bahador, Saman Nikeghbalian, Ehsan Barzideh, Ali Ariafar, Seved Ali Malek-Hosseini: Vascular complications following 1500 consecutive living and cadaveric donor renal transplantations: a single center study. In: Saudi Journal of Kidney Diseases and Transplantation 20 (2009), pp. 570–572; Jacentha Buggs, Robert Shaw, Frederic Montz, Venkat Meruva, Ebonie Rogers, Ambui Kumar, Victor Bowers: Operative versus nonoperative management of hemorrhage in the postoperative kidney transplant patient. In: The American Surgeon 86 (2020), pp. 685–689.

[7] Croatian Society of Nephrology, Dialysis and Transplantation: Croatian Registry of Renal Replacement Therapy – 2017. https://www.hdndt.org/registar-nadomjestanja-bubrezne-funkcije (accessed on 7.2.2023).

gram additional stimulus rendering our kidney transplantation program, including donor program, one of the most effective in Europe.

In Croatia, there are four kidney transplant centers. The oldest one, since 1971, is in Rijeka and it is also the Croatian Referral Center for Kidney Transplantation, Department of Urology, University Hospital Rijeka.[8] Other centers are Clinical Hospital Merkur in Zagreb, Clinical Hospital Center Zagreb, and Clinical Hospital Center Osijek. In the year 2020, there were 98 kidney transplantations performed in all Croatian transplant centers together.

Because of blood transfusion refusal, most of the Croatian transplant centers refuse to perform kidney transplantation in Jehovah's Witnesses patients. The University Hospital Rijeka is the only center in Croatia to perform kidney transplantation in Jehovah's Witnesses and two such kidney transplantations were so far performed successfully.

In this article, we will describe our experience and potential problems with kidney transplantation in this specific group of patients, with an emphasis on healthcare in Croatia.

2. Patients and Methods

For this article, we analyzed literature about kidney transplantation in Jehovah's Witnesses. The search was performed using the PubMed database. Also, the basic data of our patients, who underwent transplantation, were presented. All patient's data were presented in such a way to preserve their anonymity. Another source of information was the Croatian laws which are related to this topic. Written informed consent was obtained from both patients included in this article and we obtained approval from the Ethical Committee of University Hospital Rijeka, Rijeka, Croatia.

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[8] Dean Markić, Josip Španjol: Kidney transplantation in Rijeka – the first fifty years. In: Medicina Fluminensis 56 (2020), pp. 354–357; Davor Primc, Sanjin Rački, Miha Arnol, Marin Marinović, Ana Fućak-Primc, Amir Muzur, Simon Hawlina, Dean Markić: The beginnings of kidney transplantation in south-east Europe. In: Acta Clinica Croatica 59 (2020), pp. 135–140.

3. Results

There were two Jehovah's Witnesses patients with end stage renal disease that underwent kidney transplantation in Croatia to date. Both of them were performed in the Department of Urology, University Hospital Rijeka.

Our patients started with dialysis, but kidney transplantation was their preferred therapeutic option. The pre-transplant evaluation was standard and they met the criteria for the Eurotransplant waiting list. Both of them signed statements that they would refuse blood transfusion in any case because of their religious beliefs. The informed consent for kidney transplantation was obtained from patients before transplantation. Both patients were in good physical and mental condition. To achieve better preoperative status, the patients received iron supplements.

Both kidney transplantations were performed in 2015 and they received death-donor kidneys. The patients were male, 61 and 39 years old, and suffered from chronic glomerulonephritis as the principal kidney disease. The cold ischemia time was 11 hours and 16 minutes for the first and 12 hours and 37 minutes for the second patient. The duration of both operations was 180 minutes, with negligible blood loss. Kidney transplantation was performed in the iliac fossa by a standard extraperitoneal approach. The kidney was transplanted into the contralateral iliac fossa, with the main aim of the renal pelvis becoming the most superficial hilar structure. External iliac arteries and veins were the sites for renal anastomosis. The ureter was implanted in the urinary bladder using the extravesical Lich-Gregoir technique. JJ endoprosthesis was intraoperatively inserted and extracted 6 weeks after the operation to prevent urological complications. The early post-transplant course was uneventful in both patients. In one of them, lymphocele was visualized six months after the kidney transplantation. Percutaneous sclerosation of lymphocele was unsuccessful and laparoscopic marsupialisation was performed. Both patients have excellent kidney function seven years after the kidney transplantation.

4. Discussion

The Jehovah's Witnesses refusal of blood transfusion can be considered as a medico-legal or ethical dilemma. The Jehovah's Witnesses refusal of lifesaving blood transfusion is a morally accepted feature based on patient autonomy. The principle of respect for autonomy is associated with allowing or enabling patients to make their own decisions about which healthcare interventions they will or will not allow after being properly informed. It is also important that with his or her choice the patient does not make any harm to another individual. In the field of organ transplantation, this is especially related to a living donor, as a family member or a friend – the latter being a very unusual practice in Croatia.[9] But, when Jehovah's Witness cannot identify a living donor, which is the most frequent situation in Croatia, he or she is waitlisted for cadaveric kidney transplantation. In such a case, the transplant team may face an ethical dilemma. Certainly, we want to give a patient the best possible care – kidney transplantation in this specific situation. However, a question appears if a patient who refuses blood transfusion is acceptable for the list, at all? The majority of patients on the waiting list are willing to accept all care to optimize the success of kidney transplantation. On the contrary, with Jehovah's Witnesses refusal of blood transfusion there is a fear that organs will go to someone non-completely adherent to the proposed healthcare strategy. In the literature, we found two opinions from the ethical position for possible denying Jehovah's Witness to be transplanted – »in the name of justice«:

1. Is it justified to allocate organs for a patient with a request transfusion-free kidney transplantation, which can decrease the chance of other patients to timely obtain appropriate medical treatment?
2. »All resources should be allocated to patients who comply with the standard of care.«[10]

Their rationality is that permitting transfusion-free kidney transplantation puts more lives at risk than with transplantation in only fully

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[9] Cummins, Nicoli: Justice and respect (Note 1); Lledo-Garcia: Jehovah's Witnesses (Note 4).

[10] Cummins, Nicoli: Justice and respect (Note 1); Lledo-Garcia: Jehovah's Witnesses (Note 4).

complaint recipients – triage concept.[11] Some authors proposed acceptance of »rescue transfusion« as a prerequisite for Jehovah's Witnesses to be included in the transplant program.[12] On the other hand, in 2013. the Board of Directors of OPTN/UNOS in the United States of America approved changes to its allocation criteria which take survival benefit into account.[13] The aim of this policy is to match kidneys expected to function the longest with patients whose life expectancy is longer. In such a way, the survival benefit is ethically more acceptable compared to the triage concept whether a patient is more likely to die following transfusion-free than another patient.

Another possible issue is does neglecting of Jehovah's Witnesses will for their demands about the refusal of blood transfusion is violating the individual autonomy. The basics for this are that their refusal is based on the recommendation of their authorities. There is a possibility that the patient's refusal does not express only an autonomous choice. So, it is a question if possible giving blood products will violate individual autonomy?[14]

Medical ethics should be in close connection with modern medicine and science. The policy of excluding Jehovah's Witnesses because of seeking transfusion-free kidney transplantation must be documented by adequate and exact data from the field of transplant medicine.

We analyzed three studies and a few case reports reporting kidney transplantation in this population. Kaufman et al. from the University of Minnesota documented their experience from 13 Jehovah's Witnesses kidney transplant patients comparing standard transplant population and did not find a difference between the graft and

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[11] Cummins, Nicoli: Justice and respect (Note 1).

[12] Ugo Boggi, Fabio Vistoli, Marco Del Chiaro, Chiara Croce, Stefano Signori, Piero Marchetti, Stefano Del Prato, Gaetano Rizzo, Franco Mosca: Kidney and pancreas transplantation in Jehovah's Witnesses: ethical and practical implications. In: Transplantation Proceedings 36 (2004), pp. 601–602; Katrina A. Bramstedt: Transfusion contracts for Jehovah's Witnesses receiving organ transplants: ethical necessity or coercive pact. In: Journal of Medical Ethics 32 (2006), pp. 193–195.

[13] Cummins, Nicoli: Justice and respect (Note 1).

[14] Cummins, Nicoli: Justice and respect (Note 1); Osamu Muramato: Bioethics of the refusal of blood by Jehovah's Witnesses: Part 3. A proposal for a don't-ask-don't-tell policy. In: Journal of Medical Ethics 25 (1999), pp. 463–468.

patient survival.[15] The authors did not report the blood loss during the operation. Also, the authors noticed that Jehovah's Witnesses had increased susceptibility to early rejection episodes – Jehovah's Witnesses patients refused potent immunosuppressive T-cell depleting agent because it was perceived as a blood product by all but one of the recipients. Moreover, the consequence of early graft dysfunction from rejection was particularly detrimental to two patients who developed severe anemia and died. The authors concluded that kidney transplantation in Jehovah's Witnesses can be safely performed in most cases, except in those with anemia, and that they belong to a high-risk group for having early rejection episodes.[16] Also, we must notice that recombinant erythropoietin had just been introduced into clinical practice at that time. Kandaswamy et al. also found similar graft and patient survival of 50 Jehovah's Witnesses transplanted patients – kidney transplantation and combined kidney/pancreas transplantation – compared to standard transplant population up to 10 years after kidney transplantation.[17] The study from Brazil which included 143 transplanted Jehovah's Witnesses showed that when blood transfusion can be safely avoided, in the majority of Jehovah's Witnesses kidney transplantation results with equal graft and patient survival.[18] In a few case reports the successful kidney transplantation in Jehovah's Witnesses was also noticed.[19]

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[15] Dixon B. Kaufman, David E.R. Sutherland, David S. Fryd, Nancy L. Ascher, Richard L. Simmons, John S. Najarian: A single-center experience of renal transplantation in thirteen Jehowah's Witnesses. In: Transplantation 45 (1988), pp. 1045–1049.

[16] Kaufman, Sutherland, Fryd, Ascher, Simmons, Najarian: A single-center experience (Note 15).

[17] Raja Kandaswamy, Thigarajan Ramcharan, Arthur J. Matas: Kidney and kidney-pancreas transplants in Jehovah's Witnesses – a single center experience with 50 transplants. In: Acta Chirurgica Austriaca 33 (2001), p. 3.

[18] David Carvalho Fiel, Klaus Nunes Ficher, Julia Bernardi Taddeo, Kamilla Linhares Silva, Claudia Rosso Felipe, Wilson Aguiar, Jose Daniel Braz Cardone, Renato Demarchi Foresto, Helio Tedesco-Silva Jr, Jose Medina-Pestana: Is there sufficient evidence justifying limited access of Jehovah's Witness patients to kidney transplantation? In: Transplantation 105 (2021), pp. 249–254.

[19] Giselle Guerra, Mariella Ortigosa-Goggins, Jeffrey J. Gaynor, Gaetano Ciancio: Deceased donor kidney transplant in a 70-year-old Jehovah's Witness patient: to transplant or not to transplant-a case report. In: Annals of Translational Medicine 8 (2020), http://dx.doi.org/10.21037/atm-20-3593; Goce Spasovski, Oliver Stankov, Jelka Masin-Spasovska: Living-related donor kidney transplantation in Jehovah's Witness patient: the importance of EPO preconditioning. In: International Urology and Nephrology 46 (2014), pp. 669–670; Arthur Greenberg, Iain Macphee,

Therefore, from the strict medical point of the view and considering the available data, kidney transplantation in Jehovah's Witnesses patients is feasible, with graft and patient survival compared to the general transplant population. However, precaution is needed due to the possible problems in anemic patients. Nevertheless, the refusal of blood transfusion is not associated with a higher risk of organ loss than transplantation that is not transfusion-free. The studies show that transfusion-free kidney transplantation is possible and emphasize the value of preoperative and intraoperative strategies which can be helpful in this specific population.

The strategies which can be helpful for the avoidance of blood transfusion included preconditioning of the patient with recombinant erythropoietin, iron, B12 and folic acid, which optimizes their condition for the time of the surgery. Interventions such as acute normovolaemic hemodilution and cell salvage should be utilized to minimize the effective blood loss intraoperatively.[20] Still, despite the measures, no one can predict that major perioperative bleeding will not ensue.

Nevertheless, Jehovah's Witnesses patients and their families must be aware that even with all the aforementioned strategies, uncorrected anemia can cause prolonged postoperative course with longer hospitalization time, higher anxiety level and a higher financial cost. The most difficult consequence of non-corrected anemia can be a lethal outcome.[21] This is especially true for elderly patients above 65 years of age.[22]

Medico-legal practice is very important to patients and healthcare professionals, especially in a such sensitive area as organ transplantation in Jehovah's Witnesses. In Croatia, we must follow the two legal systems: the national one and the European – as a member of the European Union.

Joyce Popoola, Deborah Sage, Ramiz Iqbal, Nicoletta Fossati, Sarah Heap, Mohamed Morsy, Nicos Kessaris: HLA antibody-incompatible kidney transplantation between Jehovah's Witnesses – a case report. In: Transplantation Proceedings 45 (2013), pp. 2069–2071.

[20] Rodrigo S. Figueiredo, Rohan G. Thakkar, Paul R. Ainley, Colin H. Wilson: Review of abdominal solid organ transplantation in Jehovah's Witness patients. In: World Journal of Transplantation 9 (2019), pp. 94–102.

[21] Kaufman, Sutherland, Fryd, Ascher, Simmons, Najarian: A single-center experience (Note 15); Guerra, Ortigosa-Goggins, Gaynor, Ciancio: Deceased donor (Note 19).

[22] Guerra, Ortigosa-Goggins, Gaynor, Ciancio: Deceased donor (Note 19).

European Convention on Human Rights is an international convention to protect human rights and political freedoms in Europe.[23] Drafted in 1950 by the then newly formed Council of Europe, the convention entered into force on 3 September 1953. All Council of Europe member states – including Croatia – are parties to the Convention. The Convention established the European Court of Human Rights and any person who feels that his/her rights have been violated under the Convention by a state party can take a case to the Court. Judgments finding violations relate to the state of concern and they are obliged to execute them. The Committee of Ministers of the Council of Europe monitors the execution of judgments, particularly to ensure that payments awarded by the Court appropriately compensate applicants for the damage they have sustained. The Convention has several protocols, which amend the Convention framework. Article 8 of European Convention on Human Rights is about respect for private and family life. In general, this article is often cited as a person's right to self-determination and their physical integrity, including acceptance or denying specific medical treatment. Croatian legislation includes a few laws which can be problematic for the issue of blood transfusion refusal in the field of organ transplantation. The Law in Croatia guarantees that treatment must be in accordance with the patient's approval or refusal of a specific medical procedure – HealthCare Act, Act on the Protection of Patients' Rights.[24] On the other hand, medical staff or institutions can refuse to perform the medical procedure if a patient refuses to accept a proposed established procedure, like blood transfusion, for example. And when a physician or the institution were not able to accept that risk, the patient should be transferred to another physician or institution capable of such treatment modality.[25] Irrespective of a patient's right to choose a treatment, in life-threatening situation lifesaving is mandatory for physicians, as regulated in the Article

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[23] Council of Europe: European Convention on Human Rights. https://www.equalityhumanrights.com/en/what-european-convention-human-rights (accessed on 7.2.2023).

[24] Official Gazette of Croatia, 77/16: HealthCare Act. https://www.zakon.hr/z/190/Zakon-o-zdravstvenoj-zaštiti (accessed on 7.2.2023); Official Gazette of Croatia, 169/04: Act on the Protection of Patients' Rights. https://www.zakon.hr/z/255/Zakon-o-zaštiti-prava-pacijenata (accessed on 7.2.2023).

[25] Official Gazette of Croatia, 121/03: Act on Medical Practice. https://www.zakon.hr/z/405/Zakon-o-liječništvu (accessed on 7.2.2023).

16 of the Act on the Protection of Patients' Rights.[26] The Criminal Code in article 181 depicts medical malpractice »if a physician applies obviously inadequate means or method of treatment or in some other way obviously fails to follow the rules of healthcare profession or obviously acts carelessly, thereby causing the deterioration of an illness or the impairment of the health of another person or even death of the patient«, with possible imprisonment up to twelve years.[27] Article 183 of the same Code – failure to render medical aid in emergencies – describes a physician's need for immediate medical aid to a person in need of such aid, because of the risk that he or she would suffer permanent harmful consequences on his or her health or life, with possible imprisonment up to three years.[28] It is obvious that Croatian law includes contradictory rules and that the European one makes additional confusion for healthcare professionals.[29]

Thus, in reality, we have two dilemmas.

First, should Jehovah's Witnesses be enlisted for kidney transplantation because of the blood transfusion refusal? The law in Croatia is very clear: every citizen has an equal right to the best possible healthcare, no matter of his/her ethnicity, religion, nationality, etc. The ethical dilemma may exist but the usefulness of kidney transplantation in these patients overweighs some ethical concerns. The opinions of the authors are that most of the Croatian transplant community support the right of Jehovah's Witnesses to the best possible medical treatment – kidney transplantation in this case.

The second dilemma is more difficult, what to do if a Jehovah's Witnesses patient needs lifesaving blood transfusion? Compared with the first dilemma, which is more theoretical, the second one is far more practical, with profound consequences. From an ethical point of view, the patient has a total right to a made autonomous decision. On the other side, healthcare professionals are willing to help the patient and give him the best possible care. The medicolegal aspect is far more complicated and in clear contradiction. On one side the law in Croatia allows medical staff or institutions to refuse to perform the

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[26] Official Gazette of Croatia: Act on the Protection (Note 24).

[27] Official Gazette of Croatia, 125/11: Criminal Code. https://www.zakon.hr/z/98/Kazneni-zakon (accessed on 7.2.2023).

[28] Official Gazette of Croatia: Criminal Code (Note 27).

[29] Sunčana Roksandić Vidlička, Lada Zibar, Jozo Čizmić, Kristijan Grđan: Rights of Jehovah's witnesses on surgical health care in the Republic of Croatia – de lege lata. In: Liječnički Vjesnik 139 (2017), pp. 91–98.

medical procedure if a patient refuses to accept proposed established procedures, like blood transfusion, for example. On another side, there is a legal obligation that in life-saving situations physicians must try to save a patient's life. The European law also supports the patient's will and choice. Thus, whatever action healthcare professionals chose to do – or not to do – they break some law. These medico-legal contradictions are probably the main reason why the majority of transplant centers in Croatia – and worldwide, too – refuse to perform kidney transplantation in Jehovah's Witnesses. They want to avoid this situation and use medicolegal understatement as an excuse for not performing kidney transplantation, or some other medical procedures, in Jehovah's Witnesses. At the same time, we must be aware that these patients need the best medical care for their medical problems.

According to the best of our knowledge, there is not any internal document, i.e., guidelines or regulations of healthcare institutions or any medico-legal act which specifically addresses this topic. Consecutively, in practice, the healthcare professionals are on an »open field« without an adequate guide. This must be changed and improved, because of patients and healthcare professionals too.

How to make an improvement? Firstly, the problem must be recognized, presented, and a multidisciplinary team, i.e. patients, healthcare professionals, jurists, ethicists, should be included in its solving. All sides – or better the partner sides – must express their expectations and their concerns. It is notorious that healthcare professionals want to give the best possible healthcare – kidney transplantation – to Jehovah's Witnesses and this is the main goal for them and their patients. Jehovah's Witnesses must express their concern about receiving blood transfusion against their will, which is against their religious believes. Healthcare professionals must express their concern about passive behavior in life-threatening situations, with possible legal implications of their decision. Authors strongly believe that in such specific situations, national legislation in conjunction with professional associations and patients must make an appropriate and specific act or guidelines that will lead both sides through this specific situation.

5. Conclusion

Kidney transplantation is the best possible treatment modality for patients with end stage renal disease, which are capable and willing to be transplanted. This is also true for properly selected Jehovah’s Witnesses end stage renal disease patients. Despite some ethical and medico-legal dilemmas, kidney transplantation must be offered to this patient population. The existing passive resistance and possible avoidance of their inclusion into the transplant program will be better solved with appropriate and specific acts or guidelines that will lead both sides through the specific situation of blood transfusion refusal in life-threatening situations.

We strongly believe that every patient has the right to the best possible healthcare. This must be done by accepting the patient’s will and choice, but also the rights and beliefs of healthcare professionals. Thus, both sides will know what they can expect and how to react, without fear of violating their will, choice, beliefs or law.

Suzana Kunac, Aleksandar Racz

Health status and access to the healthcare system of members of the Roma national minority in the Republic of Croatia

Abstract
The Roma are one of the 22 national minority groups in Croatia representing 0.4 % of the total population. Although there is no difference between the Roma and the general population in terms of subjective assessments of general health, one of the challenges addressed by the paper is that health institutions in Croatia do not collect data on ethnicity. Therefore, there is a systematic lack of data on Roma morbidity, healthcare use or discrimination in the healthcare system on the basis of belonging to the Roma national minority. An analysis of secondary data showed that the health of the Roma in Croatia is strongly influenced by their living conditions, nutrition, and poverty, due to which the life expectancy for the Roma is significantly lower compared to the majority of the Croatian population. The largest number of Roma people were hospitalized due to respiratory diseases, mental and behavioral disorders, as well as injuries, poisoning, and other consequences of external causes. The largest number of Romani women were hospitalized due to pregnancy, childbirth, and midwifery, as well as respiratory diseases, and mental and behavioral disorders. The Roma in Croatia have experienced discrimination in the field of healthcare in the last year from 6.8 % to 10 % placing Croatia slightly above the average of EU countries where Roma live.

1. Introduction

According to the 2011 census, there are 4,284,889 people living in the Republic of Croatia, out of which 328,738 are members of the following national minorities: 17,513 Albanians (0.41 %), 297 Austrians

(0.01 %), 31,479 Bosniaks (0.73 %), 350 Bulgarians (0.01 %), 4,517 Montenegrins (0.11 %), 9,641 Czechs (0.22 %), 14,048 Hungarians (0.33 %), 4,138 Macedonians (0.10 %), 2,965 Germans (0.07 %), 672 Poles (0.02 %), 16,975 Roma (0.40 %), 435 Romanians (0.01 %), 1,279 Russians (0.03 %), 1936 Rusyns (0.05 %) Slovaks, 4,753 (0.11 %), Slovenes 10,517 (0.25 %), Serbs 186,633 (4.36 %), Italians 17,807 (0.42 %), Turks 367 (0.01 %), Ukrainians 1,878 (0, 04 %), Vlachs 29 (0.00) and Jews 509 (0.01 %).

The Roma population settled in Croatian territories in the second half of the 14th century at the latest, as part of their migration from the area of Southeast Europe. The Roma first settled in the south-eastern part of the country in the city of Dubrovnik (1362), from where they came to the central part of Croatia to the then free royal city of Zagreb (1378), and then spread to Dalmatia and Istria. After several centuries of coexistence with the majority population, mostly marked by discrimination, segregation, and genocide (Samudaripen) against the Roma during World War II, when at least 16,173 Roma were killed in concentration camps, out of which 5,608 were children and 4,887 were women. Today, according to the 2011 census, there are officially 16,975 Roma in Croatia, representing 0.40 % of the total population.[1] According to the latest available data, obtained by mapping Roma localities in 15 counties of the Republic of Croatia in 2017, it is estimated that a total of 24,524 members of the Roma national minority live in the Republic of Croatia.[2] The largest part of the Roma in the Republic of Croatia (91.1 %) were born in the territory of the Republic of Croatia, only a small part of the population was born in Bosnia and Herzegovina (3.1 %), Kosovo (2.2 %) and Serbia (1.5 %), and immigrated to Croatia after WWII or during the disintegration of the former state of Yugoslavia and the war destruction in Croatia, Bosnia and Herzegovina and Kosovo. Over 98 % of the Roma population has Croatian citizenship, while 1.8 % of the Roma in Croatia are without it.

The average age in the Croatian Roma population is 21.9 years (median: 18 years), with every fourth member of the Roma household

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[1] Office for Human Rights and the Rights of National Minorities: National Strategy for Roma inclusion for the 2013–2020 period. https://www.zagreb.hr/UserDocsImages/arhiva/Nacionalna%20strategija%20za%20uklju%C4%8Divanje%20Roma%202013-2020.pdf (accessed on 7.2.2023).

[2] Suzana Kunac, Ksenija Klasnić, Sara Lalić: Roma Inclusion in the Croatian Society: A Baseline Data Study. Zagreb 2018, p. 68.

still under the age of eight, while half are minors, and only one quarter of the population is over 33 years old.[3] In comparison, in the general population, it is estimated that since the 2011 census the average age increased from 41.7 to 42.8 years in mid-2016.

The average number of members in Romani households in the Republic of Croatia is 5.2, which is almost twice as much as the average number of members per household in the general population, which is 2.8 members per household according to the 2011 census.[4] According to the relative poverty rate, 92.3 % of the Roma in the Republic of Croatia are at risk of poverty, according to which the Roma in Croatia are in an even worse position than the already worryingly high average share of Roma households below the EU at-risk-of-poverty threshold.[5] In comparison, the material deprivation rate of the general population in the Republic of Croatia in 2019 amounted to 19.6 %, while the rate of severe material deprivation amounted to 7.3 %.[6]

Data from the European Union Agency for Fundamental Rights (EUMIDIS II) confirmed the findings on high unemployment rates among the Roma in the Republic of Croatia, finding that 74 % of Romani men are unemployed and that 85 % of Romani women are either unemployed or housewives. In comparison, in October 2021, the registered unemployment rate among the general population in the Republic of Croatia was 7.2 %.[7] The data from the 2017 national survey are in line with the stated above. According to these data, only 7.3 % of Roma in the Republic of Croatia have full-time paid jobs, while 9.2 % have occasional or temporary jobs, and 2.1 % are self-employed – which makes up only 18.7 % of the population.[8]

The aim of this paper is to systematize and analyze a recent database on the status, access, and discrimination of Roma in the healthcare system in the Republic of Croatia. Also, the goal of the work is to deepen the existing knowledge and challenges, both scientific and

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[3] Ksenija Klasnić, Suzana Kunac, Petra Rodik: Roma Inclusion in the Croatian Society: Women, Youth and Children. Zagreb 2020, p. 31.

[4] Klasnić, Kunac, Rodik: Roma Inclusion (Note 3), p. 42.

[5] Klasnić, Kunac, Rodik: Roma Inclusion (Note 3), pp. 44–45.

[6] Croatian Bureau of Statistics: Indicators of Poverty and Social Exclusion (2019). https://www.dzs.hr/Hrv_Eng/publication/2020/14-01-01_01_2020.htm (accessed on 7.2.2023).

[7] Croatian Employment Service: Statistics (2021). https://www.hzz.hr/statistika/ (accessed on 7.2.2023).

[8] Kunac, Klasnić, Lalić: Roma Inclusion (Note 2), p. 17.

research, as well as those empirically determined in the approach to the health of the Roma national minority.

In the following chapter, we will deal with the connection between material deprivation and the lower life expectancy of Roma in Croatia, as well as the difficult access to health institutions due to widespread poverty in the Roma community. We will also present data on the frequency of use of health services, the frequency of long-term diseases in relation to age (comparative perspective of the incidence of long-term diseases among Roma compared to the general population), the reasons for the insufficient availability of healthcare for members of the Roma national minority, as well as the Roma subjective perception of discrimination in the health system. In addition to these data, relevant data will be presented on the number of hospitalizations in the inpatient section of hospitals by gender and disease groups in 2018, as well as on the reproductive health of Roma women. In the final part of the chapter, we deal with the occurrence of discrimination against Roma in the health system.

The conclusions refer to the need for systematic institutional monitoring of data according to the ethnicity of the population, namely on the disease, on the use of healthcare, as well as on challenges and obstacles to the use of health services. It is necessary to conduct basic research and systematically monitor data on discrimination on the basis of belonging to the Roma national minority related to the use and access to healthcare in order to provide full equality to all Roma in the exercise of the same rights in the area of healthcare that are available to majority population.

2. Materials and method

In order to analyze gender-disaggregated data about Roma health status, access to healthcare, and incidence of discrimination in the Croatian healthcare system we used all publicly available secondary sources, that is, available professional and scientific articles, available books and available online and open data sources, including research and sources collected by the authors of the paper during earlier national field research.

Scientific methods of analysis and synthesis, the method of induction and deduction, the method of description, and the method of compilation were used during the research and processing of the problem.

3. Roma in the healthcare system in the Republic of Croatia

3.1 Roma access to the healthcare system in the Republic of Croatia

Members of national minorities exercise most ethnic rights through the regular institutions of the Republic of Croatia, like the majority of Croatian people, and thus, every person who owns a valid health insurance card also has access to free healthcare.

According to a study of the basic data on the position of the Roma in Croatia, it is stated that 92.8 % of the Roma in Croatia own a health insurance card,[9] but 11.1 % of the Roma never go to the doctor. According to the results of the survey, as many as 54.6 % of Roma households in the year preceding the survey found themselves unable to pay for a medicine or medical service needed by a household member, indicating insufficient access to healthcare and discrimination of the Roma in relation to the possibility of using healthcare. Also, according to the survey, as many as 27 % of respondents have not contacted a doctor in the last 12 months – although they needed medical help – mainly due to the lack of financial resources to access health facilities.

An analysis of secondary data showed that material deprivation and poverty of the Roma population are directly related to social determinants of health because a large part of the Roma population lives in inadequate living conditions.[10] Namely, the health of the Roma in Croatia is strongly influenced by living conditions, nutrition, and poverty. A lack of access to water, contact with harmful materials, e.g., waste and secondary raw materials, the burning of objects within

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[9] Kunac, Klasnić, Lalić: Roma Inclusion (Note 2), p. 18.

[10] Kunac, Klasnić, Lalić: Roma Inclusion (Note 2); European Union Agency for Fundamental Rights: Second European Union Survey on Minorities and Discrimination against the Roma – Selected Results (2016). https://fra.europa.eu/sites/default/files/fra_uploads/fra-2016-eu-minorities-survey-roma-selected-findings_hr.pdf (accessed 7.2.2023); Vesna Štefančić Martić (Ed.): Public health indicators of Roma health in the Republic of Croatia based on data from public health databases and registries. Zagreb 2020.

settlements near their homes and children, unhealthy habits, and the like, affect the health and life expectancy of the Roma.

Earlier research shows that the members of the Roma national minority suffer from certain chronic non-communicable diseases at a much younger age than in the general population, and certain infectious and chronic non-communicable diseases are more common in the Roma community than in the general population. There is a marked increase in the incidence of cardiovascular disease at the age of 45 years among Romani men in relation to the prevalence of the same disease in the same age group in the general population, as well as a higher prevalence of musculoskeletal diseases among middle-aged Romani men compared to what is expected in the general population. The Roma struggle significantly more with problems such as asthma and chronic bronchitis, chronic obstructive pulmonary disease (COPD), or emphysema compared to the majority population. Oral hygiene is a neglected area within the Roma community.[11] Due to all the above-mentioned reasons the life expectancy for the Roma is significantly lower compared to the majority Croatian population, and the difference between the Roma and non-Roma population can reach up to 10 years.

A 2017 survey collected data on how often members of the Roma population use certain health services and found that the largest number of members of the Roma national minority, 62.6 %, go to the doctor several times a year. In 2018, the Roma relied on primary healthcare to treat diseases of the respiratory and digestive systems and diseases of the musculoskeletal system and connective tissue.[12] Also, despite the significantly more frequent morbidity than found in the majority of the population, when it comes to going to specialist examinations, a very large proportion of the Roma in the age of 16 and over, as much as 38.5 %, have not done so in the last four years with the explanation that they do not have transportation provided or are spa-

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[11] Dragan Bagić, Ivan Burić, Ivana Dobrotić, Dunja Potočnik, Sinsa Zrinščak: Everyday life of the Roma in Croatia: Obstacles and Opportunities for Change (2014). https://www.unicef.hr/wp-content/uploads/2015/09/undp-hr-roma-everyday-2015.pdf (accessed on 7.2.2023), p. 69.

[12] Vesna Štefančić Martić (Ed.): Public health indicators of Roma health in the Republic of Croatia based on data from public health databases and registries. Zagreb 2020, p. 13.

tially significantly distant from the place of examination, which is exposure to discrimination in access to healthcare.[13]

Although there is no difference between the Roma and the general population in terms of subjective assessments of general health, the impact of age on the incidence of long-term illness has been seen to be significantly more pronounced among the Roma over 65 %-70 % of the Roma and 56 % of the general population over 65 suffer from long-term illnesses. When the data collected by the baseline survey are compared with the data for the general population, it is then evident that chronic diseases are significantly present in the Roma population compared to the general one throughout the entire age range, and that differences become drastic from 45 years onwards, as every other person of this age in the Roma population suffers from a chronic disease.[14] Oral hygiene is a neglected area within the Roma community. In the last 12 months, only 37.4 % of Roma have visited a dentist, while 14.6 % of Roma have never done so.[15] Low levels of education, and in some cases, illiteracy, often put the Roma in a situation where they do not understand their own medical obligations or prescriptions issued to them by doctors and other health workers.

There are complaints from Roma communities in isolated Roma settlements about the non-appearance of ambulances in situations where assistance was needed. Such cases have been reported in Roma settlements in the Međimurje County, and near the town of Delnice. Healthcare facilities often argue that they did not respond to the call because they did not deem the situation urgent, because they repeatedly received numerous false calls, or even that the Roma from the settlements called them only for transport to health facilities and not for emergencies.

The Roma believe that if they need medical help, they will receive it (87.4 %), they trust and have confidence in healthcare employees (82.2 %), and believe that doctors are good at their job (89.6 %). At the same time, 20.8 % of Roma had some sort of a negative experience with employees in healthcare institutions. The majority of the Roma who had some negative experiences with health services (33.4 %) felt

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[13] Kunac, Klasnić, Lalić: Roma Inclusion (Note 2), p. 18.

[14] Goran Milas, Irena Martinović Klarić: Roma inclusion in the Croatian society: Health care and social welfare. Zagreb 2020, pp. 151–153.

[15] Milas, Martinović Klarić: Roma inclusion (Note 14), p. 90.

that they had to wait longer than the rest of the population to receive healthcare.[16]

The Ministry of Health is the only institution in which data on ethnicity have not been collected systematically. Therefore, there is a systematic lack of information about the Roma in the healthcare system because health institutions do not collect data according to the ethnicity of the population.

However, the Action Plan for the implementation of the National Strategy for Roma Inclusion from 2013 to 2020, for the period from 2019 to 2020 states in the Strategic Area 3. Healthcare, that the Croatian Institute of Public Health (CIPH) is listed as responsible for the strategic area goal: Raising the level of awareness of the Roma population about responsibility for their own health, with the Ministry of the Interior (MUP) and the Ministry of Health (MIZ) as co-sponsors. Thus, in 2019 and 2020, the Croatian Institute of Public Health, in cooperation with its co-sponsors, conducted research under the following measure: Improving the monitoring of the health status and social determinants of the health of members of the Roma national minority.

Since the Ministry of Health does not systematically collect data on patients' ethnicity, the CIPH conducted the first survey in the public health system of the Republic of Croatia, which provides a clear framework based on data from several sources, and thus provides a basis for creating public health policies aimed for the Roma population, thereby establishing an innovative system of analysis and reporting in the field of Roma health by morbidity and by sociodemographic characteristics. The key findings from this research, relating to the number of hospitalizations in the inpatient part of hospitals by groups of diseases in 2018 are presented in Table 1.[17]

Disease group	**Number of hospitalizations (men)**
Respiratory diseases	299
Factors on health, contact with health services	231
Mental and behavioral disorders	154

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[16] Kunac, Klasnić, Lalić: Roma Inclusion (Note 2), pp. 153–154.

[17] Martić: Public health indicators (Note 12), p. 9.

Injuries, poisoning and other consequences of external causes	128
Symptoms, signs and abnormal clinical and laboratory findings not classified elsewhere	116
Diseases of the digestive system	78
Infectious and parasitic diseases	74
Diseases of the circulatory system	72
Certain conditions occurring in the perinatal period	68
Endocrine, dietary and metabolic diseases	58
Diseases of the genitourinary system	48
Diseases of the nervous system	45
Neoplasms	37
Congenital malformations, deformities and chromosomal abnormalities	33
Skin and subcutaneous tissue disorder	24
Other diseases	64
In total	**1,529**

Table 1: Number of men hospitalized in the inpatient part of hospitals by groups of diseases in 2018

According to Table 1, most Romani men were hospitalized due to respiratory diseases (299), and according to the frequency of hospitalizations, mental and behavioral disorders (154) were listed, while 128 Romani men were hospitalized due to injuries, poisoning and other external causes. Romani men were also hospitalized due to diseases of the digestive system (78), infectious and parasitic diseases (74), and diseases of the circulatory system (72). A total of 1,529 men belonging to the Roma national minority were hospitalized.

Disease group	**Number of hospitalizations (women)**
Pregnancy, childbirth, and midwifery	769
Factors on health, contact with health services	623
Respiratory diseases	299
Symptoms, signs and abnormal clinical and laboratory findings not classified elsewhere	123
Mental and behavioral disorders	108
Diseases of the genitourinary system	78
Injuries, poisoning and other consequences of external causes	77
Certain conditions occurring in the perinatal period	73
Endocrine, dietary, and metabolic diseases	71
Infectious and parasitic diseases	64
Diseases of the digestive system	55
Diseases of the circulatory system	54
Neoplasms	49
Diseases of the nervous system	44
Skin and subcutaneous tissue disorder	25
Other diseases	86
In total	**2,598**

Table 2: Number of women hospitalized in the inpatient part of hospitals by groups of diseases in 2018

Table 2 shows that in 2018, hospitalizations due to pregnancy, childbirth and midwifery were the most common among Romani women (769), followed by respiratory diseases (299) and mental and behavioral disorders (108).

As respiratory diseases are highly represented as causes of hospitalization of men and women belonging to the Roma national minority, the possible causes lie in the prevalence of cigarette addiction because at the age of 14 and older, more than half of the Roma population, or 55.2 %, smoke cigarettes, 58.8 % of which are men and 51.6 % women, which is significantly more than in the general population.[18]

During 2018, a total of 5,012 hospitalizations were recorded for day hospital stays, one-day surgeries and inpatient hemodialysis. Of these, 2,445 were hospitalizations of men and 2,567 of women. The most common causes for day hospital stays are the same for men and women and relate to diseases of the genitourinary system, followed by symptoms, signs and abnormal clinical and laboratory findings not classified elsewhere, and respiratory diseases.[19]

According to the data from applications for hospitalization due to mental disorders for 2019, a total of 136 Roma people (89 men and 47 women) were registered and hospitalized under the main diagnosis of mental or behavioral disorders (ICD-10 codes F00-F99). For ill people, a total of 295 hospitalizations were registered (191 for men and 104 for women). Men were hospitalized almost twice as often as women. On average, one person was hospitalized about two times, applying to both sexes. An analysis by age indicates that the most hospitalized people were aged from 20 to 39 and from 40 to 59 years.[20]

For years, the lack of data on ethnicity has made it impossible to determine the differences in births between the Roma and the average population in Croatia and in which age groups are women most likely to give birth. Thanks to a baseline survey from 2017 and linking the data on the ethnicity of women who declared themselves as Romani women with data on childbirth in healthcare institutions, certain analyzes of Roma women's births were for the first time conducted with professional help in healthcare institutions. However, it should be emphasized that the number of Romani women giving birth without professional assistance is unknown, but it is to be assumed that their

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[18] Kunac, Klasnić, Lalić: Roma Inclusion (Note 2), p. 157.

[19] Martić: Public health indicators (Note 12), p. 10.

[20] Martić: Public health indicators (Note 12), p. 16.

number is very small, as less than 0.1 % of births without professional assistance are recorded in state registers.

This data is supported by a qualitative analysis of the data from the baseline survey, where according to interviews and focus groups, the largest number of Romani women give birth in hospitals, and less and less in their homes, which was previously the case.[21] According to the quantitative results of the baseline survey of Romani women who have children, 50 % of them gave birth to their first child in a minor age, and 17 % under the age of sixteen. Only 9 % of Romani women surveyed had never given birth, while less than 1 % did not know the age at which they gave birth to their first child. The average age of first child births among women in the sample decreased slightly – from 17.8 years in the oldest to 18.1 years in younger generations – but no statistically significant difference was found in the average age of first child births among women of different age groups.[22]

In 2018, there were a total of 36,753 births in Croatia, including 593 or 1.6 % of births occurring within the Roma ethnic group. According to the estimate of the number of women of childbearing age (15–49 years) for 2018, there were 875,800 women in Croatia, of which 4,719 (0.5 %) were Romani. The birth rate in the total population of women of childbearing age was 42/1,000, and 126/1,000 among Romani women.[23]

There are significant differences between women of the Roma national minority and women from the majority population among different age groups:

- 3 births by Romani women in Međimurje County were recorded at the age of 10–14, with a rate of 6.8/1,000 Romani women of the same age in Međimurje County, and there were no births at that age in the general population;
- the birth rate for Romani women aged 15–19 is 148.5/1,000, and it is 8.7/1,000 in the general population of girls of that age;
- at the age of 20–24, the birth rate for Romani women is 231.1/1,000, and 41.2/1,000 in the general population;
- at the age of 25–29, the birth rate for Romani women is 142.4/1,000, and 87.6/1,000 in the general population;

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[21] Klasnić, Kunac, Rodik: Roma Inclusion (Note 3), p. 82.

[22] Klasnić, Kunac, Rodik: Roma Inclusion (Note 3), p. 78.

[23] Martić: Public health indicators (Note 12), p. 19.

- at the age of 30–34, the birth rate for Romani women is 107.1/1,000, and 97.1/1,000 in the general population;
- at the age of 35–39, the birth rate for Romani women is 69.0/1,000, and 47.8/1,000 in the general population;
- at the age of 40–44, the birth rate for Romani women is 28.2/1,000, and 9.8/1,000 in the general population;
- no births by Romani women were recorded between the ages of 45 and 49, and 0.4/1,000 were recorded in the general population.

The highest birth rates in the general population are between the ages of 30 and 34, and only this age group does not record large differences between the birth rates for Romani and other women. The highest birth rates in the Roma population are among women aged 20–24.

This analysis, comparing the birth rate according to the age groups of Romani women and all other women, is a contribution to the results of other research on demographic differences between the Roma and the rest of the population, and confirms that Romani women give birth very early, that the number of childbirths, i.e., children is higher than in the general population already in adolescent age, and contributes to significant demographic differences between the Roma population with a high share of younger age groups, and the rest of the population.[24]

The number of abortions and pregnancy terminations – at the request of women, for any reason – among Romani women residing in the Republic of Croatia, according to the data available in the CIPH records, in the period 2010–2016 ranged between 20–40 cases per year. In 2017, there was a significant increase (2017: 90; 2018: 101). The reasons for this increase may be improvements in the records of abortions and pregnancy terminations in healthcare institutions due to changes in the methodology of collecting and quantifying data on abortions and pregnancy terminations from hospital statistics, changes in the attitude of the Roma ethnic minority regarding the declaration of their ethnicity, and possible changes in attitudes and decisions related to childbirth that should be investigated through a special health survey. According to the said data, the total rates of abortions and legally induced pregnancy terminations among the

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[24] Martić: Public health indicators (Note 12), pp. 19–20.

Roma population in the Republic of Croatia are two to three times higher than in the general population of women of childbearing age.[25]

The availability of health services also depends on health professionals, especially doctors. Professionalism and competencies are extremely important, but when it comes to the Roma population, it is extremely important to establish appropriate communication and trust. Confidence in doctors among members of the Roma national minority is extremely high. On average, their competencies and professionalism are rated very good. Older people and those with a lower level of education have somewhat more confidence.[26]

However, one fifth of the surveyed members of the Roma national minority have negative experiences with doctors. The Roma mostly complain about discrimination related to prolonged waiting for an examination, which is an experience reported by almost every second respondent, and about the wrong treatment that every tenth respondent complains about. From these data, it could be concluded that the Roma trust doctors in general, and that only a small number of them have experienced unprofessional or discriminatory behavior.[27]

This is further evidenced by data from a 2017 survey from which it can be concluded that, although health is an extremely important value for the Roma in Croatia (94.8 % of the Roma believe that their health is extremely important), 6.8 % of them experienced discrimination in healthcare in the last year.[28] This is a slightly lower percentage than the one obtained by the EU-MIDIS II survey in 2016, where 10 % of the Roma in Croatia stated that they had experienced discrimination in the last 12 months in the field of healthcare. In this survey, Croatia was slightly above the average of all nine countries surveyed, with the Czech Republic at the average level (8 %), Spain (7 %), Portugal (5 %) and Hungary (4 %) below the average, while above Slovakia (11 %), Romania (12 %) and Greece (20 %) were also above average.[29]

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[25] Martić: Public health indicators (Note 12), p. 22.

[26] Milas, Martinović, Klarić: Roma inclusion (Note 14), p. 95.

[27] Milas, Martinović, Klarić: Roma inclusion (Note 14), p. 97.

[28] Nikola Rašić, Danijela Lucić, Branka Galić, Nenad Karajić: Roma inclusion in the Croatian society: Identity, social distance and discrimination experience. Zagreb 2021, pp. 66–126.

[29] European Union Agency for Fundamental Rights: Second European Union Survey on Minorities and Discrimination against the Roma – Selected Results (2016). https:/

A typical example of discriminatory practices in the healthcare system is the following statement, obtained during the qualitative research conducted in 2017 for the purposes of baseline research:

> »I can say that what happened in our county was a big problem – that no general practitioner wanted to enroll a Romani patient, on several occasions. The latter pediatricians did not want to enroll a child who was six months old and did not get any vaccinations. Then the social welfare center got involved, so the Romani man was attacked for not vaccinating the child, and then he came to me and explained that he had seen both a general practitioner and a pediatrician, and that none of them wanted to enroll them as patients. Then of course I took out a list of places I know, and then of course we went public with it, we reported it to the ministry and the county, and we succeeded only in the way that one of our children is barely enrolled. After that, we don't have such problems anymore because we shook it all up. People have realized that they have someone to turn to, and that I will make sure they get to exercise the rights that they have.«[30]

This is how a representative of the Roma national minority from the region of Northern Croatia described an example of discrimination in the field of healthcare, such as the refusal of primary care physicians to accept the enrollment of Roma patients, but also pediatricians who did not want to accept a Romani child who could therefore not be vaccinated. However, in this case, the representative of the Roma national minority stated that the Roma turned to state institutions, specifically the Center for Social Welfare, the county and the ministry, after which they still managed to exercise their rights.

Discrimination in healthcare does not only concern Romani patients, but also the Roma who want to become health workers, since so far, only a few Roma at the level of the Republic of Croatia have completed any form of higher education in biomedicine and health, and who faced problems during the employment process in health facilities, and who face some form of discrimination in their own workplace.[31]

/fra.europa.eu/sites/default/files/fra_uploads/fra-2016-eu-minorities-survey-roma-selected-findings_hr.pdf (accessed 7.2.2023).

[30] Rašić, Lucić, Galić, Karajić: Roma inclusion (Note 28), p. 140.

[31] Siniša Sead Music: Civil Society Report on Monitoring the Implementation of National Strategies for Roma Integration in the Republic of Croatia. Progress assessment in four key policy areas of the strategy. Zagreb 2019.

Continuity of public policy aimed at the inclusion of members of the Roma national minority in the Republic of Croatia is present since 2003, when the Government adopted the National Program for the Roma. The document was based on the provisions of international documents on human rights and the rights of national minorities to which the Republic of Croatia was a signatory party, and the experiences of countries that systematically solve problems faced by the Roma were used in its preparation.

The National Plan for Roma Inclusion for the 2021–2027 period (NPRI) sets out a strategic framework for the development of equality, inclusion and participation of members of the Roma national minority in the Republic of Croatia until 2027. Among other things, this plan is important for encouraging activities aimed at strengthening the health of members of the Roma national minority, raising the level of social services and promoting Roma social inclusion, as well as combating poverty and creating a supportive environment for Romani families. As part of the National Plan for Roma Inclusion measures in the field of Roma health, it is planned to undertake activities that promote and improve Romani women's access to healthcare and early detection examinations, prenatal and postnatal care, access to family counseling and planning services, and sexual and reproductive health services which are generally provided by national health services. Access to quality primary care and preventive measures, as well as vaccination programs intended for children, will be provided to Romani children through the implementation of the National Plan for Roma Inclusion. Furthermore, the National Plan for Roma Inclusion plans to implement activities to support health mediators and raise Roma awareness of primary prevention measures, such as promoting healthy lifestyles, preventing drug abuse and improving access to mental health services.

In addition to the above mentioned measures, part of the measures and activities of the National Plan for Roma Inclusion relate to activities that encourage the training of teachers and other school staff in the field of family law and recognizing domestic violence, reporting it and treating victims of domestic violence, raising awareness of the importance of reporting any form of violence – relating to data on physical, economic, psychological and sexual violence in families and partnerships.

Also, in order to prevent and combat discrimination against the Roma, it is important to raise awareness of healthcare and access to healthcare free of discrimination, training health professionals, medical students and health mediators in methods of identifying and addressing discrimination and its root causes, including anti-Roma sentiments and unconscious biases. It is also necessary to implement activities to combat the digital exclusion of the Roma in access to healthcare services, in a way that bridges the digital skills gap when it comes to accessing health data.

Building trust and understanding the differences of an ethnic minority is key to reducing discrimination in the health system, which can be achieved through activities that promote Roma access to medical studies and support the employment of the Roma as health workers and intermediaries, especially in regions with significant Romani populations.

In the area of healthcare, it is crucial to ensure free access to community and family services for people with disabilities, the elderly and children without parental care, e.g. development services, social housing, day care services for people with disabilities and foster care networks. Also, supporting the deinstitutionalization process by providing support to families in extremely difficult situations and people with disabilities, e.g. counseling and financial incentives, food aid, assisted living and development services, is of great importance.

During the implementation of the National Plan for Roma Inclusion 2021–2027, activities that promote the exchange and transfer of best practice on public health for the Roma should be carried out, using, for example, the public health framework of the Commission and the Member States in the Steering Group on Health Promotion, Disease Prevention and Non-Communicable Disease Management.

3. Conclusion

A national minority, understood through the Constitutional Law on the Rights of National Minorities, is a group of Croatian citizens whose members traditionally reside in the territory of the Republic of Croatia, and whose members have ethnic, linguistic and/or religious characteristics different from other citizens.

The original basis of the Constitution of the Republic of Croatia states that the Republic of Croatia is established as a national state of the Croatian people and a state of national minorities: Serbs, Czechs, Slovaks, Italians, Hungarians, Jews, Germans, Austrians, Ukrainians, Rusyns, Bosniaks, Slovenes, Montenegrins, Macedonians, Russians, Bulgarians, Poles, Roma, Romanians, Turks, Vlachs, Albanians and others who are its citizens, who are guaranteed equality with Croatian citizens and the exercise of national rights in accordance with democratic norms of the UN and free countries. According to the 2011 census, the Roma national minority is officially represented in Croatia today with 16,975 members, which represents 0.40 % of the total population. The Republic of Croatia, in accordance with positive regulations, ensures the exercise of special rights and freedoms of the Roma as members of national minorities which they enjoy individually or together with other persons belonging to the same national minority, especially the declaration as a national minority, the use of names and surnames in one's own language and script, in private and in public use, and in official use, education in the language and script used, the use of one's own signs and symbols and preservation of traditional names and symbols, cultural autonomy by maintaining, developing and expressing one's own culture, and preservation and protection of their cultural heritage and traditions, the right to manifest their religion, and the establishment of religious communities together with other members of that religion, access to the media and public communication activities – receiving and disseminating information – in the language and script used, self-organization and association with the aim of realizing common interests, representation in representative and executive bodies at the state and local level, and in administrative and judicial bodies, participation in public life and management of local affairs through councils and representatives of national minorities, and protection from any activity that threatens or may endanger their survival, the exercise of rights and freedoms, which includes the protection from all forms of discrimination in the exercise of rights and needs in the healthcare system.

Despite all of the above, the Ministry of Health is the only institution where data on ethnicity is not collected systematically, so there is a complete lack of information on the Roma in the health system, because health institutions do not collect data on ethnicity, so in the Republic of Croatia there is no systematic data on the Roma, on their use of healthcare, and thus there is no systematically monitored data on discrimination based on belonging to the Roma national minority in relation to the use and access to healthcare. An analysis of the Roma's beliefs and attitudes as part of a baseline survey conducted on a representative sample of the Roma in Croatia in 2017 showed that although 92.8 % of Roma are entitled to free healthcare, 11.1 % of Roma never go to the doctor, and 38.5 % have never had any specialist examinations in the past 4 years, with the explanation that they do not have transportation provided or are spatially significantly distant from the place of examination, which is exposure to discrimination in access to healthcare. Furthermore, since as many as 54.6 % of Romani households in a year found themselves unable to pay for a medicine or medical service needed by a member of the household, it can be concluded that there is insufficient availability at all levels, and thus also at the level of secondary healthcare relating to the possibility of exercising the right to healthcare, and the existence of discrimination against the Roma related to the possibility of using healthcare. Also, according to the survey, as many as 27 % of respondents have not contacted a hospital doctor in the last 12 months, although they needed medical help, mainly due to the lack of funding for access to health facilities, indicating that the Roma are discriminated against on the basis of both poverty and ethnicity, while Romani women in particular are also discriminated against on the basis of gender. In order to improve the position of the Roma in exercising the fundamental right to universal and free healthcare guaranteed by the Constitution, it is necessary to conduct targeted research and collect basic data, and then systematically monitor obstacles to healthcare encountered by members of the Roma minority with the aim of it correcting them and enabling full equality for all Roma in exercising the same rights in the field of healthcare that are available to members of the majority population.

III.
Healthcare professionals

Ewa Nowak, Anna-Maria Barciszewska, Karolina Napiwodzka

Diversity-sensitive healthcare delivery across Poland’s clinical landscapes

Abstract
Healthcare systems are obliged to serve patients in a diversity-sensitive way. The recent decade confronted public healthcare in Poland not only with ongoing processes of modernization, marketization, reorganization, not to mention the Covid-19 pandemic. The health system in Poland is dealing with an intensely diversifying society. It is confronted with emerging or hitherto marginalized, discriminated against or underrepresented health interests and needs of women, people with disabilities, LGBTAQI, a growing number of older people, people with different levels of education, low income, poor health insurance; and, finally, the presence of people from diverse national, ethnic and cultural backgrounds. To gain insight into how clinicians have recently dealt with patient from diverse backgrounds, a survey-based pilot study was conducted with invited key informants (N = 26) representing a variety of medical specialties, settings and universities. The results obtained confirm hypothesis of medium-high to low levels of diversity-sensitive clinical competence and, additionally, reveal a variety of facts, positions and challenges related to this deficiency.

1. Theoretical background

Social, economic and demographic inequalities in access to healthcare in Poland became the subject of regular monitoring and research only after the reform of the public health sector 1999,[1] while inequalities

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[1] Tadeusz Kaczmarek, Jerzy T. Marcinkowski, Monika Zysnarska, Tomasz Maksymiuk, Aleksandra Majewicz: Nierówności społeczne w dostępie do zdrowia [Social

related to ethnicity, culture, gender, age, sexual orientation, etc., even later, as modernization, Europeanisation, increase of sociocultural complexity proceeded after a long post-war period of homogeneity. The Polish anti-discrimination legislations are of relatively recent date. The Anti-Discrimination Act of 3 December 2010 indicates the following premises of discrimination: gender, race, ethnicity, nationality, religion, creed, belief, age, sexual orientation.[2] The Polish Constitution from 2 April 1997 in Articles 2, 32 and 68 declares that every citizen of the Republic of Poland as »a democratic state (...) implementing the principles of social justice«, »has the right to equal treatment by public authorities« including »the right to health protection«. In addition, victims of discrimination can bring a civil action under Articles 23–24 of the Civil Code and the Code of Civil Procedure. Retaliation against persons who have exercised their right against discrimination is prohibited. Polish society and its public institutions continue to learn to respect difference, diversity and complexity, and to unlearn axiologies, habits and routines maintaining marginalization, stigmatization, and exclusion. Socialization and education should play a great role in this transformation, though our study rather confirms that medical studies and clinical practice do not offer sufficient pro-diversity training.

Inequalities in access to health services are usually examined either systemically and abstractly or with reference to the patient, e.g. health neglect, but much less frequently with regard to health

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inequalities in access to healthcare]. In: Problemy Higieny i Epidemiologii 88 (2007), pp. 259–266; Agnieszka Genowska, Iwona Grzegorzewska, Magdalena Zalewska, Justyna Fryc: Nierówności w dostępie do opieki zdrowotnej według statusu społeczno-ekonomicznego [Inequalities in access to healthcare by socio-economic status]. In: Hygieia Public Health 50 (2015), pp. 383–388; Agnieszka Sowa-Kofta, Anna Szetela, Stanisława Golinowska: Health promotion for the oldest seniors in the social sector. Examples of policies and programmes from Poland and the Czech Republic. In: Epidemiology Biostatistics and Public Health 14 (2017), https://doi.org/10.2427/12512; Viktoriya Pantyley: Health inequalities among rural and urban population of Eastern Poland in the context of sustainable development. In: Annals of Agricultural and Environmental Medicine 27 (2017), pp. 477–483; Justyna Rój, Maciej Jankowiak: Socioeconomic determinants of health and their unequal distribution in Poland. In: International Journal of Environmental Research and Public Health 18 (2021), https://doi.org/10.3390/ijerph182010856.

[2] Act of 3rd December, 2010 on the implementation of some regulations of European Union regarding equal treatment. https://bip.brpo.gov.pl/en/content/act-3rd-december-2010-implementation-some-regulations-european-union-regarding-equal (accessed on 7.2.2023).

providers' competencies and virtues[3] and their training. Therefore, the authors of the following study decided to investigate how health providers themselves rate their pro-diversity knowledge and competencies in ensuring equitable access to health services for minority groups present in their clinical landscapes. Such investigations can test not only the levels of knowledge and competence, but also the extent to which actual health provision in Poland is compliant with »the vocation of the doctor who wants to treat everyone and to do so in the best possible way«.[4] The Code of Medical Ethics in Article 3 states that »A doctor should always fulfil his duties with respect for the human being, regardless of age, sex, race, genetic equipment, nationality, religion, social affiliation, material situation, political views or other conditions«. However, »In doing so, it is clearly unacceptable that the reasons for ›inequality‹ are of different nature than the clinical condition of the patient«, Duława adds.[5] In turn, »(…) how a doctor treats a patient does not depend on the age of the patient, but on the doctor's individual character traits and attentiveness.«[6] Since 2013, the medical community in Poland has been encouraged to »actively purge healthcare of discrimination based on skin color, gender, socioeconomic status, ethnicity, religion, etc.« and to ensure the availability of »uniform and adequate healthcare«; to »individually and collectively remove barriers to equitable access to health resources and services – barriers depending on the

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[3] Ala Szczepura: Access to health care for ethnic minority populations. In: Postgraduate Medical Journal 81 (2005), pp. 141–147; Marek Olejniczak: Jakiej sprawiedliwości wolno oczekiwać od lekarza? [What justice can be expected from a physician?] In: Diametros 44 (2015), pp. 78–88; Jerzy Kiszka, Dorota Ozga, Arkadiusz Mach, Romuald Krajewski: Providing help to multicultural patients in the context of contemporary population migrations in Europe. In: Pielęgniarstwo XXI wieku 17 (2018), pp. 30–36; Marcin Orzechowski, Marianne Nowak, Katarzyna Bielińska, Anna Chowaniec, Robert Doričić, Mojca Ramšak, Paweł Łuków, Amir Muzur, Zvonka Zupanič-Slavec, Florian Steger: Social Diversity and Access to Healthcare in Europe: How does European Union's Legislation Prevent from Discrimination in Healthcare? In: BMC Public Health 20 (2020), https://doi.org/10.1186/s12889-020-09494-8.

[4] Olejniczak: Jakiej sprawiedliwości (Note 3).

[5] Jan Duława: Kilka uwag na temat zasady niedyskryminacji chorych przez lekarzy [A few remarks on the principle of non-discrimination of patients by doctors]. Commentary to Andrzej Muszala: KEL: O równym traktowaniu pacjentów przez lekarza [About equal treatment of patients by the doctor]. In: Medycyna Praktyczna dla Lekarzy (11.12.2013). https://www.mp.pl/etyka/podstawy_etyki_lekarskiej/92503,kel-o-rownym-traktowaniu-pacjentow-przez-lekarza (accessed on 7.2.2023).

[6] Duława: Kilka uwag (Note 5).

level of education, legal system, financial position, place of residence and social discrimination« so that access to health and healthcare, including health promotion and prevention, becomes equitable:[7] for health and healthcare belong to primary social goods and, according to human rights, must be equally accessible in a democratic and plural society[8].

Before shifting the focus to the recent findings on (non)discrimination determinants inherent in the knowledge and competence of healthcare providers, let us draw attention to two main barriers blocking the development of pro-diversity attitudes in the Polish medical community. The first barrier identified by the community itself is macro-structural change, whereby traditional medical teleology clashes with the allocation and distribution of limited healthcare resources:

> (…) there has been a paradigm shift. Equal treatment of a patient depends less and less on the level of moral sensitivity and personal sense of responsibility of a particular physician dealing with this patient. (...) The doctor-patient relationship was transformed into a commercial activity, involving the sale of limited services and the creation of waiting lists, justified by the need for a fair distribution of limited resources. Worse still, it has decided to create institutional structures to ensure that patients are treated equally, no longer by doctors, but by the health service as an organization.[9]

The second barrier seems rooted in the organizational culture of the healthcare:

> The danger of conservatism is one of the key cultural risks of hospitals operating in a highly variable environment. Central to this is the desire to maintain and transmit the same values, traditions are cultivated (...) and the status quo (...) Conservative organizations insulate themselves from information and resist change (...) Organizational cultures of large public hospitals are particularly rigid and conservative (...) The preference for hierarchy involves the belief that people differ (...) in the powers, privileges and benefits of different groups of employees. Particular importance is attached to maintaining discipline and reinforcing

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[7] Piotr Gajewski, Anna Juda, Jacek Mrukowicz, Wojciech Strojny: Karta Lekarza [Physician's Charter]. In: Medycyna Praktyczna dla Lekarzy (18.6.2013). https://www.mp.pl/etyka/dokumenty/86822,karta-lekarza (accessed on 7.2.2023).

[8] Rui Nunes, Sofia B. Nunes, Guilhermina Rego: Health care as a universal right. In: Journal of Public Health 25 (2017), pp. 1–9.

[9] Duława: Kilka uwag (Note 5).

> the authority (...) acceptance of a strong hierarchy among employees prevails. There is a clear preference for elitist thinking.

In contrast, »the drive for equality stems from the belief that people are entitled to similar rights and the organization reflects this elementary equality.«[10]

According to organizations monitoring discrimination against patients, for instance the Polish Society of Antidiscrimination Law, gender discrimination may be understood, for instance, as a situation in which a hospital denies a woman access to prenatal tests despite the existing indications.[11] Age discrimination manifests itself e.g. by a physician's opinion that illness belongs to unavoidable signs of ageing; here age is used as a diagnosis and premise to not to call an ambulance to an elderly person as it »no longer makes sense«. Further, adults with intellectual disabilities are refused a medical procedure on the grounds that they are »unable to consciously consent to the procedure«, so they »should be placed under guardianship«. An act of discrimination will be a refusal of blood donation if a donor has non-heterosexual orientation, thus creates »an increased risk of HIV infection«.[12] Persons with foreign nationalities may face the refusal of access to certain services due to »lacking PESEL/ID number«. It is already discriminatory to have difficult access to clear and reliable information, in a language the patient understands, on eligibility for

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[10] Łukasz Sułkowski: Zmiana kulturowa w polskich szpitalach – wyniki badań [Cultural change in Polish hospitals – research results]. In: Przedsiębiorczość i Zarządzanie 14 (2013), pp. 83–96, here p. 89; Reema Harrison, Merrilyn Walton, Ashfaq Chauhan, Elizabeth Manias, Upma Chitkara, Monika Latanik, Desiree Leone: What is the role of cultural competence in ethnic minority consumer engagement? An analysis in community healthcare. In: International Journal for Equity in Health 18 (2019), https://doi.org/10.1186/s12939-019-1104-1.

[11] Joanna Z Mishtal: Matters of »conscience«: the politics of reproductive healthcare in Poland. In: Medical Anthropology Quarterly 23 (2009), pp. 161–183; Jacqueline Heinen, Stéphane Portet: Reproductive rights in Poland: when politicians fear the wrath of the church. In: Third World Quarterly 31 (2010), pp. 1007–1021.

[12] Marcin Rodzinka: Praktyczny przewodnik po zdrowiu LGBTI dla lekarzy [A practical guide to LGBTI health for doctors]. Warszawa 2017; Robert Kowalczyk, Marcin Rodzinka (Eds.): Zdrowie LGBT. Przewodnik dla kadry medycznej [LGBT Health. Guide for medical staff]. Warszawa 2016; Wiktor Dynarski, Izabela Jąderek: Transpłciowość a opieka zdrowotna w Polsce: Raport z badań [Transgenderism and healthcare in Poland: Research report]. Warszawa 2015.

assistance, how healthcare works and where to get help.[13] It will be discriminatory to deprive Muslim women staying in refugee centers of the right to choose a female doctor.[14]

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[13] Ulrike Kluge, Marija Bogic, Walter Devillé, Tim Greacen, Marie Dauvrin, Sonia Dias, Andrea Gaddini, Natasja Koitzsch Jensen, Elisabeth Ioannidi-Kapolou, Riveta Mertaniemi, Rosa Puipcinós i Riera, Sima Sandhu, Atilla Sarvary, Joaquin J.F. Soares, Mindaugas Stankunas, Christa Straßmayr, Marta Welbel, Andreas Heinz, Stefan Priebe: Health services and the treatment of immigrants: data on service use, interpreting services and immigrant staff members in services across Europe. In: European Psychiatry 27 (2020), pp. S56–S62; Karima Karmali, Linda Grobovsky, Jennifer Levy, Margaret Keatings: Enhancing cultural competence for improved access to quality care. In: Healthcare Quarterly 14 (2014), pp. 52–57; Melanie Wasserman, Megan R. Renfrew, Alexander R. Green, Lenny Lopez, Aswita Tan-McGrory, Cindy Brach, Joseph R. Betancourt: Identifying and preventing medical errors in patients with limited English proficiency: key findings and tools for the field. In: Journal for Healthcare Quality 36 (2014), pp. 5–16; Stefan Priebe, Sima Sandhu, Sónia Dias, Andrea Gaddini, Tim Greacen, Elisabeth Ioannidis, Ulrike Kluge, Allan Krasnik, Majda Lamkaddem, Vincent Lorant, Rosa Puipcinósi I Riera, Attila Sarvary, Joaquim Soares, Mindaugas Stankunas, Christa Straßmayr, Kristian Wahlbeck, Marta Welbel, Marija Bogic: Good practice in health care for migrants: views and experiences of care professionals in 16 European countries. In: BMC Public Health 11 (2011), https://doi.org/10.1186/1471-2458-11-187; Philipa Mladovsky: Migrant health in the EU. In: Eurohealth 13 (2007), pp. 9–11.

[14] Ewa Kocot, Anna Szetela: Assessing health systems' preparedness for providing care for refugees, asylum seekers and migrants: a scoping review. In: The European Journal of Public Health 30 (2020), pp. 1157–1163; Sarah Hamed, Suruchi Thapar-Björkert, Hannah Bradby, Beth Maina Ahlberg: Racism in European health care: structural violence and beyond. In: Qualitative Health Research 30 (2020), pp. 1662–1673; Anna Górska, Maryla Koss-Goryszewska, Jacek Kucharczyk (Eds.): W stronę krajowego machanizmu ewaluacji integracji: Diagnoza sytuacji beneficjentów ochrony międzynarodowej w Polsce [Towards a national integration evaluation mechanism: Diagnosis of the situation of beneficiaries of international protection in Poland]. Warszawa 2019; Augustus A. White, Beauregard Stubblefield-Tave: Some advice for physicians and other clinicians treating minorities, women, and other patients at risk of receiving health care disparities. In: Journal of Racial and Ethnic Health Disparities 4 (2017), pp. 472–479; Mona Lindqvist, Åsa Wettergren: Migrant women's negotiation of belonging through therapeutic relationships. In: International Journal of Migration, Health and Social Care 14 (2017), pp. 41–54; Jay J. Shen, Christopher R. Cochran, Olena Mazurenko, Charles B. Moseley, Guogen Shan, Robin Mukalian, Scott Neishi: Racial and insurance status disparities in patient safety indicators among hospitalized patients. In: Ethnicity and Disease 26 (2016), pp. 443–452; Eli Kvamme, Siri Ytrehus: Barriers to health care access among undocumented migrant women in Norway. In: Society, Health and Vulnerability 6 (2015), https://doi.org/10.3402/shv.v6.28668; Dorota Cianciara, Paweł Goryński, Wojciech Seroka: Hospitalizacja migrantów w Polsce [Hospitalization of migrants in Poland]. In: Problemy Higieny i Epidemiologii 92 (2011), pp. 497–503; Peter B. Bach: Unequal treatment: Confronting racial and

2. Objectives

In embarking on this study and taking into account the historical, socioeconomic and structural premises indicated in Section 1, we adopted the following hypotheses:

I. The overall sociocultural diversity related levels of knowledge, awareness and competence of fellow clinicians as assessed by key informants are medium-high to low.

II. Respondents' age, gender, specialty, and length of professional service are not significantly related to their insights and assessments of diversity-sensitive clinical competence and professional medical practices in their clinical environments.

III. Due to the workplace (e.g. a hospital/clinic vs a medical practice), assessments may differ when it comes to diversity sensitive knowledge, competence and awareness among fellow clinicians. Healthcare encompasses clinical environments with a variety of behavioral and interactionist patterns towards patients from socioculturally diverse backgrounds.

In addition, a number of specific results were expected according to the research tool used.

3. Method and procedure

A pilot study using a survey method was carried out. Designing the survey was possible with the support and permission of Prof. Robert Like, MD MS, Director of Center for Healthy Families and Cultural Diversity, Dept. of Family Medicine and Community Health, Rutgers University, whose Clinical Cultural Competency Questionnaire (CCCQ-PRE, 2001) was originally used in a project »Assessing the Impact of Cultural Competency Training Using Participatory Quality Improvement Methods« funded by the Aethna Foundation. The research tool shall eventually include demographic characteristics followed by several subscales: clinicians' 1. knowledge on diversity, 2. competence to deal with sociocultural issues, 3. self-confidence (comfort) in dealing with actual cross-cultural challenges, 4. attitudes

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ethnic disparities in health care. In: New England Journal of Medicine 349 (2003), p. 1296.

toward factors contributing to health disparities, 5. competence to identify and distinguish sociocultural identity in clinical contexts, 6. awareness of stereotypes and prejudices in clinical contexts, 7. training.

The »Attitudes« subscale was divided into two, one relating to the ability to identify sociocultural identities across the clinical environments and the other relating to awareness of stereotypes and prejudices. For a more detailed assessment, the Likert scale in which participants make their ratings was extended to 0–5 (0 for »none« and 5 for »a lot/very«) from the original version, in which it was 1–5.[15] Rather than to self-assess their personal knowledge, skills or attitudes, participants were asked to rate knowledge, competences, attitudes and awareness of fellow clinicians involved in their home clinical environments. The perspective of an observer situated in the local professional community – in terms of a setting such as hospital/clinic vs medical practice – was expected to provide more cross-sectional insights into clinical practices and interactions taking into account sociocultural diversity, rather than a perspective based on data obtained from subjective self-reports and self-declarations.[16] A pilot study was conducted in January 2022. The survey was not made available in the public domain. Participation was voluntary, consents were collected together with the completed surveys. Data and results obtained are solely the responsibility of project investigators and do not necessarily represent the official views of the Aetna Foundation and its affiliates.

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[15] Nicole Mareno, Patricia L. Hart, Lewis Van Brackle: Psychometric validation of the Revised Clinical Cultural Competency Questionnaire. In: Journal of Nursing Measurement 21 (2013), pp. 426–436.

[16] Annette Boaz, Stephen Hanney, Teresa Jones, Bryony Soper: Does the engagement of clinicians and organisations in research improve healthcare performance: a three-stage review. In: BMJ Open 5 (2015), http://dx.doi.org/10.1136/bmjopen-2015-009415; Peter Zeh, Ann-Marie Cannaby, Harbinder K. Sandhu, Jane Warwick, Jackie A. Sturt: A cross-sectional survey of general practice health workers' perceptions of their provision of culturally competent services to ethnic minority people with diabetes. In: Care Diabetes 12 (2018), pp. 501–509; Nina B. Wallerstein, Bonnie Duran: Using community-based participatory research to address health disparities. In: Health Promotion Practice 7 (2006), pp. 312–323.

3.1. Sample

We invited key informants representing outpatient and inpatient care, including residents and trainees. They were previously recommended for this role by randomly selected representatives of medical institutions. 26 persons accepted the invitation (response rate was 74 %). Of them, 73.1 % were female and 26.9 % male; Polish speakers only; aged 25–64 (SD = 7.56), of them 36 % < 40 and 64 % > 40. 88.5 % came from large cities and 11.5 % from small cities. 84.6 % of them were employed or were doing internships and work placements in hospitals or clinics, 11.5 % in medical practices and 11.5 % in non-public units. 15.38 % of the participants reported that they had been abroad, for an average of several months, for professional purposes. A total of twelve medical facilities in six cities were involved. Nearly ten various specialties have been approached (Table 1). Other significant descriptive variables are length of service and length of internship abroad in years (Figures 1 and 2).

Specialty distribution	%
Anesthesiology & intensive care	28.0
Neurology	20.0
Pediatrics	12.0
Others	40.0

Table 1: Specialty distribution in the sample

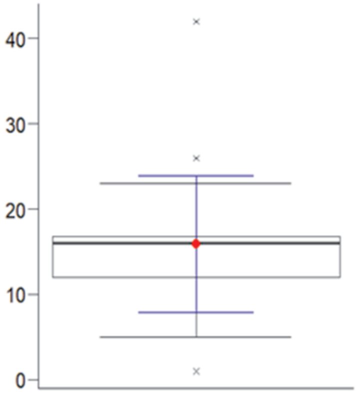

Figure 1: Length of service (in years)

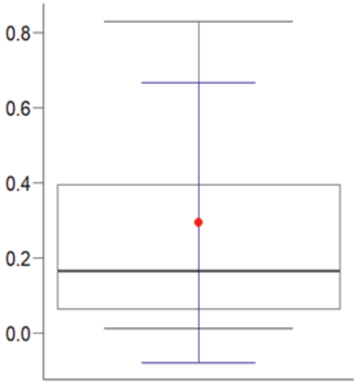

Figure 2: Length of internship abroad (in years)

The research conducted was a pilot study. Written permission was obtained for the adaptation and non-commercial use of the CCCQ-PRE scale. Respondents participated voluntarily. As neither personal questions were asked nor sensitive data collected, approval from the Ethics Committee was not necessary. The questionnaire was prefaced by an opt-out informed consent form. Privacy and confidentiality were protected by anonymization. There was no special funding for this research. No conflict of interest was identified. Data and results obtained are solely the responsibility of project investigators and do not necessarily represent the official views of the Aetna Foundation and its affiliates.

4. Results

Analyses included descriptive analysis, factor and correlation analysis. As for the statistical analysis, we note that $p = 0.05$ was taken as the significance level. The significance level is the maximum acceptable error probability of rejecting the true null hypothesis $H0$, which assumes that the groups under study do not differ in terms of the characteristic of interest. Results of $p < 0.05$ will indicate the presence of significant relationships between variables. Parametric tests (Student's T-test or ANOVA analysis of variance) or their non-parametric equivalents (Mann-Whitney U-test, Kruskal-Wallis test) were used to examine quantitative variables presented by group (subscale).

Factor	N	M	SD	Min	Max	Me
1. Clinicians' knowledge on diversity	26	2.08	0.93	0.56	4.00	2.03
2. Clinicians' competence to deal with sociocultural issues	26	2.09	1.05	0.53	4.00	2.07
3. Clinicians' self-confidence (comfort) level in dealing with actual cross-cultural challenges	26	2.15	1.01	0.33	4.33	1.92
4. Clinicians' attitudes toward factors contributing to health disparities	26	2.85	0.79	1.54	4.54	2.89
5. Clinicians' competence to identify and distinguish sociocultural identities in clinical contexts	26	3.10	1.08	0.00	5.00	3.13
6. Clinicians' awareness of stereotypes	26	3.02	1.12	1.00	5.00	3.00

Table 2: Factor solutions by subscale in terms of descriptive statistics. Abbreviations: M for mean scores, SD for standard deviation, Min for minimum scores, Max for maximum scores, Me for median

Table 2 presents descriptive statistics (for N = 26) including mean, minimum and maximum values, as well as median values of scores grouped into six subscales of the survey. For the six subscales, the mean values were medium-high to low. Respondents rated highest their fellow clinicians' competence to identify and distinguish diverse sociocultural identities in clinical contexts including patients and fellow clinicians (Me = 3.13), their awareness of stereotypes circulating among clinicians about patients and vice versa (Me = 3.0) and attitudes toward factors contributing to health disparities (Me = 2.89), as displayed in Figures 3, 4 and 5.

Figure 3: Clinicians' attitudes toward factors contributing to health disparities (median) rated by respondents

Figure 4: Clinicians' competence to identify and distinguish sociocultural identity rated by respondents

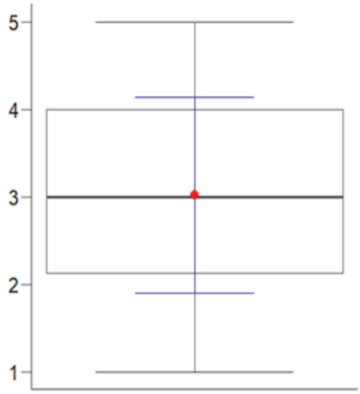

Figure 5: Clinicians' awareness of stereotypes rated by respondents

Below we tabulate detailed results by variable grouped into seven subscales contained in the survey:

Variable		*N*	*M*	*SD*	*Min*	*Max*	*Me*
Subscale 1	Demographics of diverse racial and ethnic groups	26	2.08	1.23	0.00	4.00	2.00
	Sociocultural characteristics of diverse racial and ethnic groups	26	2.31	1.32	0.00	4.00	2.00
	Health risks experienced by diverse racial and ethnic groups	26	2.04	1.34	0.00	4.00	1.50
	Health disparities experienced by diverse racial and ethnic groups	26	1.96	1.28	0.00	4.00	1.50
	Sociocultural issues in health promotion	26	2.08	1.06	0.00	4.00	2.00
	— in reproductive health	26	2.39	1.06	0.00	5.00	2.00

Variable		*N*	*M*	*SD*	*Min*	*Max*	*Me*
	— in child health	26	2.27	1.12	0.00	5.00	2.00
	— in adolescent health	26	2.15	1.26	0.00	5.00	2.00
	— in adult health	26	2.50	1.14	0.00	5.00	3.00
	— in geriatrics	26	2.19	1.10	0.00	4.00	2.00
	— in women's health	26	2.31	1.12	0.00	5.00	2.00
	Ethnopharmacology	26	1.35	1.20	0.00	4.00	1.00
	Different healing traditions	26	1.31	1.12	0.00	4.00	1.00
	Historical and contemporary impact of racism, bias, prejudices, discrimination in healthcare in Poland	26	2.00	1.41	0.00	4.00	1.50
	Domestic policy guidance on non-discrimination	26	2.35	1.55	0.00	5.00	3.00
	Domestic standards for socioculturally sensitive health services	26	2.04	1.59	0.00	5.00	1.50
Subscale 2	Greeting patients in a culturally sensitive manner	26	2.62	1.39	0.00	5.00	3.00
	Eliciting the patient's perspective about health and illness	26	2.77	1.07	0.00	5.00	3.00
	Eliciting information about use of folk and alternative remedies	26	2.12	1.21	0.00	4.00	2.00
	Eliciting information about use of folk and alternative healers	26	1.96	1.40	0.00	4.00	2.00

Variable		*N*	*M*	*SD*	*Min*	*Max*	*Me*
	Performing a culturally sensitive physical examination	26	2.15	1.52	0.00	5.00	2.00
	Prescribing or negotiating a culturally sensitive treatment plan	26	2.15	1.32	0.00	4.00	2.00
	Providing culturally sensitive education and counseling	26	2.08	1.35	0.00	4.00	2.00
	— clinical preventive services	26	1.69	1.46	0.00	4.00	1.00
	— end of life care	26	2.04	1.46	0.00	5.00	2.00
	Assessing health literacy	26	1.81	1.27	0.00	4.00	2.00
	Collaboration with medical interpreters	26	1.92	1.35	0.00	5.00	2.00
	Dealing with cross-cultural conflicts related to diagnosis or treatment	26	2.19	1.23	0.00	4.00	2.00
	Dealing with cross-cultural adherence/compliance problems	26	2.08	1.20	0.00	4.00	2.00
	Dealing with cross-cultural ethical conflicts	26	1.89	1.31	0.00	4.00	2.00
	Apologizing for cross-cultural misunderstandings/errors	26	1.92	1.38	0.00	4.00	2.00

Subscale 3	Caring for patients from culturally diverse backgrounds	26	2.96	1.34	0.00	5.00	3.00
	Caring for patients with limited Polish proficiency	26	2.96	1.40	0.00	5.00	3.00
	Caring for a patient who insists on using or seeking folk healers or alternative therapies	26	1.65	1.33	0.00	5.00	2.00
	Identifying patients'/caregivers' silent beliefs that might interfere with the treatment regimen	26	1.89	1.31	0.00	5.00	1.50
	Being attentive to nonverbal cues, culturally specific gestures that might have different meanings in different cultures	26	1.69	1.32	0.00	5.00	1.00
	Interpreting different cultural expressions of pain, distress, suffering	26	2.00	1.33	0.00	5.00	2.00
	Advising a patient to change behaviors or practices rooted in cultural beliefs that impair one's health	26	2.15	1.57	0.00	5.00	2.00
	Speaking in an indirect rather than direct way to a patient about their illness if this is more culturally appropriate	26	2.23	1.39	0.00	5.00	2.00

Subscale 3	Breaking ›bad news‹ to a patient's family first rather than to the patient when it is more culturally appropriate	26	2.00	1.47	0.00	5.00	2.00
	Working with health-care providers from culturally diverse backgrounds	26	2.23	1.39	0.00	5.00	2.00
	Working with a fellow clinician who makes derogatory remarks about patients from socioculturally diverse backgrounds	26	2.04	1.22	0.00	5.00	2.00
	Treating a patient who makes derogatory remarks about doctors' socioculturally diverse backgrounds	26	1.96	1.28	0.00	5.00	2.00
Subscale 4	Attitudes toward impact of genetics on health disparities	26	4.08	0.94	2.00	5.00	4.00
	—– impact of lifestyle …	26	4.58	0.76	2.00	5.00	5.00
	—– impact of environment …	26	4.42	0.81	2.00	5.00	5.00
	—– impact of poverty …	26	4.04	0.82	2.00	5.00	4.00
	—– impact of educational status …	26	3.77	1.07	1.00	5.00	4.00
	—– impact of illiteracy …	26	3.62	1.30	0.00	5.00	4.00
	—– impact of ageism …	26	2.62	1.44	0.00	5.00	3.00

Subscale 4	—– impact of sexism …	26	2.04	1.54	0.00	5.00	2.00
	—– impact of racism …	26	1.65	1.36	0.00	5.00	1.50
	—– impact of classism …	26	2.00	1.39	0.00	5.00	2.00
	—– impact of ableism …	26	1.92	1.55	0.00	5.00	1.50
	—– impact of sexual orientation discrimination …	26	1.89	1.40	0.00	4.00	1.00
	—– impact of other factors …	26	0.42	1.03	0.00	4.00	0.00
Subscale 5	Competence to identify patients′ sociocultural identity …	26	2.65	1.16	0.00	5.00	3.00
	—– fellow healthcare providers′ sociocultural identity …	26	3.42	1.24	0.00	5.00	4.00
	—– residents′ and medical students′ socio-cultural identity...	26	3.15	1.12	0.00	5.00	3.00
	—– staff′s sociocultural identity …	26	3.15	1.12	0.00	5.00	3.00
Subscale 6	Clinicians′ awareness of racial, ethnic, cultural stereotypes	26	3.08	1.13	1.00	5.00	3.00
	Clinicians′ awareness of biases and prejudices	26	2.96	1.15	1.00	5.00	3.00
	Number of fellow healthcare providers displaying stereotypes and prejudices	26	5.08	6.43	0.00	25.00	3.00
	Number of patients displaying stereotypes and prejudices	26	6.77	9.09	0.00	30.00	4.00

Subscale 6	How strong is the need for training in diversity-sensitive healthcare	26	3.23	1.77	0.00	5.00	3.00
Subscale 7	How often is such training offered in the medical curriculum	26	0.42	0.64	0.00	2.00	0.00
	–– during the internship	26	0.35	0.63	0.00	2.00	0.00
	–– healthcare facilities	26	0.27	0.45	0.00	1.00	0.00

Table 3: Detailed results by item-referring variables grouped into subscales. Abbreviations: M for mean scores, SD for standard deviation, Min for minimum scores, Max for maximum scores, Me for median

Key informants rated highest the awareness of fellow clinicians about which factors influence health disparities (as for subscale 4), among them especially genetic, environmental, lifestyle, and education level related factors (Me = 4 to 5). Medium-high to very low ratings were given to remaining knowledge, awareness and competence of their clinical collaborators in dealing with patients from diverse backgrounds. Regarding education (subscale 7), key informants estimated the frequency of training offerings in diversity sensitive health services at all education and career stages to be close to zero (M = 0.37 to 0.42; Me = 0.00). The results generally confirm the first of our hypotheses.

When it comes to the second hypothesis, 1) regarding age, the study showed no statistically significant differences in the examined assessments between participants aged up to 40 years and participants aged over 40 years. Participants aged over 40 years scored slightly higher on fellow clinicians' self-confidence (comfort) in dealing with actual cross-cultural challenges, attitudes toward factors contributing to health disparities, and competence to identify diverse sociocultural identities in clinical contexts. However, they scored slightly lower fellow clinicians' diversity knowledge, competence to deal with sociocultural issues and awareness of stereotypes and prejudices. 2) Regarding gender, among male participants, the mean score for rating fellow clinicians' attitudes toward factors determining health disparities was M = 2.33; SD = 0.81, while among female participants the mean was higher, M = 3.04; SD = 0.72. Female participants rated their fellow clinicians' attitudes toward factors increasing health disparities significantly higher, t(24) = 2.17; $p < 0.05$. In addition, they evaluated their collaborators' competence to identify diverse sociocultural identities slightly higher than did male participants. Regardless, this and other gender related differences were statistically marginal. 3) With respect to participants' professional specialties, no significant differences were found in individual assessments between those with the specialty in anesthesiology, neurology and other specialties involved. Anesthesiologists evaluated slightly higher than others their fellow clinicians' knowledge on diversity, competence to cope with cross-cultural issues, competence to manage actual cross-cultural challenges and to identify diverse sociocultural identities in clinical contexts, and awareness of stereotypes. Respondents with other specialties rated slightly higher fellow clinicians' attitudes toward factors affecting health disparities. However, these differences were statistically non-significant. To summarize, the specialty held does not significantly differentiate peer reviews of diversity knowledge or cross-cultural competence in home clinical contexts. 4) As for length of professional service, there were no statistically significant differences in the assessments between participants with up to 15 years of service and these with more than 15 years of service. Participants with longer professional experience slightly higher scored fellow clinicians' self-confidence (comfort) in dealing with actual cross-cultural challenges, ability to identify diverse sociocultural identities, and attitudes toward the impact of factors increasing health disparities. The same participants slightly lower scored their fellow clinicians' knowledge on diversity, competence to deal with sociocultural issues, awareness of stereotypes. However, these differences showed little statistical significance.

As for the hypothesis III that workplace significantly differentiates the discussed evaluations of healthcare workers invited to the study, because – as previously hypothesized – their units may differ (in particular, hospitals/clinics vs medical practices; public vs non-public healthcare settings) in terms of diversity-sensitive patterns of clinical practices, the study yielded selectively confirmable findings. For a reliable analysis, it was necessary to merge the small number of non-public healthcare facilities and practices (they are included under ›other‹, as in Table 4).

Variable	*Workplace*	*t/U*	*df*	*p*	*M*	*SD*	*Min*	*Max*	*Me*
Clinicians' knowledge on diversity		3.24	24	0.004					
	Hospital/ clinic				2.36	0.86			
	other				1.17	0.44			
Clinicians' competence to deal with cross-cultural issues		1.73	24	0.097					
	Hospital/ clinic				2.28	1.08			
	Other				1.47	0.66			
Clinicians' self-confidence (comfort) in dealing with actual cross-cultural challenges		1.15	24	0.263					
	Hospital/ clinic				2.27	1.11			
	Other				1.74	0.39			
Clinicians' attitudes toward factors having impact on health disparities		-2.65	24	0.014					
	Hospital/ clinic				2.65	0.68			
	Other				3.53	0.83			
Clinicians' competence to identify and distinguish sociocultural identity		29.50		0.065					
	Hospital/ clinic						0.00	5.00	3.50
	Other						1.00	3.50	2.88
Clinicians' awareness of stereotypes		0.88	24	0.389					
	Hospital/ clinic				3.13	1.10			
	Other				2.67	1.21			

Table 4: Correlation analysis between workplace (hospital/clinic vs other) and scores obtained for six essential subscales. Abbreviations: t for test statistic; U for test statistic; df for degrees of freedom; p for statistical significance; M for mean; SD for standard deviation; Me for median; Min for minimum score; Max for maximum score

Table 4 demonstrates that respondents employed in hospitals or clinics rated diversity related knowledge in their collaborators higher, M = 2.36; SD = 0.86, compared to respondents employed in other healthcare units. The second group rated the knowledge of their collaborators lower, M = 1.17; SD = 0.44. Hospital employees statistically significantly higher rated diversity related knowledge in their collaborators, $t(24) = 3.24$; $p < 0.01$. However, hospital employees rated fellow clinicians' attitudes toward factors increasing health disparities lower, $M = -2.65$; $SD = 0.68$, when compared to their counterparts employed in other healthcare units. The latter rated attitudes of their fellow clinicians higher, $M = 3.53$; $SD = 0.83$. Thus, hospital employees statistically significantly lower rated attitudes toward factors increasing health disparities, $t(24) = -2.65$; $p < 0.05$, among fellow staff. For the remaining scores, only statistically nonsignificant differences were noted between hospital vs other units' staff.

Finally, when asked about barriers to the inclusion of training in socio-culturally competent healthcare, the following responses were received: lack of time (42.11 %); lack of resources (21.05 %); lack of awareness (21.05 %); prejudices (5.26 %); other factors (36.84 %).

5. Discussion

The explanation of findings obtained can be multicausal. Some potential causes have already been identified in the introduction, and these were systemic changes in healthcare at the level of funding, resource distribution, structural hierarchies and cultures, affecting the patterns of medical professional-patient relationships. These macro phenomena may slow down the development of discussed competences crucial to ensure equitable accessibility of healthcare for patients from socioculturally diverse groups. In turn, the barriers identified by the respondents themselves are 1) poor education, and 2) the rarity of international and intercultural professional experience (work placements) that would allow familiarization with diversity among patients and relevant good practices among healthcare professionals. Nor does the community seem interested in its own internationalization. While the Ministry of Health has facilitated hiring procedures for non-EU medical workers, medical chambers slow down nostrification procedures, which is publicly perceived as »discriminatory« and not in line with the expectations of hospitals and clinics. On the other hand, the argument that by employing a doctor from the eastern border on a single job, the employer can save PLN 120,000 per year also sounds discriminatory.[17] The barriers may also lie elsewhere. For instance, less than a freestanding, declarative and contemplative purely normative ethics, what is needed here is an applied ethics, or more precisely, an engaged and transformative practice, as Matthias Kettner suggests.[18]

Additionally, the respondents stated, among other things, that »the question of culturally appropriate information about the patient's condition is at odds with the official requirement of culturally undifferentiated information transmission«. The comments from respondents suggested absolutely equal treatment. They point to a conception of equality that could be called a French relic. The French Constitution speaks of absolutely equal treatment for each individual. The aim is integration. In practice, this makes minorities invisible and produces systemic forms of discrimination against different ethnic, linguistic, religious, etc. populations.

> The »absolute« nature of equality is part of [the Revolution of 1789] legacy, with equality seen as the overarching principle in the constitutional edifice. This has been protected and enforced by the Constitutional Court on many occasions. For example, in 1999 the court decided that ratifying the European Charter for Regional or Minority Languages would be unconstitutional on grounds of ›absolute equality‹ (…). Legally, the constitutional principle of equality has been interpreted as prohibiting the government from collecting data or statistics on the racial, ethnic or religious backgrounds of its citizens, in any context. This means for example that the socioeconomic status of groups across any indicators based on racial, ethnic, religious or other grounds is unknown, and that the national census does not include any questions about race or ethnicity.[19]

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[17] Iwona Hajnosz: Czy lekarze z Ukrainy to zagrożenie dla pacjentów? Według izb lekarskich tak! [Are doctors from Ukraine a threat to patients? According to medical chambers, yes!]. In: Gazeta Wyborcza Kraków (6.2.2022). https://krakow.wyborcza.pl/krakow/7,44425,28076221,czy-lekarze-z-ukrainy-to-zagrozenie-dla-pacjentow-wedlug-izb.html?utm_source=facebook.com&utm_medium=SM&utm_campaign=FB_Gazeta_Wyborcza&fbclid=IwAR0dXJoNWdRu20cci5CxTr52awLdc7PI7x7zJdPnCQpy2PgJhDDuk14I8u0 (accessed on 7.2.2023).

[18] Matthias Kettner: Miseren des Krankenhauses, institutionelle Pathologien und klinische Organisationsethik [Hospital misery, institutional pathologies and clinical organizational ethics]. In: Ethik in der Medizin 33 (2021), pp. 159–175.

[19] Jeremie Gilbert, David Keane: How French law makes minorities invisible. In: The Conversation (13.11.2016). https://theconversation.com/how-french-law-makes-minorities-invisible-66723 (accessed on 7.2.2023).

Meanwhile, the Polish Constitution (Article 35) recognizes minorities and their rights.

Moreover, the respondents stated that »the patient's maladjustment to hospital or country conditions should also be investigated«; and »instead of equality studies, it is better to study something more useful«. The latter suggestion reorients our considerations toward education, as well as research on discriminatory behaviors among students of medical schools. For instance, Lewandowska's study has demonstrated that the number of foreign medical students in Poland is increasing successively to around 7,400 in 2020.[20] Lewandowska interviewed 121 students majoring in »Public Health« at one of the leading medical universities, undergraduate and graduate studies, about the level of acceptance of foreign students by Polish students. Among them, 29.50 % of women and 56.30 % of men declared a negative attitude towards foreign students. Interestingly, the opinions of graduate students were more neutral compared to undergraduate students, indicating that education has a moderately positive effect on acceptance levels. This impact would certainly be greater if the Polish and English-speaking groups shared classes and communicated with each other. The study raises awareness of the structural challenges facing medical education if it intends to promote sensitivity to diversity in overall clinical context among future healthcare professionals.

The research was not without limitations, e.g. supplementary evidence through further studies seems advisable, as well as the inclusion of a first-person perspective using community-based research methods, and finally the perspective of patients from diverse sociocultural backgrounds. One of the limitations may have been the privacy and confidentiality that clinical interactions between clinician and patient require, however, both clinicians and trainees have a broader perspective on this than patients.

6. Conclusion

The results presented above showed medium-high to low diversity-sensitive competence levels across about ten clinical environ-

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[20] Katarzyna Lewandowska: Foreign students seen through the eyes of Polish Public Health Students. Unpublished bachelor thesis provided by courtesy of the author. Warsaw Medical University 2019.

ments. This type of community-based participatory evaluation was conducted for the first time in Poland, as a pilot study. Growing diverse populations in society – and in healthcare professions – justify the question of whether the health sector is prepared to deal competently with patients from diverse backgrounds, to address the barriers they face in accessing healthcare services, and to bring about a social change.

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Educational needs of nurses in intensive therapy units to improve attitudes towards interculturally diverse patients in Slovenia

Abstract

Culturally competent nurses can have a positive impact on the quality of nursing care, patient satisfaction and patient health outcomes. They acquire cultural competence through education. Nurses in intensive care units treat more demanding conditions of patients with specific needs, which requires a high level of cultural competence. The aim of the research was to determine the need for the education of nurses in intensive care units with regard to their attitude towards culturally diverse patients. We used a quantitative research approach. The data were collected with a questionnaire, Healthcare Provider Cultural Competence Instrument (HPCCI) and Educational Needs Questionnaire related to multicultural healthcare. 98 healthcare providers from intensive care units in Slovenia participated in the research. The majority of participants in the study were women (73.5 %) of an average 37.7 years of age (SD = 8.5) who had an average of 14.6 years of working (SD = 10.2) in intensive care units. Participants expressed a relatively high need for education (M = 3.8; SD = 0.6) and perceived themselves as favorable towards interculturally diverse patients (M = 4.1; SD = 0.5). The need for education was statistically significantly (at $p < 0.001$) associated with the perception of the nurses' own preferences for interculturally diverse patients ($r = 0.51$). The research found that a better attitude of nurses towards patients in intensive care units predicts a higher expressed need for education.

1. Background

Culture is an extremely demanding and complex concept that includes socially transmitted behavioral patterns, art, beliefs, values, customs, and the way of life of the human population.[1] It encompasses the values, beliefs, and norms that guide group thinking and decision-making,[2] represents our identity and behavior toward other people,[3] and perceptions of health, well-being, disease, and death.[4]

Healthcare providers must recognize, respect, and integrate the cultural beliefs and practices of clients into healthcare. Thus, the provider must be culturally aware, culturally sensitive, and have some degree of cultural competence to be effective in integrating health beliefs and practices into care.[5] The biggest obstacle to achieving quality healthcare is the failure to take into account the impact of culture on health. Cultural diversity is also a major challenge for healthcare.[6] Halbwachs summarizes the UNESCO's view of the meaning of cultural diversity and states that cultural diversity does not only refer to diversity in terms of ethnic, linguistic, geographical and religious backgrounds, but also covers the spiritual, material, intellectual and emotional characteristics of a society or social group, as well as coexistence, lifestyles, value systems, traditions and beliefs.[7]

Cultural competence is an individual's evolving ability to understand the beliefs, values, behaviors, and habits of culturally diverse

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[1] Larry Purnell: The Purnell Model for Cultural Competence. In: The Journal of Multicultural Nursing and Health 11 (2005), pp. 7–15.

[2] David B. Nicholas, Leonora Hendson, Misty D. Reis: Connection Versus Disconnection: Examining Culturally Competent Care in the Neonatal Intensive Care Unit. In: Social Work in Health Care 53 (2014), pp. 135–155.

[3] Stephanie Listerfelt, Isabell Fridh, Berit Lindahl: Facing the unfamiliar: Nurses' transcultural care in intensive care – A focus group study. In: Intensive and Critical Care Nursing 55 (2019), https://doi.org/10.1016/j.iccn.2019.08.002.

[4] Madeleine Leininger, Marilyn McFarland: Transcultural Nursing. Concepts, Theories, Research and Practice. New York, Chicago, San Francisco 2002.

[5] Purnell: The Purnell Model (Note 1).

[6] Helena Halbwachs: Samozavedanje in kritična refleksija v modelih kulturne kompetentnosti v zdravstvu [Self-awareness and critical reflection in health care cultural competence models]. In: Nadja Plazar, Gorazd Voga (Eds.): Medkulturna oskrba v zdravstvu. Znanstvena monografija [Intercultural care in healthcare. Scientific monography]. Celje 2019, pp. 51–63.

[7] Halbwachs: Samozavedanje in kritična (Note 6).

individuals.[8] It is not an end point, but a conscious process that is not necessarily linear.[9] In this process, health professionals continuously strive to achieve the ability to work effectively within the cultural context of the patient, family, and community.[10] The process includes and connects cultural awareness, cultural knowledge, cultural skills, cultural encounters, and cultural desire.[11] Perng and Watson state that cultural competence is a key competence of health professionals that is needed to provide safe and effective healthcare to culturally diverse patients.[12] Lipovec Čebron et al. state that some authors have envisioned several stages of development in the process of cultural competencies, e.g. Cross et al. predicted six levels, Willis seven levels, Purnell four levels.[13]

Cultural competencies are key to implementing culturally congruent care for patients and their relatives,[14] as they allow health professionals to communicate and deliver quality care to patients with diverse sociocultural backgrounds.[15] The need for health professionals to acquire cultural competencies is urgent in order to reduce the differences in the quality of healthcare that occur due to the cultural diversity of patients.[16] In their study, the authors found that the 12-hour educational program significantly improved the cultural

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[8] Jung-Won Ahn: Structural Equation Modeling of Cultural Competence of Nurses Caring for Foreign Patients. In: Asian Nursing Research 11 (2017), pp. 65–73.

[9] Josepha Campinha-Bacote: The Process of Cultural Competence in the Delivery of Healthcare Services: A Model of Care. In: Journal of Transcultural Nursing 13 (2002), pp. 181–184; Purnell: The Purnell Model (Note 1).

[10] Campinha-Bacote: The Process (Note 9).

[11] Campinha-Bacote: The Process (Note 9).

[12] Shoa-Jen Perng, Roger Watson: Construct validation of the Nurse Cultural Competence Scale: a hierarchy of abilities. In: Journal of Clinical Nursing 21 (2012), pp. 1678–1684.

[13] Uršula Lipovec Čebron, Sara Pistotnik, Jerneja Farkaš Lainščak, Ivanka Huber: Medkulturne kompetence in zdravstvena oskrba v Sloveniji [Intercultural competencies and health care in Slovenia]. In: Nadja Plazar, Gorazd Voga (Eds.): Medkulturna oskrba v zdravstvu. Znanstvena monografija [Intercultural care in healthcare. Scientific monography]. Celje 2019, pp. 35–49.

[14] Listerfelt, Fridh, Lindahl: Facing the unfamiliar (Note 3).

[15] Robert C. Like: Educating Clinicians About Cultural Competence and Disparities in Health and Health Care. In: Journal of Continuing Education in the Health Professions 31 (2011), pp. 196–206.

[16] Mei-Hsiang Lin, Hsiu-Chin Hsu: Effects of a cultural competence education programme on clinical nurses: A randomised controlled trial. In: Nurse Education Today 88 (2020), https://doi.org/10.1016/j.nedt.2020.104385.

competencies of nurses. Hagqvist et al. came to similar conclusions from their interviews with 12 nurses-mentors, as the competence of intercultural communication was shown to have improved through continuous education to the benefit of patients and staff.[17] Weber also notes that almost all studies on inter-ethnic relations conducted in Western Europe and North America show that individuals with a higher level of education report greater tolerance for migrants and ethnic minorities.[18]

There is little research pertaining to the study of culturally diverse patients in intensive care units (ICU). However, that which is available suggests that caring for culturally diverse patients and their relatives in intensive care units is demanding, and a low level of cultural competence can lead to poor clinical outcomes for both patients and family members.[19] Benbenishty and Biswas emphasize that the cultural competencies of nurses in intensive care units are crucial, mainly because of the urgency of the ever-changing patient situation and the need to make quick decisions regarding situations, in which it is difficult to obtain patient and/or family consent.[20]

In Slovenia, there is no formal training for nurses in intensive care units, nor is there any additional training in cultural competence. The position of a nurse in an intensive care unit can be filled by graduate nurse. Respect for the diversity of patients is written only in the Code of Ethics of Nursing and Care of Slovenia in which we find the following dictum: »Factors such as race, nationality, religion, political opinion, social status, age, sex, sexual orientation, health status, and disability must not in any way affect the attitude towards the patient.«[21] That dictum stipulates the standard conduct for achieving the first

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[17] Pia Hagqvist, Ashlee Oikarainen, Anna-Maria Tuomikoski, Joanna Juntunen, Kristina Mikkonen: Clinical mentors' experiences of their intercultural communication competence in mentoring culturally and linguistically diverse nursing students: A qualitative study. In: Nurse Education Today 87 (2020), https://doi.org/10.1016/j.nedt.2020.104348.

[18] Hannes Weber: The educational divide over feelings about ethnic minorities: does more education really lead to less prejudice? In: Journal of Ethnic and Migration Studies (2020), pp. 228–247.

[19] Listerfelt, Fridh, Lindahl: Facing the unfamiliar (Note 3).

[20] Julie Benbenishty, Seema Biswas: Cultural Competence in Critical Care: Case Studies in the ICU. In: Journal of Modern Education Review 5 (2015), pp. 723–728.

[21] Zbornica Zveza: Kodeks etike v zdravstveni negi in oskrbi Slovenije [Code of ethics in healthcare and care in Slovenia]. In: Uradni list Republike Slovenije [Official Gazette of the Republic of Slovenia] 71 (2014), p. 7847.

principle of the code, which is: Nursing and healthcare providers take care to preserve people's lives and health. They are obliged to perform their work humanely, professionally, with quality, safety, compassion, responsibility, conscientiousness, and respect for the patient's needs, values and beliefs.

Culturally competent nurses should be able to transfer and apply knowledge of different cultures in practice. Cultural competence in nursing means adaptability and respect for difference. It also means that nurses know how to listen to patients and obtain all the information that significantly affects their health, i.e. the patient's beliefs, cultural habits and customs.[22]

The aim of the research was to determine the need for the education of nurses in intensive care units so that they may acquire intercultural competencies.

2. Methods and materials

Our research included 98 nursing care providers from intensive care units in Slovenia. The majority of the respondents were women (f = 72), the participants were on average 37.7 years of age (SD = 8.5) and had an average of 16.0 years of work experience (SD = 9.8), of which 14.6 years (SD = 10.2) was spent working in intensive care units.

In our research we used a quantitative research approach, descriptive and compilation research methods and a causal non-experimental method. The data were collected using the Healthcare Provider Cultural Competence Instrument (HPCCI) questionnaire,[23] and the educational needs questionnaire relating to multicultural nursing care, which we designed ourselves. The HPCCI questionnaire consists of 49 items combined into 5 sets of questions: (set I) attitudes about

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[22] Tina Razlag Kolar, Bojana Filej, Boris Miha Kaučič: Pomen kulturne kompetentnosti medicinskih sester za kakovostno in k pacientu usmerjeno zdravstveno nego in oskrbo [The importance of cultural competences of nurses for quality and patient oriented nursing care]. In: Nadja Plazar, Gorazd Voga (Eds.): Medkulturna oskrba v zdravstvu. Znanstvena monografija [Intercultural care in healthcare. Scientific monography]. Celje 2019, pp. 75–95.

[23] Joshua L. Schwarz, Raymond Witte, Sherrill L. Sellers, Rebecca A. Luzadis, Judith L. Weiner, Eloiza Domingo–Snyder, James E. Page: Development and Psychometric Assessment of the Healthcare Provider Cultural Competence Instrument. In: Inquiry – The Journal of Health Care Organization, Provision, and Financing 52 (2015), https://doi.org/10.1177/0046958015583696.

cultures (11 items), (set II) behavioral aspect of the relationship with a patient (16 items), (set III) offering options as a part of the relationship with a patient (3 items), (set IV) orientation of practice during the treatment (8 items), (set V) self-perceived sympathy. In the present study we used two sets of questions that relate to the behavioral aspect of the relationship (set II) and self-perceived sympathy (set V) towards interculturally diverse patients. Set II consists of 16 items evaluated on a 7-point Likert scale (from 1 – Never to 7 – Always, with two additional options: 8 – No opinion, 9 N/A). Set V consists of 9 items measured on a 5-point Likert scale (from 1 strongly disagree to 5 strongly agree; with additional option: 6 N/A). Schwarz et al. (2015) reported the following Cronbach's alpha for subscales of the original version of the HPCCI: awareness and sensitivity, 0.791; behavior, 0.926; patient-centered orientation, 0.764; practice orientation, 0.722; and self-assessment, 0.920. On our sample the Cronbach's alpha of original scales was somewhat lower (awareness and sensitivity, 0.633; behavior, 0.887; patient-centered orientation, 0.841; practice orientation, 0.680; and self-assessment, 0.841).

The educational needs questionnaire relating to multicultural nursing care, which was designed for this study, consisted of 15 items measuring the self-perceived need for education, tendency towards informal self-education and special knowledge required for quality work performance (languages, ethnic diversity). Items were scored on 5-point Likert scale (from 1 – I completely disagree to 5 – I completely agree). Cronbach's alpha for the scale was 0.913.

The data were collected by online survey within the project Erasmus+, KA2: Cooperation for innovation and exchange of good practices, Strategic Partnership for Higher Education and Training, Multicultural Care and European Intensive Care Units (MICE-ICU) – http://mice-icu.eu/.

The research does not involve vulnerable groups of patients, only nursing care providers, so approval from an ethics committee was not required.

3. Results

Participants expressed a relatively strong need for education (M = 3.8; SD = 0.6) and perceived themselves as sympathetic towards interculturally diverse patients (M = 4.1; SD = 0.5). It has also been reported that the described behaviors are used occasionally to frequently (M = 3.7; SD = 1.0).

The sympathy of nurses was associated with their self-reported behavior towards interculturally diverse patients (r = 0.49). More sensitive and sympathetic nurses also reported more culturally competent behavior.

The need for education was statistically significantly (at $p < 0.001$) associated with the perception of the nurses' own sympathy towards interculturally diverse patients (r = 0.51) and their behavior towards these patients (r = 0.48). Nurses who perceived themselves as more sympathetic towards the patient also reported a greater need for education. Apparently, more sensitive nurses detected greater discrepancies between their existing knowledge and the knowledge they need to work more efficiently. Moreover, nurses who described their behavior as more culturally competent perceived a greater need for additional education. Based on the literature review and presented correlations, it was concluded that at least some cultural competence was needed for nurses to become conscious of their incompetence. Just 16.5 % to 19.4 % of participants were consciously incompetent. They reported using culturally competent behavior and showing sympathy towards their patients less often, yet at the same time recognized the need for education (Table 1, Table 2). The consciously incompetent group of nurses was statistically smaller than the consciously competent group (33 % and 30.6 %) or the unconsciously incompetent and unconsciously competent groups, which could not be properly separated (50.6 % and 50.0 %).

	Need for education		
Self-assessed culturally competent behavior		No	Yes
	No	34 (35.1 %) unconscious incompetence	16 (16.5 %) **conscious incompetence**
	Yes	15 (15.5 %) unconscious incompetence	32 (33.0 %) conscious competence

Table 1: Need for education in relation to self-assessed culturally competent behavior. The difference in group sizes was statistically significant ($X^2 = 12.62$, $p < 0{,}001$)

	Need for education		
Sympathy		No	Yes
	No	34 (34.7 %) unconscious incompetence	19 (19.4 %) **conscious incompetence**
	Yes	15 (15.3 %) unconscious incompetence; unconscious competence	30 (30.6 %) conscious competence

Table 2: Need for education in relation to self-perceived sympathy. The difference in group sizes was statistically significant ($X^2 = 9.25$, $p = 0{,}002$)

Due to the correlation between culturally competent behavior, self-perceived sympathy and the perceived need for education, we formed a simple regression model predicting the need for education in cultural competence. Culturally competent behavior and self-perceived sympathy explained 31.4 % of the need for education. Both the behavioral ($\beta = 0.307$; $p = 0.002$) and attitudinal components (i.e., sympathy, $\beta = 0.307$; $p < 0.001$) of the cultural competence were important individual predictors of the concurrently assessed need for education (F (2, 95) = 23.16; $p < 0.001$; Adjusted R2 = 0.31). A more positive attitude towards cultural competence and more culturally competent behavior predicted a greater need for education regarding cultural competence. Only when individuals gain basic knowledge and experience can they become aware that they are lacking in knowledge about other cultures (conscious incompetence), resulting in a need for additional education.

4. Discussion

The research found that Intensive Care Unit nurses who have a better attitude towards patients express a greater need for education to acquire cultural competencies than those with a worse attitude towards patients. At the Intensive Care Unit, only culturally competent nurses can provide nursing care due to the complexity and vulnerability of the patients' condition, family involvement and their informational needs, and the character of nursing work. A survey of nurses from 15 European countries found that 88 % of nurses believe that education contributes to the development of cultural competences.[24] Through a review of various research notes, Weber determines that education as a process develops knowledge and cognitive skills in individuals, and consequently increases tolerance towards different ethnic groups. He also states that a higher level of education leads to a greater awareness of the importance of an ideology that does not support the stereotyping of ethnic groups.[25]

A lack of understanding of patients' cultural beliefs about the method of treatment can lead to greater insecurity, anxiety, helplessness and stress in nurses. It is therefore imperative that nurses acquire knowledge about the characteristics of different cultures.[26] In a case study, Benbenishty and Biswas studied cultural competences in the

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[24] Beata Dobrowolska, Aleksandra Gutysz-Wojnicka, Dorota Ozga, Eva Barkestad, Julie Benbenishty, Kristijan Breznik, Bojana Filej, Darja Jarosava, Boris Miha Kaučič, Ivana Nytra, Barbara Smrke, Renata Zelenikova, Bronagh Blackwood: European intensive care nurses' cultural competency: An international cross-sectional survey. In: Intensive and Critical Care 60 (2020), https://doi.org/10.1016/j.iccn.2020.102892.

[25] Weber: The educational divide (Note 18).

[26] Ahn: Structural Equation (Note 8).

Intensive Care Unit and found that a critical care environment is a demanding work environment, both physically and emotionally.[27] They also note that, in addition to providing an optimal physical environment for stabilizing the condition of patients and providing treatment, it is important to consider how to communicate, inform, counsel and comfort patients and their relatives. Therefore, there is no doubt that knowledge of different cultures is essential.

Sotler studied the instruments for measuring cultural competences in healthcare through a systematic review of the literature and found that there is a need for targeted education in cultural competences, as this significantly affects raising the level of the cultural competence of health professionals.[28] Razlag Kolar et al. analyzed the content of 27 articles and identified the expressed need for the education of health professionals to acquire cultural competencies in 12 of them.[29] Using qualitative research, Hvalič Touzery also found that the lack of cultural competencies can have a fatal impact on the course of treatment of disease, therefore appropriate education is needed that is capable of improving the level of cultural competence.[30]

Being a culturally competent nurse at the Intensive Care Unit is not easy. Nurses must first confront their own personality traits, prejudices, and perceptions in order to overcome them and ensure culturally competent care for each patient on both the personal and the institutional levels.[31]

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[27] Benbenishty, Biswas: Cultural Competence (Note 20).

[28] Robert Sotler: Merjenje kulturnih kompetenc v zdravstvu – uporabnost in zanesljivost [Measuring cultural competence in healthcare – usability and reliability]. In: Nevenka Kregar Velikonja (Ed.): Celostna obravnava pacienta. Mednarodna znanstvena konferenca [Comprehensive treatment of the patient. International scientific conference]. Novo mesto 2017, pp. 467–477.

[29] Razlag Kolar, Filej, Kaučič: Pomen kulturne (Note 22).

[30] Simona Hvalič Touzery, Sedina Kalender Smajlović, Marta Smodiš: Multikulturne kompetence kliničnih mentorjev. Rezultati projekta Soulbus [Multicultural competencies of clinical mentors. Results of the Soulbus project]. In: Sanela Pivač, Brigita Skela Savič, Simona Hvalič Touzery, Sedina Kalender Smajlović (Eds.): 8. šola za klinične mentorje: Klinično usposabljanje skozi EU direktivo in mednarodne standarde ter izkušnje v Sloveniji: količina in kakovost kliničnega usposabljanja Jesenice [8th school for clinical mentors: Clinical training through the EU directive and international standards and experience in Slovenia: quantity and quality of clinical training in Jesenice]. Jesenice 2014, pp. 56–64.

[31] Julie Benbenishty, Aleksandra Gutysz-Wojnicka, Irene Hart, Eva Barkestad, Drago Satosek, Kaisa Jacobsson, Bronagh Blackwood: The migrant crisis and the importance

5. Conclusion

The chapter present Slovenian part of the results of the study which is based on the results obtained in intensive care units in Slovenia and is part of a broader study conducted within the international research and development project MICE-ICU in which the following establishments have participated: (1) University of Ostrava, Faculty of Medicine, Department of Nursing and Midwifery, Czech Republic; (2) Association for Anesthesiology and Intensive Care, Poland; (3) Assist GmbH, Germany; (4) College of Nursing in Celje, Slovenia; (5) European Association of Nurses in Intensive Care, and (6) Danmar Computers, Poland. With the project we wanted to improve the knowledge, skills and competencies of nurses in the Intensive Care Units for the implementation of culturally sensitive patient care. Based on the evidence, the project partners prepared educational content for the self-education of Intensive Care Unit nurses, using the learning management system (e-learning platform) and divided it into three modules:

1. Cultural awareness and sensitivity;
2. Culturally diverse patients in healthcare environment;
3. Specifics when caring for culturally diverse patients on intensive care wards.

Each topic has specific objectives, precise contents, learning outcomes and listed activities, i.e reading, test, film, discussion, examples of good practice, case study, that the participant must carry out in order to achieve the objectives of the training.

This was a special challenge for Slovenia, as nurses encountered a system for using learning (e-learning platforms) and a distance self-education approach for the first time. The e-learning platform is freely available in four different languages – English, Czech, Polish and Slovenian – and is an example of successful implementation of the Intercultural Nursing educational program in the Intensive Care Unit, which took place among 120 nursing providers in Europe. Today, the online course is used not only for self-education by Intensive Care Unit nurses, but also by nurses in other professional fields of nursing (modules 1 and 2), as well as nursing students. A higher

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of developing cultural competence in the intensive care unit. In: Nursing in Critical Care 22 (2017), pp. 262–263.

level of cultural competence reduces inequality in treatment between culturally diverse patients. Due to more effective communication, health professionals better understand the patient's needs, and as a result, patients are more satisfied with the quality of nursing and care.

Sanja Pleština, Sandra Karabatić

The importance of improving education of healthcare professionals on communication with minorities – experience with Roma in the Croatian healthcare system

Abstract
Although Roma, who have civil status in the Republic of Croatia, exercise the right to healthcare in accordance with the provisions of the Health Care Act and the Health Insurance Act in the same manner and under the same conditions as all other Republic of Croatia citizens, in real life when an individual and his family members are faced with a diagnosis of severe illness and enter a healthcare system in which healthcare professionals provide healthcare, there may be a lack of understanding in this interaction, and a kind of crisis communication that has been in practice so far. In order to better understand the Roma, we have established cooperation with representatives of the Council of Roma Minorities of the City of Zagreb. The main problem lies in the lack of understanding of the customs, beliefs, and value system of the Roma. It is necessary to conduct education on the specifics of national minorities and intercultural communication, which is a precondition for the realization of guaranteed rights and the provision of quality healthcare.

1. Introduction

»Communication is perhaps the most important and difficult activity a person can engage in. It is a sensitive membrane through which people can share thoughts, ideas, feelings, dreams, and disappointments. Communication is a key component in interaction.« said Le

Boutillier.[1] The importance and impact of communication on human behavior were most interestingly described by Professor Elizabeth Keating of the Department of Anthropology, the University of Texas at Austin: »Communication is powerful: it brings friends to our side and drives our rivals, calms or warns children, and creates agreements or battle lines between us.«[2] The most famous sentence says: »We cannot but communicate«, and we must not forget that »Every act of ours is communication at the same time!«[3] By communicating, we share our beliefs, values, ideas, and emotions. »Every communication is nothing else but the creation of a relationship. Everything is in a human relationship, in a human-human relationship. Therefore, this important component of treatment in which man should be medicine to man must be emphasized.«[4] Communication can be verbal and nonverbal. The basic process of interpersonal communication contains several elements: to communicate, a sender is needed; that is a person who wants to communicate something. The sender encodes his intention into characters and a message is created. On the other side of the communication process, we have a recipient who has the task of decoding the characters sent in the message and receiving the information. The recipient usually understands the message which is verified via feedback. This simple sequence ensures that the recipient has received the message someone has sent. Are we aware that a message or notification always carries or contains several different messages at the same time? Every communication is a package with a multitude of messages.

A message has four sides:

1. subject matter or what we report;
2. self-disclosure or what we say about ourselves;

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[1] Antonija Žižak, Vlasta Vizek Vidović, Marina Ajduković: Interpersonalna komunikacija u profesionalnom kontekstu [Interpersonal communication in a professional context]. Zagreb 2012, p. 305.

[2] Larry A. Samovar, Richard E. Porter, Edwin E. McDaniel: Komunikacija između kultura [Communication between cultures]. Zagreb 2013.

[3] Smiljana Leinert Novosel: Komunikacijski Kompas [Communication Compass]. Zagreb 2015.

[4] Veljko Dordević, Marijana Braš: Komunikacija u medicini: Čovjek je čovjeku lijek [Communication in medicine: Man is man's medicine]. Zagreb 2011.

3. relevance or what I think about you and how we relate to each other, how the sender treats the recipient and what he thinks about him;
4. appeal or to what we want to encourage you.

Each message or notification first contains information about a conversation. With information, we convey many facts. We do this every day, i.e., we communicate content (7 %), but this is only part of what is currently happening between sender and recipient (93 %). Each piece of information hides information about the sender as a person, of self-manifestation or impression. With this side of information, many problems in interpersonal communication are associated, and it is psychologically very significant. How the sender and recipient relate to each other is revealed by each participant, via their choice of formulations, the color and volume of their voice, and other non-linguistic accompanying signals, body language. The recipient has a particularly sensitive »ear« for this side of the message because there, as a person, he feels accepted or rejected in a very specific way! This part defines communication, and it is a key filter. To avoid conflicts and misunderstandings we need to know that what we say is important, with what intent we are saying it, and what we say about ourselves, but most importantly of all how we treat each other.

After a crisis of communication that occurred in 2019 in our hospital department for the respiratory diseases, the crisis was followed by an analysis of the whole event.

What happened that day? A patient with advanced lung cancer was admitted through the emergency department, in poor general condition. Pain and oxygen therapy was applied, but death was expected. The patient was a member of the Roma national minority, which meant the presence of many family members who wanted to be with their dying family member. In agreement with the family, we ensured that two by two come and be with the patient. We respected their wishes, but also ensured peace for all other patients. The rest of the family, as is customary with the Roma people, does not go home, but stays in the hospital all the time, in the parking lot or the park nearby. The family wanted to take the patient home and the lead doctor promised to talk to the family after performing the agreed diagnostic procedure. Unfortunately, in the meantime, the patient passed away, and his pregnant underage daughter and wife were with him. The realization that their husband and father had passed away caused emotional shock. Emotional shock is characterized as an excessive emotional reaction whose intensity is so strong that a person temporarily loses contact with reality. Situations that cause emotional shock are sudden and threaten a person's basic life values, and basic opinion about himself, others, or the world.[5] Communicating to the family and the patient that all diagnostic and therapeutic options have been exhausted is by no means easy. In this interaction, a lack of understanding may occur.

2. Methods and Materials

After a crisis of communication that occurred in our hospital department the crisis was followed by an analysis of the whole event. The big motive was the poster slogan from 2009, when the famous »marketing guru« Philip Kotler visited Zagreb: »The crisis is a challenge!« A meeting of health professionals was held where the potential causes of the crisis were analyzed to prevent new ones or better control them. We identified communication barriers, namely emotions and sociocultural elements; collective thinking in which collective behavior dominates and stifles the decision-making process, stereotypes, conflicts of values and beliefs because culture is based on shared beliefs and values. After identifying the obstacles, we decided to get to know the Roma people better. We decided to arrange a meeting with representatives of the Council of Roma Minorities of the City of Zagreb. We sent a letter of intent to the president of the Council of National Minorities in Zagreb. In the letter of intent, we asked the representatives of the council to familiarize us with the culture and customs of the Roma in order to communicate and cooperate more simply and easily, but also to understand the reasons that led to such an emotional shock. The meeting on »What does illness and the role of the family mean for Roma« was scheduled for September 24, 2019. at 11 a.m. in the council premises in Zagreb, and nine representatives participated in the meeting. All of them gave their consent to record the conversation and all were informed about the purpose of the meeting. We went through four topics: What does family mean to Roma? What is their view of the disease? What is the role of the family

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[5] Zoran Milivojević: Emocije: psihoterapija i razumevanje emocija [Emotions: psychotherapy and understanding emotions]. Zagreb 2018.

in caring for a sick or dying member? How can we cooperate better? Approval of an ethics committee was not required as the research did not include vulnerable groups but only representatives of the Roma national minority and healthcare professionals.

3. Results

Strongly condemning any form of aggression – all members of the council distanced themselves and condemned the aggression – all participants of the meeting »What does illness and the role of the family mean for Roma« concluded that the main problem lies in the lack of understanding of Roma customs, beliefs and values.

What have we learned about the Roma? What does family mean to Roma?

For the Roma community, family is important, and, unlike our culture, the notion of the immediate family is significantly broader.

N.I.: »For us Roma, family is very important, our immediate family is our parents, brothers, sisters, cousins, and grandparents, and in important life situations, we are all together.«

R.D.: »Some families do not talk, but if a family member dies or becomes seriously ill, disagreements are forgotten and everyone is together.«

What is their view of the disease?

A.D.: »Disease is fate!«

B.G.: »Roma believe that illness occurs as a punishment and illness is bad luck.«

Most Roma, although this has been changing recently, still want their loved ones to die in their homes.

What is the role of the family in caring for a sick or dying member?

They believe that a seriously ill, and especially a dying member of their family should never be left alone. It is especially important not to die alone without the presence of family members because it entails bad energy and karma. Sickness and death are situations when quarreling families reconcile and are together with the sick.

N.I.: »When a family member is sick, other family members are always with him and he must never be alone. Above all, he must not die alone!«

B.G.: »To leave a sick family member alone, and God forbid that he die alone, is unimaginable to us and causes fate.«

With Roma, it is important to know who to communicate with and who the decision-maker is. It is wrong to assume that it is a wife, daughter, or son. When a member of their family is in the hospital everyone is present, they do not leave the hospital grounds. In order to manage many visitors successfully, it is important to come to an agreement in advance. From our experience, the word given to you by the so-called head of the family is respected and experience shows us that such agreements are really respected. We return to respect in communication and relationships as the foundation for conflict prevention.

How can we cooperate better?

R.F.: »I repeat, we condemn and do not justify aggression, but the main problem is the misunderstanding of Roma customs, beliefs, and values. We, as representatives of Roma, offer you help and you can always call us and we hope that this kind of situation will not happen again.«

In addition to receiving important information on the Roma people, a cooperation was established with the Roma Council, some joint public health campaigns were agreed on, as well as contacts exchanged in case of the need to better understand members of the Roma national minorities.

This leads to the question: do we have to know every culture that we will take care of at some point? This would be too ambitious and almost impossible, but we can always cooperate with representatives of national minorities living in Croatia to seek help in case of any misunderstanding, especially when it comes to life-threatening, dying patients.

4. Discussion

According to the Croatian Law on Compulsory Health Insurance published in the Official Gazette 80/13, 137/13, 98/19 which is in force since January 1st, 2020 in the Republic of Croatia, compulsory health insurance covers all insured persons of the Institute of Rights and Obligations from Compulsory Health Insurance on the principles of reciprocity, solidarity and equality, in the manner and under the conditions determined by the Regulation (EC).[6] According to the 2011 census, there are 4,284,889 inhabitants in the Republic of Croatia, 328,738 of which are members of national minorities: Albanians 17,513 (0.41 %), Austrians 297 (0.01 %), Bosnians 31,479 (0, 73 %), Bulgarians 350 (0.01 %), Montenegrins 4,517 (0.11 %), Czechs 9,641 (0.22 %), Hungarians 14,048 (0.33 %), Macedonians 4,138 (0.10 %), Germans 2,965 (0.07 %), Poles 672 (0.02 %), Roma 16,975 (0.40 %), Romania 435 (0.01 %), Russians 1,279 (0.03 %), Slovaks 4,753 (0.11 %), Slovenes 10,517 (0.25 %), Serbs 186,633 (4.36 %), Italians 17,807 (0.42 %), Turks 367 (0.01 %), Ukrainians 1,878 (0.04 %), Vlachs 29 (0.00 %) and Jews 509 (0.01 %).[7]

According to the above census, 16,975 members of the Roma national minority live in the Republic of Croatia. The Government of the Republic of Croatia ensures the exercise of most ethnic rights of the Roma and other members of national minorities through regular institutions of the Republic of Croatia as well as the majority of the Croatian people. The Roma who have civil status in the Republic of Croatia exercise the right to healthcare in accordance with the provisions of the Health Care Act and the Health Insurance Act, in the same way and under the same conditions as all other citizens of the Republic of Croatia. For those Roma who do not have a regulated citizenship, the Law on Health Care of Foreigners determines the conditions and manner of obtaining healthcare in the Republic of Croatia. Due to the high unemployment rate, very few able-bodied Roma are actively insured. In various Croatian regions, a certain number of uninsured Roma receive healthcare at the expense of budget funds.[8]

»People who do not have their own written history, because of the way and conditions of life and persecution in the past, who

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[6] Republic of Croatia: Compulsory Health Insurance Act: Consolidated text of the law. https://www.zakon.hr/z/192/Zakon-o-obveznom-zdravstvenom-osiguranju (accessed on 7.2.2023).

[7] The Government of the Republic of Croatia: National minorities in the Republic of Croatia. https://pravamanjina.gov.hr/nacionalne-manjine/nacionalne-manjine-u-republici-hrvatskoj/352 (accessed on 7.2.2023).

[8] Republic of Croatia: Compulsory Health (Note 6).

present their existence in a mythical way, not historical findings in the general margin are Roma«, says Mirdita Sailu in the introduction to her book »The path of the Roma from nomads to modern ethnic community« pondering on the specificity of the Roma as a people. The Roma do not have a written history neither in their own language nor in other languages in which information on historical figures and events would be available as other peoples have.[9] The existence of the Roma people is based only on oral tradition. In this fact lies the bulk of the problems and challenges when we talk about intercultural communication, which is a prerequisite for the realization of guaranteed rights and the provision of quality healthcare.

The main goal of communication is to establish understanding and cooperation with others. When interaction becomes stressful, taking on a competitive, hostile, or oppositional nature, it can be classified as conflict. Much of our social environment is characterized by interactions that include conflicts, misunderstandings, and failure to communicate. Contrary to earlier understandings of conflict, today scientists agree with the thesis that conflict in itself is neither good nor bad. It all depends on how you deal with conflict situations. Many theorists are of the opinion that conflict is welcome, because if we manage it well, it can have several useful effects, such as mobilizing the energy of individuals and groups, educating about better cooperation and acceptance, checking, and testing new ideas, etc.[10]

There has always been population migration, but today the world is more connected than ever in history. Therefore, the study of cultural patterns and specifics of communication is necessary for adaptation and participation in the »new« world. The globalized world has intensified international contacts and in today's world no nation, group or culture can remain remote or autonomous. The three phenomena that have increased intercultural contacts are certainly new technologies and information systems, changes in the world population and the global economy. It is almost certain that our private and business contacts will increasingly involve intercultural contacts. The world's population is growing at a rate of approximately 200,000 people a day, an increase of almost 80 million annually. The increase in population is accompanied by an increase in mass migration and

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[9] Mirdita Saliu: Put Roma od nomada do suvremene etničke zajednice [The path of the Roma from nomads to modern ethnic community]. Zagreb 2019.

[10] Zoran Tomić, Damir Jugo: Temelji međuljudske komunikacije [Foundations of interpersonal communication]. Mostar, Zagreb 2021.

travel. On the other hand, tourism is the fastest growing industry. However, does this have anything to do with health professionals? It absolutely does, because every tourist can need healthcare at some point, and by entering the health system asking for help the process of communication begins. Remember, interpretations of the meaning of sent messages are within people, and it is culture that is the framework for the interpretation of meaning. Culture is a set of common ideals, values, and standards of behavior. It is dynamic and changes over time. We are usually unaware of the adoption of cultural perceptions, rules, and behaviors, but by repeating key messages, we strengthen a particular culture. We are all familiar with proverbs, myths and legends, art, mass media, which also represent a hidden channel of cultural transfer. There is no doubt that we will need to improve our intercultural communication skills in our professional environment. The term Intercultural Communication according to the authors Samovar, Porter and McDaniel is when:

> (…) a member of one culture creates a message intended for a member of another culture. More specifically, intercultural communication involves the interaction of people whose cultural perceptions and symbolic systems are different enough to change the act of communication (…).[11]

With all the above in mind, let us look at the real-life situation when an individual is diagnosed with a severe, life-threatening illness and with family members enter a healthcare system. On the one hand, the patient and his family members deal with different emotions such as fear, anger, anxiety, etc. and on the other hand, there are health professionals who provide care. Talking to the family of a dying patient and a dying patient himself is perhaps the most stressful part of the professional communication of healthcare professionals. Communicating to the family and the patient that all diagnostic and therapeutic options have been exhausted is by no means easy. In this interaction, a lack of understanding may occur and a kind of crisis communication that has exactly occurred in 2019 in our University hospital center Zagreb.

Situations that cause emotional shock create the impression that the subjects of basic life values, some fundamental opinions about themselves, others or the world are endangered. As his basic

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[11] Samovar, Porter, McDaniel: Komunikacija (Note 2).

postulate of life is endangered or annulled by this stimulus situation, the subject perceives it as a complete catastrophe by refusing to accept the real situation.[12] Such a reaction and sequence of events brought us into a crisis because, according to Kathleen Fearm Banks, who states that: »A crisis is both an important and unpredictable event with potentially negative results, which can significantly damage the organization and its employees.«[13] This event was just that. Every crisis has its five steps: beginning, rise, peak, fall and end. The outcome of the crisis was: the normal functioning of the ward was disabled, alternative routes were organized so that other patients could perform the agreed examinations and therapeutic procedures, two seriously injured health workers, fear in all patients, health and non-health workers, material damage and finding the culprit for this event. The latter further deepened the crisis as the whole event quickly found its way onto social media. One post was enough to cause a wave of comments that were not affirmative, but condemning, calling for violence and individual guilt quickly grew into collectivizing guilt towards one national minority.[14]

The fundamentals of conflict are information and perception. From the information perspective, conflict can arise because one person has information that another does not, or two people have different sets of information. Now we come to the perception that people see things differently based on their unique belief systems. Canadian sociologist McLuhan pointed out the role of noise in communication that is directly responsible for poor communication, a misunderstanding that can lead to conflict. Noise can occur in the form of psychological, semantic, or mechanical disturbances. There are several types of noise or obstacles differing in the fact that obstacles are mostly of human origin, and noise can be of a technical nature. The most important psychological barriers to communication, especially communication in healthcare, are certainly emotions, followed by perception, lack of memory and, poor hearing. Let us recall for a moment the communication activities that take place in a healthcare setting. A large amount of information needs to be communicated in a limited period of time sometimes even during very stressful situations. Therefore, time, space, or fatigue can be significant barriers

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[12] Milivojević: Emocije (Note 5).

[13] Damir Jugo: Menadžment kriznog komuniciranja [Crisis communication management]. Zagreb 2017.

[14] Jugo: Menadžment (Note 13).

to communication. Furthermore, there are also socio-cultural barriers. Culture is a social phenomenon and is very powerful. Key sociocultural elements that can become barriers are:

1. collective thinking in which collective behavior dominates and stifles the decision-making process;
2. stereotypes and ethnocentrism;
3. inaccurate information, language and jargon that have several dimensions from status, class, professional differences to poor knowledge of the language in which one communicates;
4. conflict of values and beliefs because culture is based on shared beliefs and values.[15]

Furthermore, according to the report of the Croatian Institute of Public Health from September 2021, there are 16,369 deaf people and 173 deafblind people living in the Republic of Croatia.[16] Today, people with hearing impairments use more than 300 different sign languages. How much do we understand sign language? Sign languages are full-fledged languages, structurally different from spoken languages. The most common misconception about sign language is the fact that most people attribute sign language to the mother tongue of the country, which the deaf person comes from and lives in.

Hearing impaired people are also users of healthcare services and have all the rights as national minorities and the majority population. However, communication is a challenge and there are obstacles in communication with a deaf person, which we identified in a short survey conducted in the departments caring for lung cancer patients in five Croatian hospitals. Health professionals were asked the following questions concerning the availability of sign language interpreters: Are sign language interpreters available to deaf people 24 hours a day? Do you know how to contact an official interpreter if necessary? More than half of the respondents answered the first question in the affirmative, the rest assumed that they were, but they were not sure. However, concerning the second question, no surveyed health professionals knew how to contact them, which is extremely important when it comes to patients who sought help in emergency services. The results of the survey were the reason for initiating a

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[15] Samovar, Porter, McDaniel: Komunikacija (Note 2).

[16] Tomislav Benjak: Hrvatski registar o osobama s invaliditetom u Republici Hrvatskoj [Croatian register of persons with disabilities in the Republic of Croatia]. Zagreb 2021.

cooperation with the Croatian Association of the Deaf and Hard of Hearing, and an education program at the Medical Polytechnic in Zagreb has been established. What have we learned?

Deaf people learn sign language and it is their mother tongue, which means that the language of the country they live in is another language. The grammatical term of case is unknown to them, which complicates written communication significantly. They use simple short sentence forms. Sign language is not uniform and today we know about 300 types of sign language.[17] Every deaf person has the right to a sign language interpreter and a sign language interpreter should be made available. Further cooperation and education programs are planned for the future, but the COVID pandemic has prevented us from continuing our activities temporarily.

After the training, the following communication barriers with deaf people were identified:

1. sociocultural elements – ethnocentrism is an attempt to predict a person's behavior based on his belonging to a certain group and is usually associated with superficial behavior and inaccurate information;
2. language – poor knowledge of the language in which the communication takes place;
3. collective thinking in which collective behavior dominates and stifles decision-making;
4. stereotypes.

5. Conclusion

Returning to the definition of intercultural communication, but also the legal obligations to provide healthcare, which in addition to treatment must be aimed at preserving the quality of life and ensuring a dignified death, it is necessary to conduct education concerning the specifics of minorities.

A brief introduction to the specifics of the Roma national minority and deaf people raises the issue of communication competencies and social skills. If we know and are aware of potential barriers to

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[17] SignSolutions: What are the different types of sign language? (3.5.2021). https://www.signsolutions.uk.com/what-are-the-different-types-of-sign-language/ (accessed on 7.2.2023).

communication with a certain group of people, there is less chance of conflict and misunderstanding. We should not forget that each of us is an individual in our own right and that as human beings we differ in how competently we interact with others. These individual differences affect communication in a variety of interpersonal environments. Communication skills, on the other hand, have to be learned and are necessary to provide quality healthcare, avoid conflict, and understand.

For every relationship, and especially in the relationship between health professionals and patients and their family members, there should be trust. Trust needs to be built, and unfortunately can be lost very easily. So, we should start slowly with verbal communication, the most common form of interpersonal communication, which includes speaking and listening. Remember that each message has four sides and the key to the true meaning of the statement can be contained in the emphasis placed on a specific word, but also the general attitude used when speaking. Often the attitude that accompanies verbal interaction, which can be positive or negative, is more significant than the words spoken.

Nonverbal communication involves many factors that either confirm or dispute the spoken word. Facial expression, the presence or absence of eye contact, posture, and body movement, all project a direct message. Let us remember the old folk saying, »Look me in the eye and tell me«. However, we tend to forget that part of communication, especially when we talk to deaf people. Most health professionals, when talking to a deaf person, are talking to an interpreter. Indirect nonverbal messages include clothing, lifestyle, or material possessions. External signs and physical representation affect the quality of communication. Pre-created ideas and expectations interpret input – idea – from all such sources, often on an almost subconscious level. Listening is certainly an important element of clear and effective communication as any other component.

Many distractors contribute to poor listening habits. Positive communication techniques can help us be good communicators. Primarily, we should develop trust, communicate openly and honestly, maintain integrity and be reliable. We should use »I messages«. When a comment starts with »you«, the recipient's defense is activated. Using »you« in such a context sound, and is most likely intended to be, accusatory, so emotions escalate into anger quickly. Although the recipient initially tries to sound conciliatory, he soon begins to respond in a similar indicting form.

Let us make eye contact. We should keep our promises, because few things can so quickly destroy the fragile trust that develops in any interpersonal relationship such as giving and then breaking promises. Once the promise is made, everything must be done to fulfill the expectation. Sometimes it is not possible to satisfy the search; if that happens, the situation or circumstances must be explained. Let us be empathetic because empathy is an integral part of a therapeutic relationship. We should use open communication and clarify the information. Be aware of body language, because body positioning and movement send loud messages to others. In addition to eye contact, effective communication is enriched by an open attitude, such as keeping hands sideways or toward the patient rather than crossed, or leaning toward the patient to hear more clearly, rather than moving away from the patient. We should touch patients but be sensitive to each patient's personal preference and cultural differences in terms of touch. For many people, a gentle touch means showing genuine interest and concern. Patting on the back, holding hands, touching the shoulder, these are all behaviors that indicate accessibility and availability, but let us not assume, let us respect differences.

We are aware of how culture influences communication in a subtle and profound way. Our cultural background and experience partly determine the way we see the world and the way we interact with that world. »Our differences determine us, but our common humanity can redeem us«, said Karen Armstrong.[18] In addition to knowledge about a particular culture and awareness of different ways of communicating, it is necessary to know something about the person himself. Therefore, at the first meeting with a new patient, allow him to »tell his story«. Do not guess where the patient's story is leading, do not jump to conclusions, and do not think about yourself.[19]

Further research is needed on intercultural communication with minority groups in the healthcare and the impact of communication skills of healthcare professionals on patient adherence, avoidance of misunderstandings, and finally treatment outcomes.

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[18] Samovar, Porter, McDaniel: Komunikacija (Note 2).

[19] Samovar, Porter, McDaniel: Komunikacija (Note 2).

Vanja Branica, Ivana Mošić Pražetina

Improving access to healthcare for minority groups: qualitative study with social workers in Croatia

Abstract
Social workers are employed in hospitals and healthcare institutions to contribute to integrative healthcare that considers social aspects of health. Practitioners should be aware of influence that cultural background, values and structural, socio-political factors have on patients' access to healthcare system and provision of healthcare. The aim of this paper was to describe and analyze experience hospital social workers have working with patients from diverse cultural backgrounds, what are the challenges they face and what contributes to good practice. Qualitative approach was used, and two focus groups were held with 12 social workers participating in discussions. Transcripts were analyzed using thematic analysis. Six themes and twelve subthemes were identified. Social workers perceive foreigners and Roma minority as patients from diverse cultural backgrounds. Factors that contribute to good practice and positive outcome for patients are: effort that social workers invested in administrative tasks and procedures, advocacy for patients and their rights on all levels, frequent communication and counseling with patients and communication with patient's family members.

1. Introduction

Bio-psycho-social model of understanding health and disease has led to the involvement of non-medical professionals in the prevention, diagnosis and treatment of disease and preservation of health. One of the included professionals that contribute to integrative healthcare are social workers. Their work in healthcare should complement the traditional way of conducting clinical/medical work oriented towards the elimination of symptoms and treatment of disease. Social workers should assess the needs of patients, risk and protective factors and plan interventions taking into account patients existing preserved psychosocial potentials and use effort to strengthen them. Advocate for the patient in situations when he/she cannot do it for himself/herself, especially for members of minority groups who due to their social position have poorer access to social resources including healthcare. Social work in healthcare includes direct work with patients, their family members, building a bridge between, for example, hospital and community–based services.[1] In Croatia, social workers are included in healthcare system from the beginning of professionalization of social work, when the first social worker was employed at the Vrapče Psychiatric Hospital in 1955 in Zagreb. Since then, social workers are continuously employed in hospitals and clinical hospitals. In 2019, 93 social workers were employed in healthcare, mostly in the field of psychiatry and addiction, e.g. at the psychiatry departments in general hospitals, university clinics and special psychiatry hospitals, less in other parts of the healthcare system such as in public health institutes and at special hospitals, e.g. rehabilitation hospitals, long term care hospital.[2] The work of social workers in healthcare is based upon concepts like system theory, person in environment perspective, empowerment, and inclusion.

In the Constitution of the Republic of Croatia[3] the right to healthcare is proscribed to all citizens according to law. So, the system is based on the principles of inclusiveness, solidarity, reciprocity and accessibility to all citizens. According to the Central Bureau of Statistics (2020), with health insurance is covered a total of 4,188,658 people in 2019, which indicates good coverage of citizens with healthcare. The Croatian Health Insurance Institute is in charge of implementing basic health insurance. Healthcare is provided at the primary (preventive and general, family medicine), secondary (specialized and

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[1] Cèsar M. Garcès Carranza: Social work in the hospital setting: interventions. Bloomington 2012.

[2] Croatian Institute of Public Health: National Register of Health Care Provider. https://www.hzjz.hr/en/division-for-public-health/ (accessed on 7.2.2023).

[3] Republic of Croatia: Constitution of Republic of Croatia, Article 59. In: Official Gazette of the Republic of Croatia 85 (2010). https://www.usud.hr/sites/default/files/dokumenti/The_consolidated_text_of_the_Constitution_of_the_Republic_of_Croatia_as_of_15_January_2014.pdf (accessed on 7.2.2023).

hospital level) and tertiary level (the most complex forms of healthcare) and at the level of healthcare institutes.[4] Last 30 years, since the independence of Croatia, have been marked with several reforms in healthcare system. All these reforms had similar goal to rationalize and make financing of the health system more efficient. As in other countries in the world, the increased costs in healthcare are influenced by the aging population and the further development of technology in medicine and pharmacology, which allows a greater number of diagnostic and curative treatments that are becoming more expensive.[5] In Croatian public discourse, there are critics of the healthcare system regarding long waiting lists for diagnostics and specialist examination, provision and accessibility of healthcare in rural regions and on islands. According to research conducted by Economic Institute, Zagreb in 2010, patients stated that they are satisfied (40 %) or very satisfied (40 %) with quality of services physicians provide.[6]

But the differences in satisfaction and perception of accessibility of healthcare services exist and are related to socio-economic factors and minority status that contribute to existence of health inequalities.[7] Ombudswomen in Croatia emphasizes the need to systematic collect data about public services – health, social, educational – provided to national and ethnic minority to gain data and indicators that can be used for planning and delivering policies that recognize needs of

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[4] Republic of Croatia: Health Care Act. In: Official Gazete of the Republic of Croatia 100 (2018).

[5] Dubravko Mihaljek: Kako financirati zdravstvo u doba financijske krize? [How to finance healthcare in times of financial crisis?]. In: Maja Vehovec (Ed.): O zdravstvu iz ekonomske perspektive [About healthcare from an economic perspective]. Zagreb 2014, pp. 29–50.

[6] Jelena Budak: Ocjena pacijenata o kvaliteti rada zdravstvenog osoblja [Patients' assessment of the quality of work of the healthcare staff]. In: Maja Vehovec (Ed.): O zdravstvu iz ekonomske perspektive [About healthcare from an economic perspective]. Zagreb 2014, pp. 271–282.

[7] Luka Vončina, Ivan Pristaš, Miroslav Mastilica, Ozren Polašek, Zvonko Šošić, Ranko Stevanović: Use of Preventive Health Care Services among Unemployed in Croatia. In: Croatian Medical Journal 48 (2007), pp. 667–674; Zoran Šućur: Zdravlje i kvalitete zdravstvenih usluga [Health and the quality of health services]. In: Lidija Japec, Zoran Šućur (Eds.): Kvaliteta života u Hrvatskoj. Regionalne nejednakosti [Quality of life in Croatia. Regional inequalities]. Zagreb 2007, pp. 79–88; Zoran Šućur, Siniša Zrinščak: Differences that Hurt: Self-Perceived Health Inequalities in Croatia and European Union. In: Croatian Medical Journal 48 (2007), pp. 653–666.

particular group and in that way deal with structural discrimination.[8] On policy level, in new National Health Development Plan 2021 to 2027 that is in process of delivering, upbringing of healthcare for vulnerable groups is clearly stated as a priority of public policy but without any other operationalization.[9] On the system level as well as in practice there is possibility that obstacles and problems of minority group also remain »invisible« or approached by »equal treatment to everyone«[10], which has elements of culturally blind practice[11]. Especially in the light of strong predominance in number of white Croatian catholic heterosexual population in all social systems.

According to latest national Census (2011) 90.42 % declared themselves as Croats, 86.3 % as Catholic.[12] Other largest declared ethnic groups are Serbs (4.36 %), Bosnians (0.73 %), Albanians (0.41 %) and Roma (0.40 %). Since 2011. Croatia has continuing increase of immigrants coming to Croatia (from 8,534 in 2011 to 33,414 in 2020).[13] In addition, tourism is important economic branch with continually increase in number of tourist coming to Croatia (84,147,631 foreign tourists in 2019).[14] In 2020 there were 1,932 asylum seekers in Croatia.[15] All these groups bring to cultural diver-

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[8] Ombudsman Office of the Republic of Croatia: Discrimination based on race, ethnicity or color, and national origin (2020). https://www.ombudsman.hr/hr/diskriminacija-temeljem-rase-etnicke-pripadnosti-ili-boje-koze-te-nacionalnog-podrijetla-2/ (accessed on 7.2.2023).

[9] Ministry of Health of the Republic of Croatia: Nacrt prijedloga nacionalnog plana razvoja zdravstva za razdoblje od 2021 do 2027 godine [Draft proposal of the national health development plan for the period from 2021 to 2027]. https://esavjetovanja.gov.hr/Econ/MainScreen?EntityId=19191 (accessed on 7.2.2023).

[10] Derald Wing Sue, David Sue: Counseling the culturally different: Theory and practice. Hoboken 1990.

[11] Clara S. Simmons, Leticia Diaz, Vivian Jackson, Rita Takahashi. NASW cultural competence indicators: A new tool for the social work profession. In: Journal of Ethnic and Cultural Diversity in Social Work 17 (2008), pp. 4–20.

[12] National Bureau of Statistics: Croatia Census of Population, Households and Dwellings. https://www.dzs.hr/Hrv_Eng/publication/2012/SI-1469.pdf (accessed on 7.2.2023).

[13] National Bureau of Statistics: Migration of the population of the Republic of Croatia in 2020. https://www.dzs.hr/Hrv_Eng/publication/2021/07-01-02_01_2021.htm (accessed on 7.2.2023).

[14] National Bureau of Statistics: Tourist arrivals and nights in 2019. https://www.dzs.hr/Hrv_Eng/publication/2019/04-03-02_01_2019.htm (accessed on 7.2.2023).

[15] National Bureau of Statistics: Statistical indicators of persons granted international protection in the Republic of Croatia until 31.12.2020. https://mup.gov.hr/UserDoc

sity in Croatian society and their members can be users of healthcare services. In that respect, it is important for healthcare professionals to be aware of influence that cultural background, values and structural, socio-political factors have on patients' access to healthcare system and provision of healthcare. Culturally competent practice in healthcare is well known and debated in different European countries and in USA where majority of literature is produced. Cultural competence is changeable and dynamic concept, depending of individual, time, population and system.[16] In Croatian context not much about cultural competence in social work profession is problematized and researched, so we have turned to social workers in the hospitals to get insight into their experience working with patients from diverse cultural backgrounds, what are the challenges they face and what contributes to good practice.

2. Methods and Materials

Results presented in this article are part of study »Specifics of social work in healthcare during pandemic« funded by University of Zagreb in 2020. Research about social work in healthcare and about cultural diversity are rear in Croatian context, so we wanted to focus on social workers' experiences in hospital setting with patients form different cultural background. Therefore, qualitative research method was used to gain insight in social workers' personal experiences and practice related to the goal of this research. To gain insight into commonalities and differences in viewpoints of social workers the focus group as a technique of group conversation was conducted.[17]

Target population for this study consisted of healthcare social workers in Croatia. We recruited purposive sample of social workers based on inclusion criteria: a) social workers that are employed in university hospitals, clinical centers and municipality hospitals; b) have direct experience working with minority population and patients from diverse cultural background; c) social workers that agreed to participate and gave informed consent and d) come from

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sImages/statistika/2021/Medjunarodna_zastita/Medjunarodna_zastita_4kvartal2020.pdf (accessed on 7.2.2023).

[16] Simmons, Diaz, Jackson, Takahashi: NASW cultural competence (Note 11).

[17] Goran Milas: Istraživačke metode u psihologiji i drugim društvenim znanostima [Research methods in psychology and other social sciences]. Zagreb 2005.

different Croatian regions, from coastal part, heartland, rural and urban. Recruited social workers were invited to participate in focus group discussion via e-mail explaining the study goal, purpose and the aim of the focus group discussion.

Focus groups were conducted in 2021 and lasted 90 minutes. Two groups were carried out online using Zoom platform. Online way was used because of pandemic time and difficult access to hospitals and clinics. Besides that, online platform enables social workers from different part of Croatia to participate easily in focus group discussion – without traveling and other expenses. Online meetings were recorded; all the participant gave written consent to record the Zoom meeting. Later the audio was transcribed verbatim. Authors of this article led focus groups using previously agreed semi structured question guide. Both researchers are social workers, one working in hospital setting, and other teaching healthcare social work, both with experience in qualitative research. The focus group open ended question addressed experiences that social workers have working with patients with different cultural backgrounds, description of current practice, difficulties they face and how they deal with them, and examples of good practice.

Framework analysis was used »to classify and organize data according to key themes, concepts and emergent categories«.[18] Two researches, and authors of this paper, separately analyzed the transcripts, derived themes and subthemes following phases for thematic analysis:[19] (1) familiarizing with data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes and (6) producing the report. After that, process of comparing and discussing of findings was undertaken. Six themes and twelve subthemes emerged from thematic analysis of transcripts. A code for each participates was assigned to make data anonymized.

Social workers participated voluntary in the study. Separate approval of an ethics committee was not required because in this research participant were not members of vulnerable group or patients. Participants in research were social work professionals that

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[18] Jane Ritchie, Liz Spencer, William O'Connor: Carrying out Qualitative Analysis. In: Jane Ritchie, Jane Lewis (Eds.): Qualitative research practice: a guide for social science students and researchers. London, Thousand Oaks, New Delhi 2003, pp. 219–262.

[19] Virginia Braun, Victoria Clarke: Using Thematic Analysis in Psychology. In: Qualitative Research in Psychology 3 (2006), pp. 77–101.

gave informed consent to participate in the focus group discussion and to record the meeting. The participants were not anonym to researchers and to each other but were inform at the beginning of the focus group about confidentiality and way that anonymization of data will be delivered to safeguard their anonymity and confidentiality. In addition, they were informed about their right to opt out during the discussion at any time.

Two focus groups were conducted with 12 participants. All of them were women, social workers, average 40 years of age, with average 15 years working experience, and average 9 years working in healthcare system. They were working in university clinical hospital, general hospitals and special clinics from Zagreb, Rijeka, Split, Pula, Dubrovnik, Varaždin i Čakovec. Half of them are employed as hospital social worker and another half as a social worker within psychiatric hospital unit but have experiences going to other hospital units when needed, i.e., conciliatory work.

3. Results

3.1. Patients from diverse cultural background

At the beginning, before talking about the role of social workers working with patients with different cultural background, it was important to comprehend how social workers understand concept of patients from diverse cultural background.

3.1.1. Foreigners

All the participants had common understanding that when the talk is about cultural differences and patients from diverse cultural background it is about »foreigners«. Social workers define foreigners by the criteria of »formal citizenship and nationality«. By foreigners, they mean all the »patients that do not have Croatian citizenship. Therefore, during the focus group discussion examples of working with »migrants and asylum seekers, tourists, foreign workers of different national background« were described. Mainly Bosnia and Hercegovina, Serbia, Slovenia, Macedonia – people from the states that were together with Croatia part of Yugoslavia until 1990, and then from other EU countries e.g. Germany, Swiss Austria, Italy, Denmark, Hungary.

> »We are city on the coast, transit city, so we have lot of tourist, foreign workers, lot of foreigners, all countries of Europe are presented, we have Roma minority, people that do not have citizenship, just temporary stay, without health insurance.« (SW3)

3.1.2. Roma minority

Roma national minority was mentioned when »lack of health insurance and unregulated stay in Croatia« was addressed.

> »We are close to the border so working with foreigners is constant, we have lot of Slovenians, Austrians, Roma people, ethnic minority that most usual have no health insurance or unregulated stay in Croatia that we deal with.« (SW4)

3.2. Perception of working with patients from diverse cultural background

All participants agreed that work with foreigners is a »creative work« that engages all the knowledge and skills. Social workers need to be »resourceful«, with »lot of contacts and good professional network« in local community and with officers in different institutions. Also, the reactions and work need to be done »fast and prompt«.

> »Working with foreigners is exhausting because it last for weeks, but for me it is a career achievement. That is a specific field of practice that requires from social worker to use all knowledge and skills, from administrative, organizational, legal and all other knowledge that we gain through education and experience.« (SW5)

Participants stated that they did not pay much attention on how their own cultural background influenced their social work practice. They attached more importance to the »professional values« and practice, to have »individualized approach« to every patient and due to that, and they »respect every patient« with his/her »unique needs«.

> »I don't have any problems with cultural diversity, it is easier with someone and more difficult with others. Every patient is individual and unique, but it is a patient and you have to communicate, you have

> to find a way, you have to do your work, you have to be adroit, and manage.« (SW1)

3.3. Access to hospital healthcare

3.3.1. Good access to healthcare

Participants perceive that foreigners, migrants and other national minorities have »good access to emergency healthcare« services, they think »healthcare is available to anyone« who is in need for it. »Hospitals provide medical care« to help the patient, especially acute emergency care, often »without any information about patients' health insurance«. Because of that, social workers perceive that the system is open to everyone.

> »Emergency healthcare is provided without any questions.« (SW4)

Secondly, social workers try to solve healthcare insurance and coverage of medical expenses – or write-off due to social reasons – and in majority of cases, they are successful in that, so the patients get the care they need.

> »Foreigners have good access to healthcare. If they are longer here they have registered stay here, if not we always come up with something. « (SW6)

3.3.2. Social works access to patients and patients' access to social workers

Social workers talked about the way they are informed about the patient and when their intervention start. All participants stated that they are »contacted by the physicians« to provide services to patients. Medical staff ask for social work intervention »when combination and accumulation of problems are in place«. Usually they are: communication problems arising from language barrier with the patients, lack of medical insurance, not clear legal status, no documents, no family members or disturbed family relationships, obvious socioeconomic problems. One social worker stated:

> »I think they would call us in this situation and for Croatian citizens as well. They do not call us for every foreigner.« (SW5)

3.4. Role of social workers

Next theme was about the services social workers provide to patients with different cultural background.

3.4.1. *Getting to know the patient*

All participants agreed that first thing they do is »get in contact with patient« when possible – if patient is able to communicate – then »check patients′ personal identification data and documentation« and »get in touch with all contacts« that patient provides to see are there family, relatives or friends that can take care for the patient. If the communication with the patient is not possible then they try to »get all the information possible« using patient personal belongings, getting in touch with police, center for social welfare, municipality, neighbors to see »what is the life story of patient«, is there someone who can take care of patient.

> »It is like a detective work.« (SW1)
>
> »We are researchers.« (SW6)
>
> »Policeman said to one of my colleagues, you are faster than police, you can come to work with us.« (SW7)

3.4.2. *Developing the helping relationship with patient and family members*

Some social workers emphasized importance of »building relationship and trust« with the patient, using »counseling skills and techniques«. That contributes to patient ability to »accept help and have trust that interventions and suggestions from social worker are in good manner«.

> »It is a process of alignment, at the begging we are more like detectives, and then we become allies, and the patients see us that way. Patients face with difficult and complex life situations that they cannot handle with own capacities, they need support and help.« (SW8)

Others emphasized importance of building relationship through »communication with the family« members to get insight into family situation and to: a) »motivate family members« to come and take care of the patient and b) »provide support to family members« so they can take care or carry on with care for patient.

> »I provided hour and hours of phone counseling to patients son, daughter and wife who were very exhausted [caring for father who was psychiatric patient]« (SW4)

3.4.3. *Administrative and formal tasks and procedures*

All participants agreed that first thing they do is »checking patients' documentation and, identity«. Second step is according to patients' situation »resolving legal status, health insurance, post hospital care or continuing of care and transportation« in patients' homeland country or in Croatia. If the patient dies in hospital then the social worker is involved in »funeral organization – if the patient has no family, who will pay for the funeral, where it will take place«.

3.4.4. *Bridge between hospital, patient and professionals in other institution*

For the provision of all these administrative and formal tasks »cooperation with other institutions and systems is necessary«. Contacts with the »police, centers for social welfare, embassies, ministries – most usual healthcare and social care, health insurance institute, local and municipality government, general physicians, long term care hospitals or specialized hospitals, social care institutions« in country and abroad.

Cooperation with other institutions is good when they receive »quick response« to their notes, questions, e-mails with »concrete answers and directions«. Also, when the officers in other institutions are cooperative

> »It is important who is on the other side, who is official in insurance agency, in the police, to somebody nothing is problematic, and to others everything is problematic.« (SW6)

3.5. Impeding factors in provision of social work services

3.5.1. Lack of procedure and protocols

All participants stated that there is »no clear protocol« or written procedure what needs to be done, and who is in charge for what »on the level of their organization«, on the »level between institutions« and »multisector coordination«. Social worker »need to know about the laws« that determine patience rights, and they think »laws are good«, but their »provision in everyday life have obstacles«. Majority of participants described that they »wrote protocols of conduct for themselves« based on experience. Participants stated that the participation in this group discussion was empowering for them because they get confirmation for »their protocol«.

> »Now I realized that the others are doing the same things, in the same order and have similar problems.« (SW4)

3.5.2. Time

Participants problematized time it takes to do their job in two ways. One is connected with »administrative tasks and formal procedures that are time consuming«, lot of phone calls, waiting for other institutions to replay to some notes, e-mails. As there is »no clear protocol of conduct«, or clearly articulated »multisector cooperation« than lot of time is invested in writing notes and phone calls from one institution to other with the goal to »advocate the patients' rights and needs«. Secondly, time is connected with the social workers' access to patients. Physicians call social workers, sometimes at the beginning of medical treatment and sometimes at the end, then the quick solutions from social workers are expected, but not realistic due to time it takes to make all necessary work.

3.5.3. Language barriers

When patients are able to communicate then language that patents and care providers speak became impeding factor. Usually patients – migrants, tourists, foreign workers not coming from ex-Yugoslav countries – »do not speak Croatian«, and social workers »usually speak only English« and little Germany, Italian or Slovenian depending on the Croatian region they are form. Then social workers use »google translate, help from patients' friends or family« and if there are any, they hire »professional translators«.

3.6. Examples of good practice

Through focus group discussion, each social worker described a case that consider being example of good practice. Analyze of examples showed that factors that make good practice and bring to positive outcomes for the patients are:

a) »the effort that social workers invested in administrative tasks and procedures« to find the best solution for the patient, the solution that is according to law, suitable to patient's wishes and interests and feasible. This effort is manifested through »invested time« – from one month to one year, lot of phone calls and lot of written communication with social care services, police, and embassies;
b) »advocacy of the patient and their rights on all levels – from hospital to multisector cooperation«, communication with the hospital medical staff, institute for health insurance, social care services, general physicians, and other institutions;
c) »frequent communication and counseling with patients«, taking care of their needs, e.g., get clothes for patient, staff for personal hygiene, »communication with patients' family members«.

4. Discussion

In this paper, we analyzed how social workers describe their work with patients from diverse cultural backgrounds, challenges they face and what contributes to good practice. Social workers clearly related patients of diverse cultural background with the foreigners based on citizenship and by ethnicity, i.e. Roma minority. That is in accordance with the view that concept of culture refers to national origin, race, ethnicity and religious practice.[20] Influence that personal cultural

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[20] Paula Allen-Meares: Cultural Competence: An Ethical Requirement. In: Journal of Ethnic and Cultural Diversity in Social Work 16 (2007), pp. 83–92.

background has on social work practice, social workers connected with professional values and norms. Value to respect each person with his/her individual characteristic, to be respectful and focused on patients' needs were highlighted as most important. These basic ethical principles of the profession are developed through social workers' codes of ethic on local and global level.

The Code of Ethics of Croatian Association of Social Workers speak of professional activity based on the principles of social justice regardless of cultural and other differences. The concepts of social justice, respect for cultural diversity in society »taking account of individual, family, group, and community differences«[21] are included into all documents defining the profession and its activities, e.g. in the Global Standards for Social Work Education and Training[22] and the Global Social Work Statement of Ethical Principles by International Federation of Social Workers[23]. Concept of culturally sensitive practice leans on these principals, and is well known and elaborated in literature coming from more diverse societies than Croatian. Also, Croatian society is not that diverse, but it is becoming more various, it is important to talk, write and research about cultural diversity and review common work practice and methodologies. Therefore, we plead that raising awareness and open discussion about cultural diversity and professionals' cultural background can bring to social workers that »(…) become sensitized to the role culture plays in our lives, and practice the skills necessary to address issues that may arise in a cultural context.«[24]

Concept of culturally sensitive practice can be useful because it can incorporate three levels important for delivering of health and social services: micro, i.e., professionals providing help, mezzo, i.e., institutions roles and regulations, and macro, i.e., public policies and regulations. Cross, Bazron, Denis and Isaacs conceptualize cultural competence as »a set of congruent behaviors, attitudes and policies that come together in a system or agency or among professionals

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[21] International Federation of Social Workers: Global social work statement of ethical principles (2018). https://www.ifsw.org/global-social-work-statement-of-ethical-principles/ (accessed on 7.2.2023).

[22] International Federation of Social Workers: Global Standards for Social Work Education and Training. https://www.ifsw.org/global-standards-for-social-work-education-and-training/ (accessed on 7.2.2023).

[23] International Federation of Social Workers: Global social (Note 21).

[24] Allen-Meares: Cultural Competence (Note 20).

that enable effective interactions in a cross-cultural framework.«[25] Influenced by critical paradigm, theory and practice in social work become more interested in structural sources of inequality, reduction of discrimination, culture, language in which we shape reality and practice, which has led to anti-racist, anti-discrimination and culturally sensitive practices.[26] Such development leads to changes in education and practice of social work, as well as in healthcare social work, in which experts should have adequate knowledge, skills, values and are sensible to notice the needs and obstacles arising from client cultural characteristics and act in that respect.

Practitioners in this study were more focused on their direct work with patients and family member, their effort, dedication and creativity they use to advocate for patients' rights through administrative task and procedures and psychosocial support they provide. On that micro level they have direct access and possible impact. Social workers have »ability to work effectively across differences and negotiate cultural impasses in the helping relationship is at the root of our potential to achieve positive outcomes.«[27] Role of social workers can be described trough two main parts. One is development of helping relationship with patient and family members and building trust with patient in order to empower individual. Other are all administrative procedures that need to be done to realize patients' rights and complement medical care. This process of psychological and social empowerment, mobilization of all available resources is in accordance with psychosocial approach that is widely used and accepted in Croatian social work practice.

What is also important, and participants in our study talked about it, is development of cooperation and collaboration on the micro and mezzo level, within and between institutions and systems. Collaboration with other professions in multidisciplinary teams is inevitable and social workers should strive to be as visible in this

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[25] Terry L. Cross, Barbara J. Bazron, Karl W. Dennis, Mareasa R. Isaacs: Towards a culturally competent system of care (1989). https://spu.edu/~/media/academics/school-of-education/Cultural%20Diversity/Towards%20a%20Culturally%20Competent%20System%20of%20Care%20Abridged.ashx (accessed 7.2.2023).

[26] David Howe: A Brief Introduction to Social Work Theory. London 2009.

[27] Corry Azzopardi, Ted McNeill: From Cultural Competence to Cultural Consciousness: Transitioning to a Critical Approach to Working Across, Differences in Social Work. In: Journal of Ethnic and Cultural Diversity in Social Work 25 (2016), pp. 282–299.

multidisciplinary environment as in the public eye.[28] Participant stated that physicians are calling them when they evaluate that social worker intervention is needed for some patient. In that context, it is important that medical team is informed about social workers and their role and services. Better cooperation could lead to improvement in impeding factors that social workers addressed as lack of procedures and protocols and time of interventions. For social workers it would be important to start interventions as soon as the patient come to hospital and when first risk factor can be detected, e.g., lack of medical insurance. For that reason, it is important to consider development of network collaboration that implies, as Ajduković[29] stated: a) closer relationship among professionals, b) equality, c) engagement with time and resources.

On the mezzo level multisector cooperation come to place. Lack of clear procedures within hospitals as well as lack of procedures for cooperation between the systems – health and social welfare most usual – is contributing to different practice and questions equal delivery of rights and services. Talk about multisector cooperation in the social care issues such as child welfare and childcare, as well as in healthcare provision is contemporary topic in Croatian professional communities, as well on the policy level. In the new National Health Development Plan 2021 to 2027[30] that is in process of delivering, multisector cooperation between healthcare and social welfare systems is emphasized and for that purpose establishment of a separate working body with representatives of both systems is envisaged. Their role is to establish harmonized protocols and guidelines that will bring to complementary practice within social and healthcare.

We think that what Ajduković[31] wrote in Guidelines for multisector cooperation in child welfare can also be appropriate to have in mind talking about development of cooperation within healthcare and between healthcare and other systems which is complex process. Based on that Guidelines we can say that cooperation within hospitals,

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[28] Rosalie B. Pockett, Liz Beddoe: Social work in health care: An international perspective. In: International Social Work 60 (2015), pp. 126–139.

[29] Marina Ajduković: Smjernice za unaprjeđenje međuresorne suradnje u zaštiti dobrobiti djece: Kako postići »novi pogled« na »staru temu suradnje« [Guidelines for improving interdepartmental cooperation in the protection of children's well-being: How to achieve a »new perspective« on the »old topic of cooperation«]. Zagreb 2021.

[30] Ministry of Health of the Republic of Croatia: Nacrt prijedloga (Note 9).

[31] Ajduković: Smjernice za unaprjeđenje (Note 29).

between medical team and social work department should be based on a) harmonized policies, i.e., strategies, laws; b) clear standards and procedures within each department; c) identified common ground between different departments; d) knowledge about the psycho-social risks, patients' rights, cultural diversity, minorities, functioning of social welfare and health system, e) creating preconditions for development of mutual support between departments; f) competent human resources that share values and some knowledge and g) time that will be invested in cooperation.[32]

5. Limitations

Aldo's qualitative methodology and focus groups are suitable for gaining insight into people experiences and attitudes and social workers participated provided valuable and interesting information and insights. It is possible that interviews would provide alternative perspective regarding influence of personal culture to social work practice.

6. Conclusion

In modern and contemporary social work practice, professionals should have adequate knowledge, skills and values to identify needs and act respecting the differences arising from client characteristics and culture such as gender, age, nationality, ethnicity, or socio-economic differences. Professionals should be aware of their own cultural background and experiences as well as experiences of others and work for the benefit of service users and patients in healthcare.[33] Therefore, concept of cultural competence should be part of educational programs for social workers and medical professionals and part of lifelong learning programs.

The social worker should be well acquainted with the functioning of the healthcare system and social care system at the regional and local level and with available community health and social services in order to provide relevant information to patients and families,

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[32] Ajduković: Smjernice za unaprjeđenje (Note 29), here p. 17.

[33] Derald Wing Sue: Multicultural social work practice. Hoboken 2006.

to be able to take steps to advocate patients′ rights. Results show that social workers describe their role trough development of helping relationship with patient and family members and through different administrative procedures and tasks that need to be done to realize patients′ rights and complement medical care. They are aware of impact that social work interventions have on patients, especially when they have time, behave in flexible, creative way using appropriate language in proposing interventions needed to patients. All this makes up good practice and contributes to good results for patients.

To be more efficient it is important to develop clearly articulated protocols within hospitals based on shared understanding of social risks, cultural diversity and tasks that need to be performed. The clear protocols for multisector cooperation between hospital social workers, social care system, police, other state agencies are also needed to up bring professional relationship and provision of better services to patients. Till then social workers will do the best they know in helping and advocating patients in need.

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